What information do people with type 1 diabetes use?

# Information behaviour of people with type 1 diabetes in Germany Results of a quantitative survey in October 2022

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April 2023

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## Abstract

In recent years, there have been numerous technical innovations such as CGM systems or insulin pumps that have made life easier for people with type 1 diabetes. However, this also means that more and more information is available. The aim of the present study is to learn more about the daily handling of information. The following research question was asked: What information do people with type 1 diabetes use?

To answer this research question, a quantitative online survey of people with type 1 diabetes was conducted by Prof. Dr. Matthias Fank at the Technical University of Cologne. The online survey consisted mainly of 25 closed questions asked on a scale of 0 to 10. The evaluation included the responses of 1,025 people who are at least 18 years old.

The most important information for type 1 diabetics is the "current value". This has put 67.5% in 1st place. Current glucose levels are provided by CGM systems used by 94.2% of people with type 1 diabetes. Quarterly visits to the diabetologist are important and provide important information. 30.8% "wholeheartedly" agree with this statement on a scale of 0 to 10. Only 2.2% of people with type 1 diabetes are satisfied with their current diabetes therapy apps. There is a desire for a manufacturer-independent app. Almost a quarter (24.6%) of people with type 1 diabetes voted for the strongest approval with a score of 10. The study provides an insight into diabetes therapy and highlights the need for action.

## 1 Background

Type 1 diabetes is currently an incurable disease. Numerous decisions have to be made every day to keep blood sugar within an appropriate range. In recent years, there have been numerous, especially technological innovations, which are intended to facilitate the treatment of type 1 diabetes. These technological innovations mean that more and more information is available that could be dealt with all day, but this cannot really be the goal. The author himself lives with type 1 diabetes, knows this situation very well and would like to know how other type 1 diabetics are doing. So far, there are hardly any studies that have investigated how the situation looks from the point of view of those affected. The present study was conducted as part of a research semester at the TH Köln. Financial resources were not available to carry out the study, nor does it have a client.

## 2 Study design

## 2.1 Method

In order to gain a closer insight into the daily management of type 1 diabetics, a mixed-method approach was chosen. First, **qualitative interviews** were conducted with seven type 1 diabetics. All participants have had type 1 diabetes for several years and use different technical aids. The conversations were conducted and recorded online with the help of the Zoom software. One participant refused a recording for data protection reasons, so there are only written records of this conversation. The talks lasted about 60 minutes and were held in early September 2022. In addition, an interview was conducted with a doctor for diabetes. The evaluation was carried out with the MAXQDA software. Many suggestions could be drawn from these discussions and it became clear which questions should be asked in a quantitative study.

Following the qualitative interviews, an online questionnaire was developed, which formed the basis for the **quantitative study**. Before the actual field phase, pretests of the questionnaire were carried out. In the pretest, the participants of the qualitative study participated. The aim of the quantitative study was to check whether the findings gained in the interviews also apply to other type 1 diabetics. The online questionnaire was programmed with the software Questfox and was available online from 01.10. to 15.11.2022.

## 2.2 Database

Unfortunately, there is no complete register of type 1 diabetics in the Federal Republic of Germany. According to estimates, around 340,000 people older than 18 years live with the disease in Germany. (Source: German Health Report. Diabetes 2022. Die Bestandsaufnahme, p. 15). A population of around 340,000 type 1 diabetics is therefore assumed. Since a full survey is not feasible in the context of the present study, a sample survey was chosen, i.e. only parts of the population (population) were examined. The aim was to transfer findings from the sample to the population. This can be achieved if the sample size and composition are appropriate for the population. With a confidence interval of 95% and a margin of error of 5%, the sample size was 385 participants. The aim of the study was therefore to attract at least 400 participants to the survey. The sample composition was based on the study by Rosenbaum, Neu, Rothe, Seufert & Holl (diabetes types are not limited to age groups. Journal of Health Monitoring, 2019). Further explanations on the composition are given in the results section.

## 2.3 Recruitment

In the present study, no panel could be used, so a convenience sample was chosen. The public distribution of the questionnaire resulted in passive recruitment, which was accompanied by a self-selection of the respondents. In this sense, it is therefore a self-selection sample and therefore cannot be described as representative (Schallehn, 2012, p. 98). The target group or community of type 1 diabetics was set as the selection framework, assuming that a good image of the population is achieved. Several ways have been selected to directly target type 1 diabetics. On the one hand, the survey could be accessed via a study platform for diabetics, which is maintained by diabinfo. This portal is supported by Helmholtz Zentrum München, the German Center for Diabetes Research (DZD) and the German Diabetes Center (DDZ). In addition, there are some news portals through which type 1 diabetics can be reached. The portals diabetes-news and diabetes-online published a reference to the survey. Diabetes-online also included the call to participate in the survey in the newsletter and published a reel with the author on Instagram to draw attention to the survey. In order to reach people who are not online, a call for participation in the survey was published in the print

magazine "Diabetes Journal". IDAA (International Diabetic Athletes Association), an association for athletes with diabetes, also published a note on the study. The social media platform Facebook also offers numerous groups aimed specifically at type 1 diabetics. The author himself is a member of some groups in which he has posted a note and called for participation. The survey was referred to in the following groups:

_	Diabetes Typ 1	mit 25.189 Members
_	Dexcom G6/G7	mit 12.106 Members
_	Diabetes Typ 1 (LADA)	mit 1.368 Members
_	xDrip+ Germany	mit 1.970 Members
_	Nightscout Germany	mit 3.748 Members

## 2.4 Field phase

The field phase of the quantitative survey started on 1.10.22 and should be completed on 30.10.22. The above-mentioned print magazine was only able to launch the call for the study in the November issue, so that the field phase was extended to 15.11.22. In the period from 1 October to 15 November, 1,712 people accessed the link. 1,048 people completed the questionnaire. This corresponds to an absorption rate of 61.21%. The drop-out rate was mainly on the start page. This may have been due to the fact that the call on the news portals was generally aimed at diabetics and possibly also type 2 diabetics called up the survey and found that they did not belong to the target group. The average duration for the survey was 5 minutes 32 seconds. The duration was announced with 6 minutes and thus well predicted. The goal of attracting at least 400 participants was far exceeded.

