Participant Information Sheet Older Adult Intervention Group

Research Study "Data Nurse"
Research project Data Nurse: optimizing independence among older adults receiving district nursing care

Introduction
Dear reader,

With this information letter, we would like to ask if you are willing to participate in scientific research about promoting independence among older adults living at home. Participation is voluntary. You are receiving this letter because you are 65 years or older and currently receive community nursing care or will soon receive this care. This information is also important for your informal caregiver.
Whether or not you participate will not affect the care you receive. Here you will read what the research is about, what it means for you, and what is expected if you decide to participate.

Are you interested?
Please read this letter carefully.
Ask the researcher any questions you may have.
If you want to participate, please fill out the form attached.

1. General Information

The research is conducted by Amsterdam University Medical Centers (Amsterdam UMC) in collaboration with Utrecht University of Applied Sciences (HU), Vilans, and the Omaha System Foundation.

2. What is the purpose of the research?

Community nursing teams often consult with clients about how they can live independently at home. When independence improves, less professional support is needed, and living at home is possible for longer. However, expressing which community nursing care is needed can be challenging. Therefore, the Shared Decision Support Tool (Samen Beslis Hulp) was developed. This tool is a questionnaire that can be completed before a conversation with a community nurse. It includes questions about how you experience your health and your care needs related to independence. It helps to reflect on what is important so that a care plan can be created together that matches your wishes and independence. This study aims to investigate whether and how people can effectively use the Shared Decision Support Tool in their conversations with community nurses. We also want to study if the tool helps improve independence.

3. What happens if you participate?

After receiving this letter:
A community nurse will visit you. After a brief explanation about the Shared Decision Support Tool, you can complete it. Then, you will fill out three other short questionnaires about your personal information and your experience with the tool. If you have an informal

caregiver, they will complete a part of the Shared Decision Support Tool as well. The total time will be no more than one and a half hours.

Summer 2025:
You will receive an invitation asking if you are interested in an interview at your home with the researcher. If you are interested, the researcher will discuss your experiences with the Shared Decision Support Tool and shared decision-making with community nursing (around June 2025). Audio recordings will be made during this interview.

Autumn 2025:
You will be asked to complete an evaluation form about decision-making with community nursing (about 15 minutes).

4. What does participation mean for you?

You will not receive direct benefits from this study.
Your participation contributes to tailoring community nursing care to the needs of people aged 65 and older.

5. If you do not want to participate or want to stop

Participation is entirely voluntary. You may decide to stop at any time without giving a reason. We do ask you to inform us if you decide to stop. The data collected until that point will still be used in the research.

6. What do we do with your data?

By participating, you consent to the collection, use, and storage of your data for 10 years at Amsterdam UMC.

Why do we collect, use, and store your data?
We collect, use, and store your data to answer the research questions. We intend to publish the results.

The data we collect include:
Your age, gender, date of birth, education level, social situation, living situation, and the country of origin of your parents.
Via the organization providing your care, we collect information about the care you receive from community nursing (type of care, number of care moments, hours of care, duration in care), your care needs, and whether you have an informal caregiver.

What do we do with audio recordings?
If you participate in the interview, we will make audio recordings where your voice is recognizable. We will transcribe the recordings and send you a summary through your community nurse. We ask you to read the summary and let us know if you disagree with anything. We want to store the audio recordings and transcripts for follow-up research within our project and ask for separate consent on the consent form. The audio recordings will be destroyed after transcription.

How do we protect your privacy?
To protect your privacy, we assign a unique code to your data. Only this code will be on your data, not information that directly identifies you. The key to this code is securely stored at Amsterdam UMC. Only the researchers and the research team have access to it. When processing or sharing your data, only the code is used, not your name. Reports and publications will not reveal your identity.

May we use your data for other research?
Your data may be useful for other scientific research related to community nursing. We will store your data for 10 years at Amsterdam UMC (AMC location). On the consent form, you can indicate if you agree to this. If you do not consent, you can still participate in this study.

Can you withdraw your consent?
You can withdraw your consent at any time, both for this research and any other research. However, data already used for research cannot be removed from those analyses.

Would you like to know more about your privacy?
You can request an electronic copy of your data used in the study by asking the researcher. For more information on your rights regarding personal data, visit:
https://www.autoriteitpersoonsgegevens.nl/en/about-privacy/personal-data

If you have questions or complaints about your rights or privacy:
Contact the person responsible for your data processing. If you have complaints about privacy, we recommend discussing these first with the research team. You can also contact the Data Protection Officer at Amsterdam UMC: privacy@amsterdamumc.nl. Or file a complaint with the Dutch Data Protection Authority: info@autoriteitpersoonsgegevens.nl.

Where can you find more information about the research?
More information is available at: https://www.hu.nl/onderzoek/projecten/data-nurse-datagedreven-werken-in-de-wijk

7. Do you have questions?

This research has been reviewed by the non-WMO ethics committee of Amsterdam UMC. This committee determined the study does not fall under the Dutch Medical Research Involving Human Subjects Act (WMO). For questions, you can contact one of the researchers.

8. Complaints

If you have a complaint, please discuss it with the researcher.
If you prefer not to, you can contact Patient Service Support staff.
For AMC location:
Phone: 020-5666440
Email: PAZO-AMC@amsterdamumc.nl

9. Contact details of researchers:

Sigrid Wulfse-Huisman: s.m.c.l.huisman@amsterdamumc.nl
Phone: 06-43933825

Xenia Yocarini: xenia.yocarini@hu.nl
Phone: 06-37273406

Address:
Department of Geriatrics
AMC Location | Meibergdreef 9, 1105 AZ Amsterdam

Thank you for your attention.

Attachment: Participant Consent Form

Research Project Data Nurse: Optimizing Independence Among People Receiving Community Nursing

I have read the information letter. I was able to ask questions, and my questions were answered sufficiently. I had enough time to decide whether to participate.
I know that participation is voluntary. I also know I can stop at any time without giving a reason.
I give permission for the collection and use of my data in the way and for the purposes described in the information letter.
I consent to my data being stored for 10 years after this research at Amsterdam UMC.
I want to participate in this study.

Please check “yes” or “no” below:

I consent to being contacted for interviews.
O yes
O no

I consent to the collection and use of audio recordings. These recordings will be destroyed after transcription/at the end of the study.
O yes
O no

I consent to the collected audio recordings being stored for 10 years after the study for follow-up research.
O yes
O no

I consent to being contacted again after this study for follow-up research.
O yes
O no

Name of participant:

Signature: _____ Date: __ / __ / __

I declare that I have fully informed this participant about the mentioned research.
If new information arises that could influence the participant's consent, I will inform them in a timely manner.

Name of researcher:

Signature: _____ Date: __ / __ / __

The participant receives a full information letter and a copy of the signed consent form.