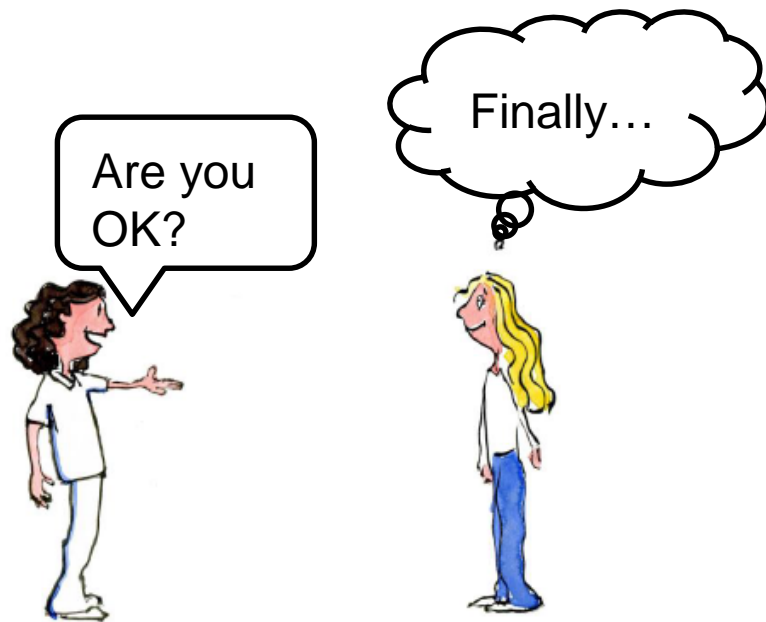


7th International Together against Stigma: Each Mind Matters
San Francisco 18th-20th February 2015



**No more doubt, silence and
taboo about mental illness!**

A Danish anti-stigma program targeting psychiatric staff

Project Manager, Psychologist Johanne Bratbo & Project Coordinator Anja Kare Vedelsby

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Agenda

- Brief presentation of ONE OF US
- Background and data
- Toolkit: The Dialogue Kickstarter
- Implementation
- Evaluation
- Questions

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ONE OF US – in Danish: EN AF OS



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Vision:

“To create a better life for all by promoting inclusion and combating discrimination connected to mental illness.”

Mission:

- ✓ To increase public knowledge on mental illness
- ✓ To reduce the distance that leads to stigma, prejudice and social exclusion
- ✓ To increase greater understanding of mental illness in schools, workplaces and all other spheres of everyday life.

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ONE OF US



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- **Project period:** 2011-2015 (so far)
- **Organisation and interventions** at both national, regional and local level
- **Partners:** Danish Health and Medicines Authority, Danish Regions, The Philanthropic Foundation TrygFonden, The Psychiatry Network (service users' and relatives' organisations), Local Government Denmark, The Danish Ministry of Social Affairs, The Danish Mental Health Fund
- **Five target areas:**
 1. Service users and relatives
 2. Psychiatric, health and social service staff
 3. Labour market
 4. Young people
 5. General population and the media
- **Contact**
www.one-of-us.nu → www.en-af-os.dk
Facebook EN AF OS

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One of five defined target areas:

Psychiatric, health and social service staff - objectives



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- More respect and cooperation in practice – policies are not enough
- More knowledge on recovery and empowerment
- Recognise resources of service users and relatives and promote a holistic approach
- Stimulate greater reflection on culture and language within systems

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Background and data

A basic challenge



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Prejudice on mental illness and people affected by it can cause:

- Rejection and exclusion from society
- Self-stigma leading to loss of relations, loneliness and low self-esteem
- Lack of acceptance of illness and of motivation to cooperate on treatment

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The significance of culture



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- **Mental health professionals' perception** of a patient's possibility of recovery has a significant impact on the level of stigma.
- **The tone on the ward** and the way staff talk about patients affect mental health professionals' perception of recovery possibilities.
(ONE OF US, 2011-2012)
- **Voicing prejudice:** In a survey among 500 young people with lived experience, 70% stated that mental health professionals had not talked to them about prejudice
(ONE OF US, 2013)

ONE OF US attitudes' survey 2011-2012: Believing in recovery



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"It does help when practitioners believe it is possible to get better. It helps both the patients and the practitioners. It is of course more important for patients. But it generates a different energy and enthusiasm when both parties believe in it. You don't have to apologise for believing in your patient all the time saying: 'Well, I know I might be seeing this through rose-coloured glasses.'"