## 2.5 Questionare

The questionnaire was created as a mobile survey, made available online and filled out selfadministered. When programming the questionnaire, care was taken to make it easy to participate with a smartphone. The questionnaire consisted of an introductory page with a reference to data protection and a final page with a thank you for participating. Between the start and end pages, participants were asked 25 questions. The last question was asked as an open question, in which the participants could enter wishes and suggestions in a free text field. This was not a mandatory question and could simply be skipped. The opportunity to express oneself freely was used differently and led to the fact that the duration of the processing fluctuated significantly.

## 2.6 Dataclearing and weighting

To increase the data quality, a data cleansing was carried out. The data set was checked for completeness, consistent answers, processing time and response behavior (Baur, Blasius, 2019, p. 794). The survey was conducted by 1,712 participants. 1,045 participants completed the survey. There are no missing values in any of the 1,045 records, except for the free text question. For the question of consistency, the consistency check determined by the program Questfox itself was used. None of the 1,045 participants showed a trend. In a further step, the processing time was examined in more detail. On average, the processing time was five and a half minutes. With a processing time of less than two and a half minutes, it is assumed that these are so-called clickers who did not seriously participate in the survey. In 13 cases, a shorter processing time was found. These were therefore removed from the sample. Too long a processing time is also considered critical. Participants who were on the survey for more than 20 minutes were also removed from the dataset. This affected 10 participants. The adjusted sample ultimately comprises 1,025 data sets that were used for analysis.

A first descriptive analysis of the 1,025 data sets in terms of demographic characteristics showed that more women (702 people) than men (321 people) participated in the survey. It can be assumed that type 1 diabetes behaves similarly in terms of gender compared to the general population. It is estimated that in the total population, 49% of people are male and 51% female. In the present sample, 30.77% are male and 69.1% female. In order to rule out a possible bias, a correlation analysis related to gender was carried out in the first step. A chi-square test was used with the result that men and women do not differ significantly in terms of the data collected. In a second step, a case weighting was carried out with the statistics program SPSS and the mean values of the weighted data set were compared with the unweighted data set. Since there were no major mean differences, it was decided to use the dataset unweighted.

The results listed below refer to 1,025 participants who participated in the study.

## 3.1 Socio-demographic characteristics

The survey recorded socio-demographic characteristics such as age, gender, educational attainment and place of residence. On the one hand, a consideration should provide information about the distribution within the study group and, on the other hand, ensure transferability to the entire group of type 1 diabetics.

## 3.1.1 Age

The query for age was carried out by previously created age ranges. According to a 2019 publication in the Journal of Health Monitoring, it was concluded that type 1 diabetes is not limited to age groups. Since there are no exact figures regarding age, the sample was compared with the statistics of the total population in Germany as of December 2021 (source: Statista). The age groups included in the sample are close to the distribution for the population as a whole, suggesting that the results of the present study are of strong significance. As a result, it can be stated that all age groups are represented in the present study. A distribution of the sample by age group and comparison with the total population in Germany can be found in the following table.

Age						
Frequency Percent Total						
T1D T1D popula						
	18-25 Years	133	13,0%	11,49%		
	26-35 Years	162	15,8%	19,17%		
	36-50 Years	313	30,5%	31,17%		
	über 50 Years	417	40,7%	38,17%		
	In total	1025	100,0	100,0		

Figure 1 Age

### 3.1.2 Gender

The second important characteristic for a meaningful study is gender, which should also be represented according to the population. As with age, there are no statistics for sex based on the population of type 1 diabetics. There are only estimates that assume that there are no significant differences in the disease in terms of gender. Therefore, the sample was compared with the total population. In the survey, participants could choose between male, female and diverse. Out of 1025 participants, 321 are male, 702 female and 2 diverse. If one compares this with the distribution in the total population, there is a difference. More women (68.5%) participated in the study. The proportion of women in the total population is only 51%.

Previous analyses have shown that there are no differences in the answers to the questions regarding gender. A case weighting was therefore dispensed with.

Gender						
Frequency Percent Total						
T1D T1D populatio						
female	702	68,5	51,0			
male	321	31,3	49,0			
divers	2	,2	-			
In total	1025	100,0	100,0			

Figure 2 Gender

#### 3.1.3 Education

A question on educational attainment was included in order to be able to determine whether as many educational qualifications as possible are also adequately represented in the sample. The participants could choose between several presets. The current highest level of education should be indicated. The different educational attainments and their distribution among the sample are shown in the following table.

			Valid	Accumulated	
	Frequency	Percent	Percent	Percent	
Secondary school I	56	5,5	5,5	5,5	
Secondary school II	200	19,5	19,5	25,0	
High school	159	15,5	15,5	40,5	
Completed education	245	23,9	23,9	64,4	
Academic degree	365	35,6	35,6	100,0	
In total	1025	100,0	100,0		

#### Level of Education

Figure 3 Level of education

The proportion of academics (35.6) is higher in the sample compared to the national average (18.5% source: Wikipedia). It is important that different degrees are represented in the sample.

### 3.1.4 Residence

With regard to the place of residence, the participants could choose between big city, small town and rural region. The aim was for all housing situations to be represented in the sample so as not to have any distortions. The different housing situations are well represented in the sample with more than 30% each. The exact distribution can be found in the following table.

