Participant Information Sheet District Nurse 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 kindly ask you to participate in scientific research. You have received this letter because you are a caregiver, nurse in district nursing, district nurse, or nursing specialist in a district nursing team. Your organization is affiliated with the Data Nurse research project, of which this study is part. This research focuses on optimizing the independence of older adults by caregivers in district nursing. We emphasize that participation is voluntary. Whether you choose to participate or not will have no consequences for your work within your organization or for the care you provide.
In this letter, you will read what kind of research it concerns, what it means for you, and what is expected of you 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 form attached.

1. General information

The research 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?

Background of the research
Caregivers from district nursing teams and older adults often make joint decisions about interventions that enable older adults to remain as independent as possible at home. Although most older adults wish to live independently at home in a way that suits them, they need time to consider what kind of help they need from district nursing. In addition, there is currently no working method for caregivers in district nursing teams to make person-centered shared decisions with older adults.
For older adults, we have developed a Shared Decision Aid (Vilans) that helps them prepare for decisions with district nursing caregivers. For caregivers in district nursing, we have developed a free e-learning about person-centered shared decision-making with the Shared Decision Aid in district nursing practice.
Furthermore, there is no overview yet of clients' independence in the electronic client dossier for district nursing. Our previous research showed that caregivers in district nursing teams desire such an overview. Therefore, we developed a dashboard for district nursing in which clients' independence over time can be viewed. Data from this dashboard can be used, for example, to assess whether independence improves with certain interventions. This dashboard is linked to the electronic client dossier and is based on the Omaha Classification System. To support its use, we developed an informative workshop about working with the dashboard.
The Shared Decision Aid, the e-learning, the independence dashboard, and the workshop together are called the Data Nurse intervention.
The goal
The aim of this research is to evaluate with caregivers from district nursing teams and older

adults whether the Data Nurse intervention is feasible in daily district nursing practice and may contribute to promoting the independence of older clients receiving district nursing care.

3. What happens if you participate in the research?

The study will last five months.

Champion and data ambassador from the team:

Before the research starts:

- Researchers will recruit two volunteers per team to become the champion and data ambassador. They will coordinate the Data Nurse intervention within the team. The champion will focus on discussing the progress of the Data Nurse intervention, including client recruitment and registering participating clients in Castor. They will also register caregivers in Castor. Castor is an electronic system for securely maintaining research data in an online environment. The data ambassador will focus on discussing the progress of the Data Nurse intervention and using the independence dashboard.
- The champion and data ambassador will be trained in their roles during a workshop about the Data Nurse intervention. This workshop will be given by the researchers at the team's office (60-90 minutes). Each team will also receive a laminated manual about using the dashboard.

Month 1:

- The champion will introduce the e-learning link to the team (5 minutes during team meeting).
- The data ambassador will provide a workshop to the team on how to use the dashboard (60-90 minutes).

Month 1 through 5:

- The data ambassador will discuss the dashboard during client meetings.
- The champion will register existing and new clients who want to participate in Castor.
- The champion and data ambassador will have a monthly online meeting with the researchers about the use of the Shared Decision Aid and the dashboard (30 minutes).

All participants in the district nursing team:

Month 1:

- Follow an e-learning about shared decision-making (60-90 minutes).
- Attend a workshop on data-driven working with the dashboard (60-90 minutes).
- Complete online questionnaires. We will ask your name, gender, date of birth, function, organization, years of work experience, job satisfaction, and your opinion about the feasibility of the Data Nurse intervention (30 minutes).

Month 3:

- If you indicate at the bottom of this letter that you want to participate in focus groups (max. 1.5 hours), you will be invited to focus groups on location to discuss the use of the dashboard and shared decision-making with the Data Nurse intervention. If you are interested, you can indicate this and will receive more information about the content, timing, and procedure of the focus groups.

Month 5:

- Complete an evaluation form about your experiences with using the Shared Decision Aid, shared decision-making with older adults, and using the dashboard (30 minutes).

Month 1 through 5:

- Recruit existing and new clients for participation. The goal is to invite all existing and new clients during the first month.
- Provide the Shared Decision Aid and questionnaire to participating clients (65+) prior to intake (5 minutes each time).
- Provide the Shared Decision Aid and questionnaire to participating clients (65+) prior to

evaluation (5 minutes each time).
- Discuss the completed Shared Decision Aid with clients during intake or evaluation (15 minutes each time).
- Store completed Shared Decision Aids and questionnaires from clients in a locked cabinet at the office.
- Discuss data from the dashboard during client meetings with the team (15 minutes per client discussion).

