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CHILDRENS' ASTHMA REGISTER

Description of a Data-System and Patient Material

By

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The treatment of asthma and all other diseases is only possible if certain crucial data are available. In acute diseases this is usually no problem. In asthma of many years duration the use of conventional patient journals in reviewing patients' data is very time-consuming and, moreover, hopelessly inaccurate. They mostly contain details of acute episodes of asthma and give no overall view of the disease. Therefore, a systematic data register of asthmatic patients might facilitate the therapy of this complex disease.

There have been only a few consistent attempts to follow-up and register the course of asthma: Falliers et al. (2), Charpin et al. (1) and Kurata et al. (5) have developed computerized systems for follow-up of asthmatic patients. These authors emphasize that patient history and follow-up should be monitored with the aid of time-saving methods, preferably automated systems for the display of patient data.

The present computerized data system was developed both for routine use and to facilitate prospective data collection for scientific purposes. The aims of the project concerning routine use were as follows:

- to collect data continuously from all known local asthmatic children and
- to develop computerized methods for a systematic data display to be utilized in the asthma clinic.

The present paper has been prepared at the stage of the project when almost all details and problems have been resolved. The data system has enabled rationalization of the asthma clinic and, above all, the monitoring and active supervision of the patients. This asthma data register can also be used for scientific purposes.

MATERIAL AND METHODS

Nearly all children with asthma diagnosed in our clinic have been entered in the asthma register since 1970. The criteria for asthma have been a clinically obvious asthmatic attack and a positive reaction to the methacholine inhalation test done in most cases. The total number of patients at the end of 1976 was 950, 770 of whom were less than 15 years of age. Of these, 590 lived in our hospital district in which there are an estimated 950 asthmatic children (prevalence 0.9 per cent, Peltonen et al. 1954). The age distribution of the patients in 1976 is given in Table 9.

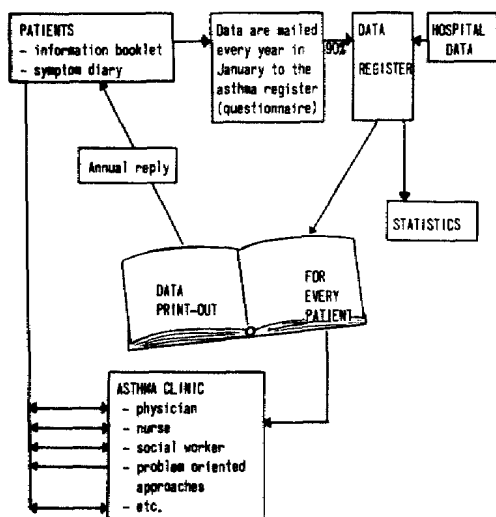


Fig. 1.

Block diagram of the data collection, handling and utilization. The contacts between patients and the asthma clinic are also described.

The specialized asthma care in our hospital is concentrated in an asthma clinic. Since 1970 paediatricians have been working at the clinic 5 hours a week assisted by a special nurse. She also takes care of allergy testing (skin and provocation testing), has one hour a week telephone consultation, and visits the patients in their homes in order to arrange dust elimination, etc. Acute illness is treated only exceptionally in the asthma clinic.

Fig. 1 shows a diagram of the continuous surveillance of the patients, data collection and utilization. The system begins with the information booklet which is given to the parents (Koivikko 1972). It consists of 14 pages of general information about asthma and its therapy. This booklet also contains a symptom diary, and the parents are instructed in how to make notes of symptoms twice a month (Table 1). They are motivated by telling them that "by giving us correct information about the symptoms of your child we are better able to understand his disease". The booklet with the notes is always asked for when the patient visits the asthma clinic. The parents can make an appointment at the asthma clinic whenever they consider it necessary, and can also phone the clinic during the nurse's telephone consultation.

The symptoms recorded in the diary are copied down annually on a questionnaire sent to the parents from the asthma register. The questionnaire also contains questions concerning therapy, environment, etc. (Table 2). The parents send this back to the asthma register, the data are punched on cards and fed into a computer. Other sources of data collection are laboratory tests and notes by the paediatrician on the computer-printed data pages of individual patients (Fig. 2). The yearly data consist of 150 to 200 items. The number of data on allergy diagnosis (Table 3) for practical purposes is not limited. IBM 1130, UNIVAC 1108 and DEC 10 computers have been used for the data handling. The annual cost of the data collection and handling has been an estimated \$ 2 to 3 per patient.