Residence						
		Total	Accumulated			
Frequency Percent population						
373	36,4	23,0	36,4			
334	32,6	47,0	69,0			
318	31,0	30,0	100,0			
1025	100,0	100,0				
	Frequency 373 334 318	Frequency Percent   373 36,4   334 32,6   318 31,0	Frequency Percent Total   373 36,4 23,0   334 32,6 47,0   318 31,0 30,0			

Residence

Figure 4 Place of residence

#### 3.2 Information behavior of type 1 diabetes

#### 3.2.1 Equipment

The available technical aids ultimately determine what information is available to a type 1 diabetic. Participants were asked which technical aids they use. You could choose from: blood glucose meter, insulin pen, insulin pump and CGM system. All 1025 participants answered this question and the following picture emerged:

Technical aids used						
Frequency						
Blood sugar meter	730	71,2				
Insulin pen	479	46,7				
Insulin pump	614	59,9				
CGM System	966	94,2				

Figure 5 Technical aids

The study clearly shows that continuous glucose monitoring (CGM) systems have become the key tool for type 1 diabetics. 94.2% of participants use such a system for their daily diabetes management, so they are more common than conventional measuring devices for measuring blood sugar. Conversely, this means that only about 5% rely solely on a conventional blood glucose meter to monitor blood sugar. Although 71.2% state that they use such a blood glucose meter, this is most likely due to the fact that this device is used when there are technical problems with a CGM system. If one analyzes the 59 participants who do not use a CGM system, 33 of the persons are older than 50 years. Non-use therefore tends to be found in older people. This association was also confirmed by a chi-square test with a significance level of 0.095.

There are two ways to administer insulin. This can be done either via a pen or a pump. The results clearly show that almost 60% of type 1 diabetics (59.9%) already have a pump. In other words, more than every second type 1 diabetic carries an insulin pump. Insulin pumps undoubtedly have advantages and their prevalence will certainly continue to increase in the coming years. When supplying artificial insulin using a pen, it is necessary either to remember exactly when you injected how much insulin or to document it manually, for example in an app. Although there are already so-called digital pens that store the amount of injected insulin, these are not yet very common. Here, pump carriers have it much easier, as they can see exactly how much active insulin is present in the body at any time. To confirm this assumption, pen users were asked to what extent this

documentation causes them difficulties. This was queried on a 10-point scale. The results are inconclusive. There are rather two camps. Some people find it difficult to keep track of how much insulin is in the body, others have no difficulty with it. Unfortunately, the reason for this cannot be deduced from the survey. A distribution of the frequency on the scale can be seen in the following graph.

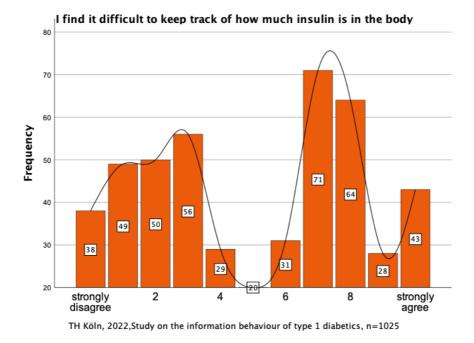
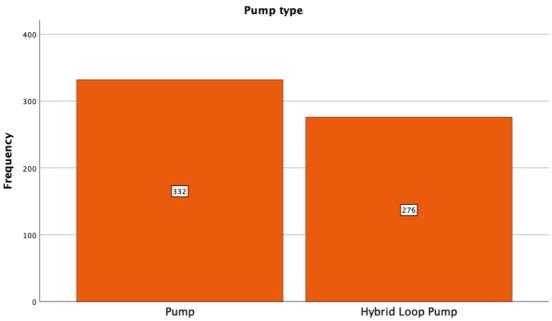


Figure 6 Observing insulin bodies

All pump carriers were asked whether they use a pump or a hybrid system for at least partially automated insulin dosing (AID). Hybrid AID systems have only been around for a short time, but they are already very widespread. Among the pump carriers, 276 participants already use such a pump and thus form almost half (45%) of the pump carriers.



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#### 3.2.2 Key Information

Here, participants were asked to select from a given number of options those they use for their daily diabetes therapy. You could choose from:

- HbA1c Value
- Current value
- Insulin on board (IOB)
- Trend arrow
- Time in range, (TIR)
- Curve

The selected options should be ranked in the second step. The choices arose from interviews with type 1 diabetics conducted prior to the study. How the values are distributed among the priorities can be seen in the following graphs.

