INFORMED CONSENT INFORMATION SHEETS
PATIENT AND CAREGIVER

Refinement and Pilot Testing of the "My Health Priorities" Program for Rural and Underserved Older Adults with Multiple Chronic Conditions in the Deep South (MyHP-South)

Principle Investigator: Deborah Ejem, Ph.D.

Sponsor: The University of Alabama at Birmingham

Protocol Number: IRB-300016725

NCT Number: Not Available

Approval Date: September 17, 2026

UAB IRB
Approved
17-Sep-2026
until
16-Sep-2027

INFORMATION SHEET FOR A RESEARCH STUDY
PATIENT

Title of Research: Refinement and Pilot Testing of the My Health Priorities Program for Rural and Underserved Older Adults with Multiple Chronic Conditions in the Deep South (MyHP-South)

UAB IRB Protocol #: IRB-300016725

Principal Investigator: Deborah Ejem, PhD

Sponsor: National Institute on Aging

General Information	You are being asked to take part in a research study. This research study is voluntary, meaning you do not have to take part in it. The procedures, risks, and benefits are fully described further in this table.
Purpose	The study will test whether MyHP-South is feasible, acceptable, and useful for older adults with multiple chronic conditions and their family caregivers.
Duration	Your participation will last about 12 weeks and require approximately 4 to 5 hours.
Overview of Procedures	You will complete telephone questionnaires, participate in a MyHP-South session with your caregiver, complete post-session questionnaires and a joint acceptability interview, use your health priorities template at a primary care visit, and complete telephone questionnaires again
Risks	Some questions may make you feel uncomfortable. There is also a small risk to loss of confidentiality
Benefits	You may not benefit directly. What we learn may help improve healthcare communication for others.
Alternatives	The alternative is to not participate in this study

Purpose of the Research Study

We are asking you to take part in a research study because you are age 65 or older, have multiple chronic health conditions, and live in a rural or underserved community. The purpose of this study is to test MyHP-South, a paper-based program that helps people identify what matters most to them and communicate their health priorities when making healthcare decisions.

The Aim 2 pilot will enroll approximately 20 older adults and 20 family caregivers at UAB. Patients and caregivers will participate in the study as pairs, but each person will decide separately whether to participate and will provide verbal consent separately.

Study Participation and Procedures

If you agree to participate, you will complete a telephone baseline assessment; participate with your family caregiver in one MyHP-South session, either through Zoom or in person; complete post-session questionnaires and a joint acceptability interview; use a completed health priorities template during an upcoming primary care visit; and complete a follow-up telephone assessment at 12 weeks. You will be enrolled in this study for a total of 12 weeks. Your total time commitment will be approximately 4 to 5 hours.

In-person study activities will take place at the UAB School of Nursing, Plaza Building, 2112 11th Avenue South, Birmingham, Alabama 35205.

Baseline Assessment:

Trained study personnel will administer the baseline assessment to you by telephone. They will read each question and the response options aloud and enter your answers into the secure study database. The baseline assessment will take approximately 45 to 60 minutes and will include:

- Demographic Questionnaire: Questions about characteristics such as your age, gender, marital status, religion, education, employment, occupation, and living arrangement.
- Older Patient Assessment of Chronic Illness Care (O-PACIC): A 10-item questionnaire about the quality and patient-centeredness of the care you receive for your chronic health conditions.
- Treatment Burden Questionnaire (TBQ): A 13-item questionnaire about the burden of managing your health conditions and treatments and how that burden affects your quality of life.
- CollaboRATE: A 3-item questionnaire about the extent to which you experienced shared decision-making during your clinical care.
- Shared Care Instrument (SCI): A 19-item questionnaire about communication, decision-making, and reciprocity between you and your family caregiver regarding your illness experience.

MyHP-South Session:

After both you and your family caregiver complete the baseline assessments, study personnel will contact you to schedule the MyHP-South session. The session will generally occur within 14 days after the second member of the pair completes the baseline assessment.

The purpose of the session is to help you identify and clearly communicate what matters most to you when making decisions about your health and healthcare. You and your family caregiver will participate together with a trained study team member. The session will use paper-based MyHP-South materials, last approximately 60 minutes, and occur through Zoom or in person, according to your preference. If you participate through Zoom, the materials will be sent to you in advance by mail or email. If you participate in person, you will receive paper materials during the visit.

