

INTEGRATED WELLNESS IN SUPPORTIVE HOUSING (IWISH) CONSENT FORM

PAPERWORK REDUCTION ACT STATEMENT OF PUBLIC BURDEN: The public reporting burden for this information collection is estimated to be 10 minutes. This burden estimate includes time for reading this information and signing the consent statement. Send comments regarding the accuracy of this burden estimate and any suggestions for reducing the burden to: U.S. Office of Personnel Management, Federal Investigative Services, Attn: OMB Number (3206-0246), 1900 E Street NW, Washington, DC 20415-7900.

TITLE OF STUDY: Integrated Wellness in Supportive Housing (IWISH)

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SPONSOR: United States Department of Housing and Urban
Development

What should I know about IWISH and the associated research?

The United States Department of Housing and Urban Development (HUD) funded Integrated Wellness in Supportive Housing (IWISH) to study the impact of trained wellness staff hired to support your health and supportive service needs.

IWISH aims to support you in better managing your health. Several outcomes interest HUD, including:

- decreasing inappropriate use of emergency rooms and hospitals;
- delaying potential admission to nursing homes; and
- supporting you in maintaining independence in your home for a longer period of time.

We are asking you to participate as part of an IWISH demonstration and its evaluation since you live in a property that has been selected to be a part of this initiative. This is a research project.

It is important that you read and understand the following explanation of the proposed IWISH activities. This form describes the purpose, activities, benefits, and risks of IWISH.

A member of the IWISH staff will read through this consent form with you and discuss the information included. If you do not understand, you are encouraged to ask questions. When you feel you understand IWISH, you will then be asked if you agree to participate. If you agree, you will be asked to sign this consent form. Once you sign the form, we will give you a signed and dated copy to keep.

You may take this form and show it to family, friends, and other supportive individuals. You may want to discuss your participation in IWISH with them to help decide if you want to participate.

Why is HUD sponsoring IWISH?

HUD seeks to understand whether IWISH is effective at meeting its primary goals of:

- supporting participants in better managing their health;
- decreasing unnecessary emergency room and hospital use;
- delaying potential admission to nursing homes; and
- supporting participants in maintaining independence in their homes.

Forty HUD properties were selected to begin IWISH, including the property at which you live. Combined the properties have nearly 5,000 residents.

How long will IWISH last?

IWISH will last through September 30, 2020. As long as you are willing to consent to the program and you continue to live at this property, we will involve you in IWISH activities.

What happens to me if I agree to take part in IWISH?

Once you agree to participate, the Resident Wellness Director and our Wellness Nurse will talk with you to get to know you and your potential health and social service needs. After this initial conversation, we will meet with you to complete a *Resident Assessment*. This assessment may take up to 80-minutes to complete, but will help us better understand your health preferences, including emergency contacts and provider details, as well as specific health conditions, medications, nutritional and falls risk, and social services you already receive or may need. You don't have to answer all the questions if you don't want to, or if you are not comfortable.

We invite you to participate in IWISH activities, including wellness programming and health education events. We request that you meet with the Resident Wellness Director and the Wellness Nurse regularly to inform us of your health and social conditions or concerns. We are also here to discuss any new needs that you experience. Please note, as a part of IWISH, we will provide wellness and services that support any transitions you may have from the hospital or a nursing home, but we will not provide any direct medical services.

Enrollment in IWISH is free. There is no cost for you to enroll or obtain services through IWISH. In exchange for your participation, you will receive coordination of your health and supportive services. These programs are designed to help you manage your health and make healthy life choices that can help you live at home longer.

Could IWISH hurt me?

Participation in IWISH is not expected to present any risks to your well-being.

Will being in IWISH benefit me?

We cannot promise any benefits to you or others from your taking part in IWISH. However, possible benefits to you include improved health and well-being, as well as less frequent use of emergency department visits and hospital stays.

What happens to the information collected about me?

To determine whether IWISH meets its goals, HUD has contracted with an independent evaluation contractor to evaluate the program. To support the evaluation, we will transfer to the evaluation contractor all the information we collect from you and about you over the course of the demonstration. The contractor will use this information to understand how IWISH benefits residents and use the personal identifying information that you provide, such as your name, social security number, and insurance number, to match with Medicare and Medicaid data and with HUD administrative records. Using these data, the evaluation will compare the use of and spending for medical, home and community, and nursing home services for residents in the 40 IWISH properties with residents not in IWISH.

