

## Information for participation in research

### BRIDGE study

#### Introduction

Dear reader,

With this information letter, we would like to ask if you would be willing to participate in (medical-) scientific research. Participation is voluntary. You are receiving this letter because you have a chronically ill child, and your child has been or was admitted to the hospital and/or Jeroen Pit House.

Participating or not participating will not affect the treatment your child receives.

You will find information here about the type of research, what it means for you, and what is expected of you if you decide to take part.

Are you interested? Please read this letter carefully.

- Ask questions to the researcher providing you with this information.
- Discuss this research with your partner, family, or friends.
- If you would like to participate, we will send you an email with more information.

#### 1. General information

The study was set up by the Amsterdam UMC and is being carried out by nurses and researchers in various hospitals in the Netherlands.

#### 2. What is the purpose of the research?

The aim of our research is to improve the transition from hospital to home. Often this transition is experienced as very big and difficult. That is why we would like to improve the care by gaining more insight into the experiences of the sick child, but also of the parents, brothers and sisters.

#### 3. What happens if you participate in the study?

If you choose to participate in the study, we will use a variety of existing data, such as:

- Name of your child
- Gender and date of birth of your child
- Data from medical records

In addition to the existing data, we also want to collect new data by means of questionnaires. These questionnaires are sent via KLIK.

The questions will focus on different aspects, such as the child's quality of life, your confidence in providing care at home, and satisfaction with the received care. To get a complete picture of the family composition and the context of the sick child, we also ask about your country of birth, marital status, religion, number of family members, work and education.

If you choose to participate in the study, please note that it will take time. We ask you to complete questionnaires at 3 moments; the time of hospital or Jeroen Pit House discharge, 3 and 12 months later. Completing the questionnaires can take about 1 hour each time, so about 3 hours in total.

We understand that this is a significant investment of time and we are very grateful if you are willing to make this time available.

#### **4. What does participation mean to you?**

You will not benefit directly from participating in this study. However, your participation can contribute to improving care for families who make the same transition in the future. As an expression of appreciation, we will regularly send updates about the ongoing research. This way, you will gain insight into how your family has contributed to the study.

By sharing your experiences and perspectives, we can develop care programs and supportive measures that better align with your needs.

#### **5. If you do not want to participate or want to stop the study**

Participation in the research is entirely voluntary. You are free to decide to stop at any point during the study. You do not need to provide a reason for stopping, but it is essential to inform the researcher immediately if you choose to do so.

The data collected up to that point will still be used for the research.

#### **6. What do we do with your data?**

Are you participating in the research? Then you also give consent for 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 address the research questions of this study. We also intend to publish the research results.

### *How do we protect your privacy?*

To safeguard your privacy, we assign a code to your data. Only this code is used on all your information.

The data that directly identify you will no longer be used. The key to the code is securely stored in the hospital. Only the researcher and members of the research team know which code corresponds to you. When processing or sharing your data, we always use only that code. In reports and publications about the research, it will not be possible for anyone to trace back that it was about you.

### *How long do we retain your data?*

We will keep your data for 10 years in the hospital after the end of the study, both for current as possibly for future/other studies

### *Can we use your data for other research?*

Your data may also be relevant for other scientific research in the field of care between hospital and home for chronically ill children after the conclusion of this study. On the consent form, you can indicate whether you agree to this. If you do not give consent, you can still participate in this research.

### *Can you withdraw your consent for the use of your data?*

You can withdraw your consent for the use of your data at any time. This applies to its use in this research and for its use in other research. However, if you withdraw your consent and researchers have already collected data for a specific study, they may still use those data.

### *Are we allowed to approach you again for a follow-up study after this research?*

After this research is completed, we may conduct a follow-up study. In that case, we will approach you to ask if you would like to participate again. On the consent form, you can indicate whether you give us permission for this.

### *Do you want to know more about your privacy?*

Perhaps you would like to receive an electronic copy of the data used for the research, pertaining to you. That is possible. You can request this from the researcher.

