ACT™ in the practice: benefits and limits

Author: Paula Herke MD.

Ambulance of Lung Diseases. Adress: Szigetszentmiklós, Viola u.1.H-2310 Hungary

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Abstract: For the follow-up of asthmatic patients the „GINA 2009" recommends validated control tests, e.g. the ACT™. Based on the everyday experience, conditions of testing might affect the ACT score.

METHOD: 205 patients were chosen randomly for the medical examination and divided into two groups (n_1 = 103, and n_2 =102). The members of the first group talked with the doctor after a spirometry test, who asked the questions of ACT. Following this, the group members filled in the ACT tests in the clinic on their own. The second group filled out the tests after the spirometry but before meeting with the doctor. The doctor has scored the verbal answers of the patients in both cases according to the criteria of ACT. Results were not told to the patients.
Respiratory function: LUNGTEST 1000. Score-ranges of ACT: The asthma was controlled at an ACT score of ≥ 20, partly controlled at scores of 19 and 18, and uncontrolled at a score of ≤ 17 (according to the chinese validation)**.**
RESULTS: From the 103 patients of group one, 23 patients had at least by one question 3 or 4 point difference, and 26 patients reached at least by one question 2 points difference between verbal and written answer (1- 5 points could be given for each question). From the 102 patients of group two, 23 patients had at least by one question more than 3 or 4 point difference and other 23 patients had at least by one question 2 points difference between verbal and written answer. Extreme deviation was less in group 2 than in group 1. The same number of people gave diverse answers in both groups. The difference between the two groups is not much remarkable, although patients were influenced by the previous meeting with the doctor: their answers came out as more positive. In addition to this, both groups gave somewhat higher scores in their second test.
In the evaluation of the test a min. 12% deviation between written and verbal answers was regarded as significant difference. 15,5% of the patients, who met with the doctor first (group 1) got higher scores in the written test, while 11,7 % of group 2 gave a more positive (verbal) answer to the doctor than their original (written) test score. On the basis of the same aspects a negative deviation was seen by 3,8% and 4,9% of the patients. Problems arose with the interpretation of question 4 and 5 in both groups (19%). Daytime cough was reported in 34% of the treated patients, who added at the same time 5 points for both questions referring to daytime symptoms (questions 1-2), which is a hardly classable complaint. We found that patient's opinion about their own condition of asthma (question 5) did not match the ACT results: the opinion of only 107 patients about their asthma control level matched the results of the ACT, while 98 patients (=48%) had a different opinion. The question asking the patients for the subjective scoring of their own health-quality did not significantly distort the result of ACT in itself. Examining the results case-by-case we found that the asthma control level assessed by GINA accords only in 60% of the patients with the ACT™. On one hand, the test can demarcate the uncontrolled group from the partly + (well) controlled groups, if the score-range is between 17 and 18 points. On the other hand, it is not

suitable for the separation of partly controlled and controlled levels. **The parameters of spirometry (FEV1, FVC_{ex}, PEF,FEF_{25-75}, $MEF_{50\%}$,) corresponds only poorly with the result of** ACT™**.**

CONCLUSION: ACT™ is suitable for the follow-up of patients after they took part in a training, if they fill out the test for themselves, and not in the presence of the medical staff, nor according to putative expectations. In this case we can ascertain the subgroups of the uncontrolled and partly controlled groups with lower scores. This could be of a great help to the self-management of well-trained patients and for general practitioners to find the asthmatics who need a professional council out of turn. The ACT™ is not suitable for the automatic classification of new patients, nor to specialists to class them into the 3 level of control assigned by GINA. Based on the experience of 8 years it would be worth to develop a new kind of test for specialists, which is attentive to the international recommendation, to the circumstances in Hungary and to the idiosyncrasy of the Hungarian language.

Key words: ACT score, ACT™, asthma control, GINA, spirometry,

The therapy of chronic illnesses is measured by the patients' lifequality. There are different levels of lifequality ranging from „nearly unbearable" to „practically asymptomatic". „Generally uncontrollable" illnesses not only prognosticate a worthening course of disease, but they mean and foretell higher financial costs. (1)

So it's not a wonder that the earlier used stadium-classification was displaced by the control-based therapy and follow-up (which came from the english terminology). For the assessing of control levels GINA gives concrete instructions, it recommends for further follow-up the validated control tests listed in Table 1. (2) „Be in control" means for people in Hungarian to „govern" or „inspect".

