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Final Report

Analysis of institutional practices for APPS in the Greater Region

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Abstracts

English

The aim of this study was to assess the existence of practices related to APPS in the cross-border region of Belgium, France, and Germany. Therefore, a cross-sectional quantitative study was performed using an online questionnaire. In total 61 out of 118 hospitals (51,7%) responded to the questionnaire. A wide range of practices were found in the three countries and the degree of implementation was mixed.

Overall, there is a clear difference in the implementation of more patient and family friendly policies and real patient participation and involvement in hospital practices. APPS was said to be present in the hospital's philosophy of care in 82% of the hospitals sampled. Furthermore, more than half had patient partnership in the strategic plan of the hospital, indicating a movement towards more concrete action.

On the other hand only a minority of hospitals have a patient committee (25,5%), patient experts trained to work with other patients as part of patient education (26,3), patients included in the production of patient resources (22,4%) or patients participating the training of physicians and other health care professionals (5,4%).

Chi-squared tests show that the existence and degree of some APPS practices indeed differ significantly among the three regions. The French regions appearing to be more advanced than those situated in Belgium and Germany indicating possible scope for cross-border learning. In general it seems that the implementation of the APPS concept is incomplete and only partially integrated into the general functioning of hospitals in the region.

German

Das Ziel dieser Studie war die Analyse von institutionellen Praktiken in Bezug auf die Patientenbeteiligung im Gesundheitswesen (APPS) der Grenzregion zwischen Belgien, Frankreich und Deutschland. Dafür wurde eine quantitative Querschnittsbefragung in Form einer Online-Erhebung durchgeführt. Insgesamt beantworteten 61 von 118 Krankenhäusern (51,7%) den Fragebogen. In den drei Ländern wurde eine breite Palette von Praktiken festgestellt, der Grad der Umsetzung war allerdings sehr gemischt.

Insgesamt gibt es einen deutlichen Unterschied zwischen der Umsetzung von Patienten- und familienfreundlichen Maßnahmen und einer echten Beteiligung von Patienten an institutionellen Praktiken. 82% der befragten Krankenhäuser gaben demnach an, dass ihr Leitbild einen partnerschaftlichen Umgang mit Patienten fördert. Darüber hinaus ist das Konzept „Patient-als-

Partner“ in über der Hälfte der befragten Krankenhäuser teil offizieller Krankenhausrichtlinien, was auf eine Ausrichtung hin zu konkreteren Maßnahmen deutet.

Auf der anderen Seite hat nur eine Minderheit der Krankenhäuser in der Großregion einen Patientenbeirat (25,5%), Patienten als Experten, die im Rahmen der Patientenschulung mit anderen Patienten zusammenarbeiten (26,3%), Patienten, die in die Produktion von Patientenressourcen einbezogen sind (22,4%) oder Patienten, die an der Ausbildung von Ärzten und anderen Gesundheitsfachkräften teilnehmen (5,4%).

Chi-Quadrat-Tests zeigen, dass die Existenz und der Grad einiger APPS-Praktiken in der Tat in den drei Regionen sehr unterschiedlich sind. Die französischen Regionen scheinen dabei fortschrittlicher zu sein als die in Belgien und Deutschland, was auf Möglichkeiten für grenzüberschreitendes Lernen hindeutet. Im Allgemeinen scheint die Umsetzung des APPS-Konzepts noch unvollständig und nur teilweise in die institutionellen Praktiken der Krankenhäuser in der Region integriert zu sein.

French

L’objectif de cette étude était d’identifier l’existence des pratiques liées à l’APPS dans les régions transfrontalières de la Belgique, la France et l’Allemagne. Par conséquent, une étude quantitative transversale a été réalisée à l'aide d'un questionnaire en ligne. Au total, 61 hôpitaux sur 118 (51,7%) ont répondu au questionnaire. Un large éventail de pratiques ont été observées dans les trois pays et le degré d’implémentation était varié.

Dans l’ensemble, il existe une nette différence entre la mise en oeuvre de politiques plus favorables aux patients et à la famille et la participation réelle des patients aux pratiques de l’hôpital. Le concept d’APPS était présent dans la philosophie de soins de l'hôpital dans 82% des hôpitaux échantillonnés. En outre, plus de la moitié avaient un partenariat patient dans le plan stratégique de l'hôpital, indiquant un mouvement vers des actions plus concrètes.

Par ailleurs, seulement environ un quart d’hôpitaux disposent d’un comité de patients (25,5%), d’experts patients, formés pour travailler avec d’autres patients dans le cadre de l’éducation des patients (26,3), les patients inclus dans la production de ressources destinée pour les patients (22,4%) ou des patients participant à la formation des médecins et autres professionnels de la santé (5,4%).

On observe que l'existence et le degré de certaines pratiques APPS diffèrent de manière significative entre les trois régions (tests chi carré). Les régions françaises semblent être plus avancées que celles situées en Belgique et en Allemagne, ce qui laisse entrevoir des possibilités d'apprentissage transfrontalier. En général, il semble que la mise en oeuvre du concept APPS soit incomplète et ne soit que partiellement intégrée au fonctionnement général des hôpitaux de la région.

1 Introduction

Much research has been done into concepts connected to the Patient Partner Approach (APPS - Approche Patient Partenaire de soin)[1], such as patient-centred care (1), patient empowerment (2,3) and patient participation (4–6). Correspondingly, numerous activities have been developed to try to encourage greater patient participation in healthcare (7–9). These range from including patients in decision making about hospital management (10), developing decision aids to encourage shared-decision making (11), patient access to medical records (12) to patient participation in health care professional training (13).

Despite the advances in our understanding of what action can encourage APPS (or related terms) there have been few attempts to systematically assess the degree to which these are implemented in healthcare settings, particularly in Europe. One such study was conducted by Herrin et al in 2015 (14). Their study investigated the use of recommended strategies for patient and family engagement in hospitals in the USA. Their questionnaire was based upon the Carman model of patient and family engagement (15). They found mixed results indicating a large variation in hospitals in the USA (14).

The movement towards greater patient participation in health care has been gaining momentum particularly in English speaking countries (15,16). However, as demonstrated by Herrin et al (2015) the extent to which hospitals have implemented the concept, or elements of it, seems varied. This study aimed to explore the degree of uptake of elements of APPS in hospitals situated in a border region in Europe.

Aim: The aim of this study was to assess the existence of practices related to APPS in the cross-border region of Belgium, France and Germany. To see whether there were significant differences between the regions regarding APPS practices on the institutional level, a comparison between the regions was carried out. To fully grasp the importance and meaning of APPS practices secondary research questions were also analysed: Do hospitals that promote partnerships with patients in the philosophy of care and/or strategic plan of the hospital have a greater 'uptake' of other interventions regarding APPS practices? Are bigger hospitals with a larger number of beds more advanced regarding practices related to APPS then smaller hospitals? And finally: Is there an association between the presence of a patient committee and implementation of a higher number of other interventions related to APPS?

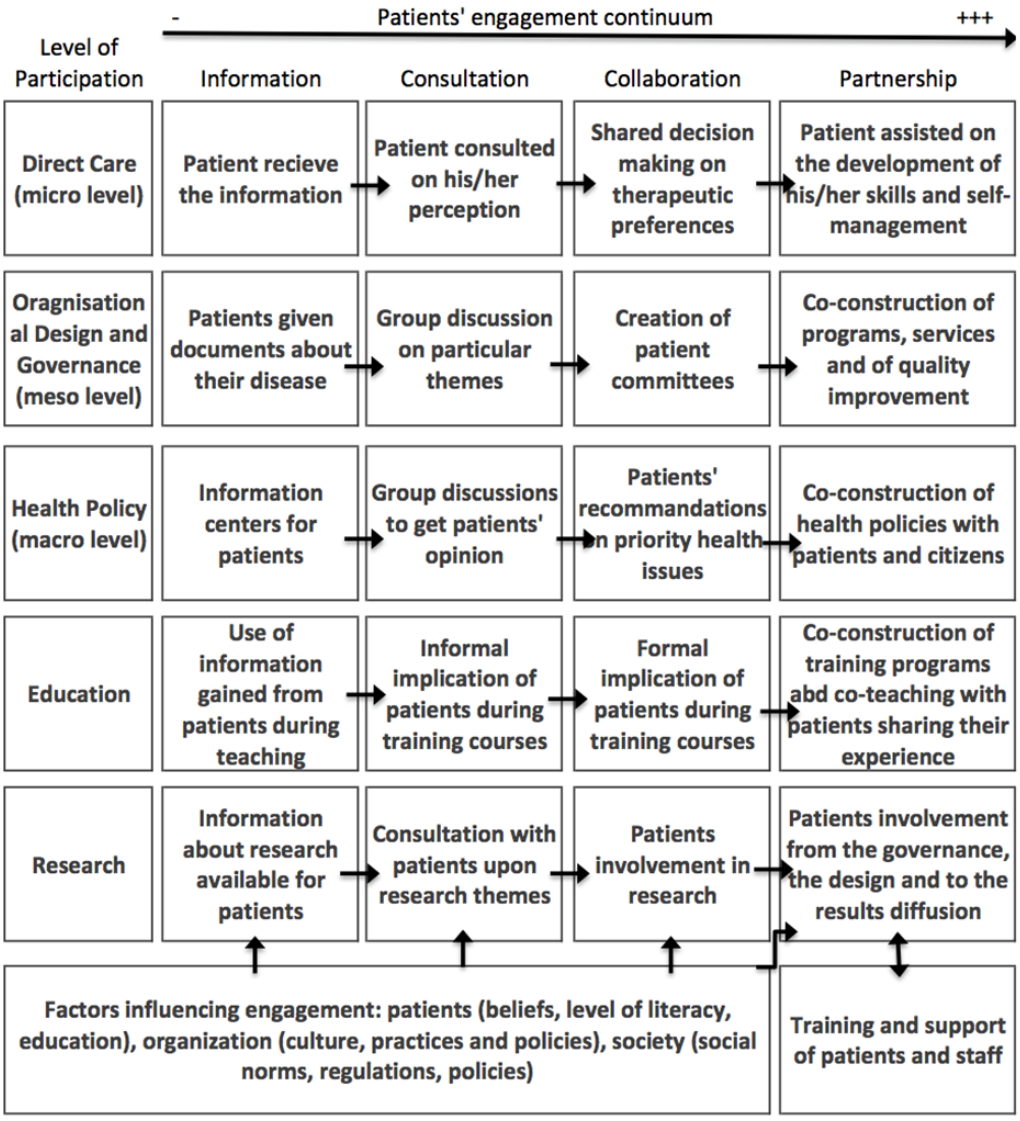
[1] APPS hereafter

2 Methodology

2.1 Theoretical framework

The concept of APPS, as with many related terms, is not very clearly operationalised and there is no overarching conceptual model that is readily applicable to this type of study. We therefore based our study on a relatively general model, the Montreal model of APPS by Pomey et al (17), see figure 1, which is an adapted version of the Carmen model of Patient and Family engagement (18).

Figure 1 Montreal Model of APPS



Source: Pomey et al 2015 (18), translated by Beatrice Scholtes and Iness Ortiz

The Montreal model extends the levels of engagement/participation to include: education and research. Additionally, a further element is introduced on the continuum of engagement raising it to four steps: information, consultation, collaboration and partnership as opposed to the three proposed

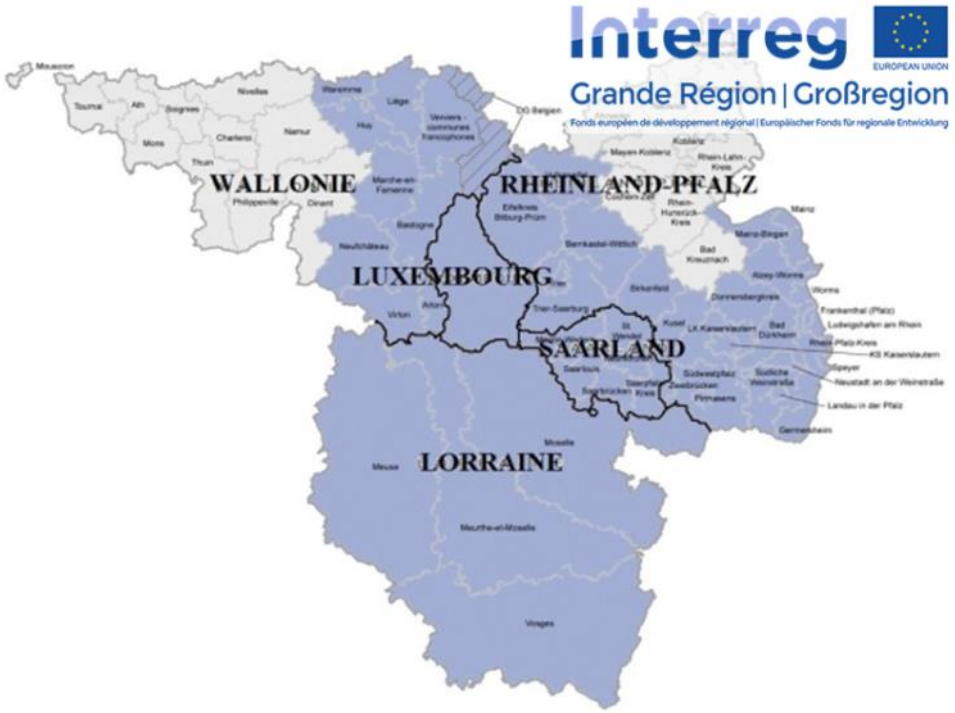
by Carman et al: consultation, involvement, and partnership shared leadership. Both of these have been discussed within the project as important components of APPS.

Given the pertinence to our objective of the study conducted by Herrin et al. and the Carman and Pomey models these, amongst other key sources, have been taken as a starting point for action 1,2.

2.2 Research design

To evaluate the existence of practices related to APPS at the institutional level in the Greater Region a cross-sectional quantitative study was performed using an online questionnaire. The questionnaire was circulated among hospitals in the Greater Region among the border regions of Belgium, France and Germany (see figure 2).

Figure 2 The Greater Region



2.3 Questionnaire development

The questionnaire was developed by members of the working group based on the theoretical framework with minor adaptions for the different health care systems in the four countries. Questions from existing questionnaires were used as much as possible – with questions only being newly developed if an existing question could not be found.

Key sources were used to construct the questionnaire. First, the theoretical models were used to inform the structure of the questionnaire (17,18). Based on these models the questionnaire was divided into six sections:

1. General hospital characteristics,

2. Hospital vision or mission,
3. Direct care,
4. Organisational design,
5. Education
6. Research.

Within each of these sections other sources were used.

Despite the large number of questions the average response time was only about 15 minutes due to many filter questions, this may also have made a difference to the number of participants that completed the whole questionnaire.

The final questionnaire had a total of 66 questions[2]. Most of the questions were operationalized as standardized, closed questions. In addition, there were also some open questions, where the participants were free to give comments. None of the questions were obligatory and many of them were filtered in an attempt to limit the time required for completion.

The questionnaire was first constructed in English and later translated into French and German. Back translations were used to standardize the wording in French and German.

To validate the content as well as consistency and clarity, the questionnaire was reviewed by diverse members of the project team. Several pre-tests were also carried out internally between the project partners to test the logic and flow of the filter-question-system as well as the time it takes to complete the questionnaire. In addition, a representative from the European Patients Forum gave feedback on the content and suggested amendments on an earlier draft. The final questionnaire was tested with health care experts in each region.

2.3.1 General hospital characteristics

This section asks questions about the size, type, location and funding mechanism of the hospital and the role of the respondent answering the questionnaire. The form of terms used were adapted to suit the region within which the hospital was located. The first question asked which region the hospital was situated in and, based on the answer, the following questions were adapted to suit that region in terms of the type of hospital, the role/function of the person completing the questionnaire and the funding mechanism of the hospital.

2.3.2 Hospital vision and mission

The section on hospital vision and mission aimed to identify if patient partnership was integrated into policy documents and the extent to which these policies were in place. The institute for patient and

[2] The whole questionnaire can be found in the appendix.

family centred care self-assessment questionnaire (19) had been used by Herrin for their questionnaire and we used the same wording. The questions that followed were inspired by the classification scheme of maturity described by Lombarts et al 2009 (20). Which aimed to quantify the extent of implementation of the policies and actions. We asked if patient partnership was integrated into the strategic plan of the hospital; if so was there an implementation plan for this dimension of the strategy and; if so, how many units had the patient partnership dimension of the strategy in place (<25% - in place in all units).

2.3.3 Direct care

The section concerning direct care was further subdivided into person-centred communication, self-management and shared decision making.

2.3.3.1 Person centred-communication

This part of the questionnaire was based strongly on the movement 'Patients included' and addressed all five clauses of the patient information resources charter (21) :

1. Patients participate in the co-creation, delivery, and review of the resources produced.
2. The disability requirements of participants are accommodated.
3. Patients are provided with the necessary support to fully contribute.
4. All resources must be freely accessible either in print and/or digitally from the internet or via a mobile app.
5. All resources must be patient-centred, free of jargon and undefined acronyms, and prepared in plain language.

Questions concerning whether patients are asked to evaluate the quality of HCP – patient communication and whether training courses are provided in how to communicate with patients.

2.3.3.2 Self-management

The section on self-management was based on questions from the patient-centred medical home assessment (22). Questions about training were developed by the working group.

2.3.3.3 Shared-decision making

The section on shared-decision making is also based on the patient-centred medical home (22). And the questionnaire by Herrin et al(14)

2.3.4 Organisational design

The organisational design section of the questionnaire was divided into five sections; patient committees, involvement of family and friends, access to medical records, quality improvement and advanced technologies.

The sections addressing patient committees, involvement of family and friends and access to medical records were all influenced by the questionnaire by Herrin et al (14). The quality improvement section was also based on the questionnaire by Herrin and partly on a study by Lombarts (23). The section on advanced technologies was devised by the working group.

2.3.5 Education

The education part of the questionnaire focussed upon whether patients were involved in the training of healthcare professionals and whether the patients themselves were trained. These questions originated from the Herrin et al questionnaire and were inspired by the Montreal model of patient partnership (18,24).

2.3.6 Research

The section of the questionnaire about research asks if there is a policy in place to include the patients in the full research cycle and to what extent the policy is implemented. These questions are based on the Montreal model (18,24) and the classification of maturity by Lombarts (20).

2.4 Target population

The questionnaire was designed for completion by members of the administration of the hospitals such as medical directors, nursing directors, CEO's or members of the quality management. The survey targeted all general and university hospitals in the territory of the Greater Region excluding psychiatric institutions.

2.5 Recruitment

For the recruitment a list of eligible hospitals was made for all four countries Overall 118 hospitals were invited to participate in the study (13 hospitals from Wallonia, 56 from Lorraine and 49 from Rhineland-Palatinate/Saarland).

A project partner in each country was responsible for sending invitations[3] and reminders to the target population in their region.

- In Belgium and Germany written invitation letters (annexe) were sent to the hospitals via post. In Belgium the invitations were addressed to the medical directors. In Germany the letters addressed the CEOs or quality managers. The letters were followed up by an email providing the personal electronic link to the online questionnaire.
- In France the letters were addressed to the hospital direction, either to the secretary or the medical directors themselves, the letters were not sent by post but in an attachment to an

[3] The invitation letters can be found in the appendix.

email. The email was followed up by a further email providing the personalized link to the questionnaire. Reminders have be done by emails and phone.

