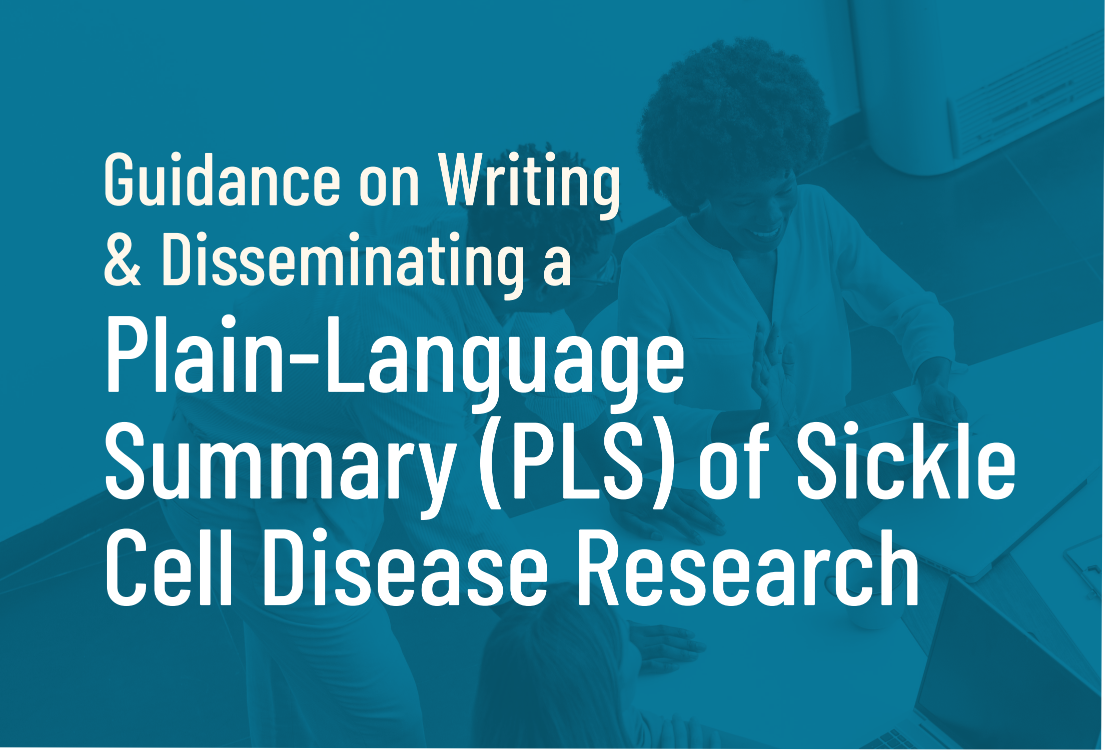

Guidance on Writing & Disseminating a Plain-Language Summary (PLS) of Sickle Cell Disease Research

SICKLE CELL DISEASE COALITION

This resource guides users through creating and sharing information about sickle cell disease research. Users will find important background information, instructions and tips, and interactive components to aid in crafting a plain-language research summary. These interactive tools can be found in Section 4 and include checklists for ensuring inclusion of necessary components, fillable templates, a glossary of key terms, and more.

Table of Contents:

1. What is a Plain-Language Summary?

A plain-language summary or summaries (PLS) are brief, easy-to-read descriptions of a research study written for people who do not have a background in science, nor specialized knowledge on the research topic. A PLS is an important tool for explaining what a study is designed to achieve as well as the results of a study after its completion. A PLS can be utilized to communicate about any type of study and studies of any size.

A PLS aims to clearly communicate key takeaways from a research study, such as:

- **What** the study aims to accomplish/accomplished
- **Why** the study is important to different stakeholders—from patients to doctors to advocates
- **How** the findings from the study can be utilized in the future

PLS can be utilized to promote community-engaged research throughout the research lifecycle, during planning, conducting, as well as disseminating a study (See Section 3 to learn about using a PLS at each stage).

Most PLS are usually written as a short paragraph with **less than 300 words**, using clear and simple language. When possible and appropriate, it is also recommended that a PLS feature **infographics, data tables, and/or other visual content** to convey important takeaways from the study.

Digital formats of communication, like videos and podcasts, are also becoming more popular and effective for creating and sharing PLS.

2. Why Are PLS Important for Sickle Cell Disease (SCD) Research?

Raise awareness of the research study, SCD, and recent advancements in knowledge.

Highlight key takeaways from the study and explain its significance to a wider audience.

Identify how the study's findings may be applied to advance SCD policy, practice, and future research.

Build public trust in, and support of, SCD research and investment in programming.

Demonstrate accountability to research contributors, donors, and funders.

Facilitate community-engaged research.

