



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

Final Report



KU LEUVEN

Written by the consortium of Ecorys, KU Leuven and GfK Belgium.

June – 2018



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Luxembourg: Publications Office of the European Union, 2018

ISBN 978-92-79-80264-5
doi:10.2875/54138
EW-01-18-175-EN-N

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SHORT SUMMARY

The overall objective of this study was to propose recommendations for improving the current level of information provision to patients by National Contact Points (NCPs). The research methodology used in this study consisted of: literature review, analysis of legal texts, website analysis, pseudo-patient investigation, NCP and patient surveys, bilateral exchanges and a workshop with NCPs. Core findings of the study are:

- There is a general lack of awareness of the existence of the Directive 2011/24/EU and NCPs. Almost five years after the implementation of the Directive, patients awareness on their rights and possibilities to access health services abroad and on the existence of NCPs is still low;
- The information provision through NCP websites was adequate, but there remains a need to further improve the websites. In particular, information on patient's rights, quality and safety standards, and reimbursement of cross-border healthcare costs require additional consideration and improvement;
- There are big organisational differences between NCPs regarding the number of NCPs in each Member State, the institution hosting the NCP, funding and staff, and organisational handling of patients. Significant improvements have been achieved since the implementation of the Directive, however there is still room for further improvement;
- Information provision for incoming patients is in general less complete compared to that for outgoing patients;
- Overall, there is still ample room for improvement in NCP practices. 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.

EXECUTIVE SUMMARY

EU legislation established a broad set of patients' rights with regard to accessing health services abroad. However, currently much of the potential of these provisions in increasing patient mobility remains unused. Due to low patient awareness, shortcomings in information provision and existing regulatory and procedural barriers, patients are limited in their possibilities to benefit from seeking cross-border healthcare. As recommended in previous studies, elimination of existing barriers in some Member States (MS), as well as more uniform practice of information provision in line with the requirements under Directive 2011/24/EU, is required. These improvements are key in providing citizens with more equal opportunities to exercise their rights to planned treatment abroad.

Against this background, the overall objective of this study was to propose recommendations for improving the current level of information provision to patients in cross-border healthcare. To that end, the study aimed to:

- Identify the legal information requirements, as well as the needs of patients, for the National Contact Points (NCPs) of the MS of treatment and of the MS of affiliation) and for healthcare providers who provide cross-border services; and to;
- Study and assess the status quo of current information provision by NCPs, as well as the degree of evolution since previous studies undertook similar performance measurement exercises.

To achieve these two aims, we used a combination of research methods, including a literature review, an analysis of legal texts, a website analysis, a pseudo-patient investigation, and surveys among NCPs and patients.

This study went beyond the existing literature by not only mapping the status quo, but subsequently also developing a toolbox and training material for the NCPs to improve the quality of information provision to patients on cross-border healthcare. More specifically, tools and training materials, as well as a set of Guiding Principles and indicators were developed in order to establish an NCP service that is in line with the requirements of Directive 2011/24/EU, that is more uniform and that is patient-centred. This will contribute to high level information provision to patients.

The draft results of the research activities were shared and discussed with the NCPs through bilateral exchanges and during an NCP workshop on March 8 2018 in Brussels. The Guiding Principles were shared with the NCPs for a final round of consultation in June 2018.

Results of the literature review

Central in the process of improving access to planned cross-border healthcare is the need for good information provision. Information provision must be seen as a powerful tool in safeguarding free provision of services and free movement of patients at all times. Enhancing information provision needs to be considered at different levels:

- Clear, accurate and accountable information empowers patients to exercise their rights and to make informed choices in cross-border healthcare;
- Informing healthcare providers on patients' rights to cross-border healthcare ensures access to health services abroad for patients and safeguards non-discrimination of patients based on nationality;
- Informing NCPs and healthcare providers on the legal framework for cross-border healthcare and on the information requirements placed under Directive 2011/24/EU, enables them to provide patients with clear, accurate and accountable information;
- Informing MSs and national authorities of their obligations to safeguard equality in accessing health services abroad may contribute to lower procedural barriers and lower limitations set on patient in and outflow, which are not justified by overriding reasons of general interest;
- Informing patients on practicing healthy lifestyle habits can have a huge impact at little expense to anyone and great benefit to many. Guiding patients, cultivating awareness and information-seeking behaviour across the socio-economic spectrum of society is an intrinsic part of leading and inspiring a healthy lifestyle.

Our study of the literature showed that limited numbers of patients make use of their right to seek treatment in another MS. However, many Europeans are willing to consider treatment abroad. The main reasons for Europeans to go abroad for medical care are to receive treatment that is not yet available in their home MS, or to receive better quality treatment. There are some socio-demographic factors determining the willingness of patients to go abroad (more specifically: age, employment and education) which *prima facie* appear to mirror health inequality disparities within the MSs. The limited number of patients seeking cross-border treatment can be explained by a general lack of awareness of the existence of the Directive 2011/24/EU and more importantly, of NCPs.

Results of the [Evaluative study](#) have shown that information provision to patients by NCPs has significantly improved over the years, e.g. NCPs provide more information and more information is provided in English. Nevertheless, it is shown that there is still a great need for improvement on different aspects. It is e.g. shown that information on quality and safety is not always provided in a sufficient manner. Moreover, patient organisations have stated that patients often find it important to be able to compare the treatment they can receive abroad with the treatment offered in the home MS, enabling them to weigh their different options, which today is often not possible. Full and accurate translations to English are also still missing on some NCPs' websites. The accessibility of these websites for incoming patients traveling from other EU/EEA countries can be questioned.

Information provision still differs greatly between NCPs, as some provide detailed information and some too general information. This makes it difficult for the patient to understand the information provided. Authors therefore point out the importance for NCPs to evolve to a more common and uniform way of providing information. To that end, cooperation between NCPs and with other actors is of great importance.

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.

Website analysis: an analysis of information provision on NCP websites

The second part of this study focussed on the evaluation of the information provision to patients through the NCP websites. The methodology for the website analysis was based on the Evaluative Study (2014) in which Specific Analytical Items (SAI) were developed to structure the website analysis. Based on a pilot that was conducted as part of the current study, analysis of relevant legal texts, a literature review and a review of studies on quality assessment of websites aimed at patients, the methodology for the website analysis was refined and updated.

The analysis of the NCP websites was performed in July 2017. Data was collected on 36 websites hosted by 33 dedicated NCPs; the UK has separate websites for England, Scotland, Wales, Northern Ireland, and Gibraltar, Luxembourg and Sweden have two NCP websites due to the fact that different organisations are responsible for information provision for incoming and outgoing patients, and Slovakia has two websites hosted by the same NCP. After data collection, the results on the individual SAIs were used to calculate the SAI category scores per NCP website. In the end, the website analysis looked at nine SAI categories, with three focussed on the website itself (in terms of technical elements, accessibility, and usability) and six categories focussed on the actual content of the website.

The three SAI categories that focussed on the website itself, and their results, are:

- **Technical elements**
This SAI category focussed on the presence of certain technical elements, such as contact information and the last date of update. The NCPs scored relatively well on the SAIs regarding the technical elements of the websites, with an average of 72%, ranging from 14% to 100% of the total points earned.
- **Accessibility**
This SAI category focused on the ease with which the NCP website can be found, opened and used, and includes SAIs such as the 'availability of options for people with decreased sensory functioning' and 'order in Google search strategy'. The analysis did not reveal any

major issues regarding the accessibility of the NCP websites. The combined average score of the NCPs is 60%, ranging from 17% to 92% of the total points earned.

- **Usability**

This SAI category concerned elements of the website that make the website easy to use for visitors. Examples of included SAIs are: the presence of most visited pages, an internal search engine and a media library. The average combined score of the NCPs was 55%, ranging from 30% to 90% of the total points earned. Only 5 out of 36 websites contained a media library hosted on the NCP website. In contrast, 31 out of 36 websites provided an internal search engine, which drastically improves the ability of visitors to navigate the website.

The six SAI categories that focussed on the actual content of the website, and their results, are:

- **General information on cross-border healthcare**

This category focussed on the content that is available on the websites. Among other things, the NCP websites were scored on containing general information concerning the Regulation (EC) 883/2004 and Directive (EC) 24/2011 and the distinction between these legal instruments, as well as information on patient rights. The combined average scores of the NCPs was 72%, ranging from 0% to 100%. Most websites included a dedicated section for inbound patients, and general information on patients' rights regarding cross-border care. Yet, a little less than half of the websites included information on the EU Directive 24/2011 and the Regulation (EC) 883/2004, and also provided some form of comparison between these two pieces of legislation.

- **Information on healthcare providers**

A combined average score of 59% was achieved by the NCPs on in-depth information on the topic of the health system of the NCP's MS and details on healthcare providers. There was a wide variation in scores which ranged between 0% to 100%. A clear and comprehensive overview of the structure of the healthcare system in the NCPs respective countries was broadly lacking, and requires extra attention.

- **Information on patients' rights**

A combined average score of 25% was achieved for this category, which shows that in-depth information on patient rights is generally lacking on the NCP websites. The percentages range from 0% to 78%. Specific SAIs of concern are 'information on patients' rights in case of undue delay' and 'presence of information on complaint procedures in case of follow-up treatment issues', with only 2 and 4 out of 36 NCP websites containing relevant information respectively. From a more positive perspective, 21 websites included (detailed) information on mechanisms to settle disputes and 17 included information on a patient's rights in case of harm.

- **Information on prior authorisation**

In order to receive reimbursement of healthcare costs, patients should in certain circumstances request prior authorisation from their insurance provider. For this category, the NCP websites received a little less than half of the points available, with a combined average score of 48%, which ranged between 0% to 100%. A total of 26 websites included information on how to obtain reimbursement, and 24 included specific information on what treatments require prior authorisation. The websites scored poorly on the SAI concerning the availability of information on the time period required for prior authorisation requests to be dealt with.

- **Information on quality and safety standards**

In order to make an informed decision, patients require information on the national strategy and policies regarding quality and safety of healthcare. In this study, the NCPs scored poorly on whether information was provided on their website regarding quality and safety standards. The combined average score of the NCP websites was 30%, and ranged between 0% to 100%. In this category, scores on the different SAIs were broadly similar across the NCP websites. Consequently, 70% of the analysed websites did not include any (relevant) information on quality and safety standards.

- **Information on entitlement for reimbursement of costs**

The combined average score of the NCP websites on information concerning the reimbursement of costs was 25%, and ranged between 0% to 83%. A total of 19 out of 36 websites included at least some form of information on which treatments are reimbursed. However, only 4 websites (Finland, the Netherlands, Slovakia - HSCA2, and Slovenia) included specific details on which treatments are not reimbursed. Additionally, the SAIs on the time period required for reimbursement to be dealt with and information on specific reimbursement tools were among the worst scoring SAIs of the website analysis.

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.

Pseudo-patient investigation: an analysis of information provision by NCPs though email and telephone

A pseudo-patient investigation was conducted as a follow-up to the Evaluative Study on the Cross-border Healthcare Directive 2011/24/EU. The main objective of was to investigate the differences, or discrepancies, between:

- the information that was provided by NCPs in response to enquiries made by pseudo-patients; and
- the information that NCPs are expected to provide based on the provisions of the Cross-border Healthcare Directive.

In order to accomplish this, the pseudo-patient investigation was conducted in the form of a traditional pseudo-patient investigation exercise. A total of 116 pseudo-patient investigations were conducted in 29 countries. The fieldwork was conducted between 21 August 2017 to 24 November 2017.

The exercise was based on pseudo-patient scenarios, which considered three key criteria:

- the type of request (incoming vs. outgoing patient);
- the type of institution (individual practitioners vs. large establishments); and
- the type of service (private vs. public).

The Directive 2011/24/EU clearly places distinctive information requirements on NCPs, depending on their role as NCP of the MS of affiliation or NCP of the MS of treatment. As the set of information requirements differs depending on the NCP's role, information provision to both outgoing and incoming patients should be evaluated equally. Furthermore, previous studies show that information provision to incoming patients is often failing, especially with regard to information on quality and safety standards. Hence, the importance to also investigate the status quo of information provision in the NCP's role as NCP of the MS of treatment.

General description of the 4 scenarios

	Scenario 1	Scenario 2	Scenario 3	Scenario 4
Description	Physical movement of the patient across the border	Physical movement of the patient across the border	Provision of services across a border	Provision of services across a border
Enquiry	A spread of two different enquiries across these two scenarios requiring prior authorisation or not			
Localisation	Outgoing	Outgoing	Incoming	Incoming
Type of service	Purely private	Public	Purely private	Public
Service provider	Individual practitioners	Large establishments	individual practitioners	large establishments
Country coverage	EU 28 Member States + Norway (taking into account regional disparities)			

As previously mentioned, a distinction in scenarios was made based on the type of health service the pseudo-patient wishes to receive. Two scenarios illustrate an inquiry from a patient who wishes to receive treatment with a healthcare provider who works within the public system (scenario 2 and 4). Generally, this will be a public healthcare provider. However, this can also be a private healthcare provider that is contracted or affiliated with the public system and thus is also entitled to provide services covered under the social security scheme. The other two scenarios concern questions about health services provided by healthcare providers offering purely private services (scenario 1 and 3). The rationale for this distinction is the scope of applicability of Directive 2011/24/EU and the Social Security Regulations respectively. The Social Security Regulations do not apply to healthcare that is provided by a healthcare provider who is solely

authorised to provide purely private health services. In case of the latter, only Directive 2011/24/EU will apply. Directive 2011/24/EU applies to healthcare provided by both public and private healthcare providers. This distinction in scenarios was made to test if NCPs inform patients correctly on this difference in application and are able to assist patients under both legal instruments.

Two scenarios related to health services provided by individual practitioners (scenario 1 and 3). The two others concerned patients requesting information on healthcare provided in larger establishments. This distinction was made to test if NCPs are able to answer questions relating to different types of situations. As a result also the specific types of health services differ between scenarios (consultation, surgery, common operation with waiting lists, rarer interventions...). In addition, a distinction was made between health services involving an overnight hospital stay or not, as the latter will often determine whether or not prior authorisation will be required.

The scenarios covered all EU28 MSs and Norway. When contacting NCPs during this task, regional disparities across health systems in different MSs were taken into account for each scenario. This included taking into account MSs with a decentralised healthcare system and following up with the relevant authorities in each case.

During the pseudo-patient investigation, the NCPs were first contacted by email. After an incomplete response, or after two weeks without a response, the NCPs were contacted via telephone, where possible. Three NCPs only allowed for contact via email and did not provide a telephone number that could be used.

Looking at all scenarios, the majority (83%) of pseudo-patients were able to get into contact with the NCP and make enquiries. In the 2015 Evaluative Study, only two out of 12 NCPs were not reached in one of the three scenarios. 19 out of 29 NCP could be reached for the four scenarios. In 17% of the scenarios, NCPs could not be reached by the pseudo-patients, or they were unable to get a response to questions. One NCP could never be reached or pseudo-patients were never able to make inquiries in any of the four scenarios during the open field period of 7 full weeks, the exact same result having been obtained in the mystery shopping round of 2014.

In order to analyse the information provision of the NCPs, all items of the four different scenarios were taken into consideration. Each item was analysed according to whether information was provided or not. The correctness of the information was not taken into consideration. 55% of the NCPs responded to at least half of the questions in the email or telephone inquiries, on average. 24% of the NCPs was able to respond to the majority of questions, on average. This shows that there is room for improvement for some NCPs – and for NCPs to learn from each other's best practices - and suggests high information provision potential of the NCPs in the future.

Based on the feedback received from the NCPs during the bilateral exchanges, some constraints were reported explaining why communication or information provision was limited. The constraints include the request by the NCPs for personal patient information or additional documentation in order to be able to proceed with communication, which could not be provided during the pseudo-patient investigation.

Results of the NCP and patient survey

To launch the NCP survey, an e-mail was sent to the NCPs of all 28 MSs and Norway, as well as to Iceland. In case of multiple CPs per State, the RCPs were given the opportunity to participate separately. The survey was open from 17 Augustus until 9 November. We achieved a response rate of 94%. A total of 31 NCPs, representing 28 MSs, completed the survey (n = 31 NCPs). In addition, four RCPs participated separately. Two NCPs (single NCPs of different MSs) remained non-responsive, however, one of these did provide the requested information during the bilateral exchange.

The NCP survey showed that there are big organisational differences between NCPs regarding the number of NCPs, the institution hosting the NCP, the NCP funding and staff, as well as the organisational handling of incoming and outgoing patients. Overall, NCPs indicated experiencing significant improvements since the implementation of Directive 2011/24/EU. However, they also indicate that 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.

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.

A survey for patients who have made use of the possibility to receive healthcare in another MS, was open from 17 August to 18 December 2017. 48 patient organisations were contacted, covering (national coalition and specialised) organisations in all 28 EU MSs and Norway. These patient organisations were asked to assist in sending an e-mail and the URL of the online survey to patients with recent experience with cross border healthcare.

In total, the responses of 11 patients were included in the data analysis, corresponding to more than 50 planned cross-border healthcare events (ranging from 1 to 20 events per patient; mean of 6 events per patient). As a result, the sample size was too small to draw any valid and representative quantitative conclusions. Nevertheless, the patient survey yielded relevant qualitative information based on the comments provided by patients throughout the survey. These comments were used to validate quantitative findings of the study.

The patient survey showed that patients' awareness of their rights and possibilities to access health services abroad and on the existence of NCPs is still low. As with the website analysis, information for incoming patients – in English – regarding patients' rights and quality and safety standards was mentioned to be lacking. For outgoing patients the study revealed shortcoming in information provision concerning undue delay and waiting times.

The surveys amongst NCPs and patients confirmed the notion that information provision for inbound patients is in general less complete than for outbound patients. Another important finding of the study was that a high number of NCPs still experience difficulties in communicating on the differences between Directive 2011/24/EU and the Social Security Regulations, while this is potentially important information for patients to obtain when seeking cross-border healthcare.

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.

Toolbox and guiding principles

Central in developing the Guiding Principles and the toolbox, was the goal to ensure information provision in accordance with the legal requirements placed on NCPs and healthcare providers by Directive 2011/24/EU as well as to ensure equal free movement of all patients. As long as this goal is achieved, NCPs are free to organise themselves according to their own insights and wishes. All instruments were validated by the NCPs themselves, during bilateral exchange and the NCP workshop on 8 March 2018. In addition, the policy proposal instruments were developed based on already established NCP practice, in all EU Member States and Norway and the Guiding Principles were shared with the NCPs for a final round of consultation in June 2018.

Another important finding of the study was that a high number of NCPs still experience difficulties in communicating the inter-linkages between Directive 2011/24/EU and the Social Security Regulations, while this is very important information for patients when seeking cross-border healthcare. The study developed some practical documents, including a set of decision trees, to facilitate NCPs in the provision of information on both the Directive 2011/24/EU and the Social Security Regulations.

The Guiding Principles aim to contribute to an equitable access to cross-border healthcare in different ways. NCPs are encouraged to make sure that the information they provide is easily accessible and understandable for all patients, regardless of their health literacy, sensory capacities or language. NCPs should provide information that is relevant to different types of patients, such as outbound and inbound patients, patients with disabilities, patients with rare diseases, patients with limited funds, and patients who reside outside the MS of social security insurance. In general, the study output aims to contribute to a more uniform and equal practice of NCP service. Where great differences are shown in NCP practice and information provision, the Guiding Principles and toolbox aim to eliminate these differences and to establish the same, high level of service in all MSs. In the same way, the instruments aim to establish transparent and equal procedures for accessing health services in all countries.

Bilateral exchange and NCP workshop

This study found that NCPs are performing fairly well in general, but that there is still ample room for improvement on specific topics, and that there were large differences between NCPs in the current level of information provision. For both the different categories included in the website analysis and the different scenarios included in the pseudo-patient investigation, NCPs who performed very well were identified. This shows that there is great potential for NCPs learning from each other and helping each other improve their information provision to patients in the context of cross-border healthcare.

Core finding 5:

Overall, there is still ample room for improvement in NCP practices. 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.

To validate the findings of this study, as well as the toolbox and Guiding Principles that were developed to assist NCPs in further improving their information provision, NCPs were consulted. For this purpose, bilateral exchange with NCPs took place, where they were provided with their individual results and with the general toolbox and Guiding Principles. The aim was to gain as much feedback from NCPs as possible, in order to validate the added value for NCP practice of this study and the provided toolbox. Based on NCPs' comments and recommendations, the project team made revisions to the different end products of the project. NCP consultation and validation was also established by organising an NCP workshop in Brussels on 8 March 2018, which was followed by a final round of email consultation regarding the adjusted Guiding Principles.

Methodological and practical contributions of this study

Overall, this study contributes to the literature on information provision for patients in cross-border healthcare by providing a systematic analysis of the status quo, based on a triangulation of results from different data collection methods: literature review, website analysis, pseudo-patient investigation, and two surveys. In addition, this study goes beyond the existing literature by not only mapping the status quo, but also providing a toolbox and training material for the NCPs to improve the quality of information provision to patients in cross-border healthcare.

This study has made specific methodological contributions by refining research protocols for the website analysis and pseudo-patient investigation. This was done both *ex-ante*, based on experiences in other studies, as well as *ex-post*, based on the experiences during the current study. These refined research protocols enable future studies to be conducted in the same way as this study, thereby allowing for the collection of information on the same variables over time. In addition, the refined research protocols provide NCPs with templates for self-assessment.

Another important methodological contribution of this study is the continuous communication and collaboration with the NCPs via multiple channels: presentations to keep NCPs updated on the (progress of) the study, bilateral exchanges (via email and telephone) to enable enquiring about, and making comments on, individual results, as well as providing feedback on the toolbox and training materials, and a workshop to jointly discuss the results, recommendations, and way forward.

Some of the practical contributions this study makes to improving information provision to patients by NCPs are the Guiding Principles, the toolbox and training material for NCPs. These can be considered as an important policy development in the field of information provision in cross-

border healthcare, as they aim to establish a more uniform and high level NCP practice, where clear and accurate information provision to patients is central.

Central in developing the Guiding Principles and the toolbox was the goal to ensure information provision in accordance with the legal requirements placed on NCPs and healthcare providers by Directive 2011/24/EU, as well as to ensure access to quality information for all patients. As long as this goal is achieved, NCPs are free to organise themselves according to their own insights and wishes. All instruments have been validated by the NCPs themselves, during bilateral exchange and the NCP workshop on 8 March 2018. In addition, the policy proposal instruments were developed based on already established NCP practice, in all EU MSs and Norway.¹

The Guiding Principles aim to contribute to an equitable access to cross-border healthcare in different ways. NCPs are encouraged to make sure that the information they provide is easily accessible and understandable for all patients, regardless of their health literacy, sensory capacities or language. NCPs should provide information that is relevant to different types of patients, such as outgoing and incoming patients, patients with disabilities, patients with rare diseases, patients with limited funds, and patients who reside outside the MS of social security insurance. In general, the study output aims to contribute to a more uniform and equal practice of NCP service. Whilst great differences exist in NCP practice and information provision, the Guiding Principles and toolbox aim to eliminate these differences and to establish the same, high level of service in all MSs. In the same way, the instruments aim to establish transparent and equal procedures for accessing health services in all countries.

Methodological limitations

While the study provides multiple practical and methodological contributions, it is also important to note that the approach used in the study suffers from some limitations.

Website analysis:

The website analysis was conducted once per NCP website, in July 2017. As also discussed during the workshop on 8 March 2018, many NCPs are continuously improving their website and its content. Consequently, the results should not be considered a final judgement on the information provision on NCP websites, but should rather be seen as indicative of the amount of information available for patients at the time of the study. It thus provides a valuable snapshot of the status quo, including elements that warrant improvement as well as best practices, thereby enabling NCPs to learn from each other.

Each NCP website was analysed by only one researcher. Therefore, it is possible that some information was overlooked. However, the research protocol was designed to reduce this risk of omission or oversight as much as possible; the researchers analysed each website thoroughly in a structured manner using a standard form. It is our belief that if information was overlooked by one of our dedicated and trained researchers, it is unlikely that this information is easily found by the average patient.

Pseudo-patient investigation:

Mystery shopping exercises have a limited sample size. As a result, this research method provides qualitative rather than quantitative insights. In practice, comparisons between NCPs should be made with caution. Our findings based on the four specified scenarios do not allow for generalisations across all cross-border patients and scenarios. Nevertheless, the pseudo-patient investigation provides valuable insights into the potential obstacles patients encounter in their search for information regarding cross-border healthcare.

In this exercise, email contact and telephone contact (if the NCP was reached) was used as a mode of contact. Personal, face-to-face contact was not evaluated. It is important to highlight that this could be presented as an option by the NCPs. However, in practice patients seeking information on cross-border healthcare will generally not do so by visiting the physical NCP

¹ Only detailed information on the NCP practice of one Member State was missing. Information on this Member State was collected in WP2 and WP3. In total two Member States did not reply on the NCP survey, however, one of them provided the information questioned in the survey during the bilateral exchange by completing the document of its country specific description.

address (especially true for incoming patients). Additionally, not all NCPs provide a physical address as a contact option. Hence, this is merely a minor limitation of the study.

Finally, a mystery shopper or pseudo-patient is subject to their own preferences and habits. This leaves some scope for personal bias to influence results. This potential of bias was minimised by the extensive briefing of the mystery shoppers and the use of strong assessment tools.

Patient survey:

Due to the limited sample size ($n=11$), it was not possible to come to any valid quantitative conclusions on patients' experiences. Due to the limited sample size robust quantitative conclusions and generalisations across all patients in planned cross-border healthcare cannot be made. Rather, the results of the patient survey should be considered as valuable qualitative indications of user experiences. Due to data protection considerations, no personal data on patients were collected, hindering the possibility to ask follow-up questions or clarifications. The patients' experiences retrieved through the survey are indirectly feeding the results and output of this study, i.e. based on findings of previous studies and published reports and recommendations of the European Patients' Forum (EPF).

Due to the combination of utilised research methodologies (desk research, website analysis, pseudo-patient investigation, and online surveys), this study is sufficiently robust and provides strong evidence on the level of information provision by NCPs, despite the mentioned limitations.

Recommendations for future research

In general, in order to evaluate the progress of information provision in practice, it would be valuable to repeat the current study at different points in time. Researchers would be encouraged to draw and build on the same research protocols that were updated and specified in the current study. In this way, valuable insight into the evolution of information provision by NCPs could be obtained.

Further research on the specific needs of certain categories of patients in cross-border healthcare - taking into account amongst others disability, income and education level and gender - would also provide the European Commission, MSs, NCPs and other stakeholders with valuable information.

In order to ensure that the proposed Guiding Principles, toolbox and training materials are indeed of added value for NCP practice and a contribution to enhanced information provision, the uptake of the instruments and their functioning in practice should be evaluated at recurrent intervals. In addition, as the content of information provision and the practice of NCPs will be subject to legislative changes and changes in other fields (such as eHealth, data protection, EU policy on patient safety, etc.), the proposed instruments and material would need to be evaluated and improved on a regular basis.

1. Introduction

In this Final Report, we present our methodology and the results for the ‘*Study on the cross-border health services: enhancing information provision to patients*’ (RfS Chafea/2016/27 – Service contract 20167401, for the implementation of Framework Contract N° EAHC/2013/Health/01 – lot 2 Health economics). This study is conducted by the Consortium of Ecorys Nederland B.V. (Ecorys) and subcontractors KU Leuven (Catholic University of Leuven) and GfK Belgium.

1.1. Background and objectives of the study

In March 2011, Directive 2011/24/EU on the application of patients’ rights in cross-border healthcare (hereafter: the Directive) was adopted. It aims to “*establish rules for facilitating access to safe and high-quality cross-border healthcare in the Union and to ensure patient mobility in accordance with the principles established by the Court of Justice and to promote cooperation on healthcare between Member States, whilst fully respecting the responsibilities of the MSs for the definition of social security benefits relating to health and for the organisation and delivery of healthcare and medical care and social security benefits, in particular for sickness.*”²

The Directive clarifies the rights of patients to seek reimbursement for healthcare received in another Member State (MS).³ Decisions about the healthcare basket to which citizens are entitled, as well as the mechanisms used to finance and deliver that healthcare, must be made at the national level.⁴

Appropriate information on all essential aspects of cross-border healthcare is necessary in order to enable patients to exercise their rights to cross-border healthcare in practice.⁵ Patients need to seek information, understand it, and use it to coordinate their care and travel in another MS.

Earlier studies have shown that information provision to patients can be further improved. Against this background, the overall objective of this study is to propose solutions for improving the status quo of information provision to patients. To that end, the study aims to:

- Identify the legal information requirements, as well as the needs of patients, for the National Contact Points (NCPs) (of the MS of treatment and of the MS of affiliation) and for healthcare providers who provide cross-border services;
- Study and assess the status quo of current information provision by NCPs, as well as the degree of evolution since previous studies undertook similar performance measurement exercises.

Based on these findings, we formulate recommendations that aim to improve information provision to patients and to support information-seeking behaviour of patients in the context of cross-border healthcare. We aim not only to propose options and solutions, but we also aim to *share* these options and solutions with, and present these to all NCPs, in the form of a toolbox and training material. This will ultimately improve information provision to patients seeking cross-border healthcare. In addition, we aim to encourage collaboration and increase sharing of good practices between NCPs of different MSs.

The study comprises various methodologies, including desk research, website analysis, and pseudo-patient investigation. More details on the approach and methodologies are presented in Chapter 3.

² Directive 2011/24/EU, recital 10.

³ Commission Report on the operation of Directive 2011/24/EU on the application of patients’ rights in cross-border healthcare, 4 September 2015, COM(2015) 421 final, p. 2.

⁴ Directive 2011/24/EU, recital 5.

⁵ Directive 2011/24/EU, recital 48.

1.2. Scope of the study

The study focuses on the way the NCPs deal with the information requirements of the Directive 2011/24/EU.

Both types of NCPs are analysed in detail, i.e. the NCPs of the MS of affiliation and the NCPs of the MS of treatment. Attention was given to the obligations that fall on healthcare providers.

The study makes a distinction as to whether the patient mobility is related to unplanned healthcare or to planned healthcare. The study also looked at patients looking for different types of care, e.g.:

- Ambulatory care;
- Care delivered in public or private hospitals or clinics;
- Telemedicine (i.e. health services provided remotely);
- Preventive medicine.

In reviewing the information requirements and evaluating the current information given by NCPs and healthcare providers (HCPs), specific attention is paid to the way information is provided on the Directive as well as on the Social Security Regulations. This is particularly important for NCPs of the MS of affiliation.

1.3. Reading guide

In this Report we present:

- (In Chapter 2) Information on the context of information provision to patients in cross-border healthcare, with information on:
 - the main requirements regarding information provision by National Contact Points (NCPs) as outlined in Directive 2011/24/EU on the application of patients' rights in cross-border healthcare (hereafter: the Directive);
 - the main differences between the Directive and the Social Security Regulations; and
 - findings of previous studies.
- (In Chapter 3) Our overall approach and methodologies in each Work Package (WP) of this study;
- (In Chapter 4-7) Our results for the:
 - Review of literature and legal texts (WP1 – Chapter 4);
 - NCP Website analysis (WP2 – Chapter 5);
 - Pseudo-patient investigation (WP3 – Chapter 6);
 - Online surveys and other information centres (WP4 – Chapter 7);
 - Resource burden estimation (WP4 – Chapter 8);
 - Equality and proportionality analysis (WP4 – Chapter 9);
 - Capacity building: Developing a toolbox and training material (WP4 – Chapter 10).
- (In Chapter 11) The discussion, containing our overall findings, the methodological contributions of this study, the main limitations, and recommendations for future research.

2. Information provision to patients in cross-border healthcare

2.1. Requirements in the Directive

The Directive asks MSs to provide information on cross-border healthcare to patients through the establishment of NCPs. An overview of the NCPs of all 28 EU MSs, Iceland, Lichtenstein and Norway can be found on the website of the European Commission.⁶

According to the Directive, NCPs should be established in an efficient and transparent way and should be able to consult with patient organisations, healthcare insurers and healthcare providers. The NCPs should have appropriate facilities to provide information on the main aspects of cross-border healthcare.⁷ NCPs must facilitate the exchange of information regarding healthcare providers and cooperate closely with each other and with the European Commission.⁸

The Directive outlines requirements for information provision to patients, by:

- The NCP of the MS of treatment;
- The NCP of the MS of affiliation;
- Healthcare providers.

Information provided by National Contact Points

The Directive asks MSs to provide patients with information through NCPs of the MS of treatment and NCPs of the MS of affiliation.

The information provided by the NCP must be easily accessible; it must be made available electronically and in formats accessible to people with disabilities, if appropriate.⁹

According to Art. 10 of the Directive 2011/24/EU, MSs must provide mutual assistance to each other, especially between their NCPs. Art. 10 states that this includes mutual assistance to clarify the content of invoices and cooperation on provisions on supervision of healthcare providers. In addition, the exchange of information, especially between NCPs, should be increased. NCPs are expected to provide patients with contact details of NCPs in other MSs, if requested.¹⁰

Information by the National Contact Point of the MS of treatment

According to art. 4.2(a) of the Directive, the MS of treatment shall ensure that upon request patients receive relevant information from the NCP on:

- Standards and guidelines on quality and safety laid down by the MS of treatment, including provisions on supervision and assessment of healthcare providers;
- Which healthcare providers are subject to these standards and guidelines; and
- The accessibility of hospitals for persons with disabilities.

In addition, according to art. 6(3), the NCP in the MS of treatment must provide patients with information on:

- A specific provider's right to provide services or any restrictions on its practice; and
- Patients' rights, complaints procedures and mechanisms for seeking remedies, according to the legislation of that MS, as well as the legal and administrative options available to settle disputes, including in the event of harm arising from cross-border healthcare.

⁶ http://ec.europa.eu/health/cross_border_care/policy_en.

⁷ Directive 2011/24/EU, recital 49.

⁸ Directive 2011/24/EU, art. 6(2).

⁹ Directive 2011/24/EU, art. 6(5).

¹⁰ Directive 2011/24/EU, art. 6(2), *in fine*.

Information by the National Contact Point of the MS of affiliation

According to art. 6(4), the NCP in the MS of affiliation shall provide patients and health professionals with information on the rights of patients and entitlements related to receiving cross-border healthcare in that MS. In particular, information must be provided on:

- the terms and conditions for reimbursement of costs, in accordance with art. 7 (6); and
- procedures for accessing and determining those entitlements and for appeal and redress if patients consider that their rights have not been respected, in accordance with art. 9.

Information by healthcare providers

According to art. 4.2(b) of the Directive, the MS of treatment shall ensure that healthcare providers deliver relevant information to individual patients. This information includes the availability of treatment options, the quality and safety of the healthcare they provide, their authorisation or registration status, and their insurance cover or other means of personal or collective protection with regard to professional liability. Furthermore, clear information on prices should be available and invoices should be comprehensible.

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

When NCPs (or healthcare professionals) inform patients seeking information on cross-border care, it is essential that a clear distinction is made between:

- the rights which patients have by virtue of the Directive; and
- rights arising from Regulation (EC) No. 883/2004 on the coordination of social security systems, as well as Regulation (EC) No. 987/2009 laying down the procedures for implementing Regulation (EC) No. 883/2004 (the so-called Social Security Regulations).

Before Directive 2011/24/EU entered into force, Regulation (EC) No. 883/2004 on the coordination of social security systems already regulated the reimbursement of healthcare costs that might become necessary during a temporary stay in another MS (if the conditions of Regulation (EC) No. 883/2004 are met). Regulation (EC) No. 883/2004 and Regulation (EC) No. 987/2009 are complex and take into account many different situations of patients:

- Residing in a MS other than the competent MS (see art. 17);
- Staying in the competent MS when residing in another MS or when the patient is a member of the family of a frontier worker (art. 18);
- Stays outside the competent MS (short-term stay where care may become necessary) (art. 19);
- Wants to travel with the purpose of receiving benefits in kind (art. 20);
- Is a pensioner who resides in another MS (art. 22); and
- Is a pensioner who stays in a MS other than the MS in which they reside (art. 27).

Some MSs have difficulties distinguishing between the Directive and the Social Security Regulations, particularly for reimbursement claims of healthcare costs that are not subject to prior authorisation.¹¹

Any patient who requests an authorisation to receive treatment (appropriate for their condition) in another MS, should be granted this authorisation under the conditions provided for in the Regulations, if the conditions of the Regulations are met. This is the case when the treatment in question is among the benefits provided for by the legislation in the MS where the patient resides, and when the patient cannot be given such treatment within a time limit that is medically justifiable, taking account of their current state of health and the probable course of the condition. However, if a patient instead explicitly requests to seek treatment under the terms of the Directive, the benefits, which apply to reimbursement, should be limited to those, which apply

¹¹ Commission Report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, p. 14).

under the Directive. Where the patient is entitled to cross-border healthcare under both the Directive and Regulation (EC) No. 883/2004, and the application of the Regulation is more advantageous to the patient, the patient's attention should be drawn to this by the MS of affiliation. Sometimes, patients have more beneficial rights under the Regulation. This is because the Regulation provides that reimbursement of costs will be done according to the legislation obtained in the MS of treatment, instead of according to the legislation of the MS of affiliation. Moreover, the Regulation may lead to a situation whereby the insured person does not have to pay the medical costs upfront.¹² Once again, it is important to note that the Directive does not have an effect on insured person's rights under the Social Security Regulations. Consequently, the Directive does not deprive patients of the more beneficial rights guaranteed by the Regulation on the coordination of social security systems when the conditions are met.¹³

In conclusion, even if a patient requests authorisation to receive treatment appropriate to their condition in another MS, they should always be confident that the authorisation under the conditions of the Regulations (EC) No. 883 and 987 will be given if they meet the conditions of these Regulations. Therefore, the NCP of the affiliation MS should inform patients on the differences between being treated abroad under the Regulation (EC) No. 883 or under the Directive, especially with regard to the administrative differences.

2.3. Findings of previous studies

The total number of information requests that NCPs yearly receive differs largely between MSs, although numbers overall are generally low. The recent Member State data report on cross-border patient healthcare following Directive 2011/24/EU shows that for the year 2016 most MSs only received less than 1,000 requests (except for the outliers Poland, Lithuania and Austria, with 16,139, 15,052 and 9,826 requests respectively).¹⁴ Most requests were written or by phone, although in some countries requests were also made in person (e.g. Denmark, Greece, and Poland). These low numbers might be an indication of the lack of awareness among patients of the existence of the NCPs.¹⁵ According to the Special Eurobarometer 425, on Patients' rights in cross-border healthcare in the EU, only one out of every ten respondents had heard of the NCPs for cross-border healthcare.¹⁶ Instead of contacting NCPs, patients might request information from healthcare providers or health insurers directly. A study undertaken by Panteli and colleagues showed that German patients who received health services abroad most often searched for information on reimbursement, entitlement to services and cost-saving.¹⁷

Previous studies show that the NCPs differ with respect to the quality and type of information they provide, as well as how they operate.^{18,19} Earlier studies have also shown that the information provision on the websites of NCPs can be improved. For example, Verra and colleagues studied the experiences of medical travellers in 2014 and concluded that *"Clear information on the necessity of this personal transfer, and clarification on reimbursement options and the authorisation procedure should be provided by NCPs and third-party payers"*.²⁰ Santorro and colleagues recommended harmonising information provided by NCP websites and assessing how

¹² Directive 2011/24/EU, recital 46.

¹³ Directive 2011/24/EU, recital 31.

¹⁴ Member State Data on cross-border patient healthcare following Directive 2011/24/EU: Year 2016 (draft report) https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_msdata_en.pdf.

¹⁵ Evaluative Study on the cross-border healthcare Directive (2011/24/EU), 2015, http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.

¹⁶ European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European union, may 2015, p. 18.

¹⁷ Panteli, D., Wagner, C., Verheyen, F., et al., 'Know before you go': information-seeking behaviour of German patients receiving health services abroad in light of the provisions of Directive 2011/24/EU, J Health Serv Res Policy, 2015;20(3):154-161.

¹⁸ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, 2015, available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf.

¹⁹ Evaluative Study on the cross-border healthcare Directive (2011/24/EU), 2015, http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.

²⁰ Verra, S.E., Kroeze, R. and Ruggeri, K., Facilitating safe and successful cross-border healthcare in the European Union, Health Policy, 2016;120(6):718-27).

this information would be best presented.²¹ Collaboration between a range of stakeholders - e.g. patient organisations, health professionals, and third-party payers – was recommended as well.²²

The European Patients' Forum (EPF) also appealed for better information on all entitlements regarding reimbursement, including where applicable the option to have certain extra costs reimbursed - e.g. those relating to disabilities or travel - or the option to benefit from a prior notification procedure in order to reduce the patients' burden of having to pay upfront.²³ The option to install a prior notification procedure is provided under art. 9(5) of the Directive, that defines the procedure of a voluntary system whereby, in return for such notification, the patient receives a written confirmation of the estimated amount of reimbursement, taking into account the patient's specific clinical case.

²¹ Santorro, A., Silenzi, A., Ricciardi, W., et al., Obtaining health care in another European Union MS: how easy is it to find relevant information? *European Journal of Public Health* 2014;25(1):29-31.

²² Panteli, D., Wagner, C., Verheyen, F., et al., 'Know before you go': information-seeking behaviour of German patients receiving health services abroad in light of the provisions of Directive 2011/24/EU, *J Health Serv Res Policy*, 2015;20(3):154-161.

²³ Directive on patients' rights in cross-border healthcare, EPF Position Statement, April 2016.

3. Approach and methodology

The overall objective of the study is to propose solutions for improving the status quo of information provision to patients. This objective is reflected in five different, but interrelated, WPs, which determined the overall structure of our approach:

- Inception phase (WP1);
- Website analysis (WP2);
- Pseudo-patient investigation (WP3);
- Developing a toolbox and training material (WP4); and
- Training in good NCP practices (WP5).

Annex C (provided in separate document) presents the overarching research protocol and illustrates how the different WPs are linked to each other.

With respect to the geographical scope: WP2 and WP3 include all 28 MSs and Norway. The online survey (part of WP4) was sent to the NCPs of all 28 MSs, The NCP of Norway, and the NCP of Iceland. WP5 includes the dissemination of individual and aggregated results among all NCPs of the 28 MSs and Norway. In addition to this communication and capacity building exercise, all NCPs are invited to the workshop on March 8th, 2018.

In WP1, the inception phase, we identified the needs for the development of the toolbox. In addition, thematic indicators for good NCP service provision were explored and a first list was drafted. Hereafter, the websites of the NCPs (WP2) as well as the functioning of the NCPs (WP3) were analysed. WP4 built on the commitments taken in WP1. In addition, findings of WP2 and WP3 were integrated and analysed further, in order to develop an appropriate training set for good information provision to patients. In WP5, the results of the previous WPs were validated with the NCPs, and improved where necessary based on the feedback. Finally, the developed training material was delivered to the NCPs via a workshop on March 8th 2018. The final results of the study will be presented in the Expert Group on Cross-border Healthcare on November 15th 2018. The methodology used in each of the WPs is described in more detail in the coming paragraphs.

3.1. WP1: Inception phase

The overall aim of WP1 was twofold:

- To further concretise the methodology of the study; and
- To outline the basis for WP2, WP3 and WP4.

WP1 consisted of the following activities:

- Analysis of the legal framework at EU level for cross-border healthcare, i.e. (1) the Social Security Regulations (EC) No 883/2004 and 987/2009 and (2) Directive 2011/24/EU;
- Review of previous findings and literature on NCPs and information provision to patients in cross-border health services; and
- First draft of guiding principles and thematic indicators for good NCP service provision.

3.1.1. Analysis of the relevant legal framework at EU-level

The rules that follow from Directive 2011/24/EU and from the Social Security Regulations - i.e. Regulation (EC) No 883/2004 and the Regulation No. 987/2009 - and relevant EU case law were analysed in detail, taking into account the many different situations that may occur (i.e. whether one deals with unplanned care or planned care, whether one is a worker, a family member of an insured person, a frontier worker, a pensioner, etc.).

3.1.2. Review of previous findings and literature on NCPs and information provision to patients

In the inception phase, pre-existing data on cross-border healthcare and NCPs, as well as on information provision to patients accessing treatment abroad were analysed. The findings emerged from past reports and available literature served as a basis for framing the methodology and key deliverables of the current study. This way, current problems and issues were explored and identified that necessitates the development of a policy intended to enhance information provision to patients (e.g. the development of Guiding Principles and Indicators).

Data emerged from public reports on cross-border healthcare in the EU and on the practice of NCPs, which were analysed.²⁴ Only data from 2013 and onwards were included, as the transposition of Directive 2011/24/EU was due by the Member States by 25 October 2013. In addition, reports of the European Patients Forum (EPF) that identify the most important issues in cross-border health services from a patient perspective were analysed.²⁵

A literature search was conducted, focussing on information provision by NCPs (both of the MS of affiliation and of the MS of treatment) to patients in cross-border health services, under the Directive 2011/24/EU and the Social Security Regulations, i.e. Regulation (EC) No 883/2004 and the Regulation (EC) No. 987/2009. The overall aim of the literature review was to list all the information items that have to be provided to patients, to gain insight into the current practice of information provision, to analyse the known shortcomings in information provision and finally, to explore possible interventions proposed in the literature.

For this purpose, health and legal databases (such as PubMed/Medline/Embase, LexisNexis) were searched for relevant literature regarding information provision in the context of cross-border healthcare. Next to scientific literature, we also searched for relevant grey literature. Sources that were used in this included Google Scholar, websites of different Directorate Generals of the European Commission (including DG SANTE), European patient organisations, European organisations of health insurers, and healthcare providers. In addition, we used cross-references from selected documents that were considered relevant.

The literature review included studies in English, Dutch, and French from the 28 EU MSs. The review focussed on studies from 2010 and onwards.

