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# Evidence-based health information about pulmonary embolism: Assessing the quality, usability and readability of online and offline patient information

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## ABSTRACT

**Objective:** Pulmonary embolism (PE) is the third most common cardiovascular disease worldwide. However, public awareness is considerably lower than for myocardial infarction or stroke. Patients suffering from PE complain about the lack of (understandable) information and express high informational needs. To uncover if reliable information is indeed scarce, this study evaluates the quantity and quality of existing patient information for tertiary prevention using an evidence-based health information paradigm.

**Methods:** We conducted a quantitative content analysis ( $n = 21$  patient information brochures;  $n = 67$  websites) evaluating content categories addressed, methodical quality, usability, and readability.

**Results:** Results show that there is not enough patient information material focusing on PE as a main topic. Existing patient information material is mostly incomplete, difficult to understand, and low in actionability as well as readability.

**Conclusion:** Our systematic analysis reveals the need for more high-quality patient information on PE as part of effective tertiary prevention.

**Innovation:** This is the first review analyzing content, methodical quality, readability, and usability of patient information on PE. The findings of this analysis are guiding the development of an innovative, evidence-based patient information on PE aiming to support patients' informational needs and their self-care behavior.

## HIGHLIGHTS

- Quantitative content analysis of patient information on pulmonary embolism
- Pulmonary embolism is hardly addressed as a main topic in information material
- Content on patients' experiences and consequences of pulmonary embolism on social and financial aspects is missing
- A minority of patient information is understandable, none is actionable, and the reading levels are above standard
- High-quality information must be developed with patients, integrating evidence-based criteria and patients' needs

## 1. Introduction

Public awareness about cardiovascular diseases is focused on myocardial infarction or stroke, while pulmonary embolism (PE) as the third most frequent acute heart-related disease worldwide receives less attention [1,2]. This is surprising given increasing incidence rates in high-income countries [3,4], high early mortality rates [5], and long-term physical [6] and psychological health consequences [7,8,9,10]. In Germany, women tend to suffer more often from PE than men [11,12], and the risk for PE

increases with age [12]. While clinical practice for the treatment of PE has improved continuously [13] and fulfills patients' needs regarding medical care in hospital [14], patients still feel left alone and not prepared for the physical and psychological consequences after experiencing PE [7,9,14].

Qualitative research already shows that patients suffering from PE express high informational needs during as well as after their hospital stay [9,10]. Particularly information about self-care behavior, long-term health effects as well as psychological problems are in demand [7,8,10]. To deal

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with the information deficit, patients search for health information online; however, search results are often described as unhelpful, scary, upsetting or distressing [7,8,10]. These negative search experiences may be an indicator for the scarcity of available information and a low quality or usability. While deficits in available patient information on PE are likely to reduce information usage and self-management of the disease, high quality patient information is essential for patients' self-care behavior [15,16,17,18].

Especially patients with lower health literacy [19,20] and older patients, which are the majority of PE patients [12,21], regularly struggle with searching and accessing (online) health information [22]. Therefore, providing patients with information should be a key point in the health care process, e.g., by handing out printed information before hospital discharge [14]. Accordingly, easily accessible information is required that 1) addresses relevant contents, 2) is of high methodical quality and 3) is usable and 4) readable for patients with different health literacy levels [15].

These four evaluation dimensions (see table 1) are independent but related aspects of patient information. The evaluation of content categories detects the scope of information material, potential deficits, and helps to decide whether existing patient information has the potential to fulfill informational needs of patients [15,17]. However, two aspects are not considered in existing assessment instruments that are exceptionally relevant for PE patients: causes of PE and patient narratives. Results from qualitative research with PE patients show that uncertainties about the cause are an important aspect of patients' anxieties [8,9]. Further, given the complex informational needs of PE patients, a combination of factual information and patient narratives seems promising [23,24,25]. Systematic reviews and meta-analyses indicate that patient narratives have various beneficial effects on patients, by e.g. enhancing recall and engagement with health information [26,27], providing emotional support and role models [27], or increasing intentions for different types of health behavior [28,29]. However, the use of narratives in patient information is discussed controversially due to their lack of neutrality [30]. Yet, it may be particularly relevant for PE patients to provide role models and emotional support, considering the impairments with daily life activities as well as persistent worries and distress [8,9].

The methodical quality of patient information covers the reliability of health information, assessing among others whether the information is biased, accurate and evidence-based [16,31]. The demands of patient information on health-literacy are reflected in its usability and readability [15]. The usability of patient information typically refers to two aspects: understandability and actionability. Patient education material is considered as understandable when "consumers of diverse backgrounds and varying levels of health literacy can process and explain key messages" [32,p. 1]. Actionability reflects whether the material recommends concrete actions for patients [32]. The readability of patient information is typically considered as a prerequisite for its usability [33]. If reading difficulty is too high, particularly patients with moderate or lower levels are not able to use the information to their advantages [15].

While several studies have evaluated the quality, usability, or readability of online and offline patient information on other cardiovascular diseases, e.g., stroke [34], heart failure [15,17,35,36], cardiovascular risks [37],

cardiovascular prevention [38], none has addressed PE. Therefore, this study evaluates all four evaluation dimensions of PE patient information.

2. Methods

2.1. Sample

Based on systematic research, we included a total of 21 brochures and 67 websites (fig. 1). Materials had to be written in German, be printable (online audiovisual information was excluded) and available free of charge, address patients (and not medical experts), and cover PE as a main or side topic.

For the sample of brochures, we contacted twelve German health institutions (10 health insurances, Ärztliches Zentrum für Qualität in der Medizin – ÄZQ, and Bundeszentrale für gesundheitliche Aufklärung – BZgA) by e-mail. Eleven answered but could not provide print-materials. Additionally, we searched Google using the search terms *PE brochure* and *PE flyer* and included hits on the first ten pages (eliminating duplicates). The sample of websites was based on a list of typical online patient information material providers by ÄZQ [39]. ÄZQ is a German competence center, offering information services on e.g., patient information. The list includes e.g., health websites, two search engines ([www.google.de](http://www.google.de) – first 10 pages – and [www.medinfo.de](http://www.medinfo.de)), and a medical link dictionary ([www.best-med-link.de](http://www.best-med-link.de)). We searched all providers on the list with the search term *pulmonary embolism* (see appendix for the full website sample).

2.2. Procedure

We conducted a quantitative content analysis to assess all brochures and websites. We used the established and tested coding instructions for Check-In and PEMAT-P. We derived coding instructions for the content categories from the guideline for evidence-based health information (GEHI) [30]. After familiarizing with all measures, two trained coders independently coded all materials using excel-sheets. During coding, coders discussed differences and agreed upon a final coding. We calculated Cohen's kappa ( $\kappa$ ) and Holsti's method (CR) for inter-coder reliability. Flesch-Reading-Ease-Score was calculated separately.

2.3. Measures

2.3.1. Content categories

14 items (fig. 2) assessed content categories based on GEHI [30]. These include information about diagnosis, risk of disease, prognosis, treatment options, medical, psychosocial, and financial consequences [30,40]. We coded all items dichotomously (0 = *criterion not met*, 1 = *criterion met*) and computed a sum index. We reached substantial inter-rater reliability [41] for the content assessment of the brochures ( $\kappa$  = .78, CR = .95) and websites ( $\kappa$  = .70, CR = .94).

