

8th International Stigma Conference  
21. September 2017



No more doubt, silence and  
taboo about mental illness!

## The ONE OF US panel

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**ONE OF US... a campaign for all of us**



**Væk med tavshed, tvivl og tabu om psykisk sygdom!**

# Agenda

- Briefly about ONE OF US
- Setting up the ONE OF US panel
- Objective of the panel
- Surveys - examples
- Use of surveys
- Questions?

# The Danish context

- Population of 5,5 mil.
- More than 500.000 people with mental illness
- 440.000 people currently on antidepressant and anxiety medication
- Number of people given non-psychotic diagnosis growing fast
- Annual expenses linked to mental illness: 7,4 bill. euro – only 10% of this spent on treatment



# Vision of ONE OF US



No more doubt, silence and  
taboo about mental illness!



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

# ONE OF US – in Danish: EN AF OS

- **Project period:** 2011-2020
- **Funding:** National Board of Health, Danish Regions and philanthropic foundation TrygFonden
- **Organisation and Interventions** at both national, regional and local level
- **Five target areas:**
  1. Service users and relatives
  2. Staff in the psychiatric, health and social sectors
  3. Labour market
  4. Youth
  5. General population and the media



# Partners behind ONE OF US



## **Mandate:**

Focus on knowledge, attitudes and behaviour related to anti-stigma

## **No mandate for:**

Criticising structure, services and financing services for people with mental illness

1. phase: 2011-2015
2. phase: 2016-2020

# What we are working for

## Mission

- To increase the knowledge on mental illness in society
- To reduce the distance that leads to stigmatisation, prejudice and social exclusion
- To increase the comprehension about mental illness in schools, work places, and all other areas where the everyday life take place

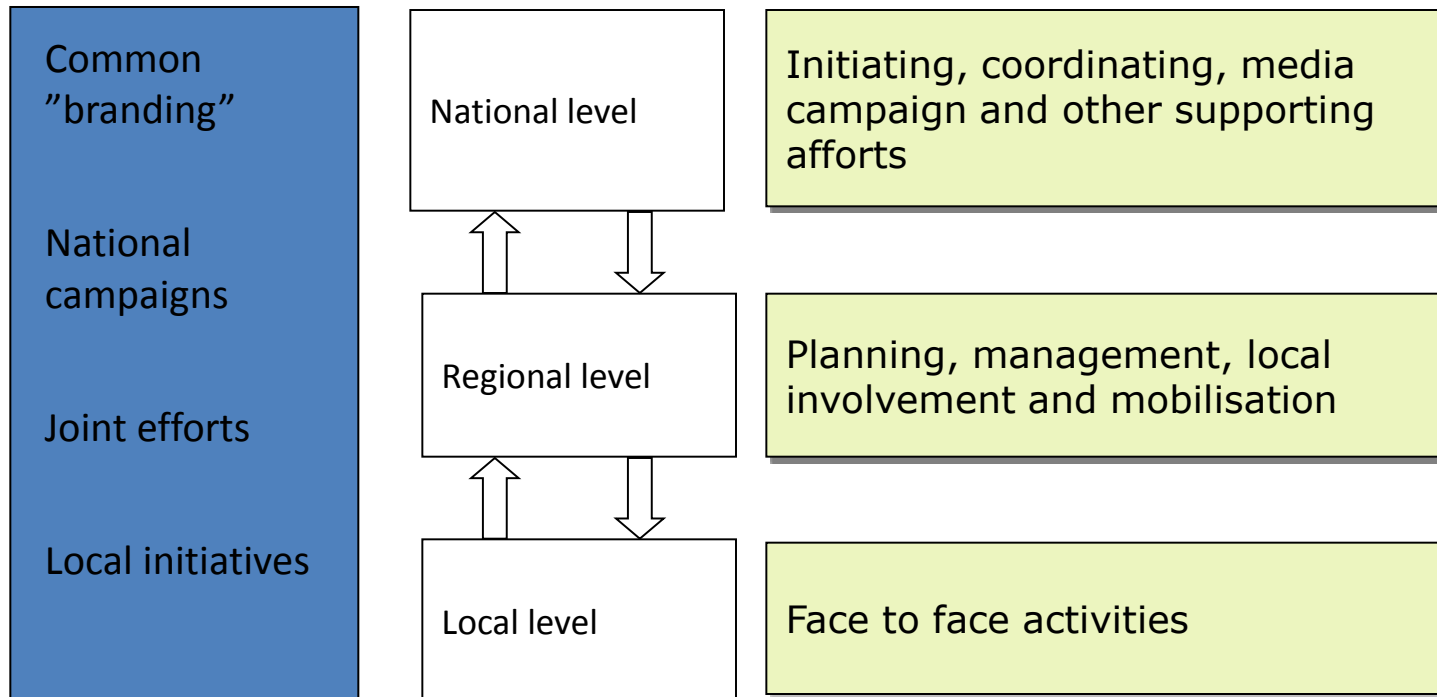
## Target areas

1. Service users and relatives
2. Staff in the health and social sectors
3. Labour market
4. Youth
5. The public and the media