The social costs of non-provision of timely and accurate information to citizens was included as a topic in the literature search as well. In addition, we paid specific attention to indications that certain patient groups (based on gender, income level, level of education, health status *et cetera*) find it more difficult to find the relevant information than others. Moreover, an equality and proportionality analysis has been conducted as part of WP4, the results of which can be found in chapter 7.4.

3.1.3. Guiding principles and thematic (RACER) indicators

It seems that patients are often faced with 'a labyrinth of confusing, sometimes insufficient and sometimes too detailed information' with regard to cross-border healthcare.²⁶ Studies have identified NCPs as having a crucial role in the success or failure of the requirements laid out in the Directive, recommending that NCPs should provide 'checklists' for individuals considering planned care abroad, and more detailed individual timelines of procedures, costs and reimbursement rates.²⁷ The Evaluative Study has shown that, according to patient groups, a

²⁴ E.g. European Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, 2015, p.20; European Commission, Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, p. 37 ; G. Zucca, A. De Negri, A. Berény, A. Kaszap, K.A. Stroetmann, P. Varnai, Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, p. 179; ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, p. 55.

²⁵ See amongst others: Summary Report: main conclusions and recommendations arising from EPF's series of Regional Conferences 2013-14, 2015, p.15 ; EPF, Recommendations for National Contact Points: arising from the EPF series of Regional Conferences 2013-14, 2015, p.7; Directive on Patients' Rights in Cross-border Healthcare: EPF Position Statement, 2016, pp. 22.

²⁶ Commission Report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, p. 8.

²⁷ Commission Report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, p. 8.

significant proportion of patients refrain from using cross-border healthcare as a result of poor information on reimbursement and prior authorisation.²⁸

In order to guarantee good NCP information provision, indicators that are Relevant, Accepted, Credible, Easy to monitor and Robust against manipulation (RACER) must be developed for use by NCPs.²⁹ While we aim to develop guiding principles and indicators that take into account or leave room for the existing differences between NCPs and how they are organised, the basis of the principles and indicators will be the legal requirements NCPs and MSs have to meet. Central is the goal of NCPs providing information to patients in accordance with the legal requirements: as long as that goal is achieved, MSs are free to organise their NCPs according to their own insights and wishes.

Therefore a two-way approach was applied, consisting of both upstream and downstream guiding principles, guidelines and corresponding RACER indicators. Firstly, general guiding principles were elaborated to ensure good NCP practice and information provision in accordance with the legal requirements imposed by Directive 2011/24/EU. Secondly, a set of more technical guidelines were developed. These guidelines consist of quantitative benchmarks, or norms that can be used as measuring instrument to check whether NCPs comply with their obligations arising from their legal requirements. The same applies for the corresponding RACER indicators. This upstream version of the guiding principles, guidelines and indicators was subject to consultation with NCPs. In WP5, a set of downstream guiding principles, guidelines and indicators was established after consultation with the NCPs, which lead to adjustments to the guiding principles and guidelines.

3.1.4. Input for other Work Packages

Based on the results of WP1, the methodology for the other WPs was completed as follows:

- The list of items that were assessed in the website analysis (WP2) was updated;
- Input on the scenarios used in the pseudo-patient investigation exercise (WP3) was provided;
- An outline of the toolbox (WP4) and training material (WP5) was developed.

The results of WP1 are presented in Chapter 4 of this Final Report.

3.2. WP2: Website analysis

WP2 focussed on the evaluation of the information provision to patients through the NCPs' websites and resulted in recommendations for improvement of this form of information provision. The findings were used in WP4 in developing the toolbox and training material. In addition, the findings were distributed to and validated by all NCPs in WP5.

This WP was divided into three activities. First, we analysed the individual websites of the NCPs. Second, we conducted a comparative analysis of the aggregated results, using stars and spider diagrams, and we formulated recommendations for improvement. Finally, we updated the research protocol for the website analysis (see also Annex D, provided in separate document).

3.2.1. Individual website analysis

The individual website analysis included 36 NCP websites, as Sweden, Luxembourg and Slovakia had multiple websites with information on cross-border healthcare and the UK was divided into: England, Scotland, Wales, Northern Ireland, and Gibraltar. An overview of the URLs of the NCPs used in the website analysis is provided in Annex K (provided in separate document).

²⁸ Evaluative Study on the cross-border healthcare Directive (2011/24/EU), 2015, http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.

²⁹ http://ec.europa.eu/smart-regulation/guidelines/tool_35_en.htm.

A brief review of all the NCP websites on 23 May 2017 revealed that all websites were available in English, except for the websites of Austria, Portugal and one of the websites of Luxembourg; these websites were only available in their national languages.

Refining the methodology used in the Evaluative Study

Our methodology for the website analysis was based on the Evaluative Study in which 48 Specific Analytical Items (SAI) were developed to structure the website analysis (see Annex D, provided in separate document).³⁰ According to the Evaluative Study, the purpose of these SAIs was to *“analyse the website design, its functionalities, its ease of access, and as well as to gauge whether a citizen would be able to find the information required under the Directive and what is necessary to access cross-border healthcare services”*.

Prior to starting the website analysis for all 36 websites, we conducted a pilot in May 2017, with a twofold goal:

- To ensure the researchers involved in the website analysis conduct the analysis in a similar manner and interpret the SAIs similarly;
- To identify opportunities for improvement of the methodology, keeping in mind the results from WP1.

Two researchers analysed three NCP websites for this pilot, using the SAIs from the Evaluative Study. The researchers involved in the pilot also performed most of the individual website analyses.

Based on the pilot results, the analysis of the legal texts (WP1), the literature review (WP1) and a review of studies on quality assessment of websites aimed at patients, we proposed a refined and updated methodology for the website analysis.

3.2.2. Comparative analysis of the aggregated results

Based on the results of the individual website analysis, we created aggregated results, showing the overall performance of the websites per SAI category. Here, we also used the methodology of the Evaluative Study as a basis and updated this where necessary.

The aggregated results – results per SAI category - are represented in this report using stars. To optimise the uptake of the tools and training materials that were developed as part of this study, it is important that NCPs are engaged in the study and open to its findings and recommendations. We have therefore changed the presentation of the aggregated results from traffic lights – as used in the Evaluative Study - to stars, as a more neutral and encouraging manner of presenting the overall results of the website analysis.

Table 3.1 Aggregated results per SAI category presented using stars

MS	Technical elements	Accessibility	Usability	General information	Healthcare providers	Patients' rights
Country X	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
Country Y	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
Etc.						

For each of the SAI categories (Technical elements, Accessibility, Usability, General Information, Healthcare Providers, Patients' Rights, Prior authorisation, Quality and safety standards, Entitlement for reimbursement of costs), the NCPs may receive a maximum of 4 stars. The SAI category scores were calculated by adding the individual SAI scores and dividing the total by the number of SAIs in that category. These scores were tracked on a scorecard, and the variation in scores were used to calculate quartiles. Hence, NCPs in the lowest quartile received a 1 star score, and NCPs in the highest quartile received a 4 star score.

³⁰ Evaluative Study on the cross-border healthcare Directive (2011/24/EU), 2015, http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.

It is important to note here that this methodology means that the stars awarded to NCP websites are *relative* to how other websites performed.

It should further be noted that the stars received by an NCP website were determined by the availability of information on the website and not by the quality of the information or accuracy of the content.

Evolution of the NCP websites

As a second part of this activity, we assessed the evolution of the NCP websites. We compared our findings with the findings of the following three previous studies that assessed the quality and quantity of information provided on the NCP websites:

- Activity Report: Implementation of National Contact Points for cross-border healthcare in EU MSs: a comparative analysis using websites and short interviews;³¹
- Obtaining healthcare in another European Union MS: how easy is it to find relevant information? by Santorro *et al.* The authors searched for the availability of information on the NCP websites, between 24 February 2014 and 7 March 2014 (22 websites of 18 MS);³² and
- The findings of the Evaluative Study of March 2015. Websites were analysed and assessed between 6 October 2014 to 6 November 2014.

As our methodology was primarily based on the methodology that was used in the Evaluative Study – and not on the methodology by Santorro *et al.* – results could be more easily compared to the Evaluative Study. For example, Santorro *et al.* did not assess how easily the NCP website could be found or whether an email address was provided on the websites.

It should be noted that with our changes to the methodology, comparing the aggregated results with the aggregated results from the Evaluative Study was less straightforward. However, as the individual website analysis was done on the SAI level, and not on the SAI category level, comparison of the results on SAI level was still possible. Therefore, we compared the performance of the NCP websites over time on individual SAI level and, building on that analysis, identified overarching themes in the evolution of the NCP websites.

We believe that the increased clarity and insight which the new categories offer, results in the website analysis being more user-friendly and accessible for the NCPs. This contributes to the up-take of the study results and recommendations by the NCPs. In addition, by using SAI categories based on recent literature and investing in a transparent and up-to-date methodology, this study is more easily comparable to other studies on either information provision regarding cross-border healthcare or on quality assessment of websites aimed at patients.

Formulating recommendations

A final part of this activity was to formulate recommendations for improvement, based on the findings of the analysis. These recommendations served as input for the toolbox and training material that are being developed in WP4.

3.2.3. Updating the research protocol

In addition to the micro data, conducted analyses and formulated recommendations, an updated research protocol based on the fieldwork carried out was delivered.

The results of WP2 are presented in Chapter 5 of this Final Report.

³¹ Activity Report: Implementation of National Contact Points for cross-border healthcare in EU MSs: a comparative analysis using websites and short interviews. Clemens, T., Cox, E. van der Zanden, B., et al., 2016.

³² Obtaining health care in another European Union MS: how easy is it to find relevant information?, Santorro, A., Silenzi, A., Ricciardi, W., et al., European Journal of Public Health, 25(1):29-31, available at: <http://eurpub.oxfordjournals.org/content/eurpub/25/1/29.full.pdf>.

3.3. WP3: Pseudo-patient investigation

The pseudo-patient investigation was a follow-up to the one conducted within the Evaluative Study on the Cross-border Healthcare Directive 2011/24/EU. The main objective of this WP was to investigate the differences or discrepancies between information that was provided by NCPs in response to enquiries made by pseudo-patients and the information that they are expected to provide based on the provisions of the Cross-border Healthcare Directive. The findings were used in WP4, when developing the toolbox and training material and the findings were distributed to and validated with all NCPs in WP5.

As a first key objective, this WP built on the Evaluative Study in assessing the quality and comprehensiveness of information provided by NCPs after an enquiry made by a pseudo-patient. The second key objective was to refine the original methodological approach taken in the context of the Evaluative Study conducted in 2014.

In order to accomplish these objectives, the pseudo-patient investigation was conducted in the form of a traditional pseudo-patient investigation exercise, or 'mystery shopping'. Twenty-nine NCPs were contacted by pseudo-patients via email and/or telephone, each seeing four different scenarios. In the following sections, we describe all the relevant steps of this exercise.

3.3.1. Scenarios

For the investigation exercise, four different scenarios were developed, each to be used as a basis for the enquiries. Three key criteria were taken into account when deciding on the proposed scenarios:

- the type of request (incoming vs. outgoing);
- the type of institution (individual practitioners vs. larger establishments); and
- the type of service (purely private vs. public).

Based on these criteria, we developed four pseudo-patient investigation scenarios. While only three scenarios were used in the Evaluative Study, the current pseudo-patient investigation was conducted based on four scenarios: two scenarios illustrating an inquiry from an outgoing patient (scenario 1 and 2) and two others illustrating an inquiry of an incoming patient (scenario 3 and 4). In the Evaluative Study, only one scenario was used with regard to an inquiry directed to the NCP of the country of treatment (incoming patient). However, Directive 2011/24/EU clearly places distinctive information requirements on NCPs, depending on their role as NCP of the MS of affiliation or NCP of the MS of treatment. As the set of information requirements differs depending on the NCP's role, information provision to both outgoing and incoming patients should be evaluated equally. Moreover, previous studies show that information provision to incoming patients is often failing, especially with regard to information on quality and safety. Hence, the importance to also investigate the status quo of information provision in the NCP's role as NCP of the MS of treatment.

The general descriptions of the proposed scenarios are summarised in Table 3.2 below.

Table 3.2 General descriptions of the four scenarios

	Scenario 1	Scenario 2	Scenario 3	Scenario 4
Description	Physical movement of the patient across the border	Physical movement of the patient across the border	Provision of services across a border	Provision of services across a border
Enquiry	A spread of two different enquiries across these two scenarios requiring prior authorisation or not			
Localisation	Outgoing	Outgoing	Incoming	Incoming
Type of service	Purely private	Public	Purely private	Public
Service provider	Individual practitioners	Large establishments	individual practitioners	large establishments
Country coverage	EU 28 Member States + Norway (taking into account regional disparities)			

A distinction in scenarios was also made based on the type of health services the pseudo-patient wishes to receive. Two scenarios illustrate an inquiry from a patient who wishes to receive treatment with a healthcare provider who works within the public system (scenario 2 and 4). Generally, this will be a public HCP. However, this can also be a private healthcare provider that is contracted or affiliated with the public system and thus is also entitled to provide services covered under the social security scheme. The other two scenarios concern questions about health services provided by healthcare providers offering purely private services (scenario 1 and 3). The rationale for this distinction is the scope of applicability of Directive 2011/24/EU and the Social Security Regulations, respectively. The Social Security Regulations do not apply to healthcare that is provided by a healthcare provider who is solely authorised to provide purely private health services. In case of the latter, only Directive 2011/24/EU will apply. Directive 2011/24/EU applies to healthcare provided by both public and private healthcare providers. This distinction in scenarios was made to test if NCPs inform patients correctly on this difference in application and are able to assist patients under both legal instruments.

Two scenarios related to health services provided by individual practitioners (scenario 1 and 3). The two others concerned patients requesting information on healthcare provided in larger establishments. This distinction was made to test if NCPs are able to answer questions relating to different types of situations. As a result also the specific types of health services differ between scenarios (consultation, surgery, common operation with waiting lists, rarer interventions...). Also a distinction was made in health services involving an overnight hospital stay or not, as the latter will often determine whether or not prior authorisation will be required.

All information requests were differentiated as much as possible to decrease the likelihood of detection or suspicion.

The following section describes the development of the four scenarios in further detail. All email templates can be found in Annex E (provided in separate document).

Scenario 1 concerned an outgoing patient enquiring about reconstructive surgery for a young adult, provided by a private healthcare provider. This type of treatment requires highly specialised doctors.

This scenario was chosen to test if NCPs fulfil their information requirements towards outgoing patients, asking information on healthcare provided by a private healthcare provider, which is probably subject to prior authorisation. By incorporating in the scenario that the surgery will be provided by a private healthcare provider, it was tested whether NCPs are aware on the different application scopes of the Social Security Regulations and Directive 2011/24/EU. NCPs should be aware of the fact that healthcare provided by a private healthcare provider does not automatically preclude the application of the Regulations. NCPs should inform patients that when the healthcare provider is contracted/affiliated with the public system, the treatment may be covered under both the Regulations and Directive 2011/24/EU.

The scenario of surgery was chosen to test if NCPs provide information on prior authorisation. When surgery involves an overnight hospital stay or highly specialised equipment, prior authorisation may also be required under Directive 2011/24/EU, depending on the national implementation of the Directive (prior authorisation is always needed under the Regulations).

In addition, reconstructive surgery was chosen as this concerns treatment that in some MSs may not be included in the range of benefits covered under the social security scheme. The treatment must be covered in the MS of affiliation in order to enjoy assumption of costs under Directive 2011/24/EU. When the patient wishes to access healthcare abroad under the Regulations, the treatment must be covered under the social security system of the MS of treatment. In order to receive prior authorisation under the Regulations, it will often be required that the treatment concerned is also covered in the MS of affiliation. NCPs should be aware of this.

Table 3.3 Scenario 1 KPIs

Explicit questions	NCP provides information on...
- Do I have the right to seek treatment in my own Member State? What is the availability and waiting time? - Do I have the right to seek private surgery in another Member State? - Do I need prior authorisation? Where and how should I seek this? How long does it take? - Will I get reimbursed? How much? Do I get reimbursed for extra costs? What paperwork do I need? Can you assist me with the paperwork? - Do I need a referral? - How can I access medical records? What does it cost? - Will follow-up care be provided at home or abroad? - Can you share information in the form of videos, reports or flyers?	- The fact that two legal instruments may apply; - Procedures of appeal and redress; - Who is responsible for reimbursement; - Payment procedures and paying upfront; - The cost of accessing medical records.

Scenario 2 also concerned an outgoing patient, this time seeking information about a hip replacement. This is a common treatment with long waiting lists in many MSs. In this scenario the patient is a pensioner who has worked in another MS all his life and is now seeking treatment back in the MS they previously worked in, which means different regulations apply.

Scenario 2 was especially chosen to evaluate whether NCPs are aware of the special schemes for some types of mobile citizens under the Social Security Regulations (i.e. special rules for frontier workers, retired frontier workers, pensioners living abroad). The pseudo-patient in this scenario was a pensioner living abroad, as this is probably the most common situation falling under the special arrangements.

The pensioner is seeking treatment back in the MS of his previous employment, which is also the competent MS (the MS under whose social security system the pensioner is insured). This scenario was chosen to evaluate if NCPs also inform patients residing in the MS of the NCP that are entitled to public healthcare in that MS but insured under the social security system of another MS (the competent MS). NCPs should be aware that in some cases the competent MS will grant more beneficial rights under annex IV Regulation (EC) 883/2004. More specifically, when the competent MS is listed under annex IV, pensioners living abroad will not only be entitled to public healthcare in their current country of residence, but will also remain entitled to healthcare during a stay back in the competent MS (based on a permanent arrangement and thus without application of article 19 or article 20 of Regulation (EC) 883/2004). When the competent MS is not listed in annex IV, the pensioner will have to follow the common rules for accessing health services abroad, either under Directive 2011/24/EU or under the articles 19 and 20 of Regulation (EC) 883/2004 (unplanned/planned care). When the first situation applies and the pensioner is entitled to healthcare under the permanent arrangement, NCPs should refer the patient to the NCP of the competent MS or should contact the other NCP directly.

Under this scenario, researchers were able to evaluate whether NCPs are aware of rules to determine which MS's social security authority is competent to grant prior authorisation (needed when the competent MS is not listed in annex IV). In general, this will be the institution of the competent MS. However, patients may submit their request to the local institution in their MS of residence which will forward the request to the competent institution. When the MS of residence is, however, listed under annex III of Regulation (EC) 987/2009 (system of reimbursement between MSs based on fixed amounts, lump sums), the institution of the MS of residence will be competent to decide on prior authorisation. NCPs should be able to inform patients which institution will finally decide on prior authorisation. In this case, the patient also knows which institution to address in case of appeal.

Additionally, scenario 2 evaluated whether or not NCPs provide information on undue delay and more specifically, on patients' rights to prior authorisation when the treatment is covered under the social security legislation of the patient's MS of residence but cannot be provided there within a justifiable time limit (as the treatment concerned hip replacement, prior authorisation will probably also be needed under Directive 2011/24/EU).

Table 3.4 Scenario 2 KPIs

Explicit questions	NCP provides information on...
- Do I have the right to seek public healthcare abroad? - Do I need prior authorisation? How do I request it? - Will I get reimbursed? How much? Do I get reimbursed for extra costs? How do I apply for it? Can you assist me with the paperwork? - Do I need a referral? - What is something goes wrong? - How will my treatment be followed up?	- The fact that two legal instruments may apply; - Referral to another Member State; - The competent body to grant authorisation or pay the costs; - Waiting period for authorisation; - Payment procedures, paying upfront; - Access to medical records.

For **Scenario 3**, an incoming patient from Germany is requesting information about cataract surgery abroad (when contacting Germany or Austria, the patient is from Belgium.) Similar to scenario 2, this treatment may have long waiting lists. The patient is a pensioner, working and residing in another MS, and seeking private healthcare.

This scenario focuses on testing whether NCPs fulfil their information requirements towards incoming patients, wishing to seek healthcare in the country of the NCP by a private healthcare provider. NCPs should inform patients on whether or not a specific private HCP is entitled to provide health services within the public system (HCP contracted/affiliated with the social security system). When the latter is indeed the case, both the Regulations and Directive 2011/24/EU will apply. If not, the patient will only be able to access healthcare abroad under the Directive.

As the patient wishes to receive surgery, prior authorisation may often also be required under the Directive (depending on the implementation in national law). NCPs should inform patients to contact the NCP in their MS of residence to check whether or not prior authorisation will be needed.

Table 3.5 Scenario 3 KPIs

Explicit questions	NCP provides information on...
- Do I have the right to seek private healthcare in your MS? - Do I need prior authorisation? - Do I need to pay upfront? What costs will be refunded? Will it cover transportation and accommodation? - Can you recommend a good private surgeon/hospital? - Do I need a referral? - What is something goes wrong? - What should I do if invoices are in another language?	- Payment procedures; - Access to medical records; - Complaint procedures; - Appeal and redress; - Quality and safety standards; - Transfer of medical records.

Scenario 4 involved an enquiry about an orthopaedic consultation for an *incoming, disabled patient* from Bulgaria (or from Romania, when contacting the Bulgarian NCP). The purpose of this scenario was to test if NCPs fulfil their information requirements towards incoming patients (working and residing in another MS), asking information regarding healthcare in that MS, which is possible under both the Regulation and the Directive and which is *not subject to prior authorisation*.

In addition, this scenario was especially chosen to test whether NCPs provide information on the accessibility of health facilities for patients with disabilities. NCPs are obliged to provide such information under article 4(2) Directive 2011/24/EU.

Table 3.6 Scenario 4 KPIs

Explicit questions	NCP provides information on...
- Do I have the right to seek an orthopaedic consultation in your MS? - Do I need authorisation - Will I be reimbursed? Do I have to pay upfront? - What are the quality and safety standards in your country? - What can you tell me about accessibility of hospitals?	- Reimbursement of extra costs; - Transfer of medical records.

• What is something goes wrong? What are our rights • What documentation do we need? • Do we need a referral? • Can you recommend a specialist?	
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3.3.2. Methodology

The goal of our revised approach was 1) to make each scenario as realistic as possible, avoiding the possibility of NCPs suspecting the true purpose of each request and 2) to collect as much information as possible by using all appropriate communication channels on a country-specific basis.

Close attention was paid to developing realistic communication materials for each scenario and adapting them to each communication channel. For each of the four scenarios, a standard email text was designed. These texts varied significantly across scenarios in terms of structure and format. To increase differentiation, we also used different writing styles while incorporating all relevant questions into the email. In order to achieve this in a realistic manner, the four emails were drafted by four different people who were blind to the specific purpose of the study. They were then revised and refined by the core team. In addition to the four email texts, an elaborate back-story was developed for each of the scenarios, thereby making the emails more realistic and personalised, as well as making each scenario unique. The four backstories were incorporated into the telephone call when necessary. For Scenarios 1 and 2, all emails developed in advance for the purpose of communicating with the NCPs were translated into the local languages, while for Scenarios 3 and 4 this email remained in English.

Communication with the NCPs was the key focus of running the study and took place via two parallel channels: email and telephone. We utilised false identities during the pseudo-patient investigation, as per the state of the art in conducting this type of service provision investigations. Email accounts were created, using the major email account providers, for each of the pseudo-patients. For all scenarios, contact was made via email³³ first, outlining the issue of the patient and asking for specific information via the standard email template. In addition, all emails requested the NCP to share their telephone number in case the pseudo-patient had any additional questions. The contact list used for the pseudo-patient investigation can be found in Annex F (provided in separate document).

3.3.3. Recruitment and briefing

The recruitment and briefing approach differed based on whether a scenario needed to take place in the local language or in English.

Scenarios 1 and 2

Since Scenarios 1 and 2 required the use of local languages, the exercises were performed by GfK agencies in all covered countries. In countries where no GfK agencies were available, we recruited experts from other agencies who speak the local language of the specific country. The key factor when recruiting experts to participate in the study was their prior experience with mystery calling methodologies, aiming to recruit a majority of research experts who are already familiar with the basic principles of pseudo-patient investigation. A dedicated local expert was recruited for each scenario (2 per country).

A written briefing document was developed by the project team (in English). In addition to a background of the study, including the research objectives, the briefing document included the following information:

- The exact steps that each pseudo-patient needed to follow to complete the assessment:
 - The specific details required at each step of the process;
 - NCP contact details.

³³ All email addresses were provided by Chafea/DG SANTE "NATIONAL CONTACT POINTS FOR CROSS-BORDER HEALTHCARE".

- An elaborate back-story to personalise the scenario;
- The specific content of the communication sent via email and followed up on by phone;
- The assessment sheets that were to be filled out at the end of the exercise; and
- Contact information.

Extensive briefing sessions on the overall structure and content of the exercise were held in the form of a conference call. Two separate briefing sessions were held, one for Scenario 1 and one for Scenario 2 on the 6th and 7th of September 2017. The briefing document was provided before the conference briefing and allowed participants to ask questions during the briefing session. In the briefing session, two specialists in this methodology from the core team provided the experts with further behavioural training focused on pseudo-patient investigations. The training included specific tips on how to avoid detection and make sure the scenario appears as realistic as possible to NCP representatives. This included developing an extended backstory with realistic details, asking questions in a non-structured way, not reading from a prepared list of questions, pretending to remember an extra question at the end of the call, etc., to make the patient's individual story more believable). This was especially important given the low number of requests that NCPs receive per month.^{34,35}

Scenarios 3 and 4

Scenarios 3 and 4 were performed locally by the two GfK specialists responsible for briefing the local experts. The GfK experts are fluent in English (and native in Bulgarian and German) and were part of the core team that developed the methodology and the new assessment form, and both have relevant research experience in designing and coordinating mystery shopping exercises. By assigning our specialists on pseudo-patient investigation, we were able to ensure high quality results and avoided detection during the phone calls to NCPs, which was a key potential issue foreseen within this methodological approach. The specialists are knowledgeable in methods for avoiding detection during phone calls. Each specialist was assigned to a specific scenario in order to avoid voice detection if the same person calls an NCP twice. For the Bulgarian, German and Austrian MSs, we recruited two other mystery shopping experts to avoid detection of the possible accents of the mystery shopping specialists.

3.3.4. Assessment Sheet and Key Topics Covered

Four different follow-up assessment sheets were designed to cover all four scenarios (these can be found in Annex G, provided in separate document). This assessment sheet was to be filled in by the pseudo-patient after final contact with the NCP. The items in the assessment sheet were based on the questions in the email enquiry and included some additional relevant information expected to be provided by the NCPs. Although there are many overlapping questions, each assessment sheet is unique. When developing the content and format of the assessment sheet to be used the questions and format used in the Evaluative Study were taken as a starting point. The topics were expanded on in order to better capture the quality and comprehensiveness of information provided to patients who seek cross-border healthcare. Additional topics that formed several additional question blocks as part of the redesigned mystery shopping assessment sheet were identified in WP1.

The key information topics included:

- Administrative information related to treatments requiring prior authorisation (procedures, processing time, documentation needed);
- The process of reimbursement and payment;
- The selection of healthcare providers that offer the desired treatment;
- Follow-up treatment provision in the patient's home country;
- Documents needed by domestic health insurance providers/authorities;
- Language barriers;
- Access to medical records;
- Complaint procedures;

³⁴ Commission Report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, 4 September 2015, COM(2015) 421 final.

³⁵ https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_msdata_en.pdf.

- Accessibility of hospitals;
- Safety standards;
- The quality of healthcare providers in specific Member States; and
- Access to additional information such as videos, flyers and brochures.

Please refer to the Box 3.1 below for more information on the design of the questionnaire.

Box 3.1 Questionnaire design

A sound questionnaire design is crucial to ensure the quality and relevance of the final data. Typically, for pseudo-patient investigation, research scenarios are built into the pseudo-patient investigation questionnaire.

The scenarios and questions part of the questionnaire should be clear, non-ambiguous and suitable for translation in a large number of languages. The first draft of the questionnaire was developed during the inception stage of the study after discussions with Chafea/DG SANTE during the kick-off meeting. Based on feedback of Chafea/DG SANTE, this version was optimised through a question-by-question assessment focussing on the following aspects:

Is this question necessary?

Questions that are not linked to the research objectives or do not bring relevant information or for which information is already available should be avoided (e.g. key areas of compliance, consumer protection rules, drivers of customer satisfaction)

Can mystery shoppers understand and answer this question?

Questions should be unambiguous and should include the majority of possible answer categories.

Will the mystery shopper be able to answer this question?

Which steps does a mystery shopper need to undertake to assess certain aspects?

Will this question be comparable across countries?

Questions should be worded to apply to all countries surveyed and should be written in standard, non-colloquial English to ensure the quality of the translations. Also very typical for pseudo-patient investigation in this relation is the use of questions that allow for a yes/no answer.

It is important to keep sight of the main survey objectives at this stage and the feedback and final survey materials were therefore assessed based on their consistency with the research questions. Close attention was paid to the flow and layout of the questionnaire.

Country coverage and regional disparities

The scenarios covered all EU28 Member States and Norway. When contacting NCPs during this task, regional disparities across health systems in different MSs were taken into account for each scenario. This included taking into account MSs with a decentralised healthcare system and following up with the relevant authorities in each case. Pseudo-patients were instructed to focus on their own native region.

3.3.5. Fieldwork

The fieldwork took place between August 21st 2017 and November 24th 2017. The last emails were sent out on the 2nd of October. All emails were sent out on a rolling basis, ensuring sufficient time between emails received by the NCP, to avoid suspicion. The email accounts were

continuously monitored throughout this period. When NCPs responded, the email was analysed by the pseudo-patients. A follow-up call was placed when several questions remained unanswered in the email. If the NCP did not respond within a two-week period, a follow-up call was also made and the information requested in the email was gathered by telephone. Email accounts were monitored for a maximum of 7 weeks and emails received until this cut-off point were included in the analysis.

The raw data from the previous study suggested that information on national ID numbers is not requested by the NCPs when dealing with information enquiries. Furthermore, GfK also made a couple of general information enquiries to NCPs during the inception period and again, national ID numbers were not asked. Therefore, it was not envisaged that in this case national ID numbers would be requested, given that the pseudo-patient investigation involved an information request and guidance from the NCPs. We have not had researchers use their real identities in other cases. When the case arose that an NCP did request a national ID number, or any personal information, the pseudo-patients were requested to inform the NCP that they are only seeking information and would prefer not to share their personal details. The back-story and briefing session allowed for the pseudo patients to create a realistic reason for not providing these details.

If pseudo-patients were asked by the NCP to contact a specific region the pseudo-patients were instructed to contact their own region.

Pseudo-patients were always instructed to take the steps that feel natural to them when following up on emails and calls. When asked to forward or resend an email or when asked to call another body this was done, but by no more than one step away from the NCP. Each pseudo-patient was asked to make three call attempts and to stay on hold for no more than five minutes.

3.3.6. Information provision analysis

The data of all four scenarios was collected in an assessment sheet and gathered in an Excel database for analysis. The database was organised by scenario and by country as each scenario had different questions. Aggregated data has been provided in the database at country level.

Star ranking analysis

Similar to WP2, when analysing the gathered data we used a ranking methodology (star rankings). Results are presented per scenario and include information on responses to e-mails and phone calls, as well as information on whether questions asked by pseudo-patients were answered. Information on responses to e-mails and phone calls is provided on a measure of four stars. The number of stars assigned was based on a legend as shown in the table below, so as to keep consistency and comparability between the NCPs.

Table 3.7 Legend analysis response to e-mail and telephone call

4 stars	3 stars	2 stars	1 star	n / a
Received an email response from the NCP addressing my enquiry	Response received from NCP, questions addressed, after placing follow-up call Response received, questions addressed, after being forwarded to another contact/body	Response from NCP received, no questions addressed, not in English for S3 and S4 Response received, no questions addressed, forwarded to another contact/body	Received no email response from NCP	
Made contact with NCP by telephone and was able to ask questions	Yes, NCP contacted, questions asked/answered via telephone, after being forwarded to another contact/body	Yes, contact was made, no questions asked/answered, after being forwarded to another contact/body via telephone Made contact with the NCP, but they did not speak English	Made no contact with NCP (no answer, answering machine, tone, on hold for 10+ minutes,...) Made no contact with NCP, was forwarded to another contact/body, which lead to a dead-end	No telephone number provided All answers provided by email

The information provided by the NCPs, either by email or by telephone, was analysed on the basis of the assessment sheet. For each item it was determined whether information was provided or not. Note that the information was *not* analysed on the basis of their correctness. A referral to another body or NCP as a response to specific question was considered as provision of information, a direct link or attachment clearly containing the information was also considered as a response. Per scenario each NCP received a *yes* or *no* score on every item in the assessment form (Annex G, provided in separate document). For each scenario for each NCP a total percentage was then calculated, based on the number of items in which information was provided. The aggregated score is an average score calculated for each NCP.

The results are represented using stars. To optimise the uptake of the tools and training materials that were developed as part of this study, it is important that NCPs are engaged in the study and open to its findings and recommendations. We have therefore changed the presentation of the results from traffic lights – as used in the Evaluative Study – to stars, as a more neutral and encouraging manner of presenting the overall results of the website analysis. For each of the scenarios the NCPs can get a maximum of 4 stars.

Table 3.8 Results presented using stars

MS	...	...	...	...	...	...
Country X	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
Country Y	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
Etc.						

The results of WP3 are presented in Chapter 6 of this Final Report.

3.4. WP4: Developing a toolbox and training material

The problems and issues in information provision in cross-border health services that were identified in the previous WPs, showed a need for further improvement of NCP services and policy development. With this purpose, a toolbox for NCPs was developed in WP4.

The toolbox aims to present guiding principles for the work of NCPs and to provide realistic pathways – at little extra cost – to improve the effectiveness of both the current NCP practices, as well as the present level of collaboration between NCPs. More specifically, the toolbox provides resources and tools that can assist NCPs in their daily practice, aiming to contribute to an NCP practice that is more uniform, of high-quality and always patient-oriented.

In light of these objectives, we developed guiding principles for good NCP services and thematic indicators to evaluate the service of NCPs. In addition, the guiding principles were created to be a framework for a more uniform practice and for encouraging a more structured cooperation between NCPs. The Guiding Principles included in Annex A will be sent to the NCPs for consultation once more in June 2018 before these are finalised. To improve the information services of NCPs, we drafted a toolbox and training material for NCPs.

Before starting the preparations for the toolbox and the guiding principles, the findings of WP1, WP2 and WP3 were supplemented with the results of an online survey amongst NCPs, a patient survey and an analysis of other information centres. The aim of both the NCP survey and patient survey was to identify potential challenges and good practices in access and information provision in cross-border health services. The analysis of other information centres aimed to identify good practices in cooperation in other fields.

WP4 thus builds on the start that was made in WP1, e.g. by studying past reports and literature, and in drafting a list of thematic (RACER) indicators, as well as the results of WP2 and WP3.

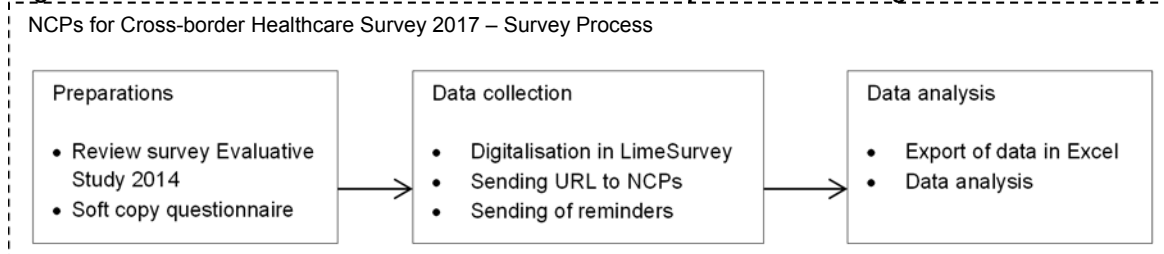
3.4.1. Online survey NCPs

In order to be able to present guiding principles for the work of NCPs, a good understanding was required regarding the way NCPs are currently working and are organised. This understanding was achieved by using information on NCPs that was gathered during the course of WP2 and WP3, as well as using an online survey among NCPs. The survey focused on the organisational structure of NCPs (FTEs, overhead, stakeholder consultation strategy, funding strategies, etc.), as well as

on their working process. In addition, the survey aimed to assess and provide a better understanding of the current practice of information provision to patients:

- *Objective of the survey:* Explore the organisational structure and working process of NCPs and provide a better understanding of their current practice of information provision;
- *Design and setting of the survey:* An online survey, running from 17 August until 9 November was sent to representatives of NCPs of all 28 MSs, Iceland and Norway.

Figure 3.1 Schematic overview of the different steps in conducting the online survey



Preparations

First, a soft copy of the questionnaire was drafted, building on the questions included in the online survey of NCPs that was part of the Evaluative Study in 2014.³⁶ The questions used in the Evaluative Study were reviewed and updated by the project team. In addition, some new questions were proposed. The soft copy of the questionnaire contained a total of 71 questions, divided into 6 main categories "General Information on the NCP", "Organisation and Working Process", "Cooperation and Information Exchange", "Cross-border Healthcare", "Information Provision to Patients", and "Views and Recommendations". The survey solicited information on the organisational structure of the NCPs (FTEs, overhead, stakeholder consultation strategy, etc.), as well as the practice of information provision to patients in cross-border healthcare. The questionnaire comprised yes/no questions, multiple choice, Likert scale questions, as well as open questions at the end of the survey for further comments and recommendations. Most of the closed-ended questions were provided with some open space for further specifications. The template of the questionnaire is attached in Annex B (provided in separate document).

Data collection

The final version of the soft copy of the questionnaire was digitalised by implementation on the online platform "LimeSurvey". A short testing phase of the online survey was held amongst the members of the project team and contracting party to verify the technical format and the need for any final adjustments. After small modifications based on the comments resulting from the testing phase, the online survey was finalised and agreed upon.

To launch the survey, an e-mail was sent to the NCPs of all 28 MSs, Iceland and Norway. The e-mail invitation included some additional information on the study, a letter of support provided by the contracting party, as well as the URL to the online survey. Contact details were provided by the contracting party. The survey was sent to all nominal contacts of the 33 NCPs as main addressees, with the respective functional NCP mailbox(-es) in CC. In case of multiple CPs per State, the RCPs were given the opportunity to participate separately. The survey was initially open from 17 August until 30 September 2017. After a period of three weeks, reminders were sent. To give non-responding NCPs a last chance to participate, an additional period to complete the survey was granted. The survey was permanently closed on 9 November 2017.

Data analysis

The completed surveys were exported and maintained into a single Excel database. After cleaning and coding of the data, data analysis by the project team commenced. Descriptive statistics were used and findings are projected descriptively. Only the NCP answers were analysed. The extra data collected on RCPs are provided as additional information whenever considered relevant.

³⁶ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015.

3.4.2. Online survey patients

In addition to the survey of NCPs, which provided information from the NCPs' point of view, an online survey among patients was conducted. The patient survey aimed to ensure that the patients' perspective was also included in the study. The survey investigated whether the experiences of patients who have received cross-border care (physically or through telemedicine) in accessing information on different aspects of seeking health services abroad had access to sufficient information before seeking this medical care (which is different from the pseudo-patient investigation in WP3 where only the amount of covered information is investigated). In conducting this survey, the same steps were taken as in the online survey for NCPs (see section 3.4.1).

Preparations

First, a soft copy of the questionnaire was drafted. This resulted in a questionnaire of 35 questions, divided into four main categories: "The right on cross-border healthcare", "Information provision", "Payment and reimbursement", and "Quality and safety". The questionnaire consisted of primarily closed ended questions, using multiple-choice answers or a five -point Likert scale. These questions were selected in line with the findings of the previous literature review and analysis of legal texts within WP1 of this study. In addition, for some items, the findings of the Special Eurobarometer 425 of May 2015 were used as a starting point.³⁷ The template of the questionnaire is attached in Annex J (provided in separate document).

Data collection

The soft copy was digitalised on the online survey platform "LimeSurvey". An e-mail was sent to a list of national coalitions of patient organisations as well as specific patients organisations across the EU (see Annex J, provided in separate document). Patient organisations were asked to assist in sending an e-mail - including the URL of the online survey - to patients whom they knew had received cross-border treatment within the last few years. Patients were also entitled to send the mail with the link to the survey to other patients they know who might have travelled abroad for medical treatment as well. In order to enhance recruitment possibilities, the patient organisations were asked to personalise the e-mail to the potential participant (name).

Inclusion criteria for patients to participate in the survey were:

- Being capable of reading and understanding English;
- Residing in a EU MS, Norway, Iceland or Liechtenstein;
- To have received planned reimbursable medical treatment in another EU MS, Norway, Liechtenstein or Iceland (physically or telemedicine);
- The event of medical travel took place after the implementation of Directive 2011/24/EU (25 October 2013).

Naturally, contacting patients was done in compliance with the legislation on privacy and processing of personal data.

The survey was initially open from 17 August to 18 December 2017. 46 patient organisations were contacted, covering (national coalition and specialised) organisations in all 28 EU countries, Iceland, Liechtenstein and Norway (for an overview see Annex J, provided in separate document). Reminders were sent on 18 September. Due to a low response rate, the deadline of the survey was extended. On 10 November, two additional organisations were contacted: European Patients' Forum (EPF) and the International Federation for Spina Bifida and Hydrocephalus. The patient survey was permanently closed on 18 December 2017. The final response rate remained low. In total, the answers of 11 patients were included in the analysis, corresponding to more than 50 planned cross-border healthcare events.

Data analysis

The completed surveys were exported and maintained into a single Excel database. After cleaning and coding of the data, data analysis by the project team commenced.

³⁷ European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European Union, May 2015.

The number of respondents corresponding with the inclusion criteria was low. A valid explanation may be the known small numbers of patients receiving planned cross-border healthcare in the EU. In addition, during the period of the survey, patients were already contacted for a consumer survey conducted on behalf of ANEC (the European consumer interest organisation) (August – September) concerning the same topics.³⁸ The scope of the ANEC consumer survey was broader covering also unplanned healthcare, which resulted in 1,656 respondents. However, the number of respondents with direct experience of planned care was also relatively low in this survey (46 events of planned treatment in the last five years).³⁹ A third factor that may explain the low response rate is that patients were not contacted directly. In the light of privacy and data protection, patients were contacted indirectly through patient organisations or national coalitions of patient organisations. Patient organisations were asked to not communicate any personal data of patients. As a result, it was hard to determine how many patients were actually contacted by patient organisations.

In total, the responses of 11 patients were included in the data analysis, corresponding to more than 50 planned cross-border healthcare events (ranging from 1 to 20 events per patient; mean of 6 events per patient). As a result, the sample size is too small to draw any valid and representative quantitative conclusions. Nevertheless, the patient survey yielded accurate qualitative measures based on the open-ended comments provided by patients throughout the survey. These comments are used to validate quantitative findings.

3.4.3. Analysis of other information centres

In order to be able to improve the operation of NCPs, an analysis was conducted of other information centres, as well as their networks. The aim of this analysis was to identify good practices, draft guidelines for the work of NCPs and to determine the need for a European web portal with clear links to websites of NCPs and FAQs, patient manuals, etc. In addition, the analysis verified whether joint network events of NCPs may be needed. The following information centres were included in the analysis, as they are comparable to cross-border healthcare NCPs and may provide valuable information on effective collaboration:

- HORIZON 2020 NCPs;⁴⁰
- FRESSCO legal experts;⁴¹
- National SOLVIT centres;⁴²
- European Network of Information Centres in the European Region;⁴³ and
- Expert Reviewers for Orphanet.⁴⁴

The idea behind this analysis was to provide realistic pathways for improving the effectiveness of the present level of collaboration between cross-border healthcare NCPs at little extra cost, drawing on intelligence available in other policy fields or in the civil society/ start-up/ business world.

Other forms of cooperation resulting from the implementation of Directive 2011/24/EU, such as the establishment of European Reference Networks or cooperation on Health Technology Assessment, are not included in the analysis. As these areas of cooperation are still in an early stage it is too early to identify established good practices.

³⁸ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, p. 55.

³⁹ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 8 -9.

⁴⁰ http://ec.europa.eu/research/participants/data/support/20131125_NCP%20Minimum%20standards.pdf.

⁴¹ <http://ec.europa.eu/social/main.jsp?catId=1098&langId=en>.

⁴² http://ec.europa.eu/solvit/contact/index_en.htm.

⁴³ <http://www.enic-naric.net/>.

⁴⁴ http://www.orpha.net/orphacom/cahiers/docs/GB/Expert_reviewers_2015.pdf?lng=EN.

3.4.4. Resource burden estimation

A resource burden estimation is also part of the current study (see Chapter 8 for further details). Based on the data recovered through the online surveys (part of WP4) and recent MS data, the study analysed the amount of resources (time, money, and expertise) that a patient/ MS needs to invest in order to successfully acquire relevant information/ satisfy their obligations under the Directive 2011/24/EU. This analysis is mainly qualitative in nature, as there was very limited availability of quantitative data on the resource burden.

3.4.5. Equality and proportionality analysis

Cross-border healthcare under Directive 2011/24/EU is sometimes associated with socio-demographic disparities. Regardless of the fact that these disparities mirror the significant disparities observed between population groups within MSs (to a greater or a lesser extent depending on the MS) and across MSs, one must not lose sight of the fact that measures should be taken to guarantee equal access to treatment abroad under the Directive at all times. In order to anticipate possible obstacles for certain socio-demographic groups, it is necessary to determine which groups are likely to encounter more difficulties and disadvantages in accessing healthcare abroad (e.g. due to age, education or employment).

For this reason, an equality and proportionality analysis was conducted (see Chapter 9 for further details). This analysis is based on The Special Eurobarometer 425 on patients' rights in cross-border healthcare in the EU, which includes information harvested through face-to-face interviews with 27,868 respondents from different social groups.

3.4.6. Creating a set of guiding principles and a list of thematic indicators

Previous studies have stressed the desirability of facilitating 'comparability and reliability of information provided to patients on quality and safety, across institutions and across MSs'.⁴⁵ Some MSs have different NCPs for 'incoming' and 'outgoing' patients. Others have regional CPs under one 'umbrella' NCP.⁴⁶ Some NCPs are based in the Ministry of Health, others in a healthcare insurer, and others in independent bodies.

