



**Maastricht University**

*Leading  
in Learning!*

# Patients' Rights in the European Union Mapping eXcercise (PRE-MaX)

Coordination meeting of National Contact Points  
representatives (Brussels, 2 December 2015)

# PRE-MaX partners

- CAPHRI School for Public Health and Primary Care, Maastricht University
  - Helmut Brand, Timo Clemens, David Townend, David Shaw
- Centre for Biomedical Ethics and Law, KU Leuven
  - Herman Nys
- European Observatory on Health Systems and Policies
  - Willy Palm



## Rationale for the Tender

“a mapping exercise of existing patients’ rights in 30 countries (including the 28 EU Member States, Norway and Iceland). This study provides an overview of the various legal frameworks as well as other policy tools and mechanisms in place (or in the making) to define, implement and enforce patients’ rights”

# Tasks

1. review of national legislation including soft laws and draft legislation in the field of patients' rights in all EU Member States, Norway and Iceland
2. the existence and functioning of the structures, procedures and mechanisms instrumental to enforce the identified patients' rights under (1).
3. To map Council of Europe activities in the field of patients' rights
4. To organise a workshop to discuss the findings of above tasks with relevant stakeholders and to develop a comprehensive list of useful and achievable patients' rights

# Patients' rights



## Basic individual rights

- informed consent
- right to privacy
- right to information of one's health
- access to medical file



## Consumer- based rights

- right to choose provider
- right to second opinion
- right to safe treatment received in a timely manner
- easy accessible information concerning basket of care



## Procedural patients' rights

- right to complain
- right to compensation
- right to choose/ participate in decision making

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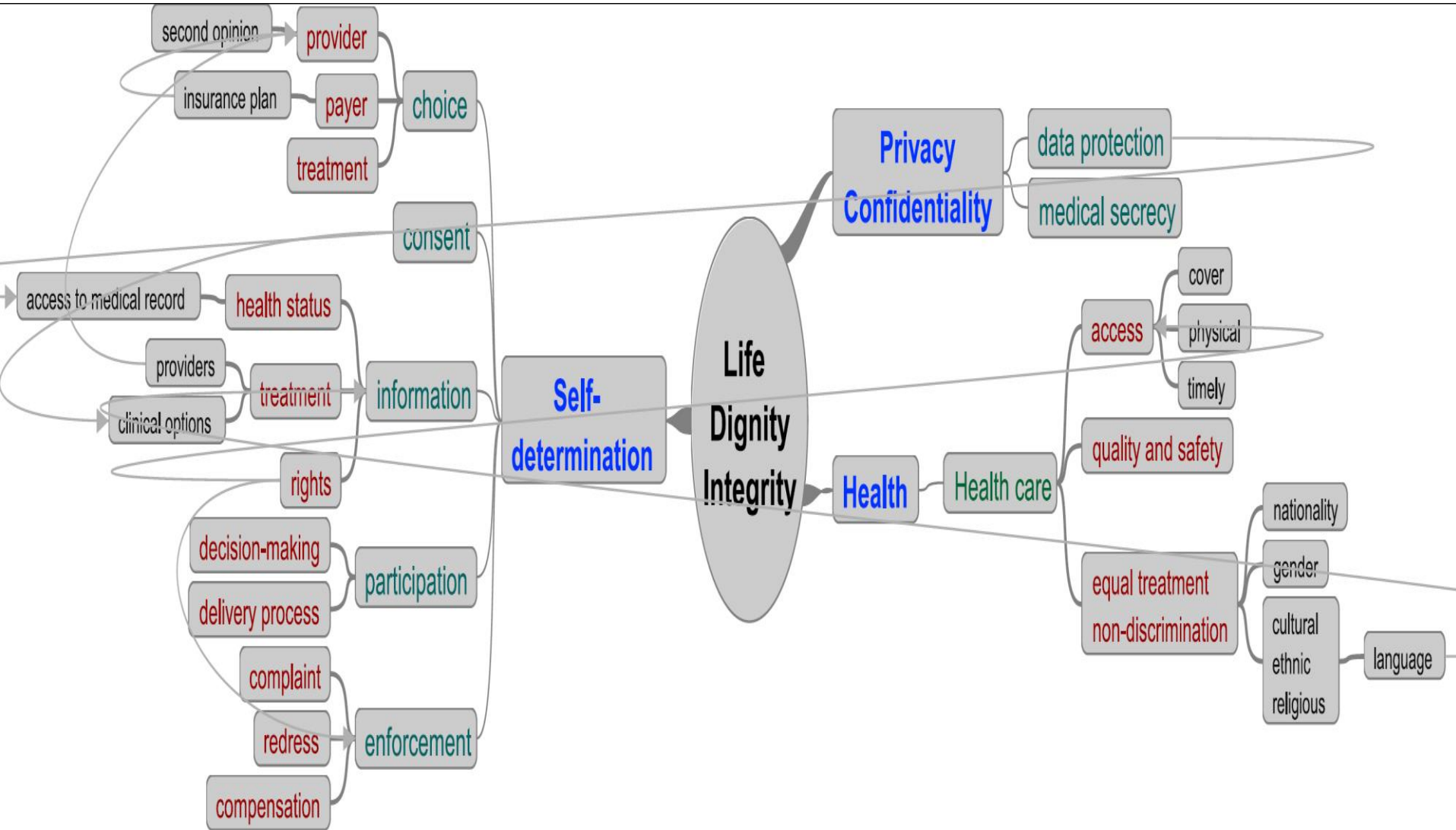
Brussels, 2 December 2015

