

**People-Centered Health Care, Public-Patient Involvement  
in Health Research, Community-University Engagement  
and training needs to make it happen.**

**What legal frameworks could enhance these  
practices?**

Barcelone, 18.5.2022

# THREE PERSPECTIVES / LEVELS/ DIMENSIONS

- 1-. The framework of “aseptic” regulation
- 2-. Participation of citizens in the procedure of elaboration of norms
- 3-. Patient involvement in Health care Decision Making: Legal recognition, and real implementation...

Two examples: intersex People and People with disabilities.

WHY THIS STRUCTURE? **because Participation = engagement / involvement**

- a. Public participation: Active group participation in developing system’s policies and plans
- b. Personal participation [here]: Participation of the person in his own health care decisions

(moreover: recognised by the law)

# THE FIRST PERSPECTIVE: Two examples

## 1. DRAFT BILL: **Organic Law of the University System**

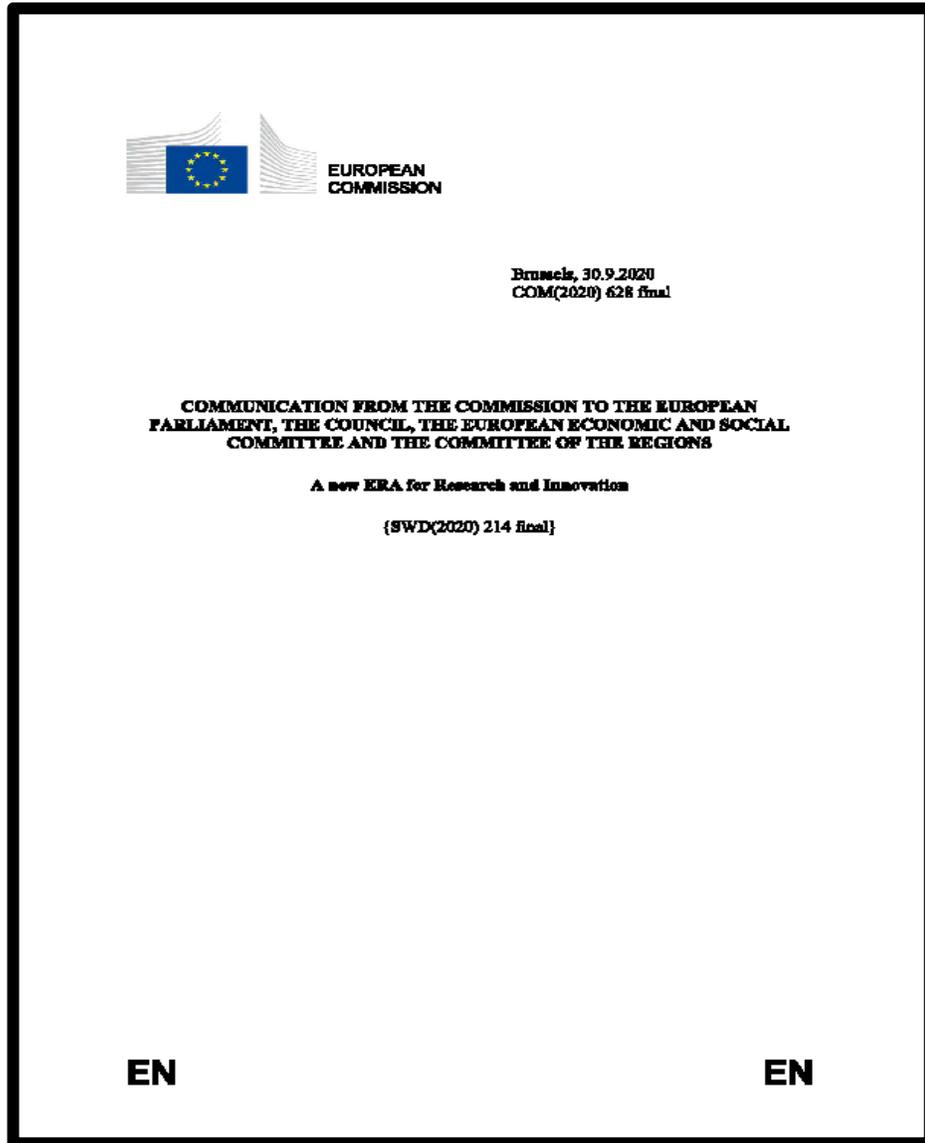
### **Article 63. Promotion of Open Science and Citizen Science.**

