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

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:
Critisising 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

Common "branding"
National campaigns
Joint efforts
Local initiatives

National level
Initiating, coordinating, media campaign and other supporting efforts

Regional level
Planning, management, local involvement and mobilisation

Local level
Face to face activities
Find us here: www.one-of-us.nu

**ONE OF US panel**

Online survey panel of approx. 2,000 people with lived experience of mental illness
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

- 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

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

• 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

- Discrimination survey (DISC-12)
  - Major intervention
  - Data processing

- Comments about somatic health services analysed

- Panel survey carried out
  - Smaller intervention
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

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

- You have encountered rejection or moralising in connection to suicide attempts or self-harm
- Physical symptoms have been passed off as psychological
- You have experienced discomfort from not being in control of whether or not someone should be informed about your...
- You have avoided seeking health care treatment in spite of needing this out of fear of prejudice based on your mental illness
- The staff's attitude has changed negatively after seeing your psychiatric diagnosis in your chart
- You have encountered a lack of understanding for exhibiting psychological reactions following a somatic illness
- Your motives for seeking health care treatment for your somatic symptoms have been addressed with suspicion
- Your psychiatric diagnosis has influenced the way others have addressed you
- Have not received necessary treatment for (signs of) serious somatic illness
- Have found it to be necessary to bring an assessor to consultations

Graph shows the distribution of responses from 0 to 70 respondents per statement, with bars indicating responses of 'Once' and 'Multiple times'.
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
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

Before the side effects occurred

After the side effects occurred

Do not know
Questions?