In all the letters the recipient was asked to refer the questionnaire to the person best placed to complete it (in terms of their function).

Online data collection was carried out between the 19.01.2018 and 24.04.2018. The program EFS-Survey from QuestBack was used to host the questionnaire and centralize the data. All collected data was centralized at Trier University and distributed to the other countries after data collection was completed.

2.6 Data analysis

Due to the small sample size only descriptive analysis and univariate statistical tests (e.g. chi-squared test, Fisher's exact test, t-test) were done. All analysis was done using IBM SPSS Statistics 25. Tests were 2-sided calculated to an alpha < 0.05.

2.6.1 Comparison of respondent and non-respondent group

A comparison of the group of hospitals that responded to our questionnaire and those that did not was undertaken to establish whether our sample was representative of the hospitals in the region. This was done using Pearson's chi-squared tests to test for differences between the characteristics of the two groups. The comparison was based on region, hospital size (number of beds), whether the hospital was in a rural or urban location, and the funding source for the hospital.

2.6.2 Comparison between regions

2.6.2.1 Descriptive comparison

To see whether there were significant differences between the regions regarding APPS practices on the institutional level, first a descriptive comparison between the regions was carried out. This was done using Pearson's chi-squared tests and Fisher's exact test to identify statistically significant differences between the regions

2.6.2.2 APPS score calculation

For further analysis we developed an additive index based on 20 selected variables of the questionnaire. The selection was limited to non-filtered questions (i.e. the questions that were posed to all participants to include the maximum of responses), based on theoretical assumptions[4] and on

[4] A factor analysis was not suitable for the data due to the small sample size. It is said that a sample size of at least 60 is needed if the commonality of each item is at least 0.6 (40). In our sample not every question was answered by all 61 hospitals so most of the questions have an n lower than 60.

the n of each question. Four sections of the questionnaire were used: hospital vision, direct care, organisational design and education.[5]

We recoded each question to a standardized scale from 0 to 1.

Table 19 in the appendix shows the selected questions. For the overall 'APPS-Score' we then totalled the results for the selected variables of each participant obtaining a scale from 0 (no approval) to 20 (maximum approval). We standardized the additive score again on a 0 to 1 scale for better interpretation and comparability.

The mean score for each participating hospital was calculated, these were combined by region and a mean score per region was calculated. The score for each region was compared using one-way ANOVA tests (analysis of variances) to test for differences between means. If there were significant differences, we used post-hoc tests (Tukey) to see which groups differ in means.

Alongside the overall score we also developed scores for the different sections of APPS practices, including only the variables from the respective sections, following the same procedure. The closer the score is to 1, the more APPS practices are implemented in the respective hospital. The combined mean scores per region were compared using one-way ANOVA tests and Turkey post-hoc tests. The descriptive statistics for the APPS score are displayed in Tables 23-25 in the appendix.

2.6.3 Further correlation tests

To test the relationship between the size of the hospital, the presence or absence of patient partnership in the hospital vision and the existence of a patient committee with the degree of APPS practices in the respective hospital further correlation test were carried out. This was again done using Pearson's chi-squared tests and Fisher's exact tests. Selected variables were included in the analysis as shown in Table 20 in the appendix.

[5] The section devoted to research was not used since very few hospitals in the sample conduct research, the n was therefore too low.

3 Results

3.1 Sample characteristics

Of the 118 hospitals surveyed, 61 (51.7%) fully responded:

- 9 out of 13 from Belgium (69.2%),
- 28 out of 56 from France (50.0%) and
- 24 out of 49 from Germany (49.0%).

Eighteen hospitals started the questionnaire but either only answered the first few questions or stopped after the start page, so they were not included in the data analysis.

The comparison of respondent and non-respondent hospitals showed no significant differences regarding hospital characteristics (see Table 1).

Table 1 Characteristics of hospitals included compared with those not surveyed

Characteristics	Not included	Responded	All eligible	p Value
N	57 (100,0)	61 (100,0)	118 (100,0)	
Region				0.124
Germany	25 (43,9)	24 (39,3)	49 (41,5)	
France	28 (49,1)	28 (45,9)	56 (47,5)	
Belgium	4 (7,0)	9 (14,8)	11 (11,0)	
Beds (category)				0.153
< 300	36 (64,3)	34 (55,7)	70 (59,8)	
300-599	15 (26,8)	15 (24,6)	30 (25,6)	
600+	5 (8,9)	12 (19,7)	17 (14,5)	
Location				0.545
rural	27 (48,2)	29 (47,5)	56 (47,9)	
urban	29 (51,8)	32 (52,5)	61 (52,1)	
Ownership				0.439
Public	24 (44,4)	23 (37,7)	47 (40,9)	
Non-Profit	21 (38,9)	31 (50,8)	52 (45,2)	
Private	9 (16,7)	7 (11,5)	16 (13,9)	

Table 2 shows the characteristics of the sample by region. Most of the hospitals in the sample were general hospitals funded by non-profit organisations. Fifty percent of respondents were hospital directors and approximately 38% members of quality management. The remaining surveys were completed by other hospital staff. Most of the hospitals surveyed are rather small hospitals with less than 300 beds and only one site.

Table 2 Characteristics of the sample by region

	DE n (%)	FR n (%)	BE n (%)	Total n (%)
type of hospital				
general	23 (95,8)	27 (96,4)	6 (66,7)	56 (91,8)
university	1 (4,2)	1 (3,6)	1 (11,1)	3 (4,9)
other	0 (0,0)	0 (0,0)	2 (22,2)	2 (3,3)
Funding				
Private hospital	1 (4,2)	6 (21,4)	0 (0,0)	7 (11,5)
Public hospital	3 (12,5)	13 (46,4)	7 (77,8)	23 (37,7)
non-profit hospital	20 (83,3)	9 (32,1)	2 (22,2)	31 (50,8)
Respondent				
Director of Nursing	2 (9,5)	7 (25,0)	0 (0,0)	9 (15,5)
Medical Director	0 (0,0)	0 (0,0)	7 (77,8)	7 (12,1)
Director of administration	0 (0,0)	13 (46,4)	0 (0,0)	13 (22,4)
Quality Management	19 (90,5)	3 (10,7)	0 (0,0)	22 (37,9)
Others	0 (0,0)	5 (17,9)	2 (22,2)	7 (12,1)
Number of beds				
< 300	9 (40,9)	14 (56,0)	2 (22,2)	25 (44,6)
300-599	9 (40,9)	6 (24,0)	3 (33,3)	18 (32,1)
600+	4 (18,2)	5 (20,0)	4 (44,4)	13 (23,2)
Number of sites				
1	15 (62,5)	12 (42,9)	3 (33,3)	30 (49,2)
2	7 (29,2)	7 (25,0)	2 (22,2)	16 (26,2)
3	1 (4,2)	6 (21,4)	2 (22,2)	9 (14,8)
4	0 (0,0)	1 (3,6)	0 (0,0)	1 (1,6)
6+	1 (4,2)	2 (7,1)	2 (22,2)	5 (8,2)

3.2 Hospital vision and mission

3.2.1 Frequencies

The first thematic section of the questionnaire deals with the integration of APPS into the vision and mission of the hospitals in the Greater Region (see Table 3). First of all, a general assessment question was asked whether patient partnership was promoted in the hospitals philosophy of care statement. About 82% of all hospitals said this was the case. 28,5% said their philosophy of care statement fully promoted partnership with the patient it serves. To assess the degree of implementation the next question asked if patient partnership was integrated into the strategic plan of the hospital. A little more than half of the hospitals in the sample said that APPS is indeed integrated into their strategic plan. For those hospitals the degree of real implementation of APPS was further elicited via two filter questions. About 76% of the hospitals with APPS integrated into their strategic plan said that there is

also an implementation plan for the dimension of the strategy concerning patient partnership. And again, in most of those hospitals (40,9%) the strategy was in place in all of the units.

Table 3 Frequencies - Hospital vision and mission

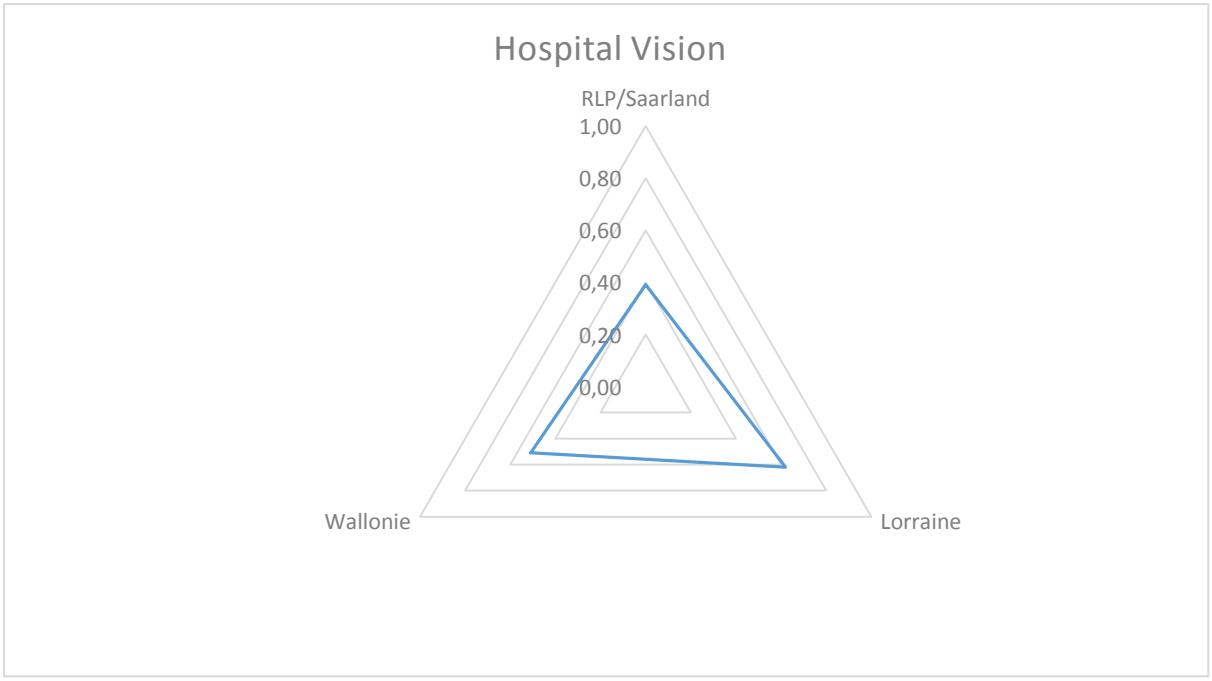
Question	Total n (%)
7. Does your organization's philosophy of care statement promote partnerships with the patients it serves?	**60 (100,0)**
Yes, fully	17 (28,5)
Yes, to some extent	32 (53,3)
Not really	9 (15,0)
No, not at all	2 (3,3)
8. Is patient partnership integrated into the strategic plan of the hospital?	**60 (100,0)**
Yes	31 (51,7)
No	29 (48,3)
9. If yes: **Is there an implementation plan for the dimension of the strategy concerning patient partnership?**	**29 (100,0)**
Yes	22 (75,9)
No	7 (24,1)
10. If yes: **How many units have the patient partnership dimension of the strategic plan in place?**	**22 (100,0)**
Less than 25 %	3 (13,6)
25 to 50 %	3 (13,6)
51 to 75 %	5 (22,7)
More than 75%	2 (9,1)
The strategy is in place in all units	9 (40,9)

3.2.2 Comparison between regions[6]

The mean of the overall score for practices related to hospital vision and mission is 0,51 on a scale from 0 to 1. The closer the score is to 1, the more APPS practices are implemented. The combined mean scores per region were compared using one-way ANOVA tests and Turkey post-hoc tests.

Significant differences between the three regions can be identified regarding practices related to hospital vision in general, as Figure 3 shows. The post-hoc test (see Table 31 in the appendix) showed that the differences were most prominent between Germany and France, with overall higher scores in France.

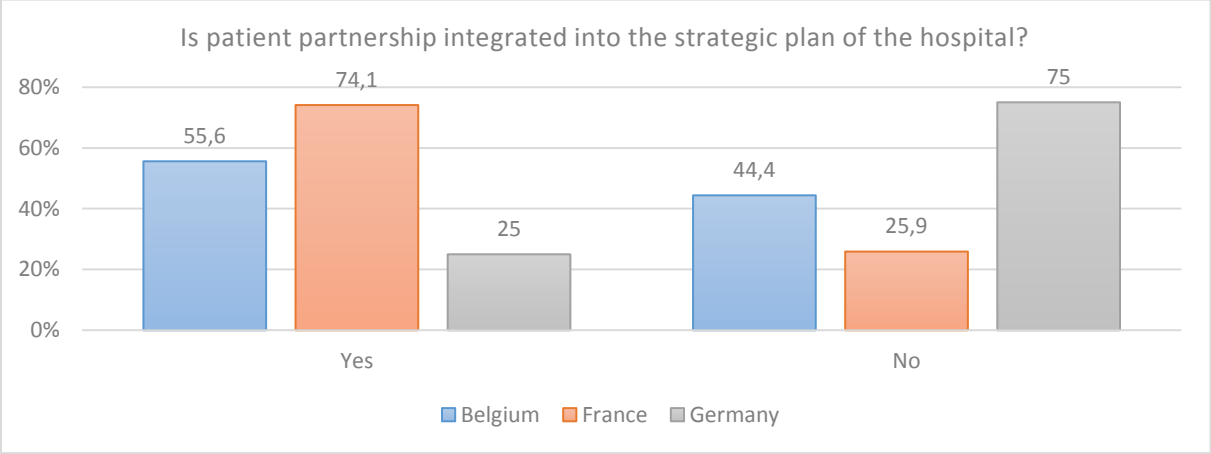
Figure 3 Apps Score - Hospital vision



Looking at the separate items measuring practices related to hospital vision and mission there are also significant differences between the three regions. In France almost three quarters of the hospitals surveyed have patient partnership integrated into their strategic plan of the hospital whereas in Germany it is only one quarter. The situation in Belgium is relatively balanced, 5 out of 9 hospitals have patient partnership integrated into their strategic plan.

[6] Only significant results are displayed in the figures. For detailed results see tables in the appendix.

Figure 4 Regional differences regarding the integration of APPS in the strategic plan of the hospitals



P value: 0.002, Fisher's Exact: 0.002

Regarding the question whether the hospitals philosophy of care statement promote partnership with the patients it serves there are no significant differences between the regions.

3.3 Direct care

In the next section of the questionnaire various practices related to direct care were analysed.

3.3.1 Frequencies

3.3.1.1 Person-centred Communication

The majority of the hospitals surveyed (61,4%) stated that health care users are regularly asked to evaluate the quality of healthcare professional patient communication. Only 17,5% said that this is not the case. In most of the hospitals (77,6%) patients are normally not included in the production of patient resources. To capture this more precisely three filter questions were asked. In the 13 hospitals in which patients are included they mostly participate in the review of the resources produces (53,8%). Those hospitals also ensure that patients' needs are fully accommodated in the production of patient resources. Meetings mostly take place in fully accessible locations (61,5%), timing is organised according to patient's needs (46,2%) and the patients are provided with all the necessary support to fully contribute (46,2%). The patient resources produced are mainly patient centred, available in print and prepared in plain language. Other forms like audio or video tapes or internet resources are rarely found.

In the next question the hospitals were asked whether they provide training for staff in how to communicate with patients. Most of the hospitals (76,3%) said that they do so. The courses were mostly provided for nurses. In each case about a quarter of hospitals also said they provide courses for physicians in how to encourage patients to ask questions, give their opinions and express concerns, approaches for eliciting patients' values, goals and needs and how to create opportunities to hear from

patients about their perspective of the care experience at the hospital. Courses for using teach-back methods were not common in the hospitals of the sample.

Table 4 Frequencies - Person-centred communication

Question	Total n (%)
11. Are healthcare users routinely asked to evaluate the quality of health care professional patient communication?	**57 (100,0)**
Yes, regularly	35 (61,4)
Yes, but not regularly	12 (21,1)
No	10 (17,5)
12. Are patients included in the production of patient resources in your hospital?	**58 (100,0)**
Yes	13 (22,4)
No	45 (77,6)
13. If yes:* How are they included?	**13 (100,0)**
Patients participate in the co-creation of the resources produced	5 (38,5)
Patients participate in the choice of method of delivery (e.g. leaflet, video etc) of the resources produced	5 (38,5)
Patients participate in the review of the resources produced	7 (53,8)
14. If yes:* In what way are patient's needs fully accommodated in the production of patient resources	**13 (100,0)**
Meetings take place in fully accessible locations	8 (61,5)
Timing is organised too fully accommodate patient's needs	6 (46,2)
Patients are provided with the necessary support to fully contribute	6 (46,2)
15. If yes:* Patient resources are…	
… patient centred	**12 (100,0)**
Always	7 (58,3)
Sometimes	4 (33,3)
Never	1 (8,3)
…available in print	**12 (100,0)**
Always	8 (66,7)
Sometimes	4 (33,3)
Never	0 (0,0)
…available in form of video tapes	**10 (100,0)**
Always	0 (0,0)
Sometimes	7 (70,0)
Never	3 (30,0)
…available in form of audio tapes	**10 (100,0)**
Always	0 (0,0)
Sometimes	2 (20,0)
Never	8 (80,0)
…available on the internet	**11 (100,0)**
Always	2 (18,2)
Sometimes	9 (81,8)

Never	0 (0,0)
…available in different languages	**11 (100,0)**
Always	3 (27,3)
Sometimes	5 (45,5)
Never	3 (27,3)
…prepared in plain language (free of jargon and undefined acronyms)	**12 (100,0)**
Always	8 (66,7)
Sometimes	4 (33,3)
Never	0 (0,0)
16. Does the hospital provide training for staff in how to communicate with patients?	**59 (100,0)**
Yes	45 (76,3)
No	14 (23,7)
17. If yes: **For each of the following practices, please indicate whether or not there is formal training provided in how to communicate with patients.***	**45 (100,0)**
How to encourage patients to ask questions, give their opinions and express concerns	
Physicians	11 (24,4)
Nurses	19 (42,2)
Administrative Staff	6 (13,3)
No training available	16 (35,6)
Approaches for eliciting patients' values, goals and needs	
Physicians	11 (24,4)
Nurses	25 (55,6)
Administrative Staff	5 (11,1)
No training available	11 (24,4)
How to create opportunities to hear from patients about their perspective of the care experience at the hospital	
Physicians	12 (26,7)
Nurses	18 (40,0)
Administrative Staff	7 (15,6)
No training available	17 (37,8)
Using teach-back methods	
Physicians	5 (11,1)
Nurses	7 (15,6)
Administrative Staff	1 (2,2)
No training available	26 (57,8)

*Multiple answers were possible. Only the results from the quoted items were displayed.

