Study on Enhancing implementation of the Cross-Border Healthcare Directive 2011/24/EU to ensure patient rights in the EU

Mapping NCP consultation arrangements with key stakeholders: analytical report

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Glossary

- Directive: Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare;
- EU: European Union;
- MS: Member State;
- NCP: National Contact Point.

Summary

Background and aim

Directive 2011/24/EU on the application of patients' rights in cross-border healthcare, states that Member States (MSs) shall ensure that National Contact Points (NCPs) consult with patient organisations, healthcare providers and healthcare insurers. In light of the 2018 study on cross-border healthcare and enhancing information provision to patients[1], it was observed that in general NCPs consider their cooperation with other stakeholders as 'very good'. Up to now it has not been assessed however, what these collaborations actually contain and whether any (formal) consultation arrangements exist between the NCPs and stakeholders.

In the same study, a toolbox for the NCPs was developed to help them improve their communication to patients, in terms of clear and accessible information on all aspects related to cross-border healthcare.

The aim of the current mapping exercise, was to provide insight into consultation arrangements between NCPs and patient organisations, healthcare insurers, and healthcare providers, as well as information on how the 2019 Toolbox is perceived by MSs. For that purpose we conducted: 1) written inquiries with NCPs; and 2) online questionnaires with patient organisations, healthcare insurers, and healthcare providers.

Data collection

NCP representatives of all MSs and EEA EFTA countries were invited to fill in the online written inquiry. The written inquiry was filled in by 41 respondents from 26 different EU countries (AT, BE, BG, CZ, DE, DK, EE, ES, FI, FR, GR, HR, IE, IS, IT, LT, LU, LV, MT, NL, NO, PL, RO, SI, SK, SE). Following the written inquiry with NCPs, a small sample of key stakeholders, including patient organisations, healthcare providers, and health insurers were invited to fill in a questionnaire. We received 23 responses from nine different EU countries, but many of these respondents did not complete the questionnaire.

Results

Consultation arrangements from NCP perspective

The majority of MSs that replied to the written inquiry, seem to have consultation arrangements with patient organisations (12), health insurers (11), and healthcare providers (13). However, for a significant share of MSs, these consultation arrangements did not take place over the last year (for 7 not with patient organisations, for 4 not with healthcare insurers, and for 7 not in the last year with healthcare providers). When asked *when* these consultation arrangements do take place, the vast majority (17 MSs) indicated that they only take place occasionally on demand. Translating this to *how* often consultations take place, this seems to correspond to 'on an exceptional basis' for quite a share of the MSs (8).

[1] European Commission. Study on cross-border health services: enhancing information provision to patients. 2018. https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2018_crossborder_frep_en.pdf

All respondents were asked whether the consultation process is formally arranged through (written) consultation arrangements between the NCP and the patient organisations, healthcare insurers or healthcare providers. This question was also asked to those respondents who indicated that they do not consult stakeholders, as even though consultations may not take place a formalised process may exist. The results showed that such a formalised process exists in less than one third of the MSs, with 6 MSs indicating that these exist with patient organisations, 9 with the healthcare insurers, and 7 with healthcare providers. To those respondents who indicated that they have formal arrangements with patients organisations, healthcare insurers and/or healthcare providers, respectively respondents from five, seven, and five MSs indicated that these consultation arrangements are made in cooperation with the stakeholders.

Despite that consultation arrangements do not seem to take place on a structural basis, it was indicated by the vast majority (28 respondents from 22 different MSs) that they do not face any challenges. Those who did indicate challenges exist, for example stated that it is difficult to engage stakeholders.

Consultation arrangements from stakeholder perspective

Patient organisations, healthcare providers, and health insurers were also asked whether consultations take place between them and the NCPs. Thirteen out of 21 stakeholders that replied to the question, answered positively, indicating that consultation take place between their organisation and the NCP. Of these 13, four indicated that the NCP is responsible for these consultations; six that it is a joint responsibility. With regard to formal arrangements, only two stakeholders indicated that they are formally arranged, which is done in cooperation with their organisation. Only one respondent indicated that there is a process in place for evaluating and improving the consultation process, consisting of a group of experts who provide guidance for cooperation.

