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'Know before you go': information-seeking behaviour of German patients receiving health services abroad in light of the provisions of Directive 2011/24/EU

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Abstract

Objective: While Directive 2011/24/EU on cross-border patient mobility makes specific provisions in relation to information availability and accessibility, little empirical evidence exists to guide best practice. This paper explores the information-seeking behaviour of German patients who received planned care abroad.

Methods: A postal survey among German patients treated in other European countries was carried out by Techniker Krankenkasse, a major German sickness fund. The influence of certain predictors on whether patients informed themselves before travelling for care was investigated using multiple logistic regression. Types and sources of information were analysed using descriptive statistics.

Results: Information activity was contingent on patients' level of education, type of service, regularity of treatment abroad and awareness of entitlement to cross-border services. Respondents most frequently enquired about elements of reimbursement, entitlement to services and cost-saving, and consulted their sickness fund for information. Differences in both content and medium of choice were observed between patient groups.

Conclusion: A structured and inclusive approach to information provision should be adopted. National Contact Points should collaborate with a range of stakeholders, who will vary depending on the health care system; however, patient organizations, health professionals and third-party payers should always be represented. Dynamically monitoring cross-border movements can help determine the range, medium and language of relevant information.

Keywords
cross-border care, European Union, patient information

Introduction

Health care is characterized by substantial information asymmetries at several levels, not least involving the patient–provider relationship.[1–3] In principle, the need for patients to have access to information that is impartial, valid and comprehensive is not contested. However, the type, delivery mode and presentation style of such information have been the subject of extensive scientific discussion. Whether and how patients actively access information before making choices for their care can also vary.[4,5]

The issue of asymmetric information is particularly relevant in the case of cross-border health care,[6] where the added dimension of a different health care system can further impede patients in making informed decisions. The importance of informed decision making in this context is clearly illustrated in the EU Directive on the application of patients' rights in

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Box 1. Specifications for information provision in Directive 2011/24/EU.

Responsibility for information provision

- Each MS must designate at least one NCP for cross-border health care (Art. 6 §1)
- MS must ensure that their NCPs consult with patient organizations, health care providers and health care insurers (Art. 6 § 1)
- Each MS can oblige other actors in the health system, such as health insurers or public authorities, to also be responsible for providing information (Rec. 20)

Member State of Affiliation

- Clear delineation of the rules governing cross-border care in national legislation (Rec. 19) and informing patients on the most advantageous system applicable to their case (Rec. 31)
- Mechanisms to inform patients on rights and entitlements, terms and conditions of reimbursement, procedures for assessing and determining entitlements as well as appeal and redress (Art. 5b), primarily through NCP(s) (Art. 6 §4)
- Information on cross-border care should make a clear distinction between entitlement under 2011/24/EU and EC 883/2004 (Art. 5b)
- System of prior authorization for specific health services needs to be clearly set out and information publicly available (Rec. 42, Art. 8 §7)

Member State of Treatment

- Governance (through NCP): information on safety and quality standards and the providers these apply for, provisions for provider supervision and assessment, accessibility of hospitals for persons with disabilities (Art. 4 §2a, Rec. 19); right of provider to practice including restrictions and information on patient rights, complaints procedures and redress mechanisms (Art. 6 §3)
- Providers: information on specific aspects of the services they offer, such as treatment options, availability, quality and safety; clear invoices and information on prices, authorization or registration status, insurance coverage and protection for professional liability (Art. 4 §2b)

cross-border health care,[7] which makes specific provisions on several information-related matters (Box 1) and underlines that it is paramount for patients to be aware of the rules governing cross-border service provision.

The main instruments for the implementation of these provisions in Directive 2011/24/EU are the so-called National Contact Points (NCPs), to be established in all Member States (MS). Various types of institutions have been designated as NCPs since the Directive's adoption.[8] The extent to which they were ready to assume their roles at the end of the Directive's transposition period into national law (25 October 2013) varied from country to country.[9]

There is little empirical evidence to guide best practice on providing cross-border patients with the information they require. It is conceivable that patients' questions would at least partially depend on their motivation for seeking care abroad. Thus, those seeking more affordable options and those travelling to acquire specialized treatment not available in their MS of affiliation would require different types of information.[10,11]