We added two extra content categories to the existing 14: causes of PE and existence of patient narratives (16 content items in total). Causes were coded (same coding instructions as above) when the material mentioned how PE occurs, e.g., by a blood clot lodging in the lung. Patient narratives were coded when insights into patients' individual experiences were given from the perspective of a patient.

2.3.2. Assessment of methodical quality

Methodical quality was assessed with the Check-In instrument [31], a revised version of DISCERN [16]. In contrast to DISCERN, which sometimes shows low inter-rater agreements for non-medical coders [42], the Check-In instrument fits to this target group. The instrument includes 28 items (6 only for online information). Items cover six quality dimensions: (1) scope and purpose, (2) involvement of stakeholders, (3) accuracy of development, (4) editorial independence, (5) clarity and design, (6) web-specific features. Coders rated all 28 items (fig. 2) dichotomously (0 = *item not fulfilled*, 1 = *item fulfilled*). Patient material is considered suitable for usage when it fulfills *mandatory items* (fig. 3) as well as the *majority of*

**Table 1**  
Four assessment dimensions.

Assessment dimension	Definition
Content categories	This dimension assesses different categories of contents that are addressed in patient information material. The categories determine the (content-related) scope and relevance of the patient material.
Methodical quality	This dimension determines how reliable the patient information is. It mainly focuses on the accuracy of the provided information and development process.
Usability	This dimension encompasses how understandable the patient information is and how easy it is to act on suggested actions.
Readability	This dimension assesses the readability based on the sentence structure of patient information material.

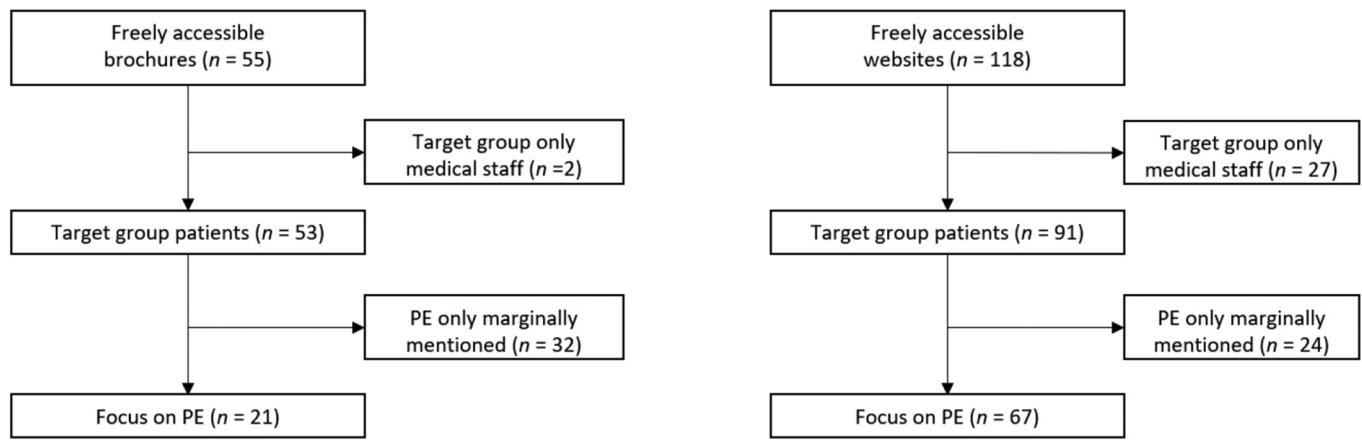


Fig. 1. Study flow diagram of brochures (left) and websites (right).

Note. PE = pulmonary embolism

the items [see 31 for details]. In case the criteria majority of items is fulfilled, but the mandatory items are not fulfilled, the material is recommended as background information [31]. Inter-rater reliability is high for brochures ( $\kappa = .83$ , CR = .94), and almost substantial for websites ( $\kappa = .59$ , CR = .93).

### 2.3.3. Assessment of usability

The Patient Education Materials Assessment Tool for Print Material (PEMAT-P) [32] was used to assess understandability (17 items) and actionability (7 items, fig. 4). Again, items were coded dichotomously (0 = criterion not fulfilled, 1 = criterion fulfilled). There is some overlap with individual items of the PEMAT-P and the Check-In instrument. However, the entirety of the PEMAT-P evaluates the usability, while the Check-In instrument focuses on methodical quality. Patient material is considered 1) understandable and 2) actionable according to PEMAT-P if it meets at least 70 % of the criteria [43]. Reliability for understandability of brochures is good ( $\kappa = .76$ , CR = .90) and moderate for websites ( $\kappa = .56$ , CR = .87). Reliability for actionability is very good for brochures ( $\kappa = .81$ , CR = .95) and substantial for websites ( $\kappa = .77$ , CR = .78).

### 2.3.4. Assessment of readability

We calculated the Flesch-Reading-Ease-Score (FRES) using an online Flesch-index calculator for German language [44], which is based on the adaption of FRES [45] for German language by Amstad [46]. Scores range from 0 to 100, where seven different score intervals translate to readability, e.g., 0 – 29 very difficult, 30 – 49 difficult or 90 – 100 very easy [47].

## 3. Results

The most common editors of the brochures were associations, foundations, or patient organizations (42.86 %,  $n = 9$ ), followed by pharmaceutical and medical technology companies (33.33 %,  $n = 7$ ), and medical doctors or clinics (23.81 %,  $n = 5$ ). For the websites, the three most common editors were ad-supported websites 28.36 % ( $n = 19$ ), followed by associations, foundations, or patient organizations (26.87 %,  $n = 18$ ), and medical doctors or clinics (25.37 %,  $n = 17$ , see table 2 for a full overview of the editors). Among this last editor type was one health insurance company.