Table 1: tests for adults recommended by GINA

• Astma Control Test **(ACT)**
• Astma Control Questionnaire (ACQ)
• Astma Therapy Assessment Questionnaire (ATAQ)
• Astma Control Scoring System (ACSS)

The question is: to what extent are the results affected by the conditions of testing and **what are its limits?** ACT™ is the most prevalent test in Hungary. Based on everyday experience came up the idea, that the conditions of testing might affect ACT™ scores, so we decided to find this out in real life situation, within a crowded clinic.

OBJECTIVES:

- To observe in everyday practice: **Do the conditions of the testing affect the reached score in ACT**? Is there any question that receives significantly different answers?
- Is there any question that patients consider as difficult to understand?

- Does the control level (calculated from the scores) accord with the one ascertained by GINA recommendations?
- Is there any spirometry-parameter, which correlates with the ACT score?

METHOD: 205 patients were divided into two groups: $n_1 = 103$, and $n_2 = 102$.The first group filled in the ACT test on the spot in the clinic, after a spirometry test and talking with the doctor, who asked the questions of ACT. Likewise, the second group filled in the tests after the spirometry, but **before** meeting with the doctor. The doctor has scored in both cases the verbal answers of the patients according to the criteria of ACT and the results weren't told to the patients. Respiratory function: LUNGTEST 1000.

According to the number of patients examined in national validations (Table 2) of ACT, our datas are comparable to the results of other scientific studies.

Table 2: number of patients in national validations (3, 4, 5, 6, 7. 8, 9, 10,11)

	n=…. patients
hungarian	133
english (West-Europe)	2949
american	313 + 471 + 4180
brazilian	290
spanish	322
arabic	40
chinese	403
pakistan	150
korean	392

The study was carried out in accordance with the Declaration of Helsinki. The study protocol was approved by an Independent Ethics Commitee (Semmelweis University, Budapest).

The ACT™ is a questionnaire including five questions (Table 3), every answer is 1-5 points worth, 5-25 points can be given alltogether (Table 4). It was registered in 2002 (QualityMetric Incorporated) and then it was divided up to two control level: uncontrolled/ controlled (well or absolutely).

Table 3: questions of ACT™

1. How many times were you restraint by your asthma to get your tasks done in school, at your workplace or at home in the last 4 weeks?
2. How often have you suffered from shortness of breath because of your asthma during the last 4 weeks?
3. How often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning during the past 4 weeks?
4. How often have you used your rescue inhaler or nebulizer medication (such as albuterol) in the last 4 weeks?
5. How would you rate your asthma control level regarding the last 4 weeks?

GINA 2009: an interational recommendation using 3 categories as control levels (uncontrolled, partly/partially controlled and controlled). The hungarian financing system works based on these levels. On one hand ACT originally doesn't include the „partly/partially controlled" concept, on the other hand GINA does not use the term of „well-" or „fully controlled". The requirements of comparison: defining the score-ranges of the well controlled level in ACT. A philosophical, but not pointless question: „partly controlled" refers to someone, who is „well controlled" but does not feel enoughly well, or a „not controlled" patient, who is fine? The answer given by the chinese validation is limiting the partly controlled zone at 18-19 points. Current study operates with these score-ranges as well (Table 5).

Table 4: the original score-ranges of ACT.

5-19 points:	**uncontrolled**
20-24 points:	**well controlled**
25 points:	**fully controlled**

Table 5: score-ranges used in the chinese validation of ACT.