Aiming to contribute towards filling the evidence gap, this paper explores the information-seeking behaviour of German patients who received planned care in other European countries. While there is no aggregated evidence on the number of patients insured in Germany who receive health care abroad (not least due to the sickness fund-based structure of the system), expenditure can be used as a proxy for the magnitude of the phenomenon. Overall expenditure for services obtained abroad reached 0.6% of total health expenditure (and thus 0.06% of GDP) in 2012, having approximately doubled since 2000. Federal Statistical Office data show a similar rise in sickness fund expenditure abroad both as a share of total sickness fund expenditure and as a share of total expenditure for services abroad (0.7% and 72.3%, respectively, compared to 0.3% and 58.0% in 2000).[12] Thus, the phenomenon of cross-border care appears to be limited. However, a continued rise in travelling patients could potentially increase overall expenditure of German sickness funds, attributable mainly to administrative costs for determining reimbursement amounts and the fact that expenditure control mechanisms implemented in Germany would not apply to providers outside the country.[13]

The *Europabefragung* is a series of anonymous surveys carried out on a regular basis by Techniker Krankenkasse (TK),[14,15] as of January 2014, the largest sickness fund in Germany. Its purpose is to help the sickness fund ensure that its services match the needs of those it insures, both in regard to providing comprehensive and valid information (e.g. on types of services, quality and costs) and to the collaborations the fund holds with specific providers abroad.[14] Based on the 2012 iteration, this paper looks at whether patients informed themselves at all before travelling for care, what type of information they sought and what medium they used to obtain it.

Methods

Efforts were undertaken to identify all individuals insured by TK who had been treated in EU/EEA countries and whose reimbursement was administered by the fund in 2010. Specific cases were subsequently excluded (online Appendix 1). Thus, the final sample was not based on explicit power calculations. Questionnaires were sent by mail to 45,189 individuals in early 2012.

Collection was finalized in May of the same year, and the anonymized data were then coded.

The questionnaire was based on those used for the previous iterations of the *Europabefragung*, comprising 40 elements in yes/no, multiple choice and Likert scale formats as well as an open question for further comments at the end. A separate section, to be filled out only by respondents who had received planned care, included a set of questions on informed choice and is the focus of this paper. The instrument was pretested by 29 participants before being dispatched.

Data were analysed using SPSS Statistics 20. Descriptive statistics are illustrated using frequencies and associations within groups explored by means of chi-square tests where appropriate. Where more than one response were allowed, multiple response sets were defined and analysed using cross-tabulation. Reported percentages are valid percentages. A multiple logistic regression model was run to investigate the influence of certain predictors on whether patients informed themselves before travelling for care. Due to the large number of missing values for the dependent variable in the model, additional bivariate and multivariate analyses were performed to explore their potential influence. The level of significance was set at 0.05.

Results

Response rate

In total, 18,339 questionnaires were returned to TK, amounting to a response rate of 41%. A total of 796 questionnaires was excluded due to either invalid responses to the question on the planned or unplanned nature of services received, or the fact that participants were underage. Thus, the responses of 17,543 participants were available for analysis.

Baseline characteristics of survey respondents

Of the 17,543 respondents, 14,236 (81%) reported requiring unplanned treatment while abroad compared to 3307 (19%) who travelled with the purpose of obtaining services (all analyses presented below refer to the latter group). The sample was balanced in terms of gender (F/M 52%/48%), with an average age of 57.2 years and a higher representation of the age groups 70–79 (24.7%) and 60–69 (21.8%). Pensioners formed the largest group of respondents (44.3%), followed by salaried employees (31%). The gender ratio was identical to that of the full sample selected for the survey, but respondents were on average 6.7 years older than the full sample average (50.5 years).

Influence of patient characteristics and type of cross-border movement on information

Of the 3307 respondents who reported having received planned care abroad, 2841 responded to whether or not they had informed themselves before travelling, with 68.3% ($n = 1940$) of these having indeed done so. Binary logistic regression was performed to test the effects of gender, age, education, place of residence, type of services and cross-border movement as well as awareness of entitlement to services abroad on information activity (Table 1). Results indicate that the model provides a statistically significant improvement over the constant-only-model (χ^2 (26, $N = 1732$) = 136.9, $p < 0.001$). Based on Nagelkerke's R^2, the model accounts for 10.5% of the total variance of the dependent variable; the correct prediction rate is 68.2%. Wald tests for individual predictors show that patients informing themselves were contingent on level of education, type of service planned, regularity of treatment abroad and the patient's awareness of entitlement to cross-border services.