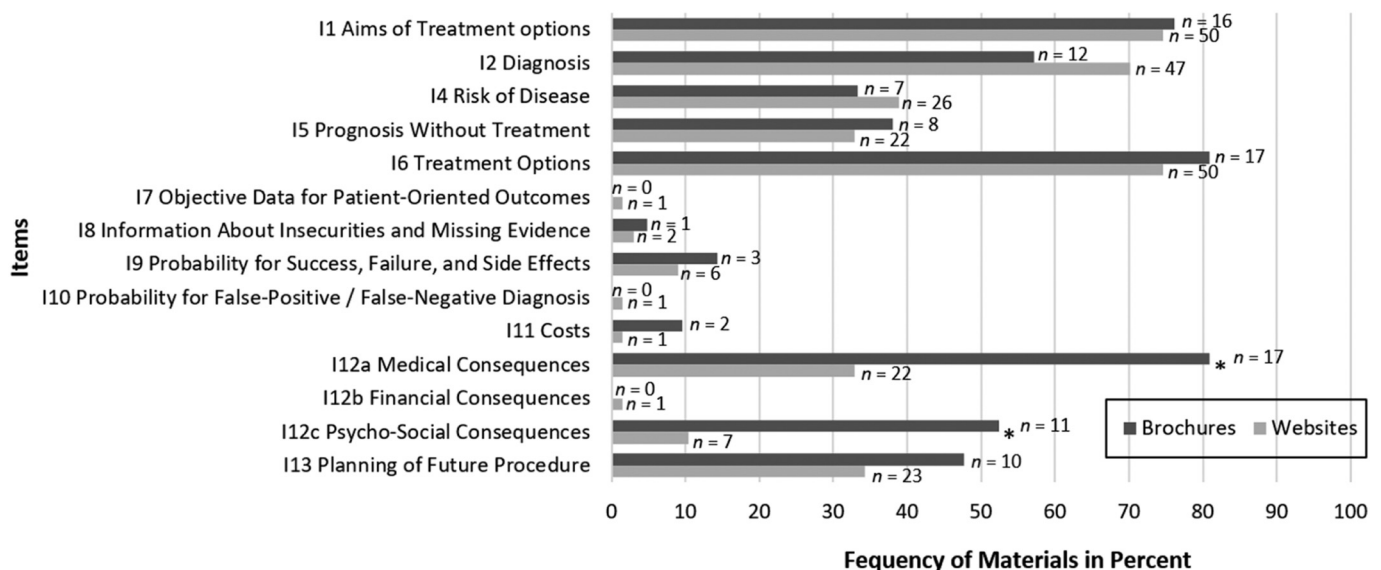


Fig. 2. Quality criteria for online and offline patient information according to the guidelines for evidence-based health information (GEHI).

Note. \*brochures and websites differ at the  $p < .005$  level, using chi-square tests.

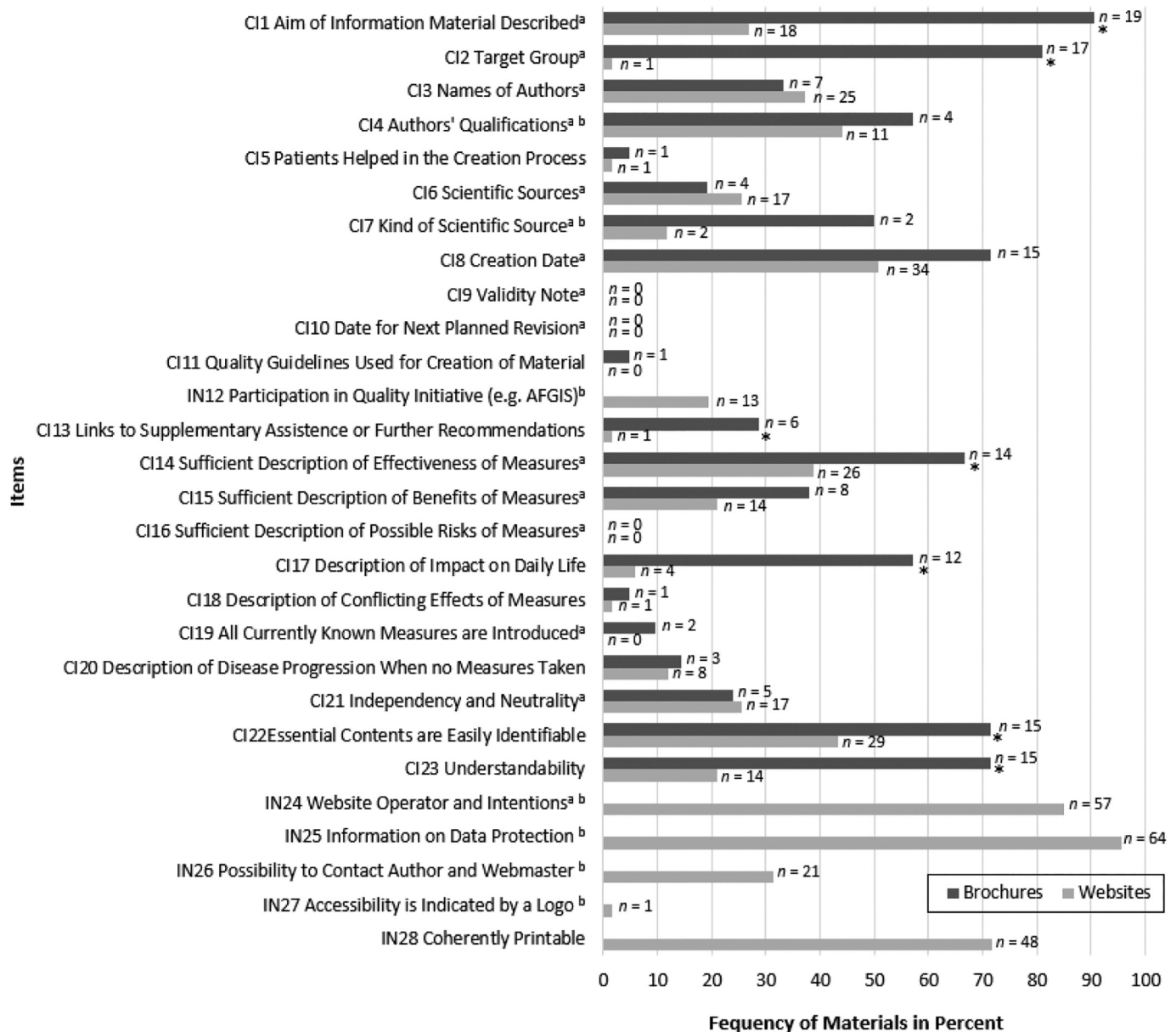


Fig. 3. Percentages of Check-In items for brochures and websites.

Note. IN = only applicable to web sources; <sup>a</sup> = obligatory items for recommending the material, <sup>b</sup> = option item not applicable, \* = brochures and websites differ at the  $p < .005$  level, using chi-square tests

### 3.1. Content categories

Only two brochures addressed PE as main topic, while all other brochures focus on topics like deep vein thrombosis or anticoagulants (90.48 %, see table 3). Unlike brochures, 56 (83.58 %) websites treat PE as a main topic.

Only one brochure and three websites cover more than 50 % of the content categories. On average, brochures cover more contents ( $M = 35.37$  %,  $SD = 17.42$  %,  $n = 21$ ) than websites ( $M = 27.61$  %,  $SD = 15.38$  %,  $n = 67$ ),  $t(86) = 1.96$ ,  $p = .054$ , but there are no significant differences between editor types,  $F(4,83) = 1.00$ ,  $p = .413$ .

Most brochures and websites provide medical facts about *treatment options* or *diagnosis* (fig. 2). Particularly, topics that are relevant for daily life are rarely addressed, e.g., *patient-oriented outcomes* (I7) or *financial consequences* (I12b). Differences between print materials and websites are visible in two dimensions: While only about one third of the websites

(32.84 %,  $n = 22$ ) covers *medical consequences* (I12a), most brochures (80.95 %,  $n = 17$ ,  $\chi^2(1) = 15.00$ ,  $p < .001$ ) do so. Similarly, 52.38 % ( $n = 11$ ) of the brochures address *psycho-social consequences* (I12c), but only 10.45 % of the websites do so ( $n = 7$ ,  $\chi^2(1) = 17.28$ , Fisher's exact test  $p < .000$ ).

Regarding narratives, the analysis shows that only one brochure and none of the websites contain *patient narratives* (I16). The second extra content category, *causes of PE* (I3), was fulfilled by most brochures (85.71 %,  $n = 18$ ) and websites (97.01 %,  $n = 65$ ,  $\chi^2(1) = 3.81$ , Fisher's exact test  $p = .086$ ).