Implementation of the 2019

With regard to the 2019-Toolbox on information provision, six MSs indicated that they consider the Toolbox as being very helpful; 16 find the Toolbox helpful to some extent. Also, most MSs (16) indicated that the Toolbox is implemented by their NCP, for example as information from the toolbox is provided on the NCP website. With regard to patients organisations, healthcare insurers and healthcare providers, it seems that they are not very familiar with the Toolbox, with only one respondent indicating that the Toolbox is used in their organisation.

Conclusion

It seems that not in all MSs consultation arrangements between NCPs and stakeholders are implemented. Moreover, in those MSs where consultation arrangements do take place, this often does not occur on a structural basis. At the same time, the vast majority of MSs seem to find that no challenges are faced with regard to consultation arrangements. This might raises the question on what the purpose should be for NCPs to consult with stakeholders.

With regard to the 2019-Toolbox, it seems that this is widely adopted by NCPs of most MSs. Patient organisations, healthcare insurers and healthcare providers, on the other

hand, do not seem to be familiar with the Toolbox on information provision on cross-border healthcare.

1 Introduction

1.1 The Crossborder healthcare Directive

In March 2011, the Directive 2011/24/EU on the application of patients' rights in cross-border healthcare (hereafter the Directive) was adopted.[2] The Directive clarifies the rights of patients to seek reimbursement for healthcare received in another Member State (MS) and ensures that these rights can be used in practice. It provides a framework for cross-border healthcare and 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 Member States 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*."[3]

The Directive sets out the conditions under which a patient may seek healthcare in another MS and when patients have the right to reimbursement of the costs by the MS of affiliation. At a national level, decisions are made about the healthcare basket to which citizens are entitled and the related financial mechanisms.[4] Before implementation of the Directive, the so-called Social Security Regulations were in place to regulate reimbursement in case healthcare costs were borne in another MS.

1.2 Information provision to patients on the Directive 2011/24

According to article 6 of the Directive, MSs should provide information on cross-border healthcare to patients through the establishment of one or more National Contact Point for cross-border healthcare (hereafter: NCPs).[5] The NCPs aim to help patients exercise their rights with regard to cross-border care and should have appropriate facilities to provide information on the main aspects of cross-border healthcare.[6] This accounts both for the NCP in the MS of treatment, as well as the NCP in the MS of affiliation.

More specifically, according to art. 6(4) of Directive 2011/24, 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 particular, information must be provided on the terms and conditions for reimbursement of costs,[7] procedures for accessing and determining those entitlements, and for appeal and redress if patients consider that their rights have not been respected.[8] With regard to the MS of treatment, for example information should be provided upon request on standards and guidelines on the quality and safety laid down by the MS of treatment and the healthcare providers that are subject to these standards and guidelines.[9]

In addition to NCPs, the MS of treatment should ensure that healthcare providers provide relevant information to patients as well.[10] This relates, for example, to

2 Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare.
3 Directive 2011/24/EU, recital 10.
4 Directive 2011/24/EU, recital 5.
5 Directive 2011/24/EU, art. 6.
6 Directive 2011/24/EU, recital 49.
7 Directive, art. 7 (6).
8 Directive 2011/24/EU, art. 9.
9 Directive 2011/24/EU, art. 4.2.(a).
10 Directive 2011/24/EU, art. 4.2(b).

information on the availability of treatment options, quality and safety of healthcare treatments, their authorisation or registration status, as well as their insurance coverage or other means of personal or collective protection with regard to professional liability. Also, clear information and comprehensible on prices should be made available to patients.

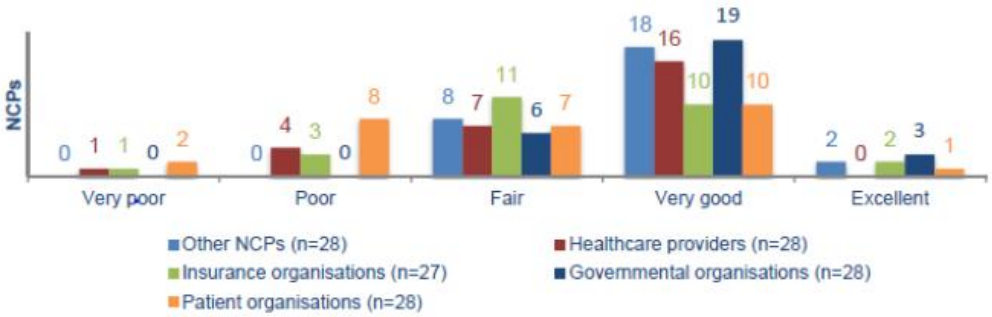
In 2018, a study was conducted in order to enhance information provision to patients on the cross-border healthcare Directive. One of the outcomes of this study was a toolbox for the NCPs to help them improve their communication to patients, providing clear and accessible information on all aspects related to cross-border healthcare. A manual for patients explaining their rights with regard to cross-border healthcare was provided as well.[11]