Utilization of the Data Register

The data stored in the computer memory are used to make a two-page print-out for every patient. The first of the computer-printed pages contains data on allergy diagnosis and hyposensitizations. The principles of data coding and display are illustrated in Table 3. Nearly 400 allergens and irritants are programmed. New allergens can be added to the system at will. This page also contains data on deep-frozen serum samples taken regularly from the patients for future use. Laboratory data of long-term interest are also printed here. The second data page (Fig. 2) contains identification information, year of onset of the different symptoms, and data on previous therapies. Symptom-data are printed in half monthly periods as in the patient diaries (Table 1). Data on therapy and environment taken from the questionnaire (Table 2), and notes by the paediatrician are printed on this page. The first data page is cumulative, but the second page contains only data from the previous 4 years.

The asthma data register is also used to compile statistics and tabulations.

TABLE 1
Example of the Symptom Diary and Explanation of the Half Monthly Notes on Symptoms.

	Jan.	Feb.	Mar.	Apr.	May	June	July	Aug.	Sept.	Oct.	Nov.	Dec.
1	0 0	0 0	X R 11 4	R X 2 5	X X 3 5	2 6	0 0	R 0 2	R X 5 4	X R 3 3	4 4	0 0
2	— —	— —	SF SC	C C	C SC	S —	— —	— S	SC C	C C	C C	— —
3	— —	— —	— +	+ +	+ + +	+ —	— —	— —	— +	+ + +	+ +	— —
4	+				+			+			+	
		</										

NR	46	FIRST/SECOND NAME	TOWN	STREET	HOUSE NR	PHONE NR
IDENT NR	021070-148A	YR 70	SOC. CL			
ATOPIC ECZEMA		YR 70	PREV HYPO			
RECURR SNEEZING/COUGH		YR 70	RESULT			
ASTHMA		YR 71	DSCG INH/NAS			
ALLERGIC RHINITIS		YR 71	STERIOD			
SYMPTOM DATA - 4 PREVIOUS YEARS						
YR 1976	JAN	FEB	MAR	APR	MAY	JUN
SEVERITY OF ASTHMA	00	00	11	4	2	5
DAYS WITH ASTHMA	00	00	11	4	2	5
SNEEZ-COUGH-FEVER	00	00	11	12	10	00
ECZEMA	00	00	01	11	12	00
MATCH-TEST	00	00	01	11	12	00
OTHER DATA FROM 4 PREVIOUS YEARS						
CHANGE OF ASTHMA	3	1	3	1	3	1
BRONCHODILAT DRUGS	5	2	3	4	4	1
ANTIHISTAMIN DRUGS	4	3	2	3	4	1
INHAL STEROIDS	00	50	50	30	30	0
DSCG INH/NAS	3	3	0	0	0	0
PHYSIOTHERAPY	...	...	...	123	1	1
HYPOSENS TH	...	...	...	1	1	1
HOME/FACTOR/PLANTS	211	211	011	011	011	7
HOME ENVIRONN	123456781	3	7	7	7	7
SOCIAL SERV A/B	11	11	10	10	10	10
SUGGEST THER	34	9	34	14	6	34
FOR CLINICAL NOTES						
CHEST DEFORM	2	1	1	0	11	0
TYPE OF BREATHING	1	0	0	1	12	0
OBSTRUCTION	2	0	0	1	13	0
SNEEZING	2	1	0	1	15	0
ECZEMA	2	2	1	1	16	0
-MAIN LOCALIS	4	4	2	2	17	0
-DRYNESS	3	3	3	3	18	0
ENVIRONMENT	12345	1	3	5	21	1
CAUSES OF SYMPT	1234	1234	1	3	26	1
ALL INFORM					30	0
HYPOTH TH					31	1
DSCG INH/NAS					37	1
INHAL STEROID					39	1
MONTH LAST VISIT/DR	12	AK	08	PT	11	AK

This is free comment from year 1977

TABLE 2
Annual Questionnaire.

