

Training Workbook

Patient Liaison/Escorts

National Institutes of Health

**National Institute of Arthritis and
Musculoskeletal and Skin
Diseases**

Community Health Center



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INTRODUCTION

Patient Liaison/Escorts (PLEs) are key to the NIAMS Community Health Center. The PLE is not just someone working in the community; they are also members of that community. They help to forge a link between the NIAMS CHC and members of the community, providing a personal connection between the NIAMS CHC and the community it serves.

The NIAMS Community Health Center PLE Training Manual is designed as a guide to provide detailed instructions to you for your interaction with patients.

As a PLE, it is your charge to:

- ❖ Provide assistance to the patient when needed.
- ❖ Make certain arrangements for patients when needed.
- ❖ Vocalize patient concerns and needs.
- ❖ Communicate important information to the patient in regards to their care.
- ❖ Work with the NIAMS CHC staff to make the environment inviting and welcoming.

You will learn the basic information dealing with the National Institutes of Health (NIH), the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), and the Community Health Center (CHC). This is to ensure that general questions about the CHC and its mission can be answered with confidence and accuracy.

Some of the patients may ask questions that are difficult to answer. In these situations, you can ask the staff at the center for assistance and they will be able to provide you with the answers you are seeking.

Always remember that you are representing the NIAMS CHC. All of your patient-PLE interactions reflect directly on the NIAMS CHC; so, please remember to always be professional, be accessible, and, most importantly, be friendly and kind.

Agenda

The NIAMS CHC Patient Liaison/Escort Training

Facilitator:

CLASS SCHEDULE

Day One (Session 1)

Introduction To The Class

Introduction to NIH and NIAMS

NIH Video Presentation

Background and Purpose of the NIAMS CHC

Biomedical Research

Activity 1:Reinforcing Section Concepts - 00 minutes
Activity 2:NIAMS CHC ----- 00 minutes
Activity 3:Terminology----- 00 minutes
Activity 4:Review of Main Points ----- 00 minutes
Activity 5:Review of Diseases ----- 00 minutes

Day Two (Session 2)

Operational Guidelines

Location of the NIAMS CHC

The NIAMS CHC Staff

Phone Number, Hours, & Services Provided

PLE Duties

Field Trip

Activity 6: Field Trip Day -----00 minutes

Day Three (Session 3)

PLE/Patient Interactions (Customer Relations)

Sensitivity

Communications in the NIAMS CHC

Scripts and Scenarios

Role Playing

Activity 7: Communications Techniques -- 00 minutes

Activity 8: How Can I Help You? ----- 00 minutes

Activity 9: Let's Talk About It----- 00 minutes

Activity 10: Where Did I Go Wrong? ----- 00 minutes

SESSION 1

BACKGROUND AND PURPOSE

WHAT IS THE NIH?

The NIH is a research center operating under the Department of Health and Human Services, DHHS, an agency within the Federal government. It was established in 1887 as a one room Laboratory of Hygiene. Its mission is to uncover new knowledge that will lead to better health for everyone.

NIH is:

- Comprised of 27 Institutes and Centers.
- Located in Bethesda, Maryland (main campus and clinical center).
- One of the foremost medical research centers in the world.

WHAT IS NIAMS?

[Handout – *Progress and Promise NIAMS*]

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is part of the National Institutes of Health (NIH).

What Does It Mean? Arthritis

Arthritis is **inflammation** in the joints (see box on **Inflammation** below). Many people refer to this as “rheumatism.”

What Does It Mean? Rheumatic diseases

Rheumatic diseases are diseases that affect the joints, bones, muscles, and skin. Arthritis occurs with rheumatic diseases.

What Does It Mean? Musculoskeletal diseases

Musculoskeletal diseases are diseases relating to muscles and to the bones.

What Does It Mean? Skin diseases

One of the goals of NIAMS is to investigate diseases of the skin. Although some rheumatic diseases have symptoms that appear on the skin, the NIAMS CHC will not be treating patients for skin diseases.

NIAMS:

- Supports research into the causes, treatments, and prevention of arthritis, rheumatic diseases, musculoskeletal, and skin diseases.
- Supports the training of scientists to carry out this research.
- Provides information on research progress to improve public health.
- Investigates many forms of arthritis, diseases of the muscular and skeletal systems, and diseases of the skin.

What Does It Mean? Inflammation

Inflammation occurs in many organs throughout the body. It is characterized by symptoms of heat, redness, swelling, and pain in the joint. Because many rheumatic diseases exhibit symptoms such as these, you’ll often hear this term being used at the NIAMS CHC.

ACTIVITY #1

Note: This activity reinforces the main concepts of this section. The students should be able to identify the acronym, NIAMS, and should be able to answer general questions in regards to some of the focal diseases of NIAMS.

TAKE HOME POINTS:

1. Arthritis is characterized by joint inflammation, that is swelling, redness, heat, and pain experienced in the joint. It can be caused by injury or disease.
 2. Musculoskeletal diseases are diseases that affect the muscles and the skeleton. Rheumatic diseases are one of several diseases placed in this category.
- Rheumatic diseases are multi-system; they can affect different parts of the body. They can affect the joints, bones, muscles, and skin. Some examples are rheumatoid arthritis, lupus (SLE), and scleroderma.

Spelling out NIAMS:

- N _____
- I _____ (of) _____
- A _____ (and) _____
- M _____ (and) _____
- S _____

Medical Terms? Fill in the blank spaces.

- Arthritis is a condition that involves inflammation of the _____.
- Signs of inflammation in a joint are _____, _____, _____, and _____.
- Musculoskeletal diseases are diseases that affect the _____ and the _____.
- Rheumatic diseases are diseases that affect the _____, _____, _____, and _____.

Some examples are rheumatoid arthritis, lupus (SLE), and scleroderma.

WHAT IS THE CHC?