Overall action plan with targets and target groups for each target area.

**Focus is on attitudes and behavior at the labour market – not job creation**

# Overall project model of ONE OF US





Find us here: [www.one-of-us.nu](http://www.one-of-us.nu)

ONE OF US

No more doubt, silence and taboo about mental illness!

The screenshot shows the EN AF OS website homepage. At the top left is the EN AF OS logo. To its right is a navigation menu with links for Nyheder, Arrangementer, EN AF OS, Din Region, Viden og værktøjer, Presse, Kontakt, and English. Below the navigation is a tagline: "Væk med tavshed, tvivl og tabu om psykisk sygdom!". The main content area features a large image of four young people talking. To the left of the image is the headline "Bryd tavsheden" and subtext "Nyt online unge undervisningsmateriale er blevet lanceret". A "Læs mere" button is at the bottom left.

Find os på facebook

The screenshot shows the EN AF OS Facebook page. The profile picture is the EN AF OS logo. The cover photo features the text "EN AF OS 39,369 likes" and "Psykisk sygdom kureres ikke med tavshed." Below the cover photo is a "Liked" button. A section titled "You and 108 other friends like this" shows a row of profile pictures of users who liked the post.

### ONE OF US panel

Online survey panel of approx. 2.000 people with lived experience of mental illness

The screenshot shows a post on the EN AF OS Facebook page. The post features a photo of a person's legs in dark pants and a hammer. The text of the post reads: "For få er klædt på til at tale om deres problemer." Below the photo is the EN AF OS logo and the text "EN AF OS Fællesskab". The post has 28,892 likes and 1,200 comments. The page navigation bar at the bottom shows "Tilsluttede", "Om", "Billeder", "Instagram", and "Flere".

# At least three important reasons to work with anti-stigma



## 1. Sensational and negative portrayal of mental illness in the media

- e.g. "Mentally ill commit more murders"...

## 2. Mental illness affects more people

- and more people get a psychiatric diagnosis

## 3. Spread the message of recovery

- break with the story of chronicity "once mentally ill, always mentally ill"



# Serious consequences of discrimination and stigma

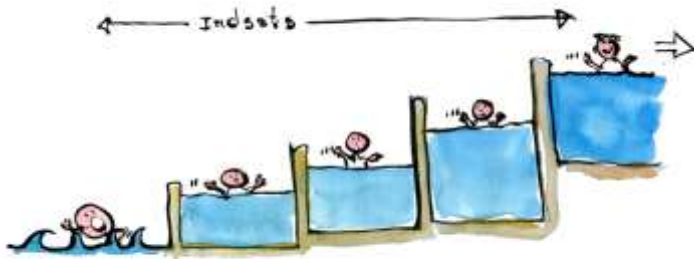


- **Major risk of exclusion**
  - from social life, educational system, work life
- **Reduced life expectancy and life quality**
  - risk of somatic symptoms neglected or downplayed in health care
- **Self-stigma**
  - internalising prejudice from society → limiting oneself, losing hope, sense of worthlessness, failure and low self-esteem

# ONE OF US activity strategy

## ONE OF US activities

- Developed specifically for target areas and target groups based on documented methods
- ✓ e.g. male dominated workplaces (challenging stereotypes with a sense of humour)



## Ambushing activities

- **Linking to activities** carried out by relevant stakeholders:
  - ✓ Saves resources not to plan and carry out all activities ourselves
  - ✓ Increases chances of implementation in the long term
  - ✓ An opportunity to be present with messages, materials and contact in settings where people usually wouldn't expect to be confronted with issues related to mental illness

# About the electronic ONE OF US panel



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- Established in 2012
- SurveyXact, Survey Monkey
- Currently consists of 2.075 members with lived experience of mental illness
- 80-90% women
- 35-40% under the age of 30
- Motivation for being an active panelist stimulated by communication of specific need and use of the data
- Members primarily recruited through Facebook and at events
- Surveys among selected demographics: Young people, men etc.