Considering the many differences in practices, a two-way approach was applied, existing of both upstream and downstream guiding principles, guidelines and corresponding RACER indicators. On the basis of the results of WP1, WP2 and WP3, as well as on relevant recent publications on cross-border healthcare, a set of guiding principles for good NCP service provision was drafted. In addition, a set of guidelines was developed. These guidelines consist of more specified quantitative benchmarks, or norms. It is obvious that to be able to verify whether an NCP is providing good NCP services according to the guiding principles and guidelines, corresponding indicators are needed. These indicators are, preferably, Relevant, Accepted, Credible for non-experts, Easy to interpret and Robust against manipulation (RACER).

Identification and development of suitable guiding principles, guidelines and indicators already started in WP1. In WP4, a final research-based proposal was drafted (upstream). This version of the guiding principles and thematic indicators was validated by all NCPs in WP5.

The two-way approach then resulted in both an upstream and a downstream version of guiding principles, guidelines and indicators:

- a version consisting of the research-based proposal for guiding principles, guidelines and indicators (upstream);
- and a post NCP consultation version (downstream).

The latter consists of the final set of guiding principles, guidelines and indicators taking into account the feedback of the NCPs after consultation.

⁴⁵ Commission Report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, p. 8.

⁴⁶ (See Commission report, p. 6).

3.4.7. Drafting a toolbox and training material

All previously gathered information was combined to develop the toolbox, which contains:

- A manual for patients with at least information on their rights under the Directive 2011/24/EU and under the Social Security Regulations and the scope of the Directive (including information on ambulatory care, care that may need prior authorisation, telemedicine, preventive medicine). This manual takes the shape of a service catalogue, making it possible for patients to know which services ought to be provided;
- A leaflet for patients entitled "Crossing a border for a medical treatment: The Top Ten Mistakes Patients make in Cross-border Healthcare", based on the "Known before you go" flyer;
- Communication material that can be used by NCPs to explain the distinction between Directive 2011/24/EU and the Social Security Regulations to patients;
- Information to be given by the NCP of the MS of treatment and by the NCP of the MS of affiliation;
- Templates for answered FAQs for the NCP website, which should at least explain the basic items of the manual, the differences between Directive 2011/24/EU and the Social Security Regulations and should reply to specific situations depending of the type of patient (pensioner, (frontier) worker, family member etc.);
- NCP checklists for consultation with patients, patient organisations, healthcare providers and insurers;
- NCP checklists for thorough and comprehensive information via email and telephone to patients.

In addition, an informative text on quality of care and patient safety is included in the toolbox. The text includes basic guidelines and minimum requirements for information provision on quality and safety by NCPs (e.g. NCPs should provide information on who sets standards, what they cover, who monitors compliance with them, which providers are covered by these standards).

An appropriate training set is developed for NCPs regarding good information provision to patients. The training set includes a PowerPoint and a digital lecture explaining the toolbox and the guiding principles for the work of NCPs. The lecture and PowerPoint should be made available in such a way, that they can be consulted at any moment by NCP staff. Regarding the manual and the checklist, a different set of materials will be provided to the NCPs depending on their role as institution of the MS of affiliation or the MS of treatment respectively.

Other deliverables included into the toolbox are: templates for evaluation exercises between NCPs in the future, for example based on a twinning initiative (with a rotating principle). In this way, NCPs could learn from each other and build strong networks in a broader umbrella network.

NCPs should be a gateway to information on cross-border healthcare, but not necessarily a one-stop shop. They should be a solution centre and a link to other stakeholders. The cooperation with, for example, patient organisations will be defined and determined with an acceptable level of precision.

The results of WP4 are presented in Chapters 7 to 10 of this Final Report.

3.5. WP5: Training in good NCP practices

The aim of this WP was to share and discuss the findings and output of previous WPs. To validate the findings of other WPs, NCPs (as party of interest) were consulted. With this purpose, a bilateral exchange with NCPs was organised. The aim was to gain as much feedback from NCPs as possible, in order to validate the added value for NCP practice of this study and the provided toolbox and training material. Based on NCPs' comments and recommendations, necessary revisions to the guiding principles and proposed toolbox were made.

NCP consultation and validation was also established by organising a workshop on 8 March 2018. On 15 November 2018, a presentation on the results of the study will be given in the Expert Group on Cross-border Healthcare.

3.5.1. *Bilateral exchanges with NCPs*

The results of WP2 (website analysis – individual micro data), WP3 (pseudo-patient investigation exercise – individual micro data) and WP4 (the toolbox – the manuals, templates, checklists, indicators, and guiding principles) were shared by email with all NCPs individually. In addition, we provided all NCPs the opportunity to engage in an individual discussion of the results of WP2 and WP3 for their country, as well as of the toolbox.

As part of the bilateral exchange, NCPs were asked to reflect on these documents and provide the project team with feedback on the findings and methodology.

The guiding principles for the work of the NCPs needed to be adopted subject to unanimous NCP agreement. As this agreement was not reached prior to the NCP workshop, we presented these guiding principles again at the workshop (see the next section) to seek this unanimous agreement.

3.5.2. *Organising a workshop to deliver the training material to the NCPs*

Two NCP staff members per MS and Norway were invited to participate in the workshop in Brussels on 8 March 2018. The aim of the workshop was to present the preliminary results of the study and to deliver and promote the training material, developed under WP4 (but based on all previous WPs), to staff members of the NCPs. The material was presented to the NCPs by the project team members. We used a voting system to gather the opinions of NCPs on the Guiding Principles and indicators.

The discussions and feedback received during the workshop were used to refine this Final Report.

4. Results of the review of literature and legal texts

This Chapter presents the results of the literature and legal texts review. In this chapter we first outline the analysis of legal texts including the Social Security Regulations and the Directive 2011/24/EU, and the distinction between these legal instruments (section 4.1). Then, we highlight findings from several reports that have been published with respect to the implementation of Directive 2011/24/EU and its application in practice (section 4.2). We then elaborate on the results of the literature review which focussed on the current issues in information provision under the Directive (section 4.3). In addition, this Chapter outlines our key findings from the literature and legal text review (section 4.4).

4.1. Results of the analysis of legal texts

In addition to a literature search to identify the current issues in information provision (presented in 4.2), the legal framework under EU legislation for accessing health services abroad was set out.

The results of the analysis of the relevant legal texts are presented per topic:

- Social Security Regulations (*section 4.1.1*);
- Directive 2011/24/EU (*section 4.1.2*);
- Distinction between Social Security Regulations and the Directive (*section 4.1.3*).

4.1.1. Social Security Regulations

This section provides an overview of the rules that follow from the Social Security Regulations, i.e. Regulation (EC) No 883/2004 and Regulation (EC) No 987/2009.

The Social Security Regulations aim to coordinate social security systems and to ensure the protection of EU/EEA or Swiss citizens when moving and travelling to another MS. The general principle under the Regulations is that patients have the right to access health services abroad and to enjoy assumption of costs as though he or she was insured under the social security system of that country and thus equally as domestic publicly insured patients.

The Regulations set out rules to determine the applicable social security legislation to which an insured person is subject. As a general rule of thumb, citizens are only subject to the social security legislation of one country at a time. In most cases, this will be the social security legislation of the country of residence. However, in a number of cases the patient will be entitled to healthcare in his/her country of residence while insured under the social security legislation of another country, i.e. the competent MS. The latter will, for example, be the case for posted workers and frontier workers.

In addition, the Regulations envisage a broad range of possibilities for accessing healthcare outside the patient's home country:

- Medically necessary treatment under the European Health Insurance Card during a short-term stay abroad, such as holiday, business trip, family visit.. (also referred to as unplanned treatment);
- Seeking healthcare abroad with the prior authorisation (S2 form) from the patient's national health service/ health insurance provider (also referred to as planned treatment);
- Special permanent arrangement for posted workers, frontier workers and pensioners residing outside the country of social security insurance.

Table 4.1 in particular looks at the entitlements to sickness benefit under social security legislation for different groups of patients.

Table 4.1 Affiliation to a national healthcare system with regard to special cross-border situation

Are entitled to sickness benefits in kind			Provided by <i>In accordance with its legislation (basket of benefits, reimbursement rates,...)</i>	At the expense of
Art. 17	<i>Residing in a MS other than the Competent MS</i>	<i>Insured person + family</i>	<i>Institution of residence (on the display of an S1 form)</i>	<i>Competent institution</i>
Art. 18	<i>Residing in another MS but stay in competent MS</i>	<i>Insured person + family</i>	<i>Competent institution</i>	<i>Competent institution</i>
		<i>! Not for family members of a frontier worker, insured in DK, IE, HR, FI, SE, UK⁴⁷ → Art. 19)</i>		
Art. 22	<i>Special rules for pensioners</i>	<i>Pension claimant + family</i>	<i>Institution of residence</i>	<i>Institution that would become competent under article 23 -25.</i>
Art.23		<i>Pension(s) in two or more MS, including the MS of residence + family</i>	<i>Institution of residence</i>	<i>Institution of residence is competent</i>
Art.24		<i>Pension(s) in one or more MS, other than the MS of residence + family</i>	<i>Institution of residence (on the display of an S1 form)</i>	<i>Competent institution Longest period Subsidiary, last subjected</i>
Art.25		<i>Pension(s) in one or more MS, other than the MS of residence, but right to benefits in kind in MS of residence⁴⁸ + family</i>	<i>Institution of residence (on the display of an S1 form)</i>	<i>Competent institution⁴⁹ Longest period Subsidiary, last subjected</i>
Art. 26	<i>Family residing in another MS than the pensioner</i>		<i>Institution of residence (on the display of an S1 form)</i>	<i>Competent institution</i>
Art. 27	<i>Pensioner residing in another MS, but staying in the competent MS</i>	<i>In general, only entitled to benefits in kind provided in MS of residence⁵⁰ → art. 19 will apply BUT More beneficial rights, only for BE, BG, CZ, DE, EL, ES, FR, CY, LU, HU, NL, AT, PL, SI and SE⁵¹ + Family</i>	<i>Competent institution</i>	<i>Competent institution</i>
Art. 28	<i>Retired frontier workers, staying in previous MS of work</i>	<i>Continuation of treatment + Family ! Not for family members in DE, IE, HR, FI, SE, UK⁵² Regardless continuation</i>	<i>Institution of the country of previous work activity (on the display of a valid S3 form)</i>	<i>Competent institution Competent institution</i>

⁴⁷ Annex III of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 11 July 2017).

⁴⁸ Due to legislation that grants the right to receive benefits in kind without insurance or activity as an employee or self-employed person, art. 26.

⁴⁹ Only to the extent that the pensioner/family member would also be entitled to such benefits if they resided in the competent MS, art. 26.

⁵⁰ The general rule is that a pensioner residing in another MS will fall under the health insurance scheme of the MS of residence and the legislation it applies. Thus, when the pensioner stays in the competent MS and is in need of medical treatment, the general rules for planned/unplanned treatment in another MS apply (see below).

⁵¹ Annex IV of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).

⁵² Annex III of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).

Are entitled to sickness benefits in kind			Provided by <i>In accordance with its legislation (basket of benefits, reimbursement rates,...)</i>	At the expense of
		for BE, DE, ES, FR, LU, AT, PT ⁵³ (both the MS of previous work as the competent MS must be included in this list) + Family ! Not for family members in DE, IE, HR, FI, SE, UK ⁵⁴	Institution of the country of previous work activity (on the display of a valid S3 form)	

In addition to the more permanent arrangements for posted workers, frontier workers and pensioners residing outside the country of social security insurance enabling them to access health services in the competent country or in the country of previous work activity, the Regulations provide for possibilities for all EU/EEA and Swiss citizens to access health services abroad and to enjoy assumption of costs based on their social security insurance. A distinction is made between unplanned treatment which becomes medically necessary during a stay abroad, (such as holiday, exchange studies, business trip or family visit) and planned treatment resulting from patients travelling abroad with the explicit purpose of accessing healthcare.

Table 4.2 shows the articles associated with unplanned and planned cross-border treatment under the Social Security Regulations.

Table 4.2 Unplanned and planned cross-border treatment under the Social Security Regulations

Benefits in kind		Provided by <i>In accordance with its legislation (basket of benefits, reimbursement rates,...)</i>	At the expense of
Art. 19	Medically necessary treatment (unplanned) (on the display of a valid EHIC)	<i>Institution of stay/treatment</i>	<i>The competent institution</i>
Art. 20	Scheduled treatment (on the display of a valid S2 form)	<i>Institution of stay/treatment</i>	<i>The competent institution / authorising institution⁵⁵</i>

Scope of application

The Social Security Regulations apply in the EU, EEA⁵⁶ and Switzerland⁵⁷. They apply to all EU/EEA- and Swiss nationals, stateless persons and refugees residing in a MS who are or have been subject to the social security legislation of one or more MSs, as well as their family members and survivors (employees, self-employed persons, students, pensioners, unemployed persons, family members...).⁵⁸

⁵³ Annex V of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).

⁵⁴ Annex III of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).

⁵⁵ In case of a family member or a pensioner (and family members) with residence in another MS than the competent MS and the MS of residence has opted for a system of reimbursement on the basis of fixed amounts (Ireland, Spain, Cyprus, the Netherlands, Portugal, Finland, Sweden, United Kingdom), the prior authorisation will be granted by the institution of the place of residence instead of the competent institution; art. 27, 5° Regulation (EC) No. 883/2004.

⁵⁶ Decision of the EEA Joint Committee No 76/2011 of 1 July 2011 amending Annex VI (Social security) and Protocol 37 to the EEA Agreement (OJ L 262, 6.10.2011, p. 33–43).

⁵⁷ Decision No 1/2012 of the Joint Committee established under the Agreement between the European Community and its MSs, of the one part, and the Swiss Confederation, of the other, on the free movement of persons of 31 March 2012 replacing Annex II to that Agreement on the coordination of social security schemes (OJ L 103, 13.4.2012, p. 51–59).

⁵⁸ Art. 2 Regulation (EC) No 883/2004.

Under Regulation (EU) No 1231/2010, nationals of third countries who are not already covered by the Social Security Regulations solely based on their nationality, as well as the members of their family and their survivors, provided that they legally reside on the territory of a MS, are also covered under the Social Security Regulations. The latter is not the case for Denmark⁵⁹ and the EFTA countries (Norway, Iceland, Liechtenstein and Switzerland).⁶⁰

Unplanned medical treatment in another MS⁶¹

Insured patients (and their families) have the right to medically necessary treatment during a temporary stay in a MS other than the competent MS (i.e. unplanned treatment). In this case, the initial purpose of the stay abroad was not to obtain medical treatment, but rather a business trip, vacation, or family visit.

The insured person has the right to access medically necessary treatment (including necessary treatment as a result of a pre-existent pathology of which the patient is aware, e.g. chronic illness, pregnancy⁶²).⁶³

No prior authorisation is needed. Access to unplanned, medically necessary treatment in another MS is granted on the simple display of a valid European Health Insurance Card (EHIC), issued by the competent MS as proof of social security insurance.⁶⁴

The insured person has the right to reimbursement of medically necessary benefits in kind provided by the institution of stay/treatment that are included in the basket of services of the MS of stay. Benefits in kind provided by a private healthcare provider or in a private hospital are (normally) excluded, as only healthcare provided by a healthcare provider working within the statutory healthcare system are covered.⁶⁵ The costs of the benefits in kind are at the expense of the competent institution.⁶⁶

Regarding the reimbursement, the procedure and the tariffs (including the reimbursement of extra costs) follow the legislation of the MS of treatment.⁶⁷ The reimbursement will not exceed the amount of actual costs incurred by the patient.⁶⁸ Whether the patient has to pay upfront or may enjoy treatment free of charge at the point of use will depend on the legislation of the MS of treatment. The patient may seek reimbursement by the institution of the MS of treatment, or directly by the competent institution upon return home.⁶⁹

Under the condition of agreement of the insured person, the competent institution may apply the rates or amounts that are provided in its own legislation.⁷⁰ When no reimbursement is foreseen in the legislation of the MS of treatment, the competent MS may decide to nevertheless reimburse the costs within the limits of and under the conditions of its own legislation, and this without the agreement of the insured person.⁷¹

As the costs of the cross-border treatment are at the expense of the competent institution, the institution of the place of stay shall be fully reimbursed by the latter. Here two different systems

⁵⁹ Recital 18 and 19 Regulation (EU) No 1231/2010; also the UK has opted out for Regulation (EU) No 1231/2010. However, third country nationals in the UK can continue to benefit from the previous Regulation (EC) No 859/2003: Recital 18 of the Council Regulation (EC) No 859/2003 of 14 May 2003 extending the provisions of Regulation (EEC) No 1408/71 and Regulation (EEC) No 574/72 to nationals of third countries who are not already covered by those provisions solely on the ground of their nationality, (OJ L 124, 20.5.2003, p. 1-3).

⁶⁰ Regulation (EU) No 1231/2010 of the European Parliament and of the council of 24 November 2010 extending Regulation (EC) No 883/2004 and Regulation (EC) No 987/2009 to nationals of third countries who are not already covered by these Regulations solely on the ground of their nationality (OJ L 344, 29.12.2010, p. 1-3) (hereinafter: Regulation (EU) No 1231/2010).

⁶¹ Art. 19 Regulation (EC) No. 883/2004.

⁶² Decision of the Administrative Commission No S3 of 12 June 2009.

⁶³ Art. 19 Regulation (EC) 883/2004.

⁶⁴ The EHIC can't be used by third-country nationals in Denmark, Norway, Iceland, Liechtenstein and Switzerland, unless they are refugees residing in a Member State or are covered as family members of an EU citizen under the Social Security Regulations, as Regulation (EU) No 1231/2010 does not apply for them.

⁶⁵ An exception is made in some cases where the MS envisaged the reimbursement of such benefits in their national health insurance legislation, which is for example the case in Austria, Belgium, Finland and the Netherlands: G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSso, January 2017, 35.

⁶⁶ Art. 19(1) Regulation (EC) 883/2004.

⁶⁷ Art. 19(1) Regulation (EC) 883/2004; Art. 25(A)(2)-(3) Regulation (EC) 987/2009.

⁶⁸ Art. 25 (B)(8) Regulation (EC) 987/2009.

⁶⁹ Art. 25 (B)(4) -(5) Regulation (EC) 987/2009.

⁷⁰ Art. 25 (B) 6) Regulation (EC) No 987/2009.

⁷¹ Art. 25 (B)(7) Regulation (EC) 987/2009.

may apply: reimbursement of actual healthcare expenditures or reimbursement on the basis of a fixed amount.⁷²

Planned medical treatment in another MS⁷³

Insured persons and their family members also have the right to travel to another MS with the purpose of receiving benefits in kind.⁷⁴

However, under the Social Security Regulations, this is only possible under the condition of prior authorisation (S2 form) granted in advance by the competent institution of the MS under whose social security legislation the patient is insured. Here, an exception can be made for family members with residence in another MS than the insured person⁷⁵ or pensioners and their family members with residence in another MS⁷⁶, if this MS of residence has opted for reimbursement on the basis of a fixed amount (Ireland, Spain, Cyprus, Portugal, Sweden, United Kingdom)^{77,78} In this case, the MS of residence shall be competent for the authorisation (i.e. the authorising institution).

The prior authorisation cannot be refused in case two cumulative conditions are met:

- The treatment for which prior authorisation is asked, is included in the basket of services of the institution of the place of residence; and
- The treatment cannot be provided in the MS of affiliation within a medically justifiable time limit, taking into account the current state of health of the patient and the probable evolution of his/her condition.⁷⁹

To obtain prior authorisation, the treatment must be included in the basket of services covered under the social security scheme of the MS of treatment. Besides, the competent institution is not obliged to grant authorisation in case the treatment is not included in its own basket of services. In this case, patients may file a request for authorisation, however, the competent institution will decide at its sole discretion whether or not authorisation will be granted. It can therefore be concluded that in order to obtain authorisation, the treatment in most cases will have to be included both in the basket of services of the MS of treatment and of the competent MS. Similar as for unplanned care under the Social Security Regulations, private care is (normally) not covered. The benefits in kind provided by the institution of the MS of stay, will be at the expense of the competent or authorising institution. The patient will be reimbursed directly by the institution of the MS of treatment, or upon return home by the competent institution.⁸⁰ The reimbursement will take place in accordance with the procedure and tariffs applied in the legislation of the MS of treatment.⁸¹ An exception is made here for the Vanbraekel supplement⁸², which consists of an additional compensation in case the patient has actually borne all or part of the medical costs of the treatment abroad (including co-payment), for which he or she had received prior authorisation (S2 form), and the tariff of the treatment abroad is lower than the costs that the competent institution should have had to assume in case the same treatment would have taken place in the own MS. In this case, the competent healthcare insurer has to reimburse, upon request, the patient up to the extent of the difference between both tariffs/reimbursement rates.⁸³ Furthermore, patients are entitled to reimbursement of costs of travel and stay which are inseparable of the treatment, that are incurred for the patient or for a person who must accompany them, where the national legislation of the competent MS foresees for compensation

⁷² Art. 35 (2) Regulation (EC) 883/2004.

⁷³ Art. 20 Regulation (EC) No. 883/2004.

⁷⁴ Art. 20 Regulation (EC) No. 883/2004.

⁷⁵ For family members of an insured person residing in another MS, which has opted for a system of reimbursement between public health systems on the basis of fixed amounts instead of actual expenditures, the insurance institution of the place of residence will be competent to grant authorisation: art. 20(4) Regulation (EC) 883/2004.

⁷⁶ A same exception is made for pensioners and their family members, who continue to be covered under the social security scheme of a previous MS, but who now reside in another MS which has opted for reimbursement based on fixed amounts: art. 27(5) Regulation (EC) 883/2004.

⁷⁷ Annex III of Regulation (EC) No. 987/2009, consolidated version of 11 April 2017 (last consulted on 19 April 2018).

⁷⁸ Art. 20(4) Regulation (EC) 883/2004.

⁷⁹ Art. 20(2) Regulation (EC) 883/2004.

⁸⁰ Art. 25 (B)(4) - (5) Regulation (EC) 987/2009.

⁸¹ Art. 20(2) Regulation (EC) 883/2004.

⁸² C-368/98 Vanbraekel.

⁸³ Art. 26(7) Regulation (EC) No 987/2009.

of such travel and stay costs in case the treatment would have been provided in the own MS. Directive 2011/24/EU.

With the implementation of Directive 2011/24/EU, patients gained rights to access healthcare abroad next to the already existing possibilities for cross-border healthcare under the Social Security Regulations. The Directive does not deal solely with the access to health services and assumption of costs, but also introduces a minimum set of requirements which apply to all healthcare providers and all health services provided aiming to ensure that patients can effectively exercise these rights in practice. These requirements relate to transparency, information and quality and safety.⁸⁴

The general rule under the Directive is that patients have the right to access health services abroad and to enjoy assumption of costs by their home country as though the treatment was provided in the own MS.

The Directive states that countries have to safeguard the access of foreign patients to health services. Patients may not be discriminated based on their nationality.⁸⁵ Furthermore, HCPs are obliged to apply the same scale of fees for incoming patients as for domestic patients.⁸⁶ In some cases, MSs can limit the access of incoming patients to health services in their country. However, such limitations to foreign patients inflow must be justified based on overriding reasons of general interest, such as planning requirements aiming to ensure a balanced range of high-quality treatment or other measures aiming to sufficient and permanent access to healthcare for domestic patients within its territory.⁸⁷

Under Directive 2011/24/EU, no distinction is made between planned or unplanned care. The Directive covers all healthcare provided in the EU, Norway, Iceland and Liechtenstein⁸⁸, including care provided by a private healthcare provider or in a private hospital.⁸⁹ Under the Directive, telemedicine services are also covered.⁹⁰

Three exceptions are made. The Directive does not apply for:

- Long-term care⁹¹;
- Organ transplantations;
- Public vaccination programs.⁹²

The MS of affiliation (i.e. the MS that is competent to grant authorisation under the Social Security Regulations⁹³) is responsible for reimbursement of cost of cross-border healthcare to the insured person. However, two exceptions are made⁹⁴:

- MSs that have opted for a system of more beneficial rights for pensioners and family members residing in another MS will provide the benefits in kind received in their country, at their own expense (*Belgium, Bulgaria, Czech Republic, Germany, Greece, Spain,*

⁸⁴ Terms of Reference, 2.

⁸⁵ Art. 4(3) Directive 2011/24/EU.

⁸⁶ Art. 4(4) Directive 2011/24/EU.

⁸⁷ Art. 4(3) Directive 2011/24/EU.

⁸⁸ The Directive 2011/24/EU is not applicable in Switzerland. However, in order to harmonise the geographical scope of application of the Social Security Regulations and the Directive, Belgium has decided to apply the national implementation of the Directive also in Switzerland; Circular VI nr. 2011/272 of 30 June 2011 of the National Institute for Health and Disability Insurance (RIZIV).

⁸⁹ Art. 1(2) Directive 2011/24/EU.

⁹⁰ On the contrary, telemedicine is not covered under the Social Security Regulations, as it expressively requires the physical presence of the patient in the MS of treatment: see art. 20 Regulation (EC) 883/2004, Commission staff working document on the applicability of the existing EU legal framework to telemedicine services, 2012, 17.

⁹¹ On the contrary, long-term care benefits are included under Regulation (EC) No 883/2004. Long-term care benefits can be defined under the Regulation as "benefits intended to improve the state of health and quality of life of persons reliant on care, i.e. persons in permanent need to assistance from others in the performance of their daily routine (bodily hygiene, nutrition, moving around, housework, and so on)"(C-160/96 Molenaar). See also the European Commission's proposal to revise Regulation 883/2004, with special attention to improve the current framework for long-term care benefits: Proposal for a Regulation of the European Parliament and of the Council of 13 December 2016 amending Regulation (EC) No 883/2004 on the coordination of social security systems and Regulation (EC) No 987/2009 laying down the procedure for implementing Regulation (EC) No 883/2004.

⁹² Art. 1(3) Directive 2011/24/EU.

⁹³ The competent MS or authorising MS in case of MS with reimbursement based on fixed amounts (see above).

⁹⁴ Art. 7(2) Directive 2011/24/EU.

France, Cyprus, Luxembourg, Hungary, the Netherlands, Austria, Poland, Slovenia and Sweden);⁹⁵

- In case there was no prior authorisation under the Directive or no application of the Social Security Regulations, the competent MS and not the MS of affiliation will ensure the expenditures of the treatment (will only be relevant in case of pensioner residing in another MS under the system of reimbursement based on fixed amount: *Ireland, Spain, Cyprus, Portugal, Sweden, United Kingdom*)⁹⁶.

The cross-border treatment should be among the benefits included in the basket of services of the institution of affiliation.⁹⁷ When this is the case, the institution of affiliation is obliged to assume the medical costs of the treatment abroad, according to the tariffs and rates applied in its legislation. The patient will in general pay the benefits in kind upfront. However, MSs are free to reduce the financial burden of upfront payment on patients.⁹⁸ More specifically, a MS may decide to put in place a mechanism of financial compensation directly between institutions, as provided for in the Social Security Regulations.⁹⁹ Furthermore, MSs are free to reimburse extra costs, such as costs for travel and stay or costs incurred by persons with disabilities, even where such costs are not reimbursed in the case of healthcare provided in their territory.¹⁰⁰

MSs may not limit the patient's right to assumption of costs for treatment abroad, as provided by the Directive. More specifically, reimbursement for cross-border treatment may only be limited based on overriding reasons of general interest.¹⁰¹

Under Directive 2011/24/EU, the general rule is that no authorisation is required. However, the MSs may opt for a system of prior authorisation. In this case, the requirement of prior authorisation will only be possible in case of:

- Healthcare which is subject to planning requirements and which involves an overnight hospital stay or highly specialised and cost-intensive medical infrastructure and equipment;
- Safety-risk for the patient or the public population;
- Treatment provided by a healthcare provider that could give rise to serious and specific concerns relating to quality or safety¹⁰².

Any system of prior authorisation must be necessary and proportionate to the objective to be achieved and may in no case constitute a means of arbitrary discrimination or an unjustified obstacle to the free movement of persons.¹⁰³ MSs are obliged to make publicly available which health services are subject to prior authorisation.¹⁰⁴ Almost all MSs have opted for a system of prior authorisation under Directive 2011/24/EU.¹⁰⁵ MSs have no absolute discretion in declining a request for authorisation.

Authorisation may not be refused in case the patient is entitled to the treatment in the MS of affiliation and cannot receive the treatment concerned on the own territory of the MS within a time limit that is medically justifiable, taking into account the patient's specific current, future or past health situation, the degree of the patient's pain and the nature of the patient's disability.¹⁰⁶

In addition, the grounds of refusal are limited as well:

- Patient-safety risk;
- Safety-risk for the general public;

⁹⁵ Annex IV of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).

⁹⁶ Annex III of Regulation (EC) No. 987/2009, consolidated version of 1 January 2018 (last consulted on 19 April 2018); Note; Sections "The Netherlands" and "Finland" will be deleted as from 1 January 2018: Commission Regulation (EU) 2017/492 of 21 March 2017.

⁹⁷ Art. 7(1) Directive 2011/24/EU.

⁹⁸ EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare: Legislation Guidance for Patient Organisations, EPF, November 2013, 9.

⁹⁹ Art. 9(5) Directive 2011/24/EU.

¹⁰⁰ Art. 7(4) Directive 2011/24/EU.

¹⁰¹ Art. 7(9) Directive 2011/24/EU.

¹⁰² Art. 9 Directive 2011/24/EU.

¹⁰³ Art. 8 (1) Directive 2011/24/EU.

¹⁰⁴ Art. 8 (7) Directive 2011/24/EU.

¹⁰⁵ Did not opt for a system of prior authorisation: CZ, EE, FI, LT, NL, NO, SE.

¹⁰⁶ Art. 9(5) Directive 2011/24/EU.

- Treatment that is considered not to be in accordance with standards and guidelines of quality care and patient safety;
- If the benefits in kind concerned can be provided on the own territory within a medically justifiable time limit, taking into account the current state of health and the probable course of the illness of the patient concerned.¹⁰⁷

4.1.2. Social Security Regulations versus Directive 2011/24/EU¹⁰⁸

Table 4.3 presents the main distinctions between the Social Security Regulations and the Directive.

Glossary Table 4.4

- Basket of services = Entire range of sickness benefits in kind that the insured population is entitled to;
- Institution of the place of stay = the institution in the MS where the healthcare was provided, i.e. the institution in the MS of treatment;
- Competent institution = Institution with which the patient concerned is insured (most often the institution of the MS where the person is employed);
- Authorising institution = Institution of residence that, due to a system of fixed amounts (i.e. Ireland, Spain, Cyprus, Portugal, Sweden and the United Kingdom,¹⁰⁹ instead of the competent institution is competent to grant prior authorisation to family members residing in another MS than the insured person;
- Institution of affiliation = institution that is competent for prior authorisation according the Social Security Regulations.

Table 4.3 Distinction between Social Security Regulations and Directive 2011/24/EU regarding cross-border healthcare during a temporary stay in another MS¹¹⁰

	Social Security Regulations		Directive 2011/24/EU
Scope of application	EU + EFTA + Swiss EU-/ EEA-/ Swiss- nationals + family members Third country nationals + family members (not Denmark).		EU + EFTA EU-/ EFTA- nationals + family members Third country nationals + family members (also Denmark).
Benefits in kind	Unplanned medically necessary treatment.	Scheduled treatment (included in the social security scheme).	All treatment, including telemedicine Excluded: Long-term care Organ transplantation Public vaccination.
provided by	Institution of place of treatment.	Institution of place of treatment.	Institution of place of treatment.
on behalf of	Competent institution.	Competent institution (or authorising institution) ¹¹¹ .	Institution of affiliation

¹⁰⁷ Art. 9(6) Directive 2011/24/EU.

¹⁰⁸ Carrascosa Bermejo, D., Cross-border healthcare in the EU: Interaction between Directive 2011/24/EU and the Regulations on social security coordination, ERA Forum 2014,15(3): p. 359-380.

¹⁰⁹ Annex III of Regulation (EC) No. 987/2009, consolidated version of 1 January 2018 (last consulted on 19 April 2018).

¹¹⁰ Based on the scheme provided by D. Carrascosa Bermejo; Carrascosa Bermejo, D., Cross-border healthcare in the EU: Interaction between Directive 2011/24/EU and the Regulations on social security coordination, ERA Forum 2014,15(3): 378. doi:10.1007/s12027-014-0358-8, although we modified the scheme and made it more detailed.

¹¹¹ For family members of an insured person who reside in another MS than the competent MS or for pensioners and family members residing in another MS than the competent MS, and the MS of residence is a MS who opted for the system of reimbursement on the basis of fixed amount (IE, ES, CY, NL, PT, FI, SE, UK), the latter will bear the costs of the benefits instead of the competent MS (art. 20,(4) and 27(5) Regulation (EC) No. 833/2004).

	Social Security Regulations		Directive 2011/24/EU
			(or Competent institution) ¹¹² .
<i>Basket of benefits</i>	Institution of place of stay.	Institution of place of treatment/Competent institution.	Institution of affiliation.
<i>Private care?</i>	No.	No.	Yes.
<i>Authorisation</i>	No authorisation, EHIC. (! For retired frontier workers, S3 form)	Prior authorisation, S2 form Issued by competent institution (or authorising institution ¹¹³).	Depends on implementation ¹¹⁴ ; Issued by institution of affiliation ¹¹⁵
<i>Payment procedure</i>	Institution of place of treatment (upfront payment or free of charge at point of use, depending on which applied in its legislation).	Institution of place of treatment (upfront payment or free of charge at point of use, depending on which applied in its legislation).	Upfront payment by the patient.
<i>Reimbursement Procedure</i>	Reimbursement between institutions Reimbursement to patient in case of upfront payment.	Reimbursement between institutions Reimbursement to patient in case of upfront payment.	Reimbursement to patient.
<i>Rates</i>	Institution of place of treatment/competent institution in case the patient agrees (or actual costs).	Institution of place of treatment (+ <i>Vanbraekel suppl.</i>) (or actual costs).	Institution of affiliation (or actual costs).

Priority of the Social Security Regulations

When a patient requests prior authorisation and the conditions for granting prior authorisation under the Social Security Regulations are met (treatment covered in the patient's home country, that cannot be provided in the own territory within a medically justifiable time limit), the authorisation will automatically be granted under the Social Security Regulations (on issuance of an S2 form). Directive 2011/24/EU will only apply on explicit request of the patient.

Interaction between both instruments

The Social Security Regulations will apply exclusively:

- In third countries under the external dimension of the Social Security Regulations;
- In case of cross-border healthcare in Switzerland;
- In case of long-term care, organ transplantation, public vaccination programmes.

The Directive 2011/24/EU will apply exclusively in case of:

- Cross-border healthcare provided by a private healthcare provider or in a private hospital (not contracted/affiliated with the social security system);
- In case of telemedicine services;

¹¹² Two exceptions apply where the benefits are provided at the expense of the competent institution instead of the authorising institution: 1° Pensioners and their family members residing in another MS than the competent MS, and the competent MS is BE, BG, CZ, DE, EL, ES, FR, CY, LU, HU, NL, AT, PL, SI or SE, will be entitled to receive benefits in kind under the Directive in the competent MS, at its own expense, as though the person concerned was a resident in that MS; 2° In case no prior authorisation is needed under the Directive and the healthcare is not provided in accordance with the Regulations, pensioners and family members residing in another MS (IE, ES, CY, NL, PT, FI, SE, UK) are entitled to receive benefits in kind under the Directive in the competent MS, at its own expense; art. 7(2)(b) and Regulation (EC) No. 883/2004.

¹¹³ In case the MS of residence that is responsible for the costs in according with the situations provided in art. 20 (4) and 27 (5), the institution of the place of residence will grant the prior authorisation (i.e. authorising institution).

¹¹⁴ Did not opt for a system of prior authorisation: CZ, EE, FI, LT, NL, NO, SE.

¹¹⁵ Authorisation will be granted by the competent institution or unless in case of applicability of art. 20 (4) or 27(5) Regulation (EC) No. 883/2004, by the institution of residence.

- Third country nationals in Denmark.

4.2. Previous findings on Directive 2011/24/EU

Member States were required to transpose Directive 2011/24/EU into national law by 25 October 2013. Several reports have been published with respect to the implementation of Directive 2011/24/EU and its application in practice.

The key findings are presented below for some reports on Directive 2011/24/EU:

- Evaluative Study of March 2015 (4.3.1.);
- Special Eurobarometer 425 of May 2015 (4.3.2.);
- Commission report of September 2015 (4.3.3.);
- Member State data: year 2015, report of October 2016 (4.3.4.);
- FreSsco Analytical Report 2016 of January 2017 (4.3.5);
- Stevens report on the implementation of the European Disability Strategy of October 2017(4.3.6);
- ANEC report of January 2018 (4.3.7).
- Member State data: year 2016 (4.3.8).

4.2.1. Evaluative Study of March 2015

The Evaluative Study on the Cross-border Healthcare Directive, commissioned by the European Commission, aimed at analysing the implementation and functioning of the Directive 2011/24/EU by means of a number of evaluative questions, presented according to three main areas: "Reimbursement", "Quality and Safety" and "Undue delay". The study was carried at EU-28 level. However, for different tools (e.g. pseudo-patient investigation) a limited number of 12 focus countries was used. The reported findings are based on data collected for the year 2014.¹¹⁶

Different stakeholders were involved in the study, such as NCPs, HCP organisations, individual health insurance providers, patient groups and national authorities. The study included desk research and a literature review, an online survey of NCPs, interviews with stakeholders, a website analysis of 32 websites, a pseudo-patient investigation, and a SWOT analysis focussing on the services provided to patients.

The study reported to be hampered by a lack of quantitative data available on cross-border healthcare. Analysis of patient mobility and flows was therefore not performed. The study was not able to present quantitative findings on the full effect of the implementation of Directive 2011/24/EU. However, some important qualitative insights on the implementation and on the main trends and obstacles in cross-border healthcare were provided.¹¹⁷

One of the key findings regarding reimbursement was the lack of awareness of patients on the possibilities of accessing health services abroad under Directive 2011/24/EU and on the existence of NCPs. Public campaigns to inform the general public took only place during a short period of time after the transposition of the Directive. The general lack of awareness can explain the low number of information requests made to NCPs, as well as the limited number of requests for reimbursement. Overall, the study reported that patients are provided information on reimbursement in a consistent way and with a satisfactory level of detail when they request so. However, detailed information on the treatments for which patient should requests prior authorisation is often lacking. This can explain why a number of health insurers indicated that patients are often not aware which health services are subject to prior authorisation. In certain cases, health insurers reported a high administrative burden, resulting from translation costs (when this burden is not placed on the patient him or herself) and the review of medical documents. Furthermore, some disparities are reported between the information provided by NCPs and by health insurance providers. The study suggested the need for better coordination of

¹¹⁶ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.

¹¹⁷ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 22-23.

information provision. On their turn, patients are responsible for providing the necessary documentations in order to receive reimbursement.

The ultimate responsibility of finding information on treatment possibilities lies with the patient that seeks treatment abroad. With regard to quality and safety, the Evaluative Study reported the lack of comprehensive and comprehensible information. The information provided was often too general and too complex. However, the interviews showed that quality and safety was not a key driver in patients' choices in accessing health services abroad. Information on procedures in case of malpractice is often also lacking. Interviews with prescribers and HCPs seemed to indicate that the right to follow-up care is always guaranteed. The study reported that there are no administrative problems incurred by stakeholders with regard to quality and safety. NCPs cooperate actively with government organisations, health insurance providers and HCPs. The level of cooperation with patient organisations varies between MSs. When health insurers wish to obtain information on a specific healthcare provider's registration and authorisation status, they contact the NCP or the treating healthcare provider abroad directly.

Finally, the study reported that a number of MSs provide information on waiting times. However, undue delay is most often assessed on a case-by-case basis. Most patients seem to be aware of their waiting time when seeking treatment abroad.

The study concludes the need for more targeted and regular publicity and communication strategies. Raising awareness on patients' rights and entitlements will enhance uptake of Directive 2011/24/EU. Furthermore, it recommends the provision of information on procedures, individual time lines and administrative aspects, as well as expanding the information provided on NCPs' websites by defining standard requirements, with the involvement of patient organisations.¹¹⁸

4.2.2. Special Eurobarometer 425 of May 2015

The Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union of May 2015 explores the awareness on patients' rights in cross-border healthcare amongst EU citizens.¹¹⁹ The survey assesses:

- how many respondents have already received treatment in another Member State in the past year and their experiences with cross-border healthcare;
- the willingness of citizens to access health services abroad and what they see as the main obstacles for cross-border treatment;
- citizens awareness on their rights and entitlements under Directive 2011/24/EU;
- information provision in cross-border healthcare and the role of national contact points.

The survey was commissioned as a follow up to the previous conducted Flash Eurobarometer survey of 2007 on cross-border health services in the EU¹²⁰, in order to assess the situation of cross-border healthcare after the enforcement of the Directive. The survey was conducted using the face-to-face methodology (different from the methodology used in the 2007 survey, where a telephone survey was used). The fieldwork was carried out in October 2014. In total, 27,868 respondents of different social and demographic groups were included in the survey. A face-to-face interview was conducted at each respondent's home in their mother tongue.¹²¹

Only a small number of respondents (5%) had received cross-border treatment in the last year (regardless of the applicable legislative framework). Only 2% of these received planned treatment. No significant increase was determined compared to the results of the previous survey of 2007, which indicated that 4% had accessed healthcare abroad in the 2007. Of the 5% of citizens that had received treatment abroad in the year 2014, a vast majority (69%) stated to not have encountered any problems with regard to obtaining reimbursement.¹²²

Around one out of two respondents (49%) indicated to be willing to access health services in another MS, a lower share than in 2007 (53%). The main reasons for citizens to consider

¹¹⁸ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 14-15.

¹¹⁹ European Commission, Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European union: Report, may 2015, p. 54; European Commission, Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European union: Summary, may 2015, p. 23.

¹²⁰ European Commission, Flash EB N°210 Eurobarometer, Cross-border health services in the EU: analytical report of May 2007, available at http://ec.europa.eu/commfrontoffice/publicopinion/flash/fl_210_en.pdf.

¹²¹ European Commission, Special Eurobarometer 425: summary, 2-3.

¹²² European Commission, Special Eurobarometer 425: summary, 4-5.

treatment abroad were to receive treatment that was not available in the respondent's home country or to receive better quality treatment. Other reasons were to receive treatment from a renowned specialist, to receive treatment more quickly and to receive better value for money treatment. Satisfaction with treatment received at home and convenience were given as main reasons for not seeking treatment abroad¹²³.

Furthermore, the survey showed that most respondents were only partially aware of their rights and entitlements to access health services abroad. Most of them knew that it was possible to be treated abroad and be reimbursed, although they were not clear on how to go about it. The majority, however, did know that they had the right to enjoy assumption of costs by their home country. Less than 30% of the respondents knew about their right to present prescriptions issued abroad. Most respondents stated to be aware of their right to access their medical records. However, confusion exists on the types of treatment that are subject to prior authorisation.¹²⁴

Fewer than two out of ten citizens consider themselves to be informed on their rights and entitlements to assumption of costs of treatment received abroad. Furthermore, only one out of ten have heard on the existence of NCPs.¹²⁵

4.2.3. Commission report of September 2015

In September 2015, the European Commission published its first report to the European Parliament and the Council on the implementation of Directive 2011/24/EU (in the light of the reporting obligation every 3 years under art. 20(1) Directive 2011/24/EU). The report sets out the state of transposition at that time, and covers the most relevant provisions, such as prior authorisation, patient mobility, reimbursement and information provision. Data were collected directly from the MSs based on a questionnaire. Furthermore, MSs were asked to participate in a data collection exercise on patient flows. The report is drawn based on data of the year 2014. A total of 26 out of 28 EU MSs provided data.

The report shows that only a limited number of patients made use of their rights to access health services abroad in 2014. The general low numbers of patients seeking treatment abroad appears to be equally the case for planned care under the Social Security Regulations.¹²⁶ More specifically, data from 17 MSs¹²⁷ showed that there were only 560 applications for prior authorisation under Directive 2011/24/EU, of which 360 were granted. Two MSs did not even receive any request for prior authorisation in 2014. Two other MSs only received one single request each.¹²⁸ For treatment that is not subject to prior authorisation, great differences are shown in the number of received requests for reimbursement. For 20 MSs¹²⁹, a total of 39,826 requests for reimbursement were made. Of this total, Denmark alone accounted for 31,032 requests. Four MSs granted more than 1,000 requests. However, 14 MSs granted fewer than 100 requests and six of them did not record any reimbursement under the Directive.¹³⁰

With regard to processing times, nine out of 16 responding MSs reported an average processing time limit of 20 days or fewer for requests for prior authorisation. Only three MSs reported time limits of 30 days or more. Four out of 15 MSs reported an average time limit of 20 days or fewer for processing a request for reimbursement for treatment not subject to prior authorisation. Three reported an average time limit of 80 days or more.¹³¹

The report was able to identify and define the existence of some significant barriers to patient mobility in a number of MSs, sometimes even resulting from intentional political choices. Firstly, the report showed that a high number of MSs does not fulfil their obligation arising from article 8(7) Directive 2011/24/EU, that provides for the obligation to make publicly available which health services are subject to prior authorisation. Furthermore, the report questions whether a system

¹²³ European Commission, Special Eurobarometer 425: summary, 6-9.

¹²⁴ European Commission, Special Eurobarometer 425: summary, 10-14.

¹²⁵ European Commission, Special Eurobarometer 425: summary, 15 and 18.

¹²⁶ Commission Report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare of September 2015, 7-8.