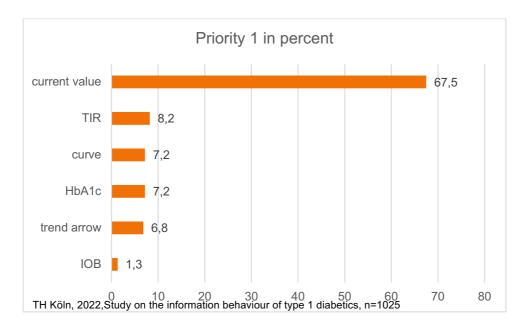


Figure 8 1st place of the most important information

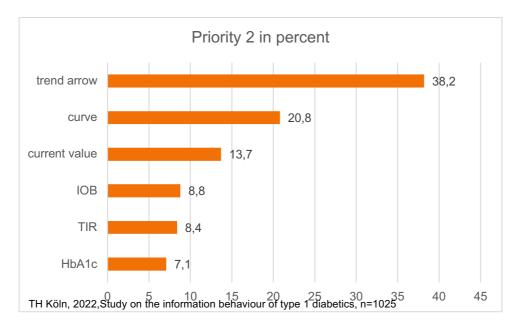


Figure 9 2nd place of the most important information

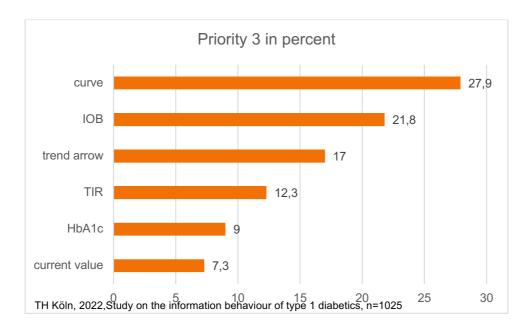


Figure 10 3rd place of the most important information

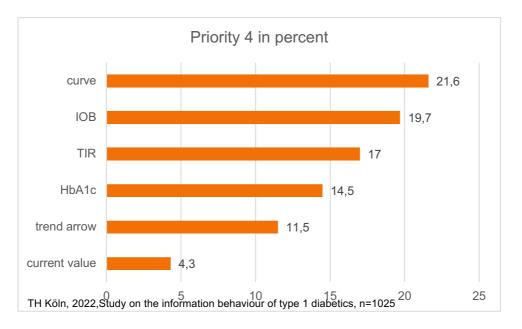


Figure 11 4th place of the most important information

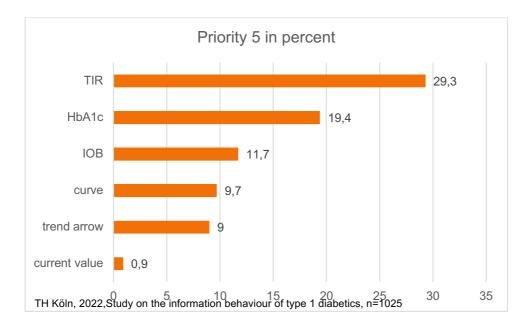


Figure 12 5th place of the most important information

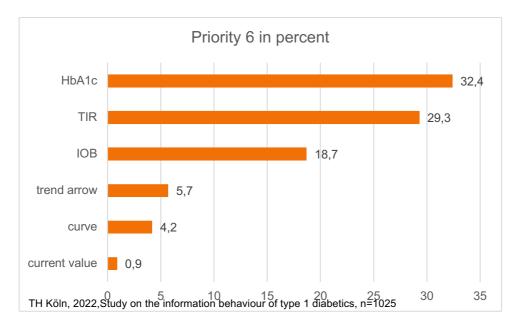
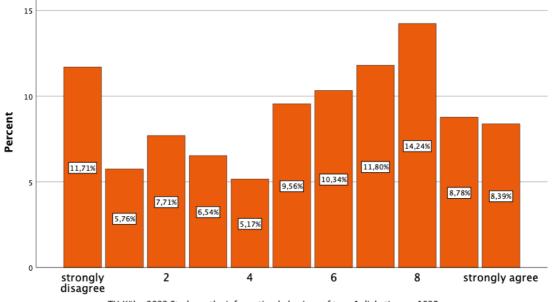


Figure 13 6th place of the most important information

The evaluation shows that the "current value" is the most important information in daily management. The trend arrow, i.e. the prognosis in which direction the glucose value will develop, is another very important piece of information for a type 1 diabetic and ranks second. Third place is occupied by the curve. All three pieces of information are offered by all CGM systems. Given the widespread use of CGM systems among type 1 diabetics, it is no surprise that this information is used and considered important. When it comes to information about how much insulin is in the body (IOB), it is slightly different. While it is provided via the pump with pump carriers, pen users have a much harder time here. It takes more effort to have this information available. Digital pens are becoming more and more widespread, which makes it easier to get this information available automatically. In order to determine the relationship between pump carriers and the priority of the value "insulin in the body", a chi-square test was performed. This is significant with a value of less than 0.001, which means that pump wearers attach much greater importance to the value "insulin in the body" than people who do not wear a pump. This correlation is plausible, but also shows how important it would be to provide such information to type 1 diabetics who use a pen.

In recent years, the specialist media and the diabetes community have reported and discussed a lot about the parameter "time in the target area". It was repeatedly emphasized that this information was more important than the HbA1c value. A CGM system manufacturer also advertises this information and emphasizes its importance. This value is not as relevant for daily decisions, as the results of this study show. This has already been confirmed in the interviews that have been conducted before. However, this does not mean that value does not matter. In the discussions, it was repeatedly emphasized that this value is quite important for a retrospective consideration. In order to confirm this, a question has been included specifically on this. This could be answered on a 10-point scale from "strongly disagree" to "strongly agree". The result is ambiguous. While 11.7% of participants said they strongly disagree, 8.39% strongly agree. All levels of the response scale were used, so that it can ultimately be assumed that the value "time in the target area" is evaluated very differently. Unfortunately, the survey cannot give an explanation or cause for the different evaluations.



I use time in range for subsequent control

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Figure 14 Time in Range

#### 3.2.3 Importance of apps for type 1 diabetes

Smartphones are widely used in Germany. Assuming a population of 83 million people, 62.6 million people have a smartphone, according to Statista. This corresponds to a rate of 75%. If you do not include small children and very old people, the number of those who have a smartphone is even higher. The smartphone as our daily companion can also play an important role in diabetes therapy. To get a better insight into how this is done, 7 questions were asked, the results of which are presented below.

First, it was asked in very general terms whether there is an optimal app at all from the point of view of type 1 diabetics. The question could be answered on a scale of 0 to 10. 0 stands for the fact that there is currently an optimal app, which only 2.2% see it that way. On the other hand, the other extreme value is that there is no optimal app, with 12.2%. If you look at the responses on the scale over time, you can see that the dissatisfaction is clearly visible.