# Objective of the panel



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Carry out own surveys – not representative, but still...

- Test campaign materials
- Background information
- New knowledge → news stories
- Give a voice to people with lived experience of mental illness
- Assist partners in the field

# Examples of surveys

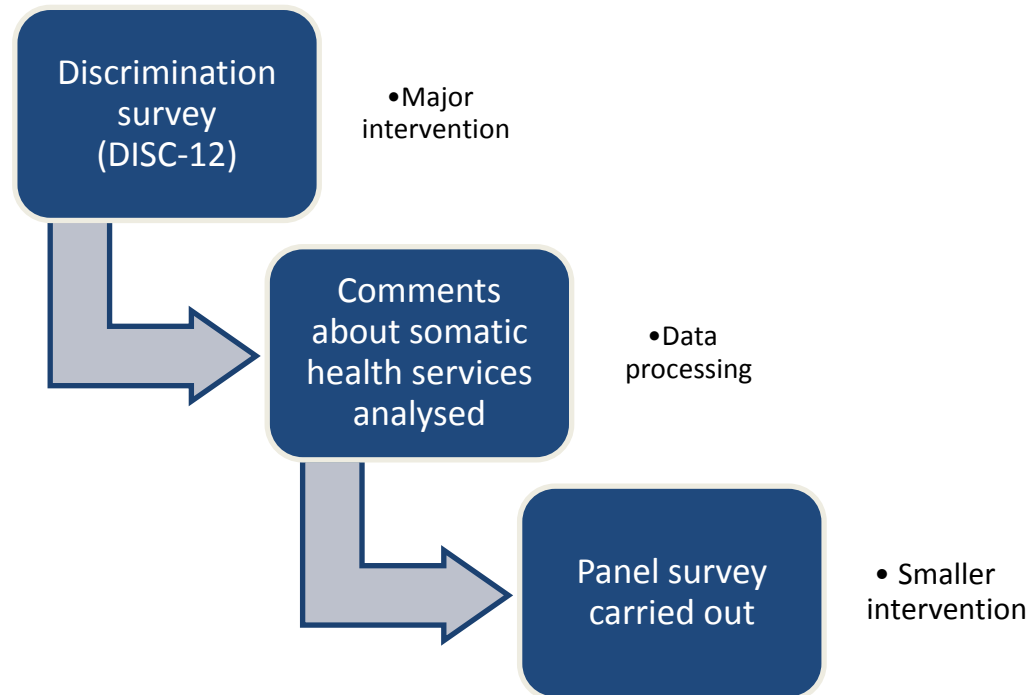


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- Part of campaign directed at young people and professionals (spring 2013) - 4 survey themes (included news stories)
  - Education
  - Family
  - Friends
  - Treatment
- Background info: Preferences on social media
  - Dilemmas
  - Specific knowledge
  - Feeling of safe space → feeling of being socially connected and less isolated
- Two surveys about the effect of media portrayals of mental illness

