

Study on cross-border health services: enhancing information provision to patients

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Aim of today's presentation

- Introduction to the study
 - Aim of the study
 - Methodology
- Guiding principles and indicators
 - Toolbox and training materials
 - Validated guiding principles and indicators
- Key conclusions

Introduction to the study



Introduction to the study

Aim & objectives

The study aims to propose options and solutions for improving the status quo of information provision to patients via NCPs and to share and present these.

Main objectives:

1. To identify the legal information requirements and the needs of the patients, for the NCPs;
2. Study the **status quo** of current information provision by NCPs, and the evolution since previous studies.

Based on these findings, we formulated **recommendations** aimed at further improvement of information provision.

Follow-up of the Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2014-2015



Introduction to the study

Scope

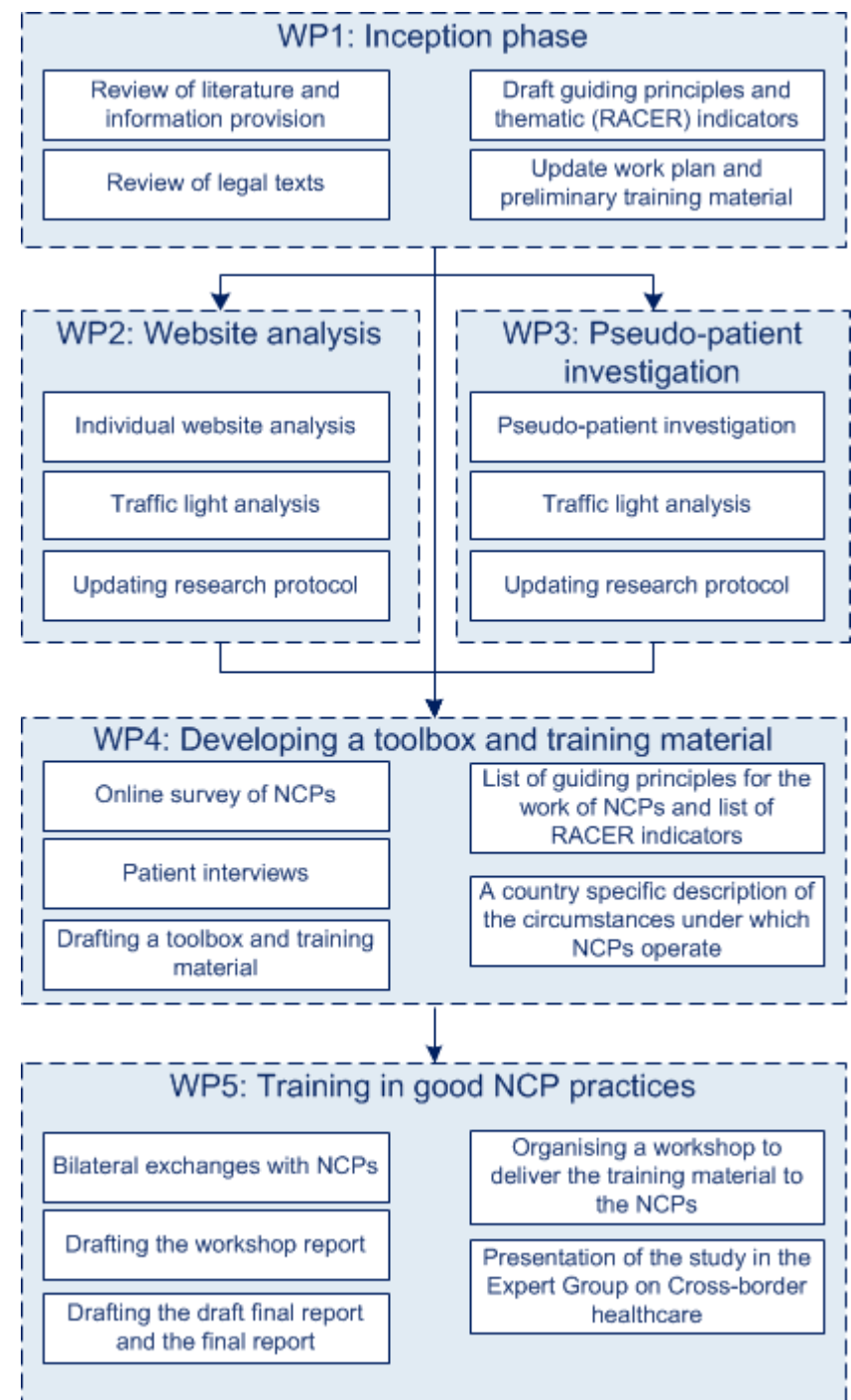
Focus on the way that NCPs and healthcare providers deal with information requirements in the Directive 2011/24/EU