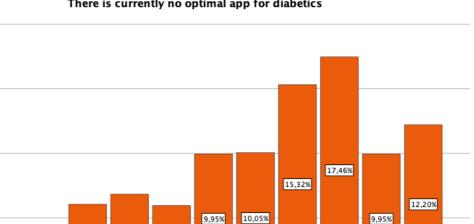
20

15

ç

0

Percent 10



6

8

strongly agree



6,83%

5,95%

4

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6,05%

2

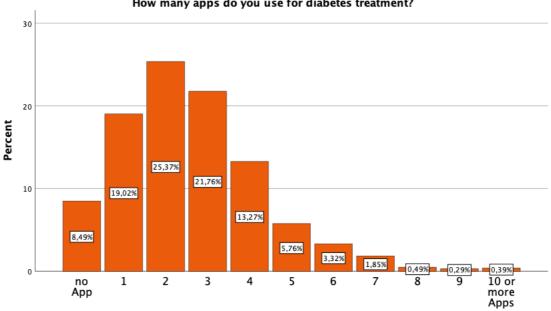
Figure 15 There is currently no optimal app for diabetics

4,00%

2,24%

strongly disagree

If there is no optimal app for many type 1 diabetics, the question arises as to how many different apps are used. These include apps for documenting glucose levels, insulin, nutrition and exercise apps. As expected, more than 90% of type 1 diabetics use apps for their diabetes management. Only 8.5% do not use an app. Two apps are used most frequently with 25.4%. Five or more apps are rarely used (6.3%). Most diabetics use one to four apps for their diabetes management.

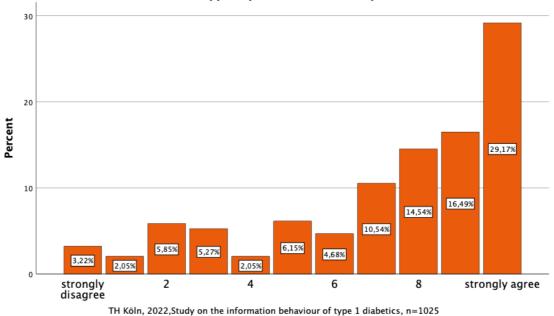


How many apps do you use for diabetes treatment?

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Figure 16 Number of apps used

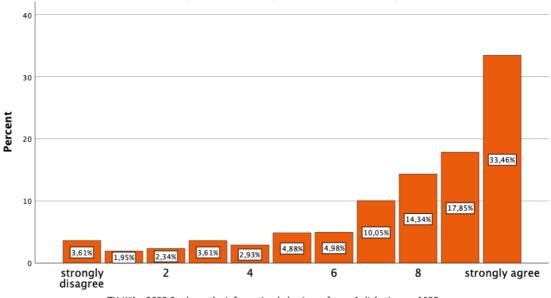
The more diabetes management apps are used, the more time it takes. This certainly cannot be in the interest of diabetics. The conversations in advance have clearly shown that you want to spend as little time as possible with diabetes in order to have time for more beautiful things in life. The statement that you want to spend as little time as possible with apps also met with great approval in the study. On a scale from 0 (strongly disagree) to 10 (strongly agree), 29.2% (level 10) want to spend as little time as possible on apps. Only 1.7% disagree at all. A distribution of the percentages to the individual scale levels can be seen in the following graphic.



I would like to use as few apps as possible so as not to spend even more time

In order to spend as little time as possible with apps and to have to resort to as few apps as possible, an app that integrates several apps would be desirable. The question of whether an app that integrates several apps is desired met with a correspondingly positive approval. The question was answered on a scale from 0 (strongly disagree) to 10 (strongly agree). The strongest approval with a value of 10 was expressed by 33.5%. If you summarize levels 10 and 9, there are 50% who want such an app. This can be interpreted as a clear indication that there is a need for action here.

Figure 17 App usage in terms of number and time

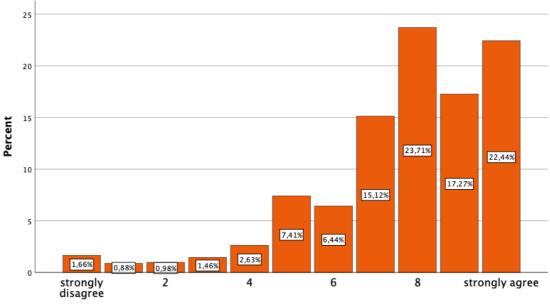


#### I want an app that integrates blood sugar, carbs, insulin, weight and exercise

The question of which information is most important for daily diabetes management has already been presented. Although there was a trend, it was not always clear. This may also be due to the fact that type 1 diabetes is treated very differently and therefore the required information is different. A possible solution could be to offer type 1 diabetics an app in which they can determine which values should be displayed and how. When asked whether an app is desired that can be adapted to one's own needs in the presentation and evaluation, the evaluation resulted in a clear statement. As before, the question was determined on a scale from 0 (strongly disagree) to 10 (strongly agree). A full agreement (10) was given by 22.4% of the study participants. Only 1.7% don't want a customizable app. A percentage distribution to the individual levels can be seen in the following graphic.

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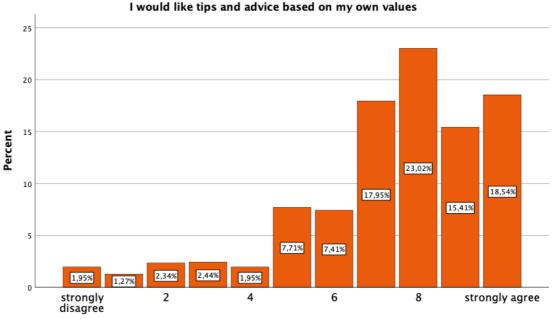
Figure 18 Desire to integrate different aspects in an app



#### I would like an app in which I can adjust the display and evaluation

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The trend arrow was mentioned as one of the most important pieces of information for daily decisions. These trend arrows are based on standardized values from research. So far, there is no app that takes personal values into account in a trend forecast. Whether there is a desire for it should be determined with the following question: I would like tips and hints from an app based on my own values. This could be answered on a scale from 0 (strongly disagree) to 10 (strongly agree). A score of 10 was chosen by 18.54% of respondents. A strong rejection was found at only 1.95%. The values and history can be seen in the following graph.