Immediate Post-Session Activities:

Immediately after the MyHP-South session, trained study personnel will administer the following questionnaires and you will participant in an Acceptability Interview:

- System Usability Scale (SUS): A 10-item questionnaire about the usability, clarity, and ease of use of the MyHP-South materials and process.

Acceptability Interview:

You and your family caregiver will participate together in one semi-structured acceptability interview with trained study personnel during the same scheduled study visit as the MyHP-South session. The

interview may be conducted through Zoom or by telephone and will include approximately 15 questions. You will be asked about the usefulness, clarity, ease of use, and cultural and contextual relevance of MyHP-South; your comfort with completing the program with your caregiver; the burden of completing and using the program; its potential value for clinical visits; barriers to using it; and recommendations for improving it.

The interview will take approximately 45 to 60 minutes. The post-session questionnaires and acceptability interview together will take approximately 60 minutes.

With your and your caregiver's permission, an interview conducted through Zoom will be audio- and video-recorded. An interview conducted by telephone will be audio-recorded using an approved recording method. The recordings will be used to prepare a written transcript. Only the written transcript will be retained and analyzed. After the transcript has been reviewed for accuracy and transferred to secure study storage, the audio and video recordings will be permanently deleted. If either you or your caregiver declines recording, you may still complete the interview, and study personnel will take structured written notes.

Health Priorities Template:
The MyHP-South priorities template is a written summary of the health priorities you identify during the session. After the session, a completed copy will be sent to you by mail or email, according to your preference. You should bring the template to your upcoming primary care visit, or otherwise have it available, and share it with your primary care clinician. Your family caregiver may also receive a copy if you give permission.

Clinical Visit:
You were identified as a potential participant because the information provided to the study team showed that you had a UAB primary care visit scheduled approximately 3 to 6 months in the future. The information provided to the study team also included the appointment date and the name of the primary care clinician associated with that appointment. The study team will use that information and will not ask you to remember the date or clinician. Study personnel will not schedule or attend your clinical visit and will not recheck your medical record to confirm whether the appointment date or clinician has changed.

Approximately one day before the appointment date provided to the study team, study personnel will send you a text message reminding you to bring or otherwise have your completed MyHP-South priorities template available and share it with your clinician. The reminder will be sent only if you agreed to receive study-related text messages. Your family caregiver may help you prepare for and participate in the visit, according to your preference. With your permission, the study team may contact the clinician after the visit and invite the clinician to complete a brief survey about the template.

12-Week Follow-Up Assessment:
12 weeks after the My-HP South Session, study personnel will contact you by telephone or text message to schedule your 12-Week Follow-Up Assessment. This assessment will take about 35-45 minutes and will include the following questionnaires: Older Patient Assessment of Chronic Illness Care (O-PACIC).

- Treatment Burden Questionnaire (TBQ).
- CollaboRATE.
- Shared Care Instrument (SCI).

Contacting Your Family Caregiver

After you agree to participate, study personnel will ask you to identify an unpaid family member or another person who provides you with assistance or support. With your permission, study personnel will use the contact information you provide to contact that person, explain the study, and ask whether the person is interested in participating as your family caregiver. Your caregiver will decide separately whether to participate and will complete a separate verbal consent process. The caregiver will participate with you in the MyHP-South session and acceptability interview and will complete the caregiver assessments required by the study.

Risks and Discomforts

Some questions or discussions may make you feel uncomfortable, particularly questions about your health, treatment burden, caregiving, or medical decisions. You and your family caregiver may have different opinions during the joint activities, which may also feel uncomfortable. You may skip any question or stop an activity at any time.

There is a small risk of loss of confidentiality. Zoom, telephone communication, electronic transmission of study materials, and recording the acceptability interview also involve a small risk of loss of privacy. When possible, you should participate from a private location. The study team will limit access to your information, use secure UAB systems, and delete the interview recordings after the transcript has been checked and securely stored.

Benefits

You may not benefit directly from participating. However, what we learn may help improve MyHP-South and healthcare communication for older adults with multiple chronic conditions and their caregivers.