≤17	**uncontrolled**
18-19	**partly/partially controlled**
20-25	**fully controlled**

Results:

I. **Do the conditions of the testing affect the reached score in ACT?**

Group 1 (verbal recording of anamnesis first, then filling out ACT on paper): **THE SUMMARY OF 103 PATIENTS' DATA,** 25 of them are active smokers. See details in Table 6. **It is clearly to see, that 46,5% of the patients repeating their verbal answers within a few minutes in written form, could reach a higher score.**

Table 6: PATIENTS GROUPED BY DEVIATION OF SCORES BETWEEN VERBAL AND WRITTEN TEST RESULTS IN GROUP 1, N=103

	n=
The doctor gave a higher score with >12%	16 =15,5%
The doctor gave a higher score with <12%	32 =31%
Gave the same score	27 =26,2%
The doctor gave a lower score with <12%	24 =23,3%
The doctor gave a lower score with >12%	4 =3,8%

From the 103 members of the first group 23 patients had at least by one question 3-4 points difference and 26 patients had at least by one question 2 points difference between verbal and written answer (1-5 points can be given for each question).

Group 2 (first ACT in written form, then verbal answering): THE SUMMARY OF 102 PATIENTS' DATA, 32 of them are active smokers. See details in Table 7. It can be determined that patients reached higher scores in the verbal repeating of the answers compared to prior written test results.We can ascertain, that 44% of the patients repeating their written answers directly in oral form, could reach a higher score.

Table 7: PATIENTS GROUPED BY DEVIATION OF SCORES BETWEEN VERBAL AND WRITTEN TEST RESULTS IN GROUP 2, N=102

	n=
The doctor gave a higher score with > 12%	5 =4,9%
The doctor gave a higher score with < 12%	26 =25,4%
Gave the same score	26 =25,4%
The doctor gave a lower score with < 12%	33 =32,3%
The doctor gave a lower score with > 12%	12 =11,7%

From the 102 members of the second group 23 patients had at least by one question 3 or 4 points difference and other 23 patients had at least by one question 2 points difference between the verbal and written answer (1-5 points can be given for each question). Extreme deviation was less in group 2 in comparison with group 1.

The graphic comparison of the scores in group 1 and 2 is shown in Figure 1.

Needless to say, the results are affected by the attitude of the patients and the subjective interpretation of the doctor as well. Equal number of group members gave a diverse answer in both groups. Whose results show at least 12 % difference between verbal and written answers? (Note, that only some minutes passed by before the repetition of the questions!)

- 15,5% of the patients, who spoke with the doctor first (group 1) received more points in the test.
- 11,7% of the members of group 2 gave a „more positive" answer to the doctor, after filling out the test.
- Only 3,8 % and 4,9% of the patients gave fewer points to the same extent to the repeated questions. The difference between the two groups is not significant.