[Handouts – *About the NIAMS Community Health Center, services map*]

The NIAMS CHC is a medical and health information center providing health care services to people affected by arthritis, lupus, and other rheumatic diseases. It offers patient care with access to medical specialist, health information and education programs, and referrals to clinical investigations for the prevention and treatment of rheumatic diseases.

NIAMS is mandated to address the health disparities found in individuals with arthritis and rheumatic diseases, in particular African Americans and Hispanics/Latinos.

What Does It Mean? Health Disparities

Health disparities refer to the difference in the incidence, prevalence, morbidity, mortality, and burden of diseases and other adverse health conditions that exist in specific groups (African Americans, Hispanic/Latino Americans, Native Americans/American Indians, Alaska Natives, Asian Americans and Pacific Islanders) compared to the general population.

The NIAMS CHC is in response to this mandate.

The NIAMS CHC provides medical information and health care services to people 18 years and older affected by arthritis, lupus, and other rheumatic diseases.

Patients who participate have access to medical specialists at the NIAMS CHC, and to other NIH clinical investigations concentrating on the prevention and treatment of rheumatic diseases.

The NIAMS CHC offers health information and education programs that can be utilized by everyone.

Understanding CHC

Community -- The NIAMS CHC is open to anyone in the community over the age of 18. There are no restrictions due to residency status, income level, or ethnic background.

Health -- Attention is placed on educating the community and treating and managing arthritis and musculoskeletal diseases.

Center -- The NIAMS CHC is a center where adult members of the community with arthritis or other musculoskeletal diseases can receive medical care. Also, anyone who wishes can receive health information.

The NIAMS CHC:

- Addresses health disparities (see box on **Health Disparities**, pg. #).
- Provides medical attention to any person who suspects they have, or have been diagnosed with, arthritis, lupus, or any other rheumatic disease.
- Is open for medical evaluation to everyone over the age of 18 who voluntarily participates. Any patient receiving care at the NIAMS CHC can decide to discontinue treatment and visits at any time, with no future obligations.
- Is staffed by:

Rheumatologists
Medical Fellows
Nursing Assistant
Health Educators

Nurse Practitioners (NPs)
Registered Nurses (RNs)
Clerical Staff

What Does It Mean? Rheumatologist

Rheumatologists are general adult medicine doctors. They receive specialized training in rheumatic diseases, arthritis, and other musculoskeletal ailments.

- Has on-site health educators available to answer any education questions related to rheumatic diseases, musculoskeletal diseases, and arthritis. This service is available to anyone visiting the NIAMS CHC.
- Does not provide treatment of skin diseases.
- Does not provide treatment to children.

Children with rheumatic, or other related illnesses, will be referred to the NIH Pediatric Rheumatology Department at the Clinical Center in Bethesda, Maryland.

- Evaluates all patients regardless of place of residence, country of origin, or immigration status. Any visitor to the NIAMS CHC seeking treatment will be seen.
- The NIAMS CHC does not maintain communications with the Immigration and Naturalization Services (INS) in regards to immigration issues. All records on every person visiting the NIAMS CHC are kept confidential.

What Does It Mean? Health Educator

A health educator is someone professionally trained to provide information on health related issues. In addition, they assist individuals in making informed decisions about matters pertaining to their health.

The NIAMS CHC health educators are available to answer visitor questions.

Also, health educators work with community members to plan health-related programs that meet the community's needs.

ACTIVITY #2

Note: The purpose of this activity is to promote discussion about the new NIAMS CHC. Students will answer general questions about the NIAMS CHC, why it was formed, and how the staff will interact with the community.

TAKE HOME POINTS:

1. The NIAMS CHC provides medical information and health care services to people 18 years and older affected by arthritis, lupus, and other rheumatic diseases.
2. It was established to provide access to rheumatology care in the community.
3. Every patient treated at the NIAMS CHC will receive all necessary information about the NIAMS protocol and its goals. Patients will be asked to sign an informed consent form (see box on **Informed Consent**, pg. 27).
4. Participation is voluntary and can be discontinued by the patient at any time.
5. The NIAMS CHC will not be treating children or patients with from skin diseases. Please note that some rheumatic diseases have symptoms seen on the skin, including rashes, itchiness, and others. These symptoms will be treated only if they are a symptom of a rheumatic disease.
6. Keeps the immigration status confidential for every person visiting the NIAMS CHC. Any visitor to the NIAMS CHC seeking treatment will be seen regardless of citizenship or residency, or immigration status.

True or False (T or F)

1. The purpose of the NIAMS CHC is to provide access to rheumatology care to the community. _____
2. The NIAMS CHC will provide health education on rheumatic diseases. _____
3. The NIAMS CHC was established to aid in understanding health disparities. _____
4. Patients of the NIAMS CHC are under obligation to continue receiving treatment at the center, even if they do not wish to. _____
5. A patient visits the NIAMS CHC in the hopes of receiving treatment for a skin disease. This patient will receive treatment at the NIAMS CHC for his condition. _____
6. Children under age 18 with rheumatic diseases can be brought to the NIAMS CHC for treatment. _____

ACTIVITY #3

Note: The purpose of this activity is to familiarize students with terminology used repeatedly in the NIAMS CHC.

TAKE HOME POINTS:

1. The NIAMS CHC provides medical information and health care services to people 18 years and older affected by arthritis, lupus, and other rheumatic diseases.
2. The physicians in the NIAMS CHC are called rheumatologists. Rheumatologists are general adult medicine doctors that specialize in the diagnosis, treatment, and study of rheumatic diseases.
3. Health disparities refer to the difference in the incidence, prevalence, morbidity, mortality, and burden of diseases and other adverse health conditions that exist in specific racial and ethnic groups compared to the general population.
4. A wide range of health information relating to arthritis and musculoskeletal diseases will be available to anyone visiting the NIAMS CHC.
5. There will be an on-site health educator available to answer any education questions, and respond to rheumatic disease related questions. The health educators will also be leading information sessions and classes for NIAMS CHC visitors.