Information provision via websites and email/telephone:

- For all 28 EU Member States and Norway (33 NCP websites)
- If relevant, both types of NCPs (MS of affiliation and MS of treatment)
- Distinction between:
 - Patient mobility related to unplanned or to planned healthcare; and
 - Different types of care (i.e. ambulatory care; care delivered in public or private hospitals or clinics; telemedicine; and preventive medicine).

Introduction to the study

Overall approach



Introduction to the study

5 work packages (WP):

- **WP1 Inception phase**
 - Analysis of legal texts: Directive 2011/24/EU and Social Security Regulations
 - Review of literature
- **WP2 Website analysis**
 - 36 NCP websites were analysed in July 2017
 - “Technical elements”, “Accessibility”, “Usability”, “Completeness of content”
- **WP3 Pseudo-patient investigation**
 - Investigate the discrepancies between information that is provided by NCPs in response to inquiries made by pseudo-patients and the information that they are expected to provide based on the provisions of the Directive; Augustus 2017 – October 2017
- **WP4 Toolbox and training material**
 - Online survey NCPs
 - Toolbox and training material for NCPs
 - Draft guiding principles and indicators
- **WP5 Training in good NCP practices**
 - Bilateral exchange with NCPs
 - NCP workshop, 8 March 2018
 - Final report and final guiding principles and indicators

Guiding principles and indicators



Toolbox and guiding principles

Recap of the overall aim and activities

- **Overall aim:**
 - To determine the current and country-specific operation of NCPs
 - To determine good practices
 - To create guiding principles for good NCP service
 - To create indicators for permanent evaluation

- **Activities:**
 - Online survey for NCPs
 - A country specific description of NCPs
 - Analysis of other information centres (e.g. Horizon 2020 NCPs, FreSsco, Orphanet,..)
 - Online survey for patients

Toolbox and guiding principles

Based on all previous findings:

- **Toolbox for NCPs**
- **Underlying Guiding Principles and Indicators**

Final aim:

- To establish guiding principles and provide tools aiming to ensure the provision of good-quality information to patients

Two versions:

- Research-based proposal (upstream)
- Validation by NCPs (downstream)

Guiding principles and RACER indicators

“Guiding Principles and Indicators for the practice of National Contact Points (NCPs) under the Cross-border Healthcare Directive 2011/24/EU”

Aim:

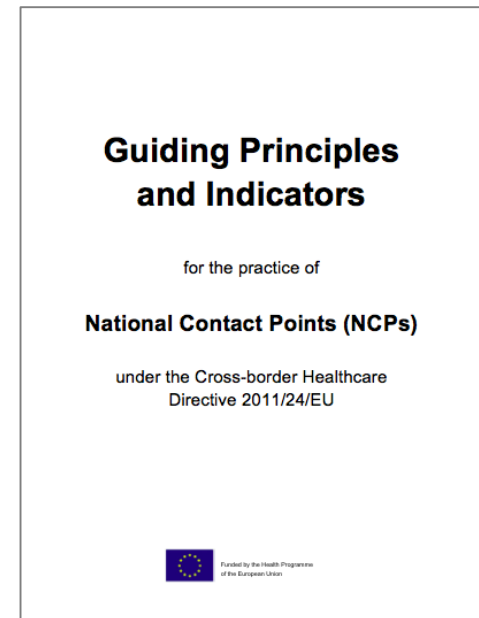
- To set out the key principles for good NCP services
- To create indicators for self-evaluation