"'Naive', we usually say or 'Okay, I guess you haven't been here that long'. It's devastating to be told just because you see resources. But when we work with patients on the cognitive model it shines through, if we don't believe what we say. We have to believe what we say."

Focus group to item 20, mixed staff

Stigma in every day life - examples



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- Patients feel **patronized**
- Patients **do not feel sufficiently involved** in decisions about own treatment
- Lack of focus on patients **resources and possibility of recovery** - 'once mentally ill, always mentally ill'



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A patient's perspective



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"But when I got this diagnosis [schizophrenia] and we left the psychiatrist, I said 'I don't have schizophrenia'. She [health professional/contact person] looks at me and says: 'So listen, you have schizophrenia. You'll need medication for the rest of your life, you won't be able to work' - I would have to apply for early retirement pension – 'You won't have children and you won't marry. But you can still have a good life.'"

Focus group, ONE OF US, discrimination survey 2013

Stigma not just a Danish phenomenon



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International data document:

- Up to one fourth of all experiences of stigma occur inside the mental health system

(Thornicroft, 2006)

Danish data document:

- Patients feel stigmatized by mental health professionals
- Mental health professionals in general are more pessimistic than the general public on whether or not it is possible to recover from mental illness.

(Nordentoft et al. 2011)

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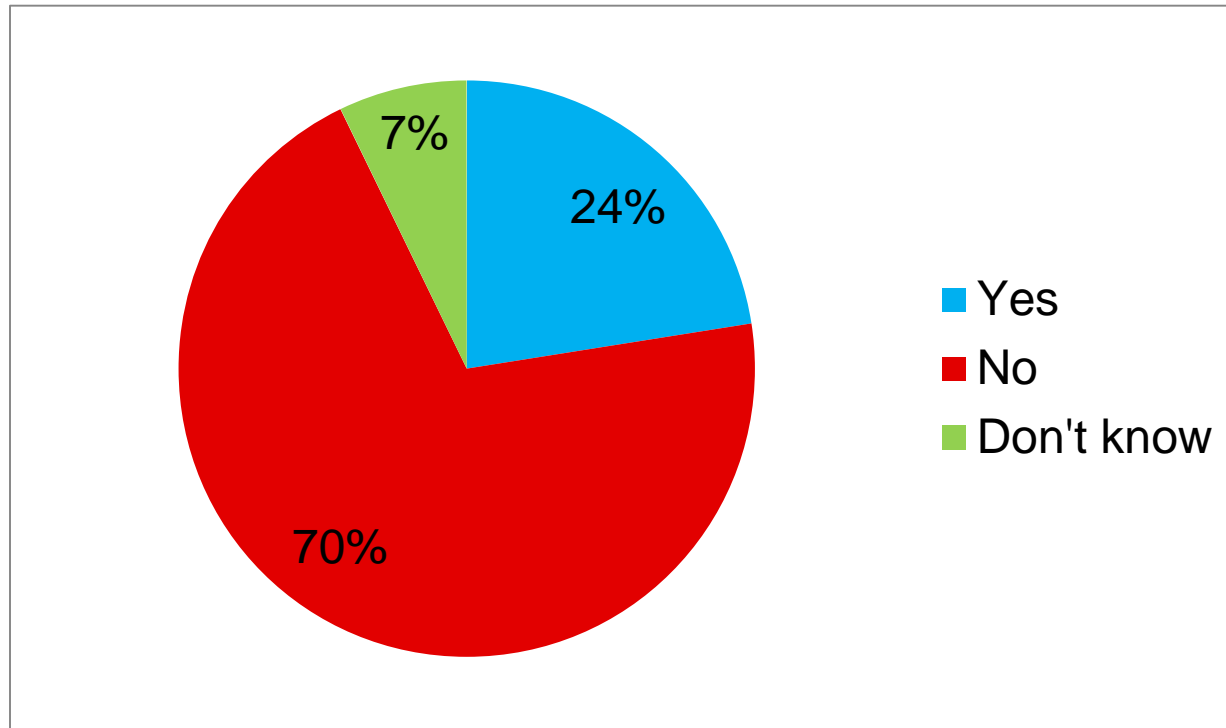
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Survey among young people 2013



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Does your doctor/therapist discuss prejudices with you?