(...) **10.** Citizen Science will be promoted as a field for generating shared knowledge between citizens and the university research system. With the aim of promoting scientific, humanistic and cultural reflection and its application to social challenges, universities will favor and promote collaboration with social actors, and with the Administrations of the Autonomous Communities and the Local Administration.

Artículo 63. Fomento de la Ciencia Abierta y Ciencia Ciudadana.

(...) 10. Se fomentará la Ciencia Ciudadana como un campo de generación de conocimiento compartido entre la ciudadanía y el sistema universitario de investigación. Con el objetivo de promover la reflexión científica, humanística y cultural y su aplicación a los retos sociales, las universidades favorecerán e impulsarán la colaboración con los actores sociales, y con las Administraciones de las Comunidades Autónomas y la Administración Local.

## 2n exemple



### • 3. CITIZENS' ENGAGEMENT

- The engagement of citizens, local communities and civil society will be at the core of the new ERA to achieve greater societal impact and increased trust in science.

### • 6. CONCLUSION

- Europe has responded to the tremendous challenges it faces by setting itself ambitious goals. The Commission, Member States and R&I stakeholders have an important role to play at this crucial moment to ensure a recovery that responds to people's needs. Building European resilience based on a greener, digitally empowered, competitive and more sustainable Union, requires joint efforts and global leadership in science and innovation, **as well as engaging and empowering citizens**

## **2n. PERSPECTIVE** Art. 134 [39/2015 Act] *Participation of citizens in the procedure of elaboration of norms with the rank of Law and regulations*

1. Con carácter previo a la elaboración del proyecto o anteproyecto de ley o de reglamento, se sustanciará una consulta pública, a través del portal web de la Administración competente en la que se recabará la opinión de los sujetos y de las organizaciones más representativas potencialmente afectados por la futura norma acerca de:

- a) Los problemas que se pretenden solucionar con la iniciativa.
- b) La necesidad y oportunidad de su aprobación.
- c) Los objetivos de la norma.
- d) Las posibles soluciones alternativas regulatorias y no regulatorias.

2. Sin perjuicio de la consulta previa a la redacción del texto de la iniciativa, cuando la norma afecte a los derechos e intereses legítimos de las personas, el centro directivo competente publicará el texto en el portal web correspondiente, con el objeto de dar audiencia a los ciudadanos afectados y recabar cuantas aportaciones adicionales puedan hacerse por otras personas o entidades. Asimismo, podrá también recabarse directamente la opinión de las organizaciones o asociaciones reconocidas por ley que agrupen o representen a las personas cuyos derechos o intereses legítimos se vieran afectados por la norma y cuyos fines guarden relación directa con su objeto.

3. La consulta, audiencia e información públicas reguladas en este artículo deberán realizarse de forma tal que los potenciales destinatarios de la norma y quienes realicen aportaciones sobre ella tengan la posibilidad de emitir su opinión, para lo cual deberán ponerse a su disposición los documentos necesarios (...)

1. Prior to the preparation of the project or draft law **a public consultation will be held**, through the web portal of the competent Administration **in which the opinion of the subjects and of the potentially most representative organizations will be obtained (...)**

2. **Without prejudice to the consultation prior** to the drafting of the text of the initiative, when the rule affects the rights and legitimate interests of people, the competent management center **will publish the text on the corresponding web portal, in order to give audience affected citizens** and collect any additional contributions that may be made by other persons or entities. Likewise, the opinion of organizations or associations recognized by law that group or represent people whose rights or legitimate interests are affected by the rule and whose purposes are directly related to its object may also be directly sought.

3. **The consultation, hearing and public information regulated in this article must be carried out in such a way that the potential recipients of the standard and those who make contributions on it have the possibility of expressing their opinion, for which the necessary documents must be made available to them**, which will be clear, concise and gather all the necessary information to be able to pronounce on the matter.

