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## Listening to the patients

*User involvement in palliative care research*

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*Publication date:*  
2018

*Document Version*  
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

*Citation for published version (APA):*

Stampe, M., Andersen, S. Ø., Bøgehøj, S., Dinesen, B. I., & Sigaard, J. V. (2018). *Listening to the patients: User involvement in palliative care research*. Poster presented at Week of Health and Innovation, WHINN 2018, Odense, Denmark.

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# Listening to the patients: User Involvement in Palliative Care Research

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## Background

The World Health Organization and The Worldwide Hospice Palliative Care Alliance estimates that annually at least 20 million people need palliative care. The majority of these are patients suffering from cancer, cardiovascular and respiratory diseases [1]. In Denmark approximately 58% of all deaths are related to one of these diseases [2].

One of the challenges associated with research on the particular patient group is that it is a very delicate matter where death is close to life and only a few studies have been dealing with user involvement in connection with palliation. One might imagine that some researchers who are not used to working with this particular patient group may be touching anxiety to overthrow patients and their relatives. Palliative care research is often complicated by the belief that persons facing the end of life should not be burdened with the load of participating and should also not be expected to share some very personal information during a difficult period of life. In addition, fatigue are also believed to be factors that would limit participation. [3,4]

Researchers on the other side describes unique benefits of research participation for terminally ill patients. Examples of benefits includes a feeling of altruism where other people will benefit from the study results in the future, the desire to be seen as more than just a dying person, getting closely followed up and the prospect of helping staff [5].

## Aim

The aim of this study was to explore the advantages and challenges when including palliative patients and their relatives in a user-driven innovation process.

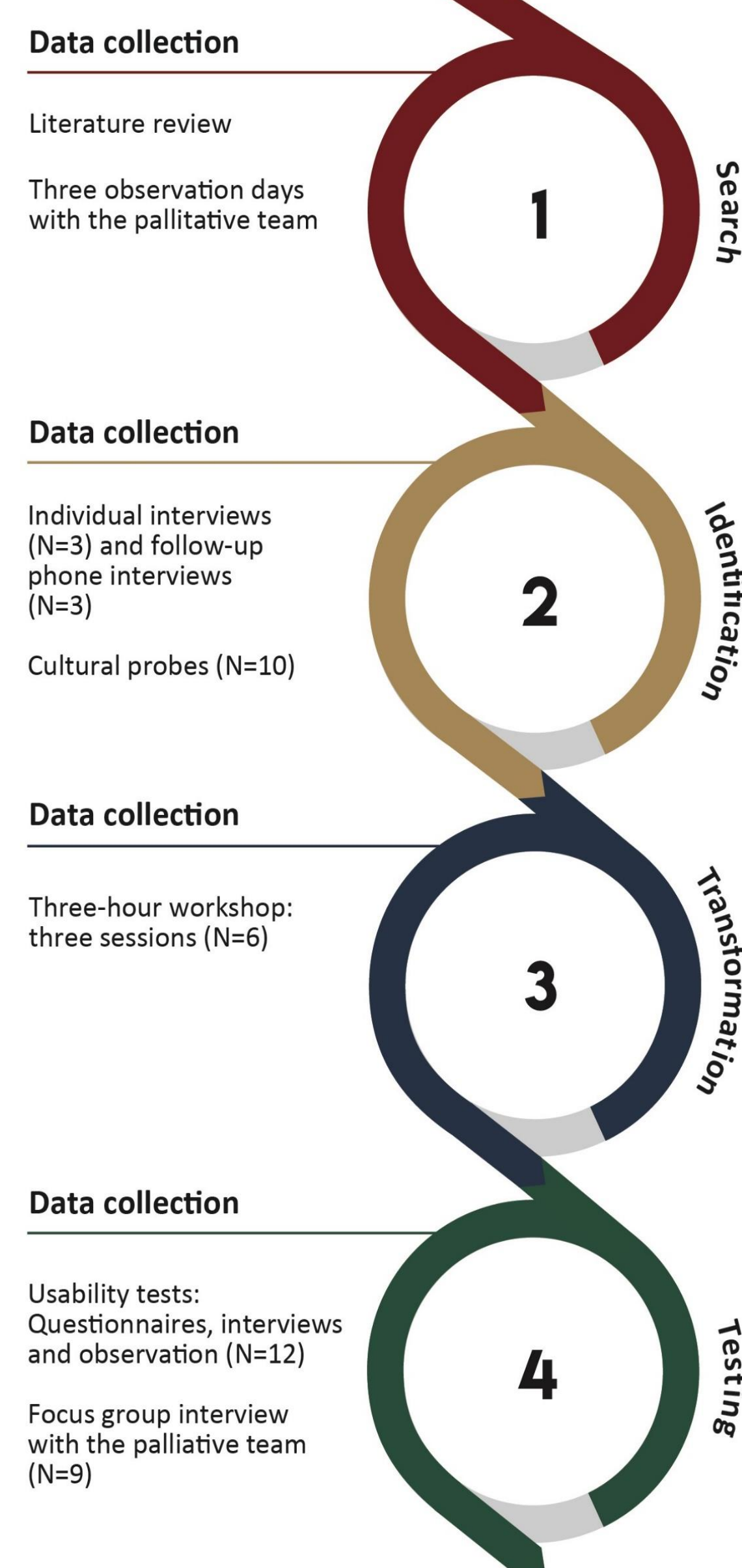
## Methods

In collaboration with the Specialized Palliative Care Team in South West Jutland, Esbjerg a user-driven innovation process was designed and implemented in spring 2018.

