

Participant Information Sheet Older Adult Control 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 kindly ask you to participate in scientific research about promoting independence among older adults living at home. Participation is voluntary. You received this letter because you are 65 years or older and currently receive district nursing care or will receive such care soon. This information is also important for your informal caregiver.

Whether or not you participate will not affect the care you receive. In this letter, you will read what kind of research this is, what it means for you, and what is expected if you decide to participate.

Are you interested?

- Please read this letter carefully.
- Feel free to ask questions to the researcher who provides you with this information. If you want to participate, please fill in the attached form.

1. General information

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

2. What is the aim of the research?

District nursing caregivers often discuss with clients how they can remain as independent as possible at home. When independence improves, less professional support is needed, and living at home becomes possible for a longer period. This study aims to investigate how people aged 65 and older, together with district nursing caregivers, decide what kind of care is needed to maintain independence.

3. What happens if you participate in the study?

The study lasts five months. Participation involves:

1. Completing a questionnaire about your personal information, your experience with decision-making together with district nursing, and your independence at the start of the study (approximately 10 minutes).
2. Completing a questionnaire about your independence at the end of the study (about 5-10 minutes).

4. What does participation mean for you?

- You will not have any direct benefits from this study.
- Your participation may contribute to improving shared decision-making in district nursing.

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

Participation is entirely voluntary. You may decide to stop at any time. You do not have to give a reason for stopping. We do ask that you inform us if you choose to stop. Any data collected up to that point will still be used for the research.

6. What do we do with your data?

If you participate, you give permission for your data to be collected, used, and stored for 10 years at Amsterdam UMC.

Data

We will collect some personal data including your age, gender, date of birth, education level, social situation, living situation, country of origin of your parents, and your independence. Through the organization providing your care, we will also collect data about the care you receive from district nursing (type of care, number of care moments, hours of care, duration of care), your care needs, and presence of an informal caregiver.

Why do we collect, use, and store your data?

To answer the research questions. We intend to publish the results.

How do we protect your privacy?

Your data will be coded with a unique number. Only this code will be used on your data. Personal identifiers will be removed. The key to the code is stored securely at Amsterdam UMC. Only the research team has access. When processing or sharing your data, only the code will be used. Reports and publications cannot identify you.

May we use your data for other research?

Your data may also be valuable for other scientific research related to district nursing. For this, your data will be stored for 10 years at Amsterdam UMC, location AMC. On the consent form, you can indicate whether you agree. If you do not agree, you can still participate in this study.

Want to know more about your privacy?

You can request an electronic copy of your data used in this study from the researcher. For more information about your rights regarding data processing, visit:

<https://www.autoriteitpersoonsgegevens.nl/en/about-privacy/personal-data>

If you have questions or complaints about privacy, please contact the person responsible for processing personal data. We advise you to discuss complaints first with the research team. You may 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 study?

More information is available at: <https://www.hu.nl/onderzoek/projecten/data-nurse-datagedreven-werken-in-de-wijk>

7. Do you have questions?

This study has been reviewed by the non-WMO ethics committee of Amsterdam UMC. The committee concluded that the study does not fall under the Medical Research Involving Human Subjects Act (WMO). If you have questions, contact one of the researchers.

8. Do you have a complaint?

If you have a complaint, please discuss it with the researcher. If you prefer not to, you can contact the Patient Service Support.

For AMC location:

- Phone: 020-5666440
- Email: PAZO-AMC@amsterdamumc.nl

9. Contact details 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

Location AMC | Meibergdreef 9, 1105 AZ Amsterdam

Thank you for your attention.

Attachment: Consent form participant

Research project Data Nurse: optimizing independence in people receiving district nursing care

- I have read the information letter. I had the opportunity to ask questions. My questions have been answered sufficiently. I had enough time to decide whether to participate.
- I know that participation is voluntary. I know I can stop participating at any time without giving a reason.
- I give permission for the collection and use of my data as described in the information letter.
- I give permission for my data to be stored for 10 years after this research within Amsterdam UMC.
- I want to participate in this research.

Please indicate yes or no below:

- I give permission to be contacted after this study for follow-up research.
O yes
O no

Name participant: _____

Signature: _____ Date: __ / __ / __

I declare that I have fully informed this participant about the study. If any new information arises that may affect the participant's consent, I will inform them in time.

Name researcher: _____

Signature: _____ Date: __ / __ / __

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