



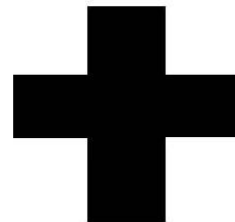
Between autonomy and paternalism – self-determination in End of Life Care

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Condition for every medical treatment

medical indication



informed consent (patient)



Informed Consent after lack of capacity to consent

Self determination



Advance health care directive



Health care proxy
(§ 284f ABGB)

No self determination



Special guardian



Study 2011-2014

- **Aim:** evaluation of the advance health care directive and the health care proxy.
- **Methods:** Quantitative (representative telephone poll among the Austrian population) and qualitative (qualitative interviews and focus group discussions with doctors, nurses, psychologists, lawyers and patients) methods.



What is an advance health care directive?

- An advance health care directive is
 - a statement of the patient
 - explaining what medical treatment he/she would **not** want in the future
 - should he/she 'lack capacity to consent'
- Binding: high formal criteria (physician + notary or lawyer)

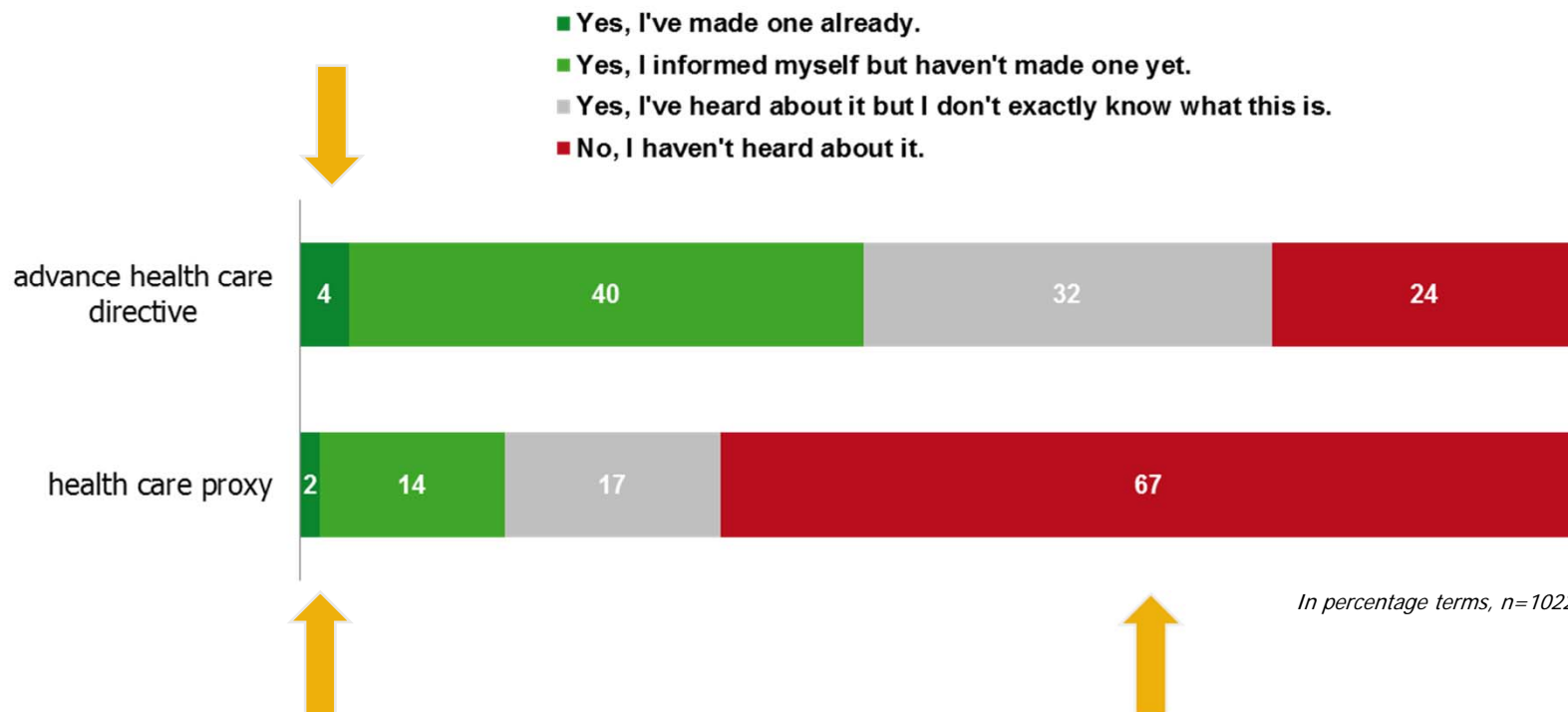


What is a health care proxy?

- durable power of attorney given by the patient to a trustworthy person
- chosen person can consent to medical treatment or refuse it