3.3.1.2 Self-management

Two questions were asked to assess the degree of self-management support in the hospitals. About three quarters of the hospitals surveyed said that self-management support is mostly accomplished by referral to self-management classes or educators. 60% said that self-management support is accomplished by the distribution of information. In the majority of hospitals the staff are trained on

teaching and encouraging patients regarding self-management. 76,9% said that all of the administrative staff and about 40% that all of the nurses and all of the other clinician staff are trained on that field. Only 18,2% stated that all physicians are trained on teaching and encouraging patients regarding self-management.

Table 5 Frequencies - Self-management

Question	Total n (%)
18. Please indicate which statement is most appropriate for your hospital. Self-management support…*	
…is accomplished by the distribution of information (pamphlets, booklets). (n=55)	33 (60,0)
…is accomplished by referral to self-management classes or educators. (n=54)	40 (74,1)
…is provided by goal setting and action planning with members of the practice team. (n=53)	22 (41,5)
…is provided by members of the practice team trained in patient empowerment and problem-solving methodologies. (n=51)	25 (49,0)
19. Are the following groups trained on teaching and encouraging patients regarding self-management?*	
Physicians	**55 (100,0)**
Yes, all	10 (18,2)
Yes, some	43 (78,2)
None	2 (3,6)
Nurses	**55 (100,0)**
Yes, all	21 (39,6)
Yes, some	31 (58,5)
None	1 (1,9)
Other Clinician Staff	**53 (100,0)**
Yes, all	21 (39,6)
Yes, some	31 (58,5)
None	1 (1,9)
Administrative Staff	**52 (100,0)**
Yes, all	40 (76,9)
Yes, some	12 (23,1)
None	0 (0,0)

*Multiple answers were possible. Only the results from the quoted items were displayed.

3.3.1.3 Shared decision making

Regarding shared-decision making 71,7% of all hospitals said that involving patients in decision-making and care is a priority. About three quarters also said that it is supported and documented by practice teams. Only 20% stated that shared decision making is supported by practice teams trained in decision-making techniques.

In most of the hospitals patients are provided with decision aids for at least some diseases (72,7%). About one quarter said that there are no decision aids in the hospital. Only one in five hospitals stated

that there are formal training programmes provided to hospital staff on partnering with patients in the care plan decision-making process. The training is mostly provided to nurses (100%), other health care professionals (100%), physicians (81,8%) or multidisciplinary groups (72,7%).

The majority of hospitals (67,3%) does not have a policy to encourage greater participation of patients at interdisciplinary meetings.

Table 6 Frequencies - Shared decision making

Question	Total n (%)
20. Please indicate which statements apply to your hospital.* Involving patients in decision-making and care…	
…is a priority. (n=53)	38 (71,7)
…is accomplished by provision of patient education materials or referrals to classes. (n=54)	28 (51,8)
…is supported and documented by practice teams. (n=53)	40 (75,5)
…is supported by practice teams trained in decision-making techniques. (n=50)	10 (20,0)
21. Are patients provided with decision aids for various health conditions?	**55 (100,0)**
Yes, for all diseases	1 (1,8)
Yes, for some diseases	40 (72,7)
No	14 (25,5)
22. Are there formal training programmes provided to hospital staff on partnering with patients in the care plan decision-making process?	**55 (100,0)**
Yes	11 (20,0)
No	44 (80,0)
23. If yes:* For which of the following groups does the hospital provide training on partnering with patients?	
Training for physicians (n=11)	9 (81,8)
Training for nurses (n=11)	11 (100,0)
Training for other health care professionals (n=10)	10 (100,0)
Training for administrators (m=10)	3 (30,0)
Training for multidisciplinary groups (n=11)	8 (72,7)
***24. If yes:* How many of the following groups have received training on partnering with patients in the care plan decision-making process?**	**11 (100,0)**
Physicians	
All	0 (0,0)
Almost all	1 (9,1)
Many	1 (9,1)
Some	7 (63,6)
Almost none	2 (18,2)
None	0 (0,0)
Nurses	
All	0 (0,0)
Almost all	1 (9,1)
Many	6 (54,5)

Some	4 (36,4)
Almost none	0 (0,0)
None	0 (0,0)
Other members of the healthcare team	
All	0 (0,0)
Almost all	1 (9,1)
Many	2 (18,2)
Some	5 (45,5)
Almost none	3 (27,3)
None	0 (0,0)
Administrative Staff	
All	0 (0,0)
Almost all	0 (0,0)
Many	0 (0,0)
Some	5 (45,5)
Almost none	4 (36,4)
None	2 (18,2)
25. Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?	**55 (100,0)**
Yes, for all diseases	2 (3,6)
Yes, for some diseases	13 (23,6)
No	37 (67,3)
The hospital does not have interdisciplinary meetings	3 (5,3)
26. If yes: **Are patients present at interdisciplinary meetings concerning their treatment plan?**	**15 (100,0)**
Always	4 (26,7)
Often	0 (0,0)
Sometimes	11 (73,3)
Never	0 (0,0)

*Multiple answers were possible. Only the results from the quoted items were displayed.

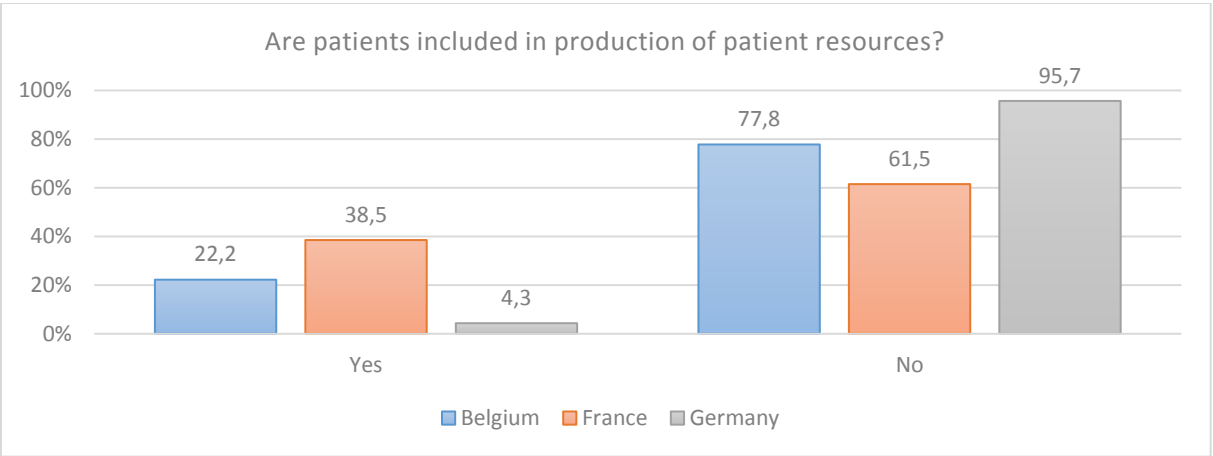
3.3.2 Comparison between regions

Regarding practices related to direct care in general no overall significant differences can be found between the regions, according to the score.

Figure 5 Apps score - Direct Care

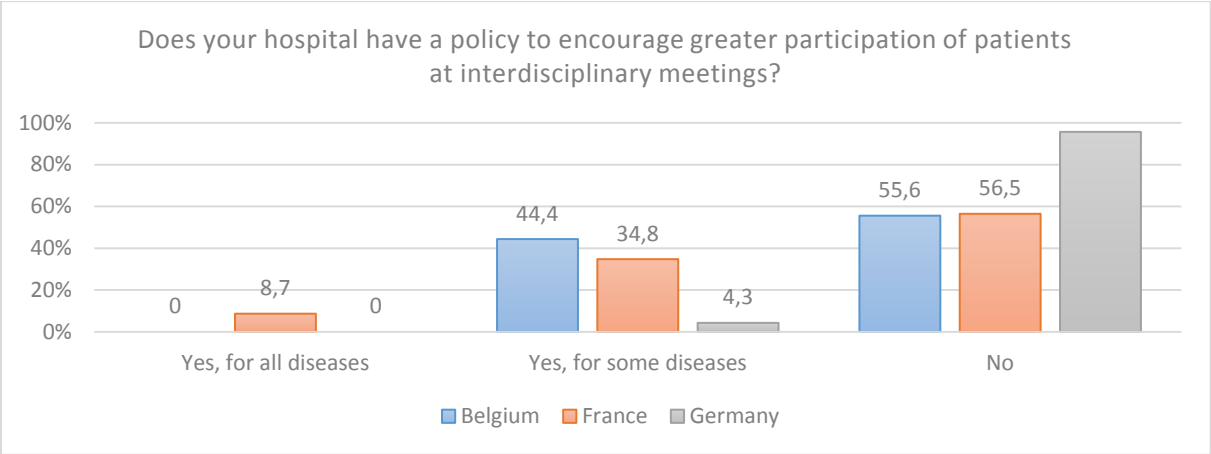
Looking into more detail, only one hospital in Germany (4.3%) stated that patients are included in the production of patient resources and that there is a policy to encourage greater participation of patients at interdisciplinary meetings, whereas in France 38,5% of the hospitals said to include patients in the production of patient resources and 43,5% that they encourage them to participate in interdisciplinary meetings.

Figure 6 Regional differences regarding the inclusion of patients in the production of patient resources



P value: 0.017, Fisher's Exact: 0.011

Figure 7 Regional differences regarding the existence of a policy to encourage greater participation of patients at interdisciplinary meetings



P value: 0.006, Fisher's Exact: 0.001

In 61.4% of the hospitals surveyed healthcare users are regularly asked to evaluate the quality of HCP/patient communication and 76.3% even provide training for hospital staff on how to communicate with patients. To help patients become involved in decision making regarding their treatment options and outcomes about three quarter of the hospitals in the sample provide patients with decision aids for various health conditions. There are no significant differences between the regions regarding all these practices related to direct care.

3.4 Organisational design

3.4.1 Frequencies

3.4.1.1 Patient committees

Patient committees seem not to be common among the hospitals of the Greater Region. Only 25,5% of the hospitals surveyed said they have a patient committee. All those patient committees exist for longer than 25 months and have bylaws or a written charter. On average the committees have met approximately 5 times in the last 12 months before the study. Only two of the hospitals with patient committees said that more than 75% of the members of the committee are patients or family members of patients.

Table 7 Frequencies - Patient committees

Question	Total n (%)
27. Does your hospital have a patient committee?	**55 (100,0)**
Yes	14 (25,5)
No	41 (74,5)
***28. If yes:* How long has the hospital had the patient committee?**	**12 (100,0)**
Less than 12 months	0 (0,0)
13 months to 24 months	0 (0,0)

More than 25 months	12 (100,0)
29. If yes: **Does the patient committee have bylaws or a written charter?**	**12 (100,0)**
Yes	12 (100,0)
No	0 (0,0)
30. How many times has the patient committee met in the last 12 months?	**12 (100,0)**
3 times	4 (33,3)
4 times	5 (41,7)
5 times	1 (8,3)
6 times	1 (8,3)
12 times	1 (8,3)
31. What percentage of the members of the patient committee are patients or family members of the patients?	**13 (100,0)**
Less than 25 %	8 (61,5)
25 to 50 %	3 (23,1)
51 to 75 %	0 (0,0)
More than 75%	2 (15,4)

At the end of this section about patient committees there was an open question (Nr. 32) asking whether patients participate in other hospital committees. The answers are the following:

- CDU = Commission of users (health sector): regulatory commission, 4 minimum meetings per year; CVS = conseil de la vie sociale (medico-social sector): regulatory commission, 3 minimum meetings per year; CLIN = committee for the fight against nosocomial infections, 1 session per year open to users; CS = Supervisory Board of the Hospital Center, representatives of users ex officio
- Certification of the establishment, development of the care project, as a patient journey project within the framework of the GHt
- Committee for the fight against pain; Committee of alimentation
- Health education committee, patient satisfaction working group, future hospital working group, quality committee,…
- User Commission decree of 1 June 2016.
- The participation of patients in hospital life, in decision-making is currently disappointing, because on one hand professionals have not been encouraged by the institution to facilitate or solicit it, on the other hand the fact insufficient understanding by patients of the complexity of the CHRU, given its size and the issues involved.
- The Conseil de la vie sociale gathers patients and families of the EHPAD and the USLD
- Patient representatives participate in certain internal bodies (Supervisory Board, Pain Control Committee (CLUD), Food Nutrition Liaison Committee (CLAN) and Health Democracy.
- Yes, via patient associations or 'self-help' and collaboration with the LUSS

- As denominational hospital, we have no patient committee but a patient advocate who is in regular, close contact with the pastoral team.

3.4.1.2 Involvement of Family and Friends

More than half of the hospitals (58,2%) said that there is a written policy enabling patients to identify their preferences with respect to which family members or other individuals they would like to have actively involved during their stay in the hospital. Of these hospitals 86,2% said the policy is implemented systematically and again 84,0% of those stated that the policy is in place in all hospital units.

About 52% of the hospitals in the sample said they have a policy or guidelines that facilitate unrestricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference. In 18,5% of the hospitals this policy exits across all hospital units.

Table 8 Frequencies - Involvement of Family and Friends

Question	Total n (%)
33. Is there a written policy enabling patients to identify their preferences with respect to which family members or other individuals they would like to have actively involved during their stay in the hospital?	**55 (100,0)**
Yes	32 (58,2)
No	23 (41,8)
34. If yes: **Is the policy implemented systematically?**	**29 (100,0)**
Yes	25 (86,2)
No	4 (13,8)
35. If yes: **How many units have the policy in place?**	**25 (100,0)**
Less than 25 %	0 (0,0)
25 to 50 %	2 (8,0)
51 to 75 %	0 (0,0)
More than 75%	2 (8,0)
The policy is in place in all units	21 (84,0)
36. Does the hospital have a policy or guidelines that facilitate unrestricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference?	**54 (100,0)**
Exist across all units	10 (18,5)
Exists across some units	18 (33,3)
Does not exist in any hospital unit	26 (48,1)

3.4.1.3 Access to medical records

The majority of hospitals provided unrestricted access for patients to their medical records. Only 18% stated that patients do not have access to their medical records. Access through an online portal is only available in two hospitals. One third of the hospitals surveyed said that patients are informed systematically on how to access their medical record. 35,7% do not give that information to patients.

In none of the hospitals do patients have the right to edit their medical record. Due to that, the following question (Nr. 40) about which part of the medical record the patients are able to edit is not listed.

Table 9 Frequencies - Access to medical records

Question	Total n (%)
37. Do patients have access to their medical records?*	**61 (100,0)**
Yes, any time while in the hospital	12 (19,7)
Yes, in the hospital but only with the authorisation of their physician	8 (13,1)
Yes, anytime through an online portal	2 (3,3)
Yes, anytime at patient's request (i.e., offline)	33 (54,1)
No, patients do not have access to their medical records	11 (18,0)
38. Is information given routinely to patients on how to access their medical records?	**42 (100,0)**
Yes, patients are informed systematically	14 (33,3)
Yes, but not systematically	13 (31,0)
No	15 (35,7)
39. Do patients have the right to edit their medical record?	**42 (100,0)**
Yes	0 (0,0)
No	42 (100,0)

*Multiple answers were possible. Only the results from the quoted items were displayed.

Again an open question (Nr. 41) was posed at the end of this section whether there was anything else the hospitals wanted to let us know about the handling of health records. The answers are the following:

- All medical patient documentation is settled by a written policy for all people involved in the documentation and is regularly audited and evaluated. The structure of the medical record as well as the filing system are set by the written policy.
- Patients can request a copy of their medical record, but they have to pay for it.
- The patient can access documents via his shared medical record (DMP).
- Our answers are based on a computerized file to which the patient does not have direct access for reasons of computer security. But if he makes the request, he is allowed access to it under the supervision of a doctor. The sending and the photocopies are invoiced to the patient, on the contrary on-site consultation is free.
- We set up a feedback programme for discharged patients to reflect on their entire patient journey. Invitation to former patients (patient temoin), presence of the health executive (nurse) of the different sectors where the patient has passed through and presence of at least a practitioner. Exploration of positive points for the patient and unmet needs ... reflection on

unidentified expectations. These points are passed on to CDU actors as part of the formalization of the CDU project.

- compliance with regulatory texts
- Special emphasis is placed on RSW membership

3.4.1.4 Quality improvement

All hospitals have a mechanism in place to allow patients to give feedback. Among various options to give feedback the most prominent ones are patient surveys. All hospitals use patient surveys as a method for patients to give feedback. Besides that, 66,7% of all hospitals have an official complaint office, 59,6% have a written complaint form and 50,9% use a suggestion box. Online complaint forms are not that common among the hospitals of the Greater Region, only 24,6% use this method. The vast majority of hospitals (88,9%) actively inform patients on their right to complain and all hospitals routinely analyse patient complaints.

In most of the hospitals (64,3%) patients are normally involved in forms of quality improvement. Patients mostly participate in quality improvement projects (78,8%), discussions of results of quality improvement projects (60,5%) or quality committees (54,6%). 40,6% said that patients also participate in the development of quality criteria, standards and/or protocols.

We also wanted to know whether the hospitals participated in one or more external audits in the few years preceding the study. International audits, voluntary and obligatory, were not that common among the hospitals in the sample. 69,7% said they have not participated in an voluntary international audit that they have not participated in an obligatory international audit. On the other hand, 72,5% of the hospitals surveyed have participated or are still participating in an obligatory national audit and 51,3% in an voluntary national audit.

48,0% of the hospitals stated that patients are routinely interviewed when a root cause analysis investigation is conducted. In three hospitals (6%) root cause analyses were not used.

Table 10 Frequencies - Quality improvement

Question	Total n (%)
42. Does the hospital have a mechanism in place to allow patients to give feedback?	**57 (100,0)**
Yes	57 (100,0)
No	0 (0,0)
43. What options are there for patients to give feedback?*	**57 (100,0)**
Patient surveys	57 (100,0)
Suggestion box	29 (50,9)
Official complaint office	38 (66,7)
Written complaint form	34 (59,6)
Online complaint form	16 (28,1)

Other	14 (24,6)
44. Does the hospital actively inform patients on their right to complain?	**54 (100,0)**
Yes	48 (88,9)
No	6 (11,1)
45. Are patient complaints routinely analysed?	**57 (100,0)**
Yes	57 (100,0)
No	0 (0,0)
46. Overall: Are patients normally involved in forms of quality improvement in your hospital?	**56 (100,0)**
Yes	36 (64,3)
No	20 (35,7)
47. If yes: **To what extent are patients involved in the following activities?**	
The development of quality criteria/ standards/protocols	**32 (100,0)**
Always	0 (0,0)
Usually	5 (15,6)
Sometimes	8 (25,0)
Never	19 (59,4)
Quality commitees	**33 (100,0)**
Always	5 (15,2)
Usually	3 (9,1)
Sometimes	10 (30,3)
Never	15 (45,5)
Quality improvement projects	**33 (100,0)**
Always	3 (9,1)
Usually	5 (15,2)
Sometimes	18 (54,5)
Never	7 (21,2)
Discussion of results of quality improvement projects	**33 (100,0)**
Always	4 (12,1)
Usually	8 (24,2)
Sometimes	8 (24,2
Never	13 (39,4)
48. Has your hospital participated in the last few years in one or more external audits?	
Voluntary national audit	**39 (100,0)**
Yes, it's ongoing	6 (15,4)
Yes, less than 2 years ago	10 (25,6)
Yes, between 2 and 4 years ago	3 (7,7)
Yes, more than 4 years ago	1 (2,6)
No	19 (48,7)
Voluntary international audit	**33 (100,0)**
Yes, it's ongoing	6 (18,2)
Yes, less than 2 years ago	4 (12,1)

Yes, between 2 and 4 years ago	0 (0,0)
Yes, more than 4 years ago	0 (0,0)
No	23 (69,7)
Obligatory national audit	**40 (100,0)**
Yes, it's ongoing	6 (15,0)
Yes, less than 2 years ago	14 (35,0)
Yes, between 2 and 4 years ago	8 (20,0)
Yes, more than 4 years ago	1 (2,5)
No	11 (27,5)
Obligatory international audit	**28 (100,0)**
Yes, it's ongoing	2 (7,1)
Yes, less than 2 years ago	2 (7,1)
Yes, between 2 and 4 years ago	0 (0,0)
Yes, more than 4 years ago	0 (0,0)
No	24 (85,7)
49. When a root cause analysis (RCA) investigation is conducted, are patients routinely interviewed?	**50 (100,0)**
Yes, always	3 (6,0)
Yes, sometimes	21 (42,0)
No, never	23 (46,0)
We don't use root cause analysis in our hospital	3 (6,0)

*Multiple answers were possible. Only the results from the quoted items were displayed.