3. When Can PLS Be Used Throughout the Research Process?

Use a PLS when ***planning a study*** to:

- **Engage** research partners, sponsors, and other key stakeholders within the SCD community to support the study.
- **Demonstrate** the study's objectives and potential impact to key stakeholders.
- **Refine** the research question, study design, and/or outcomes of interest with key stakeholders.

Use a PLS when ***conducting a study*** to:

- **Recruit** research participants.*
  *Advanced review and approval by the researcher's Institutional Review Board (IRB) required

Use a PLS when ***disseminating a study*** to:

- **Promote** publication of the research and the topic of interest.
- **Communicate** the study's findings and impact on the field to diverse stakeholders.

KEY TERMS:

- **Stakeholder:** A person, group, or organization that can affect or be affected by a research study, including patients, caregivers, health care providers, health systems, policy makers, advocates, and funders.
- **Research Partner:** An individual or institution outside of the core research team that offers expert, community-based guidance, and collaboration in leading the study.
- **Research Sponsor:** An individual or institution that provides financial or other material support for a research study.
- **Research Participant:** An individual that consensually participates in a study by completing assigned research activities.

4. How do I write a plain-language summary on SCD research?

Use the chart below in **4A** for a step-by-step guide alongside the fillable templates that follow in **4B**.

4.A. Steps & Checklists for Writing a Plain-Language Summary (PLS)

Step 1:

Clarify Your Objective

Consider why you are writing this PLS and how you would like to utilize it.

☐ **Define your objective(s) for writing and disseminating this PLS.**

- Why are you are writing this PLS? (Announce a new study or share the results of a completed study? Garner interest in your specific area of research?)
- What would you like for it to accomplish? (Increase understanding of your area of research? Reach potential clinical trial participants?)

See Section 3. "When can plain language summaries be used throughout the research process?" for ideas of potential use-cases.

☐ **Partner with community members to create the PLS.**

- Engage individuals living with sickle cell to guide the creation of the PLS through one-on-one interviews or brief online surveys.
- Gain their insights on how they would use a PLS, which key messages resonate, and how best to disseminate a PLS by asking what types of information, formatting, and distribution methods are helpful.

☐ **Identify which key messages are important to communicate.**

- What would you like the reader to learn and/or what would you like to motivate the reader to do?

Step 2:

Identify Target Audience

Think about who you would most like to engage in your research and how to best do so.

☐ **Based on the previously defined objective(s), identify the target audience for this PLS.**

- Who should know about this research study?
- Who is best suited to help you meet your defined objectives?

☐ **Identify any outcomes or other study components that would be of most interest to the target audience.**

- What finding or other aspect of this study would interest this audience most?
- Why should this target audience know about this study?

☐ **Assess the target audience's current level of knowledge of the research topic and sickle cell.**

- Is the target audience familiar with the study population and/or research topic?
- How much context and background information will this audience need?

☐ **Explore the target audience's preferred communication style.**

- Does the target audience read more written articles, or do they primarily use social media?
- Do any images or vernacular resonate more with the target audience than others?

See Section 4.C. "Worksheet to Target Audiences When Writing & Disseminating Research" for additional ways to identify and understand your readers.

Step 3:

Outline the PLS

Prioritize what information and key messages you would like to communicate.

☐ Draft a title for the PLS that reflects the identified key message(s) and target audience.

- Write out 6 to 10 key words found in the abstract and string them into various sentences. Once you have one sentence that adequately conveys the meaning of the work, try to condense it into a title while still conveying the essential message.
- Include the main, "headlining" aspects of the study that are most impactful to the target audience.

☐ Identify the key content that must be included.

When writing a **pre-intervention PLS**, focus on study objectives, study rationale and design, and take-home messages by answering the following questions:

What are the primary aims of the study?

- » What does this study aim to accomplish?
- » What are the primary questions raised in the study?

What are the scientific and clinical justifications for the study?

- » Why is this study needed (e.g., existing treatments are too expensive or have side effects; this investigational medicine has never been tested before; this investigational medicine needs to be tested for interactions with existing drugs; to examine why patients seek certain types of care; to understand the role of caregivers)? If relevant, summarize previous research that informs this study.
- » How is this intervention the same as or different from current therapies or approaches?
- » How is this study important to the target audience(s)?
- » What is the potential impact(s) of this research on the SCD community?

What does the study involve?

- » Who may be eligible for inclusion in the study?
- » What are study participants required to do for the study (e.g., how many visits, does it involve an investigational medicine, how does the study impact their current treatment plan if they have SCD)?
- » What type of study is it (e.g., case controlled)?
- » Were there any incentives (if relevant) for enrollment?
- » What were the risks and potential benefits of the study?
- » What safety precautions were implemented during the study (as relevant, e.g., IRB review, DSMB, supportive care during the study)?