### 3.2. Methodical quality of patient information

On average, offline information meet one third of the methodical quality dimensions ( $M = 34.66$  %,  $SD = 13.68$  %,  $n = 21$ ), whereas websites only meet one fourth of them ( $M = 24.17$  %,  $SD = 12.62$  %,  $n = 67$ ),  $t(86) = 2.15$ ,  $p = .034$ .



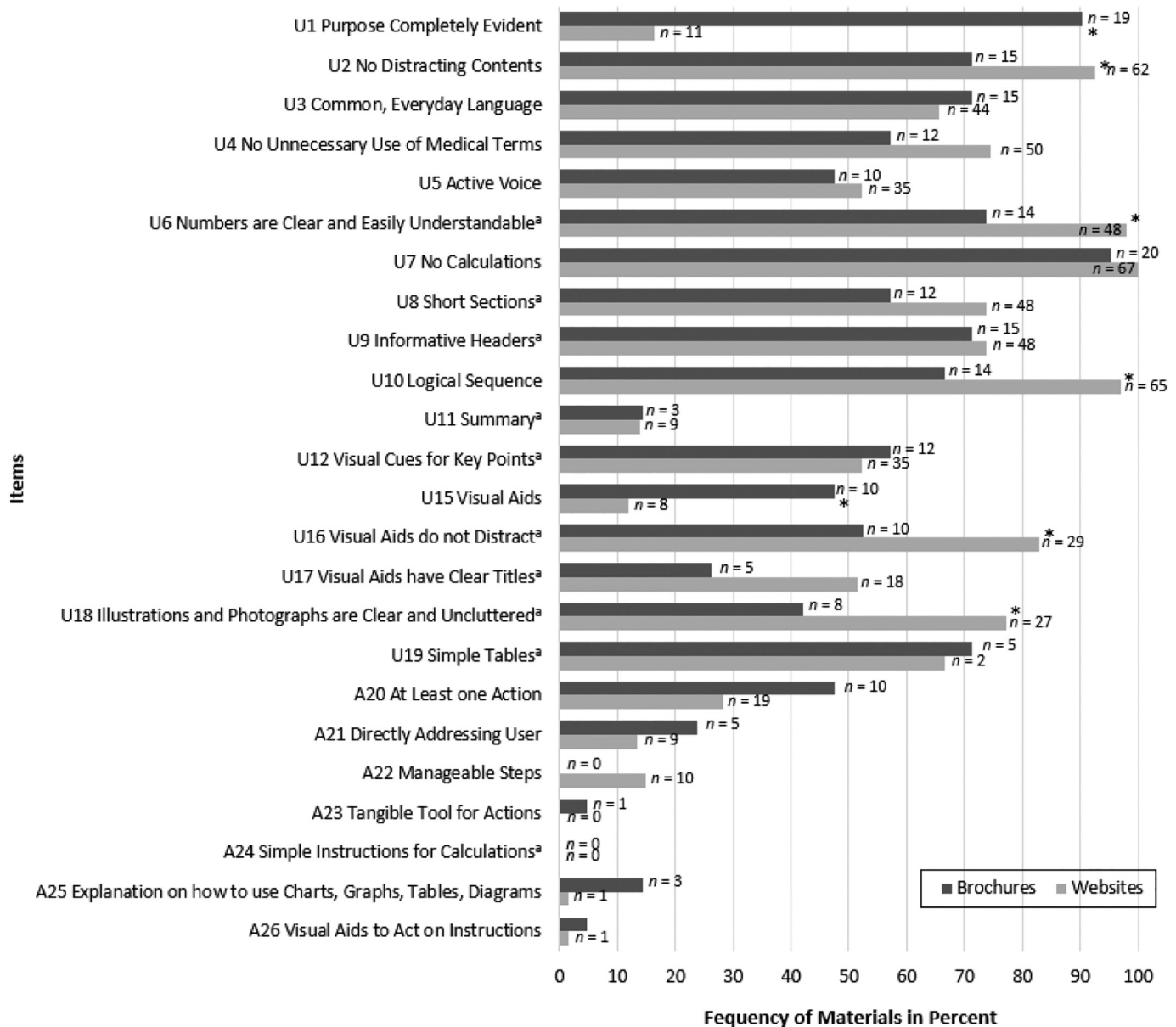


Fig. 4. Percentages of PEMAT-P items for brochures and websites

Note. <sup>a</sup> option item not applicable, \* brochures and websites differ at the  $p < .005$  level, using chi-square tests.

$n = 67$ ),  $t(86) = 3.26$ ,  $p = .002$ . According to the overall assessment, none of the materials is fully suitable and only two brochures and two websites qualify as background information. There are no differences in the overall score of methodical quality between the editor types,  $F(4,83) = 0.58$ ,  $p = .680$ .

Most of the brochures present their scope and purpose well: They describe the *aim of the information material* (CI1: 90.48 %,  $n = 19$ , fig. 3)

and clearly *address the target group* (CI2: 80.95 %,  $n = 17$ ), while most of the websites fail to do so (CI1: 26.87 %,  $n = 18$ ,  $\chi^2(1) = 26.55$ ,  $p < .001$  CI2: 1.49 %,  $n = 1$ ,  $\chi^2(1) = 62.04$ , Fisher's exact test  $p < .001$ ). The websites performed best on some of the items that are specific for online material (IN24, IN 25 and IN28). There are some items that were neither met by any brochure nor website, e.g., a *date for the next revision* (CI10) or a *validity note* (CI19).

Table 2

Editor types for brochures and websites.

Editor type	Brochures in % (n)	Websites in % (n)
Associations, foundations, or patient organizations	42.86 (9)	26.87 (18)
Pharmaceutical and medical technology companies	33.33 (7)	10.45 (7)
Medical doctors or clinics	23.81 (5)	25.37 (17)
Add-supported websites	.	28.36 (19)
Other	.	8.96 (6)
Total	100 (21)	100 (67)

Table 3

Overview PE brochures and websites.

Topic	Frequency of brochures in % (n)	Frequency of websites in % (n)
PE as main topic	9.52 (2)	83.58 (56)
Thrombosis in general and PE as sub-topic	61.90 (13)	14.93 (10)
Anticoagulants and PE as sub-topic	28.57 (6)	1.49 (1)
Total	100 (21)	100 (67)

### 3.3. Usability assessment

Results for the PEMAT-P show a mean score for understandability of  $M = 58.98\%$  for the brochures ( $SD = 18.52\%$ ,  $n = 21$ ,  $\max = 93.75\%$ ,  $\min = 14.29\%$ ) and  $M = 63.08\%$  for the websites ( $SD = 13.43\%$ ,  $n = 67$ ,  $\max = 93.75\%$ ,  $\min = 30.77\%$ ), with no differences between both types of information,  $t(86) = -1.11$ ,  $p = .270$ . There was however a significant difference between the editor types,  $F(4,83) = 2.71$ ,  $p = .035$ . Games-Howell post-hoc tests reveal that ad-supported websites ( $M = 69.30\%$ ,  $SD = 13.24\%$ ,  $n = 19$ ) show a higher understandability than information from medical doctors or clinics ( $M = 55.37\%$ ,  $SD = 13.75\%$ ,  $n = 21$ ),  $p = .019$ . Only four brochures and 19 websites fulfill more than 70 % of the requirements and are understandable, according to the PEMAT-P instrument [34].