1. General progress of asthma		some improvement	☐
better	☐	considerable improvement	☐
same	☐		
worse	☐	<i>Environment</i>	
2. Bronchodilator drugs used		11. <i>Home:</i> new, old, stone, wooden	
days/year		floor, old isolation material, oil	
3. Antihistamine drugs used		stove	
days/year		(underline correct alternatives)	
4. Corticosteroid drugs used for asthma		12. <i>Living in</i>	
months/year		country	☐
5. Inhaled disodium cromoglycate used		densely populated community	☐
capsules		town	☐
6. Nasal disodium cromoglycate used		<i>In close vicinity of</i>	
capsules		13. smoking factories	☐
7. Physiotherapy		14. bad-smelling localities	☐
none	☐	15. fields, forests, parks	☐
sometimes at home	☐	16. lake, sea, river	☐
frequently at home	☐	17. dusty localities	☐
8. Physiotherapy under supervision of a physiotherapist		<i>At home there are</i>	
times		18. feather pillows	☐
9. Hyposensitization therapy, if used, included		19. tobacco smoke	☐
pollen	☐	20. woolen articles	☐
house dust	☐	21. dog	☐
moulds	☐	22. cat	☐
10. Evaluation of hyposensitization therapy		23. animals in	
no comments	☐	closed environment	☐
worse	☐	24. flowers	☐
no improvement	☐		

Fig. 2.

The second data page. Symptom data from 1973-1975 are not illustrated here. The clinical notes are made by underlining correct alternatives. The 35-letter free comment can be used as desired. These notes are transferred into the computer at the end of each year.

Some of these are made routinely in order to follow certain trends in this material. Many of the data handlings are just trials to estimate the value of collected data.

The patients' print-outs are used for several purposes (Fig. 1):

- to give information concerning therapy to the parents (Table 4)
- for clinical use mainly in the asthma clinic
- as a source of data in the nurse's telephone consultation

TABLE 3
The Data Page of Allergy Diagnosis and Hyposensitization (First Page).

NRO	Allergen	History	Prick	i.c.	Nasal	BPT	RAST	Hyposens.
6	Birch	1A ^a	4-75 ^b		3-75 ^c		3-75 ^d	2-76 ^e
8	Alder		3-75					2-76
41	6-grass mix		1-75			0-75		
111	Aspergillus		1-75					
126	Cladosporium		2-75		1-75	0-75		
165	Penicillium		3-75		1-75	0-75		
250	House dust	1S	012-75 ^f		2-75	1-75		
277	Dog		4-75					
403	Orange	2E						
509	Ice cream	2A						

The name of an allergen is printed only if some information concerning it is stored. Data concerning one allergen are printed on the same row. Each column contains data of similar origin (patient history, prick, intracutaneous skin tests, nasal and bronchial provocation tests, RAST and hypersensitization). Data coded as follows: a) Patient history: 1 = uncertain, 2 = certain data; A = asthma, S = sneezing, E = eczema. b) Skin tests: 0 = —, 1 = +, 2 = ++, etc. c) Nasal and bronchial provocation tests: 0 = negative at top concentration of allergen, 1 = positive at 1:10 w/v (10^{-1}), 2 = positive at 1:100 w/v (10^{-2}) concentration of allergen, etc. d) RAST score from 0 to 4. e) Hypersensitization therapy: 1 = water soluble allergens, 2 = Al-precipitated allergens. f) Three skin prick tests performed with results —, + and ++. Year of last test is indicated.

- as a source of data for independent tasks involving the social worker and the asthma clinic's nurse
- to carry out problem-oriented tasks
- as a source of data for research.

This system was taken into use stepwise: The registration of symptoms by the parents was started in 1970. The booklet with primary information and diary was introduced in 1972. The data collection was started in 1974. The data system has been in regular clinical use since 1974 with minor changes every year.

TABLE 4

Annual Reply to Patient. Recommendations Are Indicated by Encircling Numbers in Question.

Following measures require to be taken for the treatment of your child's asthma.

0. No advice can be given regarding further measures. You gave too little data about your child's symptoms.
 1. Maintain present therapy (dust elimination, dietary restrictions, symptomatic drugs).
 2. Improve dust elimination and/or elimination diet.
 3. Visit to the asthma clinic suggested.
 4. Disodium cromoglycate (inhaled/nasal) might be useful. Contact your paediatrician or the asthma clinic.
 6. Hyposensitization might be necessary. Contact the asthma clinic.
 7. Continue previous hypersensitization.
 8. Previous hypersensitization needs checking. Contact the asthma clinic.
 9. Physiotherapy is recommended. A referral to a physiotherapist is enclosed.
-

Note: you may contact the asthma clinic in the case of increased or more severe symptoms. Acute symptoms (asthma, infections) are best treated by your local doctor.

