

ESRC seminar series Towards a European Understanding of Advance-Decision
Making: a comparative, interdisciplinary approach
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Workshop 6: The European and International Dimensions

“Advance-Decision Making in European Union Law: problems and potential”

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<http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx>

Is an advance decision legally binding?

Yes it is, as long as it:

- complies with the [Mental Capacity Act](#)
- is valid
- applies to the situation

If your advance decision is binding, it takes the place of decisions made in your best interest by other people. An advance decision may only be considered valid if:

- you are aged 18 or over and had the capacity to make, understand and communicate your decision when you made it
- you specify clearly which treatments you wish to refuse
- you explain the circumstances in which you wish to refuse them
- it is signed by you and by a witness if you want to refuse life-sustaining treatment
- you have made the advance decision of your own accord, without any harassment by anyone else
- you haven't said or done anything that would contradict the advance decision since you made it (for example, saying that you have changed your mind)

Table 1. Countries with specific legislation regarding advance directives

COUNTRY	YEAR OF LAW	REFUSAL OF TREATMENT BINDING OR NOT	BIOMEDICINE CONVENTION RATIFIED OR NOT
1. Austria	2006	Yes (limited to 5 y)	No
2. Belgium	2002	Yes (No time limit)	No
3. Denmark	1998	Yes, terminally ill - No in other cases	Yes (1999)
4. Estonia	2001	Text law not clear	Yes (2002)
5. Finland	2005	Yes, emergency treatment - No in other cases	Yes (2010)
6. France	2005	No (limited to 3y)	Yes (2012)
7. Germany	2009	Yes (no time limit)	No
8. Hungary	2009	Yes (limited to 2y)	Yes (2002)
9. Latvia	2009	Yes (no time limit)	Yes (2010)
10. Luxembourg	2009	In principle; unless good reasons	No
11. Netherlands	1994	In principle; not if good reasons	No
12. Portugal	2012	Yes (limited to 5 y)	Yes (2001)
13. Slovenia	2007	Yes, terminally ill - No in other cases	Yes (1999)
14. Spain	2002	In principle; not if against good medical practice	Yes (2000)
15. United Kingdom	2005	Yes	No



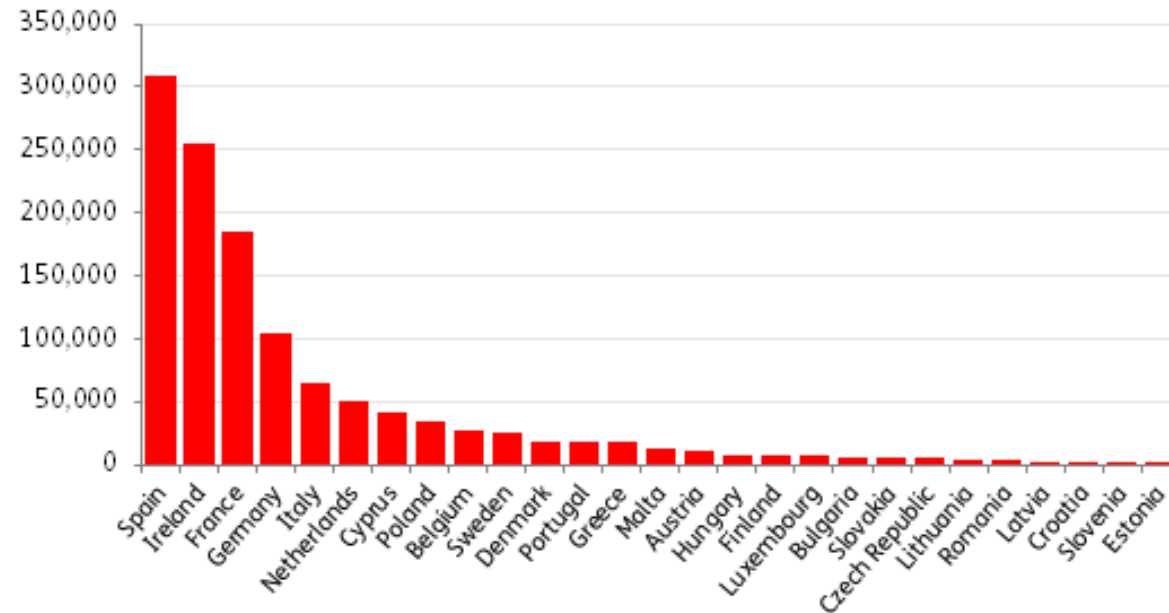
[http://www.alcove-project.eu/images/pdf/ALCOVE SYNTHESIS REPORT_VF.pdf](http://www.alcove-project.eu/images/pdf/ALCOVE_SYNTHESIS_REPORT_VF.pdf)

Who are we talking about?



Brits abroad in the EU

Number of UK born people living in other EU member states, 2015 estimates



Source: United Nations, "Trends in International Migrant Stock: Migrants by Destination and Origin", 2015 revision, table 16



<https://fullfact.org/europe/how-many-uk-citizens-live-other-eu-countries/>
<http://www.un.org/en/development/desa/population/migration/data/estimates2/estimates15.shtml>



START PLANNING HERE



If you need to make decisions about your healthcare, understanding your rights and planning in advance can give you peace of mind.

We are here to ensure your wishes will be respected.

[Learn more »](#)

What rights do I have to make decisions about my medical treatment and care?

[LEARN MORE »](#)

How are decisions about my care made if I am unable to communicate?