## *3<sup>rd</sup> perspective: Patient involvement in health care decision making: the legal reconnaissance*

### **Article 212-2 Catalan civil Code. Informed consent.**

1. People over the age of sixteen and minors who have sufficient intellectual and emotional maturity to understand the scope of their health intervention must give their consent for themselves, except in cases where the health legislation establishes another option.

2. If the person is in a physical or mental state that does not allow him to take charge of their situation or decide, consent must be obtained, in the manner established by the health legislation, from the same people who must receive the information referred to in article 212-1.4. **[family]**

3. (...) / 4. (...)

**TWO EXAMPLES: 1. Intersex and 2. Persons with disabilities**

*INTERSEX. The Draft bill of rightst of LGTBI+ where I = intersex people  
Resolution 2191 (2017) EU Parliamentary Assembly Promoting the human rights of  
and eliminating discrimination against intersex people.*

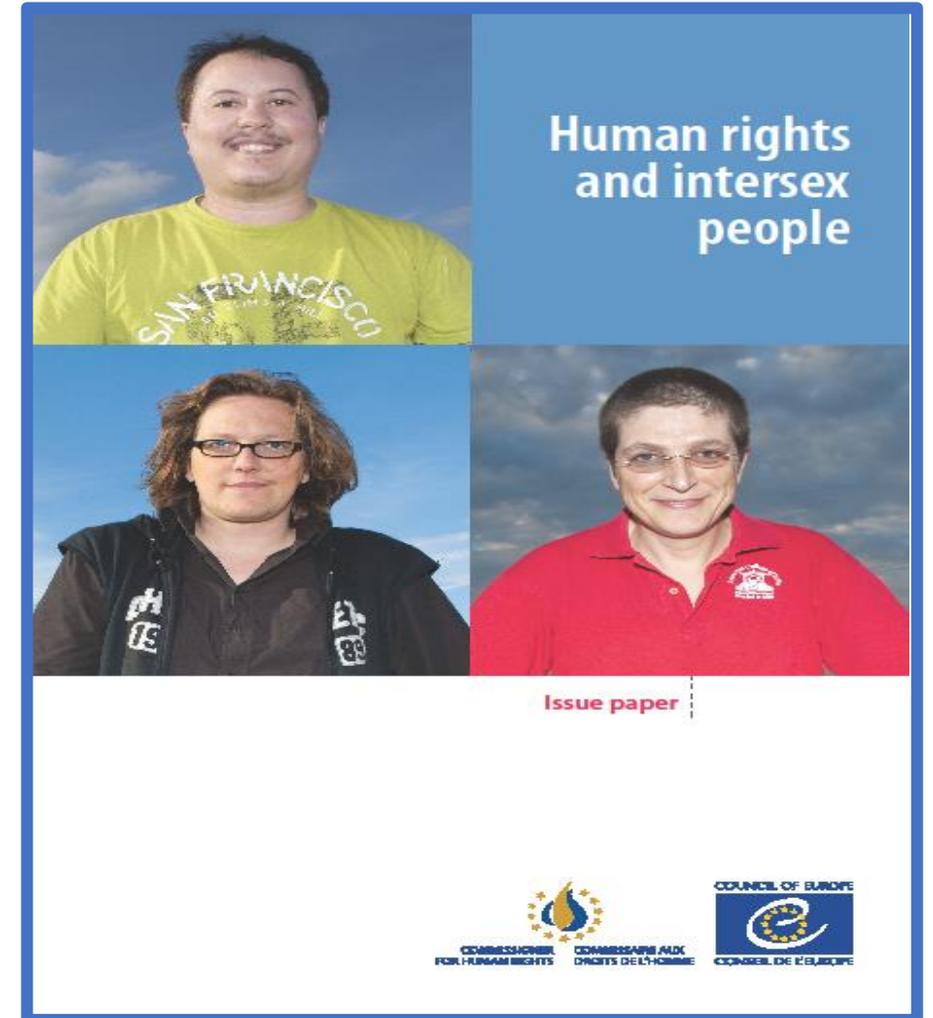
**“Intersex people are born with biological sex characteristics that do not fit societal norms or medical definitions of what makes a person male or female (...) The prevailing medical view has been that intersex children’s bodies can and should be made to conform to either a male or a female paradigm, often through surgical and/or hormonal intervention; that this should be done as early as possible; and that the children should then be raised in the gender corresponding to the sex assigned to their body”**

