FUNDAMENTAL LINGUISTIC RIGHTS IN HEALTHCARE

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AIM OF THE PRESENTATION

- Describe barriers created by intercultural and interlingual asymmetries between healthcare providers and female patients to identify cultural and linguistic discordance
- Revise the challenge of migrant integration, especially, social justice rights
- Analyze the perception of patient safety regarding IC in healthcare

ACCESS TO INFORMATION

Everyone has the right to seek, receive and impart information and ideas through any media and regardless of frontiers.

(Article 19 of the Universal Declaration of Human Rights (UDHR).



When receiving medical treatment or surgery, you have various rights

The first one is the right to receive ALL information that you need to make an informed decision

Informed consent

THE CONCEPT OF CONSENT AND ITS LEGAL STATUS



Arises from the ethical principal of patient autonomy and basic human rights



Patients have the freedom to decide what should or should not happen to their body and to gather information before undergoing a treatment, procedure, test, etc.



Hybrid document (legal and medical)

INFORMED CONSENT





IC is defined as the process during which the patient is informed of all aspects related to the procedure they are about to undergo.



Methodology

- Revise legal texts to give an update of current legislation in Spain
- Check how legislation is being applied in practice



LEGISLATION





MIGRANT/FOREIGNERS RIGHTS WHEN ACCESSING HEALTHCARE



Right to health care

UNIVERSAL DECLARATION OF HUMAN RIGHTS (1948)

• Art. 25: Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, [...] and medical care and necessary social services

International Covenant on Economic, Social and Cultural Rights (1966)

• Art. 12: The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Charter of Fundamental Rights of the European Union (2012)

• Art. 35: Health care. Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices.

MIGRANT/FOREIGNERS RIGHTS WHEN ACCESSING HEALTHCARE IN THE EU



Right to health care

REGULATION (EC) No 883/2004 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 29 April 2004 on the coordination of social security systems

- Regulation = binding legislative act. It must be applied in its entirety across the EU.
- Applies to nationals of a Member State, stateless persons and refugees resident in the territory of a Member State who are or have been **subject to the social security legislation of one or more Member States**, as well as to the members of their families and to their survivors.

MIGRANT/FOREIGNERS RIGHTS WHEN ACCESSING HEALTHCARE IN SPAIN



Right to universal public health care

Royal Decree Law 7/2018, passed in July 2018, recognises access to the National Health System as a fundamental right of every person in Spain

- Universal for whom?
 - Spanish nationals
 - EU citizens
 - Foreign nationals with permanent residence
 - +90 days of residence
 - registered in a municipality
- Non-permanent residents need a favorable report where this right is acknowledged
 - Exceptions:
 - o pregnant women
 - underaged
 - victims of human trafficking
 - people in serious condition (humanitarian reasons)

EU POLICIES



DIRECTIVE 2011/24/EU of the OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare

- Directive = legislative act that sets out a goal that EU countries must achieve. However, it is up to the individual countries to devise their own laws on how to reach these goals.
- Measures must be implemented so that patients **understand all the information** provided by healthcare staff members.
 - Lack of clarity
 - Understand information how?

HOWEVER, IN OTHER CLINICAL PRACTICES...

EU POLICIES



DIRECTIVE 2001/20/EC OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 4 April 2001 on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of **good clinical practice in the conduct of clinical trials** on medicinal products for human use

- More specific:
 - the **language** in which the information is provided and the IC must be one that is **understandable** to the patients who participate in them.
 - importance of the subjects of a clinical trial giving their **informed consent in writing**, as this is a fundamental right (art. 19 of the Universal Declaration of Human Rights).
 - the patient should receive the information and be able to ask questions in a language that they easily understand.



LINGUISTIC RIGHTS ON HEALTHCARE ASSISTANCE IN SPAIN

The use of one's mother tongue is a fundamental right.

DIRECTIVE 2011/24/EU of the OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare

- Measures must be implemented to ensure that patients understand all information provided by healthcare workers.
- Each Member State is free to provide information in languages other than the official languages.



CONTRADICTORY: UNDERSTANDING COMES HAND IN HAND WITH KNOWING THE LANGUAGE IN WHICH THE INFORMATION IS PROVIDED





Spain lacks clear policies regarding language provision in healthcare settings, leading to ambiguity and potential misunderstandings.

Act 3/2001, of 28 May, regulating informed consent and the clinical history of patients.