Alternatives

The alternative is not to participate. Your decision will not affect your medical care, benefits, or relationship with UAB.

Confidentiality

Information obtained about you for this study will be kept confidential to the extent allowed by law. However, research information that identifies you may be shared with people or organizations for quality assurance or data analysis, or with those responsible for ensuring compliance with laws and regulations related to research.

They include:

- the UAB Institutional Review Board (IRB). An IRB is a group that reviews the study to protect the rights and welfare of research participants.
- National Institute on Aging
- the Office for Human Research Protections (OHRP)
- The University of Colorado Anschutz Medical Campus may receive aggregate or de-identified information but will not receive information that directly identifies you

The information from the research may be published for scientific purposes; however, your identity will not be given out in those publications.

This research will be covered by a Certificate of Confidentiality from the National Institutes of Health. The researchers with this Certificate may not disclose or use information, documents, or biospecimens

that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other action, suit, or proceeding, or be used as evidence, for example, if there is a court subpoena, unless you have consented for this use. Information, documents, or biospecimens protected by this Certificate cannot be disclosed to anyone else who is not connected with the research except, if there is a federal, state, or local law that requires disclosure (such as to report child abuse or communicable diseases but not for federal, state, or local civil, criminal, administrative, legislative, or other proceedings, see below); if you have consented to the disclosure, including for your medical treatment; or if it is used for other scientific research, as allowed by federal regulations protecting research subjects.

The Certificate cannot be used to refuse a request for information from personnel of the United States federal or state government agency sponsoring the project that is needed for auditing or program evaluation by the National Institute on Aging which is funding this project or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA). You should understand that a Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you want your research information released to an insurer, medical care provider, or any other person not connected with the research, you must provide consent to allow the researchers to release it.

Future Use of Study Information
After all information that identifies you has been removed, the information collected during this study may be used for future research studies or shared with other researchers without asking for your additional consent. Future reports and publications will not identify you.

Voluntary Participation and Withdrawal
Whether you participate is your choice. There is no penalty for refusing. You will not lose any benefits you are otherwise entitled to receive. You may stop participating at any time by telling the Principal Investigator or study personnel. Information collected before you withdraw may still be used to protect the integrity of the research.

Cost of Participation
There will be no cost to you for taking part in this study.

Payment for Participation
You may receive up to $75: $25 after completing the baseline questionnaires, $25 after completing the acceptability interview, and $25 after completing the 12-week follow-up questionnaires. If you stop participating early, you will be paid for the activities you completed. All study payments will be provided through Greenphire ClinCards.

Questions
If you have questions, concerns, or complaints about the research, please contact the Principal Investigator, Deborah Ejem, PhD, at (205) 996-1671.

If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the UAB Office of the IRB at (205) 934-3789 or toll free at 1-855-860-3789. Regular hours are 8:00 a.m. to 5:00 p.m. Central Time, Monday through Friday.

Legal Rights

By verbally agreeing to participate, you are not waiving any of your legal rights. You will receive a copy of this information sheet.

UAB IRB
Approved
17-Sep-2026
until
16-Sep-2027

INFORMATION SHEET FOR A RESEARCH STUDY
FAMILY CAREGIVER

Title of Research: Refinement and Pilot Testing of the My Health Priorities Program for Rural and Underserved Older Adults with Multiple Chronic Conditions in the Deep South (MyHP-South)

UAB IRB Protocol #: IRB-300016725

Principal Investigator: Deborah Ejem, PhD

Sponsor: National Institute on Aging

General Information	You are being asked to take part in a research study. This research study is voluntary, meaning you do not have to take part in it. The procedures, risks, and benefits are fully described further in this table.
Purpose	The study will test whether MyHP-South is feasible, acceptable, and useful for older adults with multiple chronic conditions and their family caregivers.
Duration	Your participation will last about 12 weeks and require approximately 3 hours and 20 minutes to 4 hours and 20 minutes.
Procedures	You will complete telephone questionnaires, participate in a 60-minute MyHP-South session with the patient, complete post-session questionnaires and a joint acceptability interview, help the patient prepare to use the health priorities template, and complete telephone questionnaires again at 12 weeks.
Risks	Some questions may make you feel uncomfortable. There is also a small risk to loss of confidentiality
Benefits	You may not benefit directly. What we learn may help improve healthcare communication for others.
Alternatives	The alternative is to not participate in this study

Purpose of the Research Study

We are asking you to take part in a research study because an older adult who may join the study identified you as a family member, friend, or caregiver who helps with healthcare decisions. The purpose of this study is to test MyHP-South, a paper-based program that helps older adults identify and communicate what matters most to them when making healthcare decisions.