RESULTS

Self-Registration of Symptoms

The request to make regular notes of symptoms was properly carried out by about 75 per cent of the parents. The symptom registration alone has proved useful in many ways:

- regular notes in the diary help the parents to observe the symptoms systematically, and consider their cause

- in the asthma clinic the notes in the diary enable a quick and careful patient history to be taken. The time-saving is considerable
- the symptom diary improves the follow-up of patients. Eventual change of doctor will not interrupt the continuity in the handling of the patient
- the information booklet with symptom diaries is used throughout Finland. This creates some degree of standardization in the routine surveillance of asthmatic children in the whole country
- the data are suitable for computer use.

Total Surveillance

The response rate to the annual questionnaires has been 89 to 93 per cent. About 12 per cent of the replies are poor. However, it has been observed that in almost all cases a lacking or poor response was associated with a child with few or no symptoms at all. Thus, one can conclude, that both the quantity and quality of the feedback from the patients is sufficient from the point of view of total surveillance.

Benefits from the Computer System

The computing facilities add to the system patient data pages and a number of routine statistics. Extra cost is \$ 2 to 3 per year per patient. The cost per patient has decreased as the total number of patients has increased. The asthma clinic gains the greatest advantages from the system, and these can be described as follows:

- practically all patients come under surveillance
- annual reply, i.e. future action can be recommended to all patients. This takes about 1 min per patient for the paediatrician
- the routine work in the asthma clinic is considerably rationalized. It is hard to estimate the significance of better data, but the time-saving is noticeable. The time

needed per patient may be reduced by 15 to 30 min or even more. The time-saving effect is greatest when a "new" doctor begins to work with these patients. He does not have to waste time going through patient history and data from past examinations because the print-outs give these data quickly and more accurately than conventional journals. The data content of the print-outs is sufficient basis on which to make all decisions concerning further examinations and therapy. Only some details need be sought for and written in the conventional charts. Even storing details is possible by using the 35-letter free comment (Fig. 2)

- all parents know the fixed time when they can phone the nurse at the asthma clinic. The quickly available data has made it possible to guide parents by telephone. The nurse refers unsettled matters to the doctor. This system saves visits to the asthma clinic because many questions can be settled immediately
- the uniform data display has made it possible to develop a team work. The social worker can pick out patients whose social conditions are unsatisfactory. The nurse at the asthma clinic can pick out patients who would benefit from a home visit in order to check the dust control. Both of these workers act independently and report their findings to the doctor
- the centralized data system also makes problem-oriented work possible. If a problem is observed, the patients in question can be asked to visit the asthma clinic, or else a letter can be sent to all parents explaining the problem so that they became aware of it and can take action to control it.

General Features of Patient Material

Table 5 presents general data on all asthma patients and those in the asthma register. New patients occur at an annual rate of 90 to 100. The number of patients with many symp-

TABLE 5

Total Number of Asthmatic Children, Severity Distribution and Visits to the Asthma Clinic between 1950 and 1976.

	Year								
	-50	-55	-60	-65	-70	-73	-74	-75	-76
All known asthmatic children	20	70	250	410	670	870			
Those in the asthma register						660	760	855	950
Severity of asthma in									
15-year-old patients							637	706	770
No data							102	151	194
0 days/year							67	100	87
1-20 days/year							143	201	275
21-50 days/year							161	120	102
51-100 days/year							114	90	76
101- days/year							54	44	36
Visits to the asthma clinic					450	644	597	784	688
Visits because of acute attacks						230	277	262	222

toms (those who have more than 50 days asthma per year) has steadily decreased since the asthma register has been in function. The visits due to acute asthmatic attacks have decreased during the past few years. There have been no asthmatic deaths among these patients since 1971.

Table 6 presents the changes in asthma severity during 1 year and 2 years. It will be seen that patients with more than 50 asthmatic days per year have a definite tendency to improve. New patients in this category appear annually. Patients with primarily mild asthma have a good prognosis and only a few of them develop severe asthma.