**Willy Palm, Dissemination development Officer**





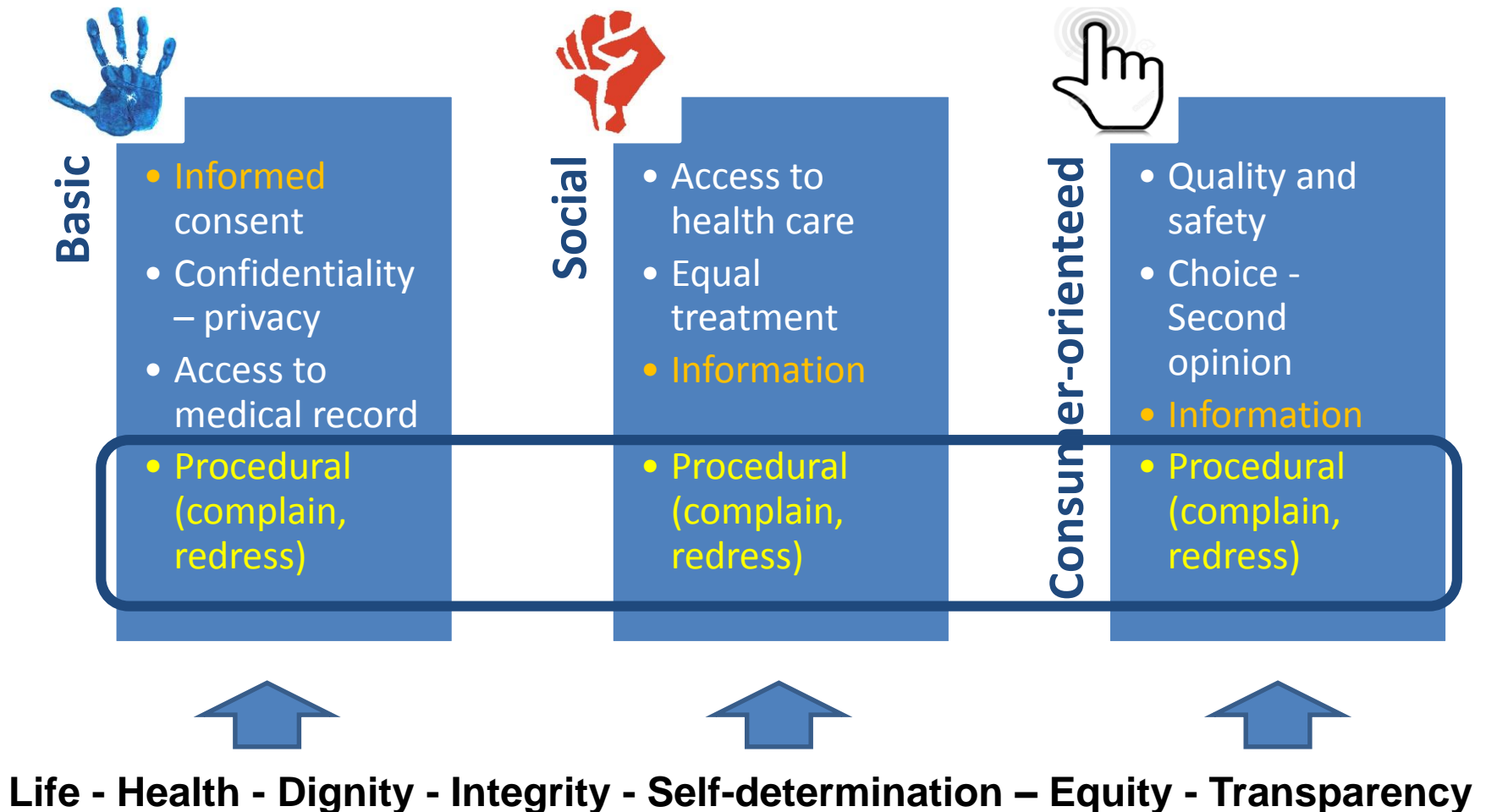
# Patients' rights: types and links





# Patients' rights types

*How do they apply in a cross-border care context?*







# Directive 2011/24/EU on the application of patients' rights in cross-border health care

*What types do we find in the Directive?*



## Legal certainty about rights and entitlements to care in another Member State

- Conditions for reimbursement of cross-border health care (benefit basket, level, formalities)
- Prior authorisation (scope, undue delay, administrative procedures)
- Guarantees of information and equal treatment (prices)



## Access to safe and high-quality cross-border healthcare

- Information on applicable quality and safety standards and on available providers
- Access to medical record
- Guarantees of non-discrimination, complaints and compensation, professional liability, data protection



## Cooperation on healthcare between Member States

- Basic duty of mutual assistance and cooperation
- Mutual recognition of medical prescriptions
- Areas of cooperation: European reference networks, Rare diseases, e-health, Health technology assessment, border regions



National  
Contact  
Points





# Types of cross-border patient mobility

*What are the specific challenges for the various types of cross-border patients?*