1.3 Consultation arrangements between NCPs and key stakeholders

According to the Directive, the NCPs shall cooperate closely with each other and with the Commission, for example by providing contact details of NCP in other MSs on patients' request.[12] Moreover, the Directive states that MSs shall ensure that NCPs consult with patient organisations, healthcare providers and healthcare insurers.[13]

In light of the 2018 study on cross-border healthcare and enhancing information provision to patients, it was observed that in general NCPs consider their cooperation with other stakeholders as 'very good' (see the figure below). [14]

Figure 1.1 Cooperation between NCPs and other stakeholders, results from the 2018 study on cross-border health services: enhancing information provision to patients



Up to now it has not been assessed however, what these collaborations actually contain and whether any (formal) consultation arrangements exist between the NCPs and stakeholders. Besides, a previous study showed that NCPs may operate very differently across the European Union, with for example, some NCPs being aligned with healthcare insurers, and other operating as separate organisations.[15]

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11 https://ec.europa.eu/health/cross_border_care/toolbox_nl.
12 Directive 2011/24/EU, art. 6(2).
13 Directive 2011/24/EU, article 6(1).
14 European Commission. Study on cross-border health services: enhancing information provision to patients. 2018. https://ec.europa.eu/health/sites/health/files/cross_border_care/docs/2018_crossborder_frep_en.pdf.
15 https://anec.eu/images/Publications/technical-studies/ANEC-TS-2017-SERV-008.pdf

1.4 Mapping of consultation arrangements

The aim of the current mapping exercise, was to provide insight into consultation arrangements between NCPs and patient organisations, healthcare insurers, and healthcare providers, as well as information on how the 2019 Toolbox is perceived by MSs. For that purpose we conducted:

- Written inquiries with NCPs;
- Online questionnaires with patient organisations, healthcare insurers, and healthcare providers.

Written inquiry with NCPs

A written inquiry (see Annex A) with NCPs was held in order to map information on:

1. *(Formal) consultation arrangements* between NCPs and patient organisations, healthcare providers and healthcare insurers;
2. *The 2019 Toolbox* and how it is perceived and implemented by the NCPs, as well as challenges that are still faced with regard to providing patient information on cross-border healthcare.

NCP representatives of all MSs and EEA EFTA countries were invited to fill in the online written inquiry. The written inquiry was filled in by 41 respondents from 26 different EU countries (AT, BE, BG, CZ, DE, DK, EE, ES, FI, FR, GR, HR, IE, IS, IT, LT, LU, LV, MT, NL, NO, PL, RO, SI, SK, SE). Hence, for a few MSs more than one respondent filled in the written inquire. From four MSs there was no reply (CY, HU, LI, PT). 29 respondents indicated that they are NCP representatives, eight were representatives from the Crossborder Healthcare Expert Group, two represented both, and two respondents indicated 'other'.

Online questionnaire with key stakeholders

Following the written inquiry with NCPs, we conducted an online questionnaires with a small sample of key stakeholders, including patient organisations, healthcare providers, and health insurers (see Annex B). As part of the written inquiry with NCPs, we asked with which organisations they have contact and/or arrangements, as well as for contact details of these organisations. Contact details of different organisations (mainly patient organisations and health insurers) were provided by eleven EU countries, including AT, BE, DE, FI, FR, GR, HR, IT, LU, MT, NL. These organisations were approached to fill in the survey and we received 23 responses from nine different EU countries (see the table below). It should be noted however, that many respondents did not finish the questionnaire.