Contribute to a **NCP practice** that is

- 1) more uniform
- 2) of high quality, and
- 3) always patient-oriented

While leaving room for the existing differences between NCPs and how they are organised

- **RACER Indicators** for self-evaluation:
Relevant, Accepted, Credible, Easy to monitor, Robust



Guiding principles and RACER indicators

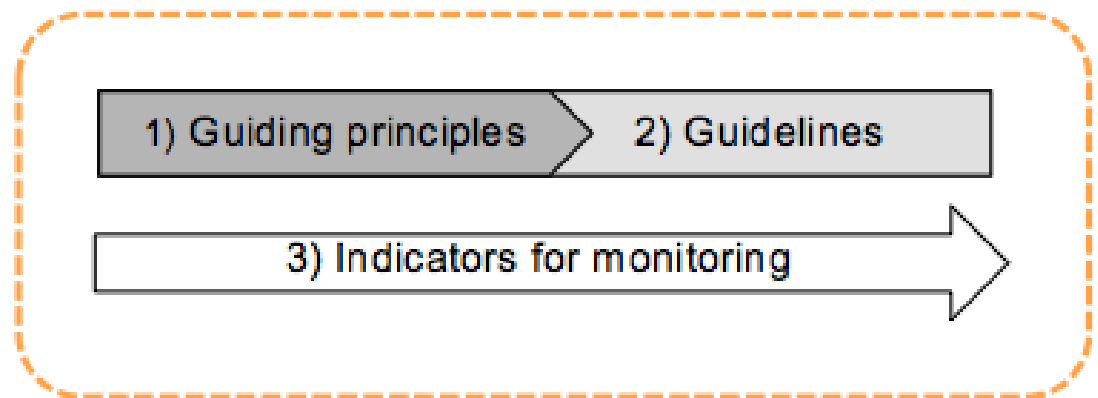
Main areas covered under the Guiding Principles:

- Accessibility and availability of the NCP service
- Compatibility of information provision with the legal requirements under Directive 2011/24/EU
- Cooperation between NCPs and with other actors

Guiding principles and RACER indicators

Methodology:

- Nine general **Guiding Principles**
- Guiding Principles are translated in more technical **Guidelines**
- Guidelines are monitored through a set of voluntary thematic **Indicators**



Guiding principles and RACER indicators

Methodology:

- Part 1: **Guiding Principles and Guidelines**
- Part 2: Voluntary Thematic Racer **Indicators**
 - Relevant, Accepted, Credible, Easy and Robust
- (**Source material for further consideration** = Proposed indicators and Guidelines that did not find common approval)

Guiding principles and RACER indicators

Methodology:

- The Guiding Principles and indicators are established based on a **two-way approach**:
 - a version consisting of the research-based proposal for guiding principles, guidelines and indicators (upstream)
 - and a post NCP consultation version (downstream)
- The Guiding Principles and indicators were discussed at **the NCP Workshop** of 8 March 2018 and following further consultations, **agreed by consensus with all cross-border healthcare NCPs**

Guiding principles and RACER indicators

Methodology:

- The **indicators** are variables that can be used to measure the performance of NCPs in the light of the Guidelines for good NCP practice
- All indicators are tested on:
 - **Relevance:**
 - Indicators are closely linked to the objectives to be reached by the guidelines.
 - **Acceptance:**
 - Indicators are built on already established good NCP practice.
 - **Credibility:**
 - Indicators are unambiguous, easy to interpret and to evaluate.
 - **Easiness to monitor:**
 - Indicators are easy to monitor, at low resources and minimum time.
 - **Robustness:**
 - Indicators are robust against manipulation, reliable and easily validated.
- NCPs should aim for an optimal uptake of all indicators. However, uptake must at any time be considered taking into account the NCP's and country's specific context.