ONE OF US' survey on mental illness among young people and their attitudes towards and experience with treatment. 573 respondents between 15 and 25 yrs. w. lived experience of mental illness

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A Danish pilot study among staff in two psychiatric wards in Copenhagen 2011-12



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Aim of survey:

- Measure attitudes among psychiatric staff in a pilot study to test the assumption that psychiatric staff are more likely to stigmatize than the population in general.
- Stimulate debate and reflection about stigma-related issues among staff

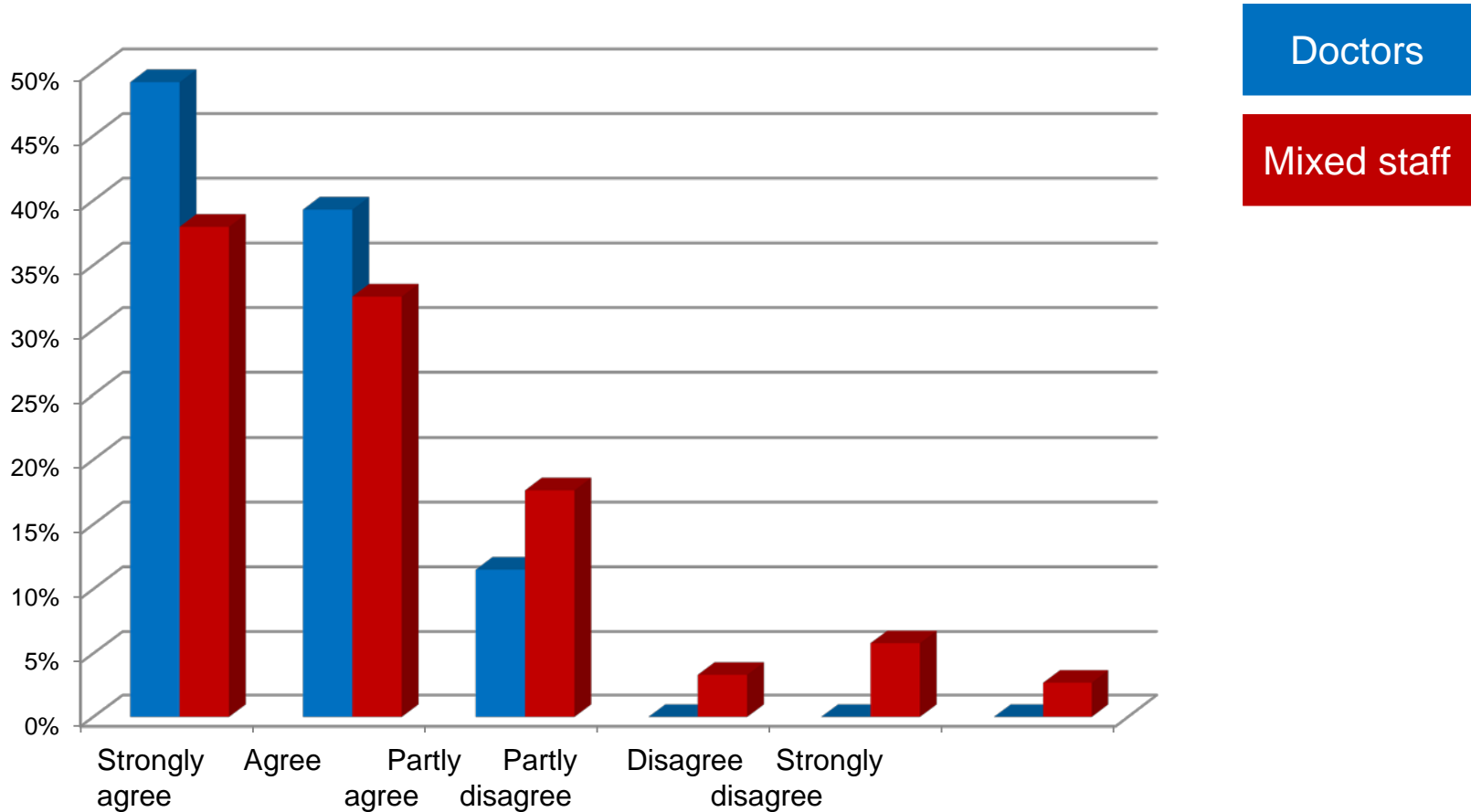
Attitudes survey

Added item: Cultural sensitivity



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18. The tone at the workplace and the way we speak about patients affect our perception of their possibility of recovery.



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Attitudes survey

Verbal and non-verbal communication



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”What you say verbally is one thing, but there can also be stigmatising body language and attitudes. Even at a medical conference. When certain diagnoses come up, some of the staff members already roll their eyes. There are many ways to be unprofessional. The attitude is: ‘You’ll never get anywhere with them’, ‘they’re always so difficult’. They distance themselves and don’t take it seriously.”

Focus group to item 18, doctors

The Tool Kit



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Challenges

Psychiatric staff have knowledge about mental illness and contact with patients but stigma still exists.

→ stimulate a process of reflection on culture and bring about the messages of:

1. Seeing 'the person behind the diagnosis'
2. Recognising the importance of the patients' first encounter with the psychiatric system.

Strength

Psychiatric management level – both national and regional - represented in the partnership of ONE OF US

→ backing the need for targeting psychiatric staff

Aim of the toolkit: The Dialogue Kickstarter



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Translation:

The Dialogue Kickstarter
– put focus on anti-stigma

- **To create awareness of communication**
- **To motivate staff to a dialogue** about respectful language and awareness of culture and social conventions
- **To stimulate that staff work more goal-oriented** to promote anti-stigma.

The Dialogue Kickstarter

– a good starting point



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The Dialogue Kickstarter allows for:

- Mutual reflections on the impact of prejudice, stigma and self-stigma in order to strengthen the quality of treatment to the benefit of patients and their relatives