If you want to know more about your rights regarding the processing of personal data, please check <https://www.autoriteitpersoonsgegevens.nl/nl/over-privacy/persoonsgegevens>

Do you have questions about your rights? Or do you have a complaint regarding your privacy? Then please contact the person responsible for the processing of your personal data.

If you have complaints about your privacy, we recommend discussing them first with the research team. You can also reach out to the Data Protection Officer of your hospital.

- Amsterdam UMC/JPH: [privacy@amsterdamumc.nl](mailto:privacy@amsterdamumc.nl)
- ErasmusMC: [functionaris.gegevensbescherming@erasmusmc.nl](mailto:functionaris.gegevensbescherming@erasmusmc.nl)
- RadboudUMC: [gegevensbescherming@radboudumc.nl](mailto:gegevensbescherming@radboudumc.nl)
- UMC Groningen: [privacy@umcg.nl](mailto:privacy@umcg.nl)
- UMC Utrecht: [privacy@umcutrecht.nl](mailto:privacy@umcutrecht.nl)

Or you can file a complaint at the 'Autoriteit Persoonsgegevens'.

*Where can you find more information about the research?*

You can find more information about the research on the following website(s): [TCU Consortium | TCU Consortium](#)

## 7. Do you have questions?

This research has been reviewed by the non-WMO review committee of Amsterdam UMC. According to this committee, this study is not subject to the Medical Research Involving Human Subjects Act (WMO). If you have any questions about this research, please feel free to contact the researcher/the research team.

## 8. Do you have a complaint?

If you have a complaint, please discuss it with the researcher or the physician treating you. If you prefer not to do so, you can contact the service representatives below.

- For location AMC/JPH: Patient information
  - o Phone number: 020- 5666440
  - o Email address: [patientenvoorlichting@amsterdamumc.nl](mailto:patientenvoorlichting@amsterdamumc.nl)
- For location Erasmus MC: Complaint mediation
  - o Website: [www.erasmusmc.nl/nl-nl/patientenzorg/klachtenopvang-en-klachtenbemiddeling](http://www.erasmusmc.nl/nl-nl/patientenzorg/klachtenopvang-en-klachtenbemiddeling)
- For location RadboudUMC: Complaint mediation
  - o Phone number 024-3613191
  - o Website: <https://www.radboudumc.nl/patientenzorg/uw-afspraak/uw-rechten-en-plichten/klachten>

- For location UMC Groningen: Complaint mediation
  - o Email address: [klachtenfunctionaris@umcg.nl](mailto:klachtenfunctionaris@umcg.nl)
  - o Website: <https://www.umcg.nl/-/contact-met-het-umcg/vertel-het-ons/klachten>
- For location UMC Utrecht: Complaint mediation
  - o Telephone number 088-755 62 08
  - o Website: <http://www.umcutrecht.nl/nl/Ziekenhuis/Ervaringen-van-patienten/Een-klacht-indienen>.
  - o Check the website of UMC Utrecht for more information about your rights: <https://www.umcutrecht.nl/nl/ziekenhuis/privacy>

**Thank you for your attention. On behalf of the entire research team.**

**Contact details:**

*Executive researcher*

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*Principal Investigators*

AmsterdamUMC

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- Prof. dr. Job B. van Woensel ([j.b.vanwoensel@amsterdamumc.nl](mailto:j.b.vanwoensel@amsterdamumc.nl))

Erasmus MC

- Prof. dr. Koen Joosten ([k.joosten@erasmusmc.nl](mailto:k.joosten@erasmusmc.nl))
- Prof. dr. Matthijs de Hoog ([m.dehoog@erasmusmc.nl](mailto:m.dehoog@erasmusmc.nl))

Radboud UMC

- Dr. I. Ahout ([Inge.Ahout@radboudumc.nl](mailto:Inge.Ahout@radboudumc.nl))
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UMC Groningen

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