

# VIGDIS HJORT // NORWAY

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## EVENT FOR RELATIVES/PATIENTS/PROFESSIONALS

PARTICIPANTS: 10 (2 men + 8 women)

SUCCESSRATE:

67 % VERY GOOD

33 % GOOD

AGE SPREAD: FROM 27 TO 68



# JON KALMAN STEFANSON // ICELAND

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EVENT FOR RELATIVES/PATIENTS

PARTICIPANTS: 14 (1 man + 13 women)

SUCCESSRATE:

100 % VERY GOOD

AGE SPREAD: FROM 23 TO 77



# SIRI ØKLAND // NORWAY

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EVENT FOR RELATIVES/HIGH-SCHOOL CHILDREN

PARTICIPANTS: 16 (8 men + 8 women)

SUCCESSRATE:

14 % VERY GOOD

86 % GOOD

AGE SPREAD: FROM 17 TO 18



# STATEMENTS FROM WORKSHOPS

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- *I hereby send you my text from your completely wonderful course. Thank you. It made a huge difference to me. I really believe that such processes are healing*

(anonymous)

- *Thank you very much for allowing me to join the workshop on cancer today. I am really happy about it and it feels like I finally got through a very massive performance block*

(anonymous)

# PARTICIPATION IN WHAT WAY?

## NINA SIMON: *THE PARTICIPATORY MUSEUM*

Model of participation	Description of role of participants	SILO Aarhus
Contribution	Participants contribute with smaller actions/ideas but have no influence on the framework or goals of the process (e.g. interaction with digital interfaces or comment boards in exhibitions)	Participants asking question to author after his/her talk
Collaboration	Participants collaborate with facilitators on producing key content but have no influence on framework or goals (e.g. crowdsourced exhibitions)	Participants affecting and changing events through their writing, but process is controlled by exercises' presented by facilitators
Co-creation	Participants co-create process with facilitators from the very beginning and thus affect the goal and design of process (e.g. community based exhibitions)	Involvement of former patients (and health experts) in shaping the setup of the event, discussing ethics, formulating invitation
Hosting	Someone offers a platform/space to participants that then run the process autonomously (e.g. user-led exhibitions)	SILO (and participants) moved between different institutional venues that hosted the participatory writing process – Hejmdal, DOKK1 library, Youth Festival

# NEXT STEP – RESEARCH ARTICLE

## “THE VALUES OF PARTICIPATORY ILLNESS WRITING”

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Short article for journal for doctors in Denmark describing the method (author talk + participant illness writing from various perspectives + conversation) and its participatory dimensions (previous slide)

Article will outline different reasons for engaging with this method by describing the values it helps produce and its strengths in terms of *producing peaceful social relations, while also offering material for critically mirroring health institutions*:

- *Therapy*: Empowerment of patients through writing process
- *Aesthetics*: Interesting sensual experiences during the events and through reading the texts
- *Relations*: Enacting peaceful understanding between the groups affected by cancer and its treatment
- *Health care*: Offers material about how patients experience themselves, the system, doctors and nurses during treatment that can be used to rethink practices in health care

Problems related to method: It attracts a rather well-educated and privileged audience (in terms of e.g. class, race) and the vast majority of participants in the voluntary workshops are women



# REFLECTING ON SOCIAL RELATIONS

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Participant (Tine) writes about her mother's illness from the mother's perspective:

*"I'm being driven to a hospice*

*It's my final wish*

*I want to die with a view over Kalø cove*

*Tine's with me*

*Now it's me*

*I'm the child*

*When we get there*

*I'm gone"*

Participant (mother) writes about her own cancer disease, but from her son's perspective. The mother reads it aloud to the son who is also present at the workshop:

*"When my mother's hair grows out it looks like the hair of a sheep. Curly and grey and very soft. I don't talk much about death. Also not now. I play music and write poems"*

# REFLECTING ON HEALTH CARE PRACTICE

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Participant about the disease of her sister.

*“Don’t fall ill in the spring. We said to each other afterwards. When before we knew what was happening we’d lost her’. Because spring is full of holidays and days off. Tests results are delayed. Laboratories are closed. There’s no vacant beds. And even the smallest examinations take forever. And the next stop was the hospice. She didn’t come back home again. She didn’t come back home again. Crazy! Not giving her any time at home felt like an act of violence”.*





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