	Types of funding: does the patient have cover for cross-border care?		
	No cover	With cover	
Types of patient motivations: why does the patient travel for care?	<b>Availability</b> <ul style="list-style-type: none"> <li>• <i>Quantity</i></li> <li>• <i>Type</i></li> </ul>	1	2
	<b>Affordability</b>	3	4
	<b>Familiarity</b>	5	6
	<b>Perceived quality</b>	7	8

*Source: Glinos, Baeten, Helble, Maarse (2010)*

1-2: Long waiting times, smaller countries, rare diseases and high-tech services (reference centers and networks), ethically controversial treatments

3-4: treatments not covered or with high user charges (e.g. dental care)

5-6: migrants, border regions, tourists and travelers, pensioners (convenience)

7-8: well-informed and mobile citizens, telemedicine



# Conceptual framework

- Broad definition:
  - Basic PRs
    - Informed consent (incl. information about one's health, choice of treatment options)
    - Privacy and confidentiality (incl. access to medical record)
  - (Social PRs)
    - Information about entitlements
  - Consumer-oriented PRs
    - Quality and safety (incl. undue delay)
    - Choice (incl. second opinion, information about provider)
  - Procedural PRs (cross-cutting)
    - Complain
    - Redress and compensation
    - (incl. information about procedures)