The study was designed as a feasibility study, where triangulation of qualitative data collection techniques was used.

A total of eight patients and eight relatives were included in the innovation process.

Data were analysed within the project group using NVivo 11.0.



## Findings

The analyses of data showed that user-driven innovation with palliative patients and their relatives is associated with both advantages and challenges.

### Advantages:

- The patients and their relatives were enthusiastic, motivated and had the energy to complete all the different activities.
- The project gave the participants a purpose and another focus than the illness.
- All the members of the project group have a professional background as nurses and physiotherapist, which has provided a trustful relation and an open dialogue with the participants.

### Challenges:

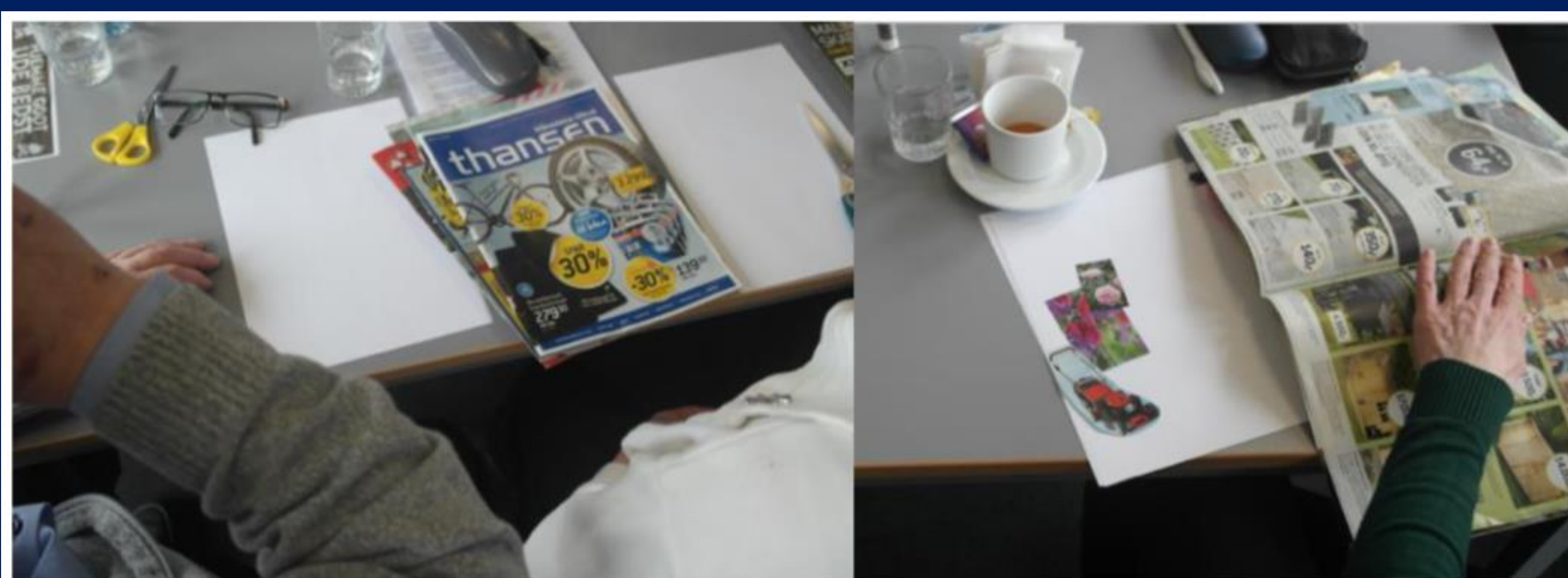
- Planning of the activities must be agile due to the rapid progression of the patients' diseases.
- Due to the patients' physical conditions, it can be a necessity to include their relatives to help the patients fulfilling the different activities.

## Conclusion

Based on the findings, we conclude that the advantages outweigh the challenges when conducting userdriven innovation with palliative patients and thus, it is beneficial to include the patients and their relatives in a user-driven innovation process. The patients were motivated to be a part of the project but their conditions must be taken into consideration when planning the process. Further research is required.

## Acknowledgement

The project is supported by Aalborg University. Thank you to patients, relatives and healthcare professionals at South West Jutland Hospital, Esbjerg.



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