As indicated by the corresponding odds ratios (ORs), patients planning inpatient hospital care were three times more likely to inform themselves than those obtaining outpatient hospital services. Respondents who sought balneotherapy services were also more likely to inform themselves than those travelling for outpatient hospital care. Those who were treated abroad regularly were 30% less likely to inform themselves prior to travelling for care, while partial or full awareness of the EU-wide right to services also increased the odds of patients informing themselves compared to those not aware of their entitlement.

An analysis of missing values for the dependent variable ($n = 466$) showed that those who skipped the question were on average 3.2 years older and had an overall lower education status than those who gave a valid response (differences statistically significant in bivariate analysis). However, in a multivariate analysis including all independent variables used in the regression model, it was only the type of provider that appeared to be associated with not answering the question: those who had received inpatient balneotherapy or dental services abroad were less likely to answer the question than those who had planned outpatient hospital services (OR 0.37 and 0.52, respectively).

Questions asked while planning health care abroad

Overall, respondents most frequently enquired about elements of reimbursement, entitlement and cost-saving (Figure 1). The combination of treatment with holidays was as much of interest as the equipment and medical quality afforded by the provider in the country

Table 1. Multiple logistic regression model including patient and movement characteristics.

	B	*SE*	Wald	*df*	*p*	OR	95% CI for OR
Predictors							
Respondent characteristics							
Female gender	−0.05	0.12	0.21	1	0.645	0.95	0.76–1.19
Age	−0.07	0.06	1.33	1	0.249	0.93	0.82–1.05
Education			16.11	5	**0.007**		
Interaction between age and education			17.23	5	**0.004**		
Residence							
New federal state	0.003	0.15	.000	1	0.985	1.00	0.74–1.35
Residence in border region							
• Residence <30 km from border	Ref		4.12	2	0.128		
• Residence 30–60 km from border	0.43	0.21	4.12	1	**0.042**	1.54	1.01–2.33
• Residence >60 km from border	0.19	0.16	1.52	1	0.217	1.21	0.89–1.65
Cross-border movement							
Type of provider							
• Ambulatory hospital care	Ref		50.64	7	<**0.001**		
• Stationary hospital care	1.13	0.29	15.33	1	<**0.001**	3.09	1.76–5.42
• Ambulatory balneotherapy	0.80	0.26	9.62	1	**0.002**	2.22	1.34–3.69
• Stationary balneotherapy	0.66	0.20	10.60	1	<**0.001**	1.94	1.30–2.90
• GP practice	−0.48	0.28	2.96	1	0.085	0.62	0.36–1.07
• Specialist practice	−0.15	0.27	0.32	1	0.571	0.86	0.51–1.45
• Dental practice	0.43	0.23	3.63	1	0.057	1.54	0.99–2.41
• Other type of provider	0.13	0.23	0.29	1	0.588	1.13	0.72–1.79
Regularity of treatment							
• Treated abroad regularly	−0.36	0.11	9.91	1	**0.002**	0.70	0.56–0.87
Awareness of entitlement to services abroad							
Not aware of entitlement	Ref		7.42	3	0.060		
Aware of entitlement to emergency services	0.32	0.15	4.69	1	**0.030**	1.38	1.03–1.84
Aware of entitlement to ambulatory services	0.20	0.21	0.91	1	0.340	1.22	0.81–1.84
Aware of entitlement to all services	0.34	0.13	6.37	1	**0.012**	1.40	1.08–1.82
Constant	3.82	4.30	0.79	1	0.37	45.77	

OR: odds ratio.
Model omnibus $\chi^2 = 136.96$ ($p < 0.001$); Nagelkerke $R^2 = 0.105$; Hosmer–Lemeshow $\chi^2 = 3.15$ ($p = 0.924$); Model predictive accuracy 68.2%.
Note: Significant p-values appear in bold.

of treatment, followed by service availability. Relatively few respondents sought information about potential risks.

Chronic patients explored options of combining treatment with holidays and the range of services available more frequently, while they were less frequently concerned about waiting times or the professional qualifications of staff. No substantial differences were found between chronic patients who were enrolled in disease management programmes (DMPs) in Germany and those who were not. Patients regularly treated abroad inquired into equipment and language skills more and patient experience less than non-regulars.