- Art. 8.2: The information shall be truthful, **understandable**, appropriate to the patient's needs, continuous, reasonable and sufficient.
- Art. 10.2: [...] the recipient of the information receives a copy of the document and that he/she has **properly understood the information**.

Act 41/2002 2 of 14 November on the regulation of the autonomy of the patient and their rights and obligations regarding information and clinical documentation

- All information will be **communicated** to the patient **in a way that they will understand** and will be adapted to their needs.
- The patient must always understand the goal, risks and consequences of the information provided.

HOWEVER...

SPANISH LEGAL FRAMEWORK



NO REFERENCE IS MADE TO THE LANGUAGE IN WHICH THIS INFORMATION WILL BE RENDERED DESPITE...



CASE EXAMPLE



- Administrative appeal
- Claim: Tubal ligations against claimants' will
- Damages: claimants will not be able to have any more children
- Claimants (a wife and her husband):
 - o no ICF regarding procedure + no translation
 - ER doctor claimed it was almost impossible to communicate with the patient due to language barrier
 - they asked for contraception methods after the surgery
- Defendant:
 - ICF had been signed:
 - the couple did not mention any difficulties in understanding the information.
 - the claimants had 4 days to check meaning with a third party
 - there is a translation service unit in the hospital
 - No statements about difficult communication.
 - ER doctor only took part in the anamnesis
 - Clinical record states that the doctor had informed the patient about aim and nature of the surgery.

CASE EXAMPLE



- Did someone in the hospital check whether both parties had fully understood the information and the ICF?
- The husband did not mention at any time having difficulties with the language. However, as the ER doctor stated, his wife did so...
 - How can one be sure that she, the person undertaking the surgery, had understood all the information?
 - Maybe the husband was performing as an ad hoc interpreter.
 - Answering questions without letting his wife reply, offering information, not interpreting comments from his wife.
 - Research shows *ad hoc* family interpreters might not translate all information (Backer et al., 1998; Angelelli, 2004)
- Were they aware about the existence of a translation and interpreting department in the hospital? Who told them? Why is it not stated in the record?
- Apart from the ER record, why is there no other record stating the language barrier?

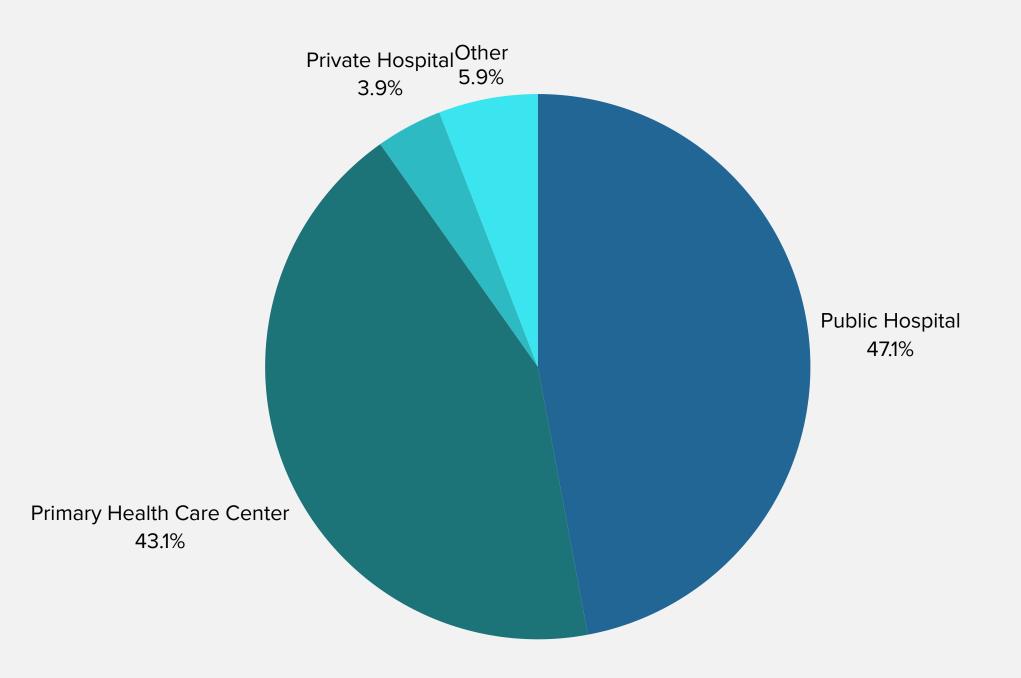
STUDY ABOUT THE REALITY OF IC USE IN SPAIN