**THE MAIN PROBLEM:  
SURGERIES**

Chau, P. L. y Herring, J. (2002). “Defining, Assigning and Designing Sex. International Journal of Law, Policy and the Family”, 16, 327-367.

# *Intersex testimonials*

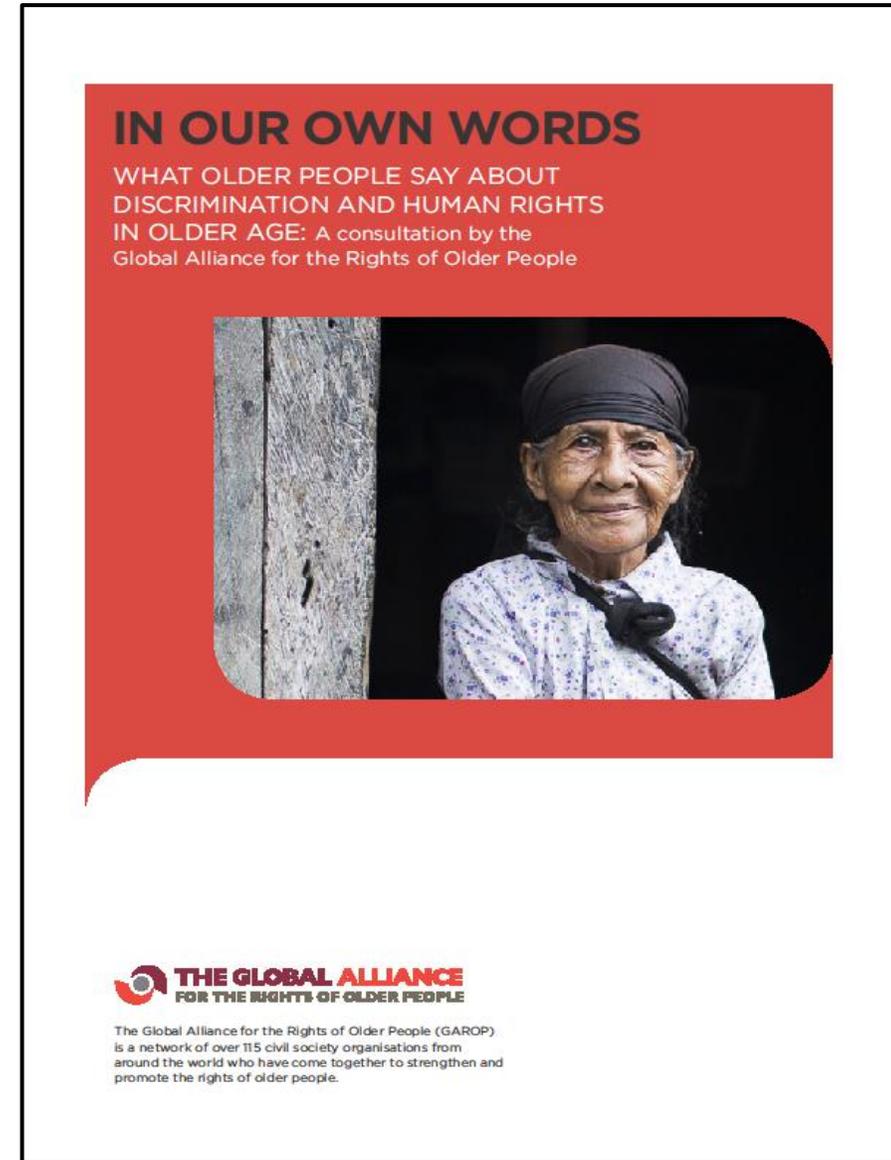
Christiane Völling (1960, Germany), born with “indeterminate external genitalia” and raised as a boy. In her autobiography, Völling stated: The castration [removal of internal testes] that I suffered and the paradoxical administration of high-dose testosterone considered as necessary resulted in physical and psychological damage such as hot flashes, depression, sleeping disorders, early osteoporosis, the disappearance of my sexuality and my reproductive capacity, trauma linked to the castration, lesion of the thyroid glands, change in my brain’s metabolism and my bone structure as well as many other secondary effects and lesions. The taking of testosterone has caused the development of a typical male hair pattern, a masculine beard, the loss of all my hair linked to the impact of the androgens, a masculinization of my previously feminine voice, the masculinisation of my facial features and the production of a male anatomy despite female predispositions.



