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# Continuity of information in general practice

## *Patient views on confidentiality*

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**Objectives** – To explore patient views on access to a variety of information in the medical record by the on-call general practitioner and by the practice assistant in relation to the perceived importance of this information for the personal doctor. To relate patient views to patient and practice characteristics.

**Design** – Postal questionnaire survey.

**Setting** – General practice.

**Subjects** – 873 patients from 35 general practices dispersed throughout The Netherlands.

**Results** – 20% of the patients stated that the on-call GP should not have access to their entire medical record and 44% did not support full access for the practice assistant. Patient consent to the on-call GP being allowed to access a variety of information ranged from 62% for life events to 93% for medication; and to the practice

assistant from 37% for home details to 82% for medication. Patients distinguished between “medically oriented information” and “lifestyle and psychosocial information”. Their views could hardly be explained by patient and practice characteristics.

**Conclusion** – Patient consent to access their medical record should not be taken for granted. We need research on the effectiveness of accessible prior knowledge, and on possibilities to segregate information. Patients should be informed more fully about everyday practice.

**Key words:** confidentiality, continuity of patient care, medical records, patient views.

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Continuity of care is one of the cornerstones of general practice. There is evidence that the process and outcome of care are influenced by the general practitioner's prior knowledge of his/her patients (1–3). In recent decades, personal continuity has declined because of the changing organisation of the profession. Meanwhile, the medical record has developed from being merely a mnemonic device for single-handed practitioners towards an important tool maintaining the continuity of care. The medical record contains prior knowledge about the patient's medical history and family history, life events, coping style, psychosocial background and health care needs and preferences. Access to prior knowledge will support consistency of care (4,5). Continuity of information necessitates proper record-keeping and information exchange by using electronic medical records and Internet technologies (6). Within primary care teams, different healthcare workers often have access to the electronic patient records. To a growing extent, this is so in the case of the on-call GP and the practice assistant. The Dutch practice assistant is a receptionist, but is also directly involved in patient care. Her work resembles that of the practice nurse more than the work of the receptionist in the UK.

However, from the patient's point of view, large parts of the medical record may contain confidential

and personal information which is supposed to be shared only with the personal GP. Security of information is therefore a prerequisite for integrated record-keeping (7), and, as the content and use of patient records evolves, the right to privacy and control over who views the record is now considered a major issue (8–10). Indeed, patients are known to have significant reservations about this information being shared across all members of primary care teams (11). Concerns have been expressed about hurried developments in the field (12). More insight into patient views can help us better inform consumers and manage their records suitably. The aim of this study was therefore to explore patient views on access to a variety of prior knowledge in the medical record by different providers quantitatively, and to relate this to the perceived importance of information for the personal GP. Furthermore, we relate patient views to patient and practice characteristics.

Personal continuity tends to shift towards continuity of information, and there are indications that patients have reservations.

- Patients entrust their own GP with more knowledge than a GP on call or a practice assistant.
- Consent to access varies with type of information.

## MATERIALS AND METHODS

In a general practice survey we posted a self-designed questionnaire to 873 patients.

### *Questionnaire design*

Before constructing the questionnaire, we conducted 10 semi-structured patient interviews. It appeared that the need for confidentiality depended on the type of prior knowledge, and on the patient's estimation of the importance of this knowledge for the personal doctor(s), unknown doctors and practice assistants. We were able to develop a structured questionnaire in which we assessed patient views on accessibility of different aspects of the medical record. A pilot study was carried out with 20 patients. Following this, changes were made to produce a definitive version of the questionnaire: 1) In general, we measured patient agreement using six statements about accessibility of the record on a 3-point Likert scale (agree-indifferent-disagree). 2) Next, we operationalised prior knowledge by choosing 12 aspects from a list of 50, covering a broad range of information. In a preceding Delphi study we found that GPs considered these 12 aspects important for continuity of care (13). Aspects ranged from medical information, such as medication and present illness, to more social information, such as life events and home details. We asked patients if they felt that this information was important for their personal GP to know, and if it should be accessible for the on-call GP and the practice assistant (3-point Likert scales). Finally, we collected basic information on patients and their GP practice: gender, age, practice type and practice area. Additionally, we collected characteristics that might be related to patient views on confidentiality, including psychosocial problems, life events, chronic illness, number of years in the practice, and number of visits to the GP in the previous 12 months.

### *Survey sample*

The study was based in the practices of 35 GPs dispersed throughout The Netherlands. We sent the practice assistants a batch of 25 questionnaires and asked them to post one to each of 25 consecutive patients (18 years or older) who had visited the GP on the first day of that week. This included a letter of recommendation on behalf of the patients' GPs and a reply paid envelope so that completed questionnaires were returned to the researchers. One practice assistant forgot to post the last two questionnaires. After 2 weeks, a combined thank you and reminder card was sent to all the patients. In order to assess response bias, we collected baseline characteristics on all 873 patients.

