How often are Patients Interviewed in Health Research? An Informetric Approach

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Abstract
In recent years research funding bodies have increased their emphasis on the engagement between researchers and the public. As part of this increased emphasis, the UK's National Institute for Health Research aims to promote a research-active population. A way in which patients can be research-active is by participating in research interviews. In order to assess the past levels of this type of contribution of patients to research, this paper investigates the extent to which health research refers to patient interviews. Co-word indicators for the interviewing and qualitative interviewing of patients are used to gauge how the levels of interviewing and qualitative interviewing in Web of Science (WoS) articles have varied over time, between science and social science and between WoS categories. The results indicate that the level of interviewing of patients, referred to in WoS articles, rose steadily between 1991 and 2013. Moreover, the amount of interviewing and qualitative interviewing varied substantially between health-related fields, with a marked tendency for more interviews in social science research and fewer in science research.

Conference Topic
Indicators

Introduction
Over the past few years research funding bodies have increased their emphasis on public involvement in health research. For example, the UK's National Institute for Health Research, in a recent strategic plan, listed as a key objective, "Citizens helping to identify and deliver research of the highest quality" (NIHR, 2014), adding that citizen participation health research "is contributing to a 'research active' nation focused on best health for all." In particular, those who are ill seem to be particularly important because they can provide first-hand understanding of the specific illness being researched. In order to understand the potential contribution of ill people to health research, it helps to understand their past contribution to health research. This paper addresses two aspects of past contribution: the extent to which this contribution has varied over time and the extent to which this contribution has varied between subjects. This paper also introduces and demonstrates a novel technique: the use of co-word metrics to gauge the levels of both interviewing and qualitative interviewing of patients, and applies it to Web of Science (WoS) articles.

Background
Informetric techniques Although the individual words in abstracts can be irrelevant to the content of the articles, analyses of the words in academic publications have been used extensively. Collections of articles have been mapped, based on the words in their titles (Leydesdorff & Zaal, 1988; Milojević et al., 2011), their titles and keywords (Whittaker, 1989), their titles and abstracts (Peters & van Raan, 1993), their titles with references used for context (van den Besselaar & Heimeriks, 2006), or their full text (Glenisson et al., 2005). However, other research with similar goals has ignored the text in articles and used subject headings instead (An & Wu, 2011). Automatic analyses of the text of articles have also been used to identify, or differentiate between, different types of methods used. For instance, this approach has been used to track the evolution, over time, of computing technologies within library and information science research and to identify articles that used specific statistical

techniques (Thelwall & Wilson, in press). One particularly relevant study searched for a set of methods-related keywords (e.g., cohort study) in the titles of health-related articles in the Web of Science, and then compared the citation impacts of the articles found for each method (Patsopoulos, Analatos, & Ioannidis, 2005).

Patient involvement in research

In addition to often being involved in decisions about their own care (Charles, Gafni, & Whelan, 1997), patients are routinely the subjects of medical research to investigate the causes of, or cures for, their maladies. Patients can also be more actively involved in research by giving their opinions in open-ended questionnaires, or in interviews, or focus groups and by participating in steering groups for the co-ordination of research. Patients may also be involved in developing or promoting informational material to fellow sufferers (Greenfield, Kaplan, & Ware, 1985) or even in developing research policies (Nilsen et al., 2006). Gaining the patient's perspective can be helpful for research, for example, to get insights into the extent to which symptoms, in practice, vary from the norm (Cotrell & Schulz, 1993) and to understand and prioritise the problems that sufferers believe to be the most important to address (Serrano-Aguilar et al., 2009). Seeking the views of patients is sufficiently widespread for systematic reviews of this practice to be published for specific ailments (Morton et al., 2010). Nevertheless, the apparently widespread knowledge of the importance of patient involvement does not ensure that it occurs for all conditions.

Research questions

This paper investigates a contribution that ill people have made to health research, namely the extent to which health research has interviewed patients. The research questions are:

1. To what extent has the level of the research interviewing (and in particular the qualitative interviewing) of patients varied over time?
2. To what extent has the level of the research of interviewing (and in particular the qualitative interviewing) of patients varied between subject categories?

Method

The main data used to address the research questions is the approximate number of articles that refer to patient interviews and approximate number of articles that refer to qualitative patient interviews. This data, obtained for different WoS databases and subject categories, must be normalised to allow comparisons between findings for different years and subjects.