Over 70 % of the brochures and websites do not expect users to perform calculations (U7) and have informative headers (U9, fig. 4). Most of the brochures also make their purpose completely evident (U1) however, this criterion is only addressed by a minority of the websites (16.42 %,  $n = 11$ ,  $\chi^2(1) = 39.03$ ,  $p < .001$ ). On the contrary, more websites (92.54 %,  $n = 62$ ) than brochures (71.43 %,  $n = 15$ ) do not include distracting information (U2;  $\chi^2(1) = 6.51$ , Fisher's exact test  $p = .019$ ). A summary of the key points is rarely provided (U11).

Actionability is rather low on all dimensions with no significant differences between websites ( $M = 11.74\%$ ,  $SD = 20.00\%$ ,  $\max = 66.67\%$ ,  $\min = 0\%$ ) and brochures ( $M = 17.30\%$ ,  $SD = 21.36\%$ ,  $\max = 60.00\%$ ,  $\min = 0\%$ ), or editor types,  $F(4,83) = 0.84$ ,  $p = .501$ . None of the information materials reach the requirements for actionability by fulfilling at least 70 % of the items [34]. Only about 47.62 % of the brochures and 28.36 % of the websites at least describe one action patients may take (A20). Information on tangible tools for actions (A23), and visual aids to act on instructions (A26) are missing.

### 3.4. Readability assessment

The Flesch-Reading-Ease-Score (FRES) shows different results for brochures and websites. While most of the brochures are difficult to read ( $M = 1.05$ ,  $SD = 0.38$ ,  $n = 21$ ), most of the websites performed even worse and are categorized very difficult or difficult to read ( $M = 0.81$ ,  $SD = 0.53$ ,  $n = 67$ ,  $t(45.93) = 2.28$ ,  $p = .027$ , fig. 5). Editor types differ regarding readability,  $F(4,83) = 3.34$ ,  $p = .014$ : pharmaceutical and technology companies provide material that is easier to read ( $M = 1.07$ ,  $SD = 0.26$ ,  $n = 15$ ) than material from medical doctors or clinics ( $M = 0.57$ ,  $SD = 0.51$ ,  $n = 21$ ),  $p = .005$ .

## 4. Discussion and conclusion

### 4.1. Discussion

Given long-term health consequences and high informational needs of patients after acute PE, patient information is essential to support the self-care behavior of patients. Overall, the quality of all evaluated patient information

is rather low. This is in line with empirical results on patient information regarding other cardiovascular diseases [15,34,35,38,48] or cancer [49].

In terms of content categories, findings show that hardly any brochure and only half of the websites address PE as a main topic. This is consistent with the perceived lack of information patients reported in qualitative studies [8,9,10]. Specifically, effects of PE on daily life (e.g., financial or psychosocial consequences) are rather scarce. This is also reflected by the absence of patient narratives that are only included in one case. This focus on general medical facts and negligence of daily life information echoes results by Lee et al. [17] for online heart failure information.

In line with the limited coverage of content categories, the methodical quality is also rather low, including some criteria that are not addressed once. Therefore, only two brochures and two websites qualify as background information, while none is fully suitable.

In terms of understandability, less than a third of the websites and one fifth of the brochures turned out to be understandable, while none of the cases can be considered actionable regarding the PEMAT-P recommendation [43]. These results are comparable with information about heart failure [15,17] as well as online decision aids for cardiovascular disease prevention [38]. Decision aids for primary cardiovascular disease prevention were evaluated slightly better in terms of understandability [38]. It is possible that such primary prevention measures are more easily described in a usable manner, compared to PE or heart failure information that addresses tertiary prevention needs.

Regarding readability, none of the materials provided information on a standard reading level. This is consistent with several empirical studies analyzing the reading level of online patient information on cardiovascular diseases [15,34,35,48]. Especially patients with moderate or lower levels of health literacy may have difficulties to understand the information. Given that, lower health literacy is also related to higher cardiovascular risks [50] there is a strong need to provide easily readable patient information [48].

To deal with the problem of limited access to relevant, high-quality, readable, and usable patient information, Waring et al. [51] recommend clinicians to directly refer patients hospitalized for acute coronary symptoms to evidence-based online sources. However, this presupposes that such sources exist. Given that neither of the evaluated materials performed well on all dimensions, the priority is to develop high-quality and usable patient information that is understandable for patients with different health literacy levels.

A limitation of our results is that we only included text-based online and offline information. Other formats like documentations, short videos, or podcasts were not considered. Written information material has the advantage, that it may be easily integrated in the professional care process (e.g., by handing out a brochure to patients before hospital release) and that it may be used by patients of all age-groups. Even if online health information becomes more and more popular for older patients, there is still a relevant group of older patients that do not use the internet for health information search, making video clips or podcasts not available for them [52]. In addition, older patients are often faced with barriers when using online information alone [22]. Given that the likelihood to suffer from PE increases with age, printed information material seems to be of high relevance for that age group.

However, some patients might prefer content that is not text-based for several reasons, or just read, watch, and listen to anything related to the topic they can find. Especially audiovisual online-content (e.g., short TikTok-videos) becomes more and more popular for various health topics [53,54] and may provide patients with more easily accessible material on PE. This may be relevant for patients with lower health literacy [55], or younger patients [53] and should therefore be investigated in future research [17].

Related to this, our focus was on information material edited by different health institutions but not by users themselves. We chose this type of information since this has the potential to fulfill evidence-based criteria in more detail. However, user generated online information in social media

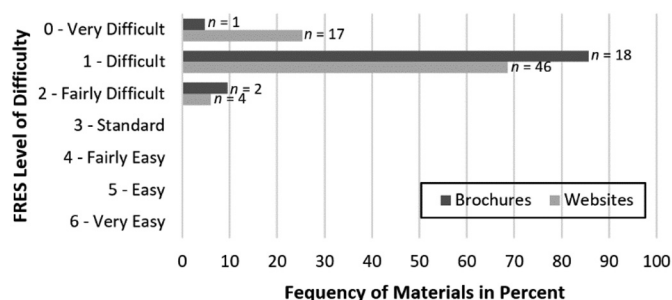


Fig. 5. Percentages of FRES levels for brochures and websites

may be a relevant source for PE-patients, in particular younger age groups, to gain peer support and should be evaluated in future research, too.

Furthermore, our analysis is restricted to German information. Thus, we cannot make any general conclusions about PE patient information in other countries and languages. While European Guidelines [13] aim to ensure comparable levels of acute hospital care in European countries, the availability of patient information may differ depending on how institutionalized and therefore quality-controlled the distribution of patient information is. However, given the comparable results to other types of cardiovascular diseases, which are from a variety of countries, it seems likely that high-quality, evidence-based health information is rare, even across different countries. Future studies should address this aspect and compare patient information on PE in different countries.

In addition, we focused on material addressing PE as main topic. However, patients often suffer from comorbidities [12] such as in-hospital surgery, arterial hypertension, deep venous thrombosis, heart failure, cancer, or diabetes mellitus [11]. Future studies should include patient information on typical comorbidities and examine whether they refer to PE as well.