# Example of use of surveys

## - converting research data into action





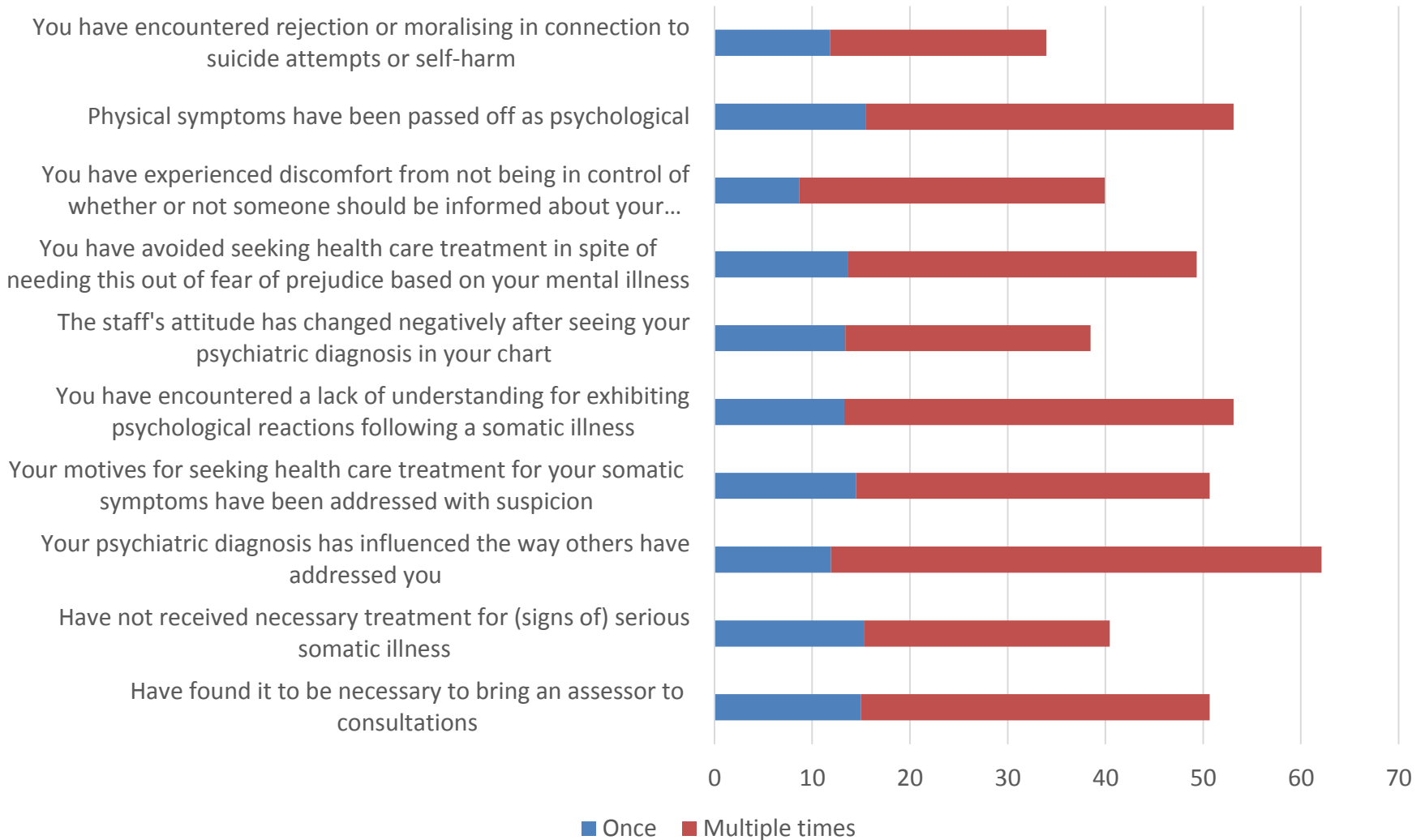
# Data processing - personal comments

*Several times I have experienced not being taken seriously by my family doctor because of my psychiatric diagnosis. Sometimes it feels like you can't have a physical problem if you have a mental illness. The consequence of this is that I no longer feel allowed to contact my family doctor which was already difficult*

## Step by step:

1. Personal comments in the discrimination survey related to somatic health care → 10 important themes were identified
2. Tested as 10 statements in a workshop with service users, relatives and professionals
3. Statements used in a ONE OF US panel survey – base for anti-stigma intervention in somatic health care

# ONE OF US-panel: Survey about experiences in somatic health care, November 2015, 932 respondents



# Panel survey about being a parent and having a mental illness – selected results

## 529 parents with lived experience responded:

- 74% had talked to their child(ren) about their mental illness. Their child(ren) reacted:
  - Loving and caring 59%
  - Relieved knowing what was wrong 45%
  - With a need to ask questions 44%
- 94% of the parents felt it is important to talk to your children about it if you have a mental illness  
(to a high degree + to some degree)
- The parents said it:
  - Helped the children to not feel guilty about mom/dad's illness (77%)
  - Gave the child(ren) a better understanding of the situation (75%)
  - Makes both the child(ren), parents and close relatives relieved (72%)

# Inequality in oral health

- Collaboration with a class of communication students at *The Danish School of Media and Journalism* → awareness raising campaign about the risk of dental problems related to the use of medication for their mental illness (both people w. lived experience **and** professionals)
- Workgroup presenting the issue - representatives from: The ONE OF US secretariat, ONE OF US ambassadors, The Dental Association and The Dental Hygienist Association
- Groups of students framed questions for a survey to form the basis for their campaign → Adjusted by the ONE OF US secretariat → Carried out fall 2016 in the ONE OF US panel

# Survey about oral health

- 1.083 respondents
- 92% have received medical treatment for their mental illness
- 61% had not been informed about possible side effects of the medicine
- Respondents lacked information from their doctor (70%) and their psychiatrist (67%) about side effects