Table 7 gives data on patient therapy and environment. Table 8 lists some environmental details which throughout the study have been observed to have a certain effect on asthma. Environmental factors which are combined significantly with an increase in asthma are: factory smoke, bad-smelling or dusty localities and animal contact in an enclosed environment. Mild asthma is often associated with domestic pets.

TABLE 6

Changes in Asthma Severity during 1974 to 1975 and 1974 to 1976.

Asthma in 1974 (days/ year)	No data	Asthma in 1975 (days/year)					Total
		0	1-20	21-50	51-100	101-	
No data	120	12	53	30	15	9	239
0	26	43	20	5	1	0	95
1-20	25	40	93	7	2	0	167
21-50	15	20	82	44	8	3	172
51-100	10	4	29	36	29	15	123
101-	3	0	6	10	18	22	59
Total	199	119	283	132	73	49	855

Asthma in 1974 (days/ year)	No data	Asthma in 1976 (days/year)					Total
		0	1-20	21-50	51-100	101-	
No data	144	16	93	42	23	16	334
0	48	33	12	1	1	0	95
1-20	44	43	74	6	0	0	167
21-50	23	23	90	21	15	0	172
51-100	16	3	44	28	24	8	123
101-	3	0	11	16	16	13	59
Total	278	118	324	114	79	37	950

Parents are willing to get rid of a pet if it is causing symptoms, but there is no effective control over these animals outside the home.

Table 9 shows that severe asthma (more than 50 days asthma per year) occurs in all age groups. The decrease in number of these patients is due to the more rapid elimination of symptoms now than in previous years. Our asthma clinic now comes in contact with the patients at an early stage. Earlier, many patients had reached the chronic stage before they came to the asthma clinic.

TABLE 7

Data Characterizing the Patients in the Asthma Register from 1974 to 1976.

	1974	1975	1976
Total number of patients	760	855	950
Patients using bronchodilators > 60 days per year	71	50	53
Treatment with disodium cromoglycate	160	214	253
- patients using > 500 capsules/year	36	55	62
Treatment with steroids*	10	15	35
Physiotherapy	99	136	138
Hyposensitization therapy	159	188	178
<i>Environment</i>			
Smoking factories and the like	155	156	162
Bad-smelling localities and the like	122	131	140
<i>At home</i>			
Feather pillows	44	43	44
Cigarette smoking	206	207	201
Dog	52	55	65
Cat	37	53	51
Animals in closed environment	163	209	217

* Beclomethasone dipropionate aerosol.

TABLE 8

Correlation between Environmental Factors and Asthma Severity.

Environmental factor	Asthma severity (days/year)					Total		P <
	0	1-20	21-50	51-100	> 100	%	N	
Distribution of all patients								
into groups of severity (1975)	37.5	33.0	15.3	8.5	5.7	100	855	
Old house	30.6	39.8	13.7	6.6	9.3	100	183	NS
<i>In the vicinity</i>								
Smoking factories	21.8	36.5	15.4	16.7	9.6	100	156	0.0005
Bad-smelling localities	20.6	37.4	17.6	13.7	10.7	100	131	0.0005
Dusty localities	27.5	35.1	19.4	10.8	7.2	100	222	0.01
<i>At home</i>								
Feather pillows	53.5	39.5	4.7	0	2.3	100	43	0.025
Tobacco smoke	34.3	37.6	15.0	9.7	3.4	100	207	NS
Dog	54.5	25.5	12.7	1.8	5.5	100	55	NS
Cat	41.4	34.0	13.2	3.8	7.6	100	53	NS
Animal contacts in stairwell	27.3	35.9	20.1	11.0	5.7	100	209	0.01

TABLE 9
Age Distribution of Asthma Severity in 1976.

Asthma severity (days/ year)	Age (years)					Total
	0-2	3-5	6-8	9-11	12-14	
No data	2	20	48	66	58	194
0	0	7	15	28	37	87
1-20	5	37	73	86	74	275
21-50	3	18	26	36	19	102
51-100	2	5	24	26	19	76
101-	1	7	11	10	7	36
Total	13	94	197	252	214	770

DISCUSSION

In recent years there has been vast progress in asthma research and the methods of treatment. However, in spite of advances, asthma is still a problem because none of the recent discoveries has led to an effective solution. Long-term therapy is still, in individual cases, a mixture of many therapeutical methods. Poor prognosis may simply be due to inactive follow-up; this is frequently observed (4).