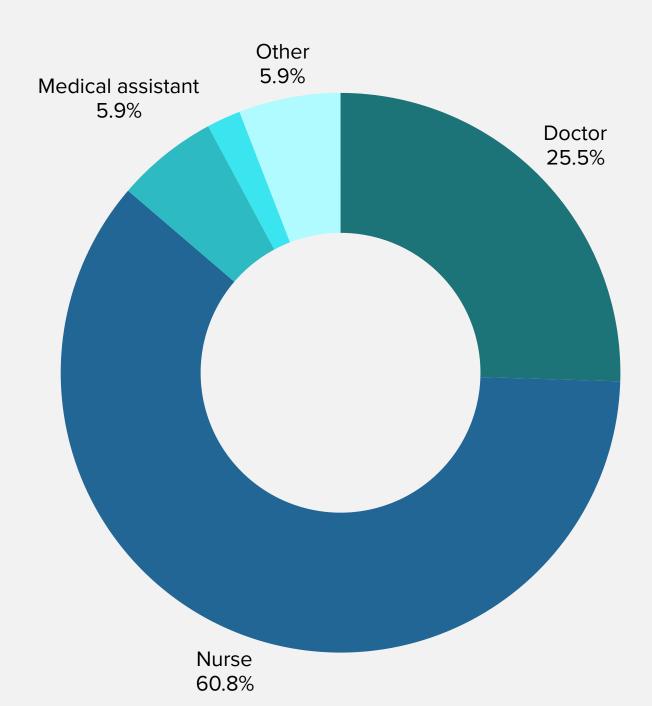
SURVEY RESPONDENTS



HEALTHCARE CENTER



JOB POSITION

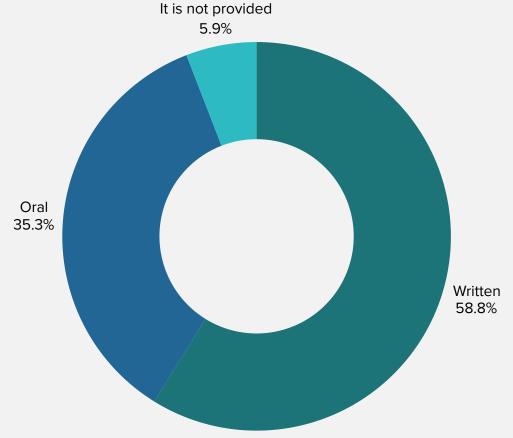


COLLECTION OF THE INFORMED



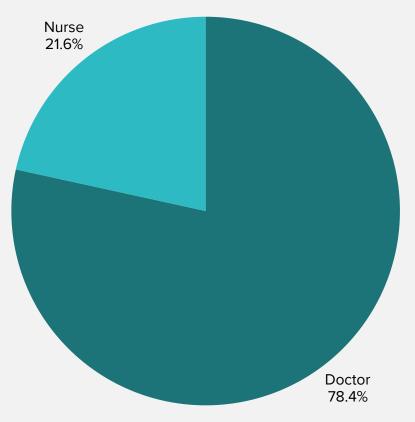
How is the informed consent collected?

CONSENT



Who collects the informed consent?

Act 3/2001, of 28 May, regulating informed consent and the clinical history of patients.