Definitions and Terms

NIAMS stands for the

CHC stands for

A Rheumatologist is

Health Disparities refers to

A Health Educator is someone who

DISEASES ADDRESSED AT THE NIAMS CHC (ARTHRITIS AND OTHER RHEUMATIC DISEASES)?

[Handouts – *Progress and Promise, refer to pamphlets for varying diseases*]

Every person employed by, or affiliated with, the NIAMS CHC should have a general, but clear, understanding of the diseases that affect those patients coming to the NIAMS CHC.

NIAMS leads the Federal medical research effort in arthritis and musculoskeletal and skin diseases. However, although NIAMS, as an institute, concentrates efforts into researching all of these diseases, the NIAMS CHC will not be treating patients for skin diseases.

The focus of the NIAMS CHC is to identify and address arthritis, rheumatic diseases, and musculoskeletal diseases.

Arthritis

- Many people use the words "arthritis" and "rheumatism" to refer to all rheumatic diseases.
- Arthritis literally means joint inflammation; that is, swelling, redness, heat, and pain caused by injury or disease in the joint.
- There are many different kinds of arthritis.

What Does It Mean? Rheumatic Diseases

Rheumatic diseases are diseases that affect the joints, bones, muscles, and skin. Some examples of these are rheumatoid arthritis, systemic lupus erythematosus (SLE) or lupus, and scleroderma.

Rheumatic Diseases

- There are over 100 rheumatic diseases.
- An estimated 43 million people in the United States have arthritis or other rheumatic conditions.

Rheumatic Diseases (con't)

- Rheumatic diseases affect people of all races and ages.

Some rheumatic diseases are:

- Osteoarthritis
- Rheumatoid Arthritis
- Fibromyalgia
- Lupus (Systemic Lupus Erythmatosus or SLE)
- Scleroderma
- Juvenile Rheumatoid Arthritis
- Ankylosing Spongylytis
- Gout
- Infectious Arthritis
- Reactive Arthritis
- Psoriatic Arthritis
- Bursitis
- Tendinitis (Tendonitis)

SOME COMMON RHEUMATIC DISEASES THAT MAY BE DIAGNOSED IN PATIENTS EVALUATED AT THE CHC

Osteoarthritis vs. Rheumatoid Arthritis

The two most common types of arthritis are osteoarthritis and rheumatoid arthritis.

Osteoarthritis (OA) is a form of arthritis that is described as a "wear and tear" arthritis. It can develop as a person ages or as a result of an injury to a joint. OA is usually localized to the affected joint, most often the joints in the fingers, knees, or hips.

Rheumatoid arthritis (RA) is an "all-over" form of arthritis. It is a disease that occurs when the body's immune system begins to "malfunction" and attacks normal, healthy tissue as it would bacteria or viruses. As a result, damage to joints and the joint lining occurs. Most often symptoms begin to show in the hands and feet. Other symptoms include feelings of sickness, fatigue, and fever.

Osteoarthritis (OA) is the most common type of arthritis. It occurs when cartilage begins to fray, wear, and decay.

Rheumatoid arthritis (RA) is an inflammatory disease of the lining of the joint. It results in pain, stiffness, swelling, deformity, and loss of function in the joints.

Lupus is a disease that affects mainly young women, often starting between the ages of 15 and 44. People of all genders and races may get lupus; however, it is much more common in African American and Hispanic/Latino women.

Fibromyalgia is a chronic disorder that causes pain and stiffness throughout the tissues that support and move the bones and joints. It affects 3 to 6 million people in the United States.

This is not a complete list of the diseases that may be seen and treated at the NIAMS CHC, just those that are more common. For more information about the diseases listed here as well as other rheumatic diseases, please refer to the Resource Folder.

ACTIVITY #4

Note: The purpose of this activity is to promote discussion of the different diseases patients will be evaluated and treated for at the NIAMS CHC.

The main goal here is to help students commit to memory some of the key terms. They should feel comfortable in their answers to basic questions about the various diseases.

It also needs to be strongly emphasized that the students should never give medical advice or portray themselves as experts on any topic concerning arthritis and rheumatic diseases. PLEs should always defer the patients to the medical staff or health educators.

TAKE HOME POINTS:

1. Rheumatic Diseases are diseases that involve the joints and the musculoskeletal system.
2. There are many different types of rheumatic diseases. A few of these are rheumatoid arthritis, lupus (Systemic Lupus Erythmatosus or SLE), and schleroderma.
3. Arthritis exhibits symptoms including heat, redness, swelling, and pain caused by injury or disease in the joint.
4. Requests for further information and answers to any questions can be referred to any of the following:
 - a. The NIAMS CHC staff
 - b. The NIAMS CHC health educators
 - c. Available information booklets and pamphlets
 - d. The 'PLE Participant's Workbook'
 - e. The NIAMS Office of Communications and Public Liaison (301-496-8190).

Name three kinds of rheumatic diseases:

1. Lupus
2. Rheumatoid Arthritis
3. Fibromyalgia

If a patient asks you to explain lupus, what are three resources you can refer to?

1. PLE Participant's Workbook
2. 'Systemic Lupus Erythematosus' Handout
3. Health Educator or Medical Staff at CHC

WHAT IS BIOMEDICAL RESEARCH?

HOW IS THE NIAMS CHC INVOLVED IN THIS TYPE OF RESEARCH? HOW ARE THE PATIENTS INVOLVED AND PROTECTED WHILE PARTICIPATING IN RESEARCH?

Every person employed by, or affiliated with, the NIAMS CHC should have a general, but clear, understanding of the definition and purpose of biomedical research, including the roles THAT the NIH, NIAMS, and the NIAMS CHC play in conducting this biomedical research.

BIOMEDICAL RESEARCH

Biomedical -- Biology is the study of life and life systems. When these studies involve work with diseases or are in some way of importance to the medical community, then they are referred to as *biomedical* studies.