# Convention on the Rights of Persons with Disabilities: 2006

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities ***to the support they may require in exercising their legal capacity.***
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. ***Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person (...)***

# HOW TO PARTICIPATE?



## What about CCentre?

**CCentre: A narrative approach to improve citizens' ageing and well-being is a professional training project funded by the EIT Health. The CCentre consortium has been working together since 2016 with the following key milestones:**

**2016-2018: design, pilot and release of four executive and professional training programmes in Newcastle, Leiden, Erasmus and Barcelona to promote a citizen-centred approach to healthcare.**

**2018: capturing of seniors' narratives and design of the narrative-training methodology**

**2019: release of the digital platform's beta version (in English) and pilots in Copenhagen and Barcelona public and private healthcare providers.**

**2020: release of the digital platform's final version (in English, Spanish, Dutch, Danish, French, Italian and Catalan), business plan elaboration and further pilots in Newcastle, Palermo and Lagos.**



**Palau Macaya**  
Barcelona  
Passeig de Sant Joan,  
108 08037 Barcelona

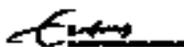
**Contact**  
[www.eithealth.eu](http://www.eithealth.eu)

**Registration**  
[eithealth17@gmail.com](mailto:eithealth17@gmail.com)

**Dr. Elena Lauroba**  
Coordinator  
[e.lauroba@ub.edu](mailto:e.lauroba@ub.edu)

**Ander Errasti**  
Project Manager  
[gisme.project.manager@gmail.com](mailto:gisme.project.manager@gmail.com)

CCentre consortium



Collaborating Institutions



# caring stories

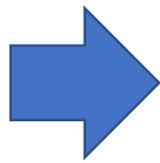
15.11.2019  
Free Registration  
Limited audience

**Narrative training  
Experience day**  
Towards the  
[caringstories.eu](http://caringstories.eu)  
European training  
platform



# ories

# The (an) effective implementation: to hear...



**28-29-30 Nov.**  
**Cosmocaixa**  
**Barcelona**

International Winter Academy  
Acadèmia d'Hivern Internacional  
Academia de Invierno Internacional

## Words and Ageing Paraules i Envel·liment Palabras y Envejecimiento

**Framework Project CCentre:**  
a narrative approach to improve  
citizens' ageing and well-being

**Projecte marc CCentre:**  
una aproximació narrativa  
per millorar l'envel·liment i  
benestar de la ciutadania

**Proyecto Marco CCentre:**  
una aproximación narrativa  
para mejorar el envejecimiento  
y bienestar de la ciudadanía



**eit** Health   
UNIVERSITAT DE BARCELONA **gisme**   
Obra Social "la Caixa"

*Collaborating institutions / Entitats col·laboradores / Entidades colaboradoras*

*In order to be able to interact effectively with patients and collect their interests for the juridical “ecosystem”, or for solving the problems/conflicts that affect patients in courts, it is essential that we, the law scholars, establish real and effective channels of collaboration with health professors and professionals.*

The last exemple:  
R.Wolkorte , I.Houwelingen, M.Kroezen:  
“Challenging behaviours: Views and preferences of people with intellectual disabilities” *Journal of Applied Research in Intellectual Disabilities*, 2019, 32(5)



UNIVERSITAT DE  
BARCELONA

*Gràcies*  
*Elena Lauroba*  
[e.lauroba@ub.edu](mailto:e.lauroba@ub.edu)