### *Analysis*

The data were entered into the statistical program SPSS 9.0. Differences for response rates were tested by chi-square and chi-square for trend. We dichotomised agreement to access by grouping the answer categories 'agree' and 'indifferent' together. We thus discriminated between patients who definitely disagreed with access to particular information, and patients who agreed or were neutral. We compared the results with the degree to which patients assessed information as important for their own GP to know. For this purpose, we discriminated between patients who considered it important that their own GP would know this information (category 'agree') and patients who considered it rather unimportant (categories 'indifferent' and 'disagree'). Exact binomial 95% confidence intervals were computed. Factor Analysis (Principal Component Analysis) was used to explore the data for structure. For the detected components, we calculated sum scores for consent to access (*agree* 2 points, *indifferent* 1 point, *disagree* 0 points). Missing values were replaced by mean values if respondents had one answer missing from a group of statements within a component. If respondents had more than one missing value, they were excluded from further analysis. We used Multiple Linear Regression analysis (General Linear Model; SAS) to compute sum scores for consent to information access (adjusted sum scores; LS means), and related sum scores to patient characteristics.

## RESULTS

Of the 873 questionnaires sent out, we received 644 useable replies (74%). Patients over 40 years of age, those with chronic illness, and those attending their GP more frequently had higher response rates (Table I).

### *Views on access in general*

Twenty percent of the respondents felt that the on-call GP should not have full access to their medical record and 40% distinguished between GPs from their own practice and on-call GPs. Forty-four percent indicated that their medical record should not be accessible to the practice assistant. Only a minority of the respondents saw a role for themselves in being responsible for their own medical records (Table II).

### *Views on access to various types of information*

Patients agreed that most aspects of prior knowledge were important for their personal GP to know. Respondents felt that most information should be accessible to the on-call GP. Patients more easily agreed with access to information about medication or ill-

Table I. Response rates. Numbers and percentages responding within subgroups (overall response = 644/873).

Characteristic		Numbers <sup>1</sup>	Response within characteristic
Age <sup>2</sup>	18–40	182/284	64%
	41–60	270/349	77%
	61–80	170/210	81%
	> 80	22/24	83%
Sex	Female	399/533	75%
	Male	245/338	72%
Chronic illness <sup>3</sup>	Yes	255/316	81%
	No	389/550	70%
Contacts with GP last 12 months <sup>4</sup>	1–2 times	122/177	69%
	3–4 times	154/221	70%
	5–10 times	244/310	79%
	> 10 times	124/162	75%

<sup>1</sup> Because of missing values for baseline characteristics, the total number of sent questionnaires in the table is 866–871.

<sup>2</sup> Response rate increasing with age,  $p < 0.001$  (chi-square for trend).

<sup>3</sup> Response rate higher for patients with chronic illness,  $p < 0.001$  (chi-square).

<sup>4</sup> Response rate increasing with higher contact frequency,  $p = 0.016$  (chi-square for trend).

Table II. Patient opinions on accessibility of the medical record (percentages, 95% confidence intervals in parentheses,  $n = 644$ ).

Statements	Agree %	Indifferent %	Disagree %
1. The GP on call should have access to my medical record	65.6 (61.6–69.3)	14.8 (12.1–17.9)	19.6 (16.5–23.0)
2. I want to decide myself what information is accessible to the GP on call	39.3 (35.4–43.4)	31.3 (27.6–35.2)	29.4 (25.7–37.2)
3. The practice assistant should have access to my medical record	33.4 (27.7–37.3)	22.4 (19.1–25.9)	44.2 (40.2–48.2)
4. I want to decide myself what information is available to the practice assistant	48.5 (44.5–52.6)	28.1 (24.6–31.2)	23.4 (20.0–26.6)
5. Within-practice GPs are different from GPs on call as regards confidentiality of my medical record	39.8 (35.8–43.8)	27.4 (23.9–31.1)	32.8 (29.1–30.7)
6. I want to administer my own medical record	13.6 (11.0–16.6)	26.3 (22.8–29.9)	60.1 (56.1–64.0)

Table III. Patient opinions on access to prior knowledge for the GP on call and the practice assistant in relation to perceived importance of information for the personal GP (percentages, 95% confidence intervals in parentheses,  $n = 644$ ).