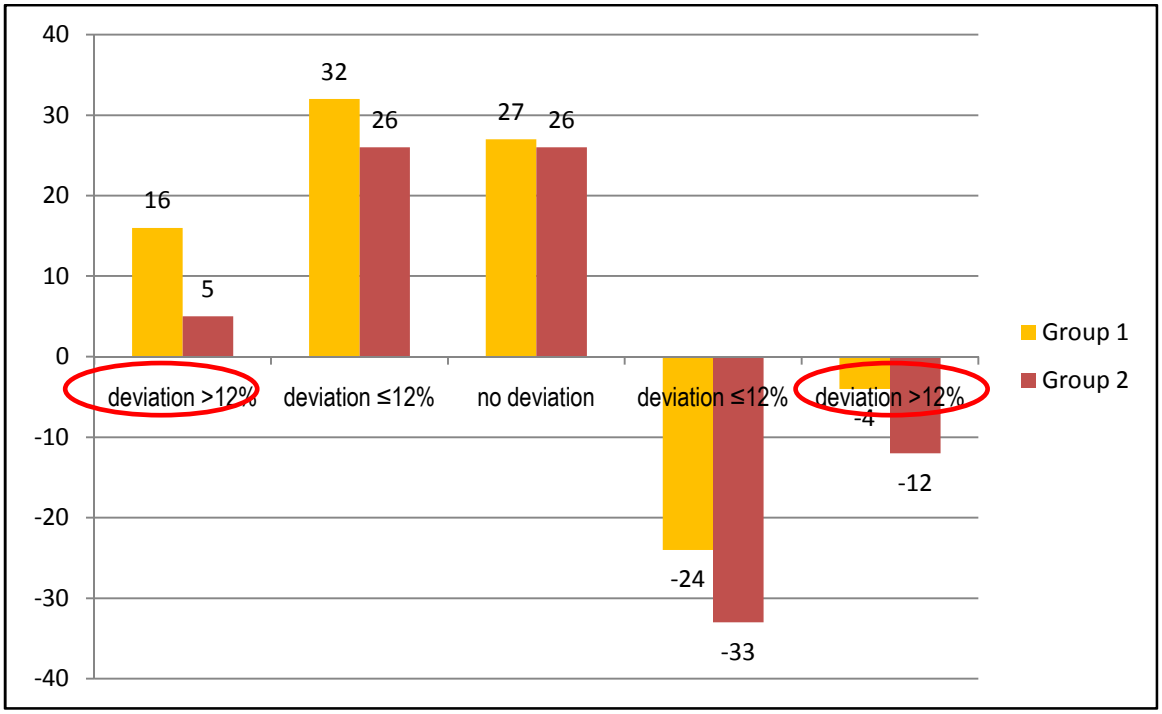


Figure 1: comparison of the scores on the basis of the deviation from the scores given by the doctor in group 1 and 2

Assessing the datas all of the 205 patients, **19%** of them reported difficulties to understand question 4 and 5, **8,5%** requested the doctor's help to read the questions for them, as they could not see the letters, and there was one illiterate person among them as well.

There is a problem with question 4 („How often have you used your rescue inhaler or nebulizer medication (such as albuterol) in the last 4 weeks?"), namingly: what should a new patient (who hasn't got such a medicine yet) or an „old" patient (who has runned out of the medicine, altough he would have needed to use it) **write**:*5 points, which means that they did not take any medicine, or the points in accordance with the real necessity? 24 patients from the examined 205 gave 5 points for this question out of the above mentioned reason. 11 of the 24 patients had a score under 17!- certainly, they could not be in „controlled"status.*

A returning problem by **question 5** is: how does the patient interpret the term of being „**controlled" (taken over from the anglo-saxon terminology)?** We will bring some examples further on.

III. Further questions to be cleared:

Does **shortness of breath on exertion means a restraint for patients in their daily routine? Question 1 or question 2 is the right place to answer it? Shortness of breath while climbing stairs is likely to be considered as a symptom independent of asthma- or it is that indeed, too…** what is the right answer for the ones climbing the stairs 3 times a day?

Coughing generally appears on the list of *symptons of dyspnoe*if it comes to coughing in fits, additionally it is mentioned as *hindrance* by the patients whose profession requires a substantial

amount of speaking. Summary: **ACT does not include the option for „coughing beside the therapy", while it appears in GINA as an assessable daytime symptom.**

- ***How many of the patients with 25 points cough?***
  Analyzing the data of all the 205 patients: 15 patients had 25 points, 13 of them does not cough, the remainig 2 said „sometimes".
- ***How many of the patients indicating „no daytime symptoms" cough?*** = 5 points for both questions referring to daytime symptoms (question 1 and 2). According toTable 8 **34%** of them **does** (more or less frequently) **cough**.

Table 8: Prevalence of coughing among the patients, who reported no daytime symptoms

	n=27
no cough	18 = 66%
just in the morning	1 (with known reflux)
in fits	**1**
when went to bed	**1**
just hawks	**2**
sometimes	**4**

IV. To what extent deviates the patients' subjective opinion on their own control level (question 5) from the control level estimated by ACT?

18% OF THE PATIENTS CATEGORIZED THEMSELVES AS UNCONTROLLED, 28,3% AS PARTLY CONTROLLED, 53,6% AS CONTROLLED (Table 9).

Table 9: the patients' own opinion on their control-level *(question 5)*

Level of control	Based on the scores of question 5 (case number) n=	
	Group 1	Group 2
uncontrolled	17	20
partly controlled	26	32
controlled	60	50

Case-by-case examined the opinion of patients on their own control level (question 5) we have found that it corresponds with the one estimated by ACT in 107 cases, while results differed in 98 cases (=48%).

What causes this significant difference? Can it be the term of „control", which remained an unexplained and foreign expression in the Hungarian language? To find this out, we have asked some of our randomly chosen patients to define in written form the expression „controlled". Answers were given **after** meeting the doctor and filling out the ACT control test.

Version I.: „CONTROLLED"= I have visited the doctor.

Version II.: „CONTROLLED"= I don't know.