A simple way of normalising is to calculate the rate of interviewing and qualitative interviewing in each subject category would be to divide by the number of articles in the dataset investigated. For some subject categories only a small proportion of articles are closely related to patients, however, and so this ratio would be flawed. For instance, less than one fifth of Pharmacology Pharmacy articles refer to ‘patient’ in the topic.

In order to normalise the interview metric, this paper divides instead by the number of articles that refer to patients. This interview metric indicates the extent to which articles that refer to also refer to interviews. This choice is based on the reasonable assumption that studies on patient interviews will in generally refer to patient in their abstracts. In order to normalise the qualitative interview metric, this paper divides by the number of articles that refer to patients and interviews. This qualitative interview metric indicates the extent to which articles that refer to patient interviews also refer to the interviews being qualitative. This metric was chosen in order to limit the metric to research that plausibly could qualitatively interview patients (i.e., where patients and interviews are mentioned).

In order to calculate the interview metric and qualitative interview metric the following data was extracted from WoS: (a) the number of articles that contain ‘patient*’ in the topic (patient frequency), (b) the number of articles that contain ‘patient*’ and ‘interview*’ in the topic

(patient interview frequency), and (c) the number of articles that contain 'patient*', 'interview*' and at least one of 'qualitative*', 'open-ended', 'in-depth', ''semi structured' and 'semistructured' in the topic (patient interview qualitative frequency). The interview metric was defined as 1000*patient interview frequency/patient frequency; the qualitative interview metric was defines as 100*patient interview qualitative frequency/patient interview frequency. The multipliers of 1000 and 100 were chosen in order for most of the findings to be expressed between 10 and 100. The definition of the qualitative interview metric was preferred to the alternative definition of 10000*patient interview qualitative frequency/patient frequency as it indicates how the proportion of interviews that are qualitative varied over time and between subjects.

A possible source of inaccuracy in the interview metric is that articles with patient and interview in the topic do not necessarily refer to patient interviews. The accuracy of the interview metric was gauged through content analysis of a random sample of 50 WoS articles containing 'patient*' and 'interview*' in the topic; 90% of the records referred to interviews of patients or people associated with their illness. A possible source of inaccuracy in the qualitative interview metric is that articles with patient, interview and an indicator of qualitative in the topic do not necessarily refer to qualitative patient interviews. The accuracy of the qualitative interview metric was gauged through a content analysis of a random sample of 50 WoS records containing 'interview*' and at least one of ''qualitative*', 'open-ended', 'in-depth', ''semi structured' and 'semistructured'; 96% of the records indicate that the interviews were qualitative. Other possible sources of inaccuracy in these metrics are false positives (e.g., 'patient' can be used in sense not related to health, i.e., not impatient) and omissions (e.g., the list of terms for qualitative research is unlikely to be exhaustive).

As a high proportion of the search terms are in the article abstracts, it is important to confine the study to periods in which a high proportion of WoS records contain abstracts. A total of 84% of the records, of a random sample of 50 WoS articles published in 1991, contain abstracts, whereas the figure for WoS articles published in 1990 is only 8% (for 2013 the figure is 100%). Consequently, this study does not investigate years prior to 1991.

Results

In this paper, ''Patient incidence' denotes the number of articles with 'patient*' in the topic, 'Interview incidence' denotes the number of articles with 'interview*' in the topic per 1,000 articles with 'patient*' in the topic, and 'Qualitative interview incidence' denotes the number of articles with the indicators of qualitative in the topic per 100 articles with 'interview*' in the topic, 'SCI only' denotes articles in the Science Citation Index (SCI) and not in the Social Sciences Citation Index (SSCI), 'SCSI only' denotes articles in the SSCI and not in the SCI, 'SCI & SSCI' denotes articles in both the SCI and SSCI, and 'A&HCI' denotes articles in the Arts & Humanities Citation Index.

Table 1: Patient, interview and qualitative interview incidences for five WoS datasets.