Lastly, we included text-based online and offline information in our study. Although both are text-based, they differ in their design possibilities. Websites are infinitely editable, can display multimedia or audiovisual formats, and offer the possibility to in-depth information presentation through hyperlinks. Brochures are finite and limited in space. Therefore, online, and offline information material might serve different needs of patients [49], which should be addressed in further studies.

#### 4.2. Innovation

This content analysis systematically evaluated existing patient information on PE based on dimensions relevant for patients. Patient information about PE is essential for self-management behavior after hospital release, however, to our knowledge, patient information on this topic has not yet been systematically analyzed.

We combined four unique but related assessment dimensions: content categories, methodical quality, usability, and readability of online and offline patient information. While often empirical studies focus on one or two of the categories, a combination of all four evaluation dimensions delivers an extensive and patient-oriented perspective on existing information. The combination of evaluative dimensions indicates that deficits of existing patient information are not limited to weaknesses on a single

dimension, but manifest on multiple dimensions. We therefore argue that a systematic development of patient information must more strictly follow information guidelines, needs to consider informational needs of patients as a central backbone and apply a patient-centered perspective. In our analysis, we highlighted content categories that target information on living with the disease by separately assessing if medical, psychological, or financial consequences are addressed – originally captured in a single item [30]. We also expanded the instrument to include causes and patient narratives to strengthen the patient-centered perspective.

#### 5. Conclusion

Overall, our results emphasize the need to develop high-quality and usable patient information on PE, which is at a minimum understandable for most patients. Based on established instruments, we offer several ideas on how to improve patient information. It is evident that there is a need for patient information material that covers PE as a main topic and that provides not only basic information on treatments and symptoms, but also offers in-depth information about how PE affects everyday life. These findings guide the development of an innovative, evidence-based patient information on PE, by identifying the major shortcomings of existing patient information. In particular the combination of providing evidence-based, complex content on diverse relevant categories in a readable and usable way seems to be most challenging.

Given the shortcomings of existing patient information on PE, it remains essential that health-care providers talk with patients about their informational needs and alert patients about the deficits of existing patient information. The aim should be that patients are motivated to engage in self-care behavior and feel empowered to take an active role in medical decision making. Lastly, high-quality evidence-based information should be developed as soon as possible.

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#### Disclosure statement

The authors report there are no competing interests to declare.



## Appendix A. Sample list for brochures and websites

Brochures				
No.	Editor	Title		Year
1	Deutsche Atemwegsliga	Lungenembolie. Informationsblatt		2019
2	Aktionsbündnis Thrombose	Thrombose? Das trifft doch nur die anderen! Tiefe Beinvenenthrombose und Lungenembolie – eine unterschätzte Lebensgefahr. Informationen für Patienten und Angehörige		.
3	Deutsche Atemwegsliga e.V.	Thrombose und Lungenembolie auf Reisen		2011
	Deutsche Lungenstiftung e.V.			
4	Bayer (Schweiz) AG	Tiefe Venen-Thrombosen und Lungenembolie. Ein kleiner Ratgeber zur Behandlung und Vorbeugung		2016
5	Bayer	Ein kleiner Ratgeber – Behandlung und Vorbeugung. Tiefe Venen-Thrombose und Lungenembolie		2018
6	Schweizerische Herzstiftung	Venenthrombose und Lungenembolie. Patienteninformation		2011
7	Deutsche Gesellschaft für Angiologie, Gesellschaft für Gefäßmedizin e.V.	Thrombose und Lungenembolie. Venen-Ratgeber		2015
8	Bayer (Schweiz) AG	Aufklärungsbroschüre. Tiefe Venenthrombose und Lungenembolie		2019
9	Bundesverband für Gesundheitsinformation und Verbraucherschutz – Info Gesundheit e.V.	Thrombose. Die unterschätzte Gefahr. Informationsbroschüre für Patienten		2018
10	Bayer Vital GmbH	Ein kleiner Ratgeber: Aktiv gegen Thrombose		
11	MediClin Klinik am Rennsteig	Venenthrombose und Embolie – Erkennen und Behandeln		2015
12	Deutsche Gesellschaft für Kardiologie – Herz- und Kreislaufforschung e.V.	Pocket-Leitlinien. Diagnose und Therapie der akuten Lungenembolie		2009
13	Thrombose-Initiative e.V.	Thromboserisiken erkennen und handeln		.
14	Bayer Vital GmbH	Ein kleiner Ratgeber – Behandlung und Vorbeugung: Tiefe Venen-Thrombose und Lungenembolie		.
15	Boehringer Ingelheim	Informationsbroschüre: Tiefe Venenthrombose und Lungenembolie. Therapieoptionen und Prävention bei Thrombosen und Embolien		.
16	Krankenhaus der Barmherzigen Brüder Trier	Leben mit Gerinnungshemmern. Informationen für Patienten, Angehörige und Interessierte.		2016
17	Universitätsmedizin Göttingen	Gerinnungshemmer. Eine Broschüre für Patienten und Angehörige		2010
18	Labors.at	Blutverdünnung – Orale Antikoagulanzen (Oak). Einflussfaktoren   Wissenswertes   Therapie		2015
19	Schweizerische Herzstiftung	Die Gerinnungshemmung. Die Patienteninformation		2016
20	Dr. med. Hannelore Rott	Marcumar. Gut leben mit Gerinnungshemmern – ein Patientenratgeber		2011
21	UNIVERSITÄTSKLINIKUM Schleswig-Holstein	Gerinnungshemmer – das muss ich wissen!		2010
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2	Stiftung Warentest	Lungenembolie – oft verkannt, aber lebensgefährlich	2017	<a href="https://www.test.de/medikamente/Medikamente-im-Test-lungenembolie-oft-verkannt-aber-lebensgefahrlisch-2999885-0/">https://www.test.de/medikamente/Medikamente-im-Test-lungenembolie-oft-verkannt-aber-lebensgefahrlisch-2999885-0/</a>
3	Gute Pillen – schlechte Pillen	Lungenembolie: Viel sitzen erhöht das Risiko	2011	<a href="https://gutepillen-schlechtepillen.de/kurz-und-knapp-lungenembolie-viel-sitzen-erhoeht-das-risiko/">https://gutepillen-schlechtepillen.de/kurz-und-knapp-lungenembolie-viel-sitzen-erhoeht-das-risiko/</a>
4	Dr. Grumpert.de	Lungenembolie	2020	<a href="https://www.dr-grumpert.de/html/lungenembolie.html">https://www.dr-grumpert.de/html/lungenembolie.html</a>
5	Charité	Pulmonale Hypertonie	.	<a href="https://kardio-cvk.charite.de/fuer-patienten/ambulante-behandlung/pulmonale-hypertonie/">https://kardio-cvk.charite.de/fuer-patienten/ambulante-behandlung/pulmonale-hypertonie/</a>
6	Netdoktor	Lungenembolie	2018	<a href="https://www.netdoktor.de/krankheiten/lungenembolie/">https://www.netdoktor.de/krankheiten/lungenembolie/</a>
7	apotheken.de	Lungenembolie	2019	<a href="https://www.apotheken.de/krankheiten/4283-lungenembolie">https://www.apotheken.de/krankheiten/4283-lungenembolie</a>
8	Medpertise	Lungenembolie, Lungeninfarkt	2020	<a href="https://www.medpertise.de/lungeninfarkt-lungenembolie/">https://www.medpertise.de/lungeninfarkt-lungenembolie/</a>
9	Lifeline – das Gesundheitsportal	Lungenembolie: Anzeichen, Ursachen & Behandlung	2018	<a href="https://www.lifeline.de/krankheiten/lungenembolie-id44143.html">https://www.lifeline.de/krankheiten/lungenembolie-id44143.html</a>
10	Deximed – Hausarztwissen online	Lungenembolie (Blutgerinnsel in der Lunge)	2020	<a href="https://deximed.de/home/b/herz-gefuesse-kreislauf/patienteninformationen/thromboseerkrankungen/lungenembolie">https://deximed.de/home/b/herz-gefuesse-kreislauf/patienteninformationen/thromboseerkrankungen/lungenembolie</a>
11	Apotheken Umschau	Lungenembolie: Symptome, Ursachen, Behandlung	2019	<a href="https://www.apotheken-umschau.de/krankheiten-symptome/atemwegserkrankungen/lungenembolie-symptome-ursachen-behandlung-736717.html">https://www.apotheken-umschau.de/krankheiten-symptome/atemwegserkrankungen/lungenembolie-symptome-ursachen-behandlung-736717.html</a>
12	G-Netz Gesundheitsnetzwerk	Lungenembolie: Ursachen, Symptome, Diagnose & Therapie	.	<a href="https://www.g-netz.com/lungenembolie/">https://www.g-netz.com/lungenembolie/</a>
13	Gesundheit.gv.at – Öffentliches Gesundheitsportal Österreichs	Lungenembolie	2018	<a href="https://www.gesundheit.gv.at/krankheiten/herz-kreislauf/venen/lungenembolie">https://www.gesundheit.gv.at/krankheiten/herz-kreislauf/venen/lungenembolie</a>
14	Cochrane	Neuartige orale Gerinnungshemmer für die Behandlung von Lungenembolie	2015	<a href="https://www.cochrane.org/de/CD010957/PVD_neuartige-orale-gerinnungshemmer-fur-die-behandlung-von-lungenembolie">https://www.cochrane.org/de/CD010957/PVD_neuartige-orale-gerinnungshemmer-fur-die-behandlung-von-lungenembolie</a>
15	Cochrane	Ausschluss einer Lungenembolie mittels D-Dimer Test bei Patienten in Unfall- und Notfallambulanzen und in der Sprechstunde im Krankenhaus	2016	<a href="https://www.cochrane.org/de/CD010864/PVD_ausschluss-einer-lungenembolie-mittels-d-dimer-test-bei-patienten-unfall-und-notfallambulanzen-und">https://www.cochrane.org/de/CD010864/PVD_ausschluss-einer-lungenembolie-mittels-d-dimer-test-bei-patienten-unfall-und-notfallambulanzen-und</a>