Version III.: „CONTROLLED"= Regular medical health checks.

No one of them wrote anything to „partly controlled" and „uncontrolled", at the same time they classed themselves as „well-controlled". Further aswers were:

- I should always and constantly have controlled medicine on hand
- therapy overseen by a physician
- my state of health is all right
- (*it means*) that my state of health is maintained
- I can expect a better state of health for a relatively longer period
- I have visited my physician.

Version IV.: „PARTLY CONTROLLED"= state of health cannot be maintained. The respondent described himself as partly controlled.

Other answers for „PARTLY CONTROLLED"=

- they don't care about me
- it is not sure, wether my health could improve or be maintained
- partly checked
- No answer.
- it could be better

How do patients interpret the expression „NOT CONTROLLED"?

- I don't care about it
- not overseen
- the medication is not properly adjusted
- they don't care about the patients at all
- not treated
- cannot be cured absolutely

Version V.: No answer. He classified his condition as „poorly controlled".

Version VI.: „I wouldn't be alive anymore, for sure." This patient gave 5 points for his condition, at the same time his total score was only 12!

Version VII.: „The doctor thinks that I don't take the prescribed medicines and I ignore lifestyle advices." On the grounds of this definition, he characterized his condition as „absolutely not controlled".

It can't be proved that the deviation between self-determined and ACT-defined control level is caused by linguistic differences, but the problem undoubtedly exists.

V. How much does the ANSWER GIVEN TO QUESTION 5, the „self evaluation" or –depending on the way of interpretation- the „assessment of therapy" influence the end results ofACT?

ACT regards a condition as „controlled" if the patient's score is ≥ 80% of the total. We have chosen the score range 69-79% for the „partly controlled" level. According to this percentual scale, the difference generated by question 5 can be calculated by classifying group members based on their scores they got for the first four questions (Figure 2 and 3).

Table 10: results of group 1

Group 1 n=103	ACCORDING TO THE SCORES OF question 5	ACCORDING TO THE SCORES OF question 1-4	ACCORDING TO THE SCORES OF ACT	ACCORDING TO THE RESULTS OF GINA (case number)
UNCONTROLLED	17	43	51	53
PARTLY CONTROLLED	26	17	14	35
CONTROLLED	60	43	38	15

Table 11: results of group 2

Group 2 n=102	ACCORDING TO THE SCORES OF question 5	ACCORDING TO THE SCORES OF question 1-4	ACCORDING TO THE SCORES OF ACT	ACCORDING TO THE RESULTS OF GINA (case number)
UNCONTROLLED	20	61	62	54
PARTLY CONTROLLED	32	16	14	37
CONTROLLED	50	25	26	11

