



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

Executive Summary (EN)



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

June – 2018



EUROPEAN COMMISSION

Directorate-General for Health and Food Safety
Directorate B — Health systems, medical products and innovation
Unit B.2 — Cross-border healthcare; Tobacco control

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Luxembourg: Publications Office of the European Union, 2018

ISBN 978-92-79-80265-2

doi:10.2875/788651

EW-01-18-177-EN-N

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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 (MSs), 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 where the patient is normally insured) 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 an [Evaluative study](#) published in 2015 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 (fieldwork carried out in 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 2011/24/EU 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 2011/24/EU 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 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 this exercise 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 and 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.

Table 1 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.

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 (contact points) per MS, the RCPs (Regional Contact Points) were given the opportunity to participate separately. The survey was open from 17 August until 9 November 2017. 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 that followed the roll-out of the survey.

The NCP survey showed that there are big organisational disparities 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 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.

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 shortcomings 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 access to quality information for 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 to 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 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 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 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.

¹ Only detailed information on the NCP practice of one MS was missing. Information on this MS was collected through the website analysis (Work Package 2) and the pseudo-patient investigation (Work Package 3). In total two MSs did not reply to the NCP survey, however, one of them provided the information gathered in the survey during the bilateral exchange by completing the document of its country specific description.

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 would need to remain a key issue for the future.



Publications Office

doi:10.2875/788651
ISBN 978-92-79-80265-2