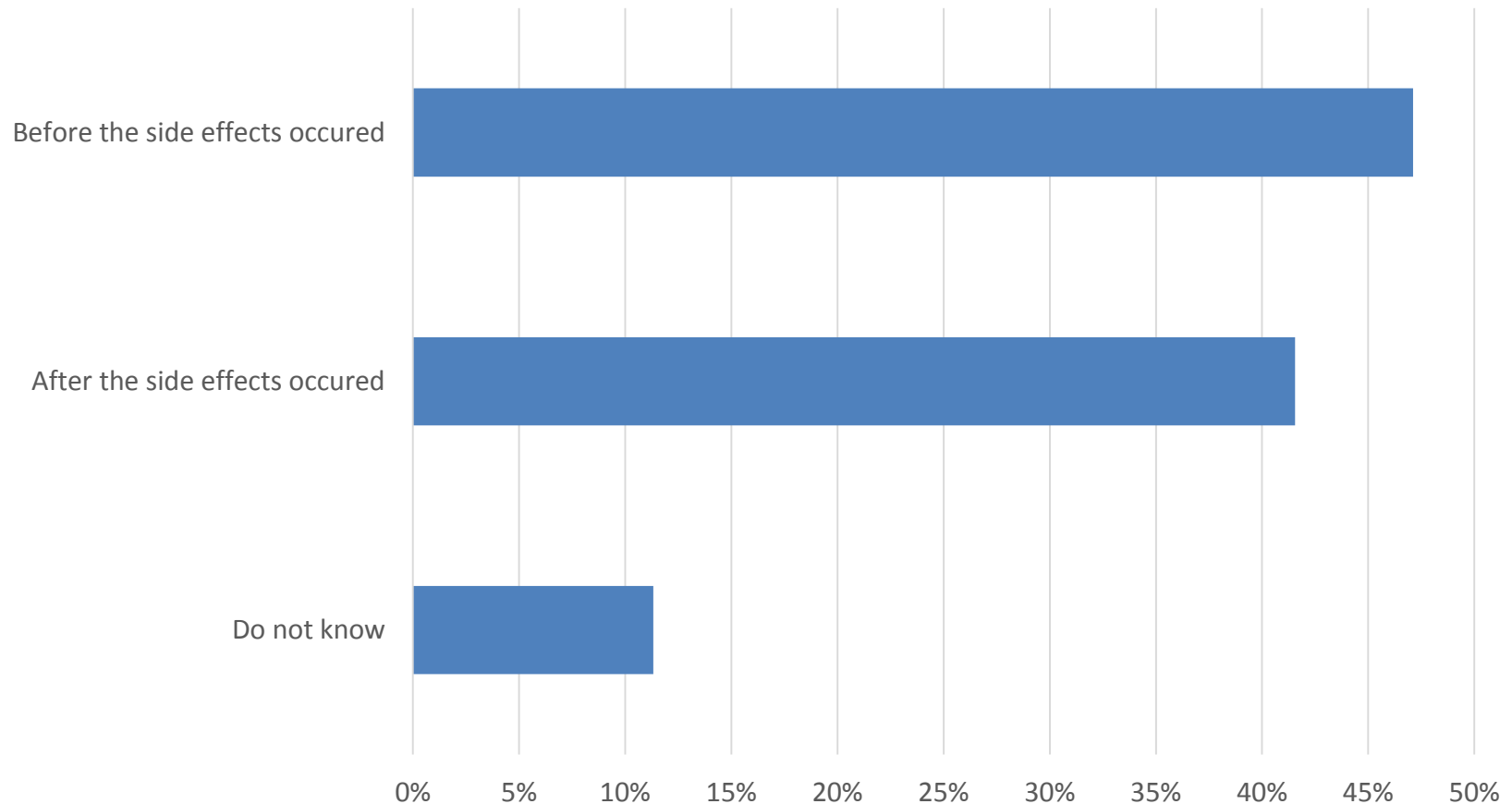


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The smile is the most positive first impression you give to other people. When you finally are happy and meet new people it is natural to smile. But with teeth that are visibly ugly, the smile is something you are very aware of, because it can show an obvious lack of care of your teeth. In addition, chronic toothache is contributing to make every day difficult both in relation to what you eat and drink, and how many painkillers you need.

# When did you get informed that dry mouth is a possible side effect?

539 respondents



Questions?