The Aim 2 pilot will enroll approximately 20 older adults and 20 family caregivers at UAB. Patients and caregivers will participate as pairs, but each person will decide separately whether to participate and will provide verbal consent separately.

Study Participation and Procedures

If you agree to participate, you will complete a telephone baseline assessment; participate with the patient in one MyHP-South session, either through Zoom or in person; complete post-session questionnaires and a joint acceptability interview; help the patient prepare to use a completed health priorities template during an upcoming primary care visit; and complete a follow-up telephone assessment at 12 weeks. You will be enrolled in this study for a total of 12 weeks. Your total time commitment will be approximately 3 hours and 20 minutes to 4 hours and 20 minutes.

In-person study activities will take place at the UAB School of Nursing, Plaza Building, 2112 11th Avenue South, Birmingham, Alabama 35205.

Baseline Assessment:

Trained study personnel will administer the baseline assessment to you by telephone. They will read each question and the response options aloud and enter your answers into the secure study database. The baseline assessment will take approximately 30 to 45 minutes and will include:

- Demographic Questionnaire: Questions about characteristics such as your age, gender, marital status, religion, education, employment, occupation, and living arrangement.
- Bakas Caregiver Outcomes Scale (BCOS): A 10-item questionnaire about changes in your social functioning, well-being, and physical health associated with providing care.
- Shared Care Instrument (SCI): A 19-item questionnaire about communication, decision-making, and reciprocity between you and the patient regarding the illness experience.

MyHP-South Session:

After both you and the patient complete the baseline assessments, study personnel will contact you to schedule the MyHP-South session. The session will generally occur within 14 days after the second member of the pair completes the baseline assessment.

The purpose of the session is to help the patient identify and clearly communicate what matters most to the patient when making decisions about health and healthcare. You and the patient will participate together with a trained study team member. You will support the patient as the patient identifies and describes personal health priorities. The session will use paper-based MyHP-South materials, last approximately 60 minutes, and occur through Zoom or in person, according to your preference. If you participate through Zoom, the materials will be sent to you in advance by mail or email. If you participate in person, you will receive paper materials during the visit.

Immediate Post-Session Activities:

Immediately after the MyHP-South session, trained study personnel will administer the following questionnaires verbally and you will participant in an Acceptability Interview:

- System Usability Scale (SUS): A 10-item questionnaire about the usability, clarity, and ease of use of the MyHP-South materials and process.

Acceptability Interview:

You and the patient will participate together in one semi-structured acceptability interview with trained study personnel during the same scheduled study visit as the MyHP-South session. The interview may be conducted through Zoom or by telephone and will include approximately 15 questions. You will be asked about the usefulness, clarity, ease of use, and cultural and contextual relevance of MyHP-South; your comfort with completing the program with the patient; the burden of completing and using the program; its potential value for clinical visits; barriers to using it; and recommendations for improving it.

The interview will take approximately 45 to 60 minutes. The post-session questionnaires and acceptability interview together will take approximately 60 minutes.

With your and the patient's permission, an interview conducted through Zoom will be audio- and video-recorded. An interview conducted by telephone will be audio-recorded using an approved recording method. The recordings will be used to prepare a written transcript. Only the written transcript will be retained and analyzed. After the transcript has been reviewed for accuracy and transferred to secure study storage, the audio and video recordings will be permanently deleted. If either you or the patient declines recording, you may still complete the interview, and study personnel will take structured written notes.

Health Priorities Template:
The MyHP-South priorities template is a written summary of the health priorities the patient identifies during the session. After the session, a completed copy will be sent to the patient by mail or email, according to the patient's preference. You may also receive a copy if the patient gives permission. The patient will be encouraged to bring or otherwise have the template available at the upcoming primary care visit and share it with the primary care clinician. You may help the patient prepare for and participate in the visit according to the patient's preference.