Research -- Research is an investigative search or a series of experimentations. Research is conducted in order to collect information or revise an already existing idea. There are many levels of research, ranging from research done at the cellular level to research conducted on the population as a whole.

What Does It Mean? Biomedical Research

Biomedical research investigates questions pertaining to the medical field in an effort to improve the overall health of people throughout the world.

Biomedical Research -- In biomedical research, questions of medical importance are asked in an effort to find answers. Researchers use proven information, as well as new methods and techniques, to obtain results. Extensive experiments are conducted to find the answers sought. After many studies, researchers are then able to incorporate this work into clinical trials. In clinical trials, volunteer agree to use innovative treatments, medicines, and diagnosis methods in the interest of improving the health of everyone.

THE NIH RESEARCH STUDY

The NIH research study is often referred to as a protocol. It is an effort to answer important questions that are significant for both researchers, the medical community, and the people throughout the world.

The NIH research study presents a question, or a hypothesis. A hypothesis is defined as a researcher's theory or idea presenting possible outcomes to the question being investigated.

In addition, it can include the procedure that will be taken, or the research method, necessary to obtain an answer. It may also include a review of all information available in relation to the question.

THE NIAMS CHC RESEARCH STUDY

One of the goals of the NIAMS CHC is to better understand the impact arthritis and other rheumatic diseases have on minority populations.

A Standard Care Protocol

The NIAMS CHC will enroll patients under a standard medical care protocol. No experimental treatments or evaluations will be used in this protocol. These patients will need to sign an informed consent form (see **Informed Consent**, pg.#).

The NIAMS CHC may in the future conduct investigative studies where experimental treatments, medications, and/or evaluations may be used. Patients will be invited to participate and will need to sign an informed consent form separate from the initial standard care informed consent form.

Patients who do not wish to participate in experimental care will not lose their right to receive or continue receiving standard medical care at the NIAMS CHC.

ETHICS OF RESEARCH [Appendix D- *Research Involving Human Subjects*]

- ***The Belmont Report - Ethical Principles and Guidelines for the Protection of Human Subjects*** establishes three fundamental ethical principles that are embodied in laws governing the use of human subjects in research. These are **Respect for Persons, Beneficence, and Justice**.

***What Does It Mean?
Informed Consent***

The process of informing patients of the research protocol, providing them with answers to their questions and concerns about the research study, and having them sign a consent form before any medical evaluation begins.

The principle of **Respect for Persons** serves to protect individuals needing special protection, including children, mentally disabled, and others. This principle requires that subjects give **informed consent** prior to participation.

The principle of **Beneficence** requires researchers to protect individuals by maximizing anticipated benefits and minimizing possible harms.

The principle of **Justice** requires that all subjects be treated fairly. It ensures that certain individuals are not excluded or included based on reasons that are not scientifically or ethically valid.

Respect For Persons

- There are laws designed to protect every patient seen at any NIH facilities.

These laws protect patients from being harmed, wronged, or inappropriately treated.

These laws ensure that there is respect for every person involved.

- a. Patient participation is voluntary.
- b. Patients are given all pertinent information before consenting to participate and will have all their questions and concerns addressed by the researcher team. This is informed consent.
- c. All patient information, consultations, and records remain confidential.
- d. All patients are informed that they have the freedom to withdraw at any time, without any future obligations.

Beneficence

- The goal of the research is to **maximize benefits and minimize the risk** to the patients. An NIH review board consisting of doctors, scientists, lawyers, ethicists, clergy, and lay people examine all studies to make sure they are safe.

Justice

- Patients are protected from being exploited or treated unfairly while participating in any research conducted within NIH and its centers.

NIH ensures equality and fairness in its programs, protocols, and research.

NIH does not permit the exploitation of groups based on age, gender, race, cultural background, economic level, social status or sexual orientation.

RESEARCH PROTECTIONS

All patients should have a clear understanding of the steps that the Federal government, the DHHS, and the NIH have taken to ensure their protection against wrong doing in any program run by, or affiliated with, NIH centers and staff.

Patient safety

Patient safety is ensured by the use of six main practices:

One -- Voluntary participation

Two -- Informed consent

Three -- Strict confidentiality

Four -- The patient's right to discontinue participation at any time

Five -- An Institutional Review Board protects patient rights

Six -- Careful monitoring of patient

The Institutional Review Board (IRB)

The federal government has instituted laws and has provided guidelines on how participants in research studies are to be treated.

The U.S. Public Health Service (PHS) requires prior review of all supported research. Some facts important to this decision:

- The National Research Act of 1974 established a National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.
- The DHHS and NIH have established mechanisms that ensure that protocols are monitored and evaluated for the ethical treatment of the patients involved.
- An Institutional Review Board (IRB) must approve all NIH protocols before they can begin. The IRBs consist of doctors, scientists, lawyers, ethicists, clergy, and lay people. They examine all studies to make certain that they are safe.

Informed Consent

As stated earlier, the Federal government has instituted laws and has provided guidelines on how participants in research studies are to be treated. One of these laws mandates that patients give **informed consent** prior to participating in a study.

Therefore, patients will:

- Receive a full explanation of the research study in straightforward, easy to understand, language.
- Have the opportunity to ask questions and get answers from those conducting the research.
- Be asked to sign a consent form after the nature of the protocol is completely explained to them.
- Maintain the right to discontinue participation at any time after signing the consent form.

ACTIVITY #5

Note: The purpose of this activity is to review the main points in this section.

TAKE HOME POINTS:

1. *The Belmont Report* establishes three fundamental ethical principles that are embodied in laws governing the use of human subjects in research. These are Respect for Persons, Beneficence, and Justice.
2. Patient safety is ensured by the use of six main practices:
 1. Voluntary participation
 2. Informed consent
 3. Strict confidentiality
 4. The right to discontinue participation
 5. Patient protection ensured by a review board
 6. Careful monitoring of patient
3. Patients that are evaluated and treated at the NIAMS CHC will need to sign an informed consent form. This is an acknowledgment that the participant understands the diagnosis, treatment, and monitoring procedures and agrees to participate. Other protocols will require a separate informed consent form.
4. Patients will be given all necessary information in regards to the mission of the NIAMS CHC as well as any important information regarding their medical care.