3.4.1.5 Advanced technologies

The use of advanced information technology/telehealth/mhealth to support or promote patient partnership is not common among the hospitals of the Greater Region. Only 21,4% of all hospitals said that they use this technology for some diseases, mainly in the areas of planning for consultation and care sessions (41,7%), medical tele monitoring (41,7%) or patient-centred communication (33,3%).

Table 11 Frequencies - Advances technologies

Question	Total n (%)
50. Does your hospital use information technology/telehealth/mhealth (e.g. smart phone applications or patient physician portals) to support or promote patient partnership?	**56 (100,0)**
Yes, for all diseases	0 (0,0)
Yes, for some diseases	12 (21,4)
No	44 (78,6)
51. If yes: **In what areas of care are these tools used?***	**12 (100,0)**
Patient-centred communication	4 (33,3)
Shared-decision making	2 (16,7)
Self-management/patient education	2 (16,7)
Access to medical records	3 (25,0)
Planning for consultation and care sessions	5 (41,7)

Medical tele monitoring	5 (41,7)
Other	3 (25,0)

*Multiple answers were possible. Only the results from the quoted items were displayed.

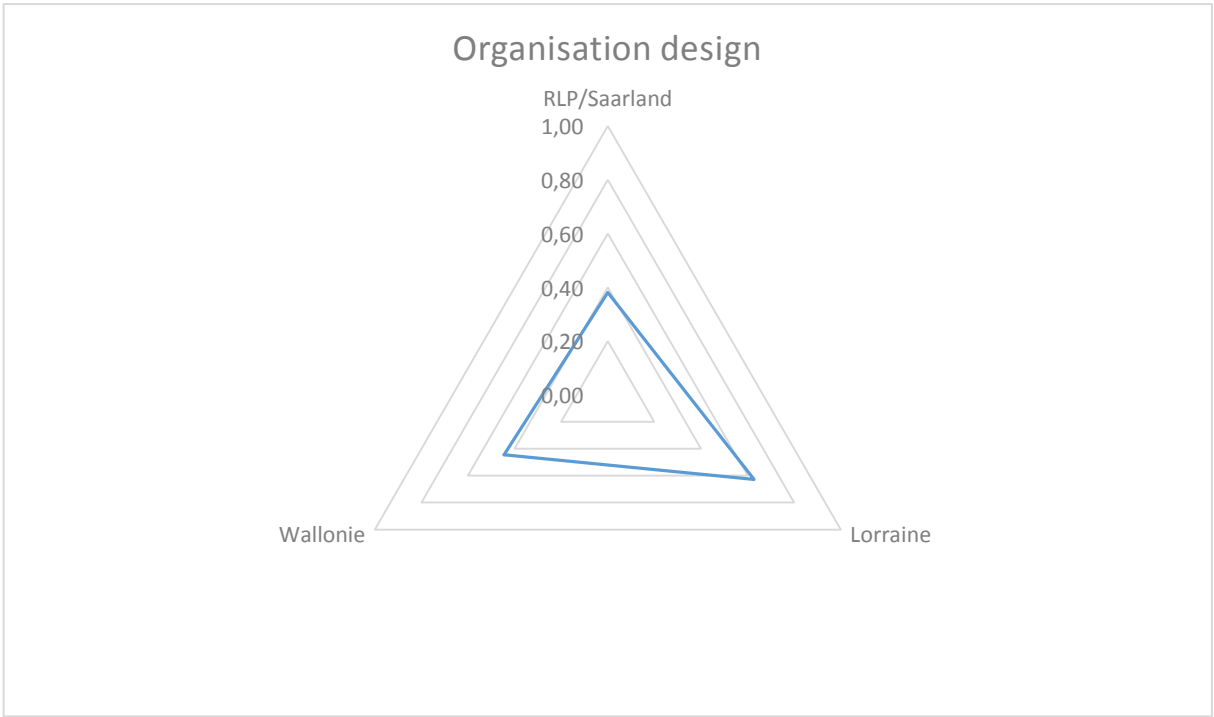
We also asked hospitals which use information technology to provide the names of the tools in an open question (nr. 52):

- 3CA4 website www.3ca4.fr
- Web application created by the hospital in form of a wiki (electronic pocketbook). Imaging via tablet via popular imaging software applications.
- site internet du CH
- T-Lor (a tool developed by the Health Cooperation Group (GCS) Télésanté Lorraine)3.4.2 Comparison between regions

3.4.2 Comparison between regions

Significant differences between the three regions can be identified regarding practices related to organizational design, as shown in Figure 8, especially between France and Germany. Whereas France has a mean score of 0,63, Germany only scores 0,38 in the section of organisational design.

Figure 8 Apps score - Organisation design

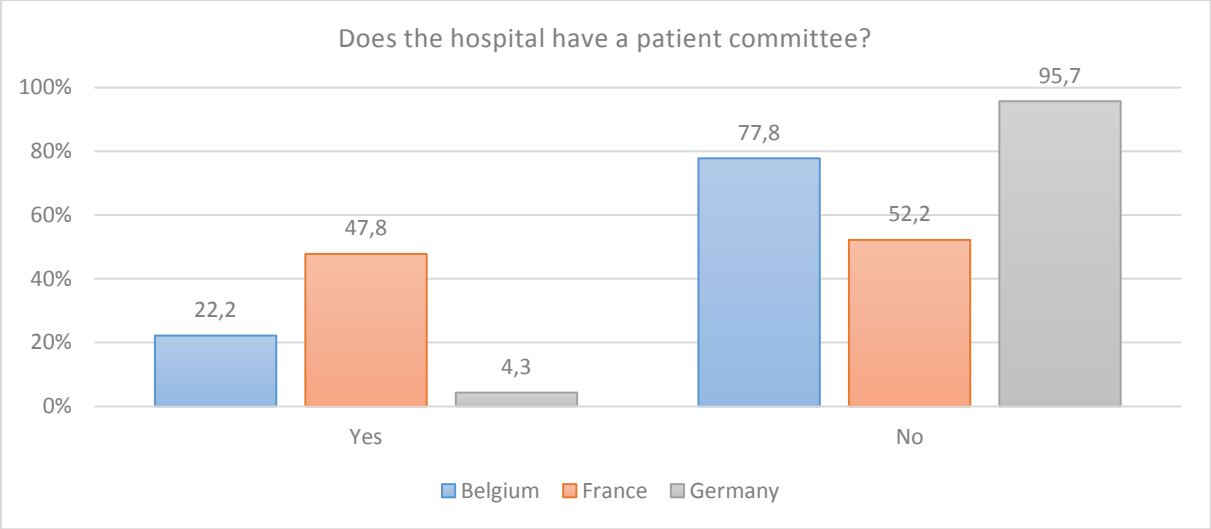


Looking at the individual items the most prominent and significant differences between Germany and the other two regions seem to be the non-existence of patient committees, the lack of information

given to patients on how to access their medical record and the non-involvement of patients in forms of quality improvement.

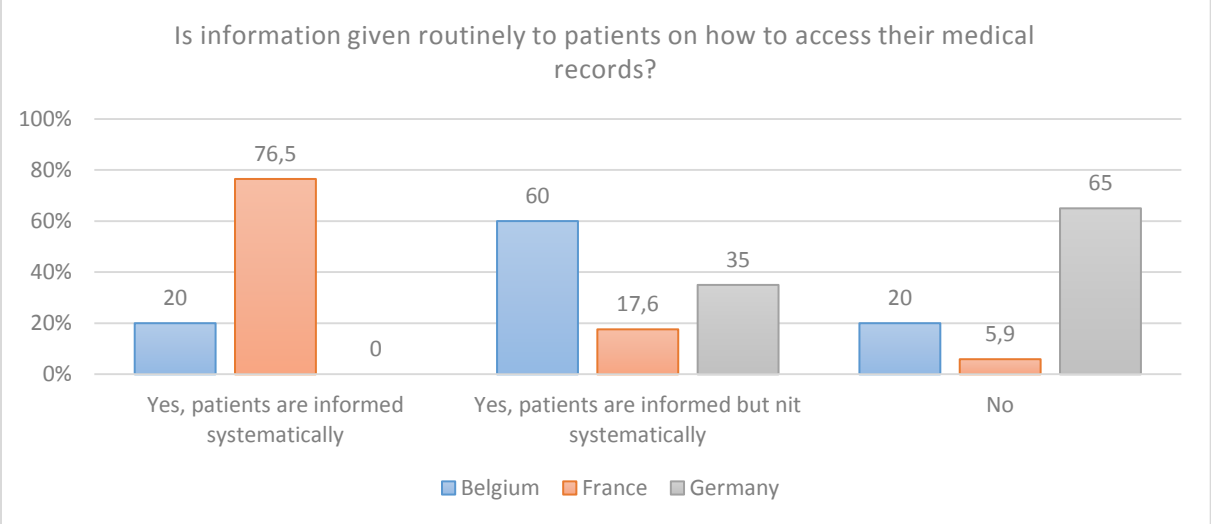
Whereas in France almost half of the hospitals have patient committees, only one hospital in Germany said so (see Figure 9). Patients also got mostly systematically informed about how to access their medical record in France, in Germany, on the other hand, 65% of the hospitals stated they do not inform the patients about that at all (see Figure 10)

Figure 9 Regional differences regarding the existence of a patient committee



P value: 0.003, Fisher's Exact: 0.002

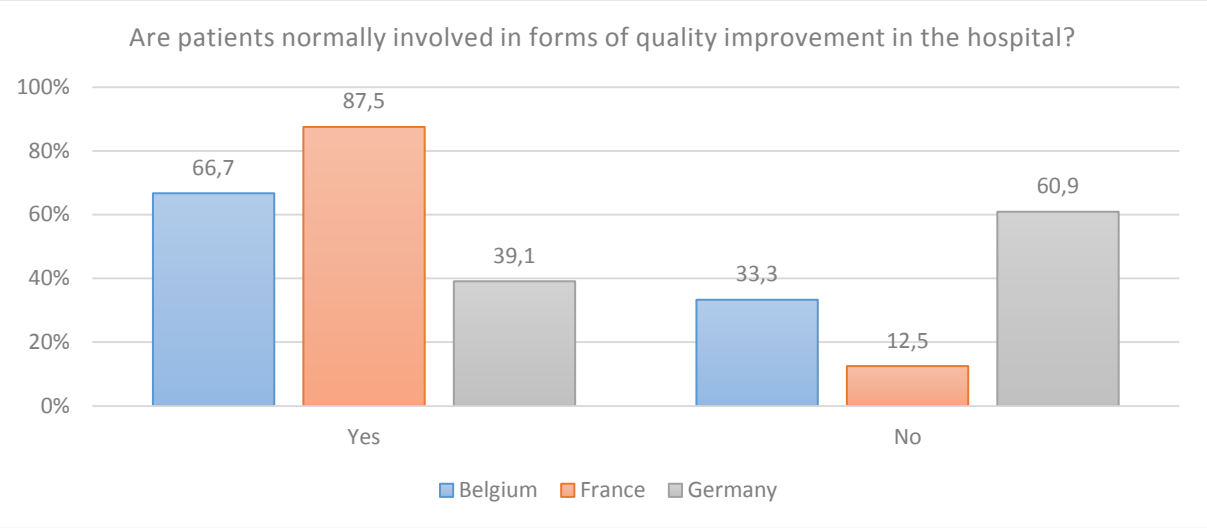
Figure 10 Regional differences regarding whether information is given routinely to patients on how to access their medical records



P value: 0.000, Fisher's Exact: 0.000

The same pattern is true for the involvement of patients in forms of quality improvement. In France and Belgium this seems to be the case in most of the hospitals, whereas in Germany only about 39% of the hospitals surveyed said so (see Figure 11).

Figure 11 Regional differences regarding the involvement of patients in forms of quality improvements



P value: 0.002, Fisher's Exact: 0.002

3.5 Education

3.5.1 Frequencies

3.5.1.1 Patient experts

Only 26,3% of the hospitals surveyed have patient experts, trained to work with other patients as part of patient education for some chronic diseases, such as diabetes (46,7%) or cancer (26,7%). Among the other diseases are: obesity (3), dialysis (1), lymphedema (1), transplants (1) and cross section paralysis (1).

Table 12 Frequencies - Patient experts

Question	Total n (%)
53. Does the hospital have patient experts, trained to work with other patients as part of patient education?	**57 (100,0)**
Yes, for all chronic diseases	0 (0,0)
Yes, for some chronic diseases	15 (26,3)
No	42 (73,7)
54. If yes:* For which diseases does your hospital have patient experts?	**15 (100,0)**
Cardiovascular diseases	2 (13,3)
Respiratory diseases	2 (13,3)
Diabetes	7 (46,7)
Cancer	4 (26,7)
Other	8 (53,3)

*Multiple answers were possible. Only the results from the quoted items were displayed.

3.5.1.2 Patient participation in HCP training

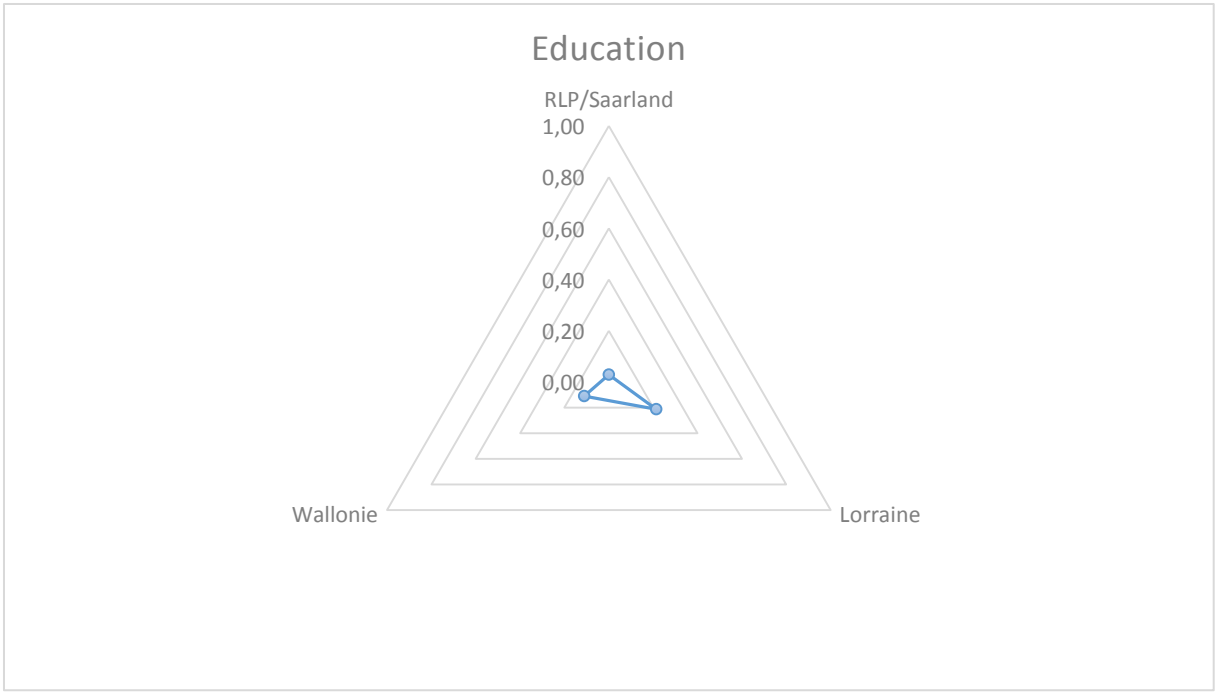
Patients do not normally participate in the training of health care professionals in the hospitals of the Greater Region. Only three of the hospitals surveyed (5,4%) said that patients participate the HCP

training in their hospital as educators and content developers. One hospital said that patients are participating as educator and content developers in the training of physicians and nurses in the area of new employee orientation and partnering with patients and families in the care plan decision-making process. In one hospital patients also participate in the training of other HCP in the area of partnering with patients and families in the care plan decision-making process. Two of the hospitals surveyed said that patients are participating as educator and content developers in the training of physicians and nurses in the area of continuing medical and paramedical education. Only one of the hospitals where patients are participating in HCP training said they provide formal training to those patients.

3.5.2 Comparison between regions

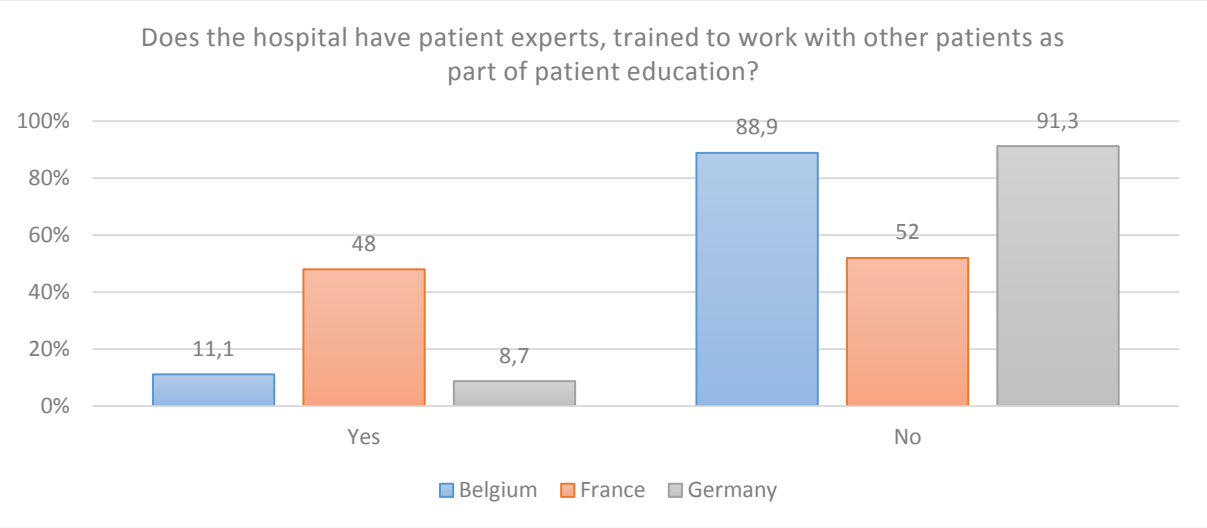
Patient's involvement in education and training of healthcare professionals seems not to be very common in the hospitals of the Greater Region at all. The overall mean score is relatively low with 0,12. But again the differences are most prominent between France (0,21) and Germany (0,03). The score of Belgium is somewhere between (0,11).