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Figure 19 Desire for a Customizable App

Figure 20 Desire for a Customizable App

Manufacturers of CGM systems, insulin pumps, blood glucose meters or insulin pens all have their own manufacturer apps. This leads to a plethora of apps available on the market. In addition, there are a few more private-sector apps, which does not make it easier to make a decision. When changing from one manufacturer to another, the data cannot be taken with you. Whether there is a desire for a manufacturer-independent app was recorded in a separate question. The scale from 0 (strongly disagree) to 10 (strongly agree) was also used here. Almost a quarter (24.6%) of type 1 diabetics voted for the strongest approval with a score of 10. Only 2% do not want such an app. The percentage distribution on the response scale is shown in a graph.

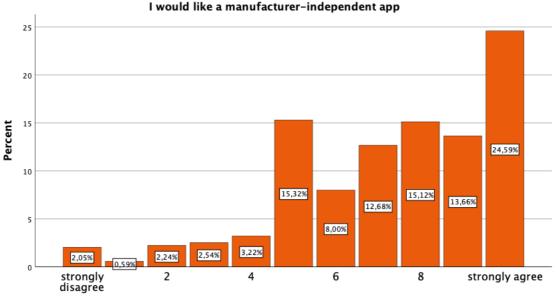




Figure 21 Desire for a vendor-independent app

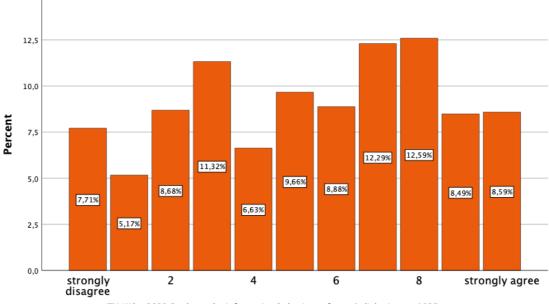
In summary, it can be stated that there is currently not one optimal app and therefore usually several apps must be used. There is a desire to spend as little time as possible on diabetes management. We want an app that combines existing apps and can be adapted to individual needs. If the app could also be used independently of manufacturers, this would be almost optimal and would thus enable a better supply of information to type 1 diabetics.

#### 3.2.4 Nutrition and diabetes

A difficult and sometimes very controversial topic is nutrition. Currently, the motto is that a type 1 diabetic can eat everything that non-diabetics are allowed to eat, so you don't have to do without anything.

The aim of the statement that as a type 1 diabetic you do not have to do without anything, is certainly to convey to affected persons that you can lead a largely normal life with diabetes. However, in order to do this, a type 1 diabetic, regardless of what he eats, must determine how many carbohydrates are contained in the food in order to be able to calculate how high the insulin requirement is. An exact calculation can be made if the food has been weighed beforehand. This is possible at home, but very exhausting and time-consuming. It gets even more difficult when you eat in a restaurant. How the real situation in type 1 diabetics presents itself will be clarified in the following. On the subject of nutrition, three questions were asked, all of which should be rated on a scale from 0 (strongly disagree) to 10 (strongly agree). First of all, it was asked quite generally whether type 1 diabetics adapt their diet to diabetes. The result is ambiguous. As previously mentioned, it is very

different how type 1 diabetics approach the topic of nutrition. The distribution can be seen in the following graphic.



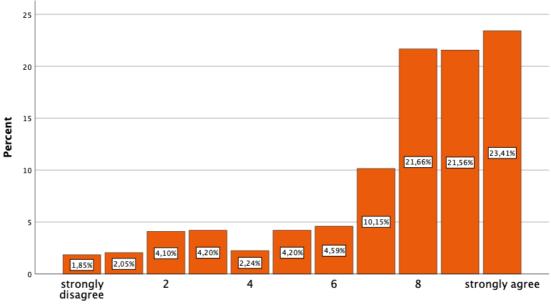
I adapt my diet to the diabetes

TH Köln, 2022, Study on the information behaviour of type 1 diabetics, n=1025

Figure 22 Dietary adjustment

Since one cannot really interpret anything from the pure frequency distribution, this question was correlated with other questions in order to find further insights. For the correlation analysis, several questions were correlated with the Likert scale and the Pearson method was used. The correlations mentioned here are all significant at the level 0.01 (2-sided). At the same time, people who adjust their diet reported having a good metabolic status (<0.001). The same applies vice versa. Another connection was found to the factor of sport. Type 1 diabetics who exercise to lower blood sugar also adapt their diet to diabetes at the same time. There is another significant correlation to the use of "time in the target area". Behind this, one seems to recognize that there are type 1 diabetics who pursue their diabetes therapy very consistently and pay attention to the diet, exercise physically, analyze their values afterwards and thus achieve a stable metabolic situation.

Whether you adapt your diet to diabetes or not, as a diabetic you are faced with the decision several times a day how much insulin to inject at a meal. Participants in the study were asked to indicate whether they value carbohydrates primarily based on their experience. There was a clear agreement on this question. Almost a quarter of type 1 diabetics (23.41%) fully agree with this statement. Only 1.8% disagree with the statement at all. The weighing and calculation of carbohydrates, as it is taught in many training courses, is thus only used to a limited extent in daily use.

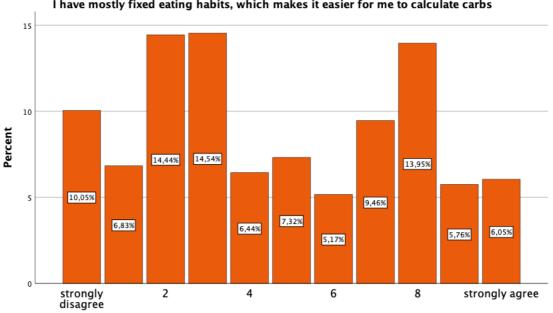


#### I appreciate KH mainly because of my experience

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Figure 23 Estimation of carbohydrates

As the previous question showed, estimating carbohydrates is very common in type 1 diabetics. Estimating could be facilitated with predominantly fixed eating habits. To what extent this is true should be found out by means of a corresponding question. There is no clear tendency. All levels of the scale from 0 (strongly disagree) to 10 (strongly agree) were chosen. It may be possible to find out how the different assessments came about by means of a correlation analysis.