Different patterns were observed when the frequency of responses was broken down by the condition for which treatment was sought. For example, patients with conditions of the eye or ear were among those most interested in the professional qualifications of treating physicians and the quality of services provided abroad, while they did not explore holiday options. Respondents travelling for services related to pregnancy or birth were among those less concerned with cost-saving but were the ones most frequently seeking information on previous patient experience. Dialysis patients were the ones most commonly exploring accompanying holiday options and less frequently interested in the experience of other patients (online Appendix 2, Table A1). Interesting patterns also emerged when responses were broken down by type of service provider (see patterned bars in Figure 1).

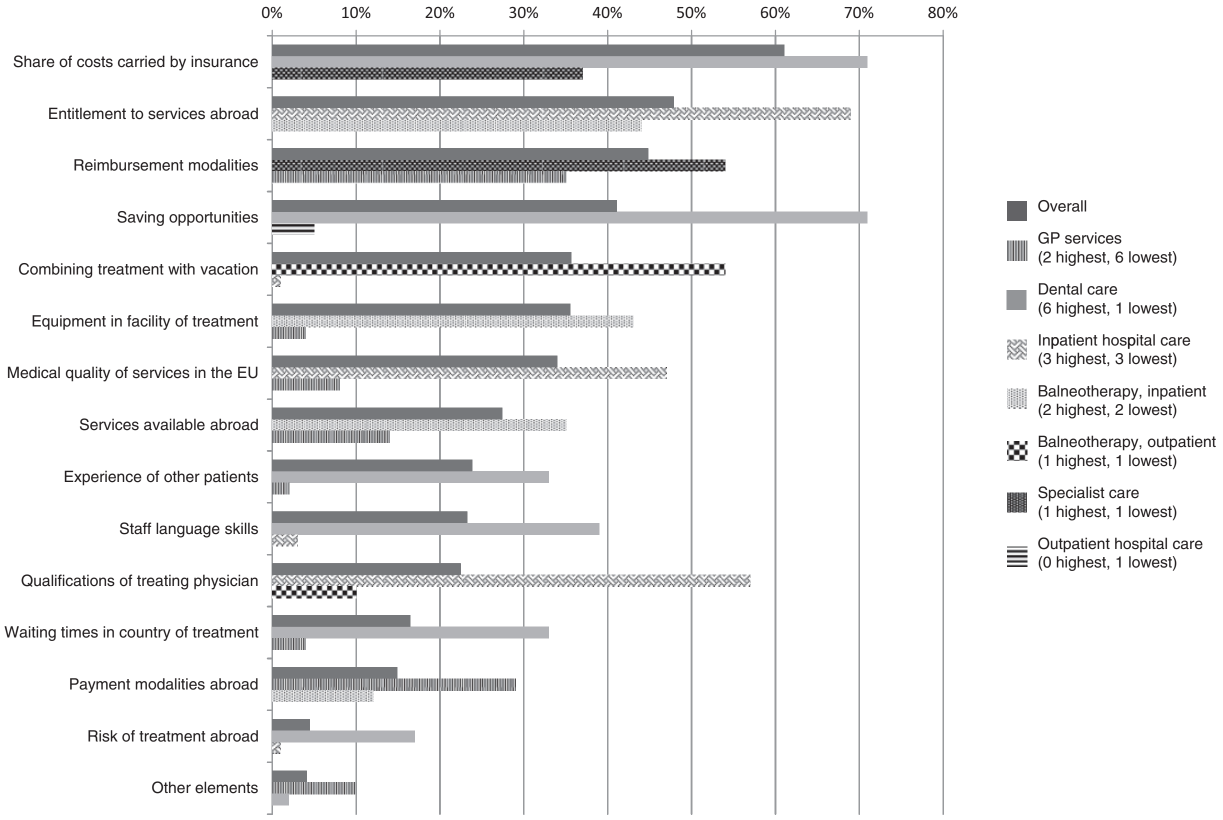

Figure 1. Percentages of respondents looking for specific types of information before travelling for care (including breakdown for subgroups most and least frequently requesting information by type of service).

Respondents residing in immediate border regions (<30 km from the border) were more interested in quality of services and professional qualifications as well as waiting times and enquired less frequently about vacation options, saving opportunities, staff language skills and risk of treatment abroad compared to those living further inland. While gender did not appear to play a role in the type of information sought, education level seemed to contribute to differences between groups although no clear pattern was discernible.