- Formal criteria: drawn up before a lawyer, notary or court

Level of awareness of those instruments

It's possible to make an advance health care directive or a health care proxy.
Did you know about this?




Why do people have an advance health care directive or a health care proxy?

- self determination
- religion/ideology
- social aspects

„I don't want to be nursed to death“

„I don't want to be lying around just for breathing“





Why do people NOT have an advance health care directive or a health care proxy?

- Lack of information
- Costs
- Time
- They think their relatives or doctors can automatically consent instead of them
- But also: „I want the maximum medical care!“



Results of the study

- There are limits of the advance health care directive and the health care proxy.
 - Patient has the obligation to provide
 - No standardized procedure how to deal with those instruments
 - Dependence on individual

 - Health care directive and the health care proxy can't be seen in isolation.
- ➔ have to be embedded in a larger context of advance care planning.

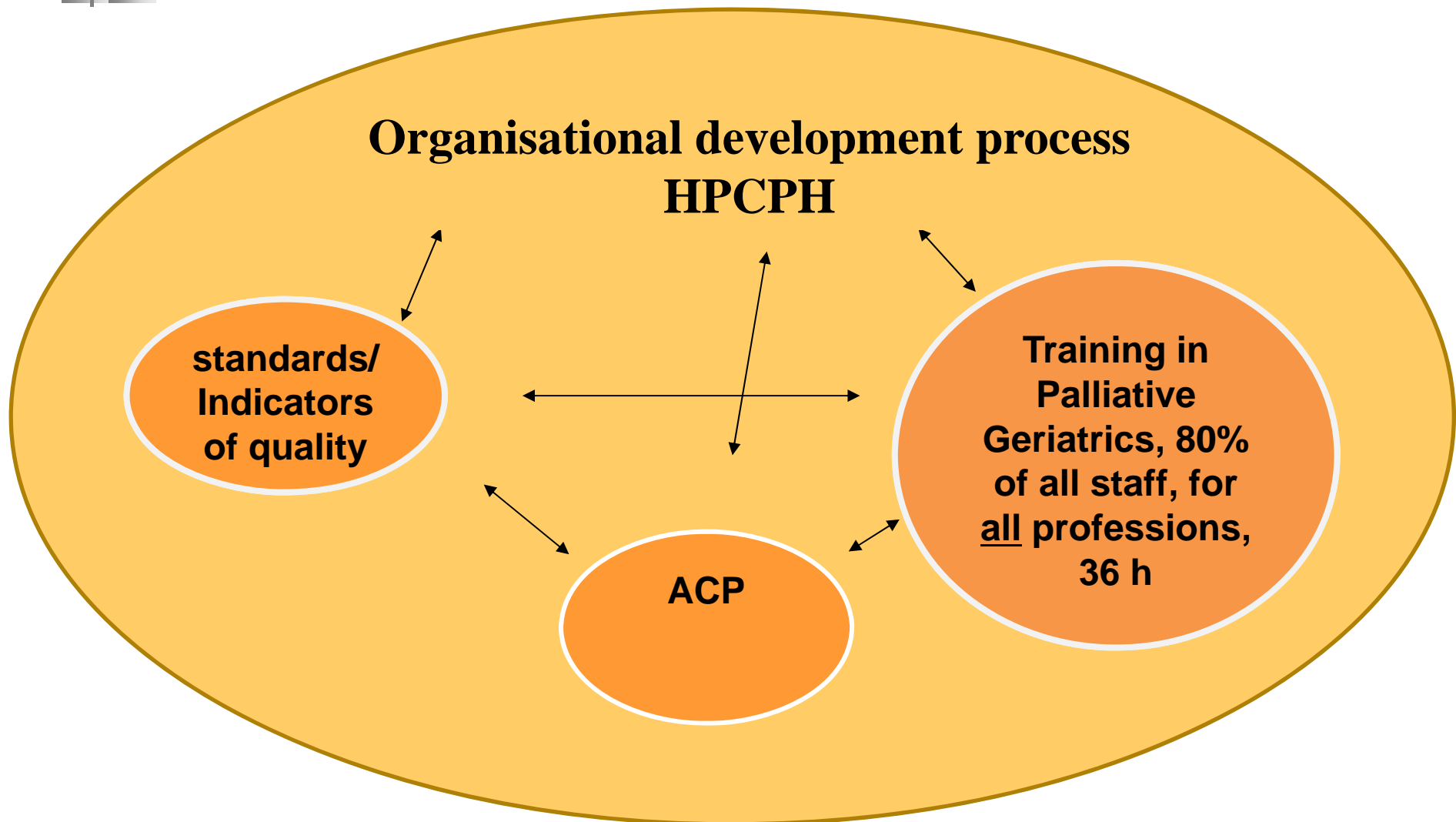
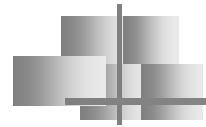
Advance Care Planning in Austrian Nursing Homes (=HPCPH)