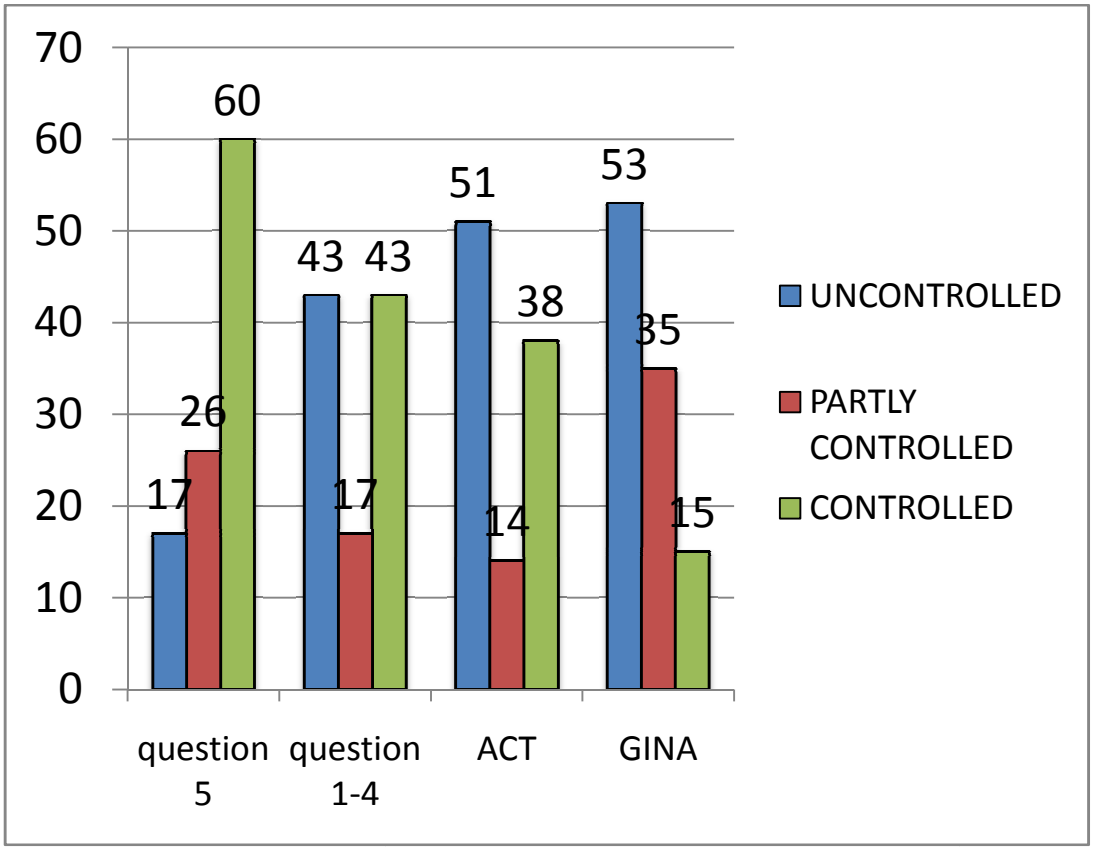


Figure 2: control level classification of 205 patients

Patients obviously tend to „beautify" their answers when it comes to rating, or they misinterpret question 5. The answers for question 1-4 (related to complaints and symptoms) match the results of GINA far better.

VI. ***In how many cases did the control level determined by the two systems (GINA/ACT) differ?***

Examining the outcomes case-by-case in goup 1 (n= 103): 59 patients got equal, but 44 people had different results.

Analyzing the outcomes case-by-case in group 2 (n=102): 66 patients were classed into the same level, but 36 patients were not.

Conclusion: control levels determined by GINA and ACT correspond only in 60% of the cases with each other.

Table 12: total distribution of control levels based on ACT and GINA results.
Score-ranges: uncontrolled ≤17, partly controlled 18-19, controlled 20-25.

level of control	**ACCORDING TO ACT Group 1 (person)**	**ACCORDING TO GINA Group 1 (person)**	**ACCORDING TO ACT Group 2 (person)**	**ACCORDING TO GINA Group 2 (person)**
uncontrolled	51	53	62	54
partly controlled	14	35	14	37
controlled	38	15	26	11