Guiding principles and RACER indicators

Guiding principles

NCP service

- Principle of Visibility
- Principle of Accessibility
- Principle of Transparency
- Principle of Inclusion

Information provision in accordance with Directive 2011/24/EU

- Principle of Duality
- Principle of Information to outgoing patients in accordance with the Directive
- Principle of Information to incoming patients in accordance with the Directive

Cooperation & information exchange

- Principle of information to healthcare providers
- Principle of Cooperation

Guiding principles and RACER indicators

Guiding principles: NCP service

1. Principle of Visibility

- NCPs are highly visible and easy to find and recognise as appropriate.
- When this is within the responsibility of the NCP and subject to available resources, NCPs try to be engaged in campaigns intended to inform the general public of their existence.
- To map the awareness of the existence of NCPs, and as far as possible NCPs collect data on the number of patients making use of the NCP service.

Guiding principles and RACER indicators

Guiding principles: NCP service

2. Principle of Accessibility

- NCPs have an accessible website that is informative and contains clear, structured and understandable information.
- Subject to available resources and as appropriate, NCPs are accessible for direct and barrier-free personal patient advice, e.g. via email, postal service, online contact forms, telephone, or in person.
- Depending on the available resources, NCPs try to provide information besides the national official language(s), in foreign languages, at least English, making the service also accessible for incoming patients.

Guiding principles and RACER indicators

Guiding principles: NCP service

3. Principle of Transparency

- NCPs provide information about their organisation and service. They try to answer all inquiries as soon as possible subject to available resources and taking into consideration domestic law.
- Taking national work processes under consideration, NCPs try to collect data about their working process, aiming to monitor their efficiency and performance.
- When this is within the NCP's competence, NCPs are transparent on the patients' rights and entitlements in accessing healthcare abroad.
- When this is within the NCP's competence, NCPs provide patients with accessible and transparent procedures regarding accessing healthcare abroad.
- When this is within the NCP's competence, NCPs provide outgoing patients with transparent procedures and clear timelines to appeal any decision regarding accessing healthcare abroad.

Guiding principles and RACER indicators

Guiding principles: NCP service

4. Principle of Inclusion

- Subject to available resources, NCPs offer informed assistance to help patients with disabilities to understand and exercise their rights in accessing healthcare abroad. Information provision by NCPs is provided in formats that are easily accessible for patients with disabilities, as appropriate.
- Subject to available resources, NCPs arrange for education and training of their staff on the specific needs of patients with disabilities, taking into consideration different types of disabilities.
- All NCPs provide information to incoming patients on the accessibility of hospitals for persons with disabilities.

Guiding principles and RACER indicators

Guiding principles: Information provision according to Directive 2011/24/EU

5. Principle of Duality

- In accordance with Directive 2011/24/EU, NCPs make a clear distinction between information provision to outgoing patients and information provision to incoming patients.
- NCPs facilitate the contact of patients with NCPs of other Member States.

Guiding principles and RACER indicators

Guiding principles: Information provision according to Directive 2011/24/EU

6. Principle of information to outgoing patients in accordance with Directive 2011/24/EU

- NCPs provide outgoing patients with information on patients' rights and entitlements in cross-border health services.
- NCPs inform patients on the existence of two parallel routes if appropriate. They make a clear distinction on the use of the Social Security Regulations versus Directive 2011/24/EU, and the respective consequences for patients.
- NCPs provide outgoing patients with information on the financial aspect of cross-border healthcare. They provide information on the terms and conditions for receiving reimbursement of costs and on what extra costs need to be covered by the patient him-/herself, including information on the procedures and competent authorities for accessing and determining those entitlements, as well as on the procedures for appeal and redress if patients consider that their rights have not been respected.

Guiding principles and RACER indicators

Guiding principles: Information provision according to Directive 2011/24/EU

6. Principle of information to outgoing patients in accordance with Directive 2011/24/EU

- NCPs inform patients on the importance of gathering sufficient information about the treatment and healthcare provider abroad. They refer the patient for this information to the NCP of the Member State of treatment.
- NCPs inform patients on the importance of the transfer of medical records. Patients should be cautioned on the risk of receiving treatment without such transfer.