Figure 12 Apps Score – education



In both Belgium and Germany there are almost no patients as experts, trained to work with other patients as part of patient education. In France 48% of the hospitals surveyed said they are using patient experts in the training (see Figure 13).

Figure 13 Regional differences regarding the existence of patient experts



P value: 0.004, Fisher's Exact: 0.005

3.6 Research

3.6.1 Frequencies

Only about one quarter (14) of the hospitals in the sample participate in research. Of these hospitals, 57,1% said they have a policy to include patients in parts of the research cycle which is mostly implemented systematically (62,5%). 35,7% of the hospitals participating in research stated to have a policy in place to keep patients informed about opportunities to participate in research. This policy is also mostly implemented systematically (80,0%).

Table 13 Frequencies - Research

Question	Total n (%)
59. Does the hospital participate in research?	**54 (100,0)**
Yes	14 (25,9)
No	40 (74,1)
60. If yes: **Does the hospital have a policy to including patients in the full re-search cycle from discussion of grant proposal until dissemination of results?**	**14 (100,0)**
Yes, in the whole research cycle	0 (0,0)
Yes, in parts of the research cycle	8 (57,1)
No	6 (42,9)
61. If yes: **Is the policy implemented systematically?**	**8 (100,0)**
Yes	5 (62,5)
No	3 (37,5)
62. If yes: **How many units have the policy in place?**	**5 (100,0)**
Less than 25 %	1 (20,0)
25 to 50 %	1 (20,0)
51 to 75 %	1 (20,0)
More than 75%	1 (20,0)

The policy is in place in all units	1 (20,0)
63. Does your hospital have a policy in place to keep patients informed about opportunities to participate in research?	**14 (100,0)**
Yes	5 (35,7)
No	9 (64,3)
***64. If yes:* Is the policy implemented systematically?**	**5 (100,0)**
Yes	4 (80,0)
No	1 (20,0)
***65. If yes:* How many units have the policy in place?**	**4 (100,0)**
Less than 25 %	2 (50,0)
25 to 50 %	1 (25,0)
51 to 75 %	0 (0,0)
More than 75%	0 (0,0)
The policy is in place in all units	1 (25,0)

At the end was a last open question (nr. 66) asking whether there are further remarks about patient participation in research. The answers are the following:

- The hospital participated in a research program (Alzheimer's disease) in 2007. No other participation since.
- The number of research projects is limited. Every patient is informed and an informed consent is required in all cases.

3.6.2 Comparison between regions

Only 14 hospitals surveyed participate in research at all and even less (8 hospitals) include patients in parts of the research cycle. Due to the small number, no APPS score was constructed for the section research. Regarding the comparison between the three regions no significant differences can be made out.

3.7 Further analysis and comparisons[7]

3.7.1 Differences dependent upon hospital governance

One hypothesis was that hospitals that promote partnerships with patients in the philosophy of care and/or strategic plan of the hospital have a greater 'uptake' of other interventions regarding APPS practices. The results are displayed in Table 15.

To assess the degree of patient participation in the hospital vision the questions 'Does the organisation's philosophy of care statement promote partnerships with the patients it serves?' and 'Is patient partnership integrated into the strategic plan of the hospital?' were combined as displayed in Table 14.

[7] Only significant results are displayed in the tables. Detailed results can be found in the appendix.

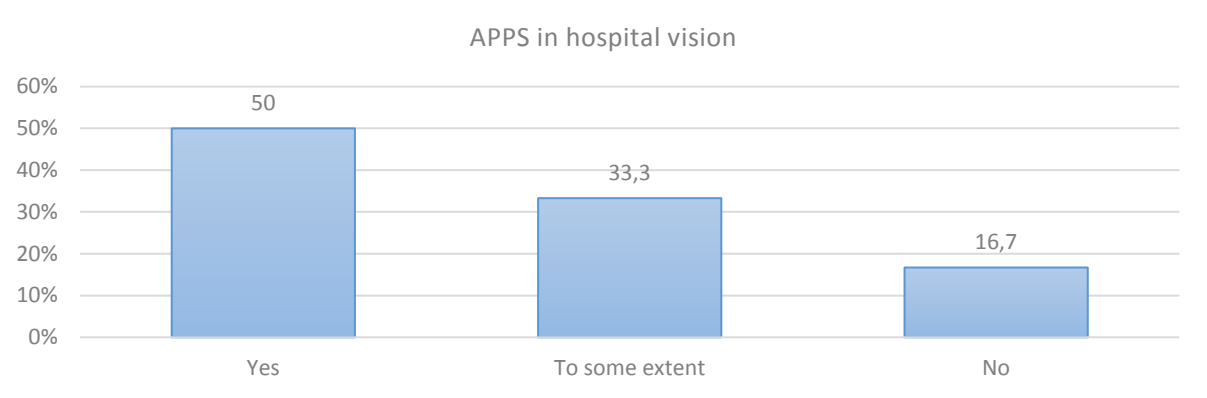
Table 14 APPS in hospital vision

		Does the organisation's philosophy of care statement promote partnerships with the patients it serves?		
		Yes	No	Total
Is patient partnership integrated into the strategic plan of the hospital?	Yes	30 (61,2)	1 (9,1)	31 (51,7)
	No	19 (38,8)	10 (90,9)	29 (48,3)
	Total	49 (100,0)	11 (100,0)	60 (100,0)

If both questions were affirmed (highlighted in green) APPS in hospital vision can be fully found. If one of the questions was negated (highlighted in yellow), APPS in hospital vision can be found to some extent. If both questions were negated (highlighted in red), no APPS in hospital vision can be found.

The distribution of the new variable is shown in Figure 14. Overall, half of the hospitals surveyed promote patient partnership in their philosophy of care statement and have the concept integrated into their strategic plan.

Figure 14 APPS in hospital vision



Hospitals that promote partnerships with patients in the philosophy of care and/or strategic plan of the hospital have only a greater 'uptake' of a few interventions regarding APPS practices. They are for example more likely to evaluate the quality of HCP/patient communication, they include patients in the production of patient resources and provide training for staff on how to communicate with patients more often and are more likely to have a policy to encourage greater participation of patients at interdisciplinary meetings.

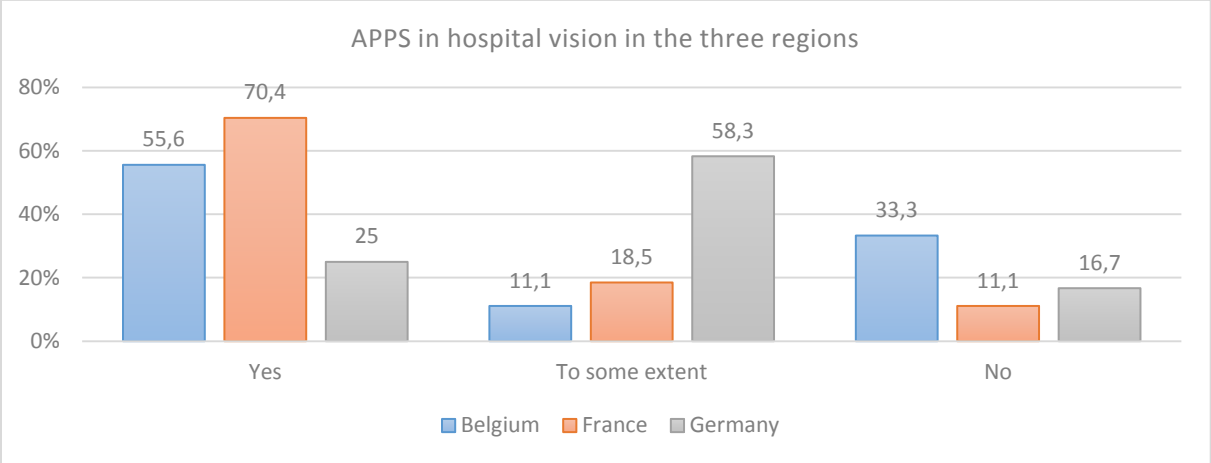
Table 15 Differences dependent upon hospital governance

	APPS in hospital vision or mission n (%)			
Question	**No**	**To some extent**	**Yes**	**Fisher's Exact**
11. Are healthcare users regularly asked to evaluate the quality of HCP/professional communication?				**0.027**
no	**5 (50,0)**	**2 (10,5)**	**3 (10,7)**	
yes	**5 (50,0)**	**17 (89,5)**	**25 (89,3)**	

12. Are patients included in production of patient resources?				**0.042**
no	**10 (100,0)**	**17 (85,0)**	**18 (64,3)**	
yes	**0 (0,0)**	**3 (15,0)**	**10 (35,7)**	
16. Does hospital provide training for staff on how to communicate with patients?				**0.024**
no	**5 (50,0)**	**6 (30,0)**	**3 (10,3)**	
yes	**5 (50,0)**	**14 (70,0)**	**26 (89,7)**	
25. Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?				**0.019**
no	**9 (100,0)**	**15 (83,3)**	**16 (57,1)**	
yes	**0 (0,0)**	**3 (16,7)**	**12 (42,9)**	

Significant regional differences are also present here (see Figure 15). Whereas in France 70.4% of the hospitals have patient partnership implemented in their hospital vision and mission, in Germany it is only one quarter.

Figure 15 APPS in hospital vision compared per region



Sig.: .005, Cramer's V: .352

For better interpretation of the cross tabulations most variables were dichotomized due to the small sample size. As expected, there were indeed some significant differences dependent upon hospital governance.

Hospitals with patient partnership integrated into their vision and mission are more likely to let patients or healthcare users evaluate the quality of HCP/patient communication and also provide trainings for staff on how to communicate with patients.

3.7.2 Differences dependent upon hospital size

Another hypothesis was that bigger hospitals with a larger number of beds are more advanced regarding practices related to APPS then smaller hospitals. As displayed in Table 16 this is true for only a few aspects of patient participation. In larger hospitals patients are more often included in the production of patient resources, there are more often formal training programs for hospital staff on partnering with patients in care plan decision making and hospitals with more beds also use

information technology/telehealth/mhealth (e.g. smart phone applications or patient physician portals) to support or promote patient partnership more than hospitals with fewer beds.

Table 16 Differences dependent upon hospital size

	Number of beds n (%)			
Question	**< 300**	**300-599**	**600 +**	**Fisher's Exact**
12. Are patients included in production of patient resources?				**0.015**
no	**21 (87,5)**	**15 (88,2)**	**6 (46,2)**	
yes	**3 (12,5)**	**2 (11,8)**	**7 (53,8)**	
22. Are there formal training programmes to hospital staff on partnering with patients in care plan decision making?				**0.001**
no	**23 (100,0)**	**11 (73,3)**	**7 (53,8)**	
yes	**0 (0,0)**	**4 (26,7)**	**6 (46,2)**	
50. Does your hospital use information technology/telehealth/mhealth (e,g, smart phone applications or patient physician portals) to support or promote patient partnership?				**0.034**
no	**22 (91,7)**	**12 (80,0)**	**7 (53,8)**	
yes	**2 (8,3)**	**3 (20,0)**	**6 (46,2)**	

3.7.3 Differences dependent upon the presence of a patient committee

We also wanted to know whether there is an association between the presence of a patient committee and implementation of a higher number of other interventions related to APPS. As shown in Table 17 there are indeed some significant differences. In hospitals with a patient committee patients are more frequently included in the production of patient resources as well as involved in forms of quality improvement in the hospital. Those hospitals also more often have policies to encourage greater participation of patients at interdisciplinary meetings than hospitals without a patient committee.

Table 17 Differences dependent upon the presence of a patient committee

	Patient committee n (%)		
Question	**No**	**Yes**	**Fisher's Exact**
12. Are patients included in production of patient resources?			**0.007**
no	**35 (87,5)**	**7 (50,0)**	
yes	**5 (12,5)**	**7 (50,0)**	
25. Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?			**0.012**
no	**34 (82,9)**	**6 (42,9)**	
yes	**7 (17,1)**	**8 (57,1)**	
46. Are patients normally involved in forms of quality improvement in the hospital?			**0.019**
no	**19 (46,3)**	**1 (7,7)**	
yes	**22 (53,7)**	**12 (92,3)**	

3.8 Summary

Overall, there is a clear difference in the implementation of more patient and family friendly policies and real patient participation and involvement in hospital practices (see Table 18).

Table 18 APPS practices, strategies and policies in the Greater Region

APPS practices, strategies and policies (n=61)	Count	%
Hospital vision or mission		
Patient partnership is integrated into the strategic plan of the hospital	31	51,7
Direct care		
Health care users routinely asked to evaluate the quality of HCP/patient communication	47	82,5
Training for hospital staff in how to communicate with patients	45	76,3
Patients are provided with decision aids	41	74,5
Policy to encourage greater participation of patients at interdisciplinary meetings	15	27,2
Patients are included in production of patient resources	13	22,4
Hospital provides training to hospital staff on partnering with patients	11	20,0
Organisational design		
Patients complaints are routinely analysed	57	100,0
Hospital actively inform patients on their rights to complain	48	88,9
Patients are given information on accessing medical records	27	64,3
Patients are involved in forms of quality improvement	36	64,3
Unrestricted access to medical record	34	64,2
Written policy enabling patients to specify which family members or other individuals they would like to have actively involved during their stay in the hospital	32	58,2
Policy facilitating unrestricted 24/7 access to hospitalized patients	28	51,8
Patient committee	14	25,5
Advanced information technologies to promote patient partnership	12	21,4
Education		
Patient experts	15	26,3
Patient participation in HCP training	3	5,4

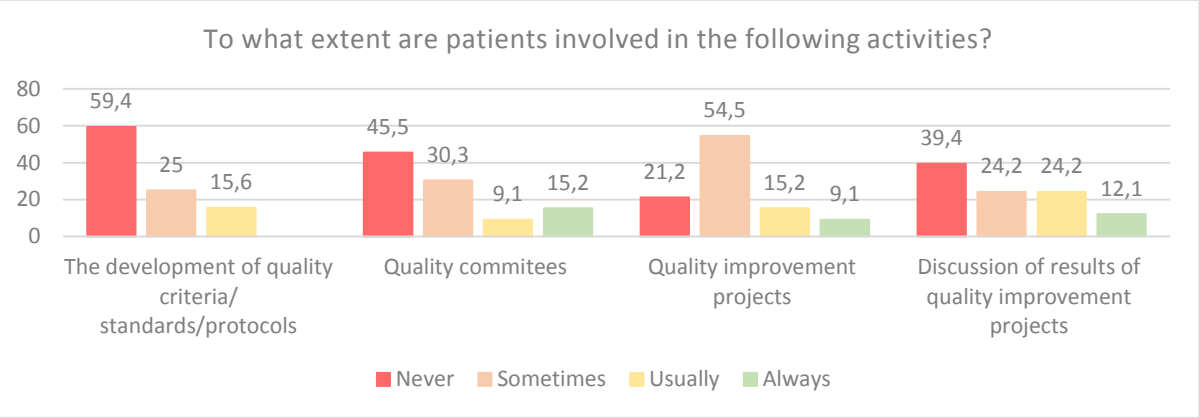
A little more than half of the hospitals have patient partnership integrated into their strategic plan. Among practices related to direct care, the most widely adopted was routinely asking health care users to evaluate the quality of HCP/patient communication (82.5%) and providing trainings for hospital staff on how to communicate with patients (76.3%). About three quarters of the hospitals in the sample provide decision aids for patients to help them become involved in forms of decision making regarding their treatment and care options.

Regarding organizational practices all hospitals have mechanisms in place to analyse patients' complaints routinely and 88.8% had a policy to actively inform patients on their right to complain. 64.2% of the hospitals allow patients to access their medical records without restriction and routinely give them information on how to access it.

On the other hand only a minority of hospitals have a patient committee (25,5%), patient experts trained to work with other patients as part of patient education (26,3), patients included in the production of patient resources (22,4%) or patients participating the training of physicians and other health care professionals (5,4%).

Even though 64,3% of the hospitals in the Greater Region say that patients are involved in forms of quality improvement, the picture becomes more differentiated when looking at the concrete forms of patient involvement (see Figure 16).

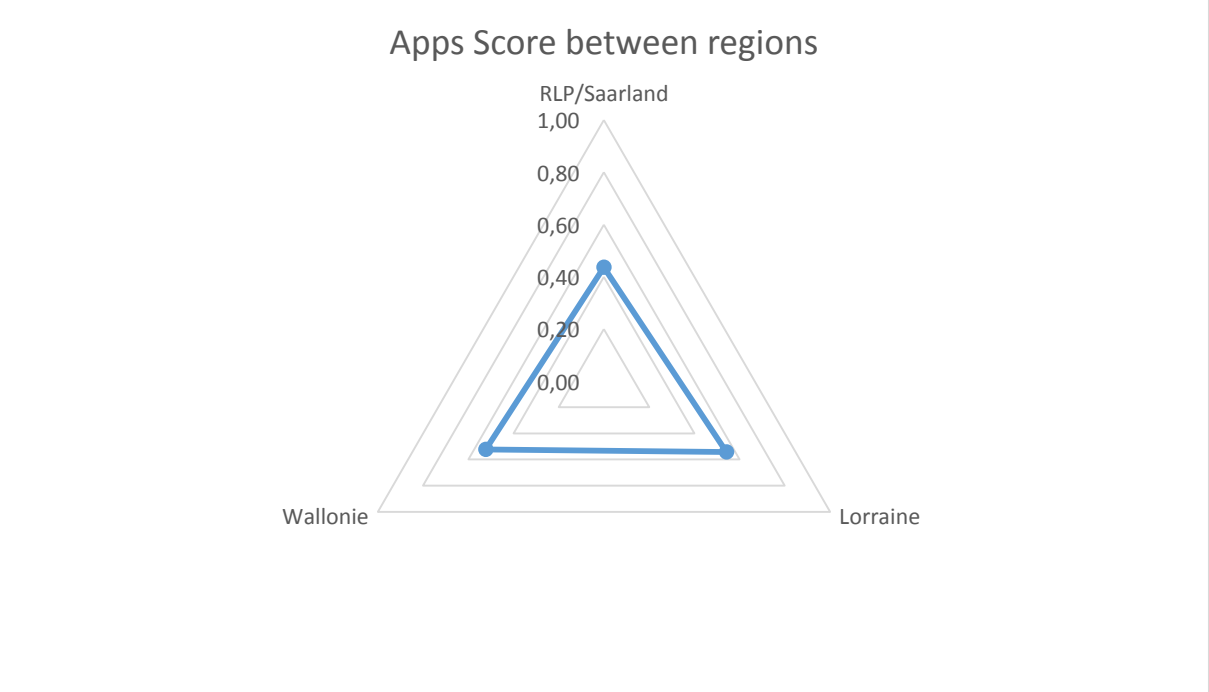
Figure 16 Patient involvement in forms of quality improvement



It is still possible though that the hospitals engage patients in other forms of quality improvement not captured in the questions we asked.