Session Review – Main Ideas. True/False and Questions.

1. All patients will receive experimental treatment at the NIAMS CHC.

True or False. (False)

2. All patients will receive standard medical care at the NIAMS CHC.

True or False. (True)

3. Patients of the NIAMS CHC are evaluated and/or treated on a voluntary basis. What form do they need to sign prior to treatment?

4. While receiving treatment by the staff at the CHC, patients' rights are protected by laws. What are the six main practices that ensure patient safety?

a. _____

e. _____

b. _____

c. _____

f. _____

d. _____

5. What is informed consent?

SESSION 2

OPERATIONAL GUIDELINES

STAFF

The staff at the main Cardozo/Shaw facility will consist of:

- Rheumatologists - Doctors specializing in rheumatic diseases.
- Rheumatology Fellows
- Nurse Practitioners - Advanced practice nurses trained in evaluating and accessing patients coming to the NIAMS CHC.
- Registered Nurses
- Nursing Assistants
- Clerical Staff - Provides patients with necessary forms, schedules appointments, answers phones, and provides other necessary clerical support at the NIAMS CHC.
- Health Educators

CURRENT STAFF

(See Appendix A)

LOCATION

The NIAMS CHC will have one main facility located in the Cardozo/Shaw area, and two outreach sites in downtown northwest and in northeast Washington, D.C. The locations, and services provided, are as follows:

The NIAMS CHC at Cardozo/Shaw will provide:

- Screening and Referrals
- Health and Nutrition Classes
- Health Information
- Community Jobs and Education

NIAMS CHC (Cardozo/Shaw)
Unity Health Care's Upper Cardozo Health Center
3020 14th Street, N.W.
Washington, D.C. 20019
(202) 673-0000 (receptionist)
(202) 673-0012 (fax)

Metro Stop: Columbia Heights (**Green** Line)

The NIAMS CHC outreach sites in downtown Washington, D.C., and in Northeast offer the following services:

- Screening and Referral
- Health Information

Some patients will need to go to the NIH main campus for certain services.
Some of these are:

- X-Rays
- Pharmacy Needs
- Other laboratory services
- Other Clinical trials

National Institutes of Health (NIH)
Clinical Center
9000 Rockville Pike
Bethesda, MD 20892

Metro Stop: Medical Center (**Red** Line)

HOURS

The NIAMS CHC at the Cardozo/Shaw location will be accepting appointments as well as walk-ins during the following hours.

Hours

- Monday, Tuesday, and Thursday 8:30AM – 4:00PM
- Wednesday 11:00AM – 7:00PM

SERVICES PROVIDED

The following are services provided at the NIAMS CHC main facility.

What Does It Mean? Nurse Practitioner

A nurse practitioner (NP) is a registered nurse with at least a master's degree in nursing and advanced education in the primary care of particular groups of clients. By assuming responsibility for preventive care, health education, routine surveillance and the management of chronic disorders, NPs free physicians to render more sophisticated or elaborate diagnostic and therapeutic services.

- Screening: Patients can visit with the **nurse practitioner (NP)**. The NP will discuss their problem with them and determine if a rheumatologist is the appropriate type of doctor to provide care.
 - Eligible patients will be enrolled a standard care study. Patients will need to sign a consent form.
 - Certain lab services will be performed at the NIH Clinical Center (also known as the Warren Grant Magnuson Clinical Center), which is located on the main campus in Bethesda, Maryland. These include x-rays and imaging studies ordered as part of patient evaluation.
 - The NIAMS CHC provides transportation to and from Bethesda for patients needing Clinical Center services.
-
- Patients may have blood drawn for tests at the NIAMS CHC, Cardozo/Shaw.
 - Prescription medications ordered by the doctor or nurse practitioner for the treatment of rheumatic diseases, and related conditions, can be filled at the NIAMS CHC free of charge. **No vouchers will be given to patients who wish to go to outside pharmacies to have prescriptions filled.** Outside prescriptions from non-NIAMS CHC doctors or nurse practitioners will not be filled at the NIAMS CHC.
 - Medical referrals will be advised when appropriate and when necessary. These referrals may involve recommending patients visit centers or doctors that are not affiliated with NIAMS or NIH. Some referrals could possibly involve fees or charges to the patient. The NIAMS CHC, NIAMS, and the NIH will not assume any responsibility for such charges nor will responsibility be assumed for any services provided by such referrals.

- Some patients may be eligible for other clinical studies (NIAMS, other NIH institutes, or non-NIH-affiliated organizations) that may include experimental treatments. For any of these additional studies, patients will need to sign a separate consent form. Anyone not wishing to participate in another study can still receive medical care at the NIAMS CHC for rheumatic, and related, diseases.
- Evaluation by physical and/or occupational therapists is available for some patients.
- Written information on the various types of arthritis, as well as diseases of the muscles, bones, and skin will be available. This includes fact sheets, brochures, and other written material.
- The NIAMS CHC will offer health education programs that teach nutrition, disease management, and other topics that affect those with arthritis and rheumatic diseases.
- The NIAMS CHC is committed to being culturally sensitive and accessible to the community for the care and clinical research of rheumatic, and related, diseases. Involvement of the community is encouraged through patient education and job opportunities such as the PLE position.