I have mostly fixed eating habits, which makes it easier for me to calculate carbs

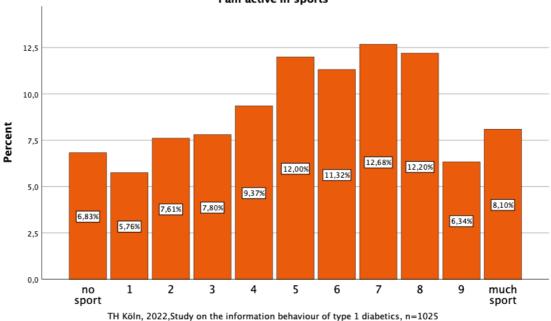
TH Köln, 2022, Study on the information behaviour of type 1 diabetics, n=1025

Figure 24 Eating habits

The likert-scaled question was correlated with other likert-based questions according to Pearson. The correlations listed are significant at the level <0.001. People who prefer fixed eating habits to facilitate the calculation of carbohydrates assess their metabolic status better than others and are more active in sports than others.

#### 3.2.5 Sports and diabetes

The fact that sport has a positive influence on blood sugar is undeniable and in many cases can also lead to a significant decrease in insulin requirements. This was confirmed by the discussions held in the run-up to the survey. It is interesting to learn how it behaves with the frequency of physical exercise or .dem sports in type 1 diabetics. The assessment of when someone is active in sports and when not, is certainly very different and also depends on the type of exercise or sport. Therefore, the participants were asked to subjectively assess whether they are active in sports or not. The question could be answered on the known scale from 0 to 10. The results are distributed quite well on the scale. Only 6.83%, i.e. 70 out of 1,025 people, state that they do not exercise at all. This means that the vast majority of type 1 diabetics are physically active, albeit to varying degrees. 8.1% even stated that they did a lot of sports. The result is as follows:

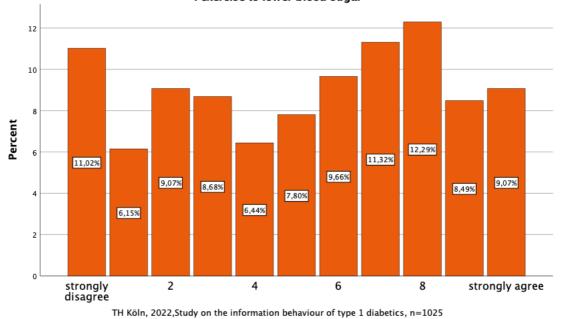


I am active in sports

Figure 25 Physical activity

Here, too, it makes sense to look at the connections to other questions. In addition to the link between exercise and nutrition that has already been reported, other interesting results can be seen. The investigation of the relationships was carried out under the Likert-based questions using the Pearson method. All correlations mentioned here are significant at the level 0.001. Some of the correlations are plausible, which also suggests that the data collected is consistent. Type 1 diabetics who exercise a lot will inevitably need multiple apps because there is no app that connects diabetes and exercise. Therefore, this group of people wants an app that enables this integration. With increasing sporting activity, the assessment of the quality of the personal metabolic situation also increases. This proves once again the positive influence sport has on the metabolism. People who are active in sports use the measure "time in the target area" significantly more frequently to subsequently control their diabetes management.

Sport can be practiced for a variety of reasons. It is interesting to learn to what extent type 1 diabetics exercise with the aim of lowering blood sugar. The question could be answered from 0 to 10 and the result looks like this:



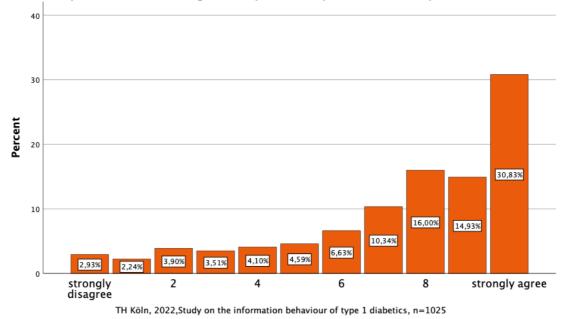
I exercise to lower blood sugar

Figure 26 Exercise to lower blood sugar

The question did not yield a clear result. While some use exercise to lower blood sugar, others pursue other goals with exercise. The correlation with other questions did not yield any new findings and only the correlations that had previously been found in the question of physical activity could be found. In a follow-up study, it would certainly be interesting to learn what motives type 1 diabetics have to do sports.

### 3.2.6 Visits

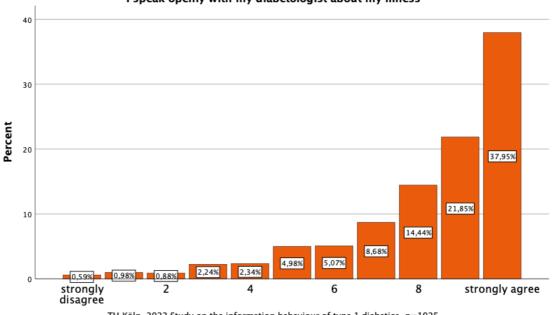
Regular visits to the doctor are an important part of good diabetes management. The extent to which type 1 diabetics themselves see this was determined in a separate question. The question can be answered clearly with yes, which can also be seen in the course on the scale from 0 to 10.



#### Quarterly visits to the diabetologist are important and provide me with important information

Figure 27 Importance of visits to the diabetologist

The fact that the doctor's visits are regarded as very important and helpful is probably also due to the fact that there is a great deal of trust in the doctors. In a second question, one was asked how openly one can talk to one's diabetologist. This question also led to a very strong consensus.