Sources of information

The most frequent source of information among respondents was the sickness fund customer service (59%). The recommendation of friends, family or the patient's physician along with the sickness fund hotline was used by approximately 29% of respondents each. Travel agencies or hotels at destination were less frequently consulted ($\approx$25%), followed by online resources ($\approx$15%). Other sources were only rarely used (Figure 2). Different sources were used most frequently depending on the type of services planned (see patterned bars in Figure 2).

When broken down by age, the younger respondents (18–29) were those who most frequently resorted to online resources, consulting the sickness fund website (35%) and other websites (62%), but also their physician in Germany (41%). Older respondents used travel agencies and hotels at destination more frequently, while the age groups 40–49 and 50–59 were those who consulted friends and family the most. Respondents who were not or only partially aware of their entitlement to services relied on information from friends and family more often, while the frequency of requiring information at the place of treatment rose with increasing awareness. Respondents in immediate border regions consulted their home physicians or the sickness fund more and hotels at destination, travel agencies or newspapers less than respondents residing further away from the border.

Different patterns were also discernible regarding choice of medium based on the type of information respondents were looking for. For questions directly related to entitlement, reimbursement, payment modalities and risk of treatment abroad, respondents relied more on the sickness fund's information sources, while those who wanted to inform themselves on professional qualifications and medical quality abroad frequently

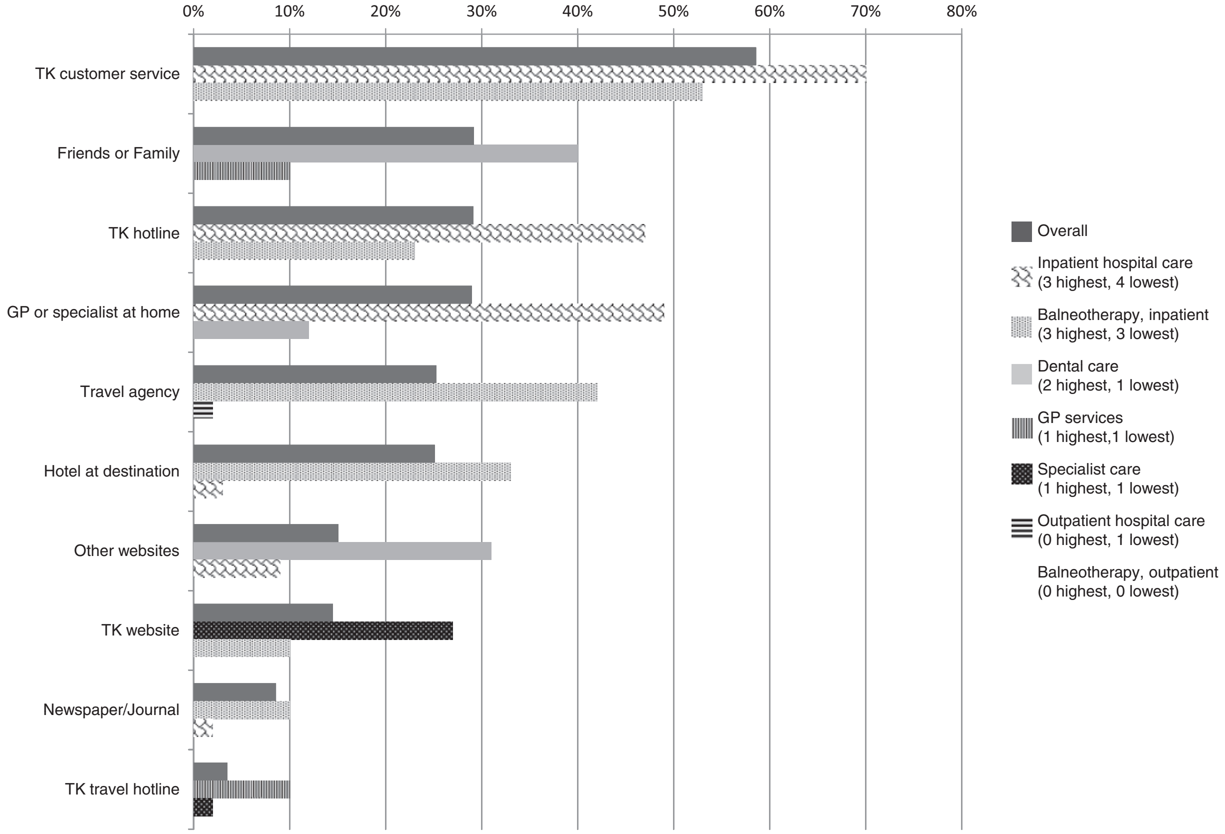

Figure 2. Percentages of respondents who used specific sources of information (including breakdown for subgroups most and least frequently consulting different sources by type of service).
TK: Techniker Krankenkasse.

consulted their physicians. Perhaps intuitively, those who wanted information on patient experience frequently consulted friends or family. However, they also often chose sickness fund sources (online Appendix 2, Table A2).

