

# THEME 3

## VARIABLES INCLUDED IN A SPINE REGISTRY

### FinSpine

## Experiences from building a registry today

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# How did we do it? Short history of FinSpine

- 2014 FSSS internal survey revealed a broad consensus to establish a national spine surgery quality registry
- 2015 FSSS registry task force was founded involving neuro- and orthopaedic surgeons from every major hospital
- 2015-2017 members of FSSS were involved in shaping the content of the registry – FinSpine IS A SOCIETY DRIVEN REGISTRY!
- 2015-2017 FinSpine platform was built with the help of a commercial IT-provider (paid by participating hospitals)
- 2017 stepwise integration with hospital IT-systems → nationwide clinical implementation of FinSpine
- 2023 the registry keeping was transferred to the Finnish Institute for Health and Welfare by a decree issued by the Finnish Ministry of Social Affairs and Health → FinSpine IS NOW A STATUTORY NATIONAL REGISTRY!

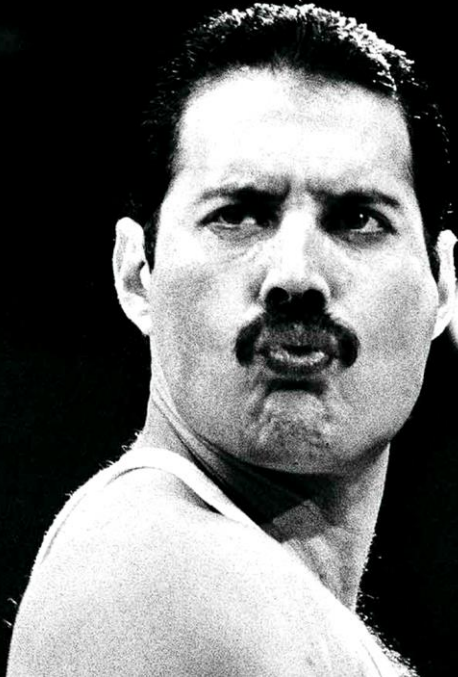
# Which variables should we include?



It is better to have it and not need it, than to need it and not have it!

- Theodore Roosevelt -

I want it all! → Euphoria!



# ...but then we realized...

- people are overwhelmed with questionnaires – survey fatigue!
- More or less, less is more!
- So, what really should be considered when building up a registry and choosing its variables today?

# Be pragmatic!

- Which variables are known and used in this country?
- What are other countries using?
- Can you use them for meaningful science?
- Can you measure outcomes with them?
- Can you measure effectiveness with them?
- Could you achieve the same with less variables?

# Be realistic!

- Make sure patients and surgeons understand the variables
  - avoid codes, use definitions, speak same language
- Make it easy for patients and surgeons to complete the variables and the forms
- Make it even easier!

# A few thoughts along the way...

- Complete data set with few variables vs. incomplete data set with many variables!
- Existing big data sets (registries) are valuable and should function as example
- Countries and cultures should have mutual minimal data set
- PRIMARY goal must be measuring the safety and effectiveness of treatments on the national level...
- ...but the HOLISTIC goal should be large homogenous international data set pools
- Communicate with registry functionaries and other stakeholders
- Have a professional and reliable IT-provider responsible for programming, system integrations and ongoing technical support
- Strive for a public/government financing
- Hire registry nurses

# Minimal registry data set – a suggestion

- Patient identifier (I)
- Hospital (I)
- Age, gender, height, weight, ASA-classification (comorbidities derived from ASA) (I)
- Method of communication with patients (email/phone) (I)
- Smoking (no/yes)
- Neurological deficiencies (affecting ambulation, myelopathy)
- Diagnosis (with definitions!)
- Type of surgery (primary, secondary, revision and their definitions!)
- Procedure (with definitions!)
- Operation level and number of levels
- Complications (at least perioperative)
- Operation and complication dates (I)
- Implant and graft data (UDI)

# Minimal pre- and postoperative PROMS and PREMS – a suggestion

- VAS/NRS
- ODI/NDI
- Global Rating Scale
- EQ-5D

Thank you  
for your  
interest in  
FinSpine!