ACTIVITY #6

Field Trip to NIH

[Insert preparation notes here]

PLE RESPONSIBILITIES

The PLE is required to perform the following duties:

- Provide assistance and aid to patients being treated at the NIAMS CHC.
 - *This includes sitting and talking with patients, escorting them between the NIAMS CHC and the NIH, in Bethesda, Maryland, if needed, and conveying any of the patient's concerns or questions to the medical staff.*
 - *This is not to imply that the escort is required to be in the examining room with the patient unless the patient specifically makes such a request and the escort feels comfortable in doing so and the doctor agrees.*
- Listen to the patient's needs and concerns.
- Relate to and communicate with a diverse population of patients and maintain a friendly and open environment while working with patients.
- Be aware of the medical evaluation activities and process and be able to communicate this process to patients.
- Be willing to learn, at a layperson's level, about rheumatic diseases, their signs and symptoms, and the treatment.
- Communicate information to the patients and their relatives or accompanying persons.
- Involve patients and/or their accompanying persons in diversion activities when necessary, e.g., activity bag, crosswords, Reader's Digest, etc.
- **Refer patients' medical questions and concerns to the appropriate medical staff.**
- **Do NOT give any medical advice.** Avoid giving advice of any kind to the patient in relation to the treatment or management of their disease.

- **Know the procedure for transporting the NIAMS CHC patient**

Be prepared to accompany patients to the NIH main campus in Bethesda.

Be prepared to answer questions in relation to leaving the "safe environment" of the NIAMS CHC.

- *"How long will this take?" Have a reasonable idea of the length of time it will take to go back and forth between the NIH and the NIAMS CHC. Always remind patients that they will need to take into account the time needed to complete the service, e.g., x-ray, they are receiving.*
- *"Do I have to pay anything?" NIAMS is covering all costs for transporting the patient back and forth between the NIAMS CHC at Cardozo/Shaw and the NIH in Bethesda.*
- *"Where exactly are we going?" Know street directions as well as Metro directions to the NIH in Bethesda. .*

SESSION 3

PATIENT/PLE INTERACTIONS (CUSTOMER RELATIONS)

PATIENT SENSITIVITY

Patient confidentiality is important. You *may not*, under any circumstances, discuss a patient's visit or information with anyone outside of the NIAMS CHC. This even includes casual conversations between the patient and you.

Many words have different impacts, depending on the person. Try not to use words such as cripple, deformed, or handicapped. Although you may occasionally hear patients using these terms when referring to themselves, as PLEs, maintain your professionalism by modeling appropriate and positive behavior. [Refer to the section 'What NOT to say']

Understand that the patient's physiological condition may not allow them to function easily. Offer assistance when necessary or when asked. Don't offer assistance unless it appears necessary. Some patients may become defensive when offered unsolicited assistance.

CULTURAL SENSITIVITY

Accept and respect differences, this includes backgrounds, customs, thoughts, beliefs, values, and traditions. Remember that, just as you do, patients take their values and beliefs very seriously and can become quite offended if they feel that their beliefs are not respected. You do not have to agree with someone else's beliefs or values in order to show respect to the patient.

Be aware of stereotypes and related views. Sometimes people can react towards others based on the assumption that he or she is viewed in a certain stereotypical way by another person, e.g., "I know he thinks that I can't open the door for myself because I'm disabled."

Do not label others beliefs and traditions as being right or wrong.

Remember the NIAMS CHC "Golden Rule" - Treat everyone the way you would like to be treated.

COMMUNICATIONS IN THE CLINIC

Patient PLEs should be made fully aware of how important communication is in this position. Since patients may view the PLE as an authority on certain topics, students should know what is appropriate to say and what terms or conversations should be avoided.

WHAT TO SAY AND NOT TO SAY

Your job as an escort requires much responsibility. The patients will look at you as an authoritative figure therefore it is important to learn what is appropriate to say and what is not appropriate to say.

What NOT to say

The following are key descriptive words that should be avoided in conversing with patients and patient families:

- Sufferer
- Victim
- Arthritic
- Crippling
- Unfortunate
- Pitiful
- Confined to a wheelchair

What to say

How patients and their actions are portrayed is very important.

- Instead of the above, PLEs should be encouraged to use the term **patient** or **person**.
- Using the term disabled is preferred to handicapped.
- When referring to a wheelchair, remember to always say the patient is **using** a wheelchair, NOT confined to a wheelchair.
- Avoid categorizing such things as walking up stairs or signing one's name as successes.
- Avoid calling people without disabilities normal; use the term non-disabled.
- Avoid using "quackery" when referring to alternative medicines or treatments patients may be using. Opt for unproven, untested, or non-traditional.
- Do not comment on any treatment or advice given by the medical professionals.
- Always maintain confidentiality and discretion when conversing with patients in public.

LISTENING TECHNIQUES

Many times, patients simply want someone to listen to them. Being a good listener shows that you, as a representative of the NIAMS CHC, care about the patients and their condition. Knowing that someone is available to listen to them and gives them undivided attention may help to relieve feelings of fear, apprehension, and anxiety about receiving care and treatment at the NIAMS CHC.

“I” VERSUS “YOU”

"I" messages allows for the expression of feelings of anger and frustration without blaming others or causing others to become defensive.

"You" messages tend to put others on the defensive and can block further means of communication.

(Refer to section on Role Playing)

RELATING TO PATIENTS' CHILDREN:

Patience

Entertaining and relating to children can be challenging, especially in a doctor's office. *Patience* is one of the most important attributes needed when dealing with children.

Realize that, with each child, a different approach may be needed. Some may be very active and have high levels of energy, while others may be reserved and wish to be left alone. Some may be very inquisitive and ask a lot of questions; some, especially those very young, may not want to be away from their parent, or caregiver, at all.

Ground Rules

It is important for you to remember some "ground" rules when interacting with children.

Always discourage wild play, throwing items, and running around. This presents a dangerous situation in which the child or someone else, e.g., another patient, may be injured. Do so gently but firmly.

Some examples of directional correction:

"Please don't run around. This isn't a good place for running. Someone could get hurt."

"Come, sit here with me. I have some toys (or books) you might like."