Discussion

Directive 2011/24/EU[7] has been greeted as an important milestone in cementing a number of principles underlying patient choice at EU level, including the right to information. It has been previously observed that patients in the European context act increasingly as ‘informed consumers’ regarding their health care choices[16] and that many patients in cross-border settings are dissatisfied with the information they obtained about their treatment both in terms of availability and quality.[17] Our data showed considerable differences among respondents in terms of awareness of entitlement to services, utilization of information and preference of information medium. How likely patients are to inform themselves on different aspects related to their care is influenced by their characteristics,[4] a fact our findings confirmed for the cross-border context.

One can argue that patients cannot fully exercise their right to informed choice if they are not aware of what they are entitled to in the first place. Indeed, our respondents’ grasp of their entitlement had an impact on whether they actively informed themselves before travelling for care. While the Directive clearly states that it should not be considered an endorsement for actively seeking out care abroad, raising awareness on the issue of entitlement to cross-border services could further enable patients to realize their rights and contribute to ensuring straightforward processes and appropriate care. As part of their role, NCPs could thus function as active proponents of informed choice for cross-border services as opposed to only providing information upon request.

Furthermore, NCPs need to be visible and easily accessible to patients if the information they provide is to be utilized. This may be facilitated if NCPs collaborate, as is foreseen in the Directive, with actors already functioning as intermediaries in patients’ home systems. For example, respondents in our survey relied heavily on their health insurer for information. A consultation with health professionals at home is at the top of the EC’s recommendations (‘know before you go’) to patients planning care abroad.[18] Other than insurers and health professionals, patient organizations can also play an important role in this respect. The European Patients' Forum (EPF) stresses the importance of dissemination at grassroots level to inform patients about NCPs.[19] Thus, NCPs can both receive and provide advice on best practice at national level.

To facilitate information provision for cross-border care, the Directive encourages the utilization of electronic means and online resources. However, NCP websites had been developed to varying degrees both in terms of functionality and content by March 2014.[9] Furthermore, respondents in our survey relied on online sources relatively rarely. This may be partially attributable to the age composition of the sample. Nevertheless, the group aged 18–29 – which most frequently used online resources – was still more likely to consult the sickness fund or a physician at home. Physicians or medical teams are the source of information preferred by older and less educated patients in general,[4] regardless of the condition they seek care for. Thus, if information is indeed to reach patients contemplating cross-border care, NCPs need to consider a number of formats, including printed material which can be then distributed to patients by their health professionals.

Lastly, the questions that patients consider relevant in the cross-border context are important when putting together information packages. This applies both to websites, which could provide different sections based on the type of care sought, and printed material. The topics most frequently addressed in our sample were in line with previous research on patient motivation[11] and willingness to travel[10] but varied for different patient groups. Thus, close co-operation between patient organizations and NCPs would also ensure that all aspects that are of interest to patients are included in an efficient and accessible manner.[19]

In summation, our findings confirm previous research in showing that patient characteristics influence information activity, and the desired range and presentation of data (for a discussion of the study's limitations, see online Appendix 1). Given that cross-border care remains a limited phenomenon, the volume and types of cross-border movements for individual countries in conjunction with the efficient use of resources should be considered when deciding how to ensure that patients are enabled to make informed decisions. NCPs could facilitate this process, co-ordinated by the European Commission.

Conclusion

Given the increased information asymmetry characterizing cross-border health care, a structured and inclusive approach should be adopted to ensure that patients are fully able to exercise their rights and make informed decisions. NCPs should collaborate with a range of stakeholders depending on the health care system in each country. Third-party payers, health professionals and patient organizations can play an important role both as intermediaries for patients and in planning, designing and putting together information. Dynamically monitoring cross-border movements at national and EU level can further aid in determining the range, medium and language of relevant information.

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