Regarding the comparison of APPS practices in the hospitals between the three regions, the overall APPS score shows that Germany has the lowest overall APPS score. Although the differences are not significant, tendencies point to similar results (see Figure 17). Hospitals in Germany only scored 0.44 points on average with a maximum score of 0.67. In comparison, hospitals in France scored 0.54 points on average with a maximum score of 1. The results for Belgium are very similar to France (0.52 on average and a maximum of 0.9).

Figure 17 APPS score between regions



4 Discussion

This study explored the presence of institutional practices for APPS in hospitals in the Greater Region. A wide range of practices were found in the three countries and the degree of implementation was mixed.

APPS was said to be present in the hospital's philosophy of care in 82% of the hospitals sampled. Indicating that hospitals seems to have, at least a degree of motivation, towards a partnership with patients. Furthermore, more than half had patient partnership in the strategic plan of the hospital, indicating a movement towards more concrete action. This is an interesting finding given the importance of organisational leadership and a facilitating setting as a basis for effective implementation of complex interventions such as APPS (25,26).

In the direct care setting patients seem to be regularly invited to evaluate professional-patient communication. Additionally, training programmes for communication with patients were offered to healthcare professionals in 76% of hospitals. This is a positive finding since the value of high quality patient-HCP communication in the direct care setting can scarcely be under-emphasised in terms of its impact on patient adherence, patient education and self-management (9,27,28). However, patients in the region are infrequently involved in the production of patient resources (22%). Recognising the value of the patient's lived experience with the disease and capturing this vital resource for other patients is central to the APPS concept (24). Thus, the limited participation of patients in the elaboration of patient resources in the Greater Region could be a sign of the immaturity of the implementation of the concept, or, a restricted vision of what patient partnership actually entails, or both.

Shared-decision making was declared to be a priority for the majority of hospitals in the region (71%), which, in many cases, is complemented by the provision of decision aids for some diseases. However, the opportunities for training for hospital staff in partnering with patients during the decision making process was somewhat lower. Training courses for practitioners is an important facilitator of shared-decision making (29,30), moreover, training courses offered by institutions has been shown to be a determinant of a facilitating organisational context (29). Thus, while motivation towards shared-decision making appears to exist in the region its application is incomplete (31,32).

Patient committees are not common in the region, in place in only 25 % of the hospitals surveyed. A much larger proportion of French hospitals declared that they had a patient committee than German or Belgian hospitals, all the patient committees have been in place for more than 12 months. The utility and power of a patient committee is dependent upon the way it functions and, more importantly, the way it is designed to function. The inherent imbalance of power between patients and hospitals means

that hospitals are in a position to distribute power to help patients influence the hospital, but, in a way the hospital 'wants' to be influenced (26). Thus, the simple fact of a hospital having a patient committee does not necessarily ensure that the hospital is listening to the views of the patients in a serious and careful manner. Furthermore, many other determinants influence the degree to which patients are ready to participate in hospital governance such as the perceived risk to their health of highlighting safety issues or criticising healthcare professionals they depend upon (33–35). Finally, there is a risk that, over time, patients become 'institutionalised' themselves and lose sight of the needs of the 'average' patient they intend to represent (36). It is difficult to draw firm conclusions therefore, on the significance of the presence of absence of patient committees for APPS. However, it could be said that a hospital that invests in a patient committee does possess a degree of interest in the views of patients.

Hospitals in the region seemed to be relatively flexible concerning the involvement of family and friends during hospitalisation, more than half the hospitals said they have written policies in place to allow patients to identify which family member be involved in their stay. However, the extent to which this policy takes a partnership approach to communication with family and friends or simply provides information is not clear. More than half of the hospitals in the sample had a policy that allowed family and friends to visit hospitalised patients 24 hours a day. Though only 18% of these had the policy in place across all units. There is a possibility, therefore, that the hospitals are reporting on a policy that has been in place in some units, for example paediatrics, for some time, rather than a policy intended to maximise the participation of patient's families and friends across all units. Interestingly the Herrin study found that 57.7% of their sample (841 hospitals) had this type of policy in place in all units (14).

Patient participation in quality improvement seemed to be relatively common in the region. 64% of hospitals said that patients were normally involved in quality improvement in the hospital. However, patients were rarely 'always' included in the development of quality criteria/standards/ protocols; quality committees; quality improvement projects or discussion of results of quality improvement projects. Statistically significant associations were found between the presence of patient committees and patient participation in quality improvement (Table 17), indicating a possible influence of a patient committee on patient participation in quality improvement.

The differences between the countries was also found to be significant. France appears to be more likely to include patients in quality improvement initiatives. It would be interesting to explore the extent to which patients are included in quality improvement based on the advancement of quality improvement in the different countries since this has been shown to vary considerably between countries (37).

Patient participation in the education of health care professionals within the hospital was very rare among our sample. Only three hospitals said that this was the case and that it was limited to physician training. However, since our sample was limited to hospitals, which is not the only location for HCP training patients may be participating in the education of HCP in other environments such as in nurse training colleges or universities.

The participation of patients in patient education was more common, 26 % of the sample said that it exists for some chronic diseases, however these were predominantly limited to France where 12 hospitals said that the hospital had expert patients. The concept of patient expert is a pillar of APPS (18) and its limited application in the region indicates, again, the partial implementation of the concept. However the relatively high uptake in France suggests that there is scope for cross-border learning from the French experience.

The participation rate in the research section of the questionnaire was low, only 14 hospitals said that they participated in research and of those only 6 said that patients participated in 'parts of the research cycle (from discussion of grant proposal to dissemination of results)'. From the results of the open questions, that mentioned informed consent, it may be the case that this question was somewhat misunderstood to mean the participation of patients as subjects of research as opposed to partners in the research process. Additionally, hospitals are only a single player in the research cycle the behaviour of universities in the region, pharmaceutical companies and funding organisations (38,39) may be more inclusive of the patient voice but these were not captured in this study.

With an average score of 0.5 on our additive scale from 0 to 1, hospitals in the Greater Region have implemented practices related to patient partnership moderately. Although the mean scores between the three regions were not significantly different, tendencies could still be identified. The same is true for the individual comparison between the regions, Germany has the lowest mean score of APPS practices (0.44) whereas in France (0.54) and Belgium (0.52) the mean scores were slightly higher. Given the lack of comparative studies on this topic in the region it is difficult to draw conclusions regarding whether progress in the field has been made, or, if our results confirm or refute a known trend. Additionally, it was beyond the scope of this study to look beyond the meso level at action at the macro governance level in the three countries which are likely to influence hospital's uptake of APPS.

4.1 Limitations

One limitation of this study is the relatively small sample size of 61 hospitals. The response rate of 52,6% is acceptable for an online survey. One possible reason for the non-responding is that hospital staff are exposed to a relatively high work load and the questionnaire was sent to hospitals with whom the researchers had no prior contact.

We found that our sample did not differ significantly from the non-responding hospitals indicating a degree of representativeness present in our sample. Nevertheless we can assume that the response pattern regarding APPS practices in the hospitals tends towards a good representation of the situation in the region However, our results cannot be generalized to all results.

There may be differences in the interpretation by participants of particular practices across the hospitals therefore we cannot be sure of the extent to which responses correspond to actual practices (social desirability bias). Triangulation of the results, checking the existence of interventions in the hospitals and linking these to the data presented in the questionnaire, would have been useful. However, given the anonymization of the data and thus the inability to trace the responses back to the participating hospitals this was unfortunately not possible.

A quantitative survey, such as this one, cannot fully grasp the depth of hospitals' commitment to a concept as complex and multi-dimensional as APPS. Nevertheless, attempts were made to evaluate the 'maturity' of the interventions which contributed important detail to the responses.

The APPS additive score was intended as a way to group the data in order to gain an overall view of regional differences. It is based on theoretical assumptions and, due to the small sample size it cannot be verified by further inferential statistical tests. The scores can therefore only be used as a guide and should be used with caution.

4.2 Further research

The results of this study are only explorative and would benefit from further verification. Further research examining APPS practices at the institutional level perhaps using a qualitative approach such as case studies, interviews or observational studies would be an interesting addition to this research. It would also be interesting to analyse additional individual practices in hospitals that were not included in our survey.

Research analysing the barriers for the hospitals to include APPS practices would also be helpful to draw a more accurate picture of the situation of patient partnership at the institutional level. In addition, the role of the external political context and the impact of policies at regional, national and international level on hospital's openness to institutional change would help complete the picture.

Finally evidence of the impact of APPS policies on health and wellbeing outcomes among patients and HCPs is vital to fully understand the value of such a movement and provide evidence to promote its expansion.

5 Conclusion

This study provides the first overview of the existence and degree of institutional practices related to patient partnership and patient participation in hospitals of the Greater Region. In general it seems that the implementation of the APPS concept is incomplete and only partially integrated into the general functioning of hospitals in the region. The French regions appearing to be more advanced than those situated in Belgium and Germany indicating possible scope for cross-border learning. Despite the limitations outlined above the research presented in this report provides a useful starting point for other activities of the APPS project and research on the region in general.

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Appendix

Further tables

Table 19 Apps Score proposed variables

	Variable values
Hospital vision or mission	
1. Does your organization's philosophy of care statement promote partnerships with the patients it serves? [v7]	
yes, fully	1,0
yes, to some extent	0,25
not really	0,25
no, not at all	0,0
2. Is patient partnership integrated into the strategic plan of the hospital? [v8]	
yes	1,0
no	0,0
Direct Care	
Person centred communication	
3. Are healthcare users routinely asked to evaluate the quality of health care professional patient communication? [v11]	
yes, regularly	1,0
yes, but not regularly	0,5
no	0,0
4. Are patients included in the production of patient resources in your hospital? [v12]	
yes	1,0
no	0,0
5. Does the hospital provide training for staff in how to communicate with patients? [v16]	
yes	1,0
no	0,0
self-care	
6. Please indicate which statement is most appropriate for your hospital (tick all that apply) Self-management support…	
…is accomplished by the distribution of information (pamphlets, booklets).	quoted 1,0 not quoted 0,0
…is accomplished by referral to self-management classes or educators.	quoted 1,0 not quoted 0,0
…is provided by goal setting and action planning with members of the practice team.	quoted 1,0 not quoted 0,0
…is provided by members of the practice team trained in patient empowerment and problem-solving methodologies.	quoted 1,0 not quoted 0,0
Shared-decision making	
7. Are patients provided with decision aids for various health conditions? [v21]	
yes	1,0
no	0,0
8. Are there formal training programmes provided to hospital staff on partnering with patients in the care plan decision-making process? [v22]	
yes	1,0
no	0,0
9. Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings? [v25]	

Yes for all diseases	1,0
Yes for some diseases	0,5
No	0,0
The hospital does not have interdisciplinary meetings	0,0
Organisational design	
Patient committees	
10. Does your hospital have a patient committee?	
yes	1,0
no	0,0
Involvement of family and friends	
11. Is there a written policy enabling patients to identify their preferences with respect to which family members or other individuals they would like to have actively involved during their stay in the hospital? [v33]	
yes	1,0
no	0,0
12. Does the hospital have a policy or guidelines that facilitate unrestricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference? [v36]	
Exist across all units	1,0
Exists across some units	0,5
Does not exist in any hospital unit	0,0
Access to medical records	
13. Do patients have access to their medical records?	
Yes, unrestriced access	1,0
Yes, but access is restricted	0,5
No	0,0
14. Is information given routinely to patients on how to access their medical records? [v38]	
No	0,0
Yes, patients are informed but not systematically	0,5
Yes, patients are informed systematically	1,0
Quality improvement	
15. Does the hospital have a mechanism in place to allow patients to give feedback? [v42]	
yes	1,0
no	0,0
16. Does the hospital actively inform patients on their right to complain? [v44]	
yes	1,0
no	0,0
17. Overall: Are patients normally involved in forms of quality improvement in your hospital? [v46]	
yes	1,0
no	0,0
Advanced technologies	
18. Does your hospital use information technology/telehealth/mhealth (e.g. smart phone applications or patient physician portals) to support or promote patient partnership? [v50]	
Yes for all diseases	1,0
Yes for some diseases	0,5
No	0,0
Education	
19. Does the hospital have patient experts, trained to work with other patients as part of patient education?	
Yes, for all chronic diseases	1,0
Yes, for some chronic diseases	0,5
No	0,0
Patient participation in HCP training	
20. Do patients participate in the training of health care professionals in your hospital? [v55]	
yes	1,0
no	0,0

Table 20 Selected variables for regional differences and comparisons[8]

Question
Does the organisation's philosophy of care statement promote partnerships with the patients it serves?
yes, fully
yes, to some extent
not really
no, not at all
Is patient partnership integrated into the strategic plan of the hospital?
yes
no
Are healthcare users regularly asked to evaluate the quality of HCP/professional communication?
yes, regularly
yes, but not regularly
no
Are patients included in production of patient resources?
yes
no
Does hospital provide training for staff on how to communicate with patients?
yes
no
Are patients provided with decision aids for various health conditions?
Yes, for all diseases
Yes, for some diseases
No
Are there formal training programmes to hospital staff on partnering with patients in care plan decision making?
yes
no
Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?
Yes, for all diseases
Yes, for some diseases
No
The hospital does not have interdisciplinary meetings
Does the hospital have a patient committee?
yes
no
Does the hospital have a policy or guidelines that facilitate un restricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference?
Does not exist in any hospital unit
Exists across some units
Exists across all units
Access to medical records
Yes, any time while in the hospital
Yes, in the hospital but only with the authorisation of their physician
Yes, anytime through an online portal
Yes, anytime at patient's request (i.e., offline)
No, patients do not have access to their medical records
Is information given routinely to patients on how to access their medical records?
No
Yes, patients are informed but not systematically

[8] The selection was limited to non-filtered questions (i.e. the questions that were posed to all participants to include the maximum of responses), based on theoretical assumptions and on the n of each question.

Yes, patients are informed systematically
Are patients normally involved in forms of quality improvement in the hospital?
Yes
No
Does the hospital have patient experts, trained to work with other patients as part of patient education?
Yes, for some chronic diseases
No
Do patients participate in the training of health care professionals in your hospital?
Yes
No
Does the hospital have a policy to including patients in the full research cycle from discussion of grant proposal until dissemination of results?
Yes, in parts of the research cycle
No

Table 21 Comparison between regions - Hospital vision and mission

Question	DE n (%)	FR n (%)	BE n (%)	Total n (%)	P value	Fisher's Exact
7. Does the organisation's philosophy of care statement promote partnerships with the patients it serves?					0.441	0.524
yes, fully	7 (29,2)	8 (29,6)	2 (22,2)	17 (28,3)		
yes, to some extent	13 (54,2)	15 (55,6)	4 (44,4)	32 (53,3)		
not really	4 (16,7)	2 (7,4)	3 (33,3)	9 (15,0)		
no, not at all	0 (0,0)	2 (7,4)	0 (0,0)	2 (3,3)		
8. Is patient partnership integrated into the strategic plan of the hospital?					**0.002**	**0.002**
yes	**6 (25,0)**	**20 (74,1)**	**5 (55,6)**	**31 (51,7)**		
no	**18 (75,0)**	**7 (25,9)**	**4 (44,4)**	**29 (48,3)**		

Table 22 Comparison between regions – Direct care

Question	DE n (%)	FR n (%)	BE n (%)	Total n (%)	P value	Fisher's Exact
11. Are healthcare users regularly asked to evaluate the quality of HCP/professional communication?					0.329	0.274
Yes, regularly	15 (68,2)	15 (57,7)	5 (55,6)	35 (61,4)		
Yes, but not regularly	6 (27,3)	4 (15,4)	2 (22,2)	12 (21,1)		
No	1 (4,5)	7 (26,9)	2 (22,2)	10 (17,5)		
12. Are patients included in production of patient resources?					**0.017**	**0.011**
Yes	**1 (4,3)**	**10 (38,5)**	**1 (22,2)**	**13 (22,4)**		
No	**22 (95,7)**	**16 (61,5)**	**7 (77,8)**	**45 (77,6)**		
16. Does hospital provide training for staff on how to communicate with patients?					0.874	0.916
Yes	19 (79,2)	19 (73,1)	7 (77,8)	45 (76,3)		
No	5 (20,8)	7 (26,9)	2 (22,2)	14 (23,7)		
21. Are patients provided with decision aids for various health conditions?					0.496	0.488
Yes, for all diseases	0 (0,0)	1 (4,3)	0 (0,0)	1 (1,8)		
Yes, for some diseases	18 (78,3)	17 (73,9)	5 (55,6)	40 (72,7)		
No	5 (21,7)	5 (21,7)	4 (44,4)	14 (25,5)		
22. Are there formal training programmes to hospital staff on partnering with patients in care plan decision making?					0.919	1.000

Yes	4 (17,4)	21,7 (5)	22,2 (2)	20,0 (11)		
No	19 (82,6)	18 (78,3)	7 (77,8)	44 (80,0)		
25. Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?					**0.006**	**0.001**
Yes for all diseases	**0 (0,0)**	**2 (8,7)**	**0 (0,0)**	**2 (3,6)**		
Yes for some diseases	**1 (4,3)**	**8 (34,8)**	**4 (44,4)**	**13 (23,6)**		
No	**22 (95,7)**	**13 (56,5)**	**5 (55,6)**	**40 (72,7)**		

Table 23 Comparison between regions – Organizational design

Question	DE n (%)	FR n (%)	BE n (%)	Total n (%)	P value	Fisher's Exact
27. Does the hospital have a patient committee?					**0.003**	**0.002**
yes	**1 (4,3)**	**11 (47,8)**	**2 (22,2)**	**14 (25,5)**		
no	**22 (95,7)**	**12 (52,2)**	**7 (77,8)**	**41 (74,5)**		
36. Does the hospital have a policy or guidelines that facilitate un restricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference?					0.168	0.188
Does not exist in any hospital unit	7 (31,8)	13 (56,5)	6 (66,7)	26 (48,1)		
Exists across some units	8 (36,4)	7 (30,4)	3 (33,3)	18 (33,3)		
Exists across all units	7 (31,8)	3 (13,0)	0 (0,0)	10 (18,5)		
37. Access to medical records					0.291	0.301
No access	2 (9,5)	5 (21,7)	4 (44,4)	11 (20,8)		
Restricted access	3 (14,3)	4 (17,4)	1 (11,1)	8 (15,1)		
Unrestricted access	16 (76,2)	14 (60,9)	4 (44,4)	34 (64,2)		
38. Is information given routinely to patients on how to access their medical records?					**0.000**	**0.000**
No	13 (65,0)	1 (5,9)	1 (20,0)	15 (35,7)		
Yes, patients are informed but not systematically	7 (35,0)	3 (17,6)	3 (60,0)	13 (31,0)		
Yes, patients are informed systematically	0 (0,0)	13 (76,5)	1 (20,0)	14 (33,3)		
46. Are patients normally involved in forms of quality improvement in the hospital?					**0.002**	**0.002**
Yes	**9 (39,1)**	**21 (87,5)**	**6 (66,7)**	**36 (64,3)**		
No	**14 (60,9)**	**3 (12,5)**	**3 (33,3)**	**20 (35,7)**		