Create diversions for upset children. Items such as a comic book, children's reading book, coloring book and crayons keep children occupied.

Some examples of interactive conversations:

"Let me show you how the nurse is going to check mommy's knee."

Remember to use encouraging words like, "You are such a big girl/boy", "Wow, I really like your picture", or "Good job!" Engage them in some conversation if they are willing. Ask about favorite TV shows, colors, etc., or what they are planning to do next school year, what sports they play, an instrument, etc.

Recognize that there are some situations when you will need to enlist the help of the parent or caregiver. Feel free to ask the nurse to relay any concerns to the parent or caregiver during his/her visit in the NIAMS CHC.

Definite No-No's

Never yell, or raise your voice, at a child.

Never grab or touch a child inappropriately. Remember that certain physical contact, even something as innocent as giving a hug or a kiss to a child may be misconstrued.

Never be overly stern with someone's child. All visitors should feel that the environment in the NIAMS CHC is warm and friendly.

Never give a child food or drinks without obtaining prior approval from the parent or caregiver. Some may have serious allergic reactions to certain foods.

Remember that the NIAMS CHC staff is available at all times to support you.

Scripts and Scenarios

ROLE PLAYING

“I” messages versus “you” messages¹

“You” message examples:

Friend 1: Hurry up! ***You’re*** always late for everything. Can’t you speed it up?

Friend 2: ***You’re*** always complaining! ***You*** just can’t seem to understand that my arthritis hurts so bad I can’t move as fast as you can. ***You*** don’t think of anybody but yourself.

Friend 1: ***You’re*** always using your arthritis as an excuse for everything.

Friend 2: Well, if ***you’d*** be more considerate, I wouldn’t have to mention it so often.

¹ Lorig, Kate R.N., Dr. P.H. Arthritis Self-Help Course. Leader’s Manual and Reference Materials. Arthritis Foundation; 1995; 5.7.

ACTIVITY #7

Communication Techniques. Re-word the following statements so that they are more patient-friendly. Discuss your suggestions with the class.

Statement: You shouldn't walk so fast. You know I can't keep up!

Alternative:

Statement: Your appointment was fifteen minutes ago. The clinic has other patients who have been waiting a long time. You should keep your scheduled appointment.

Alternative:

Statement: The doctor is still with someone. You need to be patient.

Alternative:

Statement: What are you seeing the doctor about?

Alternative:

Statement: Your child is running all over the place. I can't control him.

Alternative:

ACTIVITY #8

How Can I Help? Using the information provided, discuss how you would respond.

#1

A 20 year old man is going to the pharmacist to have a prescription filled. When he attempts to converse with the pharmacist, it is evident that he has a limited ability to communicate in English. He speaks little to no Spanish. The young man obviously needs help communicating to the pharmacist that he is seeking additional information about his prescription. What can you do to help?

#2

A 50 year old man has been asked by the doctor to go to the NIH main campus for X-rays. He is willing to go, but has concerns about how much he will have to pay to take a taxi all the way to Bethesda. What can you do to help?

#3

A mother has also been asked by the doctor to go to NIH main campus to have X-rays done. It is 10:00 in the morning; however, she is concerned about getting back in time to pick up her children from daycare. She wants to know how long this is going to take. What can you do to help?

#4

An elderly woman has brought her two grandchildren with her to the clinic during an especially busy time. Both boys appear to be about 7 or 8 years old. She tells them to wait for her quietly while she sees the doctor. Once she leaves, the boys start to toss back and forth a balled up piece of paper. What can you do to help?

ACTIVITY #9

Let's Talk About It. Read the following statements and discuss how you would respond.

#1

"I hear that this clinic was opened up to get people to try some sort of research drugs. Do you know about that?"

#2

"You know, last year I started having this aching in my joints and they get kind of swollen sometimes. Someone told me it's arthritis or something. What do you think it can be?"

#3

"I don't understand why I have to see a nurse practitioner first. Why can't I see the doctor first?"

#4

"I bet this place is going to be here for about a year and then it'll be gone."

#5

"Excuse me. I want to find out how to sign up for the nutrition class. Can you help me?"

#6

Scenario: As you and Marcus, a patient at the CHC, are walking to your respective cars, he recounts to you a story of how his younger sister went to her doctor with symptoms suggesting lupus. Marcus recalls seeing you working with one of the patients, Ms. Thomas, who told you about being diagnosed with lupus. He asks you about Ms. Thomas; particularly, what she had told you about her symptoms, so he can determine if his sister was experiencing the same. What can you tell him?

ACTIVITY #10

Where Did I Go Wrong? Evaluate the following scenarios and make suggestions as to where the escort communicated inappropriately.

#1

A patient has been advised by one of the NIAMS CHC doctors to go to the NIH Clinical Center for x-rays.

Receptionist *[to escort]*: The doctor has requested that Mrs. Ramirez go to the Clinical Center for X-rays. She's waiting for you over there.

Mrs. Ramirez *[to escort]*: I haven't eaten lunch. I'm tired, I might have to do this some other day.

PLE: The doctor said you should go today. I'll wait here for you to get your things.

#2

One of the patients has brought her young daughter with her to the CHC.

Receptionist: Ms. Leonard.

Ms. Leonard: Yes, here. *[to daughter]* I'll be right back. Wait here.

Daughter *[sadly]*: Mommy, I wanna go with you.

Ms. Leonard: Wait here. I'll be back.

The daughter starts to cry.

PLE: Now, look here. We're not going to have that noise in here. Color in this book until your mom gets back.

#3

One of the patients sitting in the NIAMS CHC waiting area begins a conversation with the PLE.

Patient: I am so achy every day. My wrists hurt and they swell sometimes.

PLE: Oh no. You poor thing. I'll bet you it's arthritis. My grandmother had the same problem. You should try wearing a copper bracelet.

#4

A patient sitting in the NIAMS CHC waiting area begins a conversation with the PLE.