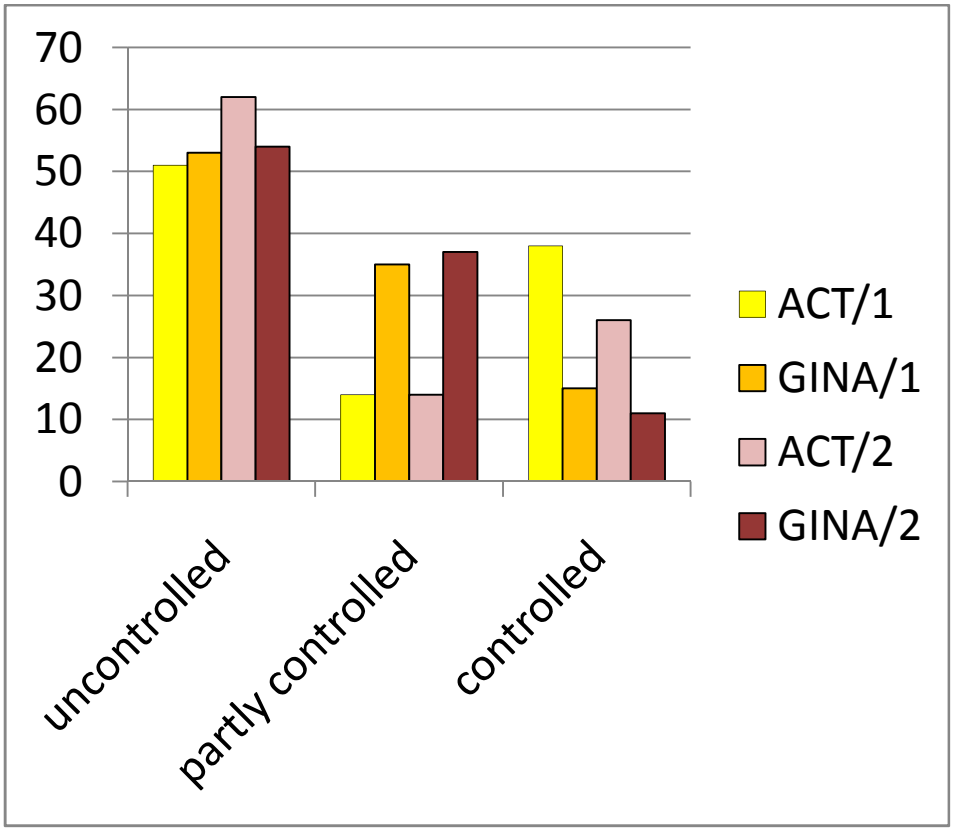


Figure 3: the total distribution of control levels based on ACT and GINA results

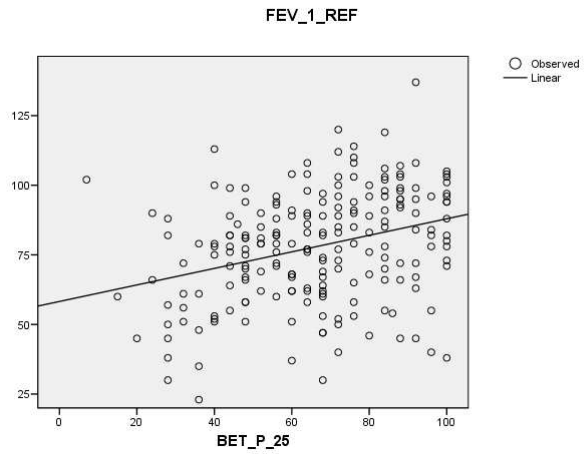
Looking at the total distribution of control levels based on ACT outcomes and GINA aspects (Table 10, Figure 3): the test can demarcate the uncontrolled group from the partly + (well) controlled groups, if the score-range is between 17 and 18 points. On the other hand, it is not suitable for the separation of partly controlled and (well) controlled levels.

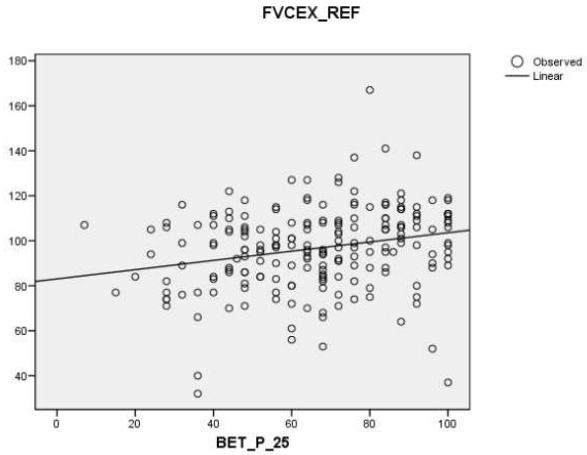
VII. Which respiratory parameters correlate with ACT scores (in % values), or with symptom-related questions only, ignoring the patients subjective opinion on his own state of health?