Table 24 Comparison between regions – Education

Question	DE n (%)	FR n (%)	BE n (%)	Total n (%)	P value	Fisher's Exact
53. Does the hospital have patient experts, trained to work with other patients as part of patient education?					**0.004**	**0.005**
Yes, for some chronic diseases	**2 (8,7)**	**12 (48,0)**	**1 (11,1)**	**15 (26,3)**		
No	**21 (91,3)**	**13 (52,0)**	**8 (88,9)**	**42 (73,7)**		
55. Do patients participate in the training of health care professionals in your hospital?					0.294	0.357
Yes	0 (0,0)	2 (8,0)	1 (12,5)	3 (5,4)		
No	23 (100,0)	23 (92,0)	7 (87,5)	53 (94,6)		

Table 25 Comparison between regions - research

Question	DE n (%)	FR n (%)	BE n (%)	Total n (%)	P value	Fisher's Exact
60. Does the hospital have a policy to including patients in the full research cycle from discussion of grant proposal until dissemination of results?					0.107	0.165
Yes, in parts of the research cycle	4 (100,0)	2 (33,3)	2 (50,0)	8 (57,1)		
No	0 (0,0)	4 (66,7)	2 (50,0)	6 (42,9)		

Table 26 Differences dependent upon hospital governance

	APPS in hospital vision or mission					
Question	No n (%)	To some extent n (%)	Yes n (%)	Total n (%)	P value	Fisher's Exact
11. Are healthcare users regularly asked to evaluate the quality of HCP/professional communication?					**0.012**	**0.027**
no	**5 (50,0)**	**2 (10,5)**	**3 (10,7)**	**10 (17,5)**		
yes	**5 (50,0)**	**17 (89,5)**	**25 (89,3)**	**47 (82,5)**		
12. Are patients included in production of patient resources?					**0.041**	**0.042**
no	**10 (100,0)**	**17 (85,0)**	**18 (64,3)**	**45 (77,6)**		
yes	**0 (0,0)**	**3 (15,0)**	**10 (35,7)**	**13 (22,4)**		
16. Does hospital provide training for staff on how to communicate with patients?					**0.028**	**0.024**
no	**5 (50,0)**	**6 (30,0)**	**3 (10,3)**	**14 (23,7)**		
yes	**5 (50,0)**	**14 (70,0)**	**26 (89,7)**	**45 (76,3)**		
21. Are patients provided with decision aids for various health conditions?					0.234	0.214
no	3 (33,3)	2 (11,1)	9 (32,1)	14 (25,5)		
yes	6 (66,7)	16 (88,9)	19 (67,9)	41 (74,5)		
22. Are there formal training programmes to hospital staff on partnering with patients in care plan decision making?					0.910	1.000
no	7 (77,8)	15 (83,3)	22 (78,6)	44 (80,0)		
yes	2 (22,2)	3 (16,7)	6 (21,4)	11 (20,0)		
25. Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?					**0.020**	**0.019**
no	**9 (100,0)**	**15 (83,3)**	**16 (57,1)**	**40 (72,7)**		
yes	**0 (0,0)**	**3 (16,7)**	**12 (42,9)**	**15 (27,3)**		
27. Does the hospital have a patient committee?					0.486	0.543
no	7 (77,8)	15 (83,3)	19 (67,9)	41 (74,5)		
yes	2 (22,2)	3 (16,7)	9 (32,1)	14 (25,5)		
36. Does the hospital have a policy or guidelines that facilitate un restricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference?					0.317	0.342
no	3 (37,5)	7 (38,9)	16 (59,3)	26 (49,1)		
yes	5 (62,5)	11 (61,1)	11 (40,7)	27 (50,9)		
37. Access to medical records					0.282	0.326
no access	4 (44,4)	2 (11,8)	5 (18,5)	11 (20,8)		
restricted access	1 (11,1)	4 (23,5)	3 (11,1)	8 (15,1)		
unrestricted access	4 (44,4)	11 (64,7)	19 (70,4)	34 (64,2)		
38. Is information given routinely to patients on how to access their medical records?					0.158	0.165

no	3 (60,0)	7 (46,7)	5 (22,7)	15 (35,7)		
yes	2 (40,0)	8 (53,3)	17 (77,3)	27 (64,3)		
44. Does the hospital actively inform patients on their right to complain?					0.651	0.846
no	1 (10,0)	1 (5,9)	4 (14,8)	6 (11,1)		
yes	9 (90,0)	16 (94,1)	23 (85,2)	48 (88,9)		
46. Are patients normally involved in forms of quality improvement in the hospital?					0.196	0.196
no	4 (44,4)	9 (50,0)	7 (25,0)	20 (36,4)		
yes	5 (55,6)	9 (50,0)	21 (75,0)	35 (63,6)		
50. Does your hospital use information technology/telehealth/mhealth (e,g, smart phone applications or patient physician portals) to support or promote patient partnership?					0.356	0.508
no	9 (90,0)	15 (83,3)	19 (70,4)	43 (78,2)		
yes	1 (10,0)	3 (16,7)	8 (29,6)	12 (21,8)		
53. Does the hospital have patient experts, trained to work with other patients as part of patient education?					0.463	0.557
no	8 (88,9)	14 (73,7)	19 (67,9)	41 (73,2)		
yes	1 (11,1)	5 (26,3)	9 (32,1)	15 (26,8)		
55. Do patients participate in the training of health care professionals in your hospital?					0.698	1.000
no	9 (100,0)	18 (94,7)	25 (92,6)	52 (94,5)		
yes	0 (0,0)	1 (5,3)	2 (7,4)	3 (5,5)		

Table 27 Differences dependent upon hospital size

	Number of beds					
Question	**< 300 n (%)**	**300-599 n (%)**	**600 + n (%)**	**Total n (%)**	**P value**	**Fisher's Exact**
APPS in hospital vision and mission					0.317	0.346
no	4 (16,7)	5 (27,8)	1 (7,7)	10 (18,2)		
to some extent	6 (25,0)	7 (38,9)	3 (23,1)	16 (29,1)		
yes	14 (58,3)	6 (33,3)	9 (69,2)	29 (52,7)		
Are healthcare users regularly asked to evaluate the quality of HCP/patient communication?					0.996	1.000
no	4 (16,4)	3 (17,6)	2 (16,7)	9 (17,0)		
yes	20 (83,3)	14 (82,4)	10 (83,3)	44 (83,0)		
Are patients included in production of patient resources?					**0.007**	**0.015**
no	**21 (87,5)**	**15 (88,2)**	**6 (46,2)**	**42 (77,8)**		
yes	**3 (12,5)**	**2 (11,8)**	**7 (53,8)**	**12 (22,2)**		
Does hospital provide training for staff on how to communicate with patients?					0.990	1.000
no	6 (25,0)	4 (23,5)	3 (23,1)	13 (24,1)		
yes	18 (75,0)	13 (76,5)	10 (76,9)	41 (75,9)		
Are patients provided with decision aids for various health conditions?					0.455	0.480
no	8 (34,8)	4 (26,7)	2 (15,4)	14 (27,5)		
yes	15 (65,2)	11 (73,3)	11 (84,6)	37 (72,5)		
Are there formal training programmes to hospital staff on partnering with patients in care plan decision making?					**0.003**	**0.001**
no	**23 (100,0)**	**11 (73,3)**	**7 (53,8)**	**41 (80,4)**		

yes	**0 (0,0)**	**4 (26,7)**	**6 (46,2)**	**10 (19,6)**		
Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?					0.119	0.136
no	18 (78,3)	13 (86,7)	7 (53,8)	38 (74,5)		
yes	5 (21,7)	2 (13,3)	6 (46,2)	13 (25,5)		
Does the hospital have a patient committee?					0.090	0.083
no	20 (87,0)	11 (73,3)	7 (53,8)	38 (74,5)		
yes	3 (13,0)	4 (26,7)	6 (46,2)	13 (25,5)		
Does the hospital have a policy or guidelines that facilitate un restricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference?					0.240	0.262
no	10 (41,7)	6 (42,9)	9 (69,2)	25 (49,0)		
yes	14 (58,3)	8 (57,1)	4 (30,8)	26 (51,0)		
Access to medical records					0.772	0.836
no access	6 (27,3)	3 (21,4)	2 (15,4)	11 (22,4)		
restricted access	4 18,2)	2 (14,3)	1 (7,7)	7 (14,3)		
unrestricted access	12 (54,5)	9 (64,3)	10 (76,9)	31 (63,3)		
Is information given routinely to patients on how to access their medical records?					0.761	0.838
no	6 (37,5)	5 (41,7)	3 (37,3)	14 (35,9)		
yes	10 (62,5)	7 (58,3)	8 (72,7)	25 (64,1)		
Does the hospital actively inform patients on their right to complain?					0.199	0.209
no	4 (18,2)	0 (0,0)	2 (16,7)	6 (12,0)		
yes	18 (81,8)	16 (100,0)	10 (83,3)	44 (88,0)		
Are patients normally involved in forms of quality improvement in the hospital?					0.241	0.256
no	10 (41,7)	6 (40,0)	2 (15,4)	18 (34,6)		
yes	14 (58,3)	9 (60,0)	11 (84,6)	34 (65,4)		
Does your hospital use information technology/telehealth/mhealth (e,g, smart phone applications or patient physician portals) to support or promote patient partnership?					**0.027**	**0.034**
no	**22 (91,7)**	**12 (80,0)**	**7 (53,8)**	**41 (78,8)**		
yes	**2 (8,3)**	**3 (20,0)**	**6 (46,2)**	**11 (21,2)**		
Does the hospital have patient experts, trained to work with other patients as part of patient education?					0.284	0.331
no	19 (79,2)	14 (82,4)	7 (58,3)	40 (75,5)		
yes	5 (20,8)	3 (17,6)	5 (41,7)	13 (24,5)		
Do patients participate in the training of health care professionals in your hospital?					0.394	0.285
no	24 (100,0)	15 (93,8)	11 (91,7)	50 (96,2)		
yes	0 (0,0)	1 (6,3)	1 (8,3)	2 (3,8)		

Table 28 Differences dependent upon the presence of a patient committee

	Patient committee				
Question	**No n (%)**	**Yes n (%)**	**Total n (%)**	**P value**	**Fisher's Exact**
Are patients included in production of patient resources?				**0.007**	**0.007**
no	**35 (87,5)**	**7 (50,0)**	**42 (77,8)**		
yes	**5 (12,5)**	**7 (50,0)**	**12 (22,2)**		

Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?				**0.006**	**0.012**
no	**34 (82,9)**	**6 (42,9)**	**40 (72,7)**		
yes	**7 (17,1)**	**8 (57,1)**	**15 (27,3)**		
Access to medical records				0.562	0.721
no access	8 (20,5)	2 (15,4)	10 (19,2)		
restricted access	7 (17,9)	1 (7,7)	8 (15,4)		
unrestricted access	24 (61,5)	10 (76,9)	34 (65,4)		
Are patients normally involved in forms of quality improvement in the hospital?				**0.019**	**0.019**
no	**19 (46,3)**	**1 (7,7)**	**20 (37,0)**		
yes	**22 (53,7)**	**12 (92,3)**	**34 (63,0)**		
Does the hospital have patient experts, trained to work with other patients as part of patient education?				0.154	0.154
no	32 (80,0)	8 (57,1)	40 (74,1)		
yes	8 (20,0)	6 (42,9)	14 (25,9)		
Do patients participate in the training of health care professionals in your hospital?				0.167	0.167
no	38 (97,4)	12 (85,7)	50 (94,3)		
yes	1 (2,6)	2 (14,3)	3 (5,7)		

Table 29 Descriptive statistics for APPS score

		N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
						Lower Bound	Upper Bound		
APPS score	RLP/Saarland	24	0,44	0,15	0,03	0,37	0,50	0,09	0,67
	Lorraine	28	0,54	0,26	0,05	0,44	0,64	0,00	1,00
	Wallonie	9	0,52	0,23	0,08	0,35	0,70	0,26	0,90
	Total	61	0,50	0,22	0,03	0,44	0,55	0,00	1,00
Hospital vision	RLP/Saarland	24	0,39	0,30	0,06	0,26	0,51	0,15	1,00
	Lorraine	27	0,62	0,32	0,06	0,49	0,75	0,00	1,00
	Wallonie	9	0,51	0,36	0,12	0,23	0,79	0,15	1,00
	Total	60	0,51	0,33	0,04	0,42	0,60	0,00	1,00
Direct Care	RLP/Saarland	24	0,43	0,18	0,04	0,35	0,50	0,00	0,73
	Lorraine	26	0,46	0,29	0,06	0,35	0,58	0,00	1,00
	Wallonie	9	0,50	0,26	0,09	0,30	0,69	0,20	0,93
	Total	59	0,45	0,24	0,03	0,39	0,52	0,00	1,00
Organisational design	RLP/Saarland	23	0,38	0,19	0,04	0,30	0,46	0,00	0,69
	Lorraine	25	0,63	0,21	0,04	0,54	0,72	0,23	1,00
	Wallonie	9	0,44	0,25	0,08	0,25	0,64	0,15	0,85
	Total	57	0,50	0,24	0,03	0,44	0,56	0,00	1,00
Education	RLP/Saarland	23	0,03	0,10	0,02	-0,01	0,07	0,00	0,33
	Lorraine	25	0,21	0,29	0,06	0,09	0,33	0,00	1,00
	Wallonie	9	0,11	0,33	0,11	-0,15	0,37	0,00	1,00
	Total	57	0,12	0,25	0,03	0,06	0,19	0,00	1,00

Table 30 Comparison of APPS score means ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
APPS score	Between Groups	0,151	2	0,076	1,560	0,219
	Within Groups	2,810	58	0,048		
	Total	2,961	60			
Hospital vision	Between Groups	0,708	2	0,354	3,451	**0,038**
	Within Groups	5,849	57	0,103		
	Total	6,557	59			
Direct Care	Between Groups	0,039	2	0,019	0,326	0,723
	Within Groups	3,337	56	0,060		
	Total	3,376	58			
Organisational design	Between Groups	0,760	2	0,380	8,582	**0,001**
	Within Groups	2,390	54	0,044		
	Total	3,149	56			
Education	Between Groups	0,409	2	0,204	3,599	**0,034**
	Within Groups	3,065	54	0,057		
	Total	3,474	56			

Table 31 Tukey post hoc test

	Differences between regions		Mean difference	Std. Error	95% Confidence Interval		Sig.
					Lower Bound	Upper Bound	
Hospital vision	Lorraine	RLP/Saarland	.236	.090	.010	.462	**.029**
Organisational design	Lorraine	RLP/Saarland	.246	.061	.093	.399	**.000**
Education	Lorraine	RLP/Saarland	.184	.069	.011	.358	**.026**

Invitation letter - Germany

Prof. Dr. Johannes Kopp
Professur für empirische Sozialforschung
und Methodenlehre
Fachbereich IV, Soziologie
54286 Trier

Einladung zur Teilnahme an der Befragung zu institutionellen Praktiken in Bezug auf die Patientenbeteiligung im Gesundheitswesen der Großregion

Sehr geehrte/r …

in den vier Ländern der Großregion, Belgien, Deutschland und Frankreich und Luxemburg, läuft zurzeit eine gesundheitswissenschaftliche Analyse der institutionellen Praktiken in Bezug auf die Patientenbeteiligung im Gesundheitswesen. In Rheinland-Pfalz und dem Saarland wird diese Erhebung durch die Universität Trier und die I. Medizinische Klinik und Poliklinik der Universitätsmedizin Mainz umgesetzt. Die Studie ist Teil eines großen interregionalen Forschungsprojekts, das vom INTERREG-Programm der Europäischen Union gefördert wird. Geleitet wird das Projekt von Prof. Michèle Guillaume, Professur für Gesundheitswissenschaften und Public Health - Ernährung, Umwelt und Gesundheit, der Universität Lüttich.

Innerhalb der letzten 50 Jahre haben sich die Gesundheitssysteme in Europa allmählich von einem „paternalistischen“ Ansatz zu einer patientenorientierten Versorgung der Patienten entwickelt. Die Einstellung des Patienten gegenüber dem Angebot im Gesundheitswesen und den Beziehungen in der Gesundheitsversorgung hat sich in den vergangenen zehn Jahren noch einmal verändert, da sich der Zugang zu den Gesundheitsinformationen vereinfacht hat und der Wunsch entstanden ist, sich bei der medizinischen Versorgung nicht mehr nur in einer passiven Rolle zu befinden. Vielmehr wollen die Patienten beim Management der eigenen Krankheit mitwirken und über eine relative Autonomie verfügen.

Hier setzt unser Forschungsprojekt an. Wir haben es uns zur Aufgabe gemacht, die Möglichkeiten für Patienten zu analysieren, sich in den vier Ländern der Großregion an

ihrer Gesundheitsversorgung zu beteiligen und Strategien zur Umsetzung der Prinzipien der Patientenbeteiligung zu entwickeln.

Von zentraler Bedeutung für diese Analyse sind die Erfahrungen, Bewertungen und Erwartungen von Experten im Bereich der Gesundheitsvorsorge und deshalb wenden wir uns heute an Sie.

Wir haben einen Online-Fragebogen vorbereitet, der durch die QM-Beauftragten in der deutschen Teilregion beantwortet werden soll. Dafür werden wir Ihnen in den nächsten Tagen eine E-Mail mit dem Befragungslink zukommen lassen.

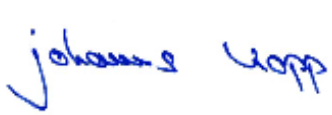
Die Befragung wird rund 15 Minuten dauern. Sie können die Umfrage jederzeit unterbrechen und später wieder fortfahren. Selbstverständlich ist Ihre Teilnahme völlig freiwillig, um aber eine möglichst umfassende und aussagekräftige Analyse durchführen zu können, ist eine hohe Beteiligung an der Befragung sehr wünschenswert.

Ihre Angaben werden anonym erfasst und ausschließlich von Wissenschaftlern des interregionalen Forscherteams ohne Personenbezug ausgewertet. Alle Angaben unterliegen dem Datenschutz. Es werden in den Veröffentlichungen keine Rückschlüsse auf einzelne Personen, Abteilungen oder Einrichtungen möglich sein.

Bei Rückfragen steht Ihnen unsere Projektmitarbeiterin, Frau Mareike Kaucher, gerne zur Verfügung. Sie erreichen Frau Kaucher per Email unter kaucher1@uni-trier.de oder telefonisch unter der Nummer +49 651 201-2035

Für Ihre Teilnahme bedanken wir uns bereits jetzt sehr herzlich.