¹²⁷ Of the MSs that have installed a system of prior authorisation under Directive 2011/24/EU, only 17 were able to present data for the year 2014 (one MS was able to present data, but could not make a difference between the data of prior authorisation under Directive 2011/24/EU and under the Social Security Regulations (Commission report on the operation of Directive 2011/24/EU of September 2015, 7).

¹²⁸ Commission report on the operation of Directive 2011/24/EU of September 2015, 7.

¹²⁹ Of the 26 MSs that have responded to the question concerned, only 23 were able to provide complete data on reimbursement of health services not subject to prior authorisation. Three of them were not able to present aggregated data for Directive 2011/24/EU and the Social Security Regulations.

¹³⁰ Commission report on the operation of Directive 2011/24/EU of September 2015, 7.

¹³¹ Commission report on the operation of Directive 2011/24/EU of September 2015, 16-18.

of prior authorisation overall is indeed justified for a number of MSs. As a system of prior authorisation needs to be justified based on overriding reasons of general interest, it may be questioned whether these conditions are met in cases where MSs yearly receive none or only few requests for prior authorisation.¹³² Furthermore, one MS reported to require patients to obtain prior authorisation for every type of health service, with the exception of one specialist consultation abroad per year per patient.¹³³

The report also shows some limitations in reimbursement. For example, some MSs set the tariff applied for assumption of costs for domestic care provided by a private or non-contracted healthcare provider as reference for reimbursement (which is considerably lower than the tariff for healthcare provided by a public or contracted provider as subscribed by article 7(4) Directive 2011/24/EU). Three MSs also require the patient to demonstrate why it was medically necessary to receive the treatment abroad. Furthermore, some MSs with a domestic system of referral only accept referrals for treatment abroad made by a GP in their country, which may be considered as in violation of Directive 2005/36/EC on the mutual recognition of professional qualifications. When a referral system applies, referral of a foreign GP must be considered equally. However, five out of 12 MSs with a domestic referral system, only recognise referrals made by a local GP. Finally, some MSs report burdensome administrative requirements, which may deter patients from seeking treatment abroad. At least four MSs oblige patients to present sworn translations. One MS even reported to require patients to get all documents certified by their consul in the country of treatment.¹³⁴

The limited number of requests for prior authorisation and reimbursement may also explain the limited number of information requests NCPs received in 2014. Based on the data of 24 MSs, 109,223 information requests were recorded. Five MSs reported fewer than 100 information requests in 2014. Ten other MSs reported to have received more than 1,000 requests. Three MSs alone accounted for nearly 77,345 requests, which may be explained by the fact that these countries also included the number of website visits in the total amount of requests. Overall, most patients made use of the NCP service by consulting the NCP website, followed by contacting the NCP via telephone, via e-mail and, finally, via face-to-face contact.

The report concludes that many MSs encounter difficulties in data collection, in particular MSs with insurance based systems that have to depend on a number of various competent institutions to provide relevant data. Furthermore, a number of MSs was not able to provide data for a whole year, as the implementation of the Directive was not yet finalised in the beginning of 2014. The report stated that therefore it was difficult to obtain comparable data between MSs.¹³⁵

4.2.4. Member State data: year 2015, report of October 2016

The report on MS data on cross-border healthcare following Directive 2011/24/EU for the year 2015, was intended to follow up on the implementation of the Directive.¹³⁶ With this purpose, a questionnaire was sent to all 28 EU MSs, Iceland and Norway. In total, 23 MSs participated. The questionnaire contained five sections with questions relating to different aspects of Directive 2011/24/EU:¹³⁷

- National contact points;
- Limitations for patient inflow;
- Healthcare subject to prior authorisation;
- Healthcare not subject to prior authorisation;
- Additional information.

¹³² Commission report on the operation of Directive 2011/24/EU of September 2015, 5.

¹³³ Commission report on the operation of Directive 2011/24/EU of September 2015, 4.

¹³⁴ Commission report on the operation of Directive 2011/24/EU of September 2015, 6-7.

¹³⁵ Commission report on the operation of Directive 2011/24/EU of September 2015, annex A, 16.

¹³⁶ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, p. 37.

¹³⁷ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 6.

No comparison is made with the data of 2014 (European Commission report of September 2015). Since the Directive was transposed at different points in time, most MSs could not provide data for the entire year 2014. In addition, many MSs were only able to provide partial data for 2014.¹³⁸

The number of information requests NCPs received in 2015 varied amongst MSs (ranging from 13 to 31,736; mean: 428). Seven MSs reported to have received more than 1,500 information requests. Poland stands out with a total of 31,736 requests. Most requests were made via the telephone, and secondly, in writing. In some MSs, requests were also made in person. The report states that these figures must be analysed in the light of the total number of insured persons. In addition, some MSs indicated that they encountered difficulties in collecting all these data. It is also likely that requests outside the scope of Directive 2011/24/EU (e.g. on the S2 form) are included in the data provided by some states.¹³⁹

Article 4(3) of Directive 2011/24/EU provides MSs the possibility to limit patient inflow where it is justified by overriding reasons of general interest, such as planning requirements to ensure domestic patients of sufficient and permanent access to healthcare. Six out of 23 MSs indicated to have implemented mechanisms that can be used to limit the access to healthcare of foreign patients. However, these mechanisms were not put into practice.¹⁴⁰

Regarding healthcare subject to prior authorisation, some MSs reported difficulties in separating requests for authorisation dealt with under Directive 2011/24/EU and requests dealt with under the Social Security Regulations. As a result, the report cautions for the importance to analyse the results in relation to the number of prior authorisation requests under the Social Security Regulations. In addition, the figures should be analysed taking into account the total number of insured persons. A majority of MSs received less than 100 requests for prior authorisation under Directive 2011/24/EU. The highest number of requests received by a MS was 334. On average, 50.2% of the requests was authorised and two MSs stand out with a very limited number of authorised requests (7.7% and 8.3%).¹⁴¹

Most requests for prior authorisation concerned health services subject to planning requirements, involving an overnight hospital stay. Most requests were made to seek healthcare in bordering MSs. Besides, most requests have been authorised for cross-border healthcare in Germany.¹⁴²

The average processing time for a request for authorisation varied widely, from three working days to 3.4 months. Also the maximum time limits set differ strongly between MSs (from five working days to 60 days). Five MSs reported that no maximum time limit was in place.¹⁴³ The average processing time for reimbursement varied widely between MSs, ranging from four days to ten months. The maximum time limits also varied widely from 20 working days to 90 days or three months.¹⁴⁴

With regard to healthcare not subject to prior authorisation, a total of 11 MSs reported to have installed a system of prior notification. The numbers of reimbursement are low in most MSs. Two MSs are an exception to this rule with more than 30,000 requests each. On average 78% of the requests was granted.¹⁴⁵ The average processing time for requests for reimbursement for health services not subject to prior authorisation differs widely from 11 working days to ten months. The same applies for the maximum time limits (from 20 working days to 90 days or three months). Nine MSs reported that they did not set a maximum time limit.¹⁴⁶

4.2.5. FreSsco Analytical Report 2016 of January 2017

The Analytical Report of FreSsco (i.e. a network of independent legal experts in the fields of free movement of workers and social security coordination within the EU) of 2016 analyses the legal framework for cross-border healthcare under EU law: both under the Social Security Regulations

¹³⁸ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 6.

¹³⁹ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 8-9.

¹⁴⁰ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 10.

¹⁴¹ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 11-13.

¹⁴² Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 13-14.

¹⁴³ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 12-13.

¹⁴⁴ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 17.

¹⁴⁵ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 19-20.

¹⁴⁶ Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 20-21.

and under Directive 2011/24/EU.¹⁴⁷ The report aims to identify the current obstacles in cross-border healthcare and to make some proposals for policy review. The research draws on previous studies. The report aims to look in depth into certain aspects of cross-border healthcare and to analyse new legal aspects resulting from recent CJEU case law and the adoption of Directive 2011/24/EU.¹⁴⁸ The analytical report makes a distinction between two scenarios of treatment in another MS:

- Access of EU nationals to healthcare in the MS of residence;
- Access to healthcare in another MS than the MS of social security insurance or national health services coverage.

In the report, the legal framework regarding accessing health services that is applicable on EU citizens and EU mobile patient is set out in detail. Different scenarios of insured persons are envisaged: employees, self-employees, students and non-active persons.

The report concludes that cross-border healthcare is regulated by a broad legal framework in which interaction of distinctive legal instruments is highly complex: Cross-border Healthcare Directive 2011/24/EU, Social Security Regulations, Residence Directive 2004/38/EU, Free Movement of Workers Regulation (EU) No 492/2011, the Treaties, national legislation, bilateral agreements and so on. In addition, the distinctive rules applied for planned and unplanned treatment under the Social Security Regulations and the lack of such rules under the Directive 2011/24/EU may also be considered as too complex and controversial. The report sets out a number of proposals for policy review, such as:¹⁴⁹

- Complete, clear and easily accessible information must be provided across the EU, in a uniform manner (e.g. through the establishment of an NCP at EU level);
- It should be considered to implement the rules on planned and unplanned cross-border healthcare in one single legal instrument. If this is not feasible, then it is recommendable to clarify rules in the Directive regarding unplanned treatment, as well as clarifying the interaction between the Regulations and the Directive;
- Uniform maximum waiting time limits for receiving treatment must be set at EU level;
- MSs must precisely determine which health services are subject to prior authorisation;
- A standardised invoicing system could solve the problems arising from different invoicing methods amongst MSs;
- Mechanisms should be set in place to safeguard that provisions derived from purely national legislation that provides more beneficial rights to patients than the EU legal instruments, shall be of preferential application;
- Mechanisms should be set in place to avoid that mobile patients are treated as private patients charged with higher supplements, which have to be paid directly, including the establishment of clear and transparent procedures for complaint;
- Reimbursement rules should be unified and *reverse discrimination*¹⁵⁰ of national patients must be prevented;
- NCPs should work more closely, both with European and national institutions involved, and with each other;
- Training opportunities should be offered for healthcare professionals and for other staff members of HCPs to enable them to provide patients with the required information;
- As long as no single EU website is established, the information provided on the distinctive NCP websites should be standardised and should provide the same level of information in the official languages as in other languages (especially in English);
- A smartphone application similar to the European Commission's EHIC-app could be developed.

¹⁴⁷ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, p. 101.

¹⁴⁸ Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 10.

¹⁴⁹ Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 92-95.

¹⁵⁰ *Reverse discrimination* refers to the event where a patient finds him or herself in a purely national legal situation. In this case only national legislation can be invoked which might turn out to be less favourable than EU law. Reverse discrimination occurs for example where national law does not foresee in the reimbursement for healthcare provided by a purely private healthcare provider, but this would be possible when accessing healthcare abroad under Directive 2011/24/EU; Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 83-85.

4.2.6. Stevens report on the implementation of the European Disability Strategy of October 2017

On 30 October 2017, the Stevens report on the implementation of the European Disability Strategy was published.¹⁵¹ The amendments proposed in the report are drafted in close consultation and collaboration with disability organisations, including the European Disability Forum's (EDF). The report is divided within four topics:

- Key areas for action;
- Obligations within the EU institutions;
- Gaps in the progress report vis-à-vis the concluding observations;
- Outlook to the new 2030 Disability Strategy.

The report calls on MSs to fully implement Directive 2011/24/EU, taking into account the needs and rights of patients with disabilities. In addition, the report recommends the European Commission to include a strong disability component in the transposition of the Directive in order to guarantee affordable and quality treatment abroad for patients with disabilities. An impact assessment should be conducted aiming to bring the Directive in line with the UN Convention on the Rights of Persons with Disabilities (CRPD) and to prepare EU-wide guidance on mainstreaming disability in the work of the NCPs with common performance criteria, including disability-specific recommendations. MSs are also encouraged to provide appropriate education and training to HCPs on the specific needs of patients with disabilities.¹⁵²

The report stresses the low level of awareness and uptake of the provisions on patients' rights and entitlements to cross-border treatment among patients with disabilities and the need for the European Commission and MSs to work closely with disability organisations to ensure that NCPs provide information that is easily accessible. The authors of the report take the view that in order to ensure a non-discrimination application of the Directive, MSs should take action in establishing mechanisms for the reimbursement of additional costs related to disabilities when patients with disabilities are unable to afford such costs. HCPs should also be educated and trained in providing patients with disabilities with information on their rights and entitlements under the Cross-border Healthcare Directive. The role of NCPs in the provision of such information should also be clarified and enhanced. Special attention should be given to information on quality and safety standards and assistance in making health choices.¹⁵³

4.2.7. ANEC report of January 2018

In January 2018, a report on the consumer attitudes and experiences in accessing medical treatment in other EU countries, commissioned by ANEC (The European Consumer Voice in Standardisation), was published.¹⁵⁴ *The study aims to "investigate the consumer experience of using healthcare services located in other European countries, with a view to informing current and future standards work in this area".*¹⁵⁵ The main tasks were described as follow:¹⁵⁶

- Identifying the existing rules and standards;
- Collect data about the experience of EU consumers;
- Identify common issues and obstacles;
- Define a list of common consumer needs.

¹⁵¹ H. Stevens, Report on implementation of the European Disability Strategy (2017/2127/(INI)), committee on employment and social affairs, October 2017, p 80.

¹⁵² Report on implementation of the European Disability Strategy, October 2017, 17.

¹⁵³ Report on implementation of the European Disability Strategy, October 2017, 17.

¹⁵⁴ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, p. 55.

¹⁵⁵ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 7.

¹⁵⁶ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 7.

The study focusses on consumer attitudes and experiences of both unplanned and planned care.¹⁵⁷ In the light of the current study, only the key findings with regard to planned care are set out below.

Two surveys were carried out: a consumer survey and a healthcare provider survey sent to NCPs. In addition, a review of legal texts (both Directive 2011/24/EU and the Social Security Regulations) and a literature review were conducted as well as secondary research to identify any existing standards in practice relevant to cross-border healthcare and to collect existing complaints data.¹⁵⁸

The URL of the online consumer survey was sent to consumer and healthcare organisations in 15 EU countries during August and September 2017. In total 1,656 respondents participated in the survey. Most of the respondents were from the UK (60%). While 37% of the respondents had received unplanned treatment, only a very limited number of respondents had sought planned treatment abroad (4%). In total, 47 experiences (events) of planned treatment, occurring within the last five years, were included. As a result, for planned treatment the sample size was considered to be too small to allow robust quantitative conclusions to be drawn. However, the survey generated a lot of valuable qualitative evidence in the form of open comments. These comments are used throughout the report to corroborate quantitative findings.¹⁵⁹

The study suggests that EU citizens lack knowledge and awareness of their rights and entitlements in cross-border healthcare, which can be considered as a major barrier for uptake of the EU legislation. 82% of the respondents indicated to be aware of their right to access health services abroad, both in case of planned and unplanned care. However, the findings showed that the awareness of rights relating to planned treatment abroad was much lower than for unplanned treatment. Only 47% of the respondents know they have the right to enjoy assumption of costs by their own health insurance provider for certain health services received abroad. The report stresses that this is in line with the findings of the Eurobarometer 425 of 2015¹⁶⁰ that stated that fewer than two out of ten patients feel they are informed on their rights. Furthermore, a low level of awareness of NCPs was shown (25%). Nevertheless, as the Eurobarometer 425 of 2015 found that only one out of ten respondents had heard of NCPs, a small increase in the level of awareness of the existence of NCPs is determined.¹⁶¹

Patients who had not received planned treatment abroad, were asked how likely they would be to do so in the future. 53% of the respondents would not consider seeking healthcare abroad. The main reason given for not considering planned treatment in another country was concerns about redress in case something goes wrong (57%). The second most common reason was the lack of awareness of patients' rights to cross-border healthcare (48%). In addition, 37% of the respondents would not consider treatment abroad as they are satisfied with medical treatment in their own country. Of the respondents that answered the question positively, the most stated reason to consider treatment abroad was to receive treatment that is not available in the patient's home country (57%). Other reasons mentioned were to receive treatment from a renowned specialist (40%) and to receive better quality treatment (37%).¹⁶² In the NCP survey, NCPs identified problems with language, lack of awareness, treatment costs, advance payments, lack of reimbursement of travel costs and geographical and cultural barriers as main obstacles deterring patients from seeking planned treatment abroad.¹⁶³

Only 4% of the respondents had received planned treatment abroad (either under Directive 2011/24/EU or under the Social Security Regulations and regardless of funding). The main reasons why patients sought access to health services abroad were to receive treatment more quickly (28%), to receive cheaper treatment (22%) and to receive better quality treatment (20%). The survey reveals that knowledge and awareness of rights, and confidence in quality and safety, can be considered key facilitators in seeking treatment abroad. The survey shows that

¹⁵⁷ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 7.

¹⁵⁸ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 8.

¹⁵⁹ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 9.

¹⁶⁰ European Commission, Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European union: Report, may 2015, p. 54.

¹⁶¹ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 16.

¹⁶² ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 18-19.

¹⁶³ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 19.

only 4.3% of the respondents who had received planned treatment had contacted an NCP for information.¹⁶⁴

The majority of the respondents that had received planned treatment was satisfied with the level of information provided. Most respondents were also highly satisfied with the level of care they had received.¹⁶⁵ However, 27.7% of the respondents claimed to have experienced problems. The most common problems reported were language and communication difficulties. Other problems were problems with regard to payment issues and quality of treatment.¹⁶⁶

Due to the limited level of patient awareness on their rights and entitlements, patients seem to be pushed towards paying for the treatment privately. A total of 40.4% of the respondents had paid for the treatment privately, without filing for reimbursement under Directive 2011/24/EU. Only 6.4% of the respondents had their costs funded by their private health insurance. Altogether, 34.1% received full or partial reimbursement. However, several of them indicated that they found the reimbursement process to be complicated and confusing.¹⁶⁷

None of the respondents who had experienced problems made an official complaint. Reasons given were that it seemed to be too complicated and difficult. In addition, respondents stated that they were reluctant to complain as they thought that their claim would probably not be successful. The study also highlighted confusion amongst respondents about where to direct a complaint. The report indicated that NCPs that had participated in the NCP survey were not able to provide any statistical data on complaints. **The report concluded there is a general lack of consistent and comparable empirical data on complaints.**¹⁶⁸

The survey concludes that while access to unplanned treatment appears to be working relatively well, much improvement is needed regarding access to planned treatment abroad. The report sets out a number of recommendations, such as:¹⁶⁹

- Measures should be taken to raise awareness of patients' rights to assumption of costs for treatment abroad. The European Commission should adopt a clear strategy to "proactively" raise awareness of consumers' rights and entitlements to access health services abroad and to promote the existence of NCPs;
- Improve cooperation between NCPs, with a central coordinating body;
- Develop a clear code of practice for NCPs, aiming to establish a more uniform practice of NCPs and to ensure consistency in procedures and data collection. In addition, minimum requirements for NCPs should be stipulated at EU level, such as time limits for processing requests for reimbursement;
- In addition to information on rights and entitlements, information on the advantages of cross-border healthcare, patient satisfaction and experiences should also be provided;
- Research should be conducted to explore the options for an independent and central source of information about healthcare providers in the EU, enabling patients to easily make comparison and map their options;
- Information and documents should be provided in the patient's language. Interpreting services should be made available when necessary;
- Patients should be made aware of their rights to file complaints and seek redress. The take-up of existing ISO complaint handling standards should be encouraged.

4.2.1. Member State data: year 2016, report of 2018

The recent report on MS data provides an overview of the data returned by MSs for the 2016. A questionnaire was sent to all 28 EU Member States, Iceland and Norway. In total, replies were received from 30 MSs. As was the case for 2015 data, several MSs had difficulties in reporting all

¹⁶⁴ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 22.

¹⁶⁵ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 22.

¹⁶⁶ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 26-27.

¹⁶⁷ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 26-27.

¹⁶⁸ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 29-30.

¹⁶⁹ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 41-48.

the requested data for 2016. Comparison with data collected in the MS data report for the year 2015 is made where possible.¹⁷⁰

Also in 2016, most NCPs received fewer than 1,000 requests (ranging from 5 to 16,139). Outliers were Poland, Lithuania and Austria with 16,139, 15,053 and 9,826 requests respectively. The data show that the total number of requests has decreased with 38% in comparison with the data for 2015. The report suggests that this decline can be explained by the increase of information on the NCP websites as well as by HCPs.¹⁷¹

Of the 24 MSs that responded, three MSs (Denmark, Estonia and Romania) reported to have implemented a mechanism that can be used to limit access to cross-border healthcare based on overriding principles in accordance with article 4(3) of the Directive 2011/24/EU. However, as in 2015, these mechanisms have not been used in practice.

With regard to cross-border healthcare subject to prior authorisation, also this report, similar to the report on 2015 data, refers to the need to analyse these data in relation to the number of prior authorisation requests issued in accordance with the Social Security Regulations. The number of prior authorisation requests made in 2016 remains low, with 14 MSs reporting to have received less than 100 requests and five MSs between 100 and 500. France was the outlier with 3,886 requests, representing over 62% of the total number of requests for prior authorisation. Since France did not provide data for the previous report, it was not possible to make a comparison with the data for 2015. With exclusion of the French data, no significant changes between 2015 and 2016 were identified.¹⁷²

In comparison with 2015, more requests were granted (over 20%) and a significant decrease in withdrawn or admissible requests was shown (50%) for the year 2016. As in 2015, in 2016, most requests for prior authorisation were made on the basis that the treatment required an overnight hospital stay. Most refused requests (53%) were refused because the treatment was considered to be available in the patient's home country within a medically justifiable time limit.¹⁷³

Similarly to the 2015 report, the recent report shows that in 2016 the time period for processing a request for prior authorisation differs strongly across MSs (ranging from 5 to 60 days, with an average of 18 days). The period of time for processing a reimbursement claim also shows great disparities (ranging from 19 to 255 days). However, most MSs remained within their targets taking into account the national maximum time limits for processing such decision. These numbers are in line with the data for 2015. Also in 2016, most prior authorisation requests were granted for cross-border healthcare in neighbouring countries.¹⁷⁴

With regard to healthcare not subject to prior authorisation, the average number of requests for reimbursement was also low, with outliers in France, Denmark, and Norway. Denmark reported over 30,000 requests, of which 90% concerned cross-border dental care. In 2015, Belgium was reported as the other outlier along with Denmark. In 2016, Belgium did not return any data on the number of reimbursement requests. The time limit for processing requests for reimbursement differ strongly between MSs, ranging from 14 to 255 days. The total reported amount spent on reimbursement in 2016 was €143,582,652, ranging from €123,000 in France to €2,675 in Spain. When prior authorisation was not required, the biggest flows were patients travelling from Denmark to Germany, from Finland to Estonia and from Norway to Spain. Germany and Czech Republic recorded the highest number of incoming patients. France, similarly as for cross-border healthcare subject to prior authorisation, recorded the highest number of outgoing patients. Most patients received treatment in a neighbouring country.¹⁷⁵

Overall, the report concluded that, although a decrease in information requests was shown between 2015 and 2016, a slow increase in uptake of patients' rights under the cross-border healthcare Directive 2011/24/EU was demonstrated. This conclusion was based on the fact that the number of granted prior authorisation requests increased with over 20% and the number of

¹⁷⁰ Member State data on cross-border patient healthcare following Directive 2011/24/EU : year 2016 (2018).

¹⁷¹ Member State data on cross-border patient healthcare following Directive 2011/24/EU : year 2016 (2018).

¹⁷² Member State data on cross-border patient healthcare following Directive 2011/24/EU : year 2016 (2018).

¹⁷³ Member State data on cross-border patient healthcare following Directive 2011/24/EU : year 2016 (2018).

¹⁷⁴ Member State data on cross-border patient healthcare following Directive 2011/24/EU : year 2016 (2018).

¹⁷⁵ Member State data on cross-border patient healthcare following Directive 2011/24/EU : year 2016(2018).

withdrawn and admissible requests was reduced by 50%. This could suggest that practice of NCPs and other stakeholders in applying the legal instruments and informing patients has improved. However, overall the numbers of patients accessing healthcare abroad under Directive 2011/24/EU remained low.¹⁷⁶

Table 4.4 Framing the methodology: methodological strengths and weaknesses of some previous studies

Report	Strengths	Weaknesses
Evaluative Study	- Broad methodological framework with a varied range of tools (e.g. NCP survey, pseudo-patient investigation, website analysis); - Stakeholder consultation (e.g. healthcare provider organisations, healthcare insurers, patient organisations, national authorities,...); - Identifying current issues and obstacles; - Swot-analysis.	- Not all aspects of information provision to patients are covered (only findings on the three main areas are reported); - Parts of the study focus on only 12 countries, with the possibility to omit good practices outside these countries.
Eurobarometer 425	- Advantages of face-to-face interviews to explore patients' experiences and insights (more uptake of questions); - Quantitative data; - Identifying significant barriers to cross-border healthcare.	- Resources needed for conducting face-to-face interviews; - Limited number of respondents who have received planned treatment.
Commission report of 2015	Identifying significant barriers to cross-border healthcare.	Problems in data collection (partial data).
Member State data	- Important insights in the status quo in different Member States; - Including information on patient flows.	- Problems in data collection (partial data due to Member States' replies); - No comparison with previous data.
Analytical report of FreSsco	- Detailed and thorough analysis of legal texts; - Taking into account different scenarios of citizens (employee, self-employee, student..) and the interaction of distinctive legal instruments; - Identifying significant barriers to cross-border healthcare; - Recommendations or proposals for policy review.	- Lack of a clear methodological framework; - Lack of field research.
Stevens report	- Identifying significant barriers to cross-border healthcare for patients with disabilities; - Consultation disability organisations; - Recommendations or proposals for policy review.	Lack of quantitative data on the current uptake of Directive 2011/24/EU by patients with disabilities.
ANEC report	- Survey patients and NCPs; - Widespread patient survey with high number of respondents (1,656); - Comparison of data with previous findings; - Recommendations or proposals for policy review.	- Low number of respondents who have received planned treatment; - No quantitative insights.
Member State data: year 2016	- Important insights in the status quo in different Member States; - Including information on patient flows; - Comparison with data for the year 2015.	Problems in data collection (partial data due to Member States' replies);

4.3. Results of the literature review on information provision

Directive 2011/24/EU lays down new patients' rights to access health services abroad, next to the already existing possibilities under the Social Security Regulations (EC) 883/2004 and 987/2009. The facilitation of the exercise of patient mobility is approached in the Directive by highlighting

¹⁷⁶ Member State data on cross-border patient healthcare following Directive 2011/24/EU : year 2016(2018).
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information in relation to such mobility.¹⁷⁷ More specifically, one of the general principles of the Directive is that appropriate information on all essential aspects of cross-border healthcare is necessary in order to enable patients to fully exercise their rights to cross-border healthcare in practice.¹⁷⁸

A literature search was conducted in order to identify and define current issues and obstacles in information provision to patients in cross-border healthcare.

The results of the literature review are presented per topic:

- Information requirements according to Directive 2011/24/EU (section 4.3.1);
- Status quo of the current information provision (section 4.3.2);
- Identified difficulties and shortcomings (section 4.3.3);
- Proposed recommendations in literature for improvement of information provision (section 4.3.4).

In addition, section 4.1.5 presents conclusion of the results of the review.

4.3.1. Information requirements according to Directive 2011/24/EU

Table 4.5 outlines the information requirements that are placed on NCPs and healthcare providers by Directive 2011/24/EU.

Table 4.5 Information requirements according to Directive 2011/24/EU

	Art.	Information requirement	Specified / comments
NCPs	6(5)	NCPs should provide information that is easily accessible and available by electronic means and in formats accessible to people with disabilities.	<i>Need of a clear and accessible website¹⁷⁹.</i>
	Rct. 48	Information that has to be provided compulsory to patients should be specified .	
	Rct. 48	Information should be provided in any of the official languages of the MS concerned.	<i>NCPs should provide information in English in order to comply with art. 6(5) that states that information should be easily accessible¹⁸⁰.</i>
	6(2)	Information, on request, on contact details of NCPs in other MSs.	
- MS of treatment			
<i>Upon request:</i>	4,(2)(a)	Information on quality and safety standards .	Including supervision and assessment of healthcare providers (HCPs) ; HCPs subjected to these standards; Accessibility of hospitals for people with disabilities .
	6(3)	Information concerning healthcare providers .	Including information on the right to practice of HCPs or any restrictions to this.
	6(3)	Information on patients' rights .	Complaint procedures and mechanisms for seeking remedies ; Legal and administrative options to settle disputes (incl. in the event of harm).

¹⁷⁷ S. De La Rosa, "The directive on cross-border healthcare or the art of codifying complex case law", Common Market Law Review (2012)49, pp. 15-46.

¹⁷⁸ Directive 2011/24/EU, recital 48.

¹⁷⁹ H. Nys, The transposition of the Directive on Patients' Rights in Cross-care Healthcare in national law by the MSs: still a lot of effort to be made and questions to be answered, Eur. J. of Health Law 21 (2014), 10.

¹⁸⁰ A. Santoro, A. Silenzi, W. Ricciardi, M. McKee, Obtaining health care in another European Union MS: how easy is it to find relevant information?, Eur J of Public Health 25(1) (2014) 29.

	Art.	Information requirement	Specified / comments
- MS of affiliation			
Publicly available:	5(b)	Information on patients' rights and entitlements .	Terms and conditions for reimbursement of costs; Related procedures (incl. information on basket of services, reimbursement of extra costs, appeal and redress,...).
	5(b) / Rct. 31	Differentiated information on Directive 2011/24/EU and on Social Security Regulations .	Patient must be informed in case the application of the Social Security Regulations is more advantageous with regard to their situation.
	8(7)	Information on prior authorisation .	Information on which healthcare is subjected to prior authorisation and the procedure of prior authorisation.
Healthcare providers	4,(2)(b)	Relevant information to help individual patients to make an informed choice .	Treatment options and availability; Quality and safety standards ; Invoices and prices ; Authorisation or registration status ; Insurance cover ; other relevant information.
→ Cooperation and consultation NCPs, patient organisations, healthcare providers and healthcare insurers.			

4.3.2. Status quo of the current information provision

In general, a limited number of information requests is received by NCPs

In general, the number of information requests received by NCPs is very low in comparison with the number of insured people.¹⁸¹ Data for the year 2015 shows that most NCPs only received a few hundred requests per year.¹⁸² However, this has to be nuanced with significant outliers. Expressed in figures, in 2015 there was an average of 428 information requests per MS (i.e. mean), with outliers along the lines of:

- only 13 requests registered in Malta or 21 in Cyprus; and on the contrary;
- no less than 31.736 information requests received in Poland.¹⁸³

Most requests were made in writing or by phone.¹⁸⁴

The recent report on MS data shows similar results for the year 2016.¹⁸⁵ In total 69,723 requests were made in 2016, which shows a decrease in requests for information since 2015 of almost 38%. Poland, Lithuania and Austria are outliers with 16,139, 15,053 and 9,826 requests respectively. On the other hand, some MS reported very low numbers of requests with, for example, 5 requests both in Sweden and Iceland, 10 requests in Malta and 14 requests in Portugal. In 2016, half of the requests was made by phone. The other half of the request was made in writing (by e-mail) or in person.¹⁸⁶

Lack of awareness among patients

MSs (health insurance providers/national health service authorities) generally receive a limited number of requests on prior authorisation in accordance with Directive 2011/24/EU. The number of requests on reimbursement for healthcare that is not subject to prior authorisation is also low. In 2015, Belgium and Denmark were the exception: they both received over 30,000 requests for reimbursement.¹⁸⁷ For 2016, the average number of requests for reimbursement not subject to prior authorisation was also overall low, with an interesting exception in Denmark, with over 30,000 requests for reimbursement and some 25,000 requests for authorisation. This number is very similar to 2015, and mainly relates to cross-border dental care. More specifically, 90% of

¹⁸¹ Report on MS data on cross-border healthcare following Directive 2011/24/EU, October 2016, 8. Available at: https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_msdata_en.pdf.

¹⁸² Report on MS data on cross-border healthcare following Directive 2011/24/EU, October 2016, 9.

¹⁸³ Report on MS data on cross-border healthcare following Directive 2011/24/EU, October 2016, 9.

¹⁸⁴ Report on MS data on cross-border healthcare following Directive 2011/24/EU October 2016, 9.

¹⁸⁵ Member State data on cross-border patient healthcare following Directive 2011/24/EU: Year 2016.

¹⁸⁶ Member State data on cross-border patient healthcare following Directive 2011/24/EU: Year 2016.

¹⁸⁷ Report on MS data on cross-border healthcare following Directive 2011/24/EU, October 2016, 20.

granted reimbursements for cross-border healthcare in Denmark in both 2015 and 2016 relate to dental care. For the year 2016, Belgium did not return data on the number of reimbursement requests not subject to authorisation. Other outliers in 2016 were France and Norway.¹⁸⁸

The overall low numbers can be an indication of the general lack of awareness of the existence of Directive 2011/24/EU or of NCPs.¹⁸⁹ Despite the fact that one out of two of the respondents of the Special Eurobarometer 425 on *Patients' rights in cross-border healthcare in the European Union*, showed some willingness to travel to another MS to receive medical treatment¹⁹⁰, another report showed that only one out of every ten European had heard of the NCPs for cross-border healthcare.¹⁹¹ The lack of awareness of the provisions of the Directive 2011/24/EU is also illustrated by the fact that a majority of the respondents thought that prior authorisation was obliged for all kind of treatments in order to obtain reimbursement.¹⁹² The Evaluative Study on the cross-border healthcare Directive 2011/24/EU of 2015 confirmed that in general, the awareness of patients of the existence of NCPs is considered to be low in most MSs.¹⁹³ This can be explained by the short period of time during which information campaigns took place and the limited publication of NCP contact details, as these are mostly only available via NCPs' websites themselves.¹⁹⁴

Significant differences in the way in which NCPs are organised and how they provide information

There are very different approaches between MSs in the way in which NCPs were formed and organised. More specifically, some MSs have different NCPs for 'incoming' and 'outgoing' patients. Some NCPs have regional CPs under one 'umbrella' NCP. Some NCPs are based in the Ministry of Health, others in the health insurer, and others in independent bodies.¹⁹⁵ NCPs also differ with respect to the quality and type of information they provide.¹⁹⁶ Information on quality and safety e.g. is provided in very different manners: some NCP websites provide links to legal documents, some NCPs give a general description of quality strategies, others provide detailed information, some direct citizens to specific sources (such as a website or a named person that can help), and some NCPs even do not mention safety and quality at all.¹⁹⁷

Room for improvement

For the NCP websites overall, the Evaluative Study showed that, in comparison with earlier studies,¹⁹⁸ NCP websites had significantly improved and were more complete than before.¹⁹⁹ Most NCPs provide information with a satisfactory level of detail when they are requested to do so.²⁰⁰ Most of the NCPs communicate the information on the possibility of accessing cross-border care, as well as general rules on entitlements and levels of reimbursement in a consistent manner.²⁰¹ Information on prior authorisation is also provided consistently.²⁰² However, NCPs do not always provide clear information on the conditions under which prior authorisation is needed. Only some

¹⁸⁸ Member State data on cross-border patient healthcare following Directive 2011/24/EU: Year 2016.

¹⁸⁹ Evaluative study on the cross-border healthcare Directive (2011/24/EU), March 2015, 12.

¹⁹⁰ European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European Union, May 2015, 10. Available at: http://ec.europa.eu/commfrontoffice/publicopinion/archives/ebs/ebs_425_sum_en.pdf.

¹⁹¹ Report on MS data on cross-border healthcare following Directive 2011/24/EU, October 2016, 18.

¹⁹² European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European Union, May 2015, 37.

¹⁹³ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 31-32.

¹⁹⁴ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 31-32.

¹⁹⁵ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 8. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf.

¹⁹⁶ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 12. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.

¹⁹⁷ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 10.

¹⁹⁸ A. Santoro, A. Silenzi, W. Ricciardi, M. McKee, Obtaining health care in another European Union MS: how easy is it to find relevant information?, *Eur J of Public Health* 25(1) (2014) 29.

¹⁹⁹ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, pp. 177; see also T. Clemens, E. Cox, B. van der zanden, M. Commers, H. Brand, Activity report: Implementation of National Contact Points for cross-border healthcare in EU MSs: a comparative analysis using websites and short interviews, Epecs, Maastricht University.

²⁰⁰ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 32.

²⁰¹ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 32; A. Santoro, A. Silenzi, A., Ricciardi, W., et al., Obtaining health care in another European Union MS: how easy is it to find relevant information? *Eur J of Public Health* 25(1) (2014) 29-31.

²⁰² Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 117.

NCPs make detailed lists of treatment available for which patients need to request prior authorisation.²⁰³ Information on quality and safety on NCPs' websites can be improved.²⁰⁴ Practical and easily understandable information to help patients make an informed choice is also often lacking.²⁰⁵ Although there is an improvement in accessibility of websites in English²⁰⁶, it is recently reported that a full and/or accurate translation of the website in English is still missing for some NCPs.²⁰⁷ Furthermore, it is reported that in several MSs, information is not only hard to find, but also too general to fulfil specific patients' needs in cross-border healthcare.²⁰⁸ As such, it was concluded that information access was often still seriously lacking in cross-border healthcare.²⁰⁹

4.3.3. Difficulties and shortcomings

Language barriers and linguistic challenges

In a simulation that took place a few months after the adoption of the Directive, language turned out to be one of the biggest expected barriers by patients wanting to access cross-border healthcare.²¹⁰ Directive 2011/24/EU obliges NCPs only to provide information in any of the official languages of the MS concerned.²¹¹ This provision could be strictly interpreted as meaning that NCPs are not obliged (if it is not one of the official languages) to provide information to incoming patients in English. However, Nys (2014) stated that *"one may wonder whether information in a language that one cannot understand is not by definition difficult or even impossible to access?"* (cfr. 6(5) Directive 2011/24/EU) and that *"If we agreed on this, this information (also) has to be offered in the language that is understood by a growing number of people in the European Union; namely, English".*²¹²

In a study assessing stakeholders' perspectives in Poland and Portugal regarding cross-border healthcare, it was stated that the need and flow of information as a result of the implementation of Directive 2011/24/EU would pose great linguistic challenges that might, for example, impact the patient's informed consent and would also result in inherent costs of translation for the authorities and the health system concerned.²¹³ The Evaluative Study reported that at least four MSs require patients to provide a sworn translation of invoices in order to obtain reimbursement.²¹⁴ A European Commission report referred to the obligation, provided by article 10 of the Directive, for NCPs to assist each other in understanding invoices.²¹⁵ As a result, such national limitations have to be analysed under article 7(7) of the Directive that stipulates that the MS of affiliation may only impose on an insured person seeking reimbursement for the costs of cross-border healthcare equal conditions and formalities, as it would impose if the healthcare were provided on its own territory.²¹⁶ Limitations may only be imposed in case this is objectively justified by planning requirements to ensure permanent accessible and high-quality treatment or

²⁰³ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 117.

²⁰⁴ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 118.

²⁰⁵ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 49-50.

²⁰⁶ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 27.

²⁰⁷ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 90-91.

²⁰⁸ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 90-91.

²⁰⁹ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 95.

²¹⁰ E. Jelfs, R. Baeten, Simulation on the EU Cross-Border Care Directive, Final Report. OSE, EHMA, AIM, 2012. Available at: http://www.ose.be/files/publication/2012/CrossBorderHealthcareSimulation_FinalRep_09052012.pdf.

²¹¹ Directive 2011/24/EU, Recital 48.

²¹² H. Nys, The transposition of the Directive on Patients' Rights in Cross-care Healthcare in national law by the MSs: still a lot of effort to be made and questions to be answered, *Eur. J. of Health Law* 21(2014) 10.

²¹³ R. Helena, Cross-border healthcare directive: assessing stakeholders' perspectives in Poland and Portugal, *Health Policy* 120(4) (2016) 373.

²¹⁴ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 40.

²¹⁵ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 6. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf.

²¹⁶ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 6. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf.

to control costs and avoid financial, technical or human resources waste.²¹⁷ Regardless of the great importance to patients, the recent Analytical report stated that in some MSs information, is still not provided in English or, in case it is provided, it is not of the same value.²¹⁸

Socio-demographic difficulties that mirror the significant disparities observed between population groups in the Member States

The likelihood that patients inform themselves on different aspects of healthcare is dependent on characteristics of the patients and on population groups defined by socio-economic clusters. For example, it is shown that patients with higher incomes, patients that are more educated and younger patients, more often make an active choice in HCP.²¹⁹ With regard to cross-border healthcare, there are also some socio-demographic factors determining the willingness of patients to go abroad (more specifically: age, employment and education).²²⁰ A study in Malta, published in 2016, has shown that there is a significant link between age, education, language literacy, literacy on cross-border healthcare and financial resources, and patients' willingness to access cross-border treatment. On the other hand, gender, employment status and occupation were not found to be significantly associated with the willingness to access treatment abroad.²²¹ A survey among German patients treated in other European countries, which was carried out by a major German sickness fund, showed that information activity was contingent on patients' level of education, type of service, regularity of treatment abroad and awareness of entitlements to cross-border healthcare.²²²

De la Rosa criticizes the text of the Directive 2011/24/EU on being silent on social and territorial inequalities in access to care and concludes that the Directive is aimed primarily at individuals or groups of individuals who have the cognitive and social resources required to be sufficiently informed in order to be able to engage in a process of mobility.²²³ It is even suggested that the system of upfront payment under Directive 2011/24/EU, where patients are often uncertain on when and how much they will be reimbursed, simply increases social inequalities and make cross-border healthcare even less accessible to those with limited financial resources.²²⁴

It should however be kept in mind that, whilst the Directive has been criticised for catering to the high socio-economic groups, this very disparity can also be observed between population groups within the MS.²²⁵ Based on Gini coefficient estimates, Europe can be called "*home to the most equal societies in the world*".²²⁶ Life expectancy across the EU has increased by more than six years since 1990.²²⁷ By 2030, Europe is expected to be the region with the oldest median age.²²⁸ However, the Country Health Profiles, established under the *State of Health in the EU* initiative, show that not all socio-demographic groups have benefited from these advancements in the same way.²²⁹ Significant disparities are not only observed across MSs, but also within most if not all MS.²³⁰ For example, the Swedish government decided in 2014 to consider as an objective for public health to close the avoidable inequalities within one generation.²³¹

The significant disparities in health between socio-demographic groups reflect on an individual's living situation, occupational status and income, education and lifestyle. Poverty and health can

²¹⁷ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 6. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf.

²¹⁸ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 90-91; S.E. Verra, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, *Health Policy* 2016;120(6):718-727.

²¹⁹ A. Victoor, D. Delnoij, R. Friele, et al., Determinants of patient choice of healthcare providers: a scoping review, *BMC Health Serv Res* 12 (272) (2012) 7-8.

²²⁰ European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European Union, May 2015, 13.

²²¹ M. Busuttill, N. Azzopardi-Muscat, N. Calleja, Patients' willingness to access cross-border healthcare, *Physiotherapy* 2016, 102(1), 193-194.

²²² D. Pantelli, C. Wagner, F. Verheyen, R. Busse, 'Know before you go': information-seeking behaviour of German patients receiving health services abroad in light of the provisions of Directive 2011/24/EU, *J Health Serv Res Policy* (2015) 3.

²²³ S. De La Rosa, "The directive on cross-border healthcare or the art of codifying complex case law", *Common Market Law Review* 49(1) (2012) 38-39.

²²⁴ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences (2018) 45.

²²⁵ State of Health in the EU: Companion Report 2017 (2017) 19.

²²⁶ White paper on the future of Europe: Reflections and scenarios for the EU27 by 2025 (2017) 10.

²²⁷ State of Health in the EU: Companion Report 2017 (2017) 19.

²²⁸ White paper on the future of Europe: Reflections and scenarios for the EU27 by 2025 (2017) 10.

²²⁹ State of Health in the EU: Companion Report 2017 (2017) 19.

²³⁰ State of Health in the EU: Companion Report 2017 (2017) 19.

²³¹ State of Health in the EU: Companion Report 2017 (2017) 19.

also be considered as highly interdependent.²³² It has been suggested that poorer social groups use healthcare less for equivalent levels of medical need than high socio-demographic groups.²³³ According to the *State of Health in the EU* report, such health inequalities can be considered as one of today's major challenges in public health.²³⁴ They are, however, avoidable. More specifically, health disparities are avoidable to the extent that they stem from identifiable policy options made by governments, such as tax policy, business and labour regulation, welfare benefits and public health funding.²³⁵

Prevention and more specific, practicing healthy lifestyle habits, are key in tackling these disparities.²³⁶ Being well-informed citizens should be seen as an intrinsic part of leading a healthy lifestyle, awareness and prevention. In the same way, it is argued that for cross-border healthcare an inclusive approach of information provision should be adopted by NCPs.²³⁷

Lack of awareness

As previously mentioned, another challenge for the future is to raise more awareness among patients on the existence of the Directive 2011/24/EU and NCPs. The lack of awareness among patients seems to be a significant problem and this may explain the current limited numbers of patients seeking cross-border healthcare as well as the (corresponding) limited number of information requests received by NCPs.

Big differences in information provision between NCPs and still NCPs that do not provide all information necessary

In general, there are significant differences between NCPs with regard to the kind and the quality of information they provide.²³⁸ For example, information on quality and safety is provided in very different manners, as some NCP websites provide links to legal document; some give a general description of quality strategies; a few provide detailed information; others direct citizens to specific sources (such as a website or a named person that can help); and some even do not mention safety and quality at all.²³⁹

Missing information at national level

A problem encountered by some NCPs is that they cannot meet the information requirements in accordance with Directive 2011/24/EU as a result of lack of such information at national level. For example, one NCP mentions that information on quality or prices of healthcare services is often missing, as public healthcare providers do not generally have such transparent information. Most public healthcare providers in the NCP's country cannot easily answer questions such as what the actual costs of a provided treatment are. The process to market health services has so far been focussed mainly on specialised healthcare, while primary care is lagging behind.²⁴⁰ In another NCP's MS, the same issue exists where it is difficult to meet the requirements of the Directive as clear information on prices is also missing for domestic patients. In addition, prices of healthcare are not published in a publicly accessible manner.²⁴¹

²³² State of Health in the EU: Companion Report 2017 (2017) 19; Communication from the commission to the European parliament, the council, the European economic and social committee and the committee of the regions, Solidarity in health: reducing health inequalities in the EU (2009) 3.