<i>Aspects of prior knowledge</i>	May be accessible for <sup>1</sup>		Important for personal GP to know %
	GP on call %	Practice assistant %	
Medication	92.9 (90.5–94.9)	81.8 (78.4–85.0)	99.4 (98.3–99.9)
Present illness	91.1 (88.5–93.4)	67.3 (63.3–71.2)	99.3 (98.2–99.8)
Past illness	83.2 (79.9–86.2)	53.6 (49.4–57.7)	99.5 (98.5–99.9)
Compliance with advice	79.2 (75.7–82.4)	58.9 (54.8–62.9)	98.1 (96.7–99.1)
Life events	62.2 (57.7–66.4)	39.1 (34.9–43.4)	96.2 (94.3–97.7)
Social and mental problems	72.6 (68.4–76.6)	43.7 (38.8–48.7)	95.0 (92.6–96.8)
Compliance with medication	83.1 (79.7–86.0)	65.7 (61.6–69.6)	94.9 (92.6–96.8)
Worries about health	79.0 (75.4–82.3)	57.4 (53.2–61.6)	93.9 (91.5–95.8)
Smoking habits	79.9 (75.4–82.3)	58.8 (53.7–63.8)	91.8 (88.3–94.7)
Who takes care when ill?	78.1 (74.4–81.5)	61.6 (57.4–65.6)	87.5 (84.4–90.2)
Alcohol	67.8 (63.0–72.4)	43.7 (38.8–48.7)	86.7 (82.9–89.9)
Home details	64.1 (59.9–68.2)	36.9 (31.8–41.2)	77.8 (73.8–81.4)

<sup>1</sup> “Agree” or “indifferent” on a 3-point Likert scale (agree – indifferent – disagree).

nesses than to information about life events or home details. Respondents clearly had reservations about the availability of information for the practice assistant, with the exception of medication (Table III). Two components were detected within information that might be accessible, both for the on-call GP and the practice assistant. One component might be considered more “medically oriented information” and the other “lifestyle and social information” (Table IV).

#### *Relation with patient and practice characteristics*

Multiple linear regression analysis showed that a model containing nine characteristics could explain 7–10% of the observed variance. Older patients more frequently agreed with access to their medical records. The difference in agreement with age was highly significant mainly for medically oriented information (Table V).

## DISCUSSION

This study shows that patient agreement to access being allowed to their medical record to an extended team should not be taken for granted. Patients clearly distinguish between different types of professionals and different types of information. The personal GP is entrusted with more knowledge than the on-call GP or the practice assistant. A considerable percentage of patients indicated that access was inappropriate for the practice assistant. In everyday practice, this assistant often has full access to the records, as has the British and Scandinavian practice nurse. This study may indicate how to handle the problem of

differential access. It suggests that designers of computer record systems should look at ways of segregating different types of information, and they should make differential access an important topic. As integrated record-keeping evolves, this will become even more important. Individual patients should be enabled to protect their privacy. Naturally, adverse effects of differential access are conceivable, and incomplete records may occasionally be harmful to the patient’s health. Patients will not always be capable of appraising this. On the other hand, we have to consider that doubts about confidentiality of information will induce patients to confide in their doctors less (11).

This study has had some limitations. We did not choose a random selection of general practices. Although this may have caused some bias, the practices were dispersed throughout the country, and the characteristics of the participating practices were comparable to a random sample of Dutch general practices. We chose to select the first 25 patients who visited the practice within a certain week using the diary, thus preventing GPs from making their own patient selection. This may have caused some bias, but we have no indications that these patients differed from patients who visited the practice later in the week. We had more older respondents, and more respondents with a chronic illness. Taking into account that these characteristics were related to more agreement to access, patient needs for confidentiality may even have been underestimated. Nevertheless, response rates of over 70% are considered to minimise this problem (14). In our survey, patient opin-

Table IV. Components of prior knowledge (principal component analysis with Varimax rotation)<sup>1</sup>.

	Prior knowledge accessible for			
	GP on call		Practice assistant	
	I	II	I	II
Medication	0.78		0.71	
Present illness	0.70		0.73	
Past illness	0.66		0.62	
Compliance with advice	0.82		0.78	
Compliance medicine	0.85		0.86	
Who takes care when ill?	0.63		0.64	
How easily worried about health?	0.69		0.72	
Social and mental problems		0.71		0.65
Life events		0.71		0.65
Home details		0.60		0.60
Smoking habits		0.67		0.66
Alcohol		0.77		0.78
Eigenvalues	4.2	2.9	4.2	2.7
Variance (%)	35	24	35	22

<sup>1</sup> Eigenvalue > 1.0, loadings > 0.6. I: Medically oriented information. II: Lifestyle and psychosocial information.