# Patients' rights development

## Stumbling blocks

- Low sensitivity
- Poor knowledge
- Paternalistic doctor-patient model

## Challenges

- Innovation in medicine and ICT
- Growing complexity and cultural diversity
- Chronic and mental diseases
- Rise in ethical questions

## Enablers

- Human rights movement
- Development of health law as a discipline
- Political transition and civil society
- International framework, (incl. Biomedicine Convention, XBC Directive)
- Media coverage
- Increased attention for patient involvement and empowerment, quality and safety, medical liability



# General context

- Only few countries without special PR law
- Variation in approaches
  - Nominate contract model (NL)
  - Special law with enforceable rights (HU)
  - Vertical public model (FI)
- Basic PRs better established as more recent consumer-oriented PRs
- Enforcement is weak element!
  - But courts more sensitive and alternative mechanisms for monitoring and assistance



# Self-determination and confidentiality

- Informed consent and privacy in general strong protection
- However ...
  - Basic consent before admission
  - No information on alternative treatment options
  - Old-fashioned approach to privacy
  - Unsafe data processing
  - Access to medical record



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  - Unsafe data processing
  - Access to medical records
- **Generally no specific provisions for XBC**
- **Language support to guarantee informed consent**
- **Common single consent model**
- **e-copy of medical file**
- **Patient and discharge summaries (minimum data set)**
- **Minimum security requirements to ensure an equivalent level of protection of personal data across the EU and to facilitate cross-border healthcare and research.**

border healthcare and research.





# Informed choice of provider and options

- **Choice** of provider considered important for trust relationship doctor-patient
- but often restricted by regulation and reality
  - Specialised care (gatekeeping)
  - Rural and remote areas
  - Higher user charges for extended choice
  - Public vs private patients = source of inequity
- **Second opinion:** least formally recognised
  - Only upon referral, only once per treatment, only certain conditions, only certain providers
- **Information** on providers: clear and coherent regulation is often still lacking
  - reliable and systematic information on performance most wanted but least available
  - Waiting times!
  - Variation in information duty of providers
  - Centralised public reporting based on different indicators
  - Private initiatives