4. What does participation mean for you?

1. By participating, your knowledge about "shared decision-making" and "learning from data" will increase.
2. Your participation may contribute to the quality of person-centered district nursing care.
3. You should consider that participation may take (extra) time to work with the new methods.

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

Participation is entirely voluntary. Even if the rest of the team participates, you do not have to participate. You may decide to stop at any time during the study without giving a reason. If you stop, we ask you to inform the researcher immediately.

Procedure for non-participation:

If you are a caregiver from the intervention team but do not participate, and the rest of the team does, you will not complete questionnaires, recruit or distribute questionnaires to clients, nor conduct intake or evaluation with the Shared Decision Aid for participating clients, because this is intervention-related. You will also not use the dashboard. However, you will still provide care to both participating and non-participating clients according to the care plan.

6. What do we do with your data?

If you participate in the study, you also consent to the collection, use, and storage of your data.

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

We collect, use, and store your data to answer the research questions. The results of the research will be made public.

How do we protect your privacy?

We collect consent forms, questionnaires, and possibly audio recordings. We also collect data about your age, gender, function, job satisfaction, years working in district nursing, and at your current organization. We do not collect medical data. The data we collect is coded, analyzed, and processed confidentially. To protect your privacy, all your data will be assigned a code, and direct identifiers will no longer be used. The key to the code is kept securely, accessible only via a password-protected environment (two-factor authentication). Only the researcher and members of the research team have access to this environment. When we process or share your data, we use only the code. Reports and publications about the research cannot reveal your identity.

May we use your data for other research?

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

What do we do with audio recordings?

If you decide to participate in focus groups, audio recordings will be made. Your voice will be recognizable on these recordings. The recordings will be automatically transcribed using Amber Script. We will send you a summary of the discussion. We ask you to read this summary and notify us if you disagree with what is written. We want to keep the recordings and written texts anonymized for follow-up research. For this, we ask separate consent on the consent form. After transcription, the audio recordings will be destroyed.
Can you withdraw your consent for data use?
You can withdraw your consent for using your data at any time. This applies to this study and other research. However, if researchers have already used your data for research before you withdrew your consent, they may still use that data.
May we contact you after this study for follow-up research?
When this study ends, a follow-up study may start. We would like to contact you to ask if you want to participate again. On the consent form, you can indicate whether you agree to this.

Want to know more about your privacy?
You may want an electronic copy of the data used about you in this study. You can request this 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 about your rights or a complaint about your privacy, contact the person responsible for processing your personal data. If you have privacy complaints, we recommend discussing them first with the research team. You can also contact the Data Protection Officer of Amsterdam UMC at: privacy@amsterdamumc.nl. Or file a complaint with the Dutch Data Protection Authority at: info@autoriteitpersoonsgegevens.nl.

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

7. Will you receive compensation for participating?
If you participate in the study, we reimburse extra travel and parking costs you make for this project. You may also register the time spent on the e-learning as work time.

8. Do you have questions?
This study has been reviewed by the non-WMO ethics committee of Amsterdam UMC. According to this committee, this study does not fall under the Medical Research Involving Human Subjects Act (WMO). If you have questions about this study, 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. If you prefer not to, you can contact the Patient Service Support staff.
For AMC location:
- Phone number: 020-5666440
- Email: PAZO-AMC@amsterdamumc.nl

Thank you for your attention.

10. Contact details researchers:
Sigrid Wulfse-Huisman: s.m.c.l.huisman@amsterdamumc.nl
Phone number: 06-43933825

Xenia Yocarini: xenia.yocarini@hu.nl
Phone number: 06-37273406
Address:
Department of Geriatrics
Location AMC | Meibergdreef 9, 1105 AZ Amsterdam

Attachment: Consent form participant

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

- I have read the information letter. I was able to ask questions. My questions were answered sufficiently. I had enough time to decide whether to participate.
- I know that participation is voluntary. I also know that I can decide to 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 check yes or no below:

- I give permission to be approached for focus groups.

O yes
O no

- I give permission for audio recordings to be made. These recordings will be destroyed after transcription/study end.

O yes
O no

- I give permission for the collected audio recordings to be kept for 10 years after the study for follow-up research.

O yes
O no

- 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 mentioned study. If during the study information arises that may affect the participant’s consent, I will inform them in time.
Name researcher:
Signature: Date: __ / __ / __