MS	Organisation
AU	Healthcare insurer
BE	Patient organisation
DE	Patient organisation
FI	National, state authority
FI	Healthcare insurer
FI	The Finnish Association of Private Care providers
FI	Healthcare insurer
FI	Other, government
FI	Healthcare insurer
FI	Other, government
FI	Other, government

MS	Organisation
FR	Healthcare insurer
FR	Healthcare insurer
GR	Social insurance security institution
IT	Patient organisation
IT	Other, please specify:
LU	Patient organisation
LU	Patient organisation
LU	Patient organisation
MT	Patient organisation
MT	Patient organisation
MT	Healthcare provider
MT	Healthcare provider

2 Results

In this Chapter we present the results on consultation arrangements. First, we present the results from the written inquiry with the NCPs in paragraph 2.1. Thereafter, in paragraph 2.2, we present the results of the online questionnaires with a small sample of key stakeholders, including patient organisations, healthcare providers, and health insurers.

2.1 Results from the written inquiry with NCPs on consultation arrangements

Consultation arrangements

In total, 16 (52%), 19 (63%), and 21 (72%) of the MSs indicated that they have consultation arrangements (either formal or informal) with patient organisations, healthcare insurers and healthcare providers respectively. The table below shows which EU countries indicated that they do have consultation arrangements with key stakeholders, and which do not.

Table 2.1 Do consultation arrangements take place between the NCP and patient organisations, healthcare insurers and/or healthcare providers?

	Yes	No
Patient organisations	**16 (52%)** AT, CZ (3), DE*, DK (2), ES, FI, HR, IE, IS (2), LT, LU (3), LV, PL (2), RO* (3), SI, SE (2)	**15 (48%)** BE, BG, DE*, EE, ES, FR, GR, IT, LV, MT, NL, NO, PL, RO*, SK
Health insurers	**19 (63%)** AT, CZ (3), DE (2), DK (2), EE, ES, FI, FR, GR, HR, IS (2), IT, LT, LU, LV, NO, PL (2), RO (4), SK	**11 (37%)** BE, BG, ES, IE, LU (2), LV, MT, NL, PL, SI, SE
Healthcare providers	**21 (72%)** AT, BG, CZ (3), DE (2), DK (2), EE, ES, FI, GR, HR, IE, IS (2), IT, LT, LU (3), LV, MT, NO, PL (2), RO (4), SI	**8 (28%)** BE, ES, FR, LV, NL, PL, SK, SE

*NB., respondents from similar MSs provided different answers.

To those respondents who indicated that they have consultation arrangements with patient organisations, health insurers and/or healthcare providers, it was asked whether the NCP is responsible for these consultations. The table below shows the responses to this question per MS.

Table 2.2 Is the NCP responsible for coordination of these consultation arrangements with patient organisations, healthcare insurers and/or healthcare providers?

	Yes	No
Patient organisations	**12 (60%)** AT, CZ, DE, DK (2), FI, HR, IE, IS, IS, LU, RO (2), SE	**8 (40%)** CZ, LT, LU (2), LV, PL (2), SI
Healthcare insurers	**11 (55%)** AT, CZ, DE (2), DK (2), FI, HR, IS (2) IT, LT, LU, RO (3)	**9 (45%)** CZ, EE, FR, GR, LV, NO, PL, PL, SK
Healthcare providers	**13 (59%)** AT, BG, CZ, DE (2), DK (2), FI, HR, IE, IS (2), IT, LU, MT, RO (3)	**9 (41%)** CZ, EE, GR, LT, LU (2), LV, NO, PL (2), SI

* Note, not all respondents who answered 'yes' under the previous question, answered this question.

To those respondents who indicated that consultation arrangements take place, it was also asked whether these consultations had taken place in the last year, which was answered as follows:

Table 2.3 Have these consultations taken place in the last year with patient organisations, health insurers and/or healthcare providers?

	Yes	No
Patient organisations	**9 (56%)** AT, DE, DK (2) FI, HR, LU (3), LV, RO*, SI	**7 (44%)** CZ (2), IE, IS (2), LT, PL (2), RO*, SE
Healthcare insurers	**16 (80%)** AT, CZ, DE (2), DK (2), FI, FR, GR, HR, IS (2), IT, LT, LU, LV, NO, PL (2), RO* (2)	**4 (20%)** CZ, EE, RO*, SK
Healthcare providers	**14 (67%)** AT, DE (2), DK (2), FI, GR, HR, IS (2), IT, LU (3) LV, MT, NO, PL (2), RO* (2)	**7 (33%)** BG, CZ (2), EE, IE, LT, RO*, SI

* Note, not all respondents who answered 'yes' under the previous question, answered this question.