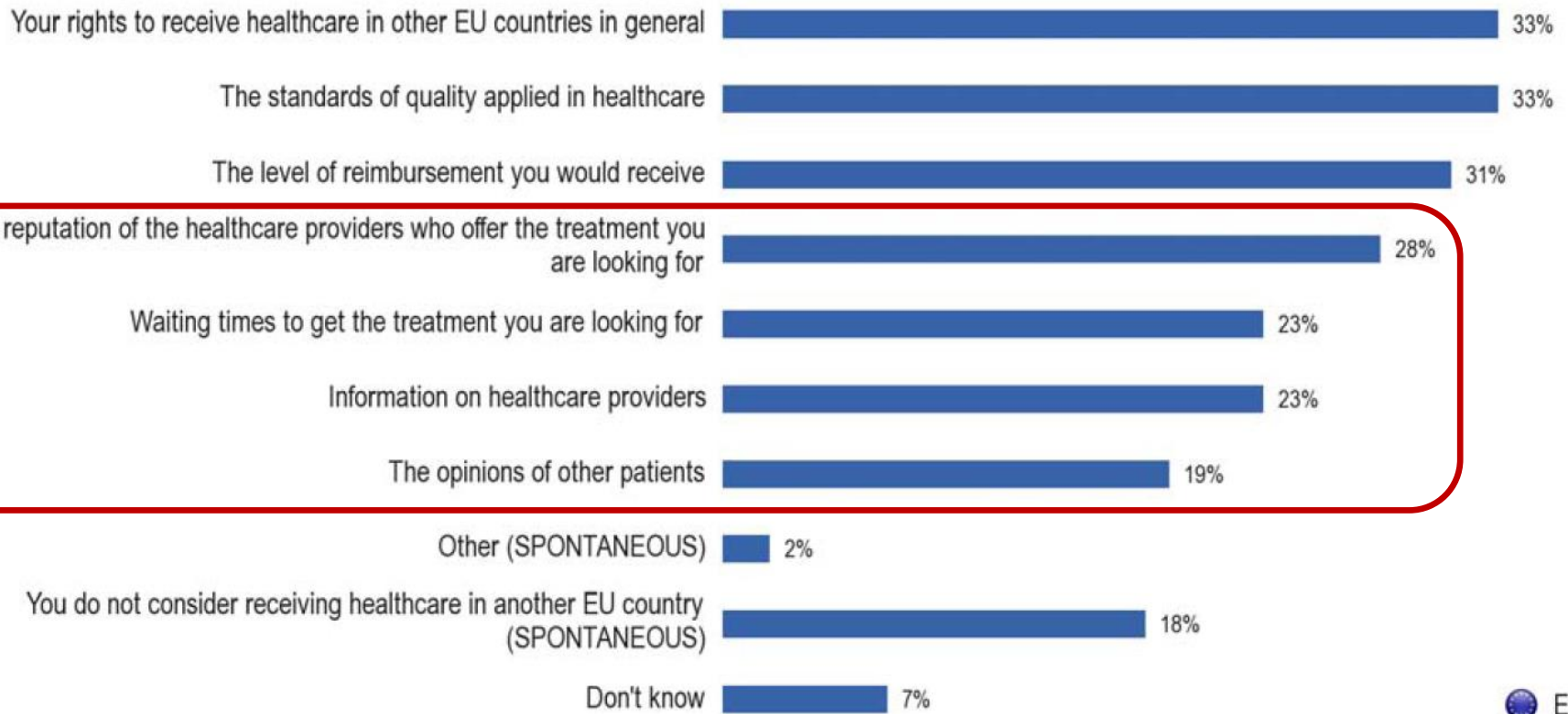
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  - **Information** on providers: clear and coherent regulation is often still lacking
    - reliable and systematic information on performance most wanted but least available
- **Clear information about referral requirements**
  - **Distinction public (contracted) – private providers**
  - **Second opinion in another Member State**
  - **Information about border region access arrangements**
  - **Access to relevant information on providers (including performance, waiting times)**
  - **Language?**
- Private initiatives



# Information on providers

QD3. If you were considering receiving healthcare in another EU country, what kind of information would you look for that would help to make your decision?  
Information on... (MULTIPLE ANSWERS POSSIBLE)



English/Engelska

Rules and rights  
Regler och rättigheter

- Rights of children and their parents or legal guardians  
Barn och vårdnadshavares rättigheter i vården
- Getting ready for a medical appointment - a 10-point checklist  
Förbered ditt läkarbesök - tio tips
- New medical evaluation, second opinion  
Ny medicinsk bedömning, second opinion
- Patient Fees  
Patientavgifter
- Patient Act  
Patientlagen
- Referrals  
Remiss
- If you are not happy with dental care  
Om man inte är nöjd med tandvården
- If you are unhappy with your healthcare  
Om man inte är nöjd med vården
- Special dental care benefit/Särskilt tandvårdsbidrag  
Särskilt tandvårdsbidrag
- Dental care for people over the age of 20 - government dental care benefits scheme  
Tandvård när man är över 20 år - statligt tandvårdsstöd
- Dental care support if you have a disability  
Tandvårdsstöd om man har en funktionsnedsättning
- Interpretation to other languages  
Tolkning till andra språk
- Professional Secrecy and Confidentiality

Examinations/tests  
Undersökningar/prov

- Prostate tissue sample  
Vävnadsprov av prostata
- F-Hb, blood in the stool  
F-HB, blod i avföring
- Colonoscopy  
Koloskopi
- PSA  
PSA
- Mammography  
Mammografi
- Gynecological pap test  
Gynekologisk cellprov

Self-care, children  
Egenvård barn

The information about self advice about what you can treat mild symptoms.