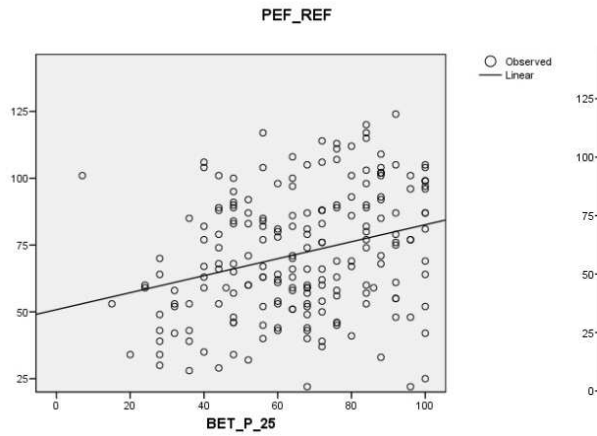
USED STATISTICAL METHOD

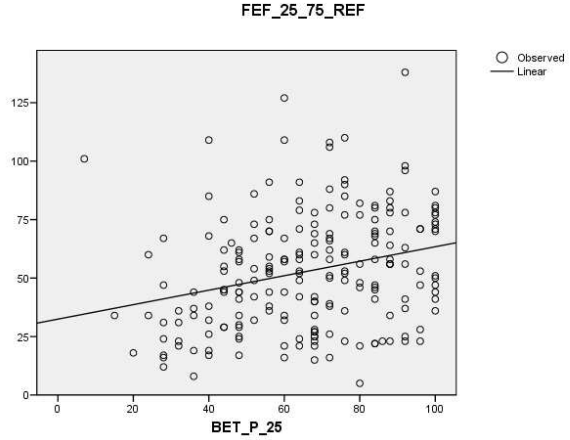
We have investigated, how much accurately can we estimate the value of functionally measured parameters (FEV_1_REF, FVCEX_REF, etc.) by applying pairwise linear regression on the data of the questionnare measuring quality of life and state of health. Applying non-linear regression did not improved the accuracy compared with linear regression method of least squares. A statisctical test was considered as significantly effectiv, if the chance for failure was under 5%. We indicated at every relationanalysis the linear equation, that defines the gradient (a) between the two variables and the constant (b).

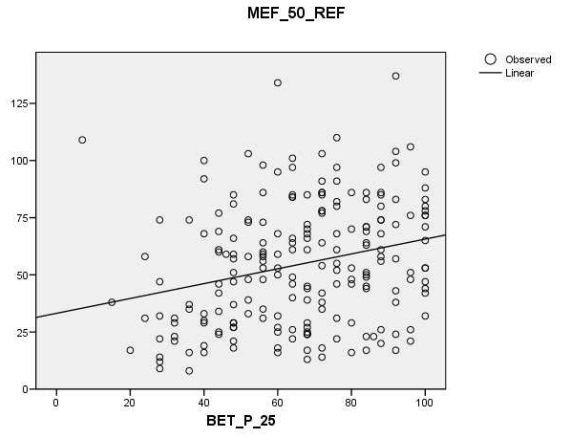
Y = a X + b











There is a moderate correlation between ACT scores and examined spirometry results (p<0.05)

CONCLUSIONS:

The outcomes of ACT and its correlation with GINA as well as its correlation with spirometrical results are influenced by several factors and so the comparability is burdened with doubtfulness.

- Such factors are from the the patient's point of view: in the patient/physician communication – beside the always present subjective factors - the interpretational and linguistic problems during respiratory examination. It seems, patients have some kind of intention to make the test results better, if the testing is conducted in the presence of the doctor. Thus, it is highly recommended to let patients complete the tests on their own, before meetig with the doctor.
- From the test's point of view: the questions of ACT do not represent accurately the symptomical aspects of GINA, moreover, we are trying to correlate a two-level (otherwise well functioning) test with an other one, which operates with three levels.

- It is suspected that deviations come not only from the patients' overestimation of their own control level or from the misinterpretation of the term „controlled", but the original score-ranges of the test also push results in this direction.

ACT is suitable for the follow-up of patients after they took part in a training, if they fill out the test for themselves, and not in the presence of the medical staff, nor according to putative expectations. In this case we can ascertain the subgroups of the uncontrolled and partly controlled groups with lower scores. This could be of a great help to the self-management of well-trained patients and for general practitioners to find the asthmatics who need a professional council out of turn. The control level ascertained by GINA and ACT only matches in 60% in the reality and 1/5 of the patients had problems with understanding the questions of the test.

This is why ACT is not suitable for:

- the automatical categorizing of new patients (question 4 and 5)

- specialists to class patients into the 3 levels of control assigned by GINA.

Based on the experience of 8 years it would be worth to develop a new kind of test for specialists, which is attentive to the international recommendation, to the circumstances in Hungary and to the idiosyncrasy of the Hungarian language.

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