A project of Hospice Austria

Hospiz Österreich/Hospice Austria: Dr.ⁱⁿ Sigrid Beyer, Mag.^a Anna H. Pissarek

Hospice and Palliative Care in Austrian Nursing Homes 2004- 2015 (= HPCPH)





Board HPCPH + Taskforce ACP

So far about 100 homes participated. During the project one of the most pressing issues turned out to be the difficult decision making in end-of-life-situations.

Thus the **HPCPH Board** of Hospice Austria assembling all relevant stakeholders decided to set up a **taskforce ACP** to develop an **Austrianwide model advance care planning tool** for inhabitants of nursing homes integrating already existing approaches in the federal states and abroad.



Aim and Purpose of ACP in nursing homes

- **Ongoing, structured and documented conversation** including residents (if possible), carers, doctors, family/loved ones with regards to quality of life and critical situations like f.ex. transfer to hospital or resuscitation when death is imminent
- In the Centre: **the resident's will**
- A means to convey **the alleged will of patients suffering from dementia**
- **Foundation for carers' and emergency doctors' decisions** considering the resident's will esp. in critical situations
- **A Facilitator's Guide to an ACP conversation, a documentation sheet and an overall introduction to the topic (concept) already exist**



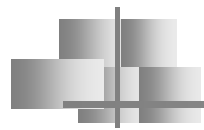
Challenges

- getting the **consent** of relevant stakeholders like the Austrian Medical Association
- **financing** (goal: doctors are paid for the extra time – or the nursing homes get the money and select appropriate doctors)
- **fear of misuse** (to put pressure on residents and force cost saving decisions): no other institution has to undergo so many checks & controls like a nursing home → integrate ACP in the control system
- **implementing ACP**



Next steps

- Integrate ACP in the **Austrian law** dealing with the living will (Ministry of Justice) - ongoing
- **Finalize** documents (Nov 2015) and consolidate wording with Austrian Medical Association
- Ensure appropriate **financing** of roll out and execution
- Start **implementation** in nursing homes in 2016 as a project in itself (train the trainers and the facilitators, ensure organisational process in homes to reach sustainability...)



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Thank you for your attention!