- Child safety, 0-3 months  
Barnsäkerhet 0 - 3 mån
- Child safety, 3 months  
Barnsäkerhet 3 - 12 mån
- Child safety, over 1 year  
Barnsäkerhet över 1 år
- Fever in children - what to do  
Feber - vad kan man göra

English/Engelska

Choosing a clinic

Välja vårdmottagning

You have the right to use the health centre or clinic of your choice when you need outpatient care. You can obtain outpatient care wherever you like in Sweden.

There may be any number of reasons that you prefer a particular health centre or clinic. For instance, it might be most convenient to choose one that is close to your home or job, or maybe some members of its staff speak your native language.

What do I have the right to choose?

You may choose a

- health centre
- child welfare centre

Skriv ut (ca 3 sidor)

English  
Engelska

Back to the start page for this theme

Artikeln ingår även i:  
Tema Patientlagen



Tema patientlagen

Patientlagen ger dig stora möjligheter att påverka din vård. Här finns samlad information om den nya lagen.

Patientlagen

Other languages

NATIONELLA MINORITETSSPRÅK	SHQIP/ALBANSKA	العربية/ARABISKA	BOSANSKI/HRVATSKI/SRPSKI/BK Bosniska/Kroatiska/Serbiska
ENGLISH/ENGLSKA	SUOMEKSI/FINSKA	FRANÇAIS/FRANSKA	KURMANJI/NORDKURDISKA
فارسی/PERSISKA (FARSI)	POLSKI/POLSKA	РУССКИЙ/RYSKA	SOOMAALI/SOMALISKA
ESPAÑOL/SPANSKA	SORANÍ /SYDKURDISKA	TECKENSPRÅK/TECKENSPRÅK	ภาษาไทย/THAILÄNDSKA Thailändska
ᏆᏚᏂ/TIGRINSKA	TÜRKCÉ/TURKISKA		

...clinic for dermatology or another

In order to be treated at an outpatient specialist clinic. The county councils or regions that receive care have their own referral procedures. Find out more here about how the different regions operate.

Health centre

You can get care when you are sick or experiencing a health problem. The centre will provide care and then refer you to an appropriate clinic if you need specialist care. You can go to the health centre, either in the county council or region where you live or elsewhere. The only exception is if you must be run by, or have an agreement with, the county council or region.

You can enrol at a particular health centre if you like. Your county council may automatically enrol you unless you actively choose another one. You are free to switch to another



# Quality and Safety

- Obligation of the provider to adhere to the standard of care
  - Broadly described, implementation spread over various institutions
  - Ensured through licensing, professional standards, clinical guidelines and protocols
  - Sometimes framed as patients' right
- In case of inflicted harm: fault-based vs non-fault-based systems
- Timeliness: variation in practice (standardised maximum waiting times (DK, NL), Individual assessment, extended choice for patients beyond max waiting times)



# Quality and Safety

- Obligation of the provider to adhere to the standard of care
  - Broadly described, implementation spread over various institutions
  - Ensured through licensing, professional standards, clinical guidelines and protocols
    - Accessible information on applied standards
    - Providers who raise quality and safety concerns?
  - Sometimes framed as patients' right
    - Definition “undue delay”
  - In case of fault-based vs non-fault-based systems
    - Information about waiting times by national contact points
  - Timeliness in practice (standardised national maximum waiting times (DK, NL), individual assessment, extended choice for patients beyond maximum waiting times)
    - Redress and compensation: proof and expectations?
    - Access to complaint and mediation mechanisms
  - Access to complaint and mediation mechanisms





# Conclusions

European Commission

Seeking healthcare in another EU Member State: **your rights**

Did you know?

You have the right to receive medical treatment in another EU Member State and the right to have your home country cover some or all of the costs.

You have the right to be informed about the treatment options open to you, how other EU countries ensure quality and safety in healthcare, and whether a particular provider is legally entitled to offer services.

Look inside to find out more...

Health and Consumers

- National variation in approaches and practice
- Patients' rights laws help to raise awareness, empower patients and guide policy makers
- Patients' rights Directive contributes to the development and implementation of patients' rights at national level (also for domestic patients!)
- Towards an integrated and broad definition of patients' rights.



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