²³³ Communication from the commission to the European parliament, the council, the European economic and social committee and the committee of the regions, Solidarity in health: reducing health inequalities in the EU (2009) 3.

²³⁴ State of Health in the EU: Companion Report 2017 (2017) 20.

²³⁵ A. Woodward, I. Kawachi, "Why reduce health inequalities?", *BMJ* 54(12) (2000), 923-929.

²³⁶ State of Health in the EU: Companion Report 2017 (2017) 19-21.

²³⁷ D. Pantelli, C. Wagner, F. Verheyen, R. Busse, 'Know before you go': information-seeking behaviour of German patients receiving health services abroad in light of the provisions of Directive 2011/24/EU, *J Health Serv Res Policy* (2015) 7.

²³⁸ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 14; Evaluative study, Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 12.

²³⁹ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 10.

²⁴⁰ M. Kattelus, Implementation of the Directive on the application of patients' rights in cross-border healthcare (2011/24/EU) in Finland, *Eur. J. of Health Law* 21 (2014) 23-32.

²⁴¹ S. Olsena, Implementation of the Patients' Rights in Cross-border Healthcare Directive in Latvia, *Eur. J. of Health Law* 21 (2014), 46-55.

Comparable information on quality and safety?

At the end of 2011, a simulation exercise took place with stakeholder groups of six MSs to tackle the key issues raised by the Directive 2011/24/EU. During the simulation, the patients' stakeholder group was clear regarding the need for information about the quality level of hospitals. In particular, the need for comparative analyses and indicators enabling them to compare the hospital abroad with the hospital in their home country.²⁴² There is no provision in the Directive that imposes such comparable information. The availability of information on quality and safety in a comparable format would raise a number of questions, such as: *what kind of standards would be needed? Who will set such standards?*²⁴³

Information can be too complex and too difficult to understand

In the above-mentioned simulation, patients also highlighted that with regard to reimbursement, decisions on the different administrative options, more specifically the application of the Directive 2011/24/EU or the Social Security Regulations, were too complex to understand. The same was thought of decisions on whether prior authorisation should be requested or not.²⁴⁴ Patient organisations have reported their concern that patients are faced with a labyrinth of confusing information that is at times insufficient and/or too detailed.²⁴⁵ The EPF identified the crucial role of NCPs in this context and recommended that NCPs would provide checklists to patients that could assist them in making their decisions, as well as more detailed individual timelines of procedures, costs and reimbursement rates.²⁴⁶ The EPF concluded that a regular partnership between NCPs and patient organisations could be the key to ensure that information provision by NCPs meets the real-life needs of patients.²⁴⁷

Missing information on patients' own responsibilities

Patients are also responsible to provide certain information (e.g. authorisation form, invoices to obtain reimbursement...) ²⁴⁸, but are often not aware of this. In a study of Verra *et al*, the experiences of medical travellers in 2014 were explored, with a focus on potential issues that may threaten safe and effective medical travel. One of the problems the authors identified was the problem of transfer of health records, as medical records were not transferred in advance for two-third of the 101 participants.²⁴⁹ Moreover, nearly 10% of these patients were treated without the information concerned transferred at all.²⁵⁰ They concluded that to facilitate safer medical travel, patients should be clearly informed on their own responsibilities regarding the transfer of medical records when their healthcare provider is unable or unwilling to ensure this transfer him- or herself.²⁵¹ It is of great importance that patients are provided with information on the many responsibilities they bear themselves in cross-border healthcare. More specifically, patients are considered to be responsible for finding information on potential treatment abroad, for demonstrating to insurers that the treatment has been carried out, for the transfer of documents

²⁴² E. Jelfs, R. Baeten, Simulation on the EU Cross-Border Care Directive, Final Report. OSE, EHMA, AIM, 2012, 21. Available at: http://www.ose.be/files/publication/2012/CrossBorderHealthcareSimulation_FinalRep_09052012.pdf.

²⁴³ H. Nys, The transposition of the Directive on Patients' Rights in Cross-care Healthcare in national law by the MSs: still a lot of effort to be made and questions to be answered, *Eur. J. of Health Law* 21 (2014) 11; D. Delnoij and W. Sauter, Patient information under the EU patients' rights Directive, *Eur. J. of Public Health* (2011) 271.

²⁴⁴ E. Jelfs, R. Baeten, Simulation on the EU Cross-Border Care Directive, Final Report. OSE, EHMA, AIM, 2012, 20.

²⁴⁵ Directive on patients' rights in cross-border healthcare, EPF Position Statement, April 2016, 6; Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 9. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf.

²⁴⁶ Commission report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, September 2015, 9. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf.

²⁴⁷ Directive on patients' rights in cross-border healthcare, EPF Position Statement, April 2016, 7.

²⁴⁸ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 88.

²⁴⁹ S.E. Verra, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, *Health Policy* 120(6) (2016) 721.

²⁵⁰ S.E. Verra, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, *Health Policy* 120(6) (2016) 721.

²⁵¹ S.E. Verra, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, *Health Policy* 120(6) (2016) 718-727.

and for clarification of invoices.²⁵² With regard to the clarification of invoices, art. 10(1) of the Directive 2011/24/EU stipulates that MSs are responsible to mutually assist each other for clarifying invoices. Practice shows, however, that some MSs do oblige patients to provide translation of invoices.

4.3.4. Proposed recommendations in literature for improvement of information provision

Enhanced cooperation between NCPs and with other actors

The Analytical report by FreSsco suggested that NCPs should work closely together, both with European and national institutions involved and with each other.²⁵³ EPF recommended a close and regular structured communication between NCPs and patient organisations in order to ensure that the information provision by NCPs meets the real-life needs of patients. This can help to improve the assistance of patients, for whom provided information often still is too complex or difficult to understand.²⁵⁴ Santoro and colleagues recommended harmonising information provided by NCP websites and assessing how this information would be best presented.²⁵⁵ The EPF recommended patient organisations to engage with NCPs and to provide feedback on the relevance and comprehensibility of the information.²⁵⁶

Information on NCP website regarding patients' responsibilities

As previously mentioned, it is recommended that patients are provided with information on their own responsibilities and are alerted to the information they themselves have to provide.²⁵⁷ In a study on facilitating safe and successful cross-border healthcare, Verra and colleagues recommended that this awareness could be increased by providing clear information and descriptions on patient responsibility on NCP websites.²⁵⁸

Information that is simple and easy to understand for patients

The European Patients' Forum (EPF) recommended that information provided by NCPs, for example, on mechanisms for complaint or redress or the system of prior notification, should be simple and easy to understand for patients.²⁵⁹ In the above mentioned study, Verra and colleagues also recommended clear information in order to facilitate safe and successful cross-border healthcare.²⁶⁰

More standardised way of information provision and guidelines to ensure quality information

The EPF recommends the use of guidelines and templates for NCPs in order to obtain a unified practice of information provision. More specifically, the EPF states that the European Commission should co-ordinate a process to develop guidelines at EU level on what is the essential information that has to be provided to patients. This will help to ensure information meets patients' needs and is understandable, accessible and of high quality.²⁶¹ In this respect, the EPF recommended that

²⁵² E. Jelfs, R. Baeten, Simulation on the EU Cross-Border Care Directive, Final Report. OSE, EHMA, AIM, 2012, 20.

²⁵³ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 94-95.

²⁵⁴ Directive on patients' rights in cross-border healthcare, EPF Position Statement, April 2016, 7.

²⁵⁵ A. Santoro, A. Silenzi, W. Ricciardi, M. McKee, Obtaining health care in another European Union MS: how easy is it to find relevant information?, *Eur J of Public Health* 25(1) (2014) 29-31.

²⁵⁶ EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare: Legislation Guidance for Patient Organisations, EPF, November 2013, 18.

²⁵⁷ S.E. Verra, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, Health Policy 120(6) (2016) 718-727; G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 88.

²⁵⁸ S.E. Verra, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, Health Policy 120(6) (2016) 718-727.

²⁵⁹ EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare: Legislation Guidance for Patient Organisations, EPF, November 2013, 18.

²⁶⁰ S.E. Verra, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, Health Policy 120(6) (2016) 718-727.

²⁶¹ Directive on patients' rights in cross-border healthcare, EPF Position Statement, April 2016, 8.

MSs apply the Core Quality Principles²⁶² from the High-Level Pharmaceutical Forum of 2008 (i.e. objective and unbiased, patient-oriented, evidence-based, up to date, reliable, understandable, accessible, transparent, relevant and appropriate, and consistent with statutory information), as a guideline for all information provision to patients.²⁶³ FreSsco, a network funded by the European Commission of independent legal experts in the field of movement of workers and social security coordination in the EU, recommended standardising the content of NCP websites in order to obtain a more uniform information provision by NCPs throughout the EU.²⁶⁴ Santoro and colleagues also recommended a harmonised information provision.²⁶⁵ FreSsco even recommended a National Contact Point at EU level and a single EU website.²⁶⁶ In addition, in line with the application for the European Health Insurance Card (EHIC) for unplanned care, FreSsco recommended a similar application for cross-border information in case of planned care.²⁶⁷ Today, the NCP's function at EU level is in a sense insured by SOLVIT and the Your Europe Advice network, as well as the Cross-border Healthcare Secretariat. The website of European Commission offers a webpage dedicated to the cross-border healthcare Directive.²⁶⁸

²⁶² Available online at http://ec.europa.eu/pharmaforum/docs/itp_quality_en.pdf.

²⁶³ Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, EPF Recommendations for a patient-centred implementation, 2014, 5.

²⁶⁴ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 90.

²⁶⁵ A. Santoro, A. Silenzi, W. Ricciardi, M. McKee, Obtaining health care in another European Union MS: how easy is it to find relevant information? *Eur J of Public Health* 25(1) (2014), 29.

²⁶⁶ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 94.

²⁶⁷ G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 91.

²⁶⁸ https://ec.europa.eu/health/cross_border_care/overview_en.

4.4. Key findings

Key findings of previous studies on the Directive

The *Evaluative Study of March 2015* highlights the lack of awareness of patients on the possibilities of accessing health services abroad under Directive 2011/24/EU and on the existence of NCPs. Furthermore, the *Special Eurobarometer 425 (May 2015)* shows that most respondents were only partially aware of their rights and entitlements to access health services abroad. This is in line with the findings from the *Commission report of September 2015* which showed that only a limited number of patients made use of their rights to access health services abroad in 2014. The general low numbers of patients seeking treatment abroad appears to be equally the case for planned care under the Social Security Regulations.

The *FreSsco Analytical Report 2016* concludes that cross-border healthcare is regulated by a broad legal framework in which interaction of distinctive legal instruments is highly complex: Cross-border Healthcare Directive 2011/24/EU, Social Security Regulations, Residence Directive 2004/38/EU, Free Movement of Workers Regulation (EU) No 492/2011, the Treaties, national legislation, bilateral agreements and so on. In addition, the distinctive rules applied for planned and unplanned treatment under the Social Security Regulations and the lack of such rules under the Directive 2011/24/EU may also be considered as too complex and controversial.

The *Stevens report on the implementation of the European Disability Strategy 2017* calls on MSs to fully implement Directive 2011/24/EU, taking into account the needs and rights of patients with disabilities. In addition, the report recommends the European Commission to include a strong disability component in the transposition of the Directive in order to guarantee affordable and quality treatment abroad for patients with disabilities.

The *ANEC report of January 2018* suggests that EU citizens lack knowledge and awareness of their rights and entitlements in cross-border healthcare can be considered a major barrier for the uptake of the EU legislation. The study stipulates that roughly half of the respondents know they have the right to enjoy assumption of costs by their own health insurance provider for certain health services received abroad. Furthermore, few patients feel they are adequately informed on their rights regarding cross-border healthcare. The ANEC report also reported a low level of awareness of the existence of NCPs under patients. The study concludes that patients seem to be pushed towards paying for the treatment privately due to the limited level of awareness on their rights and entitlements.

Member State data (2015) shows that the number of information requests the NCPs received in 2015 varies vastly amongst MSs, ranging from 13 to 31,736 (mean: 428). Recent *Member State Data (2016)* show that the total number of requests has decreased with 38% in comparison with the data for 2015. The report suggests that this decline can be explained by the increase of information on the NCP websites as well as by HCPs.

Key findings of the literature review

Limited numbers of patients make use of their right to seek treatment in another MS. However, many Europeans would consider it. The main reasons for Europeans to go abroad for medical care are to receive treatment that is not yet available in their home MS, or to receive better quality treatment. There are some socio-demographic factors determining the willingness of patients to go abroad (more specifically: age, employment and education) which *prima facie* appear to mirror health inequality disparities within the Member States. The limited number of patients seeking cross-border treatment can be explained by a general lack of awareness of the existence of the Directive 2011/24/EU and more importantly, of NCPs.

Results of the Evaluative study have shown that information provision to patients by NCPs has significantly improved over the years, e.g. NCPs provide more information and more information is provided in English. Nevertheless, it is shown that there is still a great need for improvement on different aspects. It is e.g. shown that information on quality and safety is not always provided in a sufficient manner. Moreover, patient organisations have stated that patients often find it important to be able to compare the treatment they can receive abroad with the treatment offered in the home MS, enabling them to weigh their different options, which today is often not possible. Full and accurate translations to English are also still missing on some NCPs' websites. The accessibility of these websites for incoming patients traveling from other EU/EEA countries can be questioned.

Information provision still differs greatly between NCPs, as some provide detailed information and some too general information. This makes it difficult for the patient to understand the information provided. Authors therefore point out the importance for NCPs to evolve to a more common and uniform way of providing information. To that end, cooperation between NCPs and with other actors is of great importance.

Our literature review demonstrates the need for clear, accurate and accountable information provision to patients. A direct relation between such information provision and the uptake of patients' rights to access health services abroad has been stressed several times.

5. Results of the NCP Website analysis

This Chapter presents the results of the website analysis (WP2). In this Chapter we elaborate on the findings of the website analysis, focusing on relative performance and best practices in each of the nine SAI categories (section 5.1). In addition, this Chapter outlines our recommendations for further improving information provision to patients going forward (section 5.2).

During the bilateral exchange with the NCPs concerning the website analysis, the research team received feedback from 15 NCPs. This feedback on the findings and methodology of the WP is presented in short textboxes throughout this Chapter.

5.1. Information provision on NCP websites

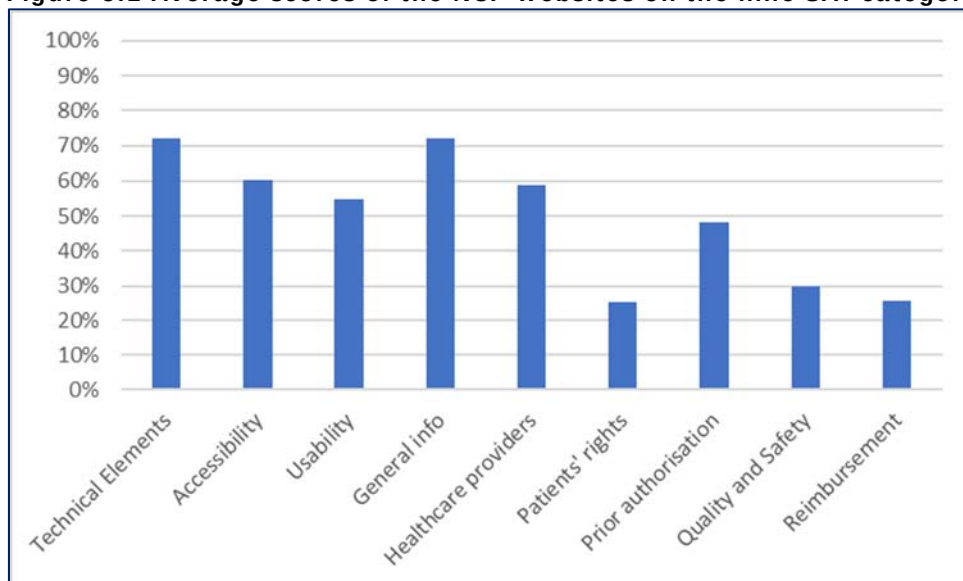
The analysis of the individual NCP websites was performed in July 2017, by three trained researchers, using a data collection template based on the developed methodology (for more details on this methodology, please see Chapter 3). Data was collected using 36 websites, from 33 dedicated NCPs, as the UK has separate NCPs for England, Scotland, Wales, Northern Ireland, and Gibraltar, and Luxembourg, Slovakia and Sweden do not have NCPs but have other organisations carry out NCP tasks (see Annex K for all NCPs and URLs, provided in separate document). After data collection, the results on the individual SAIs were used to calculate the SAI category scores per NCP website. The aim of this individual website analysis was to investigate whether the NCP websites provide incoming and outgoing patients with the information they need on cross-border healthcare.

On average, our researchers took 30 minutes or more per website to complete the data collection and fill in the template. We would expect patients to be less trained and experienced in finding information on the NCP websites than our researchers, and therefore less proficient. Any information which could not be found by our researchers would thus conceivably also not be found by the average patient.

The website analysis looks at nine SAI categories, with three of these focusing on the website itself and six categories focusing on the content of the website:

1. Technical elements of the website;
2. Accessibility of the websites;
3. Usability of the websites;
4. General information on cross-border healthcare;
5. Information on healthcare providers;
6. Information on patients' rights;
7. Information on prior authorization;
8. Information on quality and safety standards;
9. Information on entitlement for reimbursement of costs.

The average scores of all of the NCP websites on these nine SAI categories are displayed in Figure 5.1. The NCPs achieved an average score of 50% across the nine SAI categories. Furthermore, the relative scores of the NCP websites are displayed in Table 5.1.

Figure 5.1 Average scores of the NCP websites on the nine SAI categories

Source: Results website analysis, Ecorys analysis.

In the remainder of this section, we elaborate on each of the nine SAI categories, discussing the relative performance of the NCPs, highlighting best practices and comparing the results with those of three previous studies in this area.

5.1.1. Technical elements of the website

This SAI category looks at the presence of certain technical elements, such as contact information and the last date of update (see Annex D for the exact SAIs that make up each category, provided in separate document). The NCPs scored relatively well on the SAIs regarding technical elements of the websites, with an average of 72% of the total points earned.

Most NCPs developed an independent website to cater to the needs of citizens seeking information on cross-border healthcare. These websites generally include some form of contact details, with the most popular being the ability to call directly the NCP by telephone. Fifteen out of the 36 analysed websites also provide citizens with other options to communicate with the NCP, including social media and live popup chats. Almost all NCPs dedicated a part of their website to contact details of other NCPs, whether it was actual website URLs or a direct link to the European Commission's list of NCPs.

Best practices for this category include Belgium, England (UK), Latvia, Northern Ireland (UK), and Scotland (UK). These NCPs all received the maximum number of points for this SAI.

Comparing results with previous studies

The Evaluative Study²⁶⁹ published in 2015 also looked at the availability of communication channels on NCP websites, and showed similar results on this topic. The study found that 21 out of 32 NCP websites had three types of contact details available: e-mail, phone number and office address for face-to-face visit. All NCP websites provided email details and all but four provided phone numbers, which seems to show that these were the preferred channels of communication. The Evaluative Study did not pay specific attention to other communication channels, such as live popup chats.

²⁶⁹ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf. For the evaluative study on the cross-border healthcare Directive, 32 NCPs of the EU Countries were included with an available website.

Santorro²⁷⁰ *et al.* looked at a smaller number of NCP websites (18), but found that all of the websites included in the study provided an email address for their NCPs, which is in line with both our findings and the findings from the Evaluative Study. All but two websites provided contact details of NCPs in other MSs. This study provided no further information on other channels of communication.

For the study of Clemens *et al.* (2015)²⁷¹ a total of 24 NCP websites were examined. Most NCP websites provided contact details for telephone, email and an internet based contact form. Only two NCPs did not provide phone numbers, preferring written channels of communication. **The Latvian NCP was the only one on social media with its own Twitter account.**

Overall, our findings are in line with the findings from the previous studies on information provision through NCP websites. The technical side of the websites are, in general, well taken care of and has been in the past.

5.1.2. Accessibility of the website

This SAI category is focused on the ease with which the NCP website can be found, opened and used, and includes SAIs such as ‘availability of options for people with decreased sensory functioning’ and ‘order in Google search’. The analysis did not reveal any major issues regarding the accessibility of the NCP websites. Nevertheless, improvements are desirable. The combined average score of all NCPs is 60%.

None of the 36 websites were the first hit in our first Google search (NCP + ‘country’). In total, 14 NCP websites became the first hit when the search strategy was extended with the word ‘healthcare’. Of the NCP websites, 35 were flagged as ‘easy to open’ by our researchers, which means the researchers generally did not encounter any difficulties opening the URLs of the NCP websites. Initially, one NCP website could not be opened as it produced an error message when prompted to open. However, the researchers were able to open the website at a later point in time during the study period, allowing for the analysis to incorporate all 36 NCP websites.

In order to provide useful and accessible information to incoming patients (patients from another MS), we would expect NCP websites to have either an English language²⁷² version of the website or provide English language information on the main website. At the time of the data collection (July 2017) all but three websites were available in English; the websites of Austria, Portugal and one of the websites of Luxembourg were only available in the national languages. Additionally, 14 NCP websites included helpful options for people with decreased sensory functioning, such as a read-out-loud option, colour-blind mode, or an option for increasing font size.

A *best practice* in this SAI category is Slovenia, receiving almost the maximum number of points. The Slovenian NCP website only lost points because it was marked as the 2nd to 5th hit in our first Google search strategy.

During the bilateral exchange, at least one NCP indicated that they replicated the Google search, which resulted in a different position in the order of the search results. Important to note here is that the order in Google search varies due to, among other things, the device and web browser used²⁷³.

²⁷⁰ Santorro, A., Silenzi, A., Ricciardi, W., et al., Obtaining health care in another European Union MS: how easy is it to find relevant information? *European Journal of Public Health* 2014;25(1):29-31. The study of Santorro *et al.* evaluated whether MSs were meeting their legal obligations as to the provision of information for patients on their rights in relation to cross-border health care. The websites of 18 MSs were included with an available website.

²⁷¹ Activity report: The study of Clemens *et al.* (2014) provide no information on the accessibility of the website with regard to the number of hits for the search strategy.

²⁷² Given the total number of official languages being spoken in the EU, NCPs cannot be expected to provide information for inbound patients on their website in every official EU language. The choice was made to, as a minimum requirement, determine whether information for inbound patients was available in the *de facto lingua franca* of the EU: English.

²⁷³ <http://www.webpresencesolutions.net/7-reasons-google-search-results-vary-dramatically/>.

Comparing results with previous studies

The accessibility of the website in the Evaluative Study²⁷⁴ is ranked according to three different categories in this study. Of the 32 NCPs, the majority –16 NCPs – was in the “average” category. Eleven NCPs were in the upper quartile: these websites were included in the European Commission’s list of NCPs – which was one of the first results in the Google search –, and ranked first in the Google search. Only four NCPs came ranked between second and fifth in Google searches. These Google ranks are based on the results when searching “NCP + the name of the country + healthcare”. Similar to the findings from our study, the results changed substantially by adding the word “healthcare” to the search query: all rankings shifted upwards. As for the languages used, for most NCPs English was chosen as a second alternative language, with increasingly the same contents as provided on the native language website. Three NCPs presented information only in their national language.

Both Santorro *et al.*²⁷⁵ and Clemens *et al.* 2014²⁷⁶ provide no information on the accessibility of the website, based on the results from a Google search. Similar to the other studies, English is the preferred second choice of language, in addition to the official language of the MS. The majority of NCPs presented information in at least one, and up to three other languages. **However, the English language versions of the websites generally contained less information than the native language websites.** It is important to note is that both the study by Santorro *et al.* and Clemens *et al.* did not make a distinction between information that incoming patients would need and therefore should be presented in English, and information that outgoing patient would need and should be presented in the native language.

Also for this SAI category there does not appear to be a great change or evolution in the NCP websites: our findings are similar to those of the previous studies and give the same impression of NCP websites performing fairly well, while leaving some room for improvement.

5.1.3. Usability of the website

This SAI category concerns elements of the website that make the website easy to use for EU citizens: the presence of most visited pages, an internal search engine and a media library among other things. The average combined score of the NCPs for the usability SAIs was 55%. This relatively low percentage is largely due to the SAI on availability of a media library. Only 5 out of 36 websites contained a media library hosted on the NCP website. It has to be noted that there were NCP websites that linked directly to the European Commission’s webpage containing the European Commission cross-border health animated video. However, these NCPs did not receive points on this particular SAI, because we did not consider this an actual media library. In contrast, 31 out of 36 websites provided an internal search engine, which drastically improves the ability of visitors to navigate the website.

Poland can be marked as a *best practice* in the SAI category regarding usability of the website. The Polish NCP website provides a section for FAQs, most visited pages, a media library, and an internal search engine making the website very user friendly. Apart from Poland, other honorary mentions for the availability of a media library are: France, Greece, Italy, and Romania.

Comparing results with previous studies

The Evaluative Study established the user-friendliness of NCPs according to three different categories. Ten NCPs are in the upper quartile, meaning that these provided the necessary tools to help simplify understanding of the uploaded content. These tools were a media library, FAQs, and a clear and user-friendly web design, which corresponds with the SAIs used to assess usability in our study. However, in contrast to our study, the Evaluative Study did consider a link to the

²⁷⁴ Evaluative study on the cross-border healthcare Directive (2011/24/EU), March 2015, 12.

²⁷⁵ Santorro, A., Silenzi, A., Ricciardi, W., et al., Obtaining health care in another European Union MS: how easy is it to find relevant information? *European Journal of Public Health* 2014;25(1):29-31. The study of Santorro *et al.* evaluated whether MSs were meeting their legal obligations as to the provision of information for patients on their rights in relation to cross-border health care. The websites of 18 MSs were included with an available website.

²⁷⁶ Implementation of National Contact Points for cross-border healthcare in EU MSs: a comparative analysis using websites and short interviews. Clemens, T., Cox, E. van der Zanden, B., et al., 2016.

European Commission's video on cross-border healthcare an actual media library, therefore viewing the performance of the NCP websites in a slightly more positive light.

Santorro *et al.* and Clemens *et al.* presented no information on the usability of the website, as operationalised in this study.

5.1.4. General information on cross-border healthcare

Where the previous three SAI categories focussed on aspects of the NCP websites themselves, this category looks at the content that is made available on the websites: whether general information on the Regulation and Directive was present, whether general information on patients' rights was available, *etc.* The final five SAI categories go into further detail, in order to determine whether information on specific topics is presented in the NCP websites.

Similar to the technical elements of the NCP websites, the combined average scores of the NCPs was 72%. Most websites included a dedicated section for incoming patients, as well as for general information on patients' rights regarding cross-border care. Yet, a little less than half of the websites included information on both the EU Directive 24/2011 and the Regulation (EC) 883/2004, and also provided information on the distinction between these two pieces of legislation.

There are several NCP websites that scored the maximum number of points for this category. Hence, *best practices* include Austria, Croatia, Cyprus, Estonia, France, Germany, Italy, the Netherlands, Slovakia (both websites) and Spain.

Comparing results with previous studies

For 22 NCPs in the Evaluative Study, sections explaining the difference between Regulation 883/2004 and EU Directive 24/2011 were present. For the other 9 NCPs, the sections explaining the difference between Regulation and Directive were absent. The NCPs performed slightly better in the Evaluative Study than in our study on the availability of information about the Regulation and Directive. Again, this is most likely not due to changes in information provision on NCP websites, but due to how the researchers defined and interpreted the SAIs. The same can be said for the study of Clemens *et al.*, which noted that 23 out of 24 NCP websites included information on the differences between the Directive 2011/24/EU and Regulation 883/2004.

The study of Santorro *et al.* (2014) provided no general information on the EU Directive 24/2011 nor on the Regulation 883/2004.

5.1.5. Information on healthcare providers

Concerning the information available on the NCP websites on the topic of HCPs and the health system in the MS, a combined average score of 59% was achieved. There were no specific outlier SAI within this category, which highlights that across the board, all NCPs could improve and expand the provided information on this topic. Extra attention could be directed towards providing a clear and comprehensive overview of the structure of the healthcare system in the NCPs' respective countries.

Even though there were no outliers when the results were analysed on SAI level, vast differences were noted between countries with respect to the category as a whole. Similar to last SAI category, several *best practices* can be identified that received the maximum number of points. These include: Austria, Belgium, Finland, Latvia, the Netherlands, Poland, Portugal, Sweden (2), and Wales (UK).

During the bilateral exchange, one NCP indicated that while they do not provide all information on HCPs on their NCP website, they do offer this type of information to patients who call the NCP.

Comparing results with previous studies

The Evaluative Study concluded that 20 NCP websites (out of 32) provided a description of the nature of the healthcare system, main stakeholders, and/or the functions of the Ministry of Health. On 18 out of 32 websites, there was a tool made available to be able to locate national HCPs. The overall results from the Evaluative Study and from Santorro *et al.* (2014)²⁷⁷ on this topic are similar to the average score for the category from our study.

The study of Clemens *et al.* did not look at information provision on healthcare providers.

5.1.6. Information on patients' rights

A combined average score of all NCPs of 25% for this category shows that in-depth information on patients' rights is generally lacking on the NCP websites. Specific SAIs of concern are 'information on patients' rights in case of undue delay' and 'presence of information on complaint procedures in case of follow-up treatment issues', with only 2 and 4 out of 36 NCP websites containing relevant information respectively. From a positive perspective, 21 websites included (detailed) information on mechanisms to settle disputes and 17 included information on patients' rights in case of harm.

Though all NCPs would benefit from improving the available information on their website related to this SAI category, three websites performed better than average. These *best practices* are Finland, Ireland, and to a lesser extent Germany, specifically due the availability of information on complaint procedures in case of follow-up treatment on their websites. Additionally, England and Wales were the only websites to include specific information on patient' rights in case of undue delay.

During the bilateral exchange, two NCPs indicated that they do not provide information on 'the definition of waiting time' because there is no official definition of waiting lists for healthcare in these MSs. However, this does not mean that there are no waiting lists in the MSs of these NCPs. Looking at incoming patients, this might be relevant information to provide on the NCP websites as well.

Comparing results with previous studies

Information on patients' right to seek treatment in another European country was provided on the website of 29 NCPs in the Evaluative Study. Another 19 NCPs provided additional information on whom to contact in the event harm occurs. Regarding the performance of NCP websites on 'information on patients' rights in case of undue delay' and 'presence of information on complaint procedures in case of follow-up treatment issues' the Evaluative Study is again a little more positive than the current study: 14 NCPs provided information on patients' rights in case of undue delay, and 9 out of 32 NCPs provided information on complaint procedures. Similar to our findings, the Evaluative Study found that 20 NCPs provided information on mechanisms to settle disputes.

It should be noted, however, that the Evaluative Study assessed the websites in both the national language, as well as in English if available, whereas our study distinguished between the native (inpatient) and English (outpatient) version of the website. The study of Santorro *et al.* (2014) found that the English version of websites contained considerably less information compared to native language website, which could be an explanation for the lower scores from our study compared to the score of the Evaluative Study for several categories.

Several NCPs indicated during the bilateral exchange that information was not provided in English, because the information was provided through a link to a different, native language, website. While this does provide an explanation, this approach does not help incoming patients in their search for accessible information.

²⁷⁷ Santorro *et al.* (2014) established that 13 out of 18 NCPs provided a list of search engines to identify healthcare providers.

One NCP indicated that they did have an English language website, as opposed to the findings from the website analysis. However, our researchers were unable to find a link to this website on the native language site, and the only URL included on the European Commission's NCP website list was the URL of the native language website. Having information available is the first step: making sure the information can be found by others is just as important.

All 18 NCPs from the study of Santorro *et al.* (2014) provided information on patients' rights and entitlements. Seventeen NCPs provided information on complaints procedures and remedies, and 14 NCPs provided information on mechanisms to settle disputes. This study, too, assessed NCP websites in any of the official languages, resulting in higher scores on information on patients' rights than found in the current study.

In the study of Clemens *et al.*, 20 out of 24 MSs provided information on various topics under patient rights, such as access to medical records, patients' right to information, informed consent or data protection. Eighteen MSs offered information on dispute settlement procedures, although often incomplete referring to only a section of complaint procedures. Our study included more, or different, items regarding the SAI category of patients' rights that are not assessed in this previous study. Therefore, it would be biased to compare these results as such.

5.1.7. Information on prior authorisation

In order to receive reimbursement of healthcare costs, patients should in certain circumstances request prior authorisation from their insurance provider. On this important topic for patients, the NCP websites received a little less than half of the maximum points available, with a combined average score of 48%. 26 websites included information on how to obtain reimbursement, and 24 included information on what treatments require prior authorisation. The lowest number of points were earned for the availability of information on the time period required for prior authorisation requests to be dealt with.

France and Ireland are the two *best practices* that can be highlighted for this category of SAIs. Both scored the maximum number of points, most notably on the SAI for the time period required for prior authorisation.

Comparing results with previous studies

In the study of Santorro *et al.* (2014), 11 NCPs provided information on procedures requiring prior authorisation, and 10 NCPs provided an application form for prior authorisation, which is a somewhat lower score compared to the NCPs from our study and the scores of the Evaluative Study. This indicates that information on prior authorisation has been updated and/or upgraded since the previous studies.

The study of Clemens *et al.* provided no information on prior authorisation.

5.1.8. Information on quality and safety standards

Patients considering seeking healthcare in another MS need to be able to gain insight into the national policies regarding quality and safety of care, in order to make an informed decision. Information provision on quality and safety standards was generally poor at the time the website analysis was conducted. The combined average score of the NCP websites was 30%. In this category, scores on the different SAIs were broadly similar. This means that overall, 70% of the websites did not include any relevant information on quality and safety standards, which is alarming as quality of care and ensuring the safety of patients is high on the agenda for both the EU and the individual MSs.

A *best practice* for this category is Wales (UK), as it is the only NCP website which managed to earn all the points available for this category. The Welsh website included not only information on quality and safety policies, but also on actual measurements of quality.

Comparing results with previous studies

The Evaluative Study found that 19 out of 32 NCP websites provided information on national laws, regulations and policies regarding patient safety, yet only 15 websites provided information on the national quality strategy, and on medical certifications and qualifications required by the national healthcare system. The findings from our study show that 70% of websites did not include relevant information on quality and safety standards, which might be due to the fact that this information was analysed in the Evaluative Study using the native language websites and in our study using the English language websites.

The study of Santorro *et al.* found that this information was not available on NCP websites, however the quality and safety standards as set by MSs were available upon request for 12 out of 18 NCPs. This information was therefore not publicly available. In this respect, the availability of information on quality and safety standards for the NCPs of the study of Santorro *et al.* (2014) might be considered as insufficiently available. Although our study concluded that the information provision of this category is poorly represented, a few websites from our study did present some information, which might indicate a slight improvement.

In the study of Clemens *et al.*, 18 out of 24 websites were found to have sufficient information available on quality and patient safety, as links were frequently provided to the organisations, laws and other sources dealing with quality and patient safety. Although this might seem like a high score, the items were assessed satisfactory in case any information was available.

5.1.9. Information on entitlement for reimbursement of costs

The combined average score of the NCP websites on information provision on reimbursement of costs was 25%. 19 out of 36 websites included at least some form of information on which treatments are reimbursed. However, only 4 websites included specific details on which treatments are not reimbursed. Similarly, the SAIs on the time period required for reimbursement to be dealt with and information on specific reimbursement tools were among the worst scoring SAIs of the entire website analysis, with only 3 and 4 websites including some form of relevant information respectively.

For this category, for which much improvements can be made across the board, *best practices* include Estonia and Finland. The Finnish website is one of the few that includes information on what treatments are not reimbursed. And the Estonian website includes information on the time period required for reimbursement. Both websites also include information on specific reimbursement tools.

During the bilateral exchange, two NCPs indicated that they could not provide forms and/or information on reimbursement of cost, because this process differs per region and/or health insurance provider. For incoming patients, it might be relevant to provide information on the NCP website regarding these regional and other differences. There might be other websites who can provide information per region, and if so, NCPs might consider including a link to these websites, and/or other relevant contact information, to help incoming patients along.

Comparing results with previous studies

The Evaluative Study found that eleven websites out of 32 included information on requirements for the recognition of invoices/clinical information, and fourteen websites provided information on type of tariffs to be applied. Seven websites provided information on the time period for reimbursement, and only two provided information on payment tools for reimbursement. The Evaluative Study also found that 24 NCPs provided information on which treatments were subject to reimbursement and which ones were not. These last results are quite different from the results of our study. Unfortunately, it cannot be distinguished whether it were native language or English websites who provided this information in the Evaluative Study.

For the study of Santorro *et al.*, again the information on entitlement for reimbursement costs was only available on request; all NCPs provided this information when requested. Nevertheless, this did limit the accessibility to this information. Information on the other items is absent for this study.

For the study of Clemens *et al.* 23 out of 24 NCP websites had accessible ways of presenting patient's rights and procedures concerning reimbursement of cross-border healthcare. Nevertheless, no distinction has been made between different types of information presented, only that some information was present on the website.

Table 5.1 Relative NCP scores visualised with stars

	Technical Elements	Accessibility	Usability	General info	Healthcare providers	Patients' rights	Prior authorisation	Quality and safety	Reimbursement
NCP Website 1	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 2	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 3	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 4	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 5	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 6	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 7	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 8	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 9	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 10	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 11	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 12	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 13	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 14	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 15	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 16	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 17	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 18	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 19	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 20	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★

	Technical Elements	Accessibility	Usability	General info	Healthcare providers	Patients' rights	Prior authorisation	Quality and safety	Reimbursement
NCP Website 21	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 22	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 23	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 24	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 25	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 26	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 27	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 28	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 29	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 30	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 31	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 32	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 33	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 34	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 35	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★
NCP Website 36	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★	★★★★

5.2. Key findings and recommendations

Key findings of the website analysis

Our findings show that, while information provision through NCP websites was adequate for several categories, there also remains a need for further improvements. Especially information for incoming patients – in English - regarding patients' rights and quality and safety standards requires additional attention to ensure patients can make an informed decision regarding cross-border healthcare. For outgoing patients, information regarding reimbursement of healthcare costs, or information on where this type of information can be found, should be improved.

Based on the feedback that the project team received from the NCPs during the bilateral exchange, it is clear that there are at times practical reasons why NCP websites did not contain all relevant information, and/or why not all information relevant for inbound patients was available in English. While these practical reasons might be valid, a lack of accessible information means that not all NCPs are fully fulfilling their purpose of providing EU citizens with information on cross-border healthcare. We therefore encourage NCPs to look critically at their resources and how these can be best allocated towards ensuring accessible information for all patients is available online.

Of course, EU citizens also have other options available to gather information on cross-border healthcare, such as contacting their insurance provider or looking at commercial websites such as treatmentabroad.com. While these organisations and websites may provide relevant information on specific topics, NCPs have the added value of being information gateways who, generally, do not have a vested interest in where a patient seeks treatment. This might be different for these other organisations providing information on cross-border healthcare. Hence, the objective and (more) complete information provided by NCPs is of great importance to patients.

An important characteristic of the website analysis, is that it analyses the information provision on NCP websites during a specific time period. Many NCPs are continuously working on improving and changing their website and its content. During the bilateral exchange, several NCPs informed us that their website had changed in the meantime or that improvements were scheduled for the near future. Our findings should therefore not be considered a final judgement on the information provision on NCP websites, but rather as an indicator for where the websites stood in July 2017.

Recommendations for NCPs

Based on these findings, we formulated several general recommendations for the NCPs to further improve the accessibility of information for patients in cross-border healthcare on the NCP websites:

- NCPs can focus more on improving their English language website, to ensure good information provision for incoming patients. Especially look at improving or expanding English language information on patients' rights, and quality and safety of care;
- It might be worthwhile for NCPs to look at their website as if they were a patient: is it clear from the starting page where information can be found?
- NCPs can choose to have their website tested by users with sensory disabilities, to assess what disabled persons require to ensure adequate access to the website;
- We encourage NCPs to learn from the good practices identified in this study: well performing NCP websites were identified for each category, providing sufficient examples of how NCPs can improve their information provision. In particular, the websites that performed well on the categories focusing on information for incoming patients can provide useful examples for other NCPs, since that information is provided in English.
- The NCPs could make their websites even more Google friendly, for instance by incorporating a link to the European Commission NCP list on their website in case they do not already do so.

6. Results of the pseudo-patient investigation

This Chapter presents the results of the pseudo-patient investigation (WP3). First, we elaborate on whether the NCPs were successfully contacted (section 6.1). Second, this Chapter provides an aggregate overview of the information provision to the pseudo-patients (section 6.2). Last, further details are provided regarding the level of information provision within each of the formulated scenarios (Section 6.3). In addition, this Chapter outlines our key findings and recommendations for further improvement of information provision to patients based on the experiences and findings of the pseudo-patients (section 6.4).

The aim of the pseudo-patient investigation was to follow-up on the one conducted within the Evaluative Study. The main objective was to investigate the information that is provided by the NCPs in response to inquiries made by patients. A total of 116 pseudo-patient investigations were conducted in 29 countries, 4 scenarios per country. First contact was made between 21 August 2017 until 2 October 2017 (for more information on this methodology, please see Chapter 3).

The results of the individual items per scenario for each NCP are presented in Annex H (provided in separate document).

6.1. Contacting the NCP

During the pseudo-patient investigation, the NCPs were first contacted by email. After an incomplete response, or after two weeks, the NCPs were contacted via telephone, where possible. Three NCPs only allow for contact via email and did not provide a telephone number.

In Annex H (provided in separate document), a detailed overview is provided laying out the different communication channels used and if the NCPs were successfully reached via these channels. The Annex also provides more details on the different steps that were needed to reach the NCP, such as resending or forwarding the email, or language barriers faced.

Table 6.1 describes whether the pseudo-patient was able to make contact with the NCP (via any channel) and receive information. The details are analysed by scenario and by NCP.

Table 6.1 Was the NCP reached?

	Scenario 1	Scenario 2	Scenario 3	Scenario 4
NCP 1	★★★★	★★★★	★★★★	★★★★
NCP 2	★★★★	★★★★	★★★★	★★★★
NCP 3	★★★★	★★★★	★★★★	★★★★
NCP 4	★★★★	★★★★	★★★★	★★★★
NCP 5	★★★★	★★★★	★★★★	★★★★
NCP 6	★★★★	★★★★	★★★★	★★★★
NCP 7	★★★★	★★★★	★★★★	★★★★
NCP 8	★★★★	★★★★	★★★★	★★★★
NCP 9	★★★★	★★★★	★★★★	★★★★
NCP 10	★★★★	★★★★	★★★★	★★★★
NCP 11	★★★★	★★★★	★★★★	★★★★
NCP 12	★★★★	★★★★	★★★★	★★★★
NCP 13	★★★★	★★★★	★★★★	★★★★
NCP 14	★★★★	★★★★	★★★★	★★★★
NCP 15	★★★★	★★★★	★★★★	★★★★
NCP 16	★★★★	★★★★	★★★★	★★★★
NCP 17	★★★★	★★★★	★★★★	★★★★
NCP 18	★★★★	★★★★	★★★★	★★★★
NCP 19	★★★★	★★★★	★★★★	★★★★
NCP 20	★★★★	★★★★	★★★★	★★★★
NCP 21	★★★★	★★★★	★★★★	★★★★
NCP 22	★★★★	★★★★	★★★★	★★★★
NCP 23	★★★★	★★★★	★★★★	★★★★
NCP 24	★★★★	★★★★	★★★★	★★★★
NCP 25	★★★★	★★★★	★★★★	★★★★
NCP 26	★★★★	★★★★	★★★★	★★★★
NCP 27	★★★★	★★★★	★★★★	★★★★

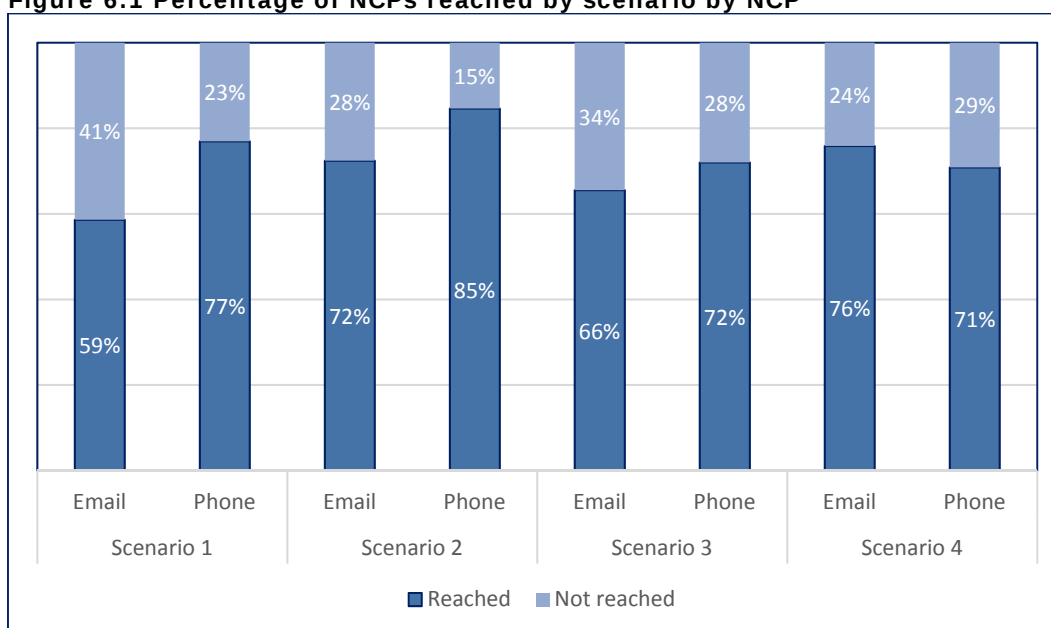
	Scenario 1	Scenario 2	Scenario 3	Scenario 4
NCP 28	★★★★	★★★★	★★★★	★★★★
NCP 29	★★★★	★★★★	★★★★	★★★★

Note. 4 stars: made contact by email/phone and was able to make inquiries, 3 stars: made contact by email/phone after being forwarded or resending an email and was able to make inquiries, 2 stars: was able to make contact by email/phone but no inquiries addressed, 1 star: was unable to make contact by email/phone and no inquiries were addressed.