Who are the partners and/or funders?

- » Who is a partner in conducting the research (e.g., a university, clinic, company, or nonprofit or community-based organization)?
- » Who is sponsoring or funding the study?

continued on next page

Step 3 continued

When writing a **post-intervention PLS**, focus on study rationale, key results, conclusions, and take-home messages by answering the following questions:

What were the primary aims of this study?

- What did this study aim to accomplish?
- What are the primary questions raised in the study?

What were the scientific and clinical justifications for the study?

- Why was this study needed?
- How is this intervention the same as or different from current therapies or approaches?

What did the study involve?

- What was the study design (e.g., case controlled)?
- What was the intervention (e.g., an investigational medicine, a survey to complete)?
- Who was included?
- How long did the study last, how many visits were required, what were the length and nature of those visits, and what type of follow-up is required?
- Were there any incentives (if relevant) for enrollment?
- What were the risks and potential benefits of the study?
- What safety precautions were implemented during the study (as relevant, e.g., IRB review, DSMB, supportive care during the study)?

What are the results of the study?

- Within the boundaries of the study, what are the possible answers to those questions?
- What did the study findings show?
- How can findings from this study be applied to the real world and/or be used in the future?
- What is the potential impact(s) of this research on the SCD community?

Who were the partners/funders of the study?

- Who was a partner in conducting the research (e.g., a university, clinic, company, or nonprofit or community-based organization)?
- Who sponsored or funded the study?

Step 4:

Draft the PLS Content

Focus on how you want to communicate this information.

☐ Organize content into a clear, easy-to-understand structure.

- Structure the PLS so that the information flows together and makes sense to the reader.
- A sample outline for consideration is shared below:
  - » **Introduction (1 sentence)** – Offer the "bottom line up front" by clearly stating the focus of this study and why it is important.
  - » **Topic Overview (1-3 sentences)** – Provide any essential background information that a non-specialist would need to know to understand your research, both in the context of science and society.
  - » **Study Overview (1-3 sentences)** – Explain what the study aims/aimed to discover and how the researchers aim/aimed to do it.
  - » **Study Summary (Pre-Intervention) OR Findings Summary (Post-Intervention) (1-3 sentences)** – Summarize what the study will entail for participants OR summarize your findings at a high-level. Highlight 1-2 data points of most interest to this audience.
  - » **Key Takeaways (1-2 sentences)** – Explain the scientific importance or societal relevance of your research and why it should specifically matter to the target audience(s).

☐ Write in a clear, easy-to-understand manner.

- Use short, simple sentences that do not exceed 20 words.
- Use active voice and strong verbs.
- Do not assume readers' medical or scientific knowledge.
- Avoid using technical jargon, research terms, or unnecessary acronyms. Define any complex terms that you must use.
- Explain all acronyms and do not use more than 3.
- Be consistent with terminology and formatting throughout the document.
- Do not add unnecessary information.
- Try to write the full PLS in 300 words or less.

☐ Use community-centered terminology.

- Use first person pronouns, like "you" and "I", to be direct, clear, and friendly in your writing.
- Use terms that your target audiences are familiar with in their patient or caregiving settings.
- Consider language requirements while addressing your specific population's health needs.

See Appendix: **Glossary of Plain-Language & Community-Centered SCD Research Terms**.

continued on next page

Step 4 continued:

☐ **Present data concisely and clearly to prevent misinterpretation.**

- The reader should not be expected to do any calculations; only essential numbers should be included.
- Whole numbers should be used and displayed either as absolute numbers, percentages, or natural frequencies (e.g., 1 out of 10 people).
- Denominators and timeframes should be consistent throughout.
- Avoid complicated statistics.
- Only include data that is consistent with the data included in the scientific article.
- Clearly title all graphics and tables used and ensure that all variables are properly labeled.

☐ **Use format and design elements to help the reader digest the content.**

- Use headings, tables, text boxes, and graphics to enhance clarity, help readers skim, and highlight important information, such as study findings.
  - » Choose icons to help illustrate ideas, such as a medicine bottle if the study involves taking a pill.
  - » Use a non-editable format such as PDF so that any design elements do not move in the printing or sharing of the file, and wording can't be changed.
  - » Make sure that the PLS is accessible for all users, including those with disabilities that impact vision (e.g., a text reading tool will require that images include accompanying explanatory text).

Step 5:

Conduct Quality Reviews to Refine & Finalize the PLS

Consider how the target audience will interpret this information and opportunities for improvement.