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18	Schweizer PH-Verein für Menschen mit pulmonaler Hypertonie	Lungenembolie (Blutgerinnsel in der Lunge)	2003	<a href="https://www.lungenhochdruck.ch/lungenembolie-blutgerinnsel-in-der-lunge/">https://www.lungenhochdruck.ch/lungenembolie-blutgerinnsel-in-der-lunge/</a>
19	Qualitätskliniken.de – Das Reha-Portal	Lungenembolie	2020	<a href="https://www.qualitaetskliniken.de/erkrankungen/lungenembolie/">https://www.qualitaetskliniken.de/erkrankungen/lungenembolie/</a>
20	Wikipedia	Lungenembolie	2020	<a href="https://de.wikipedia.org/wiki/Lungenembolie">https://de.wikipedia.org/wiki/Lungenembolie</a>
21	Lungenärzte im Netz	Was ist zu tun bei akuter Lungenembolie?	2019	<a href="https://www.lungenaerzte-im-netz.de/news-archiv/meldung/article/was-ist-zu-tun-bei-akuter-lungenembolie/">https://www.lungenaerzte-im-netz.de/news-archiv/meldung/article/was-ist-zu-tun-bei-akuter-lungenembolie/</a>
22	Median Kliniken	Reha bei Lungenembolie	.	<a href="https://www.median-kliniken.de/de/behandlungsgebiete/kardiologie/lungenembolie/">https://www.median-kliniken.de/de/behandlungsgebiete/kardiologie/lungenembolie/</a>
23	Servona	Lungenembolie - Beschreibung	.	<a href="https://www.servona.de/unternehmen/betroffene/ratgeberfuerkrankheiten/lungenembolie/lungenembolie-beschreibung/">https://www.servona.de/unternehmen/betroffene/ratgeberfuerkrankheiten/lungenembolie/lungenembolie-beschreibung/</a>
24	MeinMed.at	Lungenembolie	2020	<a href="https://www.minimed.at/medizinische-themen/lunge/durch-lungenembolie-gefuesse-blockiert/">https://www.minimed.at/medizinische-themen/lunge/durch-lungenembolie-gefuesse-blockiert/</a>
25	Frankfurter Rotkreuz Kliniken	Lungenembolie	.	<a href="https://www.rotkreuzkliniken.de/lungenembolie.html">https://www.rotkreuzkliniken.de/lungenembolie.html</a>
26	NDR	Lungenembolie: Symptome rechtzeitig erkennen	2019	<a href="https://www.ndr.de/ratgeber/gesundheit/Lungenembolie-Symptome-rechtzeitig-erkennen,lungenembolie101.html">https://www.ndr.de/ratgeber/gesundheit/Lungenembolie-Symptome-rechtzeitig-erkennen,lungenembolie101.html</a>
27	Leading Medicine Guide	Lungenembolie - Verschlepptes Blutgerinnsel	.	<a href="https://www.leading-medicine-guide.com/de/erkrankungen/kreislauf/lungenembolie">https://www.leading-medicine-guide.com/de/erkrankungen/kreislauf/lungenembolie</a>
28	MSD Manual – Ausgabe für Patienten	Lungenembolie (LE)	2018	<a href="https://www.msdmanuals.com/de-de/heim/lungen-und-atemwegserkrankungen/lungenembolie/lungenembolie-le">https://www.msdmanuals.com/de-de/heim/lungen-und-atemwegserkrankungen/lungenembolie/lungenembolie-le</a>
29	München Klinik	Lungenembolie	2020	<a href="https://www.muenchen-klinik.de/lungenkrankheiten-atemwegserkrankungen/lungenembolie/">https://www.muenchen-klinik.de/lungenkrankheiten-atemwegserkrankungen/lungenembolie/</a>
30	Sanofi	Lungenembolie	2018	<a href="https://patienten.thromboseportal.eu/krankheitsbild/arten-und-folgen-der-thrombose/lungenembolie">https://patienten.thromboseportal.eu/krankheitsbild/arten-und-folgen-der-thrombose/lungenembolie</a>
31	Lecturio	Lungenembolie	.	<a href="https://www.lecturio.de/lexikon/lungenembolie">https://www.lecturio.de/lexikon/lungenembolie</a>
32	BILD der Frau	Gefährlich wie ein Herzinfarkt. Lungenembolie: Kennen Sie die unscheinbaren Symptome?	2020	<a href="https://www.bilderfrau.de/gesundheit/krankheiten/article207557635/Lungenembolie-Symptome-werden-oft-nicht-erkannt.html">https://www.bilderfrau.de/gesundheit/krankheiten/article207557635/Lungenembolie-Symptome-werden-oft-nicht-erkannt.html</a>
33	T-online	Woran Sie eine Lungenembolie erkennen	2020	<a href="https://www.t-online.de/gesundheit/krankheiten-symptome/id_62683552/woran-sie-eine-lungenembolie-erkennen.html">https://www.t-online.de/gesundheit/krankheiten-symptome/id_62683552/woran-sie-eine-lungenembolie-erkennen.html</a>
34	Herzzentrum Stuttgart	Lungenembolie	.	<a href="https://herzzentrum-stuttgart.de/krankheitsbilder/lungenembolie/">https://herzzentrum-stuttgart.de/krankheitsbilder/lungenembolie/</a>
35	Ada	Wissenswertes zum gesundheitsbewussten Leben für Patienten mit Lungenembolie	2020	<a href="https://ada.com/de/conditions/pulmonary-embolism/">https://ada.com/de/conditions/pulmonary-embolism/</a>
36	BILD	Entstehung, Behandlung, Vorbeugung. Was genau ist eine Lungenembolie?	.	<a href="https://www.bild.de/ratgeber/gesundheit/chronische-lungenembolie/lungenembolie-entstehung-vorbeugung-gefahr-41758594.bild.html">https://www.bild.de/ratgeber/gesundheit/chronische-lungenembolie/lungenembolie-entstehung-vorbeugung-gefahr-41758594.bild.html</a>
37	Venencentrum Pforzheim	Venöse Thrombose und Lungenembolie	.	<a href="https://www.venencentrum-pforzheim.de/venoese-thrombose-und-lungenembolie.html">https://www.venencentrum-pforzheim.de/venoese-thrombose-und-lungenembolie.html</a>
38	Knappschaftsklinikum Saar	Thrombosen und Lungenembolie	.	<a href="https://www.kksaar.de/puettlingen/Kliniken-Zentren/Fachabteilungen-Krankenhaus-Puettlingen/Gefasschirurgie/Thrombosen-und-Lungenembolie.php">https://www.kksaar.de/puettlingen/Kliniken-Zentren/Fachabteilungen-Krankenhaus-Puettlingen/Gefasschirurgie/Thrombosen-und-Lungenembolie.php</a>
39	Meine-gesundheit.de	Lungenembolie	2019	<a href="https://www.meine-gesundheit.de/krankheit/krankheiten/lungenembolie">https://www.meine-gesundheit.de/krankheit/krankheiten/lungenembolie</a>
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43	Liebenswert Magazin	Lungenembolie sofort erkennen und behandeln	2019	<a href="https://www.liebenswert-magazin.de/lungenembolie-sofort-erkennen-und-behandeln-5631.html">https://www.liebenswert-magazin.de/lungenembolie-sofort-erkennen-und-behandeln-5631.html</a>
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50	Onmeda	Lungenembolie	2019	<a href="https://www.onmeda.de/krankheiten/lungenembolie-id201486/">https://www.onmeda.de/krankheiten/lungenembolie-id201486/</a>
51	Inselspital – Universitätsspital Bern	Lungenembolien	.	<a href="http://www.kardiologie.insel.ch/de/unser-angebot/lungenembolien/">http://www.kardiologie.insel.ch/de/unser-angebot/lungenembolien/</a>