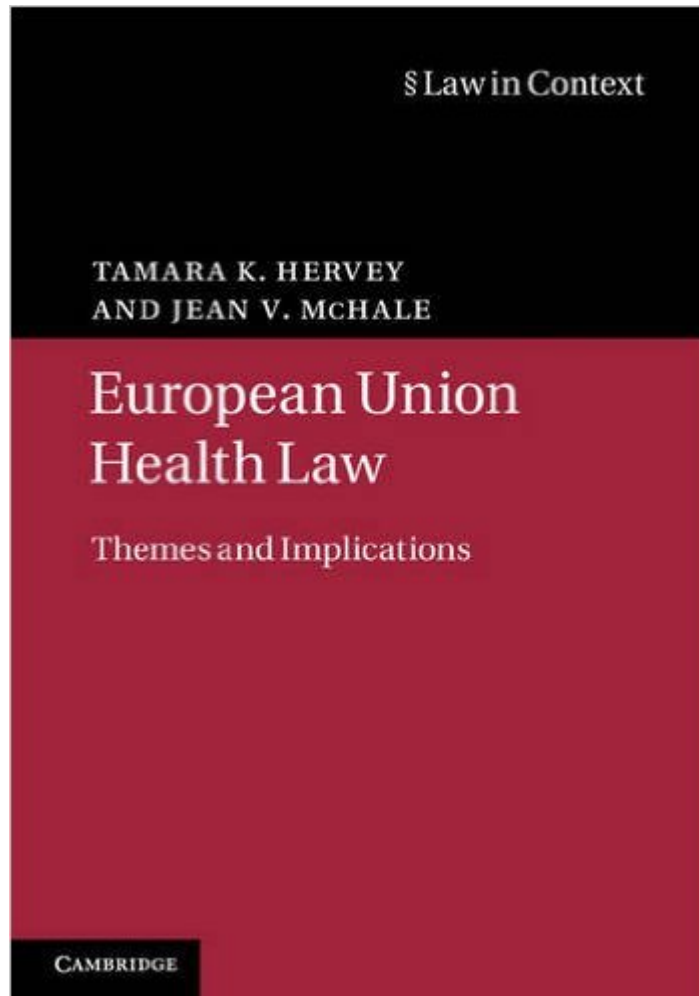
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Can I make decisions on the behalf of family and friends?

[LEARN MORE »](#)

How can I ensure my wishes about treatment and care are respected?

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- Article 56 TFEU
- Case law of CJEU
- Social security coordination Regulation
- Patients' Rights Directive
- Mutual recognition of Qualifications Directives
- Human-rights compliant interpretation under the EU Charter of Fundamental Rights
- EU legislative competence?



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Alzheimer Europe

“j) Alzheimer Europe urges governments to provide a clear statutory basis for effective advance directives with appropriate safeguards and a framework of procedures to ensure their effectiveness.

A growing number of its members consider that governments should legally recognise advance directives and make refusals of treatment expressed in advance directives legally binding albeit with adequate safeguards.”



ALzheimer COoperative Valuation in Europe

<http://www.alzheimer-europe.org/Policy-in-Practice2/Our-opinion-on/Advance-directives>

CONCLUSIONS & MAIN RECOMMENDATIONS

Contextual provisions of Advance Directives for persons living with dementia

- [1] **Advance directives should be part of the broader context of advance care planning.** An advance directive is a means to provide high quality care in line with the wishes and will of the person living with dementia, and not a goal in itself or an end product of advance care planning. It is an opportunity for starting and maintaining a process of communication between the person living with dementia and his or her carers.
- [2] **National authorities are encouraged to provide a legal framework on advance directives adapted to the specific needs of people living with dementia.**
- [3] **Proper models and good practices specifically oriented towards people living with dementia need to be implemented, further developed and disseminated,** because all stakeholders – patients, relatives, informal and formal carers, healthcare policy organisations, ... – have to be made aware of the specificities and complexities regarding advance care planning and advanced directives for people living with dementia.
- [4] **The person's current attitude towards a certain treatment or a care intervention - ascertained feelings, desires and wishes - should always be taken into account,** even if there is an advance directive or a designated proxy, since there can be major changes in values and preferences between the time when persons complete their advance directive and when it comes into effect.
- [5] **Although the use of advance directives should be promoted, nobody can be forced to make up an advance directive.** If a person does not want to address issues about future care and treatment or end-of-life for his- or herself, this needs to be respected.
- [6] **Doctors and other healthcare professionals involved in the care of people living with dementia should be properly trained in advance care planning and the use of advance directives.**
- [7] **In order to increase peoples' knowledge about advance directives and to encourage their use, the costs for drafting and registering these directives should be minimal for the person living with dementia.**



INNOVATION UNION

A Europe 2020 Initiative

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European Innovation Partnership on Active and Healthy Ageing

About the Partnership

The Partnership brings together a wide array of stakeholders to work in a collaborative way on shared interests and projects geared towards achieving common goals and promoting successful technological, social and organisational innovation.

Innovative actions

The Partnership's Strategic Implementation Plan identifies 14 priority areas. 5x actions have now started.

Join the partnership

How can you participate in the European Innovation Partnership on Active and Healthy Ageing?

Funding

Open calls for projects in support of the Strategic Implementation Plan of the Pilot European Innovation Partnership on Active and Healthy Ageing

Events

Past and future events organised in the context of the Partnership

Marketplace

Designed and owned by people and organisations involved in the Partnership. Join other partners in innovating for active and healthy ageing!

Contacts

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