12-Week Follow-Up Assessment:
12 weeks after the My-HP South session, study personnel will contact you by telephone or text message to schedule your 12-Week Follow-Up Assessment. This assessment will take about 20-30 minutes and include the following questionnaires:

- Bakas Caregiver Outcomes Scale (BCOS).
- Shared Care Instrument (SCI).

Risks and Discomforts
Some questions or discussions may make you feel uncomfortable, particularly questions about caregiving, the patient's health, or medical decisions. You and the patient may have different opinions during the joint activities, which may also feel uncomfortable. You may skip any question or stop an activity at any time.

There is a small risk of loss of confidentiality. Zoom, telephone communication, electronic transmission of study materials, and recording the acceptability interview also involve a small risk of loss of privacy. When possible, you should participate from a private location. The study team will limit access to your information, use secure UAB systems, and delete the interview recordings after the transcript has been checked and securely stored.

Benefits
You may not benefit directly from participating. However, what we learn may help improve MyHP-South and healthcare communication for older adults with multiple chronic conditions and their caregivers.

Alternatives
The alternative is not to participate. Your decision will not affect your medical care, benefits, or relationship with UAB.

Confidentiality

Information obtained about you for this study will be kept confidential to the extent allowed by law. However, research information that identifies you may be shared with people or organizations for quality assurance or data analysis, or with those responsible for ensuring compliance with laws and regulations related to research.

They include:

- the UAB Institutional Review Board (IRB). An IRB is a group that reviews the study to protect the rights and welfare of research participants.
- National Institute on Aging
- the Office for Human Research Protections (OHRP)
- The University of Colorado Anschutz Medical Campus may receive aggregate or de-identified information but will not receive information that directly identifies you

The information from the research may be published for scientific purposes; however, your identity will not be given out in those publications.

This research will be covered by a Certificate of Confidentiality from the National Institutes of Health. The researchers with this Certificate may not disclose or use information, documents, or biospecimens that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other action, suit, or proceeding, or be used as evidence, for example, if there is a court subpoena, unless you have consented for this use. Information, documents, or biospecimens protected by this Certificate cannot be disclosed to anyone else who is not connected with the research except, if there is a federal, state, or local law that requires disclosure (such as to report child abuse or communicable diseases but not for federal, state, or local civil, criminal, administrative, legislative, or other proceedings, see below); if you have consented to the disclosure, including for your medical treatment; or if it is used for other scientific research, as allowed by federal regulations protecting research subjects.

The Certificate cannot be used to refuse a request for information from personnel of the United States federal or state government agency sponsoring the project that is needed for auditing or program evaluation by the National Institute on Aging which is funding this project or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA). You should understand that a Certificate of Confidentiality does not prevent you from voluntarily releasing information about yourself or your involvement in this research. If you want your research information released to an insurer, medical care provider, or any other person not connected with the research, you must provide consent to allow the researchers to release it.

Future Use of Study Information

After information that directly identifies you has been removed, information collected during this study may be used for future research studies or shared with other researchers without asking for your additional consent. Future reports and publications will not identify you.

Voluntary Participation and Withdrawal

Whether you participate is your choice. There is no penalty for refusing. You will not lose any benefits you are otherwise entitled to receive. You may stop participating at any time by telling the Principal Investigator or study personnel. Information collected before you withdraw may still be used to protect the integrity of the research.

Your decision will not affect the patient's medical care or your relationship with the patient or UAB.

Cost of Participation
There will be no cost to you for taking part in this study.

Payment for Participation
You may receive up to $75: $25 after completing the baseline questionnaires, $25 after completing the acceptability interview, and $25 after completing the 12-week follow-up questionnaires. If you stop participating early, you will be paid for the activities you completed. All study payments will be provided through Greenphire ClinCards.

Questions
If you have questions, concerns, or complaints about the research, please contact the Principal Investigator, Deborah Ejem, PhD, at (205) 996-1671.

If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the UAB Office of the IRB at (205) 934-3789 or toll free at 1-855-860-3789. Regular hours are 8:00 a.m. to 5:00 p.m. Central Time, Monday through Friday.

Legal Rights
By verbally agreeing to participate, you are not waiving any of your legal rights.