As shown in the table above, looking at all scenarios, the majority (82%) of pseudo-patients were able to get into contact with the NCP and make enquiries (3 or 4 stars). Eighteen out of 29 NCPs (62%) were always reachable for the four scenarios (3 or 4 stars). In 18% of the scenarios, NCPs were not reached by the pseudo-patients, or they were unable to get a response to questions (2 stars or 1 star). One NCP was never reached. Two NCPs were reached at least once however pseudo-patients were never able to make inquiries in any of the four scenarios.

Figure 6.1 provides an overview of the percentage of NCPs reached by the pseudo-patients, via any channel.

Figure 6.1 Percentage of NCPs reached by scenario by NCP



In scenario 1 and scenario 2 (for outgoing patients), NCPs seem slightly more easy to reach by phone than by email. 77% (scenario 1) and 85% (scenario 2) of the NCPs were reached by phone and 59% (scenario 1) and 72% (scenario 2) of the NCPs responded to the emails. For the incoming patients (scenario 3 and 4), there is a less evident difference between responsiveness by phone or email; as at least 66% of the pseudo-patients managed to reach the NCP by email and by phone.

In terms of reachability, there are some variations between NCPs for several reasons. NCPs may provide a reply later than the cut-off point of seven weeks, others were not reachable due to language barriers, and yet others were difficult to reach due to being forwarded or the need to resend the enquiry. Others requested the provision of additional or personal information (e.g., health insurance numbers, doctor's referrals) before responding to the questions, which pseudo-patients were unable to give.

Considering only reachability, *best practices* include Austria, Croatia, Denmark, Germany, Estonia, Finland, France, Latvia, Malta, Norway, Poland, Slovakia, Slovenia, and the Netherlands, who were always reached by the pseudo-patient investigators for each scenario without the need for resending or forwarding the inquiry, or other barriers.

6.2. Aggregated data on information provision

In order to analyse the information provision of the NCPs, the different items²⁷⁸ of the four different scenarios were taken into consideration. Each item was analysed according to whether information was provided or not. The correctness of the information was not taken into consideration. The total scores per scenario for each NCP, and other detailed results, can be found in Annex H (provided in separate document).

An overview of the scores per scenario and an aggregated score per NCP is provided in the table below. The stars are calculated based on the percentage of items on which information was provided.

Table 6.2 NCP scores of information provision, visualised with stars

	Scenario 1	Scenario 2	Scenario 3	Scenario 4	Aggregated
NCP 1	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 2	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 3	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 4	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 5	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 6	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 7	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 8	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 9	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 10	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 11	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 12	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 13	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 14	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 15	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 16	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 17	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 18	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 19	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 20	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 21	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 22	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 23	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 24	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 25	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 26	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 27	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 28	★★★★	★★★★	★★★★	★★★★	★★★★
NCP 29	★★★★	★★★★	★★★★	★★★★	★★★★

Note: 4 stars = information was provided for at least 75% of the items in the inquiry. 3 stars = information was provided for 50%-74% of the items. 2 stars = 25% - 49% of all items. 1 star = less than 24% of items.

As shown in Table 6.2, 55% of the NCPs responded to at least half of the questions in the email or telephone inquiries, on average. 24% of the NCPs were able to respond to the majority (four stars) of questions, on average. A total of 10% of the NCPs were not able to provide any information to the pseudo-patients.

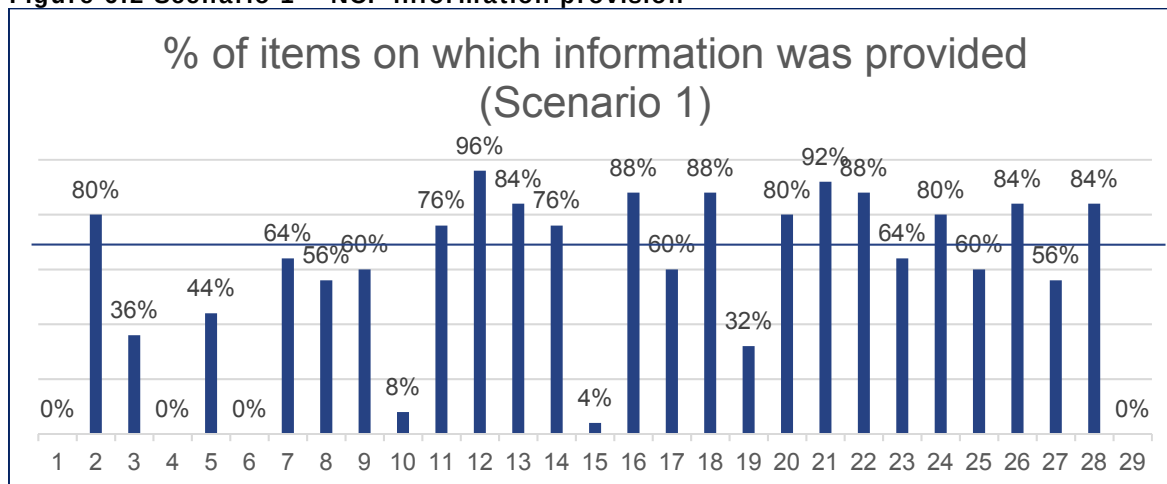
In terms of information provision, *best practices* include the NCPs of Czech Republic, France and Greece who were able to provide information on more than 80% of the items in all four scenarios. The NCP of Italy was never reached in any of the four scenarios. Two NCPs were reached but never provided the pseudo-patients with direct information on the enquiries.

²⁷⁸ During the bilateral exchange phase several items were excluded from the analysis. This was agreed because several items were not directly addressed in the communication with the NCP.

6.3. Information provision by the NCPs for all scenarios

The figures below provide the NCPs total scores per scenario provided to the pseudo-patients for each of the items either by email or telephone. Note that the correctness of the information was not analysed.

Figure 6.2 Scenario 1 – NCP information provision

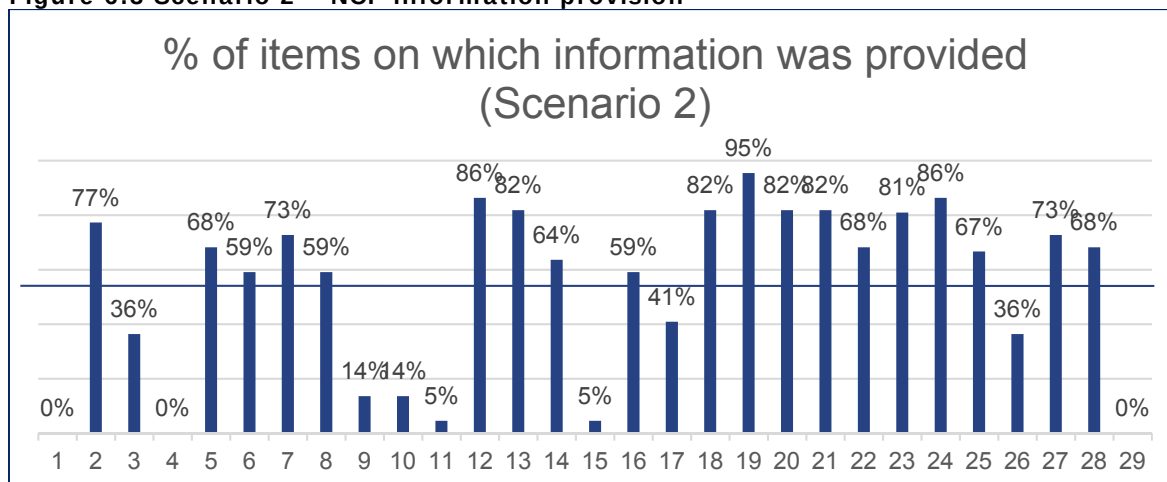


As demonstrated in Figure 6.2 above, although they received the email and/or telephone calls, some NCP did not address all or some of the items in which the pseudo-patient was interested. On average the NCPs responded to 57% of the items, 14 NCPs scored above average. One NCP indicated that they could not provide general information and needed further personal information to be able to address the questions, therefore the pseudo-patient was unable to proceed with the investigation otherwise they would have jeopardised the entire mystery call exercise. Similarly, another NCP explained that they cannot provide further information without a formal reference from a doctor. Yet another NCP referred the pseudo-patient to another body. One NCP was never reached, and the pseudo-patient reported that another NCP did not provide the requested information.

Best practice in this scenario was the Czech Republic, responding to 96% of the items. Slovenia, Finland, Germany, Estonia, Poland, Ireland, Hungary, Greece, France, Austria, Denmark and the Netherlands also responded to at least 75% of the items.

The same data is provided for all NCPs for Scenario 2, below.

Figure 6.3 Scenario 2 – NCP information provision



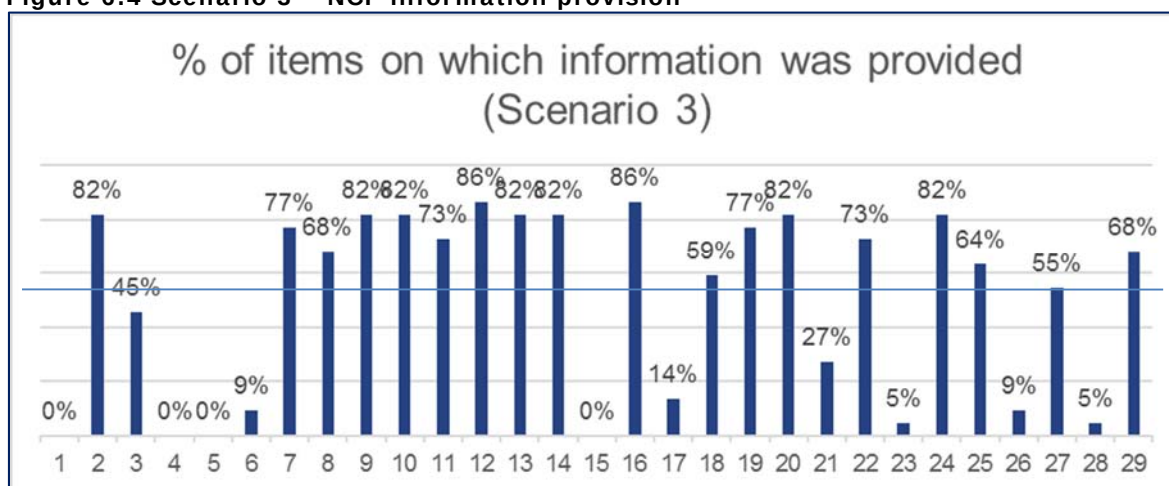
The average percentage of items responded to is 54%, for scenario 2. 19 NCPs scored above average. As in scenario 1, two NCPs could not provide information without the provision of additional personal information from the pseudo-patient. Two other NCPs were reached but no items were directly responded to. One NCP was not reached via any means. Another NCP

responded via email and correctly referred the patient to the competent NCP, they did not, however, respond to individual items. Yet another NCP was reached on several occasions but did not get back to the pseudo-patient with follow-up information, as was promised.

Best practice for this scenario was Slovakia with 95% of the items responded to. This is followed by Czech Republic, Greece, France, Poland, Finland, Slovenia, Spain and Austria who each responded to at least 75% of the items.

Figure 6.4 below presents the NCP scores for Scenario 3, for incoming patients.

Figure 6.4 Scenario 3 – NCP information provision

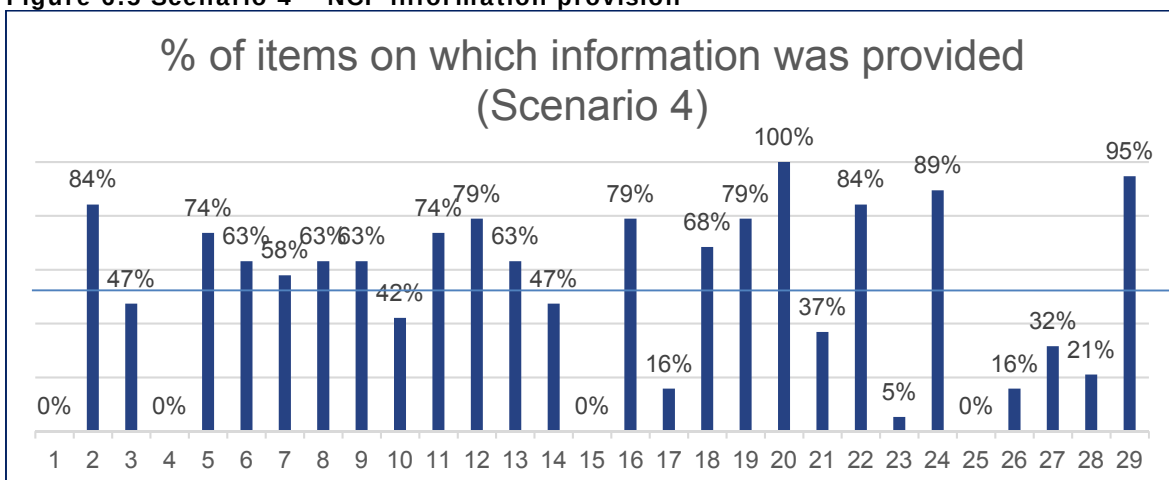


Although the majority of the NCPs responded to inquiries, not all of them were able to provide information on all items. The average score is 52%, 18 NCPs scoring above average, as shown in the figure above. In scenario 3 two NCPs were never reached. One NCP responded after the 7 week cut-off point and were not reached by telephone. Three NCPs were reached but they were not able to provide any information.

Best practices in this scenario were Czech Republic, Estonia, France, Greece, Austria, Poland, Malta, Denmark and Cyprus responding to more than 80% of the questions. Slovakia and Norway also responded to more than 75% of the items.

Figure 6.5 below describes the percentage of items responded to for Scenario 4, by NCP.

Figure 6.5 Scenario 4 – NCP information provision



On average 51% of the items were responded to by the NCPs, 15 NCPs scored above average. As with the previous scenario, two NCPs were never reached by the pseudo-patients. Three NCPs were reached but no response to the inquiries was made. *Best practices* are France, scoring 100%. Followed by Luxembourg, Greece, Germany, Austria, Czech Republic, Estonia and Slovakia each responding to at least 75% of the items.

Performance in terms of information provision of NCPs for outgoing versus incoming pseudo-patients differs within countries. The data suggests that performance for outgoing scenarios is slightly better.

6.4. Key findings and recommendations

Key findings of the pseudo-patient investigation

The findings show that the vast majority of NCPs were reachable for the pseudo-patients. A total of 90% of the pseudo-patients were able to get into contact with their NCP. However, there is still need for improvement as it remains important that *all* NCPs can be reached by patients. When NCPs were reached over half of the requested information (57%) was, on average, successfully provided. Considering the large number of questions asked, these are positive results. However, there are considerable variations in performance. One out of four NCPs were able to provide information on the majority of the questions asked, while one out of ten never provided any information at all. This shows that there is room for improvement for some NCPs – and for NCPs to learn from each other's best practices – and suggests high information provision potential of the NCPs in the future.

Based on the feedback received from the NCPs during the bilateral exchanges, some constraints were reported explaining why communication or information provision was indeed limited. The constraints include the request by the NCPs for personal patient information or additional documentation in order to be able to proceed with communication. Furthermore, it is important to note that pseudo-patients were often redirected to other institutes and organisations such as healthcare providers and health insurance providers to obtain the necessary information. This is the reason why in some instances NCPs did not provide an answer but guided the pseudo-patient to take the required, suitable next steps in their quest for information.

It is important to note that pseudo-patient investigations are a snapshot of continuously learning and improving NCPs. During the bilateral exchange several NCPs reported improved reachability and other changes to information provision, where necessary. These findings, although reflective of the situation late 2017, should be seen as an indicator from where NCPs have continued to develop.

Recommendations for NCPs

Based on the findings we formulated several recommendations for the NCPs to further improve information provision to patients through :

- Provide information via telephone and email in another language in addition to the local language(s); for incoming patients, English is preferred;
- Provide the correct contact information on the website and synchronise it with the contact information provided by DG SANTE. Make sure that the patient is not forwarded to other agencies/contacts;
- Ensure that email inquiries are responded to, especially if this is the only way for a patient to reach the NCP;
- Send automatic replies to email inquiries confirming the reception of the email along with an indication on when a formal reply to the email can be expected;
- Ensure that telephone menus are available in English, or allow for direct contact with a receptionist;
- Avoid using technical terms and legal jargon in communication with patients.

7. Results of the online surveys and other information centres

This chapter presents the results of WP4. In this chapter we elaborate on the results of the online survey among NCPs (section 7.1), the results of the online survey among patients (section 7.2), and the analysis of other information centres (section 7.3). In addition, we outline our key findings and recommendations harvested from the online surveys and other information centres (section 7.4).

7.1. Online survey - NCPs

The aim of the online survey was twofold:

- To explore the organisational structure and working process of NCPs;
- To assess and provide a better understanding of the current practice of information provision to patients.

The survey was sent to the NCPs of all 28 MSs, Iceland²⁷⁹ and Norway²⁸⁰ ($n = 33$ NCPs²⁸¹).²⁸² We achieved a response rate of 94%. A total of 31 NCPs, representing 28 MSs, completed the survey ($n = 31$ NCPs). In addition, four RCPs participated separately. Two NCPs (single NCPs of different MSs) remained non-responsive. For more information on the methodology, please see Chapter 3.

7.1.1. Findings NCP survey

The key findings of the online survey are presented here, and a more extensive overview of the gathered data is provided in Annex B (provided in separate document).

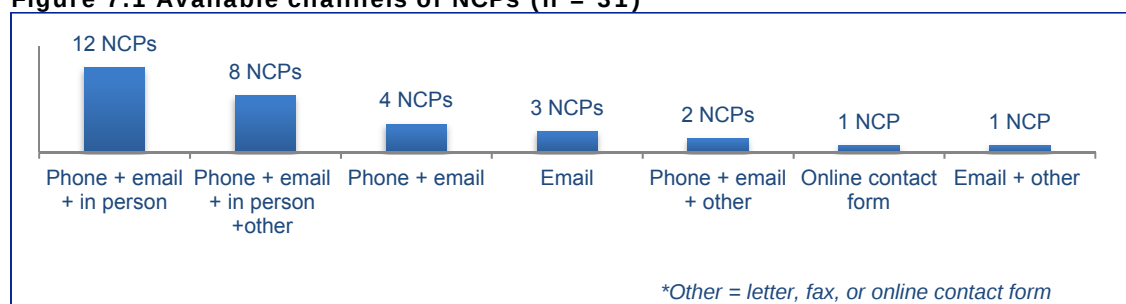
Big organisational differences

The online survey showed that there are substantive organisational differences between MSs regarding the number of NCPs, the institution hosting the NCP, the NCP funding and staff, as well as the organisational handling of incoming and outgoing patients.

A variety of communication channels

Most NCPs can be reached through a variety of communication channels and also offer the possibility of in-person consultations. All NCPs have a website available. Eight out of 31 NCPs stated they were considering adding additional communication channels.

Figure 7.1 Available channels of NCPs (n = 31)



These findings are in line with the findings of the Evaluative Study, where it was reported that 21 NCPs could be reached via at least telephone, email and in person, our study shows that 20 NCPs

²⁷⁹ Despite of the fact that Iceland was initially excluded from the scope of the study, it was decided to include Iceland in the online survey exercise considering the comparability with the Member State data reports on cross-border healthcare.

²⁸⁰ Since the Directive 2011/24/EU is not yet implemented in Liechtenstein and Liechtenstein does not participate in the cross-border healthcare expert group set up by the European Commission, Liechtenstein is not included in the online survey exercise.

²⁸¹ Lithuania, Luxembourg and Sweden each have two NCPs (one for incoming and one for outgoing patients).

²⁸² Since the Directive 2011/24/EU is not yet implemented in Liechtenstein and Liechtenstein does not participate in the cross-border healthcare expert group set up by the European Commission, Liechtenstein is not included in the online survey exercise.

could still be reached via these channels.²⁸³ A slight increase is also shown in the NCPs' willingness to add more communication channels (two NCPs in 2014 in comparison with eight NCPs in the current study).²⁸⁴

Accessibility of the NCP website

A number of NCP websites was already developed on the basis of the W3C Web Content Accessibility Guidelines 2.0, according to the NCPs. However, the online survey showed there is still room for improvement.

Figure 7.2 Website accessibility (n = 25)

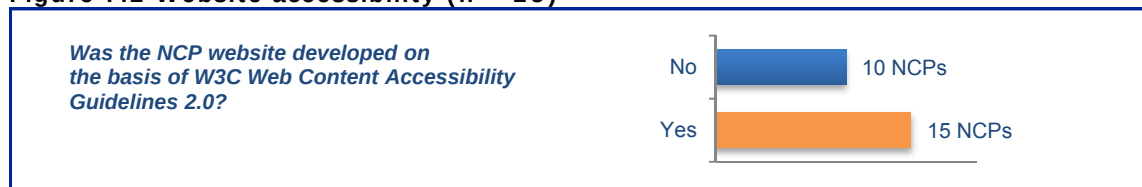
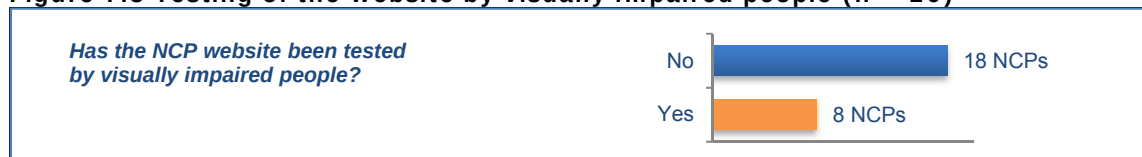


Figure 7.3 Testing of the website by visually impaired people (n = 26)



In regard to web accessibility for patients with disabilities, no comparison with the Evaluative Study can be provided, as these topics were not questioned in the NCP survey of 2014.

Languages

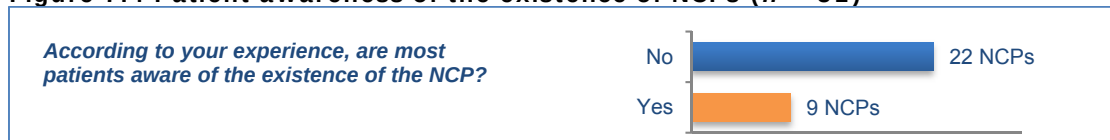
Almost all NCPs stated that they provide information in English. In addition, information is sometimes also provided in other non-official languages.

These findings are in line with the findings of the Evaluative Study, where all 12 NCPs indicated they received requests in English and are able to answer these questions.²⁸⁵

Patient awareness

Half of the NCPs were aware of activities carried out in order to inform the general public of the existence of the NCP. However, some NCPs referred to the information on the NCP website, which already presupposes a level of awareness on the part of the patient. This may explain why patient awareness of the existence of NCPs is generally considered to be low, as well as the limited number of information requests some NCPs receive.

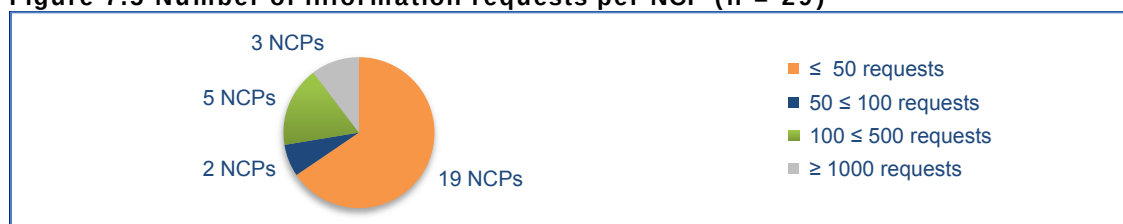
Figure 7.4 Patient awareness of the existence of NCPs (n = 31)



²⁸³ Evaluative Study on the cross-border healthcare Directive (2011/24/EU), 2015, 34.

²⁸⁴ Evaluative Study on the cross-border healthcare Directive (2011/24/EU), 2015, 34.

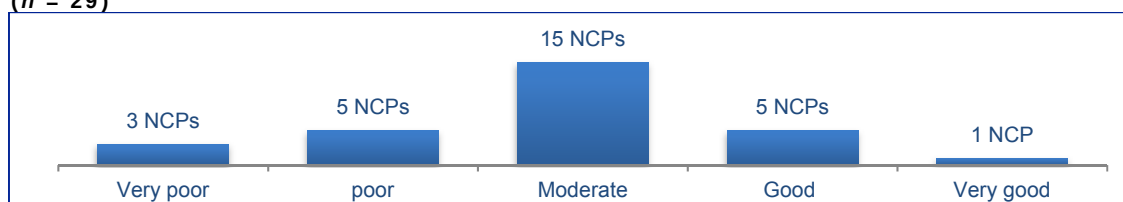
²⁸⁵ Evaluative Study on the cross-border healthcare Directive (2011/24/EU), 2015, 138.

Figure 7.5 Number of information requests per NCP (n = 29)

The Evaluative Study showed that six out of nine NCPs were aware of public campaigns being carried out. The findings of the Evaluative Study showed that campaigns were mostly carried out during a short period of time after the implementation of Directive 2011/24/EU.²⁸⁶ However, the current study shows that several NCPs carry out campaigns on a regular basis.

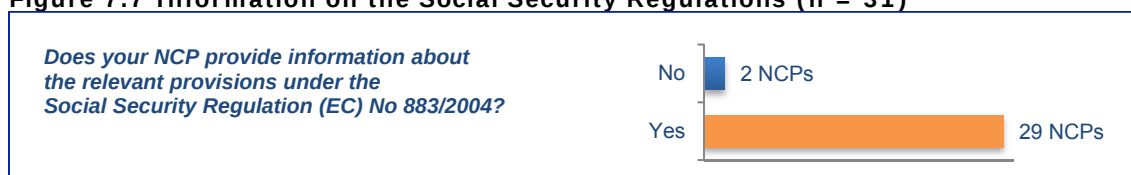
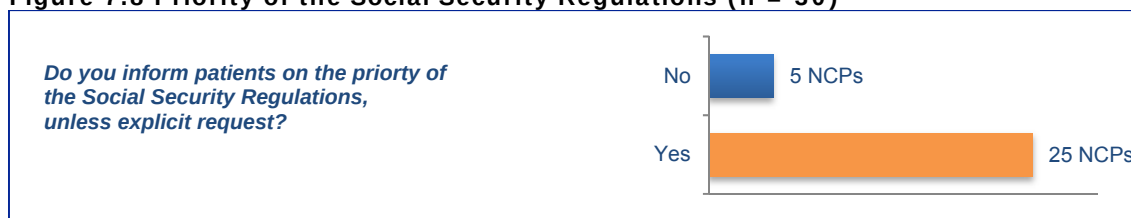
In the Evaluative Study, most NCPs reported a low level of patient awareness on the existence of NCPs (eight out of nine NCPs). Moreover, the Evaluative Study showed that seven out of nine NCPs received less than 99 requests a month and no NCP received more than 1,000 requests.²⁸⁷ Regardless of the fact that most NCPs still receive less than 50 requests a month, an increase in information requests is shown for a small number of NCPs.

Generally, NCPs considered patient awareness of the existence of the right on cross-border healthcare under Directive 2011/24/EU and the Social security regulations to be low.

Figure 7.6 Patient awareness of the right on reimbursable cross-border treatment (n = 29)

Distinction between information on Directive 2011/24/EU and the Social Security Regulations

Almost all NCPs indicated that they provide information on the Social Security Regulations. In addition, most NCPs stated that they make a clear distinction between the right to cross-border treatment under the Directive 2011/24/EU and under the Social Security Regulations.

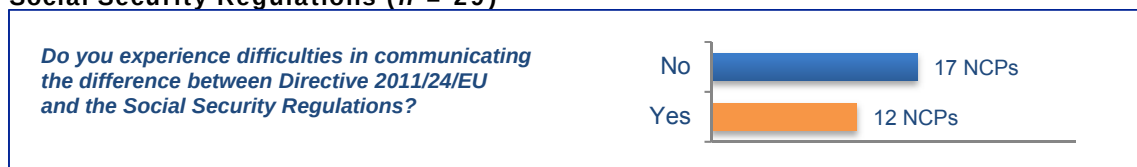
Figure 7.7 Information on the Social Security Regulations (n = 31)**Figure 7.8 Priority of the Social Security Regulations (n = 30)**

²⁸⁶ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 129.

²⁸⁷ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 129-130.

However, 12 out of 29 NCPs report experiencing difficulties in providing information on this distinction. In light of the legal requirements under Directive 2011/24/EU, this finding seems noteworthy.

Figure 7.9 Difficulties in making a distinction between Directive 2011/24/EU and the Social Security Regulations (n = 29)

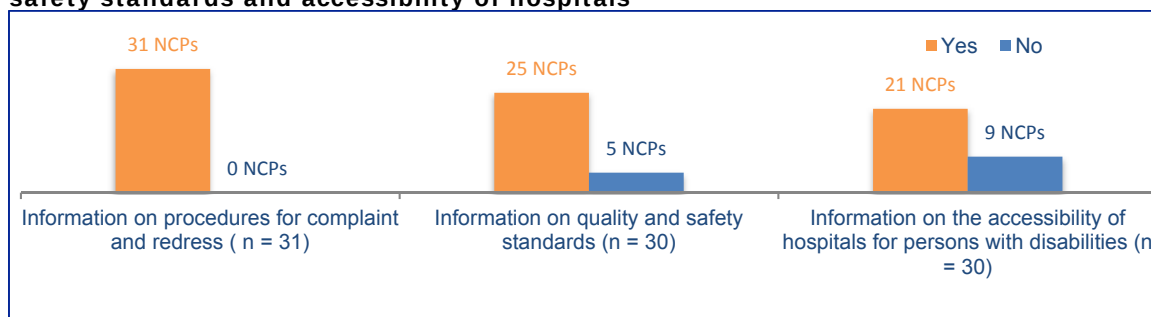


The Evaluative Study showed comparable findings on the distinction between Directive 2011/24/EU and the Social Security Regulations. However, the current study shows an increase in information provision by NCPs on the Regulations. Where in 2014 only five out of eight NCPs stated they provided information about these provisions, almost all NCPs answered the question positively in the current study. On the contrary, no improvements over time are shown on the difficulties NCPs encounter in communicating on the distinction between the Directive and the Social Security Regulations (four out of nine NCPs in 2014 compared to 12 out of 29 NCPs in 2017).²⁸⁸

Information provision

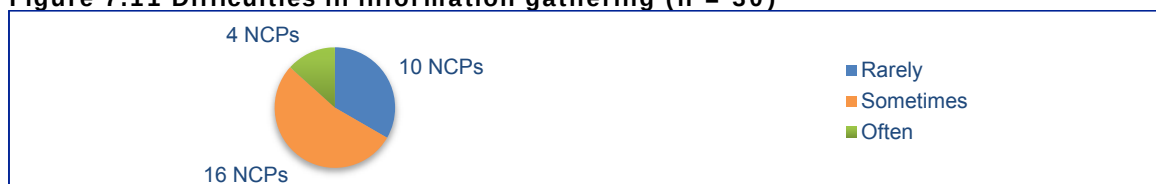
Five out of 30 NCPs indicated they do not provide information on quality and safety standards. In addition, 9 NCPs stated that they do not provide information on the accessibility of hospitals. The latter can be considered a high number, particularly in light of the specific obligation to provide such information under Directive 2011/24/EU.

Figure 7.10 Information provision on procedures for complaint and redress, quality and safety standards and accessibility of hospitals



The survey showed that one out of two NCPs sometimes experiences difficulties in gathering information needed to answer patients' questions. Four NCPs stated that they often encounter such difficulties.

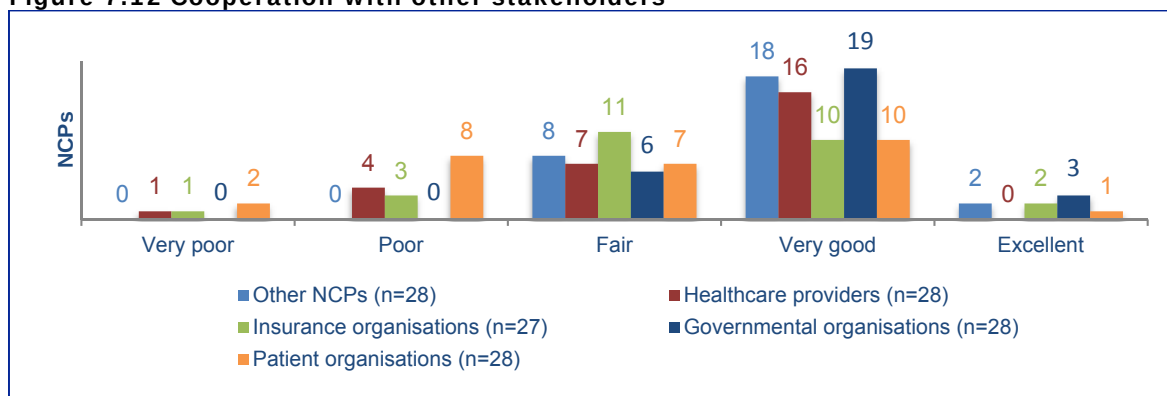
Figure 7.11 Difficulties in information gathering (n = 30)



Cooperation and information exchange

NCPs explained that, in general, they cooperate well with other stakeholders. However, 10 out of 28 NCPs evaluated the cooperation with patient organisations negatively. NCPs seem to be most satisfied with the cooperation with other NCPs and with governmental organisations.

²⁸⁸ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 140.

Figure 7.12 Cooperation with other stakeholders

In line with the findings on cooperation in the current study, the Evaluative Study showed that the level of cooperation between patient organisations and NCPs needed improvement (the level of cooperation was considered to be rare by six out of eight NCPs).²⁸⁹ The current findings show that efforts still need to be made in order to improve cooperation with patient organisations.

Room for improvement

Overall, NCPs indicated experiencing significant improvements since the implementation of Directive 2011/24/EU. However, they also indicated that 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.

Below some quotes of respondents are provided:

- "Sharing information of accessibility of special healthcare service on EU common portals";
- "The information provided on the various websites of foreign NCPs is often succinct, general and rarely discloses the concrete information that patients need";
- "Language barriers";
- NCP: "We have felt that we are lacking knowledge about other MSs healthcare systems";
- More international exchanges of health system functioning";
- "Better cooperation between NCP's of all EU MSs";
- "More efficient cooperation with healthcare providers and patients' organizations";
- "More cooperation between NCPs. Not only meetings where all NCPs are present, but meetings between just a couple of NCPs would be a learning experience";
- "Better sharing of information among NCPs. IT systems could help (for example, website or IT based forum) to share actual information of NCPs";
- "It would be also good to have a platform to exchange thoughts from time to time in certain cases";
- "NCPs could team up to be involved in projects collecting info from all MS on priority issues such as quality and safety, a summary/presentation of the national health system, using e.g. checklists or templates, which would feed into the websites of the NCPs network";
- "Raise awareness among the general public on the existence of the NCPs and their role (i.e. explain very well what they can do but also be clear what not)";
- "The standardization of invoices for reimbursement process (mandatory data and standard codification of the procedures)" / "Standardization of e-invoicing";
- "Create better visibility by campaigns".

²⁸⁹ Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 140.

7.1.2. Country specific description NCPs

A country specific description of the circumstances under which the NCPs are working, including their operational organisation, was developed as part of the study. The information has been mainly distilled from data gathered from the NCP survey, sometimes clarified with information found on the NCP websites, results from earlier WPs, as well as other desk research.

The data was collected for DG SANTE in a separate Excel file, that consists of 4 worksheets: "NCP organisation"; "NCP working process"; "Cross-border healthcare"; "Background information MS". Worksheets 1 to 3 outline the country specific description of the NCPs. In worksheet 4 general background, information on the health systems of the different MSs is provided.

The data of the country specific description was part of the bilateral exchange with the NCPs, providing them with the possibility to share their remarks and to make additions or corrections where necessary.

7.2. Online survey - patients

The aim of the online survey amongst patients was to explore patients' experiences with gathering information in the event of cross-border healthcare and to provide a better understanding of the importance of good information provision to patients in cross-border healthcare (for more information on the methodology, please see Chapter 3).

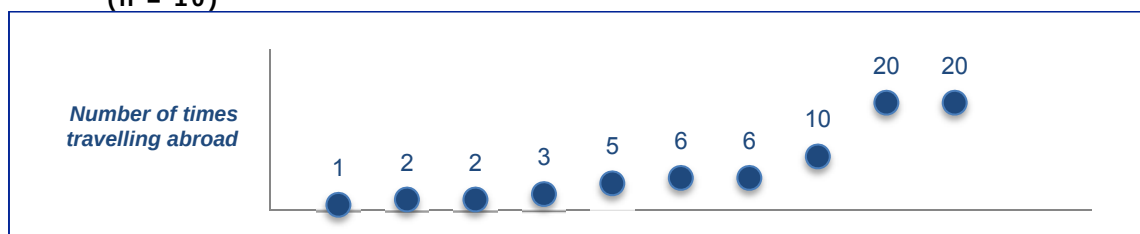
In total, the responses of 11 patients were included in the data analysis, corresponding to more than 50 planned cross-border healthcare events (ranging from 1 to 20 events per patient; mean of 6 events per patient). As a result, the sample size is too small to draw any valid and representative quantitative conclusions. Nevertheless, the patient survey yielded accurate qualitative information based on the comments provided by patients throughout the survey. These comments are used to validate quantitative findings of the study.

7.2.1. Findings patient survey

Sample characteristics – Cross-border healthcare

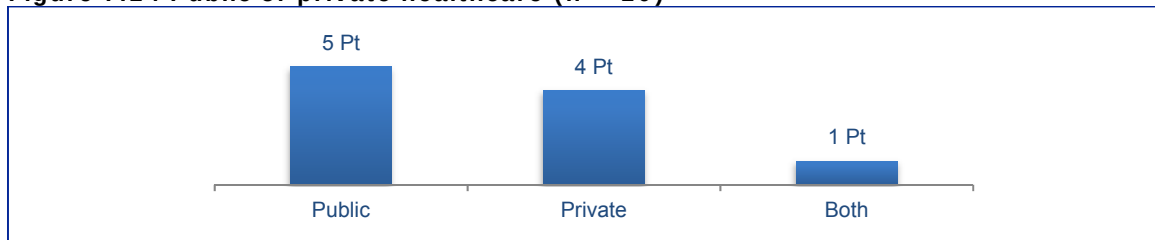
To identify the characteristics of the sample of the survey, patients were asked how many times they have already travelled to another MS with the purpose of receiving planned medical treatment. The ten patients that answered the question had on average travelled to receive cross-border healthcare between seven and eight times (range 1 to 20; mean = 7.5).

Figure 7.13 Number of times of receiving planned treatment abroad per patient (n = 10)



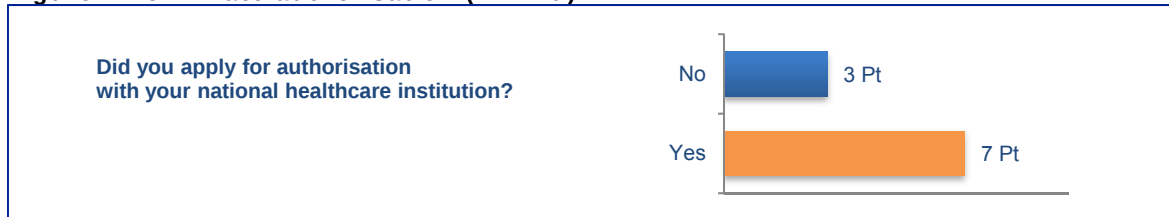
All of these ten patients received physical cross-border treatment. None of the patients stated to have used telemedicine. Five patients out of ten received public treatment. Four patients received private care. One patient indicated receiving both.

Figure 7.14 Public or private healthcare (n = 10)



The survey showed that most of the patients received cross-border treatment after prior authorisation of the healthcare insurer.

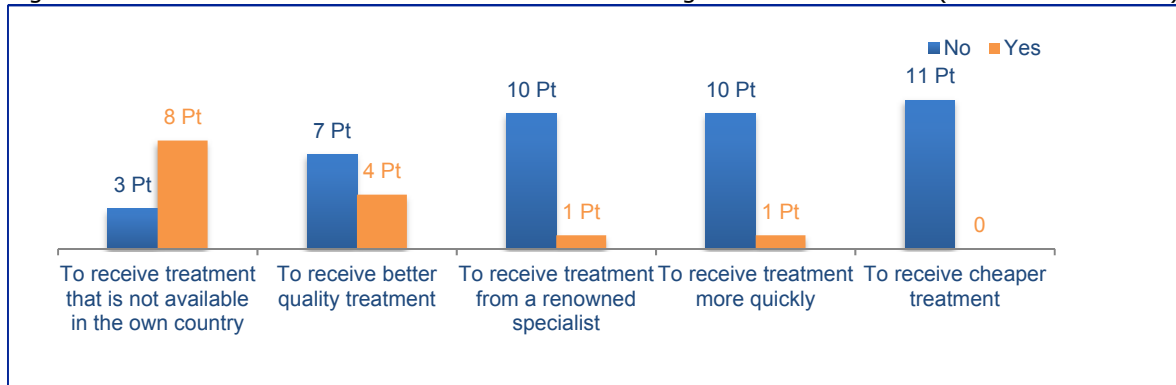
Figure 7.15 Private authorisation (n = 10)



In a second question, patients were asked if they indeed required prior authorisation in order to receive the healthcare abroad. One of the patients that had not applied for it stated s/he had actually needed prior authorisation in order to receive reimbursement. By contrast, one of the patients had applied for authorisation when it was actually not required.

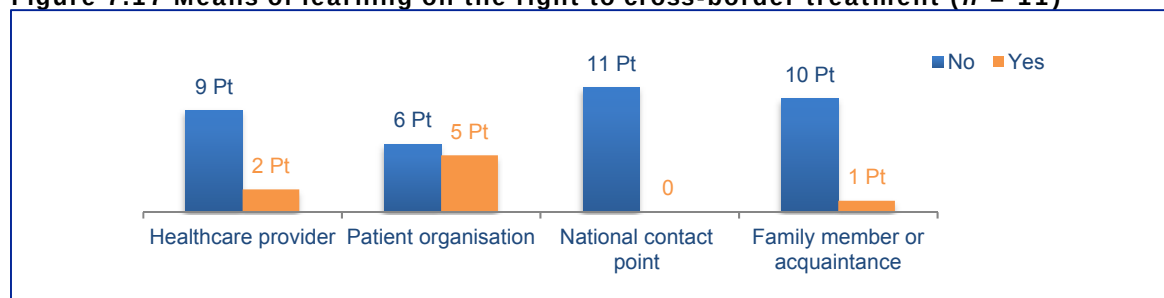
The online survey showed that most patients sought cross-border treatment due to the fact that the treatment concerned was not available in their home country. None of the patients had travelled abroad in order to receive treatment that was less expensive.

Figure 7.16 Reasons for travelling abroad (n = 11)

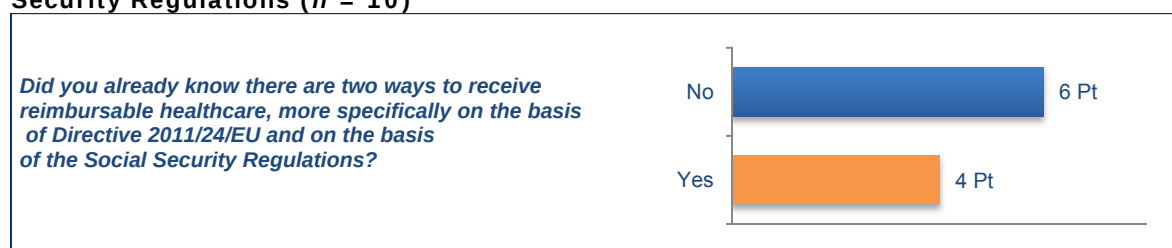


Patient awareness

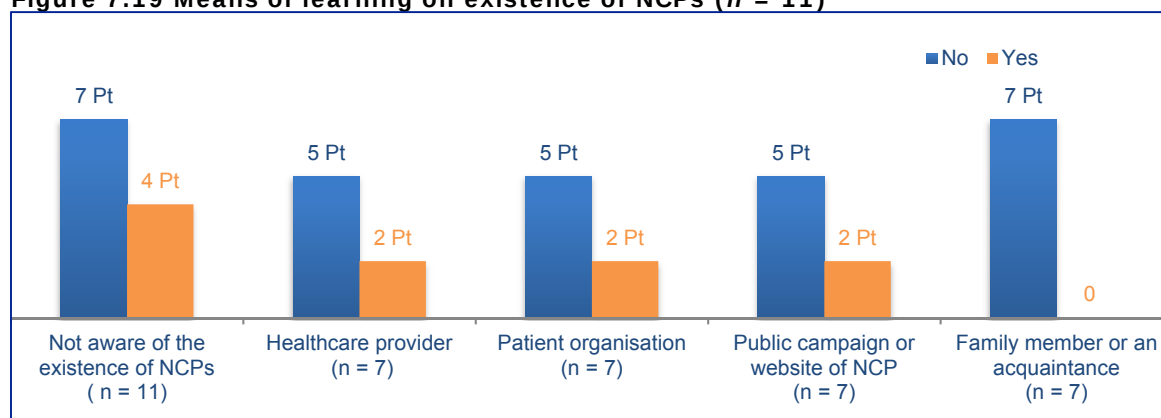
Eight out of ten patients said that they already knew about the right to receive medical cross-border treatment and the right to be reimbursed for that treatment by the own health insurance institution. Most patients became acquainted with the right to reimbursable treatment through a patient organisation. None of the patients learned about it through an NCP.

