patient participation in 10 projects in palliative care

No registrations found.

Ethical review Positive opinion

Status Recruiting

Health condition type

Study type

Summary

ID

NL-OMON22964

Source

NTR

Health condition

palliative care, terminal care

Sponsors and support

Primary sponsor: Zorgbelang Limburg, Hogeschool Zuyd, Huis voor de Zorg

Source(s) of monetary or material Support: ZON-MW, The Netherlands Organization for

Health Research and Development

Intervention

Outcome measures

Primary outcome

The impact of patient participation from the perspective of patient(representatives) and researchers. Additionally, the underlying processes, how the impact was created, will be studies by using the context-mechanism-outcome classification.

Secondary outcome

N/A

Study description

Background summary

Participation of patients in palliative care is a relatively new development. Professionals often want to do more in patient participation. However, they lack the knowledge and experience to put the mechanisms of participation into meaningful practice. The main objective of this study is to sustainably strengthen patient participation in the context of palliative care in education, research and care practice projects.

This study consists of participatory action research with multiple case studies. The study will be carried out within a national research programme on palliative care. Ten out of 18 projects will be involved covering a range of different palliative care contexts such as education, research and practice.

The participants are patient (representatives) and senior and junior researchers.

The first part, implementation of patient participation, consists of several implementation activities: a)training and support for patient(representatives); b) training and coaching for research; c) working with the participation matric; d) setting up a participation community of practice among all 10 participating projects; e) development-oriented evaluation and creating sustainable conditions.

The second part focus on researching the impact of patient participation from the perspective of patient(representatives) and researchers. Additionally, the underlying processes, how the impact was created, will be studies by using the context-mechanism-outcome classification.

During the implementation data is collected through field notes, observations, informal conversations and video recordings. In the evaluation of the impact the data will be collected by in-depth interviews and focus group discussions. Data will be analyzed using content analysis.

Study objective

The main objective of this study is to study the impact of patient participation from the perspective of patient(representatives) and researchers in 10 projects in palliative care. And to sustainably strengthen patient participation in the context of palliative care in education, research and care practice projects.

Study design

During the implementation data is collected through field notes, observations, informal conversations and video recordings. In the evaluation of the impact the data will be collected by in-depth interviews and focus group discussions.

Intervention

the implementation of patient participation, consists of several implementation activities: a)training and support for patient(representatives); b) training and coaching for research; c) working with the participation matric; d) setting up a participation community of practice among all 10 participating projects; e) development-oriented evaluation and creating sustainable conditions.

Contacts

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Eligibility criteria

Inclusion criteria

The participants are patient (representatives) and senior and junior researchers.

Exclusion criteria

N/A

Study design

Design

Intervention model: Other Control: N/A , unknown

Recruitment

NL

Recruitment status: Recruiting
Start date (anticipated): 15-06-2016

Enrollment: 30

Type: Anticipated

Ethics review

Positive opinion

Date: 08-06-2016

Application type: First submission

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register ID

NTR-new NL5474 NTR-old NTR5891 Register ID

Other METC Zuyderland-Zuyd : 16-N-108

Study results

Summary results

N/A