

EVENT DESCRIPTION SHEET

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PROJECT	
Participant:	[52] - [EUMANS]
PIC number:	[887839352]
Project name and acronym:	[TransEuropa Assemblies] — [TEA Project]

EVENT DESCRIPTION		
Event number:		[3]
Event name:		Transnational European Assembly on End of Life Decisions and Palliative Care
Type:		Transnational Assembly
In situ/online:		<i>In situ</i>
Location:		Belgium - Brussels
Date(s):		6th December 2022
Website(s) (if any):		https://eumans.eu/transnational-european-assembly-end-life-decisions-video-and-final-declaration
Participants		
Female:		33
Male:		21
Non-binary:		3
From country 1 [Italy]:		19

From country 2 [Belgium]:		15		
From country 3 [France]:		8		
From country 4 [Netherlands]:		3		
From country 5 [Denmark]:		1		
From country 6 [Finland]:		2		
From country 7 [Spain]:		1		
From country 8 [Portugal]:		1		
From country 9 [Poland]:		1		
From country 10 [Austria]:		1		
Total number of participants:		52	From total number of countries:	10

On the 6th of December, we held our first-ever Transnational European Assembly on end-of-life decision at the European Economic and Social Committee, in Brussels. The session focused on how informed individual choices should be treated as a fundamental right all over the European Union as recommended by the citizens' panels of the Conference on the Future of Europe (recommendation n. 24).

In particular, the Assembly aimed to gain consensus on a declaration to cover three main areas, which were discussed in smaller groups:

- Decisions on refusals of treatments and access to palliative care
- Assisted Suicide and Euthanasia: legislations on voluntary death with medical support
- Living Will and End of Life Decisions within and among different EU Member

The citizens partaking in the assembly devised 14 concrete proposals for end-of-life decisions. You can find the final declaration below.

In particular, the Assembly aimed to gain consensus on a declaration to cover three main areas, which were discussed in smaller groups after a thorough introduction of the legislative background and the terminology to be referred to prepared by the Legal Team of the partner organisation Associazione Luca Coscioni.

This legal team included lawyers Alessia Ciatelli and Francesca Re, who first provided legal background information on end-of-life decision both in Italy and at EU level to participants. They then acted as key knowledge-helpers and supported the subgroup discussions in providing any needed additional legal knowledge for participants to be able to formulate proposals actually implementable as new policy proposals. The assembly also included Marco Cappato as a keynote speaker, who shared his experience as a grassroots activist in Italy and testified about the numerous occasions during which he accompanied people seeking the right to ending their life, usually accompanying them to Switzerland.

METHODOLOGY FOR THE SELECTION OF PARTICIPANTS

The goal of the Assembly was to have a diverse pool of participants. Three main segments were covered:

- Members of groups and organisations across the European Union and in Brussels interested in the advancement of right-to-die legislations (patients organisations, caregivers organisations, advocates for the right to die)
- Activists and experts on the advancement of Democratic rights in the European Union
- Citizens and communities usually less involved in the law making process of the European Union and belonging to marginalised groups (migrants, LGBTQIA+ communities, ...)

In order to increase the level of diversity in the group EUMANS contacted the Brussels-based organisation Agora Brussels which organised in the past years different sortition-based citizens Assemblies in the Region of Brussels and therefore has access to a pool of randomly-selected residents of the Region.

The call-for participation in the TEA Project Assembly was launched through the Agora Brussels database and 12 randomly selected participants joined the Assembly through this process.

DECLARATION ON END-OF-LIFE DECISIONS

Recommendation about “Decisions on refusals of treatments and access to palliative care”

1. We recommend that in the EU, palliative sedation is accessible to all terminally and/or irreversibly ill patients, provided they can make an informed decision about their choice to refuse treatment, and that this practice is standardised.
2. We recommend EU Institutions to promote awareness of the right to palliative sedation and refusal of treatment (after diagnosis of terminal and/or irreversible illness) within the European convention of human rights (through, for example, the inclusion of health topics of self-determination at end-of-life in secondary education and art).

Recommendation about “Assisted Suicide and Euthanasia: legislations on voluntary death with medical support”

1. We recommend using the language of the World Federation of Right to Die societies: Voluntary Assisted Dying (VAD), instead of Assisted Suicide or Euthanasia, by either self administered or doctor administered drug.
2. We recommend the EU to recognize that every human being has the fundamental right to choose how and when to end their own life. Voluntary Assisted Dying (VAD) is NOT a medical, not political, not financial and not family decision but an individual and personal decision.
3. In cases of VAD it is the person's own definition of unbearable suffering that is taken into account. This includes terminal illness, irreversible illness, chronic illness, mental illness, or even just life completion (for example in Switzerland after 75 years of age).
4. We recommend advanced healthcare directives both for when the individual is still capable of refusing treatment and for the right to voluntary assisted dying after losing capability (for example with illnesses such as Dementia, ALS, brain injury, etc.)
5. We recommend that health professionals are better educated in facilitating the decisions and implementation of said decisions. Health professionals must also be supported both in terms of end of life choices for their patients and cultural, religious, and ethical aspects related to dying.

Recommendation about “Living Will and End of Life Decisions within and among different EU Member States”

1. We recommend EU Institutions to develop a European Directive, or otherwise encourage the introduction of legislation in member states, on Advanced Healthcare Directives based on the Declaration of Human Rights.
2. We recommend EU Institutions to mutually recognize living wills across borders.
3. We recommend EU Institutions to use the EU Health Standards to document and communicate this will.

4. We recommend EU Institutions to create a European database that stores advanced healthcare directives, to ease the access of medical information and limit the burden of medical personnel.
5. We recommend EU Institutions to facilitate awareness through the development of info session infrastructure and validate end-of-life decisions.

NEXT STEPS

The Declaration will be used as a key document in the initiatives carried on by EUMANS at the European level, potentially becoming the basis for a European Citizens Initiative and other paneuropean actions aiming at reforming the Charter of Fundamental Rights as well as the program of the political parties at the European Elections in 2024.

The Assembly is part of a series of Transeuropean Assemblies (TEA PROJECT) to be held in Poland, Germany, Romania, Spain and Italy.

HISTORY OF CHANGES		
VERSION	PUBLICATION DATE	CHANGE
1.0	01.04.2022	Initial version (new MFF).