With regard to when consultations take place (i.e., in which situations), it was indicated by most EU countries that have consultations with patient organisations, healthcare insurers, and/or healthcare providers that these consultations take place occasionally on demand.

Table 2.4 When consultations between NCPs and key stakeholders take place

	# MSs	MSs
Occasionally on demand	17 (71%)	BG, CZ (2), FI, FR, GR, HR, IE, IS (2), LT, LU (3), LV, MT, PL (2), RO,(3), SI, SK, SE
On a regularly	2 (8%)	DE*, DK (2)
Both, occasionally and regularly	4 (17%)	AT, DE*, IT, NO
Other	1 (4%)	EE

* Note, not all respondents who answered 'yes' under the previous question, answered this question.

It was also explored, how often NCPs consult key stakeholders and the table below shows that many NCPs consult stakeholders on an exceptional basis.

	# NCPs	MSs
Monthly	2 (8%)	DE*, HR
Yearly	2 (8%)	DK (2), CZ
Exceptional basis	8 (32%)	BG, IS (2), LV, PL (2), RO (2), SI, SK, SE
Other	13 (52%)	AT,CZ, DE*, EE, FI, FR, GR, IE, IT, LT, LU (3), MT, NO

* Note, not all respondents who answered 'yes' under the previous question, answered this question.

Those NCPs answering 'other', 15 further specified:

- With the Health insurance institutions we have regular meetings the other stakeholders we contact occasionally on demand;
- Yearly scheduled meetings and ad hoc as needed;
- Yearly with health insurers, on exceptional basis with healthcare providers;
- We try to keep the contact at least once a year but the one to one contact with our provider regional and local and with patient association are more frequent and on demand;
- 4 times a year with healthcare insurers, occasionally with the others;
- Upon requests;
- As required and in response to issues as they arise. In the early years I engaged in a public information campaign with the assistance of public representatives and when COVID-19 has passed I hope to resume public information sessions;
- Health insurers on a weekly basis, others on demand;
- There is no clear formal timeframe;
- When need arises;
- Occasionally on demand (for example only when questions arise and decisions need to be made for a certain patient);
- Depends on the need from nil in a month to a number of consultations in a month;
- Whenever the handling of cases is the responsibility of the health insurance funds;
- There are no regular consultations.

With regard to the way consultations take place, three respondents indicated that they consult via email, three others indicated having consultations both via email and telephone, and three others choose the option 'other', e.g. having yearly meetings. 21 respondents from 16 different MSs, indicated that it depends on the situation which type of communication they use for consultation arrangements.

We asked respondents, whether they could provide examples on the topics that are discussed during consultations. With regard to *patient organisations*, some of the following examples were provided:

- Rare diseases, patient´s needs, patient´s expectations, specific contacts;
- Issues related to the application of the Directive, as well as the yearly report on cross-border healthcare and information from DG SANTE/the Commission is shared;
- Treatment protocols;
- Information for insured persons;
- Everything to do with the Directive, reimbursement, prior authorisation, patient pathways, etc.;
- Patients' rights/ general information on right to cross-border healthcare;
- Specific patient cases;

- Organisation and functioning of the National Contact Point, types of medical services, cooperation between National Contact Points.

With regard to *healthcare insurers*, the following examples were provided:

- Patients' rights/ general information on right to cross-border healthcare (also in light of social security regulations);
- Issues related to the application of the Directive, as well as the yearly report on cross-border healthcare and information from DG SANTE/the Commission is shared;
- Projects of the NCP in the last year, problems with healthcare in the last year;
- Differences between treatment options and benefits;
- Questions related to reimbursements and entitlement to treatment (also on making claims on behalf of patients);
- Questions related to (the refusal of) prior authorisation;
- Issuing of EU entitlement certificates (EHIC/PRC, S1), check of social security numbers (AMKA), affiliation with the national social security system;
- If some healthcare institution is contracted;
- Access to healthcare.