At the conclusion of this project, findings may be published in a summary format. No information gathered can be used to identify you and will not be used in any publication or presentation.

What are my responsibilities if I take part in IWISH?

As a participant in IWISH, medical or health status information about you may be used and disclosed, as you deem appropriate. At any time you may request access to information collected as part of your participation in IWISH.

Your Health Information Rights

You have the right to:

- Receive a copy and an explanation of this consent for participation in IWISH.
- Understand how we intend to use and share your information with others, as approved by you, or required by law.
- Look at and/or receive a copy of your records (subject to some restrictions).
- Request that your records be changed if you believe the information is incomplete or incorrect (subject to some restrictions).
- File a complaint if you believe your rights under this agreement have been violated.
- Revoke any authorization that you give for use and disclosure of your health information at any time.

Our Responsibilities

This HUD-assisted property, as required by law, accepts the responsibility to maintain the privacy of any health information that you share with us and to provide to you this Notice of its privacy practices. We will follow the terms of this Notice. You will be promptly notified in writing if there are any major changes to any of the privacy practices stated in this Notice. You will also be notified if there is ever an unauthorized use or disclosure of your health information.

This research is covered by a Certificate of Confidentiality from the National Institutes of Health. The researchers with this Certificate may not disclose or use information or documents 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 or documents 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 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 of Confidentiality will not be used to prevent disclosure as required by federal, state, or local law of abuse and neglect, or harm to self or others. The Certificate of Confidentiality will not be used to prevent disclosure for any purpose you have consented to in this informed consent document.

With your authorization, we will use and/or share your health information to:

- Develop your Individual Healthy Aging Plan (IHAP), and develop the Community Healthy Living Plan.
- Coordinate care and supports for you with community partners.
- Support transitions home for you from hospital and nursing home stays.
- Schedule or remind you about upcoming appointments.
- Let you know about services that may be of interest to you.
- Conduct operations, such as quality assurance, performance improvement, staff supervision, staff education, accreditation and compliance reviews, or business planning.
- Record your information in a cloud-based server, electronically.
- Information may be shared with people overseeing the research. This includes evaluators, the New England Independent Review Board, and the Office for Human Research Protection.

Who can answer my questions about this research?

If you have questions, concerns, or complaints, or think this research has hurt you or made you sick, talk to the research team at the phone number listed above on the first page.

This research is being overseen by New England Independent Review Board (“NEIRB”). You may talk to them at (800) 232-9570, info@neirb.com if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research
- You have questions about your rights as a research subject.

What happens if I agree to be in IWISH, but I change my mind later?

Participation is voluntary. You can withdraw your participation and consent for IWISH at any time. Participation in IWISH and receipt of supportive services are completely voluntary. Your ability to continue to live in your home does not depend on participation in IWISH. No negative action will be taken based on participation or non-participation in IWISH. Refusal to participate or discontinuation of participation will involve no penalty or loss of benefits which you are otherwise entitled.

If you decide to withdraw your consent to participate from IWISH you will no longer be eligible for certain enhanced and new services provided under IWISH. However, you will continue to receive the same level of service coordination that you have always received.

PARTICIPANT'S STATEMENT:

I agree that I have been given a chance to ask questions about IWISH. These questions have been answered to my satisfaction. I may contact Lisa Alecxih at 703-269-5542 if I have any more questions about taking part in IWISH.

My participation in IWISH is voluntary. I may quit IWISH at any time without harming my future medical care or losing any benefits to which I might be entitled. The investigator in charge of this study may decide at any time that I should no longer participate in this study.

If I have questions about my rights as a research subject, other concerns, or complaints about the research, or I am unable to reach the investigator; I can contact:

New England Independent Review Board

Telephone: 1-800-232-9570

By signing this form, I have not waived any of my legal rights.

I agree to participate in IWISH. I will be given a copy of this signed and dated form for my own records.

Study Participant (signature)

Date

Print Participant's Name

Person who explained this study (signature)

Date