Guiding principles and RACER indicators

Guiding principles: Information provision according to Directive 2011/24/EU

7. Principle of information to incoming patients in accordance with Directive 2011/24/EU

- NCPs inform patients on the importance of gathering sufficient information on needed application forms and reimbursement. They refer the patient for this information to the NCP of the Member State of affiliation.
- To make patients acquainted with healthcare in their country, NCPs provide incoming patients with general information on their healthcare system, as it pertains to the individual patient as appropriate.
- To ensure safe cross-border treatment, NCPs provide incoming patients with general information on quality and safety standards enforced in their MS, as well as information on which healthcare providers are subjected to these standards.

Guiding principles and RACER indicators

Guiding principles: Information provision according to Directive 2011/24/EU

7. Principle of information to incoming patients in accordance with Directive 2011/24/EU

- NCPs provide incoming patients with accurate information on healthcare providers and healthcare facilities established in their MS in so far as possible. NCPs provide general information on supervision and assessment of healthcare providers. Besides, NCPs inform patients on a specific provider's right to provide services or any restrictions on this practice, e.g. suspension, as available via the IMI or the NCP network.
- NCPs inform incoming patients on patients' rights, complaints procedures and mechanisms for seeking remedies. Besides, NCPs provide information on the legal and administrative options available to settle disputes, including in case of harm arising from the event of cross-border healthcare, bearing in mind that this will mainly relate to referring the patient to the relevant responsible body.

Guiding principles and RACER indicators

Guiding principles: Information provision according to Directive 2011/24/EU

8. Principle of information to healthcare providers

- NCPs provide healthcare providers with information on patients' rights and entitlements in cross-border health services under Directive 2011/24/EU and the Social Security Regulations.
- NCPs provide healthcare providers with information on their duty to provide information towards their patients according to Directive 2011/24/EU.

Guiding principles and RACER indicators

Guiding principles: Good cooperation and information exchange

9. Principle of cooperation amongst NCPs

- NCPs should maintain partnerships amongst each other, making it easy to exchange information and build on each other's best practices.
- NCPs should assist each other in answering patients' inquiries and finding solutions that are the best fit for the specific patient's needs during the entire process of treatment abroad.
- NCPs should consult with other stakeholders, such as healthcare providers, national health insurance funds, patient organisations,...

Toolbox and training material

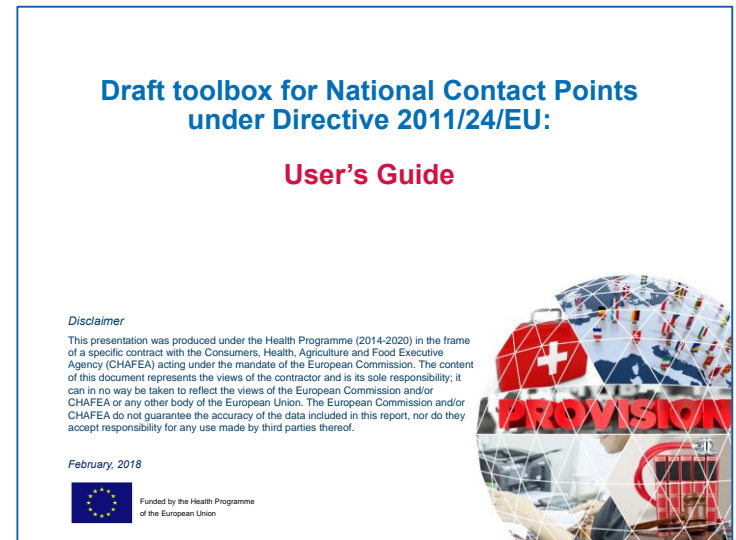
Providing a toolbox and training material

Aim:

- To provide NCPs with a set of good practices and tools covering different aspects of the NCP service
- To foster a NCP practice that is more uniform, of high quality and always patient-oriented.