Mit freundlichen Grüßen,



Prof. Johannes Kopp

Prof. Michèle Guillaume

Invitation letter – Belgium

Liège, le 16 janvier 2018

Dr ,

Le Département des Sciences de la Santé publique de l'Université de Liège dirige actuellement un programme de recherche relatif à l'approche « patient partenaire de soins » dans les systèmes de santé. L'objectif général de ce programme consiste à mieux identifier la place que pourrait occuper le patient dans le système de soins et les conditions nécessaires au développement optimal de cette approche. Financé par les Fonds Européens FEDER et les autorités publiques (programme INTERREG V A N° 032-3-06-013), ce programme est réalisé de manière conjointe dans 5 régions transfrontalières de 4 pays limitrophes (la Wallonie pour la Belgique, le Grand-Duché de Luxembourg, la Lorraine en France, la Sarre et la Rhénanie-Palatinat pour l'Allemagne).

Une des premières étapes de la recherche consiste à mieux connaître les pratiques actuelles concernant les patients « partenaires, experts, ressources ou témoins » dans les établissements hospitaliers.

Votre expérience, vos souhaits et vos attentes, mais également les freins et limites que vous auriez pu identifier, en rapport avec la participation des patients dans votre établissement, sont d'une importance essentielle pour cette première phase de travail.

Dans ce cadre, nous sollicitons tous les directeurs des hôpitaux de cette région transfrontalière afin de remplir un questionnaire en ligne (via un lien internet). Nous vous laissons la liberté d'adresser ce questionnaire à la personne la plus à même de le remplir au sein de votre établissement. Il s'agit d'une série de questions fermées (choix multiples) dont le temps de remplissage est estimé à 20 minutes. Il est possible d'interrompre le remplissage du questionnaire à tout moment et de le poursuivre plus tard.

Votre participation est entièrement volontaire, toutefois pour arriver à des conclusions valides, un taux de participation important est hautement souhaitable.

Toutes les données recueillies seront anonymisées et traitées dans le respect des exigences de protection des données. Elles seront analysées exclusivement par des scientifiques de l'équipe de recherche européenne, aux seules fins du présent programme de recherche. Les conclusions seront limitées à des comparaisons inter-régionales. Aucune comparaison entre établissements ne sera effectuée, ni rendue publique.

Nous espérons vivement que vous accepterez de participer à cette étude. Pour ce faire, nous vous enverrons cette semaine un lien vers le questionnaire par e-mail. Si vous avez la moindre question, n'hésitez pas à nous contacter au 04 366 9299 ou par mail beatrice.scholtes@uliege.be.

Je vous prie d'agréer, Docteur, l'expression de mes sentiments respectueux.

Professeur Michèle Guillaume
Département des Sciences de la Santé publique
Université de Liège

Invitation letter – France

CHRU de NANCY

9, avenue du Maréchal de Lattre de Tassigny

CO 60034 - 54035 NANCY CEDEX

Nancy, le 06 Février 2018

Monsieur le… / Madame la…

Cher/Chère (nom),

Le Département des Sciences de la Santé publique de l'Université de Liège dirige actuellement un programme de recherche relatif à l'approche « patient partenaire de soins » dans les systèmes de santé. L'objectif général de ce programme consiste à mieux identifier la place que pourrait occuper le patient dans le système de soins et les conditions nécessaires au développement optimal de cette approche. Financé par les Fonds Européens FEDER et les autorités publiques (programme INTERREG V A N° 032-3-06-013), ce programme est réalisé de manière conjointe dans 5 régions transfrontalières de 4 pays limitrophes (la Wallonie pour la Belgique, le Grand-Duché de Luxembourg, la Lorraine en France, la Sarre et la Rhénanie-Palatinat pour l'Allemagne).

Une des premières étapes de la recherche consiste à mieux connaître les pratiques actuelles concernant les patients « partenaires, experts, ressources ou témoins » dans les établissements hospitaliers.

Votre expérience, vos souhaits et vos attentes, mais également les freins et limites que vous auriez pu identifier, en rapport avec la participation des patients dans votre établissement, sont d'une importance essentielle pour cette première phase de travail.

Dans ce cadre, nous sollicitons tous les directeurs des hôpitaux de cette région transfrontalière afin de remplir un questionnaire en ligne (via le lien internet suivant). Nous vous laissons la liberté d'adresser ce questionnaire à la personne la plus à même

de le remplir au sein de votre établissement. Il s'agit d'une série de questions fermées (choix multiples) dont le temps de remplissage est estimé à 20 minutes. Il est possible d'interrompre le remplissage du questionnaire à tout moment et de le poursuivre plus tard.

Votre participation est entièrement volontaire, toutefois pour arriver à des conclusions valides, un taux de participation important est hautement souhaitable.

Toutes les données recueillies seront anonymisées et traitées dans le respect des exigences de protection des données. Elles seront analysées exclusivement par des scientifiques de l'équipe de recherche européenne, aux seules fins du présent programme de recherche. Les conclusions seront limitées à des comparaisons inter-régionales. Aucune comparaison entre établissements ne sera effectuée, ni rendue publique.

Nous espérons vivement que vous accepterez de participer à cette étude. Pour ce faire, nous vous envoyons le lien suivant (lien à insérer) et le code d'accès suivant : vous permettant de compléter le questionnaire. Si vous avez la moindre question, n'hésitez pas à contacter les collaborateurs lorrains :

- Madeline Voyen au CHRU de Nancy au 03.83.15.43.26 ou par mail : m.voyen@chru-nancy.fr
- Mohamed Younsi à l'Université de Lorraine au 03.72.74.63.52 ou par mail : mohamed.younsi@univ-lorraine.fr

Je vous prie d'agréer, Madame/Monsieur (insérer nom), l'expression de mes sentiments respectueux.

Michèle Guillaume
Professeur Ordinaire
Présidente du département des Sciences de la Santé publique
Service Nutrition, Environnement et Santé
Université de Liège

Olivier Ziegler
PU-PH d'endocrinologie, diabétologie et nutrition
CHRU de Nancy-Université de Lorraine
Coordinateur du projet pour la région Lorraine

Questionnaire

1 General hospital characteristics

1. In which region is the hospital located?	
RLP/Saarland	❑
Lorraine	❑
Wallonie	❑

2. What is your position in the hospital?	
Quality Manager	❑
Director of quality management	❑
Director of nursing	❑
Medical director	❑
Director of administration	❑
CME	❑
Other	❑

3. In what kind of hospital do you work?	
General hospital	❑
University hospital	❑
Other	❑

4. Is the hospital a...	
Public hospital	❑
Private hospital	❑
Non-profit hospital	❑
Mixed hospital	❑

5. How many beds does the hospital have?
_____

6. How many sites does the hospital occupy?	
1	❑
2	❑
3	❑
4	❑
5	❑
6 and more	❑

2 Hospital vision or mission

Source: Institute for Patient- and Family-Centred care(19)

7. Does your organization's philosophy of care statement promote partnerships with the patients it serves?	
Yes, fully	❑
Yes, to some extent	❑
Not really	❑
No, not at all	❑

Source: Herrin(14)

8. Is patient partnership integrated into the strategic plan of the hospital?	
Yes	❑
No (→ continue with question 11)	❑

If yes:

9. Is there an implementation plan for the dimension of the strategy concerning patient partnership?	
Yes	❑
No (→ continue to question 11)	❑

If yes:

10. How many units have the patient partnership dimension of the strategic plan in place?	
Less than 25 %	❑
25 to 50 %	❑
51 to 75 %	❑
More than 75%	❑
The strategy is in place in all units	❑

3 Direct care

3.1 Person-centred Communication

11. Are healthcare users routinely asked to evaluate the quality of health care professional patient communication?	
Yes, regularly	❑
Yes, but not regularly	❑
No	❑

Source: Patients included(21)

12. Are patients included in the production of patient resources in your hospital?	
Yes	❑
No (→ continue with question 17)	❑

If yes:

13. How are they included? *(Tick all that apply)*	
Patients participate in the co-creation of the resources produced	❑
Patients participate in the choice of method of delivery (e.g. leaflet, video etc) of the resources produced	❑
Patients participate in the review of the resources produced	❑

14. In what way are patient's needs fully accommodated in the production of patient resources (tick all that apply)	
Meetings take place in fully accessible locations	❑
Timing is organised too fully accommodate patient's needs	❑
Patients are provided with the necessary support to fully contribute	❑

15. Patient resources are…	Always	Sometimes	Never
… patient centred	❑	❑	❑
…available in print	❑	❑	❑
…available in form of video tapes	❑	❑	❑
…available in form of audio tapes	❑	❑	❑
…available on the internet	❑	❑	❑
…available in different languages	❑	❑	❑
…prepared in plain language	❑	❑	❑

16. Does the hospital provide training for staff in how to communicate with patients?	
Yes	❑
No (→ continue to question 19)	❑

If yes:

17. For each of the following practices, please indicate whether or not there is formal training provided in how to communicate with patients.	Physicians	Nurses	Administrative staff	No training available
How to encourage patients to ask questions, give their opinions and express concerns	❑	❑	❑	❑
Approaches for eliciting patients' values, goals and needs	❑	❑	❑	❑
How to create opportunities to hear from patients about their perspective of the care experience at the hospital	❑	❑	❑	❑
Using teach-back methods	❑	❑	❑	❑

3.2 Self-management

Source: PCMH assessment(22)

18. Please indicate which statement is most appropriate for your hospital (tick all that apply)	
Self-management support…	
…is accomplished by the distribution of information (pamphlets, booklets)	❑
…is accomplished by referral to self-management classes or educators.	❑
…is provided by goal setting and action planning with members of the practice team.	❑
…is provided by members of the practice team trained in patient empowerment and problem-solving methodologies.	❑

19. Are the following groups trained on teaching and encouraging patients regarding self-management?	None	Yes, some	Yes, all
Physicians [n=55]	❑	❑	❑
Nurses [n=55]	❑	❑	❑
Other Clinician Staff [n=53]	❑	❑	❑
Administrative Staff [n=52]	❑	❑	❑

3.3 Shared decision making

Source: PCMH assessment(22)

20. Please indicate which statements apply to your hospital		
Involving patients in decision-making and care…	Yes	No
…is a priority. [	❑	❑
…is accomplished by provision of patient education materials or referrals to classes.	❑	❑
…is supported and documented by practice teams.	❑	❑
…is supported by practice teams trained in decision-making techniques.	❑	❑

Source: Herrin(14)

21. Are patients provided with decision aids for various health conditions? ***Patient decision aids are informational health materials and literature that help people become involved in decision making by making explicit the decision that needs to be made, providing information about treatment options and outcomes, and helping the patient clarify personal values.***	
No	❑
Yes, for some diseases	❑
Yes, for all diseases	❑

Source: Herrin(14)

22. Are there formal training programmes provided to hospital staff on partnering with patients in the care plan decision-making process?	
Yes	❑
No (→ continue with question 26)	❑

If yes:

23. For which of the following groups does the hospital provide training on partnering with patients?	Yes	No
Training for physicians	❑	❑
Training for nurses	❑	❑
Training for administrators	❑	❑
Training for multidisciplinary groups	❑	❑

If yes:

24. How many of the following groups have received training on partnering with patients in the care plan decision-making process?	All	Almost all	Many	Some	Almost none	None
Physicians	❑	❑	❑	❑	❑	❑
Nurses	❑	❑	❑	❑	❑	❑
Other members of the healthcare team	❑	❑	❑	❑	❑	❑
Administrative Staff	❑	❑	❑	❑	❑	❑

25. Does your hospital have a policy to encourage greater participation of patients at interdisciplinary meetings?	
Yes for all diseases (→ continue to question 27)	❑
Yes for some diseases (→ continue to question 27)	❑
No (→ continue with question 28)	❑
The hospital does not have interdisciplinary meetings (→ continue with question 28)	❑

26. Are patients present at interdisciplinary meetings concerning their treatment plan?	
Yes, consistently	❑
Yes, occasionally	❑
Sometimes	❑
Never	❑

4 Organisational design

4.1 Patient committees

Source: Herrin(14)

27. Does your hospital have a patient committee?	
Yes	❑
No (→ continue with question 34)	❑

If yes:

28. How long has the hospital had the patient committee?	
Less than 12 months	❑
13 months to 24 months	❑
More than 25 months	❑

29. Does the patient committee have bylaws or a written charter?	
Yes	❑
No	❑

30. How many times has the patient committee met in the last 12 months?
_____

31. What percentage of the members of the patient committee are patients or family members of the patients?	
Less than 25 %	❑
25 to 50 %	❑
51 to 75 %	❑
More than 75%	❑

32. Do patients participate in other hospital committees? If so which ones? Feel free to add further information about patient committees and participation below.
_____ _____ _____ _____

4.2 Involvement of Family and Friends

33. Is there a written policy enabling patients to identify their preferences with respect to which family members or other individuals they would like to have actively involved during their stay in the hospital?	
Yes	❑
No (→ continue with question 37)	❑

If yes:

34. Is the policy implemented systematically?	
Yes	❑
No (→ continue with question 37)	❑

If yes:

35. How many units have the policy in place?	
Less than 25 %	❑
25 to 50 %	❑
51 to 75 %	❑
More than 75%	❑
The policy is in place in all units	❑

36. Does the hospital have a policy or guidelines that facilitate unrestricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference?	
Exist across all units	❑
Exists across some units	❑
Does not exist in any hospital unit	❑

4.3 Access to medical records

Source: Herrin(14)

37. Do patients have access to their medical records? (Tick all that apply)	
Yes, any time while in the hospital	❑
Yes, in the hospital but only with the authorisation of their physician	❑
Yes, anytime through an online portal	❑
Yes, anytime at patient's request (i.e., offline)	❑
No, patients do not have access to their medical records	❑

38. Is information given routinely to patients on how to access their medical records?	
Yes, patients are informed systematically	❑
Yes, but not systematically	❑
No	❑

39. Do patients have the right to edit their medical record?	
Yes	❑
No (→ continue with question 42)	❑

If yes:

40. Which part of the medical record can patients edit? (Tick all that apply)	
Who the patient's preferred family or partners in care are	❑
Demographic information	❑
Family medical history	❑
Allergic episodes	❑
Do not resuscitate (DNR) orders	❑
Advanced directives	❑
Any information	❑

41. Is there anything else you want to let us know about the handling of health records in your hospital? Feel free to add further information
_____ _____ _____ _____

4.4 Quality improvement

Source Lombarts (23)

42. Does the hospital have a mechanism in place to allow patients to give feedback?	
Yes	❑
No (→ continue to 47)	❑

43. What options are there for patients to give feedback?	
Patient surveys	❑
Suggestion box	❑
Official complaint office	❑
Written complaint form	❑
Online complaint form	❑
Other, please specify_____	❑

44. Does the hospital actively inform patients on their right to complain?	
Yes	❑
No	❑

45. Are patient complaints routinely analysed?	
Yes	❑
No	❑

Source: Herrin(14)

46. Overall: Are patients normally involved in forms of quality improvement in your hospital?	
Yes	❑
No (→ continue with question 52)	❑

If yes:

47. To what extent are patients involved in the following activities?	Never	Sometimes	Usually	Always
The development of quality criteria/ standards/protocols [n=32]	❑	❑	❑	❑
Quality commitees [n=33]	❑	❑	❑	❑
Quality improvement projects [n=33]	❑	❑	❑	❑
Discussion of results of quality improvement projects [n=33]	❑	❑	❑	❑

48. Has your hospital participated in the last few years in one or more external audits?	No	Yes, more than 4 years ago	Yes, between 2 and 4 years ago	Yes, less than 2 years ago	Yes, it's ongoing
Voluntary national audit	❑	❑	❑	❑	❑
Voluntary international audit	❑	❑	❑	❑	❑
Obligatory national audit	❑	❑	❑	❑	❑
Obligatory international audit	❑	❑	❑	❑	❑

49. When a root cause analysis (RCA) investigation is conducted, are patients routinely interviewed?	
Yes, always	❑
Yes, sometimes	❑
No, never	❑
We don't use root cause analysis in our hospital	❑

4.5 Advanced Technologies

50. Does your hospital use information technology/telehealth/mhealth (e.g. smart phone applications or patient physician portals) to support or promote patient partnership?	
Yes for all diseases	❑
Yes for some diseases	❑
No (→ continue with question 55)	❑

If yes:

51. In what areas of care are these tools used ?	
Patient-centred communication	❑
Shared-decision making	❑
Self-management/patient education	❑
Access to medical records	❑
Planning for consultation and care sessions	❑
Medical telemonitoring *(an act whereby a medical professional interprets the data necessary for the medical follow-up of a patient)*	❑
Other, please specify_____	❑

52. Please provide the names of the tools the hospital uses
_____
_____
_____

5 Education

5.1 Patient Experts

53. Does the hospital have patient experts, trained to work with other patients as part of patient education?	
Yes, for all chronic diseases	❑
Yes, for some chronic diseases	❑
No (→ continue with question 57)	❑

If yes :

54. For which diseases does your hospital have patient experts?	
Cardiovascular diseases	❑
Respiratory diseases	❑
Diabetes	❑
Cancer	❑
Other, please specify_____	❑

5.2 Patient participation in HCP training

55. Do patients participate in the training of health care professionals in your hospital?	
Yes	❑
No (→ continue with question 62)	❑

If yes:

56. For each of the following training areas, please indicate whether or not patients participate as *educators* in the training of *physicians, nurses, other health care professionals (HCP) and administration staff]*					
	Physicians	Nurses	Other HCP	Admin staff	not applicable
New employee orientation	❑	❑	❑	❑	❑
Continuing medical and paramedical education	❑	❑	❑	❑	❑
Non-clinical training programmes	❑	❑	❑	❑	❑
Partnering with patients and families in the care plan decision-making process	❑	❑	❑	❑	❑

57. For each of the following training areas, please indicate whether or not patients participate as *content developers* in the training of *physicians, nurses, other health care professionals (HCP) and administration staff*					
	Physicians / pharmacists	Nurses	Other HCP	Admin staff	trainng course does not exist
New employee orientation	❑	❑	❑	❑	❑
Continuing medical and paramedical education	❑	❑	❑	❑	❑
Non-clinical training programmes	❑	❑	❑	❑	❑
Partnering with patients and families in the care plan decision-making process	❑	❑	❑	❑	❑

58. Does the hospital provide formal training to the patients who participate in education and content development?	
Yes	❑
No	❑

6 Research

59. Does the hospital participate in research?	
Yes	❑
No (→ end of questionnaire)	❑

If yes:

60. Does the hospital have a policy to including patients in the full research cycle from discussion of grant proposal until dissemination of results?	
Yes, in the whole research cycle	❑
Yes, in parts of the research cycle	❑
No (→ continue with question 66)	❑

If yes:

61. Is the policy implemented systematically?	
Yes	❑
No (→ continue with question 66)	❑

If yes:

62. How many units have the policy in place?	
Less than 25 %	❑
25 to 50 %	❑
51 to 75 %	❑
More than 75%	❑
The policy is in place in all units	❑

63. Does your hospital have a policy in place to keep patients informed about opportunities to participate in research?	
Yes	❑
No (→ continue with question 69)	❑

If yes:

64. Is the policy implemented systematically?	
Yes	❑
No (→ continue with question 69)	❑

If yes:

65. How many units have the policy in place?	
Less than 25 %	❑
25 to 50 %	❑
51 to 75 %	❑
More than 75%	❑
The policy is in place in all units	❑

66. If you have any further remarks about patient participation in research please include them here.
_____ _____ _____

Thank you for participating!