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53	Vital	Lungenembolie: Lebensgefährlicher Blutstau	<a href="https://www.vital.de/gesundheits/symptome/lungenembolie-lebensgefaehrlicher-blutstau-2116.html">https://www.vital.de/gesundheits/symptome/lungenembolie-lebensgefaehrlicher-blutstau-2116.html</a>
54	Kardionet – Ihr Herz-Kreislauf-Portal	Lungenembolie – tückisches Nachspiel einer Thrombose	<a href="https://www.kardionet.de/lungenembolie-thrombose/">https://www.kardionet.de/lungenembolie-thrombose/</a>
55	Herz und Gefäßzentrum Bad Bevensen	Lungenembolie und tiefe Venenthrombose	<a href="https://www.hgz-bb.de/herz-gefaesse/die-gefaesse/venen/lungenembolie-und-tiefe-venenthrombose/">https://www.hgz-bb.de/herz-gefaesse/die-gefaesse/venen/lungenembolie-und-tiefe-venenthrombose/</a>
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61	Barmherzige Brüder Krankenhaus Regensburg	Lungenembolie	<a href="https://www.barmherzige-regensburg.de/pneumologie-und-konservative-intensivmedizin/unser-behandlungsangebot/lungenembolie.html">https://www.barmherzige-regensburg.de/pneumologie-und-konservative-intensivmedizin/unser-behandlungsangebot/lungenembolie.html</a>
62	Novaria. Schweizer Verein der Lungentransplantierten	Was ist eine Lungenembolie?	<a href="https://novaria.ch/lungenembolie-blutgerinnsel-in-der-lunge/">https://novaria.ch/lungenembolie-blutgerinnsel-in-der-lunge/</a>
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64	Medizindoc	Lungenembolie – alles zu Ursachen, Symptomen und Behandlung.	<a href="https://medizindoc.de/lungenembolie/?gclid=CjwKCAjw88v3BRBFiEwApwLevS4AhGCpvk8i3V5qTCJi9atjaMvZc9jyEm_7TluKmgLoSsXoNAN66xoCQJoQAvD_BwE">https://medizindoc.de/lungenembolie/?gclid=CjwKCAjw88v3BRBFiEwApwLevS4AhGCpvk8i3V5qTCJi9atjaMvZc9jyEm_7TluKmgLoSsXoNAN66xoCQJoQAvD_BwE</a>
65	Apotheke Langenzenn	Lungenembolie	<a href="https://apotheke-langenzenn.de/gesundheits-themen-lz/gesundheits-heute.html?SDKArtikel%5bcategory%5d=89&amp;SDKArtikel%5bid%5d=4283">https://apotheke-langenzenn.de/gesundheits-themen-lz/gesundheits-heute.html?SDKArtikel%5bcategory%5d=89&amp;SDKArtikel%5bid%5d=4283</a>
66	Infozentrum für Prävention und Früherkennung	Lungenembolie: jährlich bis zu 100.000 Todesfälle	<a href="https://www.vorsorge-online.de/magazin/vorsorge-in-zahlen/details/lungenembolie-jaehrlich-bis-zu-100000-todesfaelle">https://www.vorsorge-online.de/magazin/vorsorge-in-zahlen/details/lungenembolie-jaehrlich-bis-zu-100000-todesfaelle</a>
67	Deutsche Gesellschaft für Nuklearmedizin e.V.	Untersuchungen – Diagnostik. Lungenembolien rechtzeitig entdecken	<a href="https://www.nuklearmedizin.de/patienten/patienteninformation/embolie.php?navid=21">https://www.nuklearmedizin.de/patienten/patienteninformation/embolie.php?navid=21</a>

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