☐ Review your draft PLS for the following:

- Clarity of the article to non-specialists
- Use of active voice and first-person language
- Correct spelling, grammar, and punctuation
- Inclusion of clear definitions for all acronyms or technical terms in PLS
- Limit to no more than 3 different acronyms throughout PLS
- Inclusion of appropriate formatting devices, such as a publication date and page numbers
- Consistency in formatting throughout the document
- Length, and trim if need be

☐ Conduct an external review of the draft PLS with a member of your target audience.

- Engage external reviewer(s) to ensure clear and effective communication.
- Ask the external reviewer(s) to:
  - » Read the draft PLS and examine any graphics or icons,
  - » Explain their interpretation of the document, and
  - » Offer feedback on ways to improve its clarity and impact.
- Incorporate their feedback into your draft to improve the PLS.

☐ Calculate the reading level and accessibility of your PLS.

- Write plain-language content at no higher than an 8th grade reading level.
- For any complex medical terms that can't be shortened or avoided, include a definition.
- Use an online readability tool to calculate your text and guide any necessary adjustments:
  - » **Automatic Readability Checker – Readability Formulas**
  - » **Measure the Readability of Text - Text Analysis Tools - Readable**
  - » **Readability Test – WebFX**

☐ Determine if you will need to translate the PLS into a different language(s) to meet the needs of your target audience.

- Review information about your target audience, gathered in Step 2, to determine language preferences.
- Engage a translation service or a staff member with translation skills, and ask a representative member of your target audience about preferred terminology (e.g., can the term "doctor" be used to mean all types of health care providers or solely a physician?).

4.B. Templates for Writing a Plain-Language Summary: Pre-Intervention & Post-Intervention

1. Writing a Plain-Language Summary: Pre-Intervention

INSTRUCTIONS

Before drafting the PLS, complete **Steps 1 and 2** of the **Steps & Checklists for Writing a Plain-Language Summary in Section 4.A.** to clarify your objective(s) and learn how to identify the target audience(s). A **Worksheet to Identify Target Audiences When Writing & Disseminating Research** is also available in **Section 4.C.** to help you determine audience(s) for your PLS. Complete this pre-intervention template using the checklists in **Section 4.A** as you proceed. At the end of this template is a sample outline to help pull the content together in a structured and organized manner.

After drafting the PLS, conduct **Step 5** in Section 4.A, "Conduct Quality Reviews to Refine & Finalize the PLS."

FILLABLE TEMPLATE WITH TIPS AND GUIDANCE

TITLE

Draft a title for the PLS that reflects the identified key message(s) and target audience. Keep it short and concise, so that the reader knows precisely what the topic is from the title.

See Step 3 of Section 4.A.

Title:

____

____

____

PRIMARY AIMS OF THIS STUDY

Describe the overall study objective(s), highlighting important aspects of this study and why the reader(s) might be interested in it. Organize the content into a clear, easy-to-understand structure. Craft clear sentences using community-centered terminology.

See Steps 3 and 4 of Section 4.A.

***See Appendix:* Glossary of Plain-Language & Community-Centered SCD Research Terms**

Primary Aims of This Study:

SCIENTIFIC AND CLINICAL JUSTIFICATIONS FOR THE STUDY

Explain why the study is important to the Sickle Cell Disease community. Provide clear context for the rationale for the study, such as the need for less expensive treatments or the need to understand care-seeking patterns.

See Step 4 of Section 4.A.

See Appendix: Glossary of Plain-Language & Community-Centered SCD Research Terms

Scientific and Clinical Justifications for This Study:

WHAT DOES THE STUDY INVOLVE?

Using clear language, describe the research strategy at a high level. Infographics or icons can be useful to help illustrate information about the study, including the type of study design and study requirements for participants.

See Step 4 of Section 4.A.

See Appendix: Glossary of Plain-Language & Community-Centered SCD Research Terms

What Does the Study Involve?

PARTNERS, FUNDERS, AND CONTACT INFORMATION [if relevant]

If relevant, identify partners in this study, such as a university, clinic, company, CBO or nonprofit. Provide contact information in case anyone would like to learn more about the study.

Partners, Funders, and Contact Information:

SAMPLE OUTLINE

Structure the PLS so that the information flows together and makes sense to the reader.

- **Introduction (1 sentence)** – Offer the "bottom line up front" by clearly stating the focus of this study and why it is important.
- **Topic Overview (1-3 sentences)** – Provide any essential background information that a non-specialist would need to know to understand your research, both in the context of science and society.
- **Study Overview (1-3 sentences)** – Explain what the study aims to discover and how the researchers aim to do it.
- **Study Summary (1-3 sentences)** – Summarize what the study entails for participants.
- **Key Takeaways (1-2 sentences)** – Explain the scientific importance or societal relevance of your study and why it should specifically matter to the target audience(s).