- Strengthening cross-cutting dialogue between professionals to increase awareness of language and culture in the everyday treatment effort
- Strengthen readiness to an open dialogue with patients and relatives on taboo, prejudice and the risk of self-stigma

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Elements of The Dialogue Kickstarter



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All materials can be downloaded from
www.en-af-os.dk/dialogstarteren

- Videos 'Maybe I'm just a unique human being' w/ questions for debate
- Case vignettes w/ questions for debate
- Videos: 'Plain talk' w/ questions for debate
- Personal story - ONE OF US ambassador
- Memo (to be filled in to keep focus on anti-stigma)
- Exercise: 'Have you encountered these attitudes?'
- Electronic evaluation
→ database and evaluation

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The educational setting

– easy access and use



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- Easily accessible and easy to administer
- Different levels/steps: 1, 2 or 3 hours (+ extra 1 hour)
 - with step by step instructions
- Provides an opportunity to include service users and relatives (defined goal)
- Identification as strongest means:
 - Personal stories by ambassadors (in person)
 - Personal stories by ambassadors on video
 - Case vignettes related to every day life within mental health care

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Information material – poster and postcard



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Information material

– stickers with messages to remember



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- No one is just a diagnosis
- Have you asked your patient for his or her opinion?
- Hope is always part of recovery
- Have you asked your patient for his or her experiences of prejudice?

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Video:

'Don't ask questions all the time'



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Video: 'I shouldn't ask too many questions'



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Questions for debate:

- Do you recognise any of the described situations?
- Have you experienced other situations where patients have felt stigmatized? What happened, and could you have done anything differently?
- Have you experienced relatives feeling stigmatised? What happened, and could you have done anything differently?

In the video we learn how patients feel stigmatised by the glass wall.

- What is your conference culture like?
- Is there anything that could be done differently and if so, how?

In the video we also learn that the first encounter with the psychiatric system is vital.

- Which values do you emphasise when you meet patients. Is there room for improvement and perhaps a more systematic approach in your daily practice?