This project was started in 1969 in order to make a comprehensive investigation of the various aspects of childhood asthma. A data register comprising a large patient population was considered necessary and this was ready in 1974. For 3 years this system has proved to be an ideal medium in the execution of asthma care. Easily available data have increased the efficiency of the asthma clinic to such an extent that it can survey and treat a large patient population. Although asthma care has been the first priority, this system serves also as a medium for asthma research: it facilitates the selection of material for special studies and an investigator of a special problem has a ready supply of basic data on the patients. It has been interesting to observe

how eager and willing the parents of the children are to participate in the different study programmes.

Previous systems for monitoring asthma have had methods which are not easy to adapt to a regional asthma system. Falliers et al. (2) rely primarily on self-measurement of the peak expiratory flow rate (PEFR) which is impossible with many hundreds of patients. Kurata et al. (5) have developed a method in which daily subjective symptoms are recorded on a punch card. Such accuracy is seldom necessary for clinical purposes and takes up space on the data print-out. The system developed by Charpin et al. (1) relies on questionnaires compiled by the staff, and repeated visits to the asthma clinic. In the present approach it was observed that carefully prepared questionnaires with not too difficult and detailed questions were usually answered accurately by the parents. Children with minimal symptoms need only be seen once every 3 to 4 years. Therefore, a yearly questionnaire by post is preferred to a yearly visit. A further argument in favour of the mailed-questionnaire-method is a better rate of feedback information from the patients. With this system, approximately 90 per cent of the parents make an annual report. A feedback system based only on annual visits to the asthma clinic is apt to give a low rate of feedback (40 per cent) as reported by Charpin et al. (1).

The most important function in this system is the recording of symptoms (Table 1). "Asthmatic day" was observed to be superior to any other proved coding method. A half monthly registration period gives sufficiently detailed information for most clinical purposes. This type of registration is also accepted by most parents, which is important from the point of view of feedback. Also the other questions presented annually (Table 2) have proved appropriate. The questionnaire system does not aim to be exhaustive, and the more complex questions can always be discussed personally at the asthma clinic.

The present system is still in many ways a collection of subjectively estimated data. Everybody using the system must

create his own opinion about the accuracy of different data and take action accordingly—one also does this with the “old” system. The present system is probably no worse than the “old” system which depends on patient memory and journals. The systematic data display of the present system enables one to estimate the accuracy of data. This is impossible with the “old” system.

This “mass” activity might be considered adverse to individual asthma therapy. However, one can observe that the asthma register function improves asthma care and also saves time. The time saved can be used to meet the need of the individual patient.

One might consider it unnecessary for children with mild or “cured” asthma to be included in this system. However, experience from this project shows that asthma can worsen at any age without warning. There are no criteria for predicting this. An important argument in favour of keeping all asthmatic children in the asthma register is that most parents willingly participate in this type of project and the cost is low. Regular contact (by mail only) with an asthma clinic enables preventive measures to be taken in time.

Much attention has been given to patient education and continual guidance. In addition to the booklet about asthma therapy the parents receive help in many ways. From the point of view of total asthma care this parent activation has a most important (and often forgotten) function. It is the means by which the physician’s concept of the best therapy can be translated into language understood by the parents and thus enlist their help in carrying it out. This process acts as a kind of PR-function for the system by motivating the parents to fulfil their task (symptom registration) for the system.

In recent years the prognosis of asthma has improved among the patients in the asthma register. It is difficult to evaluate the relative significance of the various factors involved. For example perennial asthma among the youngest children has considerably decreased. This is probably due

to better education regarding diet. It has not been possible to eradicate asthma with many symptoms, but one is better able to recognize these patients and organize studies for a better understanding. When asthma can be seen progressing from a mild stage to a severe stage, and vice versa, it is possible to begin to understand the reasons.

SUMMARY

An asthma data register which collects annually certain data from all known local asthmatic children has been presented. The data register is utilized to make a two-page print-out for every patient, and statistics of the whole material. These data make the continuous surveillance and guidance of the patients possible. The easy-to-use and accurate data material has contributed to rationalization of routine work in an asthma clinic. Team work has also improved because the uniform data material enables various workers to quickly pick out a specific problem from the whole material. The cost, \$ 2 to 3 per patient per year, is low compared with the immediate benefit. Indirect benefit is to be expected because the system helps to investigate the problems of asthmatic children.

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