I speak openly with my diabetologist about my illness

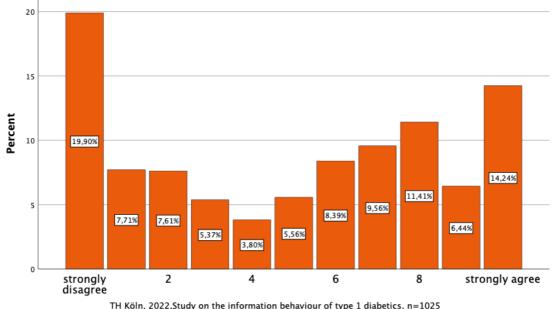
TH Köln, 2022,Study on the information behaviour of type 1 diabetics, n=1025

Figure 28 Open communication with the diabetologist

### 3.2.7 Other sources of information

From the areas of personal life and social media, a question was included to learn what role these sources play in diabetes management.

With regard to private life, the question was asked to what extent partners and relatives are involved in diabetes management. The question is answered on a scale from 0 (strongly disagree) to 10 (strongly agree).

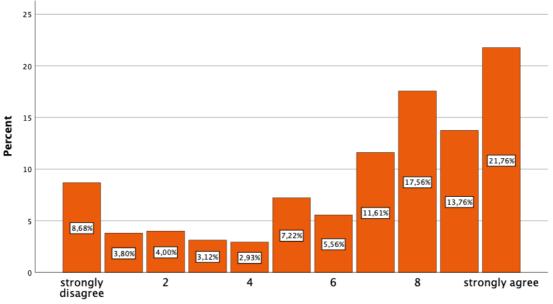


I involve partners and friends in my diabetes management

The group of type 1 diabetics is divided into two camps when it comes to the question of involving partners and acquaintances. Some strongly disagree (19.90%), while others strongly agree (14.24%). An explanation cannot be derived from the question itself. Therefore, a correlation analysis was also carried out here to find possible clues. Likert's scaled questions were analyzed according to Pearson. At a significance level of 0.001 (2-sided), a correlation was found with the use of social media, trust in the doctor and the importance of doctor visits. Among diabetics, there seems to be a group that seeks and uses the exchange, regardless of whether it is the partner, acquaintance, doctor or a social media platform. Others, on the other hand, make less use of this exchange of information. This is mainly the case for people who are older (<0.01), who are more likely to live in a big city (<0.01) and have a higher level of education (<0.01). This was determined by a chi-square test, the results are all two-sided asymptotically significant.

The use of social media is often viewed critically, especially in the case of illnesses, and leads to rejection. On the other hand, one has to accept that there is a great deal of exchange about these sources. For example, there is a group for type 1 diabetics on Facebook with over 25,000 members. The question of using social media to inform and/or exchange information should be answered on a scale from 0 (strongly disagree) to 10 (strongly agree).

Figure 29 Diabetes management and partners



#### I use social media to get information and exchange ideas

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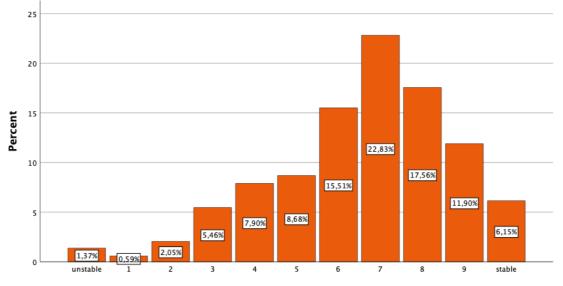
Figure 30 Use of social media

Even though experts often warn against the use of social media for medical topics, many type 1 diabetics use these platforms and obviously find it positive. A clear rejection is indicated by only 8.68%, which is compared to a full approval with 21.76%.

#### 3.2.8 Metabolic status

The size by which successful diabetes management can be judged cannot be clearly decided. The discussion about the HbA1c value and the time in the target area alone shows that there is not a single number in diabetes management that provides comprehensive information about how well diabetes management works. There is hardly a type 1 diabetic who does not know the question: "Are you well adjusted?". A question that implies a very mechanistic picture and is not really easy to answer. It was therefore omitted in the survey to ascertain what the current HbA1c value is or what percentage of the time one is in the target range. A near-normal HbA1c value may have been achieved, for example, by many hypoglycemias. In the present study, the collection of concrete figures was omitted and the participants were asked to subjectively assess their assessment of the current metabolic situation. The assessment was based on a scale from 0 (unstable) to 10 (stable). The result of the study shows that many type 1 diabetics are in a stable metabolic state.

#### How do you rate your current metabolic status?



TH Köln, 2022, Study on the information behaviour of type 1 diabetics, n=1025

#### Figure 31 Assessment of the current metabolic status

Even if it is a subjective assessment, interesting connections with this question to others emerged in the context of the evaluation. This has already been referred to in several places in this report. Here are the most important correlations that have been statistically checked:

- Type 1 diabetics, who assess their metabolic status as stable, adapt their diet more closely to diabetes.
- People who tend to describe their metabolic status as unstable have less fixed eating habits and are more likely to appreciate carbohydrates.
- A good metabolic situation is mainly spoken of by people who also do sports.
- The study shows a correlation between the metabolic status and the level of education. Type 1 diabetics with a higher level of education assess their metabolic status significantly more positively.

## 4 Result

One strength of the study is certainly the large sample. Even though it is a self-selection sample, the study shows that there is great interest among people with type 1 diabetes to report on their current situation. This willingness should be used more in the future and more attention should be paid to the concerns of people. A stronger customer orientation would be desirable. Although over 90% use a CGM system and more than one in two use an insulin pump, little is known about how to use these technologies.

Apps play a central role in diabetes therapy. Those affected consider the current situation to be in need of improvement. Apps for displaying the glucose value are not sufficient in diabetes therapy. In order to understand a course, further information is necessary, e.g. when and what was eaten in what quantity. Since diet has a direct influence on glucose levels, this must be taken into account when assessing glucose levels. The same applies to the insulin administered. Time and quantity have an influence on the glucose value. A third important influencing factor is exercise or sporting activity. Currently, there is no app that