Case example: On parenthood



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Dorte is 25 years old and diagnosed with schizophrenia. She is at her final appointment with her psychiatrist, Pernille, and contact nurse, Henriette, in outpatient treatment. She has been through a long treatment plan which she has benefitted greatly from and now reports to be without symptoms.

During treatment she has talked about neglect in her childhood and her wild teens with many different boyfriends. She is studying to become a kindergarden teacher and for the first time in her life she is in a longterm relationship with Asger who has a 5-year-old daughter from a previous relationship.

The conversation ends with Dorte sharing her and Asger's hope of having a child together and becoming 'a real family'. Both Pernille and Henriette tell Dorte that she should really think it over thoroughly because 'having a baby is a huge challenge'.

Debate questions:

- How would you react to Dorte's wish to have a baby?
- Have you ever been in a similar situation? How did you deal with it? How do you think Pernille and Henriette should respond?

Implementation of the Dialogue Kickstarter



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1st phase strategy

- Regional briefing about ONE OF US to relevant psychiatric staff
- Attitudes survey among psychiatric staff (MICA 2 & 4) – supplemented by focus groups
- Road show with results of survey presented to respondents

2nd phase strategy

- Development of toolkit for mental health professionals: The Dialogue Kickstarter - a cooperation between the ONE OF US secretariat, a group of mental health professionals, ONE OF US ambassadors/service users and ONE OF US regional coordinators
- Strategy to disseminate and implement toolkit
 - cooperation with psychiatric top management in all five regions
 - regional action plans for implementation

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Primary Actors



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PSYCHIATRY:

Psychiatric management top level

Unions for psychiatric staff

Psychiatric wards' management level
Development consultants
Relevant committees

Ward management
Union representatives
Staff

National level

Regional level

Local level

ONE OF US:

Board
Resource group
Unions for psychiatric staff
Umbrella organisation for service users and relatives

Regional coordinators' group

Regional coordination groups

Ambassadors

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Regional action plans – general messages



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Region	Time frame	Target groups	Scale	Implementing staff
Capital	Feb. 2014-April 2015	Staff and management	Staff in all psychiatric wards	Information centre staff
Zealand	Jan. 2014→	Management, staff and service users	Introductory presentation to all management teams	Two part-time employees with service user background
Southern Denmark	2014→	All staff with primary patient contact	All wards plan their own effort. Integrated in other projects	
Central Denmark	2014→	Students, three pilot wards, patient meetings		Teachers, ward managements
Northern Denmark	1st half of 2014→	All wards and outpatient clinics	Thorough information process. Management is ambassadors internally	Information centre staff



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Evaluation of The Dialogue Kickstarter

Link to electronic evaluation:

- In the printed material
 - In the online material
-
- Documents the use of The Dialogue Kickstarter
 - Evaluation of ONE OF US



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Evaluation results – November 2014

- 47 registrations
- 73% first time users of the material
- 27% previously worked with the material
- 27% included a personal – in person – story by an ambassador
- 15% did not include a personal story by an ambassador but expected to do so
- 68% worked with the material at a staff meeting
- A wide range of mental health professionals have worked with the material

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Results from working with the Dialogue Kickstarter – essential findings



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More than 75% "agree" or "strongly agree" that working with The Dialogue
Kickstarter:

- Increased their knowledge of the significance of prejudice which will be useful in their daily work
- Refreshed their knowledge about the significance of prejudice which will be useful in their daily work
- Increased their awareness of use of language
- Increased their awareness of promoting dialogue with patients and relatives

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Satisfaction with the Dialogue Kickstarter



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75% are "satisfied" or "very satisfied" with:

- Content
- Structure
- Proportions
- Benefits

Memo



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HUSKESEDDEL

HER ARBEJDER VI MED AT FREMME AFSTIGMATISERING VED AT:
(SKRIV TRE MÅL)

1. _____

2. _____

3. _____

VI MØDES IGEN D. _ / _ FOR AT TAGE TEMPERATUREN PÅ VORES FREMSKRIFT.
HILSEN _____

- Accessibility
- Unwritten rules
- Language – to and about the patient
- Cooperation with relatives
- Communicating hope
- Awareness of what kind of activities are carried out in public areas
- See the person behind the diagnosis

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