2. Writing a Plain-Language Summary: Post-Intervention

INSTRUCTIONS

Before drafting the PLS, complete **Steps 1 and 2** of the **Steps & Checklists for Writing a Plain-Language Summary** in **Section 4.A.** to clarify your objective(s) and learn how to identify the target audience(s). A **Worksheet to Identify Target Audiences When Writing & Disseminating Research** is also available in **Section 4.C.** to help you determine audience(s) for your PLS. Complete this post-intervention template using the checklists in **Section 4.A.** as you proceed. At the end of this template is a sample outline to help pull the content together in a structured and organized manner.

After drafting the PLS, conduct **Step 5** in **Section 4.A.**, "Conduct Quality Reviews to Refine & Finalize the PLS."

FILLABLE TEMPLATE WITH TIPS AND GUIDANCE

TITLE

Draft a title for the PLS that reflects the identified key message(s) and target audience(s). Keep it short and concise, so that the reader knows precisely what the topic is from the title.

See Step 3 of Section 4.A.

Title:

PRIMARY AIMS OF THIS STUDY

Describe the overall study objective(s), highlighting important aspects of this study and why the reader(s) might be interested in it. Organize the content into a clear, easy-to-understand structure. Craft clear sentences using community-centered terminology.

See Steps 3 and 4 of Section 4.A.

See Appendix: **Glossary of Plain-Language & Community-Centered SCD Research Terms**

Primary Aims of This Study:

SCIENTIFIC AND CLINICAL JUSTIFICATIONS FOR THE STUDY

Explain why the study is important to the Sickle Cell Disease community. Provide clear context for the rationale for the study, such as the need for less expensive treatments or the need to understand care-seeking patterns.

See Step 4 of Section 4.A.

See Appendix: **Glossary of Plain-Language & Community-Centered SCD Research Terms**

Scientific and Clinical Justifications for This Study:

WHAT DID THE STUDY INVOLVE?

Using clear language, describe the research strategy at a high level. Infographics or icons can be useful to help illustrate information about the study, including the type of study design and study requirements for participants.

See Step 4 of Section 4.A.

See Appendix: Glossary of Plain-Language & Community-Centered SCD Research Terms

WHAT DOES THE STUDY INVOLVE?

STUDY RESULTS

Describe at a high level the research findings (e.g., primary and secondary outcomes, side effects or adverse events), and explain how the audience can learn more about the research results.

See Step 4 of Section 4.A.

See Appendix: Glossary of Plain-Language & Community-Centered SCD Research Terms

Study Results:

PARTNERS, FUNDERS, AND CONTACT INFORMATION [if relevant]

List relevant partners and funders of this study, e.g., university, clinic, company, CBO, nonprofits.

Partners, Funders, and Contact Information:

SAMPLE OUTLINE

Structure the PLS so that the information flows together and makes sense to the reader.

- **Introduction (1 sentence)** – Offer the “bottom line up front” by clearly stating the focus of this study and why it is important.
- **Topic Overview (1-3 sentences)** – Provide any essential background information that a non-specialist would need to know to understand your research, both in the context of science and society.
- **Study Overview (1-3 sentences)** – Explain what the study aimed to discover and how the researchers aimed to do it.
- **Findings Summary (1-3 sentences)** – Summarize the results of the study.
- **Key Takeaways (1-2 sentences)** – Explain the scientific importance or societal relevance of your study and its findings, and why it should specifically matter to the target audience(s).

4.C. "Worksheet to Target Audiences When Writing & Disseminating Research"

INSTRUCTIONS

Review **Step 2** of the **Steps & Checklists for Writing a Plain-Language Summary** in **Section 4A** to learn how to identify the target audience(s). Use this worksheet to document answers to important questions to ensure that the PLS both meets your objectives while meeting the needs of readers.

- Who should know that this study is being conducted or has been completed (e.g., patients, caregivers, or health care professionals)?
- Who is best suited to help you meet your objectives in communicating about the study (e.g., community-based organizations, caregivers, or health care professionals)?
- Who is most affected by the results of the study (e.g., patients, caregivers and families, health care professionals, funders, or other researchers)?

Target Audience(s):

1) ______________________________
2) ______________________________
3) ______________________________

Identify a representative(s) of your target audience(s) to consult before drafting, after drafting but before dissemination, or both to determine if the PLS meets your communications objectives.

1) ______________________________
2) ______________________________
3) ______________________________

- How knowledgeable is your target audience(s) about the topic of the study (e.g., are they longtime sickle cell disease patients, health care professionals, or individuals new to caring for someone with sickle cell disease)?
- How familiar is your target audience(s) with sickle cell disease terminology (e.g., are they longtime sickle cell disease patients, health care professionals, or individuals new to caring for someone with sickle cell disease?)?
- What types of communications tools work best for your target audience(s) (e.g., printed materials, or website or social media content)?
- Will your target audience require the PLS to be translated into another language or are there other accessibility needs to consider (e.g., do members of the target audience primarily speak another language, or will a text reader or high-color contrast be needed for individuals who are visually impaired)?