With regard to *healthcare providers*, the following examples were provided:

- The costs of different kind of treatments;
- The procedure for reimbursement of medical expenditures under Directive 2011/24;
- Issues related to the application of the Directive are discussed, as well as the yearly report on cross-border healthcare and information from DG SANTE/the Commission is shared;
- Problems with treatments or bills;
- Differences between treatment options and benefits;
- Practicalities related to treatment, e.g., places of treatment, waiting times for treatment, availability of services;
- Patients' rights, medical files, charging incoming patients, access to healthcare, complaints, guidelines for cross-border healthcare under the Social Security Regulations and the Directive;
- Issuing PRC for EHIC for insured person;
- Everything related to the Directive, reimbursement, prior authorisation, patient pathways, paper work, reimbursement rates, DRG codes;
- Patient specific related questions, e.g., issues they encounter in finding the right procedures in order to provide care to cross border patient;
- Treatment options for incoming patients (Regulations vs. Directive);
- Clarification on basket of benefits, clarifications on health personnel's' right to provide healthcare in a given MS;
- Information on the nature of contractual relations with health insurance providers. Information on providing medical services to insured persons in other MSs.

Formal consultation arrangements

All respondents were asked whether the consultation process is formally arranged through (written) consultation arrangements between the NCP and the patient organisations/healthcare insurers/healthcare providers. This question was hence also asked to those respondents who indicated that they do not consult stakeholders, as even though consultations may not take place a formalised process may exist. The table

below shows that in most EU countries, consultation arrangements between the NCP and stakeholders are not formally arranged.

Table 2.5 Is the consultation process formally arranged through (written) consultation arrangements between the NCP and patient organisations/healthcare insurers/healthcare providers?

	Yes	No
Patient organisations	**6 (21%)** DK, HR, IE, IS, RO (2), SE	**26 (79%)** AT, BE, BG, CZ, DE, EE, ES, FI, FR, GR, IS, IT, LT, LU (3), LV, MT, NL, NO, PL (2), RO, SI, SK
Healthcare insurer	**9 (33%)** AT, CZ, DE, DK, HR, IS, IT, NO, RO (3)	**18 (67%)** BE, BG, EE, ES, FI, FR, GR, IE, IS, LT, LU (3), LV, MT, NL, PL (3), SI, SK, SE
Healthcare providers	**7 (26%)** DK, HR, IE, IS, MT, NO, RO (3)	**20 (74%)** AT, BE, BG, CZ, DE, EE, ES, FI, FR, GR, IS, IT, LT, LU (3), LV, NL, PL (3), SI, SK, SE

To those respondents who indicated that they have formal consultation arrangements with patients organisations, healthcare insurers and/or healthcare providers, respectively respondents from five, seven, and five different MSs indicated that these consultation arrangements are made in cooperation with the stakeholders.

The question "can you please elaborate on what these consultation arrangements contain between the NCP and patient organisations, healthcare insurers and/or healthcare providers", the following answers were provided:

Table 2.6 Elaboration on content of consultation arrangements

Patient organisations	Healthcare insurers	Healthcare providers
Face to face meeting	Face to face meeting	Face to face meeting
General information	Discussion of specific patient inquiries (individual cases that are not so easy to answer), legal innovations (e.g. Brexit), exchange of new information from conferences, meetings (e.g. Cross Border Expert Meetings), new technical (e.g. SDG) or legal developments.	We consult healthcare providers on several aspects including type of healthcare, availability of healthcare, costs
Information for insured person	It contains details of cooperation between NCP and health insurers, basic processes	These are usually one to one (HSE to Provider) meetings and may cover the Directive in general or specific topics.
With patient organisations it is usually a response to a written invitation to provide a presentation on the Directive to the membership.	updating cross boarder issues simplifications of procedures publication of new information on national and regional/local websites (where present)	Yearly meetings in a committee.
Yearly meetings in a committee.	Yearly meetings in a committee.	

Patient organisations	Healthcare insurers	Healthcare providers
	Discussions and clarifications on procedures	

Challenges with regard to consultation arrangements

It was also asked whether there are any challenges with regard to consultations between NCPs and patients organisations, healthcare insurers and/or healthcare providers. The vast majority of the respondents (n=28 from 22 different MSs) answered that no challenges are faced. Two respondents indicated that they do face challenges with patient organisations, one respondent with healthcare insurers, and four respondents encounter difficulties with regard to consulting healthcare providers. When asking to elaborate on the challenges faced, the following answers were provided:

- It can be difficult to ensure that patient organisations engage in a meaningful way rather than expect that the meeting can be used as a mechanism to set aside the rules or expand the scope;
- Some patient group meetings are very useful particularly those by public representative which include members of the general public as opposed to organised patient groups. Other challenges are the time available to conduct these meetings, the facilities and balancing information with promotion;
- Health insurers do not engage with the public health services;
- Healthcare provides have a specific agenda to seek to circumvent the rules to maximise the profit they could make from the patients. These are always difficult meetings trying to balance being helpful with ensuring the rules are understood;
- It is difficult to get in touch with them, there is no main/umbrella organisation;
- They are not interested in this topic;
- In our MS, municipalities are responsible of organising public healthcare services and the information on treatment options is scattered;
- Misinformation on charging of incoming patients under the Social Security Regulations or the Directive.

To the question whether there a process in place to evaluate and improve the consultation system between the NCP and patient organisations, two respondents replied positive; with regard to health insurers and healthcare providers only one respondent indicated that such a process is in place, indicating that they always look for ways to inform the stakeholders better.

2.2 Results from the online questionnaire with key stakeholders on consultation arrangements

As part of the online questionnaire, patient organisations, healthcare providers, and health insurers were also asked whether any consultations take place between them and the NCPs. Thirteen out of the 21 stakeholders that replied to the question, replied positively to this question, indicating that indeed consultation take place between their organisation and the NCP. Of these 13, four indicated that the NCP is responsible for these consultations, six indicated that it is a joint responsibility. The three remaining respondents did not provide an answer to this question.

Only two stakeholders indicated that the consultation arrangements are formally arranged between them and the NCPs, which is done in cooperation with their organisation. With regard to the question whether any challenges are faced with regard

to consultation arrangements, four stakeholders indicating that this is the case, providing the following explanations:

- Due to the coronavirus it was more challenging to reach the NCP;
- It could be very useful for us to collaborate with NCP to help improve the information system on cross-border mobility, in particular, also at the European level;
- We have a very good informal arrangement with the NCP however we are never consulted officially or in any way. We would like to work better together;
- According our data, the main challenges are the following:
  - NCPs should have an essential role to play but in reality it is far to be the reality: lack of economic resources provided by EU Institutions and the MS to increase awareness of the role of NCPs;
  - About the NCPs role there is still a lack of information & low awareness among citizens & patients;
  - In-depth information on CBHC patients' rights is generally lacking;
  - Across Europe, disparities amongst NCPs in the way they operate;
  - Dialogue very limited only with some PAGs linked with Eurordis, and a broader cooperation among stakeholders dealing with CBHC issues is still missing: art. 6 of the Cross-border Dir. not fully implemented; increase the role of NCPs in the cooperation between ERNs & multi stakeholders dealing with CBHC.

Only one respondent indicated that there is a process in place to evaluate and improve the consultation process between the NCP and their organisation, consisting of a designated group of experts who, if necessary, provide guidance for cooperation.

Stakeholders were also asked whether they face challenges with regard to information provision to patients on crossborder healthcare. Three respondents indicated that they do not provide information to patients, six indicated that they do not face any challenges in this regard, and six other stakeholders (all patient organisations) indicated that they do face challenges with regard to information provision. These six patient organisations further elaborated on these challenges, stating the following:

Most important challenges
Beneath the rough guidelines, every country has its own legal and health care system with their own specifications, if you want to inform the patients correctly you have to do a lot of research to get the right information. For example, it is difficult to explain the differences in reimbursement to the patient, to explain the difference between the systems of private healthcare and statutory health insurance patients.
Difficult to find the relevant information due to: different legal systems across the countries: e.g. prior authorisation is mandatory in some countries, in other no prior authorisation is required, difficult for the patients to understand the procedures, different forms of reimbursement due to the different systems which are applied, treatments in a country outside the European Union. Also, patients have difficulties to understand and to make the difference between the Directive 2011/24/EU and the Social Security Regulations (EC) 883/2004 and 987/2009.
Unawareness of the existence of the 2 schemes of many patients and even some health care providers. Confusion for patients as to which of the 2 schemes to use in their particular situation. Lack of clear information regarding conditions applying, administrative steps to take before and after, tariffs and reimbursement policy, etc. Administrative complexity for authorization and reimbursement, generating delays and financial uncertainty. Upfront payments associated with the Directive's scheme, supplementary costs and hidden costs (travel, accommodation, translation, etc.).