Figure 7.17 Means of learning on the right to cross-border treatment (n = 11)

Patients were asked if, prior to completing the survey, they already knew of the existence of two parallel routes for obtaining cross-border treatment, namely the Directive 2011/24/EU and the Social Security Regulations. Six out of ten patients stated that they were not aware of this.

Figure 7.18 Awareness of the distinction between Directive 2011/24/EU/ Social Security Regulations (n = 10)

The survey showed that almost two out of three patients did not know about the existence of NCPs (n = 10). Only three out of ten patients stated that they had contacted an NCP during their process of cross-border treatment. Two of them had been in contact with the NCP of the MS of residence, the other one with the NCP of the MS of treatment.

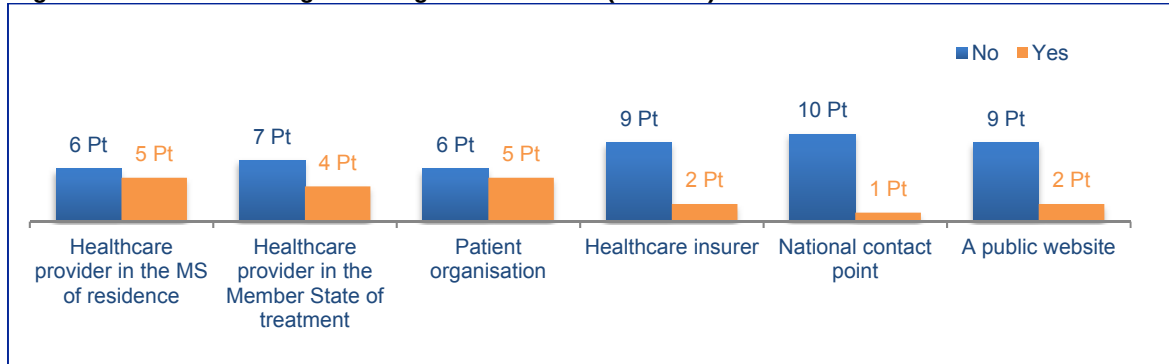
Figure 7.19 Means of learning on existence of NCPs (n = 11)

Transfer of medical records

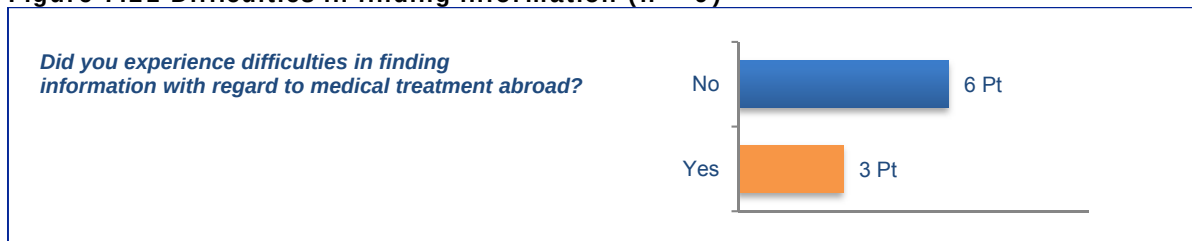
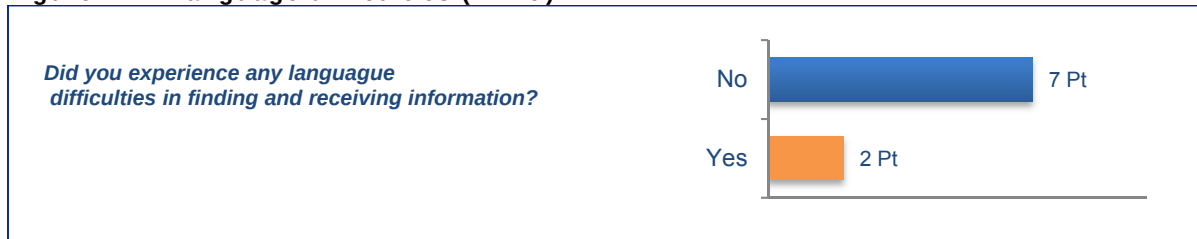
One out of two patients indicated having encountered difficulties in the transfer of medical documents (n = 10). One patient experienced the transfer as a very long procedure. Another patient mentioned that the translation of documents was very expensive. Two patients organised the transfer of the medical records themselves. One patient stated that the HCPs abroad were denied access to any medical data.

Information provision

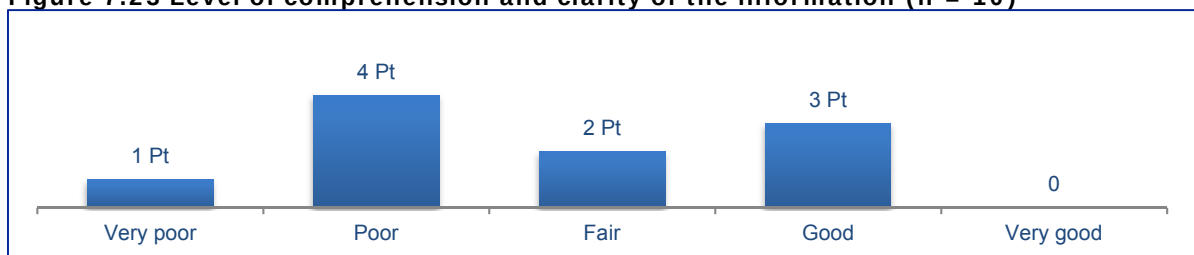
Patients were asked which institution or webpage they contacted in order to gather information on the cross-border treatment process. Most patients had contacted an HCP, either at home or in the MS of treatment, or a patient organisation. One patient additionally mentioned having searched for information in medical peer-reviewed publications. Another patient mentioned having consulted the website of the European Union.

Figure 7.20 Means of gathering information (n = 11)


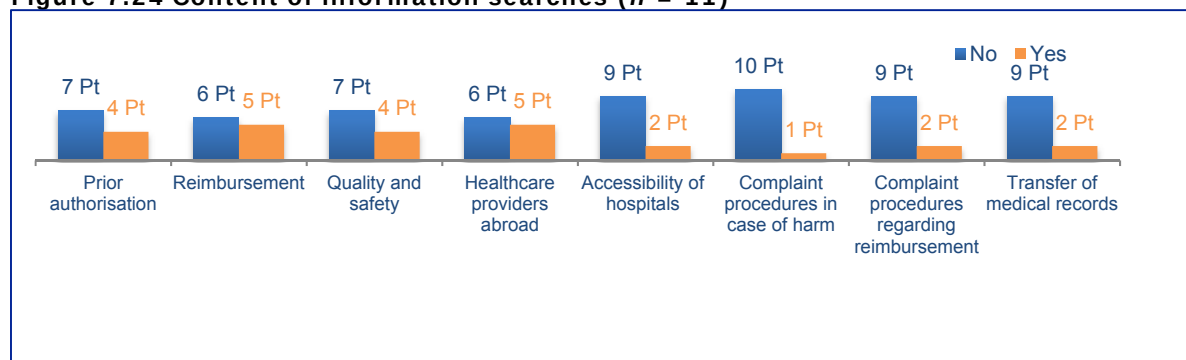
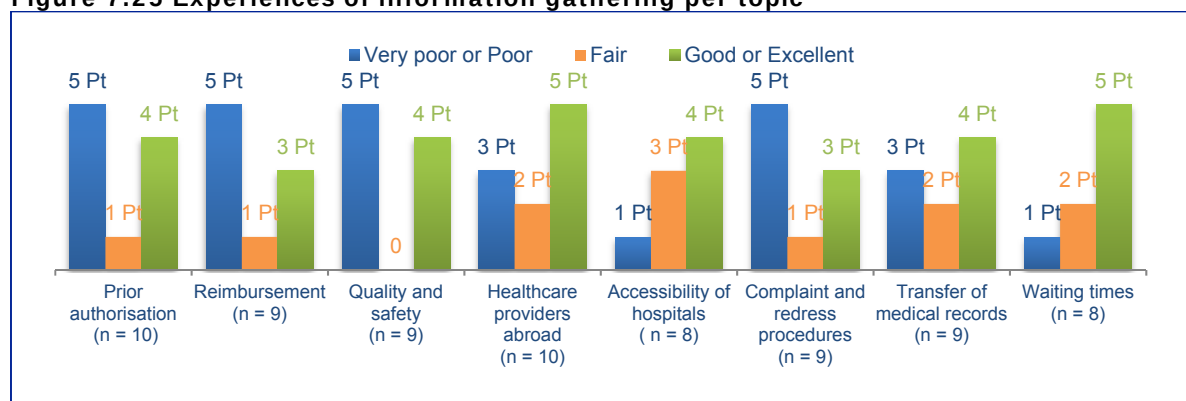
Most patients did not encounter difficulties in finding the information they needed. Most of the patients indicated not having experienced any language difficulties in finding information. The survey shows that 7 out of ten patients searched for information in English.

Figure 7.21 Difficulties in finding information (n = 9)

Figure 7.22 Language difficulties (n = 9)


However, half of the patients evaluated the level of comprehension and clarity of the information negatively.

Figure 7.23 Level of comprehension and clarity of the information (n = 10)


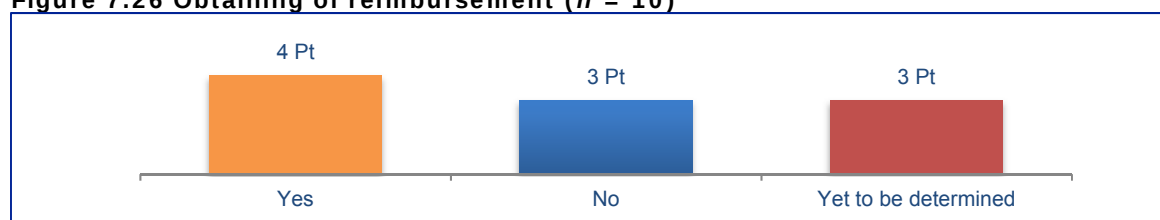
Patients were also asked on which topic they searched for information. Most patients indicated having searched for information on prior authorisation, reimbursement and healthcare providers abroad.

Figure 7.24 Content of information searches (n = 11)**Figure 7.25 Experiences of information gathering per topic**

In general, patients were not positive about the experience of information gathering on prior authorisation, reimbursement, quality and safety, and complaint and redress procedures.

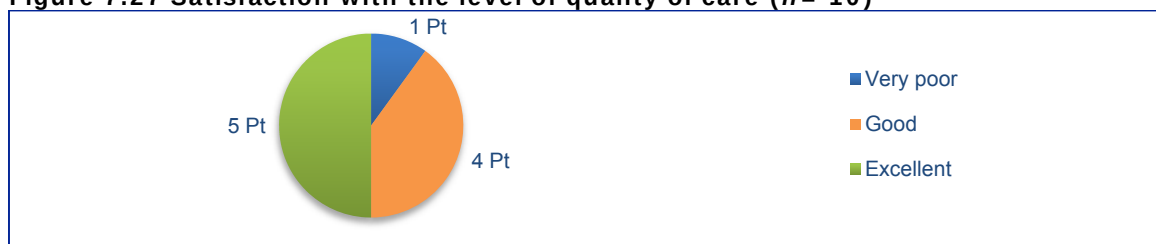
Reimbursement

Four patients out of ten had already received reimbursement of costs. Three of them stated having received full reimbursement or having received medical treatment free at point of use. Only one patient paid the treatment upfront and received partial reimbursement afterwards.

Figure 7.26 Obtaining of reimbursement (n = 10)

Quality and safety

Most patients were satisfied with the quality of care they received abroad. Six out of ten patients stated having searched in advance for information on quality and safety of care in the country where they wished to receive treatment. Three of them experienced difficulties in finding such information.

Figure 7.27 Satisfaction with the level of quality of care (n= 10)

Room for improvement

In a few final open questions, patients were asked if, overall, they had encountered difficulties during their process of accessing healthcare abroad and if there were specific aspects which they felt could be improved. Six out of seven patients who answered these questions, reported to have indeed experienced difficulties.

One patient shared that multiple difficulties and issues they encountered during the process of trying to access cross-border healthcare for their son, who was diagnosed with very aggressive cancer. The respondent reported that cross-border HCPs were denied access to the medical records of their child, which were kept in their home country. Furthermore, the respondent indicated to have encountered multiple difficulties during the treatment abroad: linguistic difficulties, refusal to answer questions, refusal of asking a second opinion, refusal of transfer to another hospital, refusal of transferring medical records, *etcetera*. Overall, the respondent stated that *"there are so many problems I could write a book about it"*. The respondent considered it very important that *"Patients must have the choice to choose the cross-border healthcare provider. The institution must be able to communicate, written and orally, in a language that the patient understands"*.

Another respondent answered that they experienced many difficulties in obtaining reimbursement. For the first two and a half years, the respondent had received a S2 document for accessing cross-border treatment for a rare disease. Since then, the respondent had paid upfront for the treatment and had received partial reimbursement from their own healthcare insurer. The respondent answered that obtaining reimbursement for top expertise in 120km distance of the respondent's residence should not be this difficult considering the fact that a *"rare disease where expertise is rare and so important for the quality of life"*. Two other respondents also reported problems in obtaining reimbursement. One of them, who was also a patient with a rare disease, did not receive any reimbursement for the treatment abroad that was not available in the respondent's home country.

Two other patients explicitly mentioned to have encountered problems in finding information on cross-border healthcare. One of them even stated that in the respondent's home country it *"is hard to find information for medical treatment abroad. When the information is found the institutions and most doctors do whatever they can to not let you go for treatment or diagnostic tests abroad"*. The respondent concludes that in most cases citizens *"should find ways to pay themselves without reimbursement"*. The other respondent had experienced similar issues, stating that the main problem in finding information is *"that you can't talk directly to a person and find the information. The number at the National Contact Point is always busy"*. The respondent answers that mainly, there should be *"more information about existent services [...] available"*.

7.3. Analysis of other information centres

The analysis of other information centres is provided in Annex I (provided in separate document).

Five main recommendations can be formulated based on the results of the analysis:

1. The development of standardised measuring instruments, such as guiding principles and indicators;
2. The use of support and information materials (e.g. manuals, FAQ, e-learning tool, webinar);
3. The collection of analytical information on the NCP practice for monitoring and benchmarking;

4. The creation of an EU web portal for NCPs, including analytical information, website feedback, information on the healthcare system per MS;
5. The establishment of joint networks between NCPs.

7.4. Key findings and recommendations

Key findings and recommendations by topic

Raising patient awareness

The findings show that almost five years after the implementation of Directive 2011/24/EU, patient awareness on their rights and possibilities to access health services abroad and on the existence of NCPs is still low. NCPs are key facilitators in enabling patients to access information on different important aspects of cross-border healthcare, such as patients' rights, quality and safety, reimbursement and complaint procedures.

Information on patients' rights and the existence of NCPs should be disseminated in a proactive way, aiming to reach as many mobile patients and potential mobile patients as possible. Proactive communication strategies, such as the proactive distribution of leaflets, social media presence and campaigns in traditional media should be encouraged. Clear communication strategies should be developed based on multi-stakeholder cooperation, including for example NCPs, healthcare providers, health insurance providers, patient organisations and national authorities.

As part of the toolbox, a leaflet for patients was developed aiming to caution patients on the top ten mistakes frequently made in cross-border healthcare and providing them with practical tips to ensure safe treatment abroad. The leaflet also raises awareness on the existence of NCPs and the need to consult these information centres when wishing to obtain more information on accessing health services abroad. The leaflet can be included in the broader communication strategy that each MS might wish to develop. To maximize the impact, the leaflet and other communication materials should be disseminated to a wide audience through different stakeholders such as patient organisations, healthcare providers, hospitals, and health insurance providers.

Special attention should be paid to ensuring that the information on the existence of the Directive 2011/24/EU and the NCPs also reaches specific categories of patients who could potentially benefit from seeking healthcare abroad, such as patients with disabilities, patients with rare diseases or autochthon minorities who wish to receive treatment closer to family members.

Enhancing information provision

The study shows that in general NCPs are performing fairly well. However, there is still room for improvement on different aspects of the NCP service. NCPs should evaluate their own organisation and working process and make improvements if necessary, in order to ensure full accessibility. In addition, information in other languages (at least English) than the official languages of the MS should be provided in order to guarantee equal accessibility of the NCP service for inbound patients.

In general, information provision to outbound patients seems to be more complete than information provision to inbound patients. For example, information on quality and safety needs improvement. Great differences are shown in the way NCPs inform patients on quality and safety. In some MSs information on safety and quality is very limited. Comprehensive, comprehensible and comparable information could empower patients in exploring and comparing their options.

The proposed Toolbox and training materials aim to contribute to more uniform and clear procedures for accessing health services abroad. In addition, NCPs should be encouraged to help limit the current barriers on cross-border healthcare or to inform the competent (national) authorities on the importance of this.

The study revealed shortcomings in information provision to outgoing patients. Most NCPs do not provide information on undue delay and waiting times. Clear information on which specific type of care is subject to prior authorisation and on reimbursement is also often missing. In addition, more in-depth information on the procedural aspects of applying for prior authorisation and reimbursement should be provided. Patients should be informed of the different steps they have to take and of the estimated timeframe for obtaining a decision. The same room for improvement is found with regard to information on complaint procedures.

An important finding of the study was that a high number of NCPs still experience difficulties in communicating on the differences between Directive 2011/24/EU and the Social Security Regulations. However, due to the important interaction of both legal instruments, clear and accurate information on these instruments can be considered essential for good information provision to patients. Regardless of their organisational structure, all NCPs should provide information on both the Directive and on the Social Security Regulations, including information on the priority given to the Regulations. The study aimed to develop some practical documents, including a set of decision trees, in order to facilitate NCPs in the provision of information on both the Directive 2011/24/EU and the Social Security Regulations.

Information to be provided by healthcare providers should also be monitored and evaluated. Contacting a healthcare provider is often the first step in accessing health services abroad. **Therefore, it is important that healthcare providers know how to inform patients on their rights and their possibilities in accessing healthcare abroad.**

Tools for a more uniform and complete practice of information provision by NCPs and healthcare providers were developed as part of this study, including templates and checklists. These tools were based on information requirements under Directive 2011/24/EU, as well as on already established good NCP information practices, and can be found in the Toolbox.

Eliminating barriers and discrimination in accessing health services abroad

The proposed Toolbox and training materials aim to contribute to more uniform and clear procedures for accessing health services abroad. In addition, NCPs should be encouraged to help limit the current barriers on cross-border healthcare or to inform the competent (national) authorities on the importance of this.

Equitable access to health services abroad in the EU should be safeguarded at all times. However, different barriers in seeking treatment abroad still exist. For example, financial issues seem to be an important obstacle for patients. Previous studies show the financial burden of upfront payment under Directive 2011/24/EU. In the current study, a number of patients also mentioned having encountered difficulties in obtaining reimbursement after having travelled abroad to receive treatment. **To limit these barriers, MSs should be encouraged to install a system of prior notification** according to article 9(5) of Directive 2011/24/EU, **as a minimum**. As shown in the recent Member State data report, ten Member States did install such prior notification system, i.e. a voluntary system of prior notification whereby the patient receives a written confirmation of the amount to be reimbursed on the basis of an estimate, taking into account his or her specific situation. Compensation mechanisms directly between MSs as provided under the Social Security Regulations would be a welcome development. MSs could also consider to establish mechanisms that allow to reimburse extra costs, for example costs relating to disabilities, for persons with limited resources, according to article 7(4) of Directive 2011/24/EU. Regardless of the fact that such system is not obliged under the Directive, it can be implemented to reduce the financial burden on patients in some situations.

Almost all patients responding to the survey mentioned having encountered difficulties at one point in their process of accessing health services abroad. Issues mentioned were: difficulties with regard to the reimbursement process, with regard to finding information on quality and safety, with regard to accessing medical records, with regard to translation costs and with regard to reaching the NCP and finding someone who directly provides information. **One patient even felt that cross-border healthcare in general was strongly discouraged and even disincentivised by institutions and healthcare providers in their MS.** All issues that were mentioned by patients can be considered as unjustified obstacles in the light of Directive 2011/24/EU.

Enhancing cooperation

Regardless of the fact that most NCPs evaluated the level of cooperation with each other and with other stakeholders positively, a lack of formal partnerships was shown. **Most NCPs only cooperate with other stakeholders on a case-by-case basis.** Especially, cooperation with patient organisations and involvement of patient organisations in the NCP service call for improvement. Patients organisations can be considered as important stakeholders enabling to include patients' perspectives and needs in the NCP service. Projects such as the exchange of experiences between NCPs or the involvement of other stakeholders in the NCP function should be encouraged.

Safeguarding quality of care

Information provision on quality and safety standards is often limited. Most NCPs only provide general information on healthcare providers and on the country's health system. Patients repeatedly mentioned the difficulty in finding information on quality and safety. However, such information can be considered as very important in enabling patients to choose the health service that best suits their specific needs and wishes.

A key finding of this study is the difficulties patients experience in transferring medical records. However, such transfers can be considered an absolute prerequisite in establishing safe and high-quality cross-border healthcare. MSs should take appropriate measures to facilitate the access to medical records, for example by informing healthcare providers on their obligations and by providing translation or interpretation assistance for patients that are not able to pay for translation themselves.

Enabling data collection and comparison

In line with previous findings, the NCP survey showed that a number of NCPs was not able to provide all requested information. As a result, comparison between all MSs is often difficult. However, data collection and comparison of such data are of great importance in evaluating the status quo of patient mobility as well as the NCP service.

For example, some NCPs were not able to present data on the numbers of granted prior authorisation or reimbursement requests as well as the estimated time limits in these procedures. The main reason given by NCPs was that data was only available for the health insurance provider(s). **MSs should encourage a system of data collection that is also accessible for NCPs, given the fact that they are an important facilitator in cross-border health services.**

Besides, MSs/NCPs seem to collect data differently. For example, with regard to time limits, some NCPs measure in function of days, others in working days, some in weeks and some even in months. **A more uniform way of data collection should be encouraged in order to ease comparison.**

Legal framework – Guiding patients through health systems with strong NCPs

The findings of this study show the complexity of the current legal framework for cross-border healthcare. Stakeholders and patients encounter many issues in navigating this complex framework. The visibility of NCPs should continue to be encouraged across the board so that citizens, as a bare minimum, become aware of their services in case of need. The Toolbox and training material provided to NCPs lend a helping hand in mastering the options supported by the legal framework and empowering NCPs to guide citizens through a labyrinth of scattered health services across different health systems to the benefit of the patient.

8. Resource burden estimation

An estimation of the resource burden was conducted to map the resources (time, money, expertise) a patient, HCP or MS has to invest in order to successfully navigate the requirements introduced under Directive 2011/24/EU. First, we elaborate on the resource burden estimate for MSs (section 8.1). Second, the resource burden estimate for healthcare providers is further detailed (section 8.2). Third, we expand upon the resource burden estimate for patients (section 8.3). In addition, this Chapter outlines our key findings concerning the overall resource burden estimation of information provision to patients in cross-border healthcare.

8.1. Resource burden estimate for a Member State

Resource burden due to patient flows

Significant increase in patient flow under Directive 2011/24/EU could result in a considerable additional burden on availability and quality of care, as well as financial sustainability of national health systems. Accordingly, the Directive foresees in the possibility for MSs to impose measures to limit patient flows, where it is justified by overriding reasons of general interest, such as planning requirements relating to the aim of ensuring sufficient and permanent access to a balanced range of high-quality treatment in the MS concerned, or to the wish to control costs and avoid, as far as possible, any waste of financial, technical and human resources, to adopt measures regarding access to treatment aimed at fulfilling its fundamental responsibility to ensure sufficient and permanent access to healthcare within its territory.²⁹⁰ However, up to today, patient flow numbers under Directive 2011/24/EU are limited and no mechanisms to limit access are set in place.²⁹¹

The recent MS data report shows that in 2016, the number of request for prior authorisation remain low. In total 5,538 requests for prior authorisation were received (n= 20 MSs), with fourteen MSs reporting receipt of fewer than 100 requests, and five between 100 and 500. The outlier was France with 3,886 requests. In total, 3,942 requests for prior authorisation were authorised in 2016.²⁹² The total reported reimbursement amount spent across thirteen MSs was €24,654,929. Eleven MSs spent less than €500,000. With regard to cross-border healthcare not subject to prior authorisation, in total 138,851 requests for reimbursement were granted in 2016. The total reported amount spent for cross-border care not subject to prior authorisation across the 22 MSs that return data was €143,582,652, ranging from a high of €123,000,000 to €2,657. Of the other twenty MSs reporting, eight reported spending of under €100,000, six €100,000 to €1,000,000 and six €1,000,000 to just over €6,000,000.²⁹³ In the future, when patient flows under Directive 2011/24/EU would increase, for example due to a higher level of awareness, this will mean an increase in costs and administrative burden for MSs.

National Contact Points

Under Directive 2011/24/EU, each MS is obliged to install an NCP.²⁹⁴ Most NCPs are integrated into another host institution (national health insurance fund, ministry of health..). Therefore, the NCP function is often merged with other functions of the organisation. According to the NCP survey, most NCPs have between one and three FTEs. All the NCPs with four or more FTE (n=8), are established within the national health service authority/national health insurance fund. This could be explained by the fact that NCPs located within national health service authorities/ national health insurance funds may have more funding. The NCP staff in such NCPs are, however, often also tasked with other functions (e.g. cross-border healthcare under Regulation (EC) No 883/2004). In addition, based on necessity, relevant other personnel of the host institution may be involved. Regardless of how the NCP is organised, NCP staff should be experts in cross-border healthcare, both under national and EU law. NCPs have to invest in education and training of their staff on a regular basis. The NCP staff should regularly be involved in congresses and workshops on cross-border healthcare. The online survey found that almost all NCPs self-report to provide information through the NCP staff in English.

²⁹⁰ Art. 4(3) Directive 2011/24/EU.

²⁹¹ Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.

²⁹² Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.

²⁹³ Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.

²⁹⁴ Art. 6(1) Directive 2011/24/EU.

In general, the online survey showed that most NCPs are funded directly from the budget of the competent ministry or through general taxation. A number of NCPs is funded within the financing system of the national health insurance fund or social health insurance institute, or by compensations of all health insurance funds. Another funding strategy mentioned was funding by different stakeholders based on a common agreed distribution key. Finally, the survey showed that for two out of 29 NCPs, there is no special funding.

The online survey demonstrated that NCPs receive on average 185.6 requests each month. A total of 19 NCPs received less than 50 requests each month ($n = 19$; range 1 to 50; mean = 14). Eight of these 19 NCPs received less than ten requests. The recent MS data report shows that most requests are made by phone. The other half is equally spread by information requests by e-mail or in person.²⁹⁵ In addition, the online survey conducted as part of this study demonstrated that for most NCPs, it takes less than a week to process an information request (18 out of 29 NCPs). For four NCPs it takes a week; for six NCPs more than a week, and for one NCP several weeks. When necessary, NCPs either consult with other stakeholders or forward the patient's query to other organisations.

According to the online survey results, one out of two NCPs sometimes experiences difficulties in gathering information needed to answer patients' questions. Four NCPs stated to often encounter such difficulties. Collecting information from other stakeholders may take some time. Information gathering on other national healthcare systems or prior-authorisation systems is considered to be difficult. The Czech NCP mentioned that the *"system of pre-authorisation is chaotic - it is not easy to inform patients about various systems in various countries of origin"*. MSs are obliged to publish information on which healthcare services are subject to prior authorisation (article 8(7) of Directive 2011/24/EU). However, the online survey demonstrated that only 13 out of 30 NCPs indicated that a detailed list of treatments subjected to prior authorisation was published in their MS.

Cooperation with other stakeholders can be considered as an important aspect of NCP practice. NCPs will have to invest in cooperation with other stakeholders and each other. This will require both time, money and expertise. NCPs will have to set up meetings with, and attend presentations of, colleague NCPs and other stakeholders, such as national health insurance funds, patient organisations, governments and HCPs. It is recommended that MSs invest in technology enabling to share information between NCPs. For example, in the online survey, one NCP stated that *"it would be also good to have a platform to exchange thoughts from time to time in certain cases"*.

The online survey shows that 12 out of 29 NCPs sometimes experience difficulties in communicating the differences between both cross-border healthcare under Directive 2011/24/EU and the Social Security Regulation (EC) No 883/2004. In addition, information provision on other national healthcare systems and prior-authorisation systems was also considered as difficult. The Czech NCP mentioned that the *"system of pre-authorisation is chaotic - it is not easy to inform patients about various systems in various countries of origin"*. In the NCP workshop that was organised as part of this study, it was shown that it can be considered as a high burden for NCPs to provide accurate information based on a variety of legal frameworks, but that is at the same time also clear and easy to understand for patients. In the online survey, one of the NCPs mentioned that *"the coexistence of the directive 2011/24/EU and the coordination regulation is not optimal as it leads to a difficult articulation of the rules and the impossibility to give a simple explanation to patients"*. NCPs are obliged to provide accurate information that is also easily accessible.²⁹⁶ Considering this, one may assume that information provision will be extra time-consuming, constantly balancing between both requirements. Furthermore, one NCP stated that *"nationally, there is a need for further HR support and funding of the communication of the Directive's scope and objectives to the stakeholders involved"*.

In line with the obligations under art. 5(5) of the Directive, all NCPs have developed a dedicated website or webpage. The website of NCPs that are integrated in other institutions is often integrated in the website of the host institution. In general, the costs of developing a website (cost of software, design, hiring a developer) as well as non-development costs, such as for a domain name, hosting and maintenance of the website, SSL certificates, etc., should be kept in mind. Furthermore, to be in compliance with art. 5(5), the NCP website should be available in formats accessible to people with disabilities. NCPs have to invest in extra software to increase accessibility of the NCP website for patients with disabilities with a minimum standard of screen

²⁹⁵ Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.

²⁹⁶ Art. 5(5) Directive 2011/24/EU.

reader compatibility, self-voicing applications, alt-text for images, font size adjusters, high contrast mode, keyboard navigation, sitemap and transcripts for video and audio (according to the W3C Web Content Accessibility Guidelines 2.0). Translation costs will also have to be kept in mind. Regardless of the fact that the Directive 2011/24/EU only obliges NCPs to provide information in the national official languages, to fulfil their obligation to provide accessible information, one may assume that information addressed to incoming patients is, at a minimum, also provided in English.²⁹⁷ A couple of NCPs already have made major adjustments to their websites over the years. The content of NCP websites needs to be reviewed on a regular basis, ensuring that all information is still accurate and in line with the legislative dispositions.

The provision of accurate and timely information on cross-border healthcare is a very important obligation set on NCPs. NCP staff will have to constantly inform themselves of legislative changes in cross-border healthcare and developments in other related fields. MSs themselves will have to make all efforts to fully implement new EU law at all times.

National health insurance / national health service

Most MSs (except of Czech Republic, Estonia, Finland, Lithuania, Netherlands, Norway and Sweden) have installed a system of prior authorisation for certain types of cross-border healthcare under Directive 2011/24/EU. This means that for each prior authorisation question, a case-by-case analysis of the request will have to be conducted. Healthcare insurers will have to analyse whether or not the conditions for prior authorisation are met and under which legal framework the authorisation will be granted (Directive 2011/24/EU, Regulation (EC) No 883/2004, regional initiatives...). The online survey showed that on average it takes 31 days to grant or refuse a request for prior authorisation (n = 19).

The Evaluative Study of 2015 showed that the main source of administrative burden on national health service authorities/national health insurance providers, includes the translation of invoices and the reviewing and processing of medical documentation. In the current online survey, 10 out of 24 NCPs stated that health insurance companies experience difficulties in the recognition of treatments provided in another MS. Most common reasons mentioned were difficulties resulting from different invoicing systems, making it often challenging for health insurers to determine which specific healthcare was provided. NCPs also stated that the use of different DRG coding systems is experienced as a significant barrier. One NCP mentioned as one of the aspects of NCP practice that needs improvement: *"Structural differences of reimbursement and invoicing schemes of national systems - simple tooth extraction is invoiced in totally different ways - it is usually not easy to match two different tariffs"*. Another NCP stated that *"if a system of reconciling DRG codes used by each country could be developed this would be a significant help [...]"*. Additionally, the same NCP acknowledges that *"the most important improvement would be whereby providers abroad are not allowed to recruit patients and are required to publish their costs so that a [Cross-border Directive] patient is not charged more than a home country patient"*.

Thereby it was shown that cross-border healthcare reimbursement processes are normally slightly longer than purely national processes.²⁹⁸ According to the recent Member State data report, it takes national health service authorities/national health insurance funds on average 42 days to provide reimbursement for a treatment with prior authorisation (n = 16 MSs). For the reimbursement of treatment not subject to prior authorisation, it takes on average 57 days (ranging from 14 to 255 days, with removal of the outlier at 255 days).²⁹⁹ For healthcare not subject to prior authorisation, some Member States (Denmark, Estonia, Greece, Italy, Malta, Poland, Sweden, UK, Norway and Iceland) have adopted a procedure of prior notification according to article 9(5) of Directive 2011/24/EU.³⁰⁰ This is a voluntary system of prior notification whereby the patient receives a written confirmation of the amount to be reimbursed on the basis of an estimate, taking into account their specific situation. Although the directive does not require such a prior notification system, it may be implemented voluntarily.³⁰¹ Overall, Member States must ensure that transparent administrative procedures are in place regarding the reimbursement

²⁹⁷ Recital 48 and art. 5(5) Directive 2011/24/EU.

²⁹⁸ G. Zucca, A. De Negri, A. Berény, A. Kaszap, K.A. Stroetmann, P. Varnai, Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 45.

²⁹⁹ Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.

³⁰⁰ Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.

³⁰¹ Article 9(5) Directive 2011/24/EU.

of cross-border healthcare,³⁰² requiring clear policies, expertise and employees specialised in cross-border healthcare requests.

Communication strategy and dissemination of information

The limited number of cross-border healthcare events under Directive 2011/24/EU, and the known low level of patient awareness on the existence of the Directive and NCPs, make it important for MSs to invest in communication strategies and the dissemination of information across their citizens. The Belgian NCP states in the online survey that one of the points for improvement in NCP practice is to *"raise awareness among the general public on the existence of the NCPs and their role (i.e. explain very good what they can do but also be clear what they are not). To do this, one would probably need a (media) campaign which requires the support of the Member States, political will, cooperation of the stakeholders of the healthcare system..."*.

In the online survey, eight out of 31 NCPs stated to be active on social media. However, this has to be nuanced as only five NCPs listed real social media channels, like Twitter, Facebook and LinkedIn. The other three NCPs clarified to be active on conventional media, such as newspapers, website, radio and television. 15 out of 29 NCPs indicated that activities are carried out to inform the public of their existence, such as announcements in the media, press conferences, presentations, trainings for healthcare providers, and participation in public events. Two NCPs stated to have distributed a leaflet. The Polish NCP has issued a book and a briefer leaflet on the comparison between the Directive and the Social Security Regulations. The NCP in Luxembourg has developed informative leaflets explaining the NCP mission. Since 2016, the flyer is made available in most hospitals and other healthcare structures in the MS, and is resent on demand.

Data collection

In order to comply with their duty under Article 20(2) of Directive 2011/24/EU, MSs will have to collect data and estimates of patient numbers in cross-border healthcare. National health service authorities/health insurance providers, as well as NCPs who are collecting data for informative purposes, who store data of patients, or who forward inquiries of patients to other stakeholders, should be aware of their obligations with regard to data protection. The General Data Protection Regulation (GDPR)³⁰³, entering into force on 25 May 2018, will set a number of requirements on every organisation working with data. To comply with the duties under the GDPR, MSs will have to take a number of measures, requiring time, money and expertise. For example, every national health insurance fund/ national health service authority or NCP will have to designate a Data Protection Officer (DPO). The designation of a DPO is obliged when the processing (i.e. collection, recording, structuring, storage, consultation, use, dissemination, etc.) of data is carried out by a public authority or body; the core activities of the organisation involve regular and systematic monitoring of individuals, on a larger scale; or the core activities involve processing of sensitive data, including health data.³⁰⁴ A group of undertakings may designate a single DPO. In addition, in case of a public authority or body, a single data protection officer may be designated for several of such authorities or bodies.³⁰⁵ Non-compliance with the GDPR can lead to administrative fines of up to 20,000,000 euro, or in case of an undertaking, up to 0.4% of the total worldwide annual turnover, depending on which amount is higher.³⁰⁶

Information on quality and safety and healthcare providers

MSs should take systematic and continuous efforts to make sure that the national quality and safety standards are improved in line with the June 2006 Council Conclusions on Common values and principles in European Union Health systems³⁰⁷ (universality, access to good quality care, equity, and solidarity) and taking into account developments in international medical science and

³⁰² Article 9(1) Directive 2011/24/EU.

³⁰³ Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016, on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (OJ L 119, 4.5.2016, p. 1–88).

³⁰⁴ Article 37(1) General Data Protection Regulation.

³⁰⁵ Article 37(2) and (3) General Data Protection Regulation.

³⁰⁶ Article 83 General Data Protection Regulation.

³⁰⁷ Council Conclusions on Common values and principles in European Union Health systems (OJ C 146, 22.6.2006, p. 1–3).

generally recognised good practices as well as taking into account new technologies.³⁰⁸ MSs should ensure that mechanisms for the protection of patients in the event of harm are in place for healthcare provided on their territory.³⁰⁹ This may for example include the provision of an Ombuds-service.

NCPs are obliged to provide information on which HCPs are subject to the above mentioned quality and safety standards.³¹⁰ MSs should, if this is not already provided, ensure the existence of central databases on HCPs/healthcare facilities making it possible for NCPs to collect such kind of information.

8.2. Resource burden estimate for Healthcare providers

The Directive 2011/24/EU places a number of information requirements on HCPs towards patients.³¹¹ Therefore, HCPs have to invest time in informing and educating themselves on cross-border healthcare under Directive 2011/24/EU. In turn, HCPs must take the time to inform patients (in an understandable and accessible manner) about, amongst other things, available treatment, treatment option and risks of treatment. In addition, HCPs have to inform incoming patients on their registration status and insurance cover, as required under Directive 2011/24/EU.³¹² HCPs have to invest time in communicating with patients speaking a different language. When necessary, HCPs will have to communicate through an interpreter, accompanying the patient. HCPs must also take the time for communicating with NCPs, health insurance providers or other stakeholders in cross-border healthcare.

HCPs can have an increased administrative burden due to the patient's right under Directive 2011/24/EU to access their medical records or ask for a copy of it. Furthermore, HCPs should document closely which healthcare is provided, avoiding interpretation differences later on by the health insurance provider in the patient's home country.

8.3. Resource burden estimate for Patients

Patients in cross-border healthcare will have to invest time in gathering relevant information in liaison with the NCP, healthcare insurer, HCP and/or other stakeholders. The online survey demonstrated that most patients contacted an HCP, either at home or in the MS of treatment, or a patient organisation. Other means of information gathering that were mentioned were medical peer-reviewed publications and the website of the European Union.

In the online survey, two patients explicitly mentioned to have encountered problems in finding information on cross-border healthcare. One of them even stated that in the respondent's home country it *"is hard to find information for medical treatment abroad. When the information is found the institutions and most doctors do whatever they can do to not let you go for treatment or diagnostic tests abroad"*. The respondent concludes that in most case citizens *"should find ways to pay themselves without reimbursement"*. Also the other respondent had experienced similar issues, stating that the main problem in finding information is *"that you can't talk directly to a person and find the information. The number at the National Contact Point is always busy"*. The respondent answered that mainly, there should be *"more information about existent services [...] available"*. Information will also often be considered as difficult and not easy to understand. More specifically, in the online survey, half of the patients evaluated the level of comprehension and clarity of the information negatively.

As shown in the online survey, literature review and previous studies, Directive 2011/24/EU places a high administrative burden on patients. When necessary, patients have to request information on prior authorisation. It is shown that patients are often not aware of which treatment is subject to prior authorisation and which is not. For example, in the Special Eurobarometer 425, it was demonstrated that 40% of the respondents thought prior authorisation was needed for all kind of

³⁰⁸ Recital 22 Directive 2011/24/EU.

³⁰⁹ Recital 24 Directive 2011/24/EU.

³¹⁰ Article 4(2)(a) Directive 2011/24/EU.

³¹¹ Article 4(2)(b) Directive 2011/24/EU.

³¹² Article 4(2)(a) Directive 2011/24/EU.

treatment.³¹³ The survey showed that, on average, it takes 31 days to grant or refuse a request for prior authorisation (n = 19).

Patients should invest time (and sometimes money) in transferring their medical documents to the healthcare provider abroad. One can assume that such transfer is done directly between HCPs. However, in a study of Vera *et al.*, one of the problems that the authors identified was related to the transfer of health records, as medical records were not transferred in advance for two-third of the 101 participants.³¹⁴ Also in the current online survey, one out of two patients indicated having encountered difficulties in the transfer of medical documents (n = 10). One patient experienced the transfer as a very long procedure. Another patient mentioned that the translation of documents was very expensive. Two patients organised the transfer of the medical records themselves. Of these, one patient stated that *"after the first: we didn't get any documents" [...] we organize the transfer of documents [ourselves], because it is much easier and more sure that they received the right documents"*. Another patient stated that *"translations [of medical records] are needed and it becomes very expensive when there are a lot of documents"*.

Upfront payment is identified as an important financial burden on patients. When accessing healthcare abroad without prior authorisation or prior notification according to Article 9(5) of Directive 2011/24/EU, patients are uncertain on the exact amount that will be reimbursed. In addition, extra costs of travel and stay will normally not be covered under the Directive. The burden of translation costs were also mentioned by multiple patients. These financial implications have to be considered as extra burdensome, particularly noting the fact that patients in cross-border healthcare are often ill patients with already high medical bills in the home country. For example, two patients included in the online survey were patients suffering from rare diseases who required treatment on a regular basis. One of these patients stated that obtaining reimbursement for top expertise in 120km distance of the respondent's residence should not be difficult in case of a *"rare disease where expertise is rare and so important for the quality of life"*.

In the online survey, NCPs were asked which documents must be submitted by patients in order to receive reimbursement. Most frequently returning answers include prior authorisation forms, referrals, medical records of the treatment, and invoices. Other documents mentioned were an official application for reimbursement, a waiting list document, proof of payment, proof of the professional status of the HCP abroad, prescriptions, an official translation of medical records, and translation of invoices. Some MSs require translation of invoices, thereby placing an additional administrative burden on patients. The survey showed that, on average, it takes 45 days for patients to obtain reimbursement for healthcare received abroad (n = 19). However, for three NCPs, the time-limit mentioned is only applicable when there is no need for gathering additional information. When additional information is required, patients will have to wait longer before being reimbursed. Moreover, the ANEC study demonstrated that the lack of awareness pushes people towards paying for treatment privately. The majority of planned healthcare was funded privately, with only 34.1% seeking reimbursement of costs from their national healthcare insurer.³¹⁵

The current patient survey showed that nine out of ten patients was satisfied with the level of quality of care. However, as demonstrated in the ANEC study of 2018, the propensity to complain in case of dissatisfaction is extremely low. Patients are reluctant to make an official complaint. The most common reasons for not filing a complaint were: not knowing who to submit the complaint to, or thinking it would be too complicated or difficult. For the respondents that had complained, satisfaction with the outcome was low.³¹⁶

³¹³ Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 37-38.

³¹⁴ S.E. Verra,, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, *Health Policy* 120(6) (2016) 721.

³¹⁵ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences (2018) 6.

³¹⁶ ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences (2018) 6.

8.4. Key findings

Key findings resource burden estimation

It may be concluded that overall, the resource burden set on HCPs is limited. The main burden on MSs include the organisation of NCPs, the administrative burden linked to reimbursement of cross-border healthcare, and informing the general population. With regard to the obligation to provide an NCPs, this burden will likely be higher for NCPs not located in bigger host institutions. NCPs that are hosted in bigger institutions (such as the national health insurance fund) are often funded from the budget of the host institution and can make use of the expertise of the staff of other functions within the host institution when needed. The highest burden demonstrated is the administrative burden set on patients, including the transfer of medical records to the HCP abroad and the provision of medical documentation to the national health insurance funds. In the case of healthcare not being subject to prior authorisation, upfront payment form a high financial burden for patients. It is shown that all stakeholders have to make efforts in information provision in cross-border healthcare, including the patient. Untimely or insufficient information leads to patients not knowing if prior authorisation is required, patients travelling abroad without knowing the full extension of the financial implications, patients paying for the treatment privately, healthcare insurers refusing reimbursement due to missing information and documents of proofs, healthcare providers treating patients without a full medical history, and so on. In order to limit the cost of untimely or insufficient information, preventive awareness campaigns and strong cooperation between all stakeholders is required. In the online survey, one of the NCPs concludes the following: *"At this moment, I have the feeling we find ourselves in a vicious circle: as the NCPs are not known, they do not receive many questions; as the NCPs do not receive many questions, stakeholders are not inclined to invest in the improvement of the functioning of the NCPs..."*.

9. Results of the equality and proportionality analysis

In this chapter the results of the equality and proportionality analysis are presented. This analysis was based on the Special Eurobarometer 425 on patient rights in cross-border healthcare 2015.

As already discussed under the results of the literature review (section 4.3.3), cross-border healthcare under Directive 2011/24/EU is sometimes associated with socio-demographic disparities. Regardless of the fact that these disparities mirror the significant disparities observed between population groups within MSs (to a greater or a lesser extent depending on the MS) and across MSs,³¹⁷ one must not lose sight of the fact that measures should be taken to guarantee equal access to treatment abroad under the Directive at all times. In order to anticipate possible obstacles for certain socio-demographic groups, it is necessary to determine which groups are likely to encounter more difficulties and disadvantages in accessing healthcare abroad (e.g. due to age, education or employment)^{318,319}

The Special Eurobarometer 425 on patients' rights in cross-border healthcare in the EU³²⁰, including face-to-face interviews with 27,868 respondents from different social groups, showed that people who would not be willing to access cross-border healthcare, tend to be older (i.e. 58% of the + 55 year respondents), less educated (i.e. 61% of those who left school at age 15 or younger) and retired or house persons (62% and 49%, respectively).

