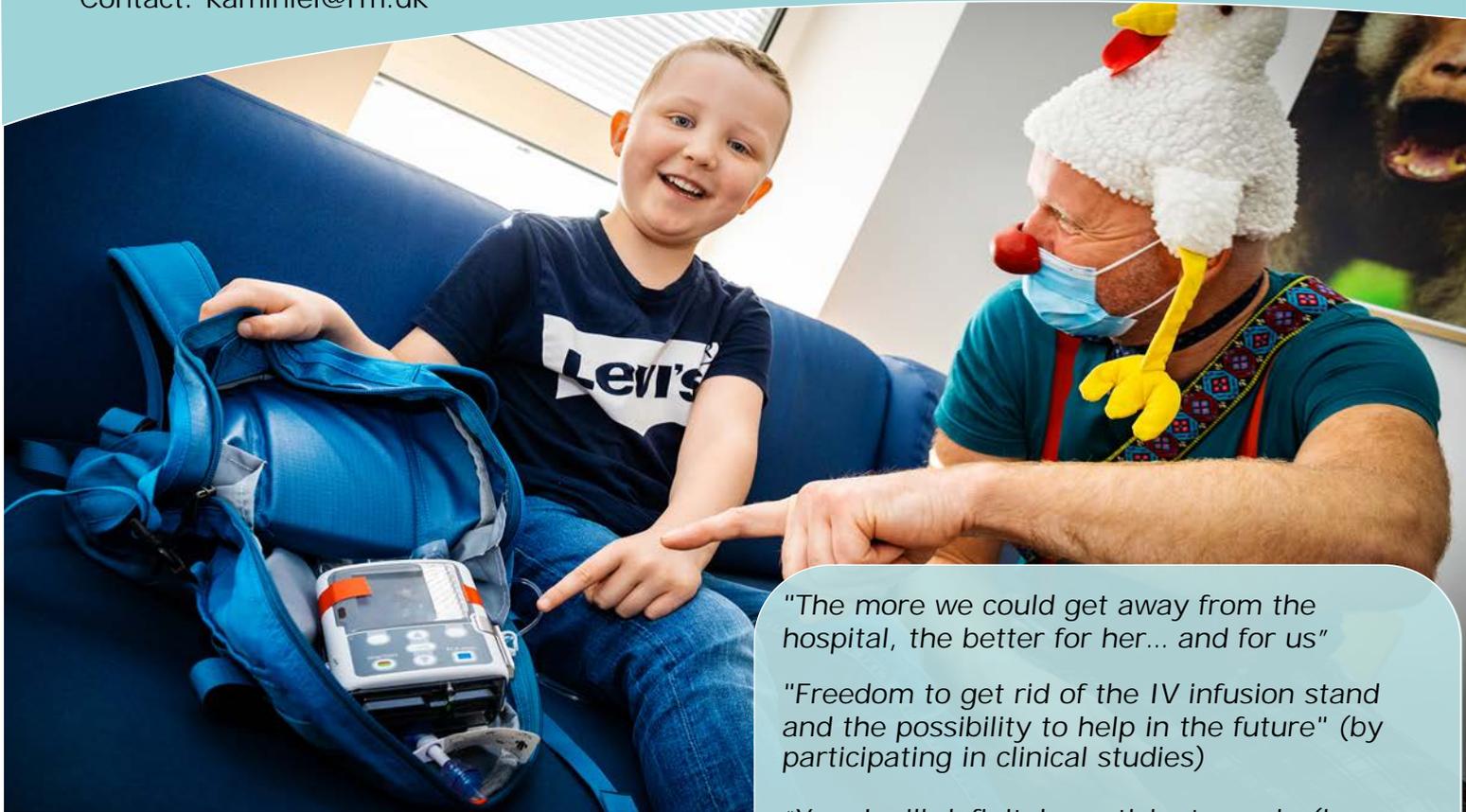


# Participation in clinical studies leads to improved quality of life; experiences of parents, children and adolescents

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*"The more we could get away from the hospital, the better for her... and for us"*

*"Freedom to get rid of the IV infusion stand and the possibility to help in the future" (by participating in clinical studies)*

*"Yes, I will definitely participate again (in clinical studies) – you don't feel being admitted to hospital"*

*"The possibility to go home; that gives us freedom"*

## Introduction

Besides immediate health benefits, other factors are important when parents consent for their underaged children to participate in a clinical study.

A possible association has been reported between patient and family experiences during participation in clinical studies and dropout rates, willingness to re-enter or enter new clinical studies, and overall quality of life.

## Aims

To gain insight into the experiences of families participating in a clinical study, and clarify patient benefits, motivational or discouraging factors related to participation.

## Methods

- A qualitative method was applied.
- Observations of experiences from parents, children and adolescents were made throughout a clinical study of continuous infusion of antibiotics in 38 febrile (68 fever episodes) children with cancer at Aarhus University Hospital.
- Informal patient/parent conversations in clinical situations related to start-up, during the course of and at the end of antibiotic treatment were used followed by semi-structured interviews.
- Interview data were analysed using thematic analysis.

## Conclusion

- Parents described participation in this clinical study as a positive experience.
- Main themes included improved quality of life for the sick child/adolescent and the family due to increased sense of freedom and less time spent at the hospital.

## Results

The 6 semi-structured interviews and 32 informal patient/parent-conversations revealed certain motivational factors for participation in and re-entering clinical studies:

- Increased freedom
- Less hospitalisation
- Increased time spent at home.

The motivational factors are illustrated by the statements above.