Guidance for good NCP practice:

- Voluntary
- Respect for the specific NCP context



Toolbox and training material

Toolbox:

- Toolbox Users' Guide
- Background information (legislation and previous studies)
- Communication material on the distinction between Directive 2011/24/EU & Social Security Regulations (including decision trees)
- A manual and checklist for patients
- Leaflet for patients (https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2018_10mistakes_en.pdf)
- Templates with answered FAQs for incoming and outgoing patients
- Templates and checklists for consultation with patients
- Templates and checklists for consultation with patient organisations, healthcare providers and health insurers
- Informative text on quality and safety
- Informative text on compliance with Regulation (EU) 2016/679 (GDPR)

Training material:

- Power points & *digital lectures*
- *Self-evaluation sheets*

Toolbox and training material

General tools

A. Toolbox User's Guide

#1	Toolbox User's Guide	PowerPoint
#2	Toolbox User's Guide	Web lecture
#3	Glossary	PDF

B. Background

#4	Legislative texts	Overview
#5	Studies and data	Overview

D. Directive 2011/24/EU versus Social Security Regulations

#9	Directive <i>versus</i> Social Security Regulations	PDF
#10	Decision trees	PDF
#11	Directive <i>versus</i> Social Security Regulations	Web lecture

G. Practical documents

#23	Quality and safety	PDF
#24	Data protection	PDF



Guiding Principles for good NCP provision

C. Guiding Principles and Indicators

#6	"Guiding principles and Indicators for the practice of NCPs under the Cross-border Healthcare Directive 2011/24/EU"	Overview
#7	Guide for the Guiding Principles	PowerPoint
#8	Guide for the Guiding Principles	Web lecture

Tools for information provision

E. Information provision in cross-border healthcare

#12	Template for information provision to outgoing patients	PDF
#13	Checklist for consultation outgoing patients	PDF
#14	FAQ outgoing patients	PDF
#15	Checklist for consultation incoming patients	PDF
#16	FAQ incoming patients	PDF
#17	Template for information provision to healthcare providers	PDF
#18	Checklist for consultation health insurance providers	PDF
#19	Checklist for consultation patient organisations	PDF

Tools for patients

F. Documents for patients

#20	Manual for patients	PDF
#21	Checklist for patients	PDF
#22	<i>The Top Ten Mistakes Patients make in Cross-border Healthcare</i>	Leaflet

Evaluation tools

H. Evaluation

#25	Self-assessment sheet NCP practice	Excel
#26	Self-assessment sheet NCP website	Excel

Key conclusions



Key conclusions of the study

Core finding 1:

*There is a **general lack of awareness** of the existence of the Directive 2011/24/EU and NCPs. The findings of the study show that almost five years after the implementation of Directive 2011/24/EU, patients' awareness on their rights and possibilities to access health services abroad and on the existence of NCPs is still low.*

Key conclusions of the study

Core finding 2:

*The information provision through NCP websites was adequate, even so there remains **a need to further improve the NCP websites**. In particular, information on **patient's rights** (for incoming patients), **quality and safety standards** (for incoming patients) and **reimbursement** of cross-border healthcare costs (for outgoing patients) require additional consideration and improvement.*

Key conclusions of the study

Core finding 3:

There are *big organisational disparities between NCPs* regarding the number of NCPs in each MS, the institution hosting the NCP, funding and staff, and organisational handling of incoming and outgoing patients. Significant improvements have been achieved since the implementation of the Directive 2011/24/EU and the establishment of the NCPs, which did not predate the Directive. However, there is *still room for further improvement regarding comparability of invoices, NCP websites, visibility of NCPs and patient awareness, as well as regarding cooperation and information exchange between NCPs.*

Key conclusions of the study

Core finding 4:

*Information provision for **incoming patients** is in general less complete compared to information targeted at outgoing patients. This has been concluded from the website analysis, the online surveys, and to a lesser extent from the pseudo-patient investigation.*

Key conclusions of the study

Core finding 5:

*There is especially great potential for NCPs to **learn from each other and help each other improve** their information provision to patients in the context of cross-border healthcare.*

Thank you for your attention !