Patient: My uncle gave me some of his medicine to rub on my shoulders when they start to bother me. He is always looking out for me; he hates to see me in this pain.

PLE: You've got to be kidding. You shouldn't be taking someone else's medicine. Don't you know that it could be bad for you?

#5

A patient's child is sitting in the NIAMS CHC waiting area.

Child in waiting room [to PLE]: Can I have some of your chocolate candy, please?

PLE: I'll have to ask your mom when she gets back.

Child: Oh, it's okay. She always says yes. Please?

PLE: Oh, all right, then. Here, sweetie, have two.

#6

Patient: Some people get mad when I park my car because I get the convenient "handicap" spot. They just don't realize how hard it is for me. My symptoms aren't necessarily visible, you know.

PLE: I see. You look so normal to me. I would have never guessed you were handicapped. Some people are so insensitive.

GLOSSARY

Arthritis--a disease where inflammation in the joint occurs.

Autoimmune Disease--an attack initiated by the body's immune system against its own tissues.

The **Belmont Report**--establishes three fundamental ethical principles that are embodied in laws governing the use of human subjects in research. These are respect for persons, beneficence, and justice.

Biomedical Research--research that involves the investigation of questions pertaining to the medical field.

Care Protocol--a natural history study that involves providing standard and usual care to patients in order to study the history of a disease or disorder following treatment or a treatment regimen.

CHC--Community Health Center.

Connective Tissue--tissue that is the framework of the body that supports organs and tissues (joints, muscles, and joints).

DHHS--Department of Health and Human Services; a federal agency.

Experimental Protocol--a clinical trial study that involves the use of new, or previously untested, experimental treatment, screening, or medications.

Health Disparities--a social condition where the burden of illness and death is significantly higher in the United States minority populations as compared to the non-minority population.

Health Educator--an educator who is skilled in the training of individuals on health related topics.

Inflammation--swelling, redness, and pain experienced in an area of the body.

Informed Consent--The process of ensuring that patients have all pertinent information and providing them with answers to their questions and concerns about the research study prior to their consent or agreement to participate in a research protocol.

Musculoskeletal--of, or related to, the muscles and to the skeleton.

NIAMS--the National Institute of Arthritis and Musculoskeletal and Skin Disorders.

NIH--National Institutes of Health.

Nurse Practitioner--a registered nurse with at least a master's degree in nursing and advanced education in the primary care of particular groups of clients.

Rheumatic Diseases--diseases affecting the joints, bones, muscles, and skin.

Rheumatologist--an internal medicine or pediatric doctor who studies, diagnoses, and treats rheumatic diseases.

APPENDIX A
(Current Staff Names To Be Inserted)

Attending Physicians

Medical Fellows:

Clinical Research Nurses:

Nursing Assistant:

Unit Clerk:

Health Educators

**APPENDIX B
(Map Information)**

[Attach color map of NIAMSCHC]

APPENDIX C
(Transportation Information)

Modes of Transportation

Rules of Transportation

Getting To NIH Bethesda campus

Getting Around the Clinical Center

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APPENDIX D
**(Guidelines for the Conduct of Research Involving Human Subjects at the
National Institutes of Health)**

(To Be Inserted)

APPENDIX E
(Quick Overview of the NIAMS CHC and PLE Duties)

THE NIAMS CHC MISSION (SESSION 1)

The NIAMS CHC provides medical information and health care services to people 18 years and older affected by arthritis, lupus, and other rheumatic diseases.

Patients who voluntarily participate have access to medical specialists at the NIAMS CHC, and to other NIH clinical investigations concentrating on the prevention and treatment of rheumatic diseases.

The NIAMS CHC offers health information and education programs that can be utilized by everyone.

THE NIAMS CHC LOCATIONS (SESSION 2)

The NIAMS CHC will have one main facility located in the Cardozo/Shaw area, and two outreach sites in downtown northwest and in northeast Washington, D.C. These locations are as follows:

Main Facility

NIAMS CHC (Cardozo/Shaw)
Unity Health Care's Upper Cardozo Health Center
3020 14th Street, N.W.
Washington, D.C. 20019
(202) 673-0000 (receptionist)
(202) 673-0012 (fax)

Metro Stop: Columbia Heights (**Green** Line)

National Institutes of Health Main Campus

Some patients will need to go to the NIH main campus for certain services.
The address is:

National Institutes of Health (NIH)
Clinical Center
9000 Rockville Pike
Bethesda, MD 20892

Metro Stop: Medical Center (Red Line)

THE NIAMS CHC HOURS (SESSION 2)

The hours at the Cardozo/Shaw location are:

Monday, Tuesday, and Thursday from 8:00AM - 5:00PM

Wednesdays from 11:00AM - 7:00PM

The NIAMS CHC will be accepting appointments as well as walk-ins.

THE NIAMS CHC STAFF (SESSION 2)

The staff in the NIAMS CHC consists of:

Rheumatologists	Medical Fellows
Nurse Practitioners	Registered Nurses
Nursing Assistant	Clerical Staff
Health Educators	

PLE DUTIES (SESSION 2)

The general duties of the PLE are summarized briefly below. In addition to these, the PLE will be flexible and assist the patients and staff as needed.

1. Provide assistance and aid to patients being treated at the NIAMS CHC. This includes sitting and talking with patients, escorting them between the NIAMS CHC and the NIH, in Bethesda, Maryland, if needed, and conveying any of the patient's concerns or questions to the medical staff.
2. Communicate with a diverse population of patients, and maintain a friendly and open environment while working with patients.
3. Be aware of the medical evaluation activities and process at the NIAMS CHC and communicate this process to patients.
4. Learn about rheumatic diseases, their signs and symptoms, and the treatment at a layperson's level, and communicate this information to the patients and their relatives or friends, at the patient's request.
5. Maintain an open line of communication with the NIAMS CHC staff and refer patients' medical questions and concerns to the appropriate staff member.

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Resource

Folder