Datasets	*Articles containing patient* in the topic*	*Interview articles per 1000 patient articles*	*Qualitative interview articles per 100 interview articles*
WoS	2,570,556	23.7	26.0
SCI only	2,309,924	11.0	16.5
SSCI only	67,088	134.5	35.1
SCI & SSCI	192,749	137.1	32.1
A&HCI	2,810	74.4	35.9

As can be seen in Table 1, for both SSCI only and SCI & SSCI the incidences of interviews are over 12 times the incidence for SCI only and the incidence of qualitative interviews is 90% higher than the incidence for SCI only. These differences are likely to be partly due to the different sizes of the databases and partly due to differences in the proportion of articles that mention patients. The table also indicates that interviews are relatively prevalent in social science research relating to patients and rare in science research relating to patients. Because of the small number of A&HCI articles that contain 'patient*' in the topic, this paper does not further investigate this dataset.

In response to Question 1 (variation over time) the incidence of interviews for WoS rose by 175% between 1991 and 2013 (Figure 1, left). The incidence for SCI only undulated between 1998 and 2013, (10.2 in 1998, 11.1 in 2013), whereas, during the same period, the levels of SSCI only and SCI & SSCI rose steadily (the 2013 levels are respectively 48% and 36% higher than the 1998 levels). Thus, the use of interviews in patient-related research seems to have risen more rapidly in the social sciences than in science, despite the lower initial prevalence of interviews in science research. The use of qualitative methods in interviews appears to have risen substantially in all the areas investigated. However, the increase is more rapid in social sciences research than in science research (Figure 1, right).

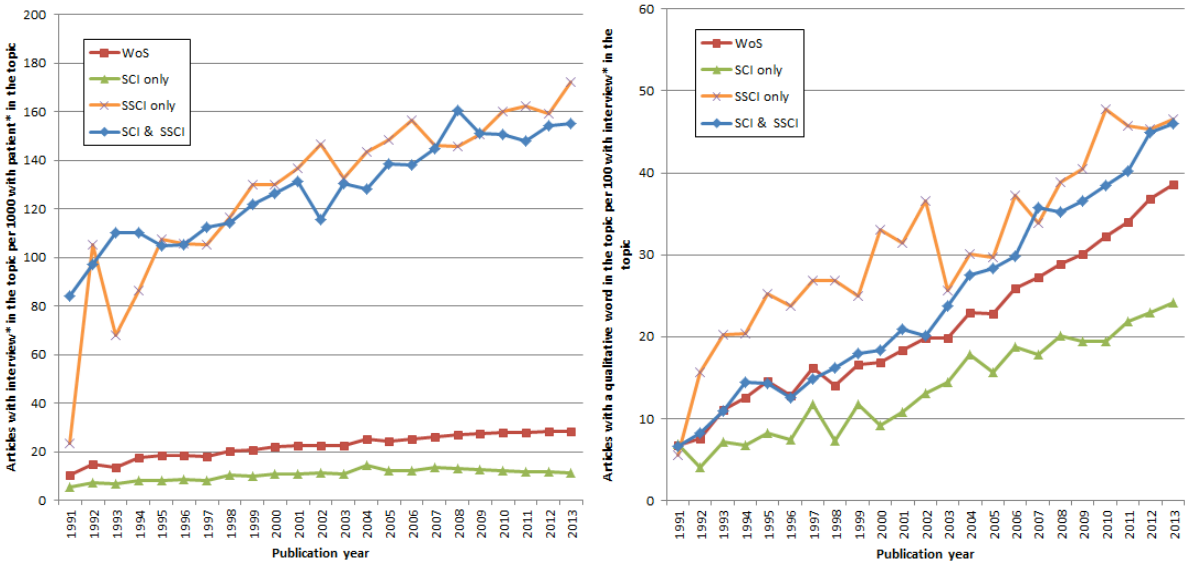

Figure 1. Annual incidence of interviews (left) and qualitative interviews (right).

In order to analyse disciplinary differences in more detail (Question 2), WoS categories were identified for each of the datasets SCI only, SSCI only and SCI & SSCI with at least 50 articles containing patient* and interview* in the topic. The ten categories identified were Clinical neurology, Health care sciences services, Health policy services, Nursing, Oncology, Pharmacology pharmacy, Psychiatry, Psychology, Public environmental occupational health and Rehabilitation. The incidence of interviews varies greatly between the ten categories, in addition to between science and social science research in the same category. The most extreme case is oncology, for which interviews are rare in science, but common in social science research (Table 2).