Figure 9.1 Willingness to access cross-border healthcare according to socio-demographic determinants

Q08 Would you be willing to travel to another EU country to receive medical treatment?					
	Yes	No	It depends on the EU country (SPONTANEOUS)	It depends on the type of medical treatment (SPONTANEOUS)	Don't know
EU28	33%	46%	3%	13%	5%
 Age					
15-24	37%	38%	5%	14%	6%
25-39	38%	40%	3%	14%	5%
40-54	37%	41%	3%	13%	6%
55 +	24%	50%	2%	11%	5%
 Education (End of)					
15-	24%	61%	2%	9%	4%
16-19	31%	47%	3%	14%	5%
20+	39%	41%	3%	13%	4%
Still studying	40%	33%	6%	14%	7%
 Socio-professional category					
Self-employed	43%	34%	4%	14%	5%
Managers	35%	43%	4%	14%	4%
Other white collars	36%	39%	3%	15%	7%
Manual workers	35%	43%	3%	14%	5%
House persons	29%	49%	2%	13%	7%
Un-employed	38%	46%	2%	10%	4%
Retired	22%	62%	2%	10%	4%
Students	40%	33%	6%	14%	7%

Source: Special Eurobarometer 425 on patients' rights in cross-border healthcare (2015) 13.

With regard to the reasons for obtaining treatment abroad (e.g. to receive treatment that is not available at home, to receive better quality treatment or to receive treatment from a renowned specialist), no striking socio-demographic differences were observed. However, respondents motivated by better quality treatment tend to be younger (57% of those aged 15-24 vs. 49% of those aged +55), more educated (55% of those who have ended school at age 20 or later vs. 49% of those who left school at age 15 or younger), and see themselves as upper class (61% vs. 50% of those who see themselves as working class). Furthermore, receiving treatment more

³¹⁷ See *supra* section 4.3.3.

³¹⁸ See *supra* section 4.3.3.

³¹⁹ European Commission, Impact Assessment Guidelines (2009) 23.

³²⁰ Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) p. 54 + T25.

quickly was more often mentioned by respondents with a higher level of education (39%), managers (42%), and those who consider themselves as upper class (45%).³²¹

Concerning the reasons for which type of treatment respondents of the Special Eurobarometer 425 would consider to access healthcare abroad, the socio-demographic analysis showed that men slightly tended to mention more items than women, with the exception of cancer where more women answered 'yes'. No striking differences were shown by social or educational level. However, house persons, unemployed respondents and retired people were least likely to mention any of the items.³²²

With regard to factors discouraging people from accessing healthcare abroad, socio-demographic determinants differ from item to item:³²³

- "Satisfaction with medical treatment in one's country": this item was most mentioned by respondents who had studied the longest (59% of those who have ended school at age 20 or later vs. 53% of those who left school at age 15 or younger), managers (67% against 50% of unemployed persons and students), and those who had almost never had problems paying their bills (59% vs. 46% who did experience such financial difficulties);
- "Convenience": this item was most mentioned by those who positioned themselves low on the social scale (51% vs. 45% amongst those who positioned themselves high on the social scale);
- "Linguistic barriers": this item was most mentioned by respondents who were older (31% of those aged +55 vs. 20% of those aged 15-24), higher educated (33% of those who had left school at age 15 or younger vs. 19% of those still studying), and house persons and retired persons (both 31%);
- "Lack of information about availability and quality of treatment abroad": this item was more frequently mentioned by students (26%), other white collars (25%) than by house persons (16%), retired persons or unemployed persons (both 19%);
- "Unable to afford treatment abroad": this item was most frequently mentioned by those who did experience difficulties in paying their bills most of the time (33%, against those who almost never had these difficulties, 15%), house persons (27%, against 10% of managers), those who had studied least (25% of those who had left school at age 15 or younger vs. 14% of those who had studied till aged 20 or older) and by those self-positioned low on the social scale (32% against 11% of those self-positioned high on the scale);
- "Not being sure of being reimbursed": this item was mentioned equally in all socio-demographic categories

With regard to the knowledge of rights in cross-border healthcare, no significant disparities were shown for the respondents that had one correct answer. However, respondents who gave two or three correct answers to the formulated questions tended to belong to higher social categories. Respondents with two correct answers were higher educated (44% of those studied until the age of 20 or later vs. 33% of those who left school at age 15 or earlier) and daily internet users (43% vs. 34% of those who never use the internet). Respondents with three correct answers were mostly higher educated (20% of those who studied until age 20 or later vs. 14% of those who left school at age 15 or earlier). Respondents with a lower education and respondents who never used the internet were more likely to give no correct answer.

Respondents in the Special Eurobarometer survey were also asked if prior authorisation was a pre-condition for obtaining reimbursement for cross-border healthcare. Respondents with the lowest level of education were least likely to think prior authorisation from the healthcare insurer was required (55% of those who had left school at age 15 or earlier vs. 69% for those who had studied until age 20 or later). House persons and retired persons were also less likely to think prior authorisation was needed (both 58% vs. 71% of managers).³²⁴

³²¹ Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 17.

³²² Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 23.

³²³ Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 28.

³²⁴ Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 39.

Respondents were also asked how knowledgeable and informed they felt about their rights in cross-border healthcare. Respondents who answered that they do not feel well informed in their home country, tended to be significantly less educated (59% of those who had left school at age 15 or earlier vs. 40% for those who had studied until age 20 or later) and respondents with difficulties in paying their bills most of the time (61% vs. 45% of those who did not have these problems). Less significant disparities were shown regarding information abroad. However, respondents feeling less well informed are likely to be less educated (85% of those who had left school at age 15 or earlier vs. 71% for those who had studied until aged 20 or more), as are house persons (86 vs. 70% of managers).³²⁵

With regard to preferred sources of information on cross-border healthcare, respondents with the highest level of education and managers are more likely to gather information from their healthcare insurer, the internet and the ministry of health. People with less education or financial difficulties tend to turn to their healthcare provider or hospital staff. Here gender played a role in the preferred source of information. Men were more likely to consult the internet (37%), while women tend to turn to their healthcare provider more often (41%).³²⁶

Finally, the respondents most likely to know of the existence of NCPs were those with the highest level of education (12% of those who had studied until age 20 or later vs. 6% who had left school at age 15 or earlier), and managers (14% vs. 8% of house persons and retired people).³²⁷

It can be concluded that age, education, occupation and financial status are significant socio-demographic determinates of cross-border healthcare under Directive 2011/24/EU. This is not surprising, given the well-known disparities between these socio-demographic groups in accessing healthcare within MSs (see section 4.3.3.). As long as there are inequalities between socio-demographic groups in accessing healthcare in general, both within as across MSs, there will be some with more disadvantages in navigating their rights under Directive 2011/24/EU than others.

Therefore, MSs should keep investing in measures necessary to obtain equal access to healthcare on its territory as well as in cross-border healthcare. For example, MSs should develop communication strategies for ensuring that information on Directive 2011/24/EU and NCPs reaches mobile (and potential mobile) patients from all socio-demographic segments (e.g. amongst people with rare diseases, people in elderly care, amongst public centres for social welfare, through brochures via postal mail...). In addition, MSs have to be encouraged to limit the financial barriers for some people in accessing healthcare abroad. For example, by installing a system of prior notification (article 9(5) Directive of 2011/24/EU) or by voluntary decision to reimburse extra costs, such as costs for travel and stay or extra costs which may incur for patients with disabilities, in accordance with article 9(4) of Directive 2011/24/EU.

³²⁵ Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 43.

³²⁶ Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 47.

³²⁷ Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 52.

10. Capacity Building: Developing a toolbox and training material

This Chapter presents the toolbox, including a set of guiding principles, and training material developed as part of WP4. These tools and training material are developed to better equip the NCPs to provide adequate information to patients in cross-border healthcare. First, the guiding principles and RACER indicators are discussed (section 10.1). Then, we further elaborate on the toolbox and training materials that were developed (section 10.2).

10.1. Guiding principles and RACER indicators

The guiding principles and indicators are provided in Annex A (provided in separate document) and in a standalone document for NCPs that is part of the toolbox. As previously mentioned, these include the upstream version, more specifically the objective consultancy-based version which is developed from the existing legal obligations and standards that fall on NCPs under Directive 2011/24/EU, as well as from the results of the previous WPs, and findings of the Evaluative Study. In addition, to ensure patient centeredness, recommendations by the EPF are taken into account.³²⁸

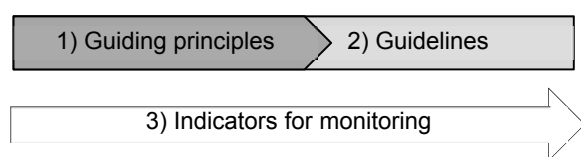
The purpose of the “Guiding Principles for Cross-border Healthcare NCPs” is to set out key principles for good NCP services, in line with NCPs’ obligations under Directive 2011/24/EU. The Guiding Principles are designed to assist NCPs in their daily public task of providing clear and accurate information on the main aspects of cross-border healthcare.

The document that is part of the toolbox consists of two parts and an Annex (extension of Annex A):

- “Part 1. Guiding Principles for Cross-border Healthcare National Contact points (NCPs)”;
- “Part 2. Indicators for the Guiding Principles for Cross-border Healthcare National Contact points (NCPs)”
- Annex. Additional Guiding Principles for voluntary good practices based on review of evidence

The final framework includes nine guiding principles. Each guiding principle in its turn provides the underlying framework for the more specific and technical NCP Guidelines. There are up to five key Guidelines per Guiding Principles whilst the remainder represent voluntary good practices based on review of evidence. In order to monitor the implementation of the guiding principles, a supplementary and voluntary set of thematic indicators is created for each guideline.

Schematic overview:



The indicators were carefully evaluated according to the RACER methodology. The RACER evaluation framework originates from the European Commission’s Impact Assessment Guidelines. The indicators have been adapted by the project team in order to ensure full relevancy of the RACER criteria for evaluation of the Guiding Principles for Cross-border Healthcare NCPs.

All indicators are evaluated on their:

- Relevance:
Indicators are closely linked to the objectives to be reached by the guidelines;

³²⁸ See amongst others the main conclusions and recommendations arising from the EPF series of Regional Conferences 2013-14, Summary Report: Cross-border Healthcare, available at <http://www.eu-patient.eu/contentassets/9863f24f267c4fd6a40e7facfd9f4f77/cbhc-summary-report-final-for-external-dissemination.pdf>.

- 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.

An overview of the Guiding Principles, Guidelines and Indicators is provided in Annex A (provided in separate document).

10.2. Toolbox and training material

Based on the findings of all previous WPs, as well as the findings and recommendations provided in previous studies, recommendations and solutions for improving the status quo of information provision to patients are proposed. These recommendations and solutions are presented in the form of a toolbox and training material.

The toolbox covers different aspects of the NCP service.

Schematic overview different tools included in the toolbox:

General tools			Guiding Principles for good NCP provision		
A. Toolbox User's Guide			C. Guiding Principles and Indicators		
#1	Toolbox User's Guide	PowerPoint	#6	"Guiding principles and Indicators for the practice of NCPs under the Cross-border Healthcare Directive 2011/24/EU"	Overview
#2	Toolbox User's Guide	Web lecture	#7	Guide for the Guiding Principles	PowerPoint
#3	Glossary	PDF	#8	Guide for the Guiding Principles	Web lecture
B. Background			Tools for information provision		
#4	Legislative texts	Overview	E. Information provision in cross-border healthcare		
#5	Studies and data	Overview	#12	Template for information provision to outgoing patients	PDF
D. Directive 2011/24/EU versus Social Security Regulations			#13	Checklist for consultation outgoing patients	PDF
#9	Directive versus Social Security Regulations	PDF	#14	FAQ outgoing patients	PDF
#10	Decision trees	PDF	#15	Checklist for consultation incoming patients	PDF
#11	Directive versus Social Security Regulations	Web lecture	#16	FAQ incoming patients	PDF
G. Practical documents			#17	Template for information provision to healthcare providers	PDF
#23	Quality and safety	PDF	#18	Checklist for consultation health insurance providers	PDF
#24	Data protection	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	The Top Ten Mistakes Patients make in Cross-border Healthcare	Leaflet
			Evaluation tools		
			H. Evaluation		
			#25	Self-assessment sheet NCP practice	Excel
			#26	Self-assessment sheet NCP website	Excel

Together, the toolbox and the guiding principles aim to:

- Raise awareness of patients on their rights and entitlements in cross-border healthcare and the existence of NCPs (tools #20 and #22);
- Raise awareness of patients of the different practical steps in accessing health services abroad and their own responsibilities (tool #21);
- Achieve clear, accurate and accountable information provision (all tools);
- Assist NCPs' and healthcare providers' in meeting the information requirements under Directive 2011/24/EU (tools #12 to #19);

- Clarify the interaction between Directive 2011/24/EU and the Social Security Regulations (tools #9 to #11);
- Raise awareness on the equal right to access health services abroad for all patients, regardless of their financial status, health literacy, disabilities,... (tools #6 to #8);
- Raise special attention to patients with disabilities (tools #6 to #9);
- Establish a more uniform information practice of information provision (all tools);
- Contribute to EU-wide clear time lines and transparent procedures for patients (tools #6 to #8);
- Establish more formal partnerships and cooperation between NCPs and with other stakeholders (tools #6 to #8);
- Contribute to continuous improvement of the NCP practice (tools #25 to #26).

11. Discussion – Raising Awareness, Harnessing Mobility

The overall objective of this study was to gain insight into the current level of information provision to patients by NCPs and to propose solutions for improving this status quo.

EU legislation has established a broad set of patients' rights with regard to accessing health services abroad. However, currently much of the potential of these provisions in increasing awareness of patients' rights at home or elsewhere in the EU remains unused. Due to low patient awareness, shortcomings in information provision and existing regulatory and procedural barriers, patients are limited in their possibilities to benefit from seeking cross-border healthcare.

Central in the process of improving access and well-being in planned cross-border healthcare is the need for good information provision and cultivating information-seeking behaviour across the socio-economic spectrum of society. Information provision must be seen as a powerful tool in safeguarding free provision of services and free movement of patients at all times. Enhancing information provision needs to be considered at different levels:

- Clear, accurate and accountable information empowers patients to exercise their rights and make informed choices in both cross-border and domestic healthcare;
- Informing healthcare providers on patients' rights to cross-border healthcare will empower patients to access health services abroad and will safeguard non-discrimination of patients based on nationality;
- Informing NCPs and healthcare providers on the legal framework for cross-border healthcare and on the information requirements under Directive 2011/24/EU will enable them to provide patients with clear, accurate and accountable information;
- Informing MSs and national authorities of their obligations to safeguard equality in accessing health services abroad may contribute to lower procedural barriers and lower limitations set on patient in and outflow, which are not justified by overriding reasons of general interest;
- Informing patients on practicing healthy lifestyle habits can have a huge impact at little expense to anyone and great benefit to many. Guiding patients, cultivating awareness and information-seeking behaviour across the socio-economic spectrum of society is an intrinsic part of leading and inspiring a healthy lifestyle.

As already recommended in previous studies, the elimination of existing barriers in some MSs, as well as a more uniform practice of information provision in line with the Directive 2011/24/EU, is required. Such improvements are the key for providing citizens with more equal opportunities to exercise their rights to planned treatment abroad.

This study reaches beyond the objectives of previous studies, as it does not merely formulate concrete recommendations for policy review, but also offers tailor-made solutions for improving the status quo of information provision. **More specifically, different tools and training materials, as well as a set of Guiding Principles and indicators were developed in order to establish an NCP service that is in line with the requirements of Directive 2011/24/EU, that is more uniform and that is always patient-centred.** This will simultaneously contribute to high level information provision to patients.

11.1. Overall findings & conclusions

Our study of the literature showed that a limited numbers of patients exercise their right to seek treatment in another MS. However, many Europeans are willing to consider seeking treatment abroad.³²⁹ The main reasons for Europeans to go abroad for medical care are to receive treatment that is not yet available in their home MS, or to receive better quality treatment.³³⁰ Nevertheless, different barriers in seeking treatment abroad still exist. The limited number of patients seeking cross-border treatment can be partly explained by a general lack of awareness of the existence

³²⁹ European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European Union, May 2015, 10.

³³⁰ European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European Union, May 2015, 14-15.

of the Directive 2011/24/EU and the NCPs for cross-border healthcare.³³¹ Specific barriers that prevent patients from seeking treatment abroad include the financial burden of upfront payment under Directive 2011/24/EU and difficulties in obtaining reimbursement after having travelled abroad to receive treatment.

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.

The website analysis looked at nine SAI categories, with three of these focusing on the website itself and six categories focusing on the content of the website. Our findings show that, while information provision through NCP websites was adequate for several categories, there also remains a need to further improve the websites. Especially information for incoming patients – in English – regarding patients’ rights and quality and safety standards requires additional attention to ensure patients can make an informed decision regarding cross-border healthcare. For outgoing patients, information regarding reimbursement of healthcare costs, or information on where this type of information can be found, should be improved. Based on the feedback that the research team received from the NCPs during the bilateral exchange, it is clear that there are at times practical reasons why NCP websites did not contain all relevant information, and/or why not all information relevant for inbound patients was available in English. While these practical reasons might be valid, a lack of accessible information means that not all EU citizens are equipped to adequately inform their decision on attaining cross-border healthcare.

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.

Focussing on the pseudo-patient investigation, the majority (83%) of pseudo-patients were able to get into contact with the NCP and make enquiries. 19 out of 29 NCP could be reached for the 4 scenarios. In 17% of the scenarios, the pseudo-patients did not reach the NCPs, or they did not receive replies to their posed questions. One NCP could never be reached. Hence, pseudo-patients were never able to make inquiries in any of the four scenarios during the open field period of 7 full weeks. On average, 55% of the NCPs responded to at least half of the questions in the email or telephone inquiries, on average. One out of four NCPs were able to provide information on the majority of the questions asked, while one out of ten never provided any information at all. This shows that there is room for improvement for some NCPs – and for NCPs to learn from each other’s best practices – and suggests high information provision potential of the NCPs in the future.

Based on the feedback received from the NCPs during the bilateral exchanges, some constraints were reported explaining why communication or information provision was limited. The constraints include the request by the NCPs for personal patient information or additional documentation in order to be able to proceed with communication, which could not be provided during the pseudo-patient investigation.

The NCP survey showed that there are big organisational differences between NCPs regarding the number of NCPs, the institution hosting the NCP, the NCP funding and staff, as well as the organisational handling of incoming and outgoing patients. Overall, NCPs indicated experiencing significant improvements since the implementation of Directive 2011/24/EU. However, they also indicate that 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.

³³¹ Report on MS data on cross-border healthcare following Directive 2011/24/EU of October 2016, 8.
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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.

The patient survey showed that patients' awareness of their rights and possibilities to access health services abroad and on the existence of NCPs is still low. As with the website analysis, information for incoming patients – in English – regarding patients' rights and quality and safety standards was noted to be lacking. For outgoing patients, the study revealed shortcoming in information provision concerning undue delay and waiting times.

The surveys amongst NCPs and patients confirmed the notion that information provision for incoming patients is in general less complete than for outgoing patients.

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.

Another important finding of the study was that a high number of NCPs still experience difficulties in communicating the inter-linkages between Directive 2011/24/EU and the Social Security Regulations, while this is very important information for patients when seeking cross-border healthcare. The study developed some practical documents, including a set of decision trees, to facilitate NCPs in the provision of information on both the Directive 2011/24/EU and the Social Security Regulations.

Overall, this study found that there is still substantial room for improvement in NCP practices. Large differences were found in the current level of information provision by the NCPs. For both the categories included in the website analysis and the scenarios included in the pseudo-patient investigation, NCPs who performed very well were identified. This shows that there is great potential for NCPs learning from each other and helping each other improve their information provision to patients in the context of cross-border healthcare. In addition NCPs should evaluate their own organisation and working process and make improvements if necessary. In order to guarantee equal accessibility of NCP services for incoming patients information in other languages (at the minimum in English) in conjunction with information in the official MS languages should be provided. Comprehensive, comprehensible and comparable information could empower patients in exploring and comparing their options.

Core finding 5:

Overall, there is still ample room for improvement in NCP practices. 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.

11.2. Methodological and practical contributions of this study

Overall, this study contributes to the literature on information provision for patients in cross-border healthcare by providing a systematic analysis of the status quo, based on a triangulation of results from different data collection methods: literature review, website analysis, pseudo-patient investigation, and two surveys. In addition, this study goes beyond the existing literature by not only mapping the status quo, but also providing a Toolbox and training material for the NCPs to improve the quality of information provision to patients in cross-border healthcare.

This study has made specific methodological contributions by refining research protocols for the website analysis and pseudo-patient investigation. This was done both *ex-ante*, based on experiences in other studies, as well as *ex-post*, based on the experiences during the current study. These refined research protocols enable future studies to be conducted in the same way as this study, thereby allowing for the collection of information on the same variables over time. In addition, the refined research protocols provide NCPs with templates for self-assessment.

Another important methodological contribution of this study is the continuous communication and collaboration with the NCPs via multiple channels: presentations to keep NCPs updated on the (progress of) the study, bilateral exchanges (via email and telephone) to enable enquiring about, and making comments on, individual results, as well as providing feedback on the toolbox and training materials, and a workshop to jointly discuss the results, recommendations, and way forward.

Some of the practical contributions this study makes to improving information provision to patients by NCPs are the Guiding Principles, the Toolbox and training material for NCPs. These can be considered as an important policy development in the field of information provision in cross-border healthcare, as they aim to establish a more uniform and high level NCP practice, where clear and accurate information provision to patients is central.

Central in developing the Guiding Principles and the toolbox was the goal to ensure information provision in accordance with the legal requirements placed on NCPs and healthcare providers by Directive 2011/24/EU, as well as to ensure equal free movement of all patients. As long as this goal is achieved, NCPs are free to organise themselves according to their own insights and wishes. All instruments have been validated by the NCPs themselves, during bilateral exchange and the NCP workshop on 8 March 2018. In addition, the policy proposal instruments were developed based on already established NCP practice, in all EU Member States and Norway.³³²

The Guiding Principles aim to contribute to an equitable access to cross-border healthcare in different ways. NCPs are encouraged to make sure that the information they provide is easily accessible and understandable for all patients, regardless of their health literacy, sensory capacities or language. NCPs should provide information that is relevant to different types of patients, such as outgoing and incoming patients, patients with disabilities, patients with rare diseases, patients with limited funds, and patients who reside outside the MS of social security insurance. In general, the study output aims to contribute to a more uniform and equal practice of NCP service. **Whilst great differences exist in NCP practice and information provision, the Guiding Principles and toolbox aim to eliminate these differences and to establish the same, high level of service in all MSs.** In the same way, the instruments aim to establish transparent and equal procedures for accessing health services in all countries.

11.3. Limitations of this study

While the study provides multiple practical and methodological contributions, it is also important to note that the approach used in the study suffers from some limitations.

Website analysis:

The website analysis was conducted once per NCP website, in July 2017. As also discussed during the workshop on 8 March 2018, many NCPs are continuously improving their website and its content. Consequently, the results should not be considered a final judgement on the information provision on NCP websites, but should rather be seen as indicative of the amount of information available for patients at the time of the study. It thus provides a valuable snapshot of the status quo, including elements that warrant improvement as well as best practices, thereby enabling NCPs to learn from each other.

Each NCP website was analysed by only one researcher. Therefore, it is possible that some information was overlooked. However, the research protocol was designed to reduce this risk of

³³² Only detailed information on the NCP practice of one Member State was missing. Information on this Member State was collected in WP2 and WP3. In total two Member States did not reply on the NCP survey, however, one of them provided the information questioned in the survey during the bilateral exchange by completing the document of its country specific description.

omission or oversight as much as possible; the researchers analysed each website thoroughly in a structured manner using a standard form. It is our belief that if information was overlooked by one of our dedicated and trained researchers, it is unlikely that this information is easily found by the average patient.

Pseudo-patient investigation:

Mystery shopping exercises have a limited sample size. As a result, this research method provides qualitative rather than quantitative insights. In practice, comparisons between NCPs should be made with caution. Our findings based on the four specified scenarios do not allow for generalisations across all cross-border patients and scenarios. Nevertheless, the pseudo-patient investigation provides valuable insights into the potential obstacles patients encounter in their search for information regarding cross-border healthcare.

In this exercise, email contact and telephone contact (if the NCP was reached) was used as a mode of contact. Personal, face-to-face contact was not evaluated. It is important to highlight that this could be presented as an option by the NCPs. However, in practice patients seeking information on cross-border healthcare will generally not do so by visiting the physical NCP address (especially true for incoming patients). Additionally, not all NCPs provide a physical address as a contact option. Hence, this is merely a minor limitation of the study.

Finally, a mystery shopper or pseudo-patient is subject to their own preferences and habits. This leaves some scope for personal bias to influence results. This potential of bias was minimised by the extensive briefing of the mystery shoppers and the use of strong assessment tools.

Patient survey:

Due to the limited sample size ($n=11$), it was not possible to come to any valid quantitative conclusions on patients' experiences. Due to the limited sample size robust quantitative conclusions and generalisations across all patients in planned cross-border healthcare cannot be made. Rather, the results of the patient survey should be considered as valuable qualitative indications of user experiences. Due to data protection considerations, no personal data on patients were collected, hindering the possibility to ask follow-up questions or clarifications. The patients' experiences retrieved through the survey are indirectly feeding the results and output of this study, i.e. based on findings of previous studies and published reports and recommendations of the European Patients' Forum (EPF).

Due to the combination of utilised research methodologies (desk research, website analysis, pseudo-patient investigation, and online surveys), this study is sufficiently robust and provides strong evidence on the level of information provision by NCPs, despite the mentioned limitations.

11.4. Avenues for further research

In general, in order to evaluate the progress of information provision in practice, it would be valuable to repeat the current study at different points in time. Researchers would be encouraged to draw and build on the same research protocols that were updated and specified in the current study. In this way, valuable insight into the evolution of information provision by NCPs could be obtained.

Research aiming to identify the possibilities for quality and safety standards within the EU could be of high value. A more uniform approach to quality and safety could be considered an important contribution in patient empowerment in choosing health services that best suit patients' needs. Moreover, information provision on quality and safety within the EU would be facilitated.

Further research on the specific needs of certain categories of patients in cross-border healthcare - taking into account amongst others disability, income and education level and gender - would also provide the European Commission, MSs, NCPs and other stakeholders with valuable information.

In addition to research focussing on NCPs, studies into cooperation between MSs in other fields of cross-border healthcare, such as ERNs, eHealth, Health Technology Assessment, could form an interesting addition to the current level of research.

In order to ensure that the proposed Guiding Principles, Toolbox and training materials are indeed of added value for NCP practice and a contribution to enhanced information provision, the uptake of the instruments and their functioning in practice would need to remain a key issue for the future.

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139. Due to legislation that grants the right to receive benefits in kind without insurance or activity as an employee or self-employed person, art. 26.
140. Only to the extent that the pensioner/family member would also be entitled to such benefits if they resided in the competent MS, art. 26.
141. The general rule is that a pensioner residing in another MS will fall under the health insurance scheme of the MS of residence and the legislation it applies. Thus, when the pensioner stays in the competent MS and is in need of medical treatment, the general rules for planned/unplanned treatment in another MS apply (see below).
142. Annex IV of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).
143. Annex III of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).
144. Annex V of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).
145. Annex III of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).
146. In case of a family member or a pensioner (and family members) with residence in another MS than the competent MS and the MS of residence has opted for a system of reimbursement on the basis of fixed amounts (Ireland, Spain, Cyprus, the Netherlands, Portugal, Finland, Sweden, United Kingdom), the

- prior authorisation will be granted by the institution of the place of residence instead of the competent institution; art. 27, 5^o Regulation (EC) No. 883/2004.
147. Decision of the EEA Joint Committee No 76/2011 of 1 July 2011 amending Annex VI (Social security) and Protocol 37 to the EEA Agreement (OJ L 262, 6.10.2011, p. 33–43).
 148. Decision No 1/2012 of the Joint Committee established under the Agreement between the European Community and its MSs, of the one part, and the Swiss Confederation, of the other, on the free movement of persons of 31 March 2012 replacing Annex II to that Agreement on the coordination of social security schemes (OJ L 103, 13.4.2012, p. 51–59).
 149. Art. 2 Regulation (EC) No 883/2004.
 150. Recital 18 and 19 Regulation (EU) No 1231/2010; also the UK has opted out for Regulation (EU) No 1231/2010. However, third country nationals in the UK can continue to benefit from the previous Regulation (EC) No 859/2003: Recital 18 of the Council Regulation (EC) No 859/2003 of 14 May 2003 extending the provisions of Regulation (EEC) No 1408/71 and Regulation (EEC) No 574/72 to nationals of third countries who are not already covered by those provisions solely on the ground of their nationality, (OJ L 124, 20.5.2003, p. 1–3).
 151. Regulation (EU) No 1231/2010 of the European Parliament and of the council of 24 November 2010 extending Regulation (EC) No 883/2004 and Regulation (EC) No 987/2009 to nationals of third countries who are not already covered by these Regulations solely on the ground of their nationality (OJ L 344, 29.12.2010, p. 1–3) (hereinafter: Regulation (EU) No 1231/2010).
 152. Art. 19 Regulation (EC) No. 883/2004.
 153. Decision of the Administrative Commission No S3 of 12 June 2009.
 154. Art. 19 Regulation (EC) 883/2004.
 155. The EHIC can't be used by third-country nationals in Denmark, Norway, Iceland, Liechtenstein and Switzerland, unless they are refugees residing in a Member State or are covered as family members of an EU citizen under the Social Security Regulations, as Regulation (EU) No 1231/2010 does not apply for them.
 156. An exception is made in some cases where the MS envisaged the reimbursement of such benefits in their national health insurance legislation, which is for example the case in Austria, Belgium, Finland and the Netherlands: G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 35.
 157. Art. 19(1) Regulation (EC) 883/2004.
 158. Art. 19(1) Regulation (EC) 883/2004; Art. 25(A)(2)–(3) Regulation (EC) 987/2009.
 159. Art. 25 (B)(8) Regulation (EC) 987/2009.
 160. Art. 25 (B)(4) –(5) Regulation (EC) 987/2009.
 161. Art. 25 (B) 6) Regulation (EC) No 987/2009.
 162. Art. 25 (B)(7) Regulation (EC) 987/2009.
 163. Art. 35 (2) Regulation (EC) 883/2004.
 164. Art. 20 Regulation (EC) No. 883/2004.
 165. Art. 20 Regulation (EC) No. 883/2004.
 166. For family members of an insured person residing in another MS, which has opted for a system of reimbursement between public health systems on the basis of fixed amounts instead of actual expenditures, the insurance institution of the place of residence will be competent to grant authorisation: art. 20(4) Regulation (EC) 883/2004.
 167. A same exception is made for pensioners and their family members, who continue to be covered under the social security scheme of a previous MS, but who now reside in another MS which has opted for reimbursement based on fixed amounts: art. 27(5) Regulation (EC) 883/2004.
 168. Annex III of Regulation (EC) No. 987/2009, consolidated version of 11 April 2017 (last consulted on 19 April 2018).
 169. Art. 20(4) Regulation (EC) 883/2004.
 170. Art. 20(2) Regulation (EC) 883/2004.
 171. Art. 25 (B)(4) –(5) Regulation (EC) 987/2009.
 172. Art. 20(2) Regulation (EC) 883/2004.
 173. C-368/98 Vanbraekel.
 174. Art. 26(7) Regulation (EC) No 987/2009.
 175. Terms of Reference, 2.
 176. Art. 4(3) Directive 2011/24/EU.
 177. Art. 4(4) Directive 2011/24/EU.
 178. Art. 4(3) Directive 2011/24/EU.
 179. The Directive 2011/24/EU is not applicable in Switzerland. However, in order to harmonise the geographical scope of application of the Social Security Regulations and the Directive, Belgium has decided to apply the national implementation of the Directive also in Switzerland; Circular VI nr. 2011/272 of 30 June 2011 of the National Institute for Health and Disability Insurance (RIZIV).
 180. Art. 1(2) Directive 2011/24/EU.
 181. On the contrary, telemedicine is not covered under the Social Security Regulations, as it expressly requires the physical presence of the patient in the MS of treatment: see art. 20 Regulation (EC) 883/2004, Commission staff working document on the applicability of the existing EU legal framework to telemedicine services, 2012, 17.
 182. On the contrary, long-term care benefits are included under Regulation (EC) No 883/2004. Long-term care benefits can be defined under the Regulation as “benefits intended to improve the state of health and quality of life of persons reliant on care, i.e. persons in permanent need to assistance from others in the performance of their daily routine (bodily hygiene, nutrition, moving around, housework, and so on)” (C-160/96 Molenaar). See also the European Commission’s proposal to revise Regulation 883/2004, with special attention to improve the current framework for long-term care benefits: Proposal for a Regulation of the European Parliament and of the Council of 13 December 2016 amending Regulation

- (EC) No 883/2004 on the coordination of social security systems and Regulation (EC) No 987/2009 laying down the procedure for implementing Regulation (EC) No 883/2004.
183. Art. 1(3) Directive 2011/24/EU.
 184. The competent MS or authorising MS in case of MS with reimbursement based on fixed amounts (see above).
 185. Art. 7(2) Directive 2011/24/EU.
 186. Annex IV of Regulation (EC) No. 883/2004, consolidated version of 11 April 2017 (last consulted on 19 April 2018).
 187. Annex III of Regulation (EC) No. 987/2009, consolidated version of 1 January 2018 (last consulted on 19 April 2018); Note; Sections "The Netherlands" and "Finland" will be deleted as from 1 January 2018: Commission Regulation (EU) 2017/492 of 21 March 2017.
 188. Art. 7(1) Directive 2011/24/EU.
 189. EU Directive 2011/24/EU on the application of patients' rights in cross-border healthcare: Legislation Guidance for Patient Organisations, EPF, November 2013, 9.
 190. Art. 9(5) Directive 2011/24/EU.
 191. Art. 7(4) Directive 2011/24/EU.
 192. Art. 7(9) Directive 2011/24/EU.
 193. Art. 9 Directive 2011/24/EU.
 194. Art. 8 (1) Directive 2011/24/EU.
 195. Art. 8 (7) Directive 2011/24/EU.
 196. Did not opt for a system of prior authorisation: CZ, EE, FI, LT, NL, NO, SE.
 197. Art. 9(5) Directive 2011/24/EU.
 198. Art. 9(6) Directive 2011/24/EU.
 199. Carrascosa Bermejo, D., Cross-border healthcare in the EU: Interaction between Directive 2011/24/EU and the Regulations on social security coordination, ERA Forum 2014,15(3): p. 359-380.
 200. Annex III of Regulation (EC) No. 987/2009, consolidated version of 1 January 2018 (last consulted on 19 April 2018).
 201. Based on the scheme provided by D. Carrascosa Bermejo; Carrascosa Bermejo, D., Cross-border healthcare in the EU: Interaction between Directive 2011/24/EU and the Regulations on social security coordination, ERA Forum 2014,15(3): 378. doi:10.1007/s12027-014-0358-8, although we modified the scheme and made it more detailed.
 202. For family members of an insured person who reside in another MS than the competent MS or for pensioners and family members residing in another MS than the competent MS, and the MS of residence is a MS who opted for the system of reimbursement on the basis of fixed amount (IE, ES, CY, NL, PT, FI, SE, UK), the latter will bear the costs of the benefits instead of the competent MS (art. 20(4) and 27(5) Regulation (EC) No. 883/2004).
 203. Two exceptions apply where the benefits are provided at the expense of the competent institution instead of the authorising institution: 1° Pensioners and their family members residing in another MS than the competent MS, and the competent MS is BE, BG, CZ, DE, EL, ES, FR, CY, LU, HU, NL, AT, PL, SI or SE, will be entitled to receive benefits in kind under the Directive in the competent MS, at its own expense, as though the person concerned was a resident in that MS; 2° In case no prior authorisation is needed under the Directive and the healthcare is not provided in accordance with the Regulations, pensioners and family members residing in another MS (IE, ES, CY, NL, PT, FI, SE, UK) are entitled to receive benefits in kind under the Directive in the competent MS, at its own expense; art. 7(2)(b) and Regulation (EC) No. 883/2004.
 204. In case the MS of residence that is responsible for the costs in according with the situations provided in art. 20 (4) and 27 (5), the institution of the place of residence will grant the prior authorisation (i.e. authorising institution).
 205. Did not opt for a system of prior authorisation: CZ, EE, FI, LT, NL, NO, SE.
 206. Authorisation will be granted by the competent institution or unless in case of applicability of art. 20 (4) or 27(5) Regulation (EC) No. 883/2004, by the institution of residence.
 207. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.
 208. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 22-23.
 209. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 14-15.
 210. European Commission, Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European union: Report, may 2015, p. 54; European Commission, Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European union: Summary, may 2015, p. 23.
 211. European Commission, Flash EB N°210 Eurobarometer, Cross-border health services in the EU: analytical report of May 2007, available at http://ec.europa.eu/commfrontoffice/publicopinion/flash/fl_210_en.pdf.
 212. European Commission, Special Eurobarometer 425: summary, 2-3.
 213. European Commission, Special Eurobarometer 425: summary, 4-5.
 214. European Commission, Special Eurobarometer 425: summary, 6-9.
 215. European Commission, Special Eurobarometer 425: summary, 10-14.
 216. European Commission, Special Eurobarometer 425: summary, 15 and 18.
 217. Commission Report on the operation of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare of September 2015, 7-8.
 218. Of the MSs that have installed a system of prior authorisation under Directive 2011/24/EU, only 17 were able to present data for the year 2014 (one MS was able to present data, but could not make a difference between the data of prior authorisation under Directive 2011/24/EU and under the Social

- Security Regulations (Commission report on the operation of Directive 2011/24/EU of September 2015, 7).
219. Commission report on the operation of Directive 2011/24/EU of September 2015, 7.
220. Of the 26 MSs that have responded to the question concerned, only 23 were able to provide complete data on reimbursement of health services not subject to prior authorisation. Three of them were not able to present aggregated data for Directive 2011/24/EU and the Social Security Regulations.
221. Commission report on the operation of Directive 2011/24/EU of September 2015, 7.
222. Commission report on the operation of Directive 2011/24/EU of September 2015, 16-18.
223. Commission report on the operation of Directive 2011/24/EU of September 2015, 5.
224. Commission report on the operation of Directive 2011/24/EU of September 2015, 4.
225. Commission report on the operation of Directive 2011/24/EU of September 2015, 6-7.
226. Commission report on the operation of Directive 2011/24/EU of September 2015, annex A, 16.
227. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, p. 37.
228. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 6.
229. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 6.
230. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 8-9.
231. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 10.
232. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 11-13.
233. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 13-14.
234. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 12-13.
235. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 17.
236. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 19-20.
237. Member State data on cross-border healthcare following Directive 2011/24/EU: year 2015, 2016, 20-21.
238. G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, p. 101.
239. Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 10.
240. Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 92-95.
241. *Reverse discrimination* refers to the event where a patient finds him or herself in a purely national legal situation. In this case only national legislation can be invoked which might turn out to be less favourable than EU law. Reverse discrimination occurs for example where national law does not foresee in the reimbursement for healthcare provided by a purely private healthcare provider, but this would be possible when accessing healthcare abroad under Directive 2011/24/EU; Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, 83-85.
242. H. Stevens, Report on implementation of the European Disability Strategy (2017/2127/(INI)), committee on employment and social affairs, October 2017, p 80.
243. Report on implementation of the European Disability Strategy, October 2017, 17.
244. Report on implementation of the European Disability Strategy, October 2017, 17.
245. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, p. 55.
246. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 7.
247. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 7.
248. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 7.
249. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 8.
250. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 9.
251. European Commission, Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European union: Report, may 2015, p. 54
252. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 16.
253. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 18-19.
254. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 19.
255. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 22.
256. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 22.
257. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 26-27.
258. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 26-27.
259. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 29-30.
260. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, 41-48.

261. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016 (2018)
262. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016 (2018)
263. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016 (2018)
264. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016 (2018)
265. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016 (2018)
266. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016(2018)
267. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016(2018)
268. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf. For the evaluative study on the cross-border healthcare Directive, 32 NCPs of the EU Countries were included with an available website.
269. Santorro, A., Silenzi, A., Ricciardi, W., et al., Obtaining health care in another European Union MS: how easy is it to find relevant information? European Journal of Public Health 2014;25(1):29-31. The study of Santorro et al. evaluated whether MSs were meeting their legal obligations as to the provision of information for patients on their rights in relation to cross-border health care. The websites of 18 MSs were included with an available website.
270. Activity report: The study of Clemens et al. (2014) provide no information on the accessibility of the website with regard to the number of hits for the search strategy.
271. Given the total number of official languages being spoken in the EU, NCPs cannot be expected to provide information for inbound patients on their website in every official EU language. The choice was made to, as a minimum requirement, determine whether information for inbound patients was available in the *de facto lingua franca* of the EU: English.
272. <http://www.webpresencesolutions.net/7-reasons-google-search-results-vary-dramatically/>.
273. Evaluative study on the cross-border healthcare Directive (2011/24/EU), March 2015, 12.
274. Santorro, A., Silenzi, A., Ricciardi, W., et al., Obtaining health care in another European Union MS: how easy is it to find relevant information? European Journal of Public Health 2014;25(1):29-31. The study of Santorro et al. evaluated whether MSs were meeting their legal obligations as to the provision of information for patients on their rights in relation to cross-border health care. The websites of 18 MSs were included with an available website.
275. Implementation of National Contact Points for cross-border healthcare in EU MSs: a comparative analysis using websites and short interviews. Clemens, T., Cox, E. van der Zanden, B., et al., 2016.
276. Santorro et al. (2014) established that 13 out of 18 NCPs provided a list of search engines to identify healthcare providers.
277. During the bilateral exchange phase several items were excluded from the analysis. This was agreed because several items were not directly addressed in the communication with the NCP.
278. The NCP of the Netherlands correctly referred the pseudo-patient to another NCP but did not respond to any other questions.
279. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015. Available at: http://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.
280. Despite of the fact that Iceland was initially excluded from the scope of the study, it was decided to include Iceland in the online survey exercise considering the comparability with the Member State data reports on cross-border healthcare.
281. Since the Directive 2011/24/EU is not yet implemented in Liechtenstein and Liechtenstein does not participate in the cross-border healthcare expert group set up by the European Commission, Liechtenstein is not included in the online survey exercise.
282. Lithuania, Luxembourg and Sweden each have two NCPs (one for incoming and one for outgoings patients).
283. Since the Directive 2011/24/EU is not yet implemented in Liechtenstein and Liechtenstein does not participate in the cross-border healthcare expert group set up by the European Commission, Liechtenstein is not included in the online survey exercise.
284. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 34.
285. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 34.
286. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 138.
287. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 129.
288. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 129-130.
289. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 140.
290. Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 140.
291. See *supra* section 4.1.3.
292. See *supra* section 4.1.3.
293. European Commission, Impact Assessment Guidelines (2009) 23.
294. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) p. 54 + T25.
295. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 17.

296. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 23.
297. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 28.
298. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 39.
299. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 43.
300. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 47.
301. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 52.
302. Art. 4(3) Directive 2011/24/EU.
303. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.
304. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.
305. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.
306. Art. 6(1) Directive 2011/24/EU.
307. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.
308. Art. 5(5) Directive 2011/24/EU.
309. Recital 48 and art. 5(5) Directive 2011/24/EU.
310. G. Zucca, A. De Negri, A. Berény, A. Kaszap, K.A. Stroetmann, P. Varnai, Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 45.
311. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.
312. Member State data on cross-border patient healthcare following Directive 2011/24/EU: year 2016.
313. Article 9(5) Directive 2011/24/EU.
314. Article 9(1) Directive 2011/24/EU.
315. Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016, on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (OJ L 119, 4.5.2016, p. 1–88).
316. Article 37(1) General Data Protection Regulation.
317. Article 37(2) and (3) General Data Protection Regulation.
318. Article 83 General Data Protection Regulation.
319. Council Conclusions on Common values and principles in European Union Health systems (OJ C 146, 22.6.2006, p. 1–3).
320. Recital 22 Directive 2011/24/EU.
321. Recital 24 Directive 2011/24/EU.
322. Article 4(2)(a) Directive 2011/24/EU.
323. Article 4(2)(b) Directive 2011/24/EU.
324. Article 4(2)(a) Directive 2011/24/EU.
325. Special Eurobarometer 425 on patients' rights in cross-border healthcare in the European Union (2015) 37–38.
326. S.E. Verra,, R. Kroeze, and K. Ruggeri, Facilitating safe and successful cross-border healthcare in the European Union, *Health Policy* 120(6) (2016) 721.
327. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences (2018) 6.
328. ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences (2018) 6.
329. See amongst others the main conclusions and recommendations arising from the EPF series of Regional Conferences 2013–14, Summary Report: Cross-border Healthcare, available at <http://www.eu-patient.eu/contentassets/9863f24f267c4fd6a40e7facfd9f4f77/cbhc-summary-report-final-for-external-dissemination.pdf>.
330. European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European Union, May 2015, 10.
331. European Commission, Special Eurobarometer 425 Patients' rights in cross-border healthcare in the European Union, may 2015, 14–15.
332. Report on MS data on cross-border healthcare following Directive 2011/24/EU of October 2016, 8.
333. Only detailed information on the NCP practice of one Member State was missing. Information on this Member State was collected in WP2 and WP3. In total two Member States did not reply on the NCP survey, however, one of them provided the information questioned in the survey during the bilateral exchange by completing the document of its country specific description.

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