Participant Information Sheet District Nurse 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 if you would like to participate in scientific research. You are receiving this letter because you are a caregiver, nurse, district nurse, or nursing specialist in a district nursing team. Your organization is participating in the Data Nurse research project, of which this study is part. This research aims to optimize the independence of older adults by caregivers in district nursing. Participation is voluntary. Whether or not you participate will not affect your job at your organization or the care you provide.

In this letter, you will find information about the research, what it means for you, and what is expected from you if you decide to participate.

If you are interested:

- Please read this letter carefully.
- Feel free to ask the researcher any questions you may have.

If you want to participate, please complete the attached consent form.

1. General Information

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

2. What is the purpose of the study?

Background of the study

Caregivers from district nursing teams and older adults often make decisions together about interventions so that older adults can remain as independent as possible at home. Although most older adults wish to remain independent in their own home in a way that suits them, they need time to consider what kind of help they require from district nursing. Moreover, district nursing teams currently lack a standard approach for person-centered shared decision-making with older adults.

To support older adults, we have developed a Shared Decision-Making Tool (Vilans) that helps them prepare for decisions with district nursing caregivers. For caregivers, we

developed a free e-learning module about person-centered shared decision-making using the Shared Decision-Making Tool in district nursing practice.

Additionally, there is currently no overview of clients' independence in the electronic client record used by district nursing. Our previous research showed that caregivers want this. Therefore, we developed an independence dashboard for district nursing, which shows clients' independence over time. This dashboard is linked to the electronic client record and is based on the Omaha Classification System. We also developed an informative workshop on working with the dashboard.

Together, the Shared Decision-Making Tool, the e-learning, the independence dashboard, and the workshop are called the **Data Nurse intervention**.

The aim
The aim of this study is to evaluate, together with district nursing caregivers and older adults, whether the Data Nurse intervention is feasible in daily district nursing practice and whether it contributes to promoting the independence of older clients receiving district nursing.

Participation in the control group
This study includes an intervention group and a control group. The intervention group receives the Data Nurse intervention; the control group does not. To measure the effect of the Data Nurse intervention on older adults' independence, we will compare the independence of older adults in both groups. We will also compare how caregivers in district nursing teams practice person-centered shared decision-making in both groups. This information letter is for the control group.

3. What happens if you participate in the study?

Before the study:

- Each participating team will recruit a volunteer who will act as a coordinator.
- The coordinator will attend an online workshop explaining their tasks. During this session, there will also be an introduction to Castor. Castor is an electronic system used to securely manage research data online.

During the study:

- We will ask you to recruit older adults (65+) for participation and provide them with a questionnaire.
- You will be asked to safely store the completed paper questionnaires from participating older adults in a locked cabinet.
- The coordinator will register the data of participating older adults in Castor (approximately 5 minutes per client).
- You will be asked to complete an online questionnaire about yourself, including personal characteristics such as name, gender, date of birth, function, organization, years of work experience, and job satisfaction.

- Midway through the study, you may be invited by email for a telephone interview about shared decision-making and the use of data, if you indicate at the bottom of this letter that you want to participate in this.

4. What does participation mean for you?

1. Your participation may contribute to the quality of person-centered district nursing care.
2. Please consider that participation may take extra time as you start working with the new procedures.

5. If you do not want to participate or want to stop
Participation is entirely voluntary. Even if the rest of your team participates, you do not have to. You may decide to stop at any time without providing a reason. If you stop, please inform the researcher immediately.

Procedure if you do not participate:
If you are a caregiver in the control team who does not participate while the rest of the team does, you will not fill out questionnaires, recruit clients, or distribute and collect client questionnaires. Intakes and evaluations may still be done for participating and non-participating clients, as the intervention will not be applied. You will continue to provide care according to the care plan for both participating and non-participating clients.

6. What do we do with your data?

If you participate, you consent to your data being collected, used, and stored.

Why do we collect, use, and store your data?
To answer the research questions.

How do we protect your privacy?
We collect consent forms and questionnaires, and personal data including age, gender, role, job satisfaction, and years of experience in district nursing and your current organization. We do not collect medical background data. All data are coded and processed confidentially. Directly identifiable information is replaced by a code, and the key to the code is securely stored. Access is protected by passwords and two-factor authentication. Only the researcher and the research team can access the data. Reports and publications will never identify you.

How long do we keep your data?
Your data will be stored for 10 years at Amsterdam UMC.

Can you withdraw your consent?
You can withdraw your consent at any time for this and future research. However, data already used in analyses may still be used.

May we contact you for future research?
After this study, we may want to contact you about follow-up research. On the consent form, you can indicate if you agree to be contacted again.

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

If you have questions or complaints about your privacy, contact the person responsible for data processing. If you prefer, you can 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. Will you receive compensation for participating?
There is no compensation for participation.

8. Do you have questions?
This study was reviewed by the non-WMO ethics committee of Amsterdam UMC. This study does not fall under the Dutch Medical Research Involving Human Subjects Act (WMO). If you have questions, please contact the researchers:
Sigrid Wulfse-Huisman or Xenia Yocarini.

9. Do you have a complaint?
If you have a complaint, please discuss it with the researcher first. If you prefer not to, you can contact Patient Service Zorgsupport.

At AMC location:

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

Thank you for your attention.

10. Researcher contact details:
Sigrid Wulfse-Huisman: s.m.c.l.huisman@amsterdamumc.nl | Phone: +31 6 43933825

Xenia Yocarini: xenia.yocarini@hu.nl | Phone: +31 6 37273406
Address:
Department of Geriatrics
AMC Location | Meibergdreef 9, 1105 AZ Amsterdam

Attachment: Consent Form for Participants
"Research project Data Nurse: optimizing independence among people receiving district nursing"

- I have read the information letter. I was able to ask questions and they were answered sufficiently. I had enough time to decide whether to participate.
- I understand participation is voluntary. I may withdraw or stop at any time without giving a reason.
- I consent to the collection and use of my data as described in the information letter.
- I consent to my data being stored for 10 years at Amsterdam UMC.
- I want to participate in this study.

Please tick "yes" or "no":

- I consent to be contacted for a telephone interview.
  O Yes
  O No
- I consent to be contacted after this study for possible follow-up research.
  O Yes
  O No

Participant name: _____

Signature: _____ Date: __ / __ / __

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

Researcher name: _____

Signature: _____ Date: __ / __ / __

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