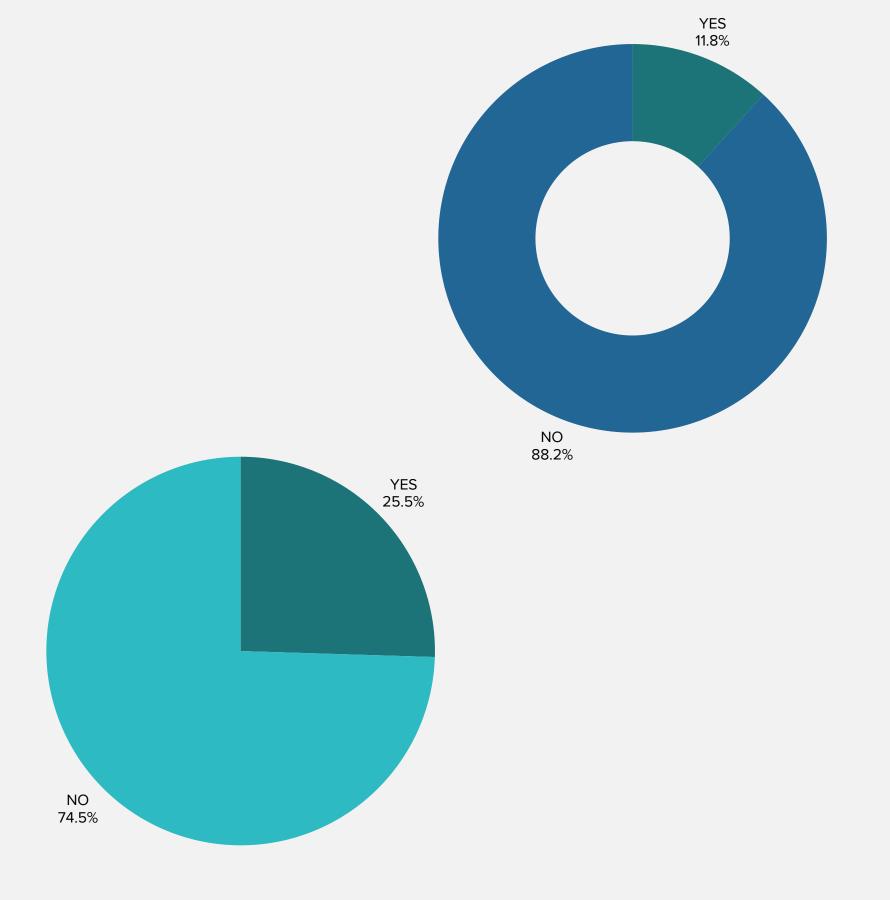


LINGUISTIC ASSISTANCE



Is the informed consent translated?

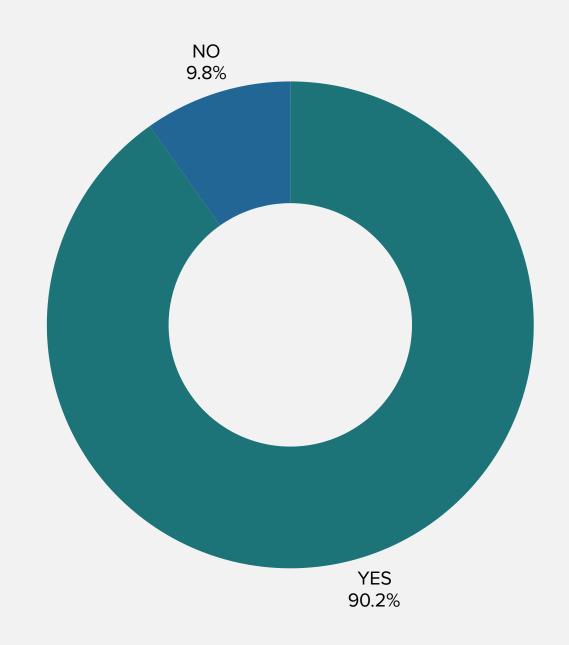
Is there any interpreter who assist foreign patients?



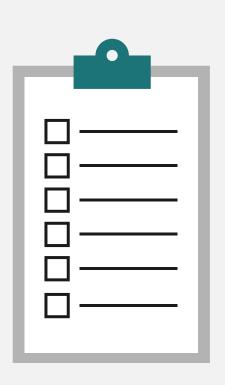
LINGUISTIC ASSISTANCE



Does the lack of translation of the informed consent form hinder effective communication with the patient?



HOW DO THEY DEAL WITH THIS PROBLEM?



- 1. Automatic translation
- 2. Explain the information in his/her language
- 3. Contact an interpreter
- 4. Explain the information through images, infographics, videos, etc
- 5. Search on internet for similar documents





Do you think the informed consent must be translated?



SUMMARY



A Spanish Supreme Court case highlights the dismissal of a claim due to language barriers. This emphasizes the need for clearer policies to ensure linguistic accessibility in a so-called universal healthcare settings.

Clearer policies are necessary to uphold patients' rights to informed decision-making and autonomy, particularly for migrants.



National research project: INTERCULTURAL COMPETENCE IN FEMALE HEALTH INTERLINGUISTIC COMMUNICATION







THANK YOU