5. How do I disseminate a plain-language summary on SCD research?

A PLS provides important insights into advances in sickle cell disease, however its value is inherent in reaching intended target audiences. At the same time, many researchers and organizations do not have the staff or resources to widely market materials. The guidance below offers tips for disseminating PLS, serving as a condensed version of the Sickle Cell Disease Coalition's SCD Strategic Dissemination Model (a full version is available for distribution).

While the full dissemination model includes 5 phases, the steps related to defining objectives, identifying target audiences, and tailoring methods (Phases 1, 2, and 3) have already been addressed in this document. The tips below focus on Phases 4 and 5, identifying opportunities to disseminate PLS and measuring dissemination efforts.

1. **DEFINE OBJECTIVE** ✓
2. **TARGET AUDIENCES** ✓
3. **TAILOR METHODS** ✓
4. **IDENTIFY OPPORTUNITIES**
5. **PLAN EVALUATION**

Phase 4: Identify Opportunities

To help identify opportunities to disseminate a PLS, consider the categories and questions below.

☐ Events

- What events does your target audience regularly attend?
- What events focus on sharing information and resources related to the topics of your PLS?
- Do these events typically occur in-person or virtually?
- Are there opportunities to table/exhibit, present, or otherwise share your work?

Examples: Awareness events, scientific/educational symposia, fundraisers, webinars, and training workshops

☐ Holidays

- What awareness days relate to the material you're sharing and defined call to action or key takeaway messages?
- What national, international, and or/religious holidays connect to this material, if any?

Examples: International Clinical Trials Day (May 19), World Blood Donor Day (June 14), World Sickle Cell Day (June 19), National Sickle Cell Awareness Month (September), and Human Rights Day (December 8)

☐ Networks

- What communities and small group initiatives exist within your target audience(s)?
- What established programs, initiatives, and organizations does your target audience already look to for guidance related to your material/topic?
- What information sharing opportunities and tools already exist within these communities?

Examples: Professional societies/associations, volunteer groups, support groups, organizational newsletters/social media accounts, online discussion boards, and training programs and cohorts

☐ Influencers

- Have any celebrities spoken about this topic?
- Are there any high-profile activities, industries, or events related to this material to engage as a spokesperson?

Examples: Athletes/sports, singers/music, actors, entrepreneurs and non-medical business, and authors/thought leaders

Phase 5: Plan Evaluation

Phase 5 of this model, the last, involves determining how you will evaluate the effectiveness of your dissemination. This crucial step will help identify what worked as well as what didn't, helping you refine your strategy for future dissemination efforts. Please consider the five subcomponents below and their accompanying questions to help you develop your evaluation plan.

☐ Methods

Decide which questions you will ask to evaluate your dissemination efforts and how you will use the answers. Look back at both *how* you disseminated the PLS and the *effectiveness* of the PLS itself. Consider these sample questions:

Process (Evaluating *how* you disseminated the PLS)

- How was the material disseminated/made available?
- Was the material received by target audiences?
- Were there any barriers to audiences receiving the material?
- Who is using the material (and with whom are they sharing it)?

Outcomes (Evaluating the effectiveness of the PLS)

- Did the target audience understand what the resource intended to convey?
- Did the material achieve the intended objective?

☐ Metrics

Decide which data is useful for evaluating the reach resulting from dissemination efforts.

- In what ways can dissemination be measured (e.g., number of hard copies of the PLS distributed, number of website downloads)?
- What tools will you use to gather information (e.g., surveys, Google analytics)?

☐ Data Collection

Decide how to gather data to best serve dissemination efforts.

- Who will be responsible for collecting data (e.g., the lead researcher or a member of the study staff)?
- How should metrics be collected and compiled (e.g., excel)?
- How frequently and for how long should metrics be collected (e.g., quarterly or annually)?

☐ Reporting

Consider how best to document the data collected to reflect on and improve dissemination efforts.

- What format should be used for the report (e.g., a narrative summary or a presentation)?
- How frequently should a report be compiled (e.g., annually, or after each dissemination)?

☐ Refinement

Learn from the evaluation findings to improve dissemination strategies for subsequent PLS.

- Does the content of the PLS need to be corrected or changed (e.g., does terminology or the format need to be changed)?
- What actions can help improve reach, engagement, and use of PLS (e.g., finding additional health care settings to target)?
- Who or what groups need to make the decisions to act on feedback (e.g., a board, research funders, or outreach team)?
- Are there any lessons learned that can be applied to future PLS (e.g., are there better ways to track use or are there organizations missing from distribution lists)?