The incidence of qualitative interviews differs between science and social science in each individual category; qualitative interviews are more prevalent in social science research in 8 out of 10 categories (Table 2). For SCI only, the incidence of interviews is substantially lower for Clinical neurology, Oncology and Pharmacology pharmacy (average 12.0) than for the other seven categories (average 59.6). The incidence of qualitative interviews is also much lower for Clinical neurology, Oncology and Pharmacology pharmacy (average 14.0)

compared with the other seven categories (30.7). Hence, there are substantial disciplinary differences in the incidences of interviews and qualitative interviews within science.

Table 2: Incidence of interviews for ten WoS categories.

	Interviews			*Qualitative interviews*		
WoS category	*SCI*	*SSCI*	*Both*	*SCI*	*SSCI*	*Both*
Clinical neurology	16.5	65.1	107.3	11.9	25.0	17.6
Health care sciences services	92.2	99.9	157.5	41.4	30.3	46.5
Health policy services	76.0	182.7	125.4	31.6	47.6	39.0
Nursing	81.5	199.9	196.4	51.8	53.5	61.0
Oncology	7.2	226.3	195.2	15.0	47.7	45.7
Pharmacology pharmacy	12.3	199.2	67.6	15.2	58.0	17.8
Psychiatry	36.0	136.6	139.7	12.9	21.8	14.4
Psychology	46.0	102.2	115.5	25.9	17.7	19.4
Public environmental occupational health	53.3	219.8	170.6	20.0	44.3	37.0
Rehabilitation	32.5	86.7	137.9	31.0	34.5	52.4
Mean	**45.3**	**151.8**	**141.3**	**25.7**	**38.0**	**35.1**

For Clinical neurology, Oncology and Pharmacology, the percentage of articles in SCI only with patient* in the topic is particularly high: the percentage (in terms of articles in SCI or SSCI with patient* in the topic) for Clinical neurology is 89.3%, for Oncology is 96.4% and for Pharmacology pharmacy is 93.8%, whereas the average percentage for the other seven categories is 30.7%. There is a statistically significant Spearman correlation of -.81 between the interview incidence of SCI only and the percentage of articles with patient* in the topic that are in SCI only. This correlation reflects science categories having few interviews.

Limitations and conclusions

A limitation is that some studies with 'patient*' and 'interview*' in the topic do not interview patients (e.g., they interview physicians or carers of patients) and some studies with 'interview*' or indicators of qualitative in the topic do not conduct qualitative interviews (e.g., they combine quantitative interviews with qualitative analysis of patient records). But, as this research is comparative and the variations over time and between subjects are substantial, it seems likely that this limitation would not greatly affect the overall findings. Another limitation is that the results rely on the WoS journal subject classifications for journals. This may have a significant impact on the results for individual subject categories, as individual journals may have a substantial minority of the articles in a category. It would be useful to apply the techniques here to the full text of papers to help assess how often patient are involved in research but this is not discussed in the abstract of a paper.

After adjusting for the increase in the number of articles with 'patient*' in the topic, the number of WoS articles with 'interview*' in the topic increased by 175% from 1991 to 2013, suggesting that the use of patient interviews has increased substantially over the past 23 years. This may reflect a general trend towards involving patients more frequently in research, or an increase in the amount of research published, or indexed in WoS in research areas that typically involve patient interviews, such as nursing. In addition, after adjusting for the increase in the number of articles with 'patient*' and 'interview' in the topic, the number of articles that also had an indicator of qualitative in the topic increased by 511% from 1991 to 2013. This suggests that qualitative approaches are increasingly prevalent in health interviews, or that the qualitative nature of the research is more frequently specified. An

alternative explanation is that the amount of research published, or covered in WoS, has expanded in areas in which qualitative interviews are particularly common.

The incidences of interviews were particularly low amongst articles that were in SCI only; for 1991-2013 the incidence is less than one twelfth of the incidence for SSCI articles. When confining the study to categories present in both the SCI and the SSCI, there was a very marked difference between the datasets; however, the difference was substantially lower when excluding categories in which over 85% of the articles are in the SCI.

In the context of the NIHR aim of promoting a research-active population, the increased prevalence of patient interviews and qualitative interviews is encouraging, but categories with low percentages of interviews (e.g., Clinical neurology, Oncology and Pharmacology pharmacy) need to be further investigated to check whether individual subject areas are giving too little credence to patient interviews. Finally, this paper indicates that the technique of using simple co-word metrics based on the presence of words in the topic of WoS records can be applied usefully to informetric tasks. However, when investigating articles published prior to 1991, it is important to take into account that only a low percentage of WoS records for articles published in 1990 have abstracts.

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