Table V. Agreement with access to information in relation to patient characteristics (GLM model; adjusted sum scores (ASS) range 1–10; a higher sum score means more agreement with access; p = p-value for characteristic).

		Agreement with access to information for the ...							
		<i>GP on call</i>				<i>Practice assistant</i>			
		<i>Psychosocial and lifestyle</i>		<i>Medical</i>		<i>Psychosocial and lifestyle</i>		<i>Medical</i>	
		5.9 (SD = 3.8)		7.7 (SD = 2.9)		3.4 (SD = 3.6)		5.5 (SD = 3.6)	
<i>Characteristics</i>	Mean sum score	ASS	p	ASS	p	ASS	p	ASS	p
Age	18–40	5.1	0.07	6.8	<0.001	2.4	0.06	4.7	<0.001
	41–60	5.9		7.3		3.2		5.7	
	61–80	6.3		8.3		3.8		6.8	
	>80	9.1		9.6		5.2		7.3	
Gender	Male	6.7	0.70	8.2	0.19	3.8	0.44	6.1	0.96
	Female	6.5		7.9		3.5		6.1	
Having chronic illness	Yes	6.8	0.35	8.2	0.21	3.7	0.70	6.3	0.52
	No	6.4		7.8		3.6		6.0	
Life event(s) past 5 years	Yes	6.2	0.06	7.8	0.09	3.9	0.21	6.3	0.23
	No	7.0		8.2		3.4		5.9	
Psychosocial problem(s) past 5 years	Yes	6.8	0.53	8.2	0.32	3.9	0.39	6.2	0.68
	No	6.4		7.8		3.5		6.0	
No. of visits to GP in the past year	1–2	6.2	0.25	7.9	0.74	3.4	0.35	6.1	0.44
	3–4	6.6		8.0		3.9		6.5	
	5–10	6.4		7.9		3.3		5.8	
	>10	7.2		8.3		4.1		6.2	
No. of years in the practice	<1	6.9	0.14	8.6	0.25	3.9	0.60	5.9	0.89
	1–2	7.0		8.1		3.7		5.9	
	3–4	7.8		8.2		4.5		6.3	
	5–10	6.8		8.4		3.5		6.4	
	>10	4.5		7.0		2.5		6.2	
Practice area	City	6.0	0.39	8.4	0.18	3.2	0.59	6.4	0.22
	Town	6.9		7.3		3.8		5.9	
	Comm. belt	6.5		8.3		3.6		5.7	
	Countryside	6.9		8.2		4.0		6.4	
Practice type	Single-handed	6.7	0.96	7.9	0.38	3.7	0.11	5.8	0.44
	Two-person	6.7		8.5		3.2		6.0	
	Group	6.7		7.9		3.9		5.8	
	Health centre	6.3		7.9		4.5		6.5	
Variance (R <sup>2</sup> )		8% (p = 0.07)	10% (p < 0.001)	7% (p = 0.10)	8% (p = 0.01)				

ion on confidentiality could only be recorded for hypothetical examples. It may be said that patients are not able to give adequate answers to such questions. However, we did not find that patient views on confidentiality of information about life events and social problems differed, even between respondents who themselves differed in these characteristics.

Our results add to views and expectations of patients comprising patient panels and consumer groups who are vocal on the matter of privacy of information in several countries. These panels are

usually composed of a select group of patients. Patient views in our study may be considered conservative, but they are in line with a recent UK study where a minority of patients indicated that the practice nurse should have access to their records (11). Patient expectations on confidentiality have appeared to be quite different from actual practice with regard to access by secretarial staff. Patients expected more confidentiality (15). Furthermore, it has been shown that doctors and medical students are less reserved in sharing information than patients believe (16), and patients have been found to be concerned about

a loss of confidentiality when computers are used (17,18). This gives reason for concern.

What are the implications of this survey? These days, patient records are accessible not just to the personal GP, but also to other staff, such as the practice nurse, the practice assistant, and the on-call GP. We have to realise that a considerable number of patients disapprove of this practise. We may have to reconsider the structure of the electronic patient record, and enable a division of medically oriented information and information concerning lifestyle and psychosocial circumstances. An alternative challenge would be to study the relationship between accessibility of various kinds of information and the quality of patient care. Recent reviews conclude that there is no evidence that the use of the electronic patient record improves the quality of care, but, so far, studies have been limited to the effectiveness of electronic reminders (19,20). If access to different types of prior knowledge improves the quality of care, we must be able to explain its benefits to our patients. Until more research in this domain is carried out, our patients should at least be more fully informed about everyday practice, and should be asked to consent to access to their medical record by medical professionals other than their personal doctor.

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