Burden for patients to manage (medical) information flux and uncertainty about medical follow-up.
Lack of knowledge on regulations in other countries (on patients' rights, reimbursement,...)
The main challenges are: • lack of homogeneous assistance; • a complicated system of prior authorization, different from MS to MS; • little or denied reimbursements; • long or complicated administrative procedures; • common obstacles in the patient's journey the current EU framework is composed of two pieces of legislation which each lay out a different, but equally complex, patient journey; • the 'Directive on Patients' Rights in Cross-Border Healthcare' and the 'Regulation on the Coordination of Social Security Systems'; • limited awareness among clinicians and patients of these two pathways, and of the Regulation especially. The lack of economic resources do not support the full development of the area of cross-border healthcare nor the full implementation of the Directive: in the EU only 2% of citizens had planned treatment abroad but, if properly adopted, the Directive can help reduce health inequalities not only among the MS but within each country and with benefits for the rest of 98% of the EU population.
We work mostly through our member organisations and use social media & our website to send out relevant information to patients. We do not have staff or financial resources to make more personal contact with patients who could potentially benefit from the Cross-border health care. Due to the fact that we lack regular contact with NCP there may be developments or procedures in place on a national level that we are not aware of and thus we cannot give up to date information to patients. To our knowledge the patients are getting information about the crossborder healthcare from their healthcare providers but those who don't receive this may be deprived of their right due to lack of knowledge.

2.3 Results on implementation of the Toolbox

In addition to questions on consultation arrangements, it was also asked to what extent NCPs consider the 2019-Toolbox on information provision helpful. Six MSs (23%) indicated that they consider the Toolbox as being very helpful, 16 (62%) find the Toolbox helpful to some extent, one NCP indicated that the Toolbox is not helpful. Three MSs (12%) answered this question with 'I do not know'.

16 out of 25 (65%) MSs indicated that the Toolbox is implemented by their NCP, and when asking to specify which elements are implemented to following examples were provided:

- Texts of the tools are copied and pasted in the answers of e-mail inquiries;
- Road map consultations;
- Information is posted on the NCP website;
- Toolbox is linked in our NCP website;
- Some parts of the toolbox are implemented in our internal guidelines, which are available for health insurers. Our website is also inspired by the toolbox;
- The NCP uses elements in the toolbox to provide certain information in multiple languages.

Respondents who indicated that the Toolbox is not implemented by their NCP, were asked to explain why this is the case. Two NCPs indicated that the process of

implementation is ongoing, and one NCP stated to consider using the toolbox for future evaluations and online information. Two NCPs could not tell why the Toolbox is not implemented. Three respondents provided specific reasons for the lack of implementation, with one NCP stating that the information is not available in their national language, one finding the information in the Toolbox as not being accurate, and one other stating that the requirements or recommendations of the Toolbox do not match with the overall structure of their website "that has to satisfy many different needs of different people".

It was also asked whether any information is missing in the Toolbox, and it was indicated by one respondent that "The description on the right to medically necessary treatment pursuant to EC Regulation No. 883/2004 is inaccurate as it is stated that the need for treatment is unforeseen and due to sudden illness or injury. In our opinion information regarding medically necessary treatment relating to chronic diseases and existing illness is lacking in the tool box".

Also in the online questionnaire to stakeholders, respondents were asked whether they use or know the Toolbox, with only one respondent indicating that his or her organisation uses the Toolbox. The six other respondents who actually filled in the this question, indicated that the toolbox is not used, with as main reason that their organisation is unfamiliar with the existence of the toolbox.

3 Conclusion

Although Directive 2011/24/EU states that Member States (MSs) shall ensure that National Contact Points (NCPs) consult with patient organisations, healthcare providers and healthcare insurers, it seems that not in all MSs consultation arrangements between NCPs and stakeholders are implemented. Moreover, in those MSs where consultation arrangements do take place, this often does not occur on a regularly or structural basis. At the same time, the vast majority of MSs seem to find that no challenges are faced with regard to consultation arrangements. This might raises the question on what the purpose should be for NCPs to consult with key stakeholders.

With regard to the 2019-Toolbox, it seems that this is widely adopted by NCPs of most of the MSs. Patient organisations, healthcare insurers and healthcare providers on the other hand, do not seem to be familiar with the Toolbox on information provision on cross-border healthcare.

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