Appendix

Glossary of Plain-Language & Community-Centered SCD Research Terms

SICKLE CELL DISEASE TERMS TO KNOW:

Acute Chest Syndrome: A condition caused by fast-onset chest pain, cough, fever, and difficulty breathing. It is a potentially life-threatening complication of SCD.

Acute Hypoxemia: Sudden decrease of oxygen in the blood.

Amniocentesis: A test for sickle cell disease and sickle cell trait conducted during pregnancy (15-20 weeks).

Anemia: Low red blood cell (the part of the blood that carries oxygen) levels.

Avascular Necrosis: When poor blood supply to an area leads to bone death.

Carrier: Someone who has the gene for a disease but does not show symptoms. For example, people with only 1 abnormal hemoglobin gene are carriers/have sickle cell trait.

Cerebral Ischemia: A type of stroke where there is not enough blood flow to the brain.

Cerebral Vasculopathy: When a blood vessel in the brain or spinal cord becomes inflamed and less able to carry oxygenated blood to tissue.

Chorionic Villus Sampling: A test using a thin needle that tests cells for hemoglobin S and sickle cell trait during pregnancy (10-13 weeks).

Chromosomes: Coiled DNA around proteins called histones.

Chronic Care Model: A way to support and care for people with chronic diseases in a primary care office.

Chronic Splenomegaly: Enlargement of the spleen, which can be caused by obstructed blood flow.

Cirrhosis of the Liver: Late-stage scarring in the liver.

Comorbidities: When a person has two or more chronic diseases.

Crizanlizumab: A drug that prevents vaso-occlusive crises (pain crises) in people with sickle cell anemia.

Dactylitis: Painful swelling of the hands and feet caused by blocked blood flow to the small bones in the extremities.

Exchange Transfusion: A blood transfusion where some of your blood is replaced by the blood of a donor.

Fetal Hemoglobin (Hgb.F): Normal hemoglobin found in newborn babies and decreases in quantity with age. This hemoglobin doesn't allow the red blood cells to sickle.

Functional Asplenia: When the spleen is present but doesn't work, a symptom of sickle cell disease.

Gallstone: When pieces of solid material form in the gallbladder, a complication in sickle cell disease.

Gene: A part of DNA that instructs the body to produce a certain protein. A person gets ½ of their genes from each of their parents.

Genetic Counseling: A process that teaches people about their genetic conditions and helps them make informed decisions about treatment, having children, and testing.

Genetic Mutation: A change in the make-up of a gene, which affects the chromosome that the gene is on and the DNA make up.

HbSC: A type of sickle cell disease where someone inherits on HbS gene (sickling hemoglobin) and one HbC gene (abnormal hemoglobin).

HbSS: A type of sickle cell disease called sickle cell anemia where someone has two copies of the sickling hemoglobin (HbS) gene.

Hematologist: A doctor who manages blood disorders.

Hematopoietic Stem Cell Transplantation: Also known as a bone marrow transplant, this procedure replaces unhealthy bone marrow/stem cells with health stem cells.

Hematuria: Blood in the urine.

Hemoglobin A: Normal hemoglobin in adults made up of 2 alpha globin units and 2 beta globin units.

Hemoglobin Electrophoresis: A way to determine what kind of hemoglobin a person has.

Hemoglobin S: Sickling hemoglobin where the beta globin subunit is mutated, causing it to clump together and results in a sickle-shaped red blood cell.

Hemoglobin: A protein in red blood cells that gives them their red color and carries oxygen to different parts of the body through the blood.

Hemolysis: Rupture of a red blood cell.

Hemophilia: A blood disorder that results in the inability for the blood to clot (usually because of a lack of a coagulation factor).

Hydroxyurea: A medication that people with sickle cell disease can take to help their red blood cells stay rounder and more flexible. This is because the medication increases the amount of fetal hemoglobin in the blood.

Inherit: To acquire traits from a parent.

Ischemia Reperfusion: Injury to tissue caused by blood flowing back to an area that was previously hypoxic (a lack of blood flow/oxygen supply).

Jaundice: Yellowing of eyes and skin that can result from many red blood cells burst over a short period of time.

Ketorolac: A medication used to treat severe chronic pain.

Malaria: A disease transmitted by mosquitoes through the blood. Having one copy of HbS (sickle cell trait) protects someone from malaria.

Methylprednisolone: A medication used to suppress the immune system and reduce inflammation.

Myelosuppression: When the bone marrow has decreased activity, which results in a lack of red and which blood cells, as well as platelets.

Pain Crisis: When sickled blood cells block blood vessels and causes extreme pain (also known as a vaso-occlusive crisis).

Platelets (thrombocytes): A part of blood that contributes to clotting.

Pre-eclampsia: A serious condition during pregnancy that is characterized by high blood pressure.

Priapism: A painful erection that lasts a long time caused by sickled red blood cells blocking blood flow.

Recessive Trait: A trait that only is expressed if an individual has two copies of the gene. Sickle cell disease is a recessive trait because a person has to inherit two copies of abnormal hemoglobin to acquire the disease.

Red blood cells (erythrocytes): Round and flexible (when healthy) blood cells that contain hemoglobin (a pigment that transports oxygen to tissues and carbon dioxide away from tissues).

Sickle Cell Anemia: The most common and severe type of sickle cell disease. It occurs when an individual has two copies of the HbS gene.

Sickle Cell Disease: A group of disorders that result in a person's red blood cells becoming rigid and sickle shaped. These abnormal red blood cells don't live as long and are less efficient at carrying oxygen throughout the body.

Sickle Cell Trait: When a person has one copy of HbS (sickling hemoglobin) and one copy of HbA (healthy hemoglobin).

Sickle: A c-shaped farm tool. This is what red blood cells in people with sickle cell disease look like.

Splenic Infarction: When blood flow to the spleen is blocked, potentially by sickled red blood cells getting caught in a blood vessel.

Splenic Sequestration: When red blood cells get caught in the spleen, leading to enlargement and a lack of blood going to the rest of the body.

Thalassemia: An abnormal gene in red blood cells which impairs their ability to produce hemoglobin (a protein that carries oxygen).

Transfusion: Giving someone healthy blood.

Transplant: When an organ or tissue group is replaced. Bone marrow transplants can cure someone of sickle cell disease.

Unusual Hemoglobin: Any hemoglobin besides A or F.

Venous Thromboembolism: A blood clot that forms in a vein.

White blood cells (leukocytes): Cells that help the body fight disease and are a part of the blood along with red blood cells, platelets, and plasma.

CLINICAL TRIAL TERMS TO KNOW:

Clinical Research: Research that involves people to test medical treatments.

Clinical Trial: A study with human subjects that are assigned to various interventions to test the effects and outcomes of a treatment.

Diagnostic Trial: A type of clinical trial that aims to find better ways of diagnosing a certain condition or illness.

Double-Blind Study: When neither the researchers nor the human subjects know which intervention is given to what group.

Healthy Volunteer: When the human subject in a clinical trial has no known significant health conditions.

Inclusion/Exclusion Criteria: Factors that allow or disallow someone to participate in a clinical trial.

Informed Consent: Explanation of the potential risks and benefits of enrolling in a clinical trial. This is a necessary step in the enrollment process.

Natural History Studies: A type of clinical trial that aims to provide information ab how disease and health progress over time.

Patient Volunteer: When the human subject in a clinical trial has the medical condition that the researchers are studying.

Phase 1 Trials: When an experimental drug is tested on a group of 20-80 human subjects to evaluate its safety and effects.

Phase 2 Trials: When an experimental drug is tested on a group of 100-300 human subjects to evaluate how well it treats a condition and its safety.

Phase 3 Trials: When an experimental drug is tested on a group of 1,000-3,000 human subjects to confirm its effectiveness, evaluate side effects, and compare it to other treatments.

Phase 4 Trials: When a drug is further evaluated after it has been approved by the FDA.

Placebo: A substance that looks the same as the treatment but has no active ingredients.

Prevention Trials: A type of clinical trial with the aim of finding effective ways to prevent a disease from occurring or returning in a patient population.

Protocol: The plan in a clinical trial that is designed to answer research questions and upkeep the patients' health.

Principal Investigator: A doctor who leads the clinical trial and monitors the health of the human subjects.

Quality of Life Trials: A type of clinical trial that aims to improve the quality of life of those with chronic conditions.

Randomization: An important part of an effective clinical trial in which treatments and/or placebos are randomly assigned across subject groups.

Research Participant: Individual that consensually participates in as study by completing assigned research activities.

Research Partner: An individual or institution outside of the core research team that offers expert, community-based guidance, and collaboration in leading the study.

Research Sponsor: Individual or institution that provides financial or other material support for a research study.

Screening Trials: A type of clinical trial with the aim to find better ways to detect a given disease.

Single-Blind Study: When the researchers are aware of the treatment each participant is receiving but the subjects are not given that information.

Stakeholder: A person, group or organization that can affect or be affected by a research study, including patients, caregivers, health care providers, health systems, policy makers, advocates, and funders.

Treatment Trials: A type of clinical trial that tests new treatments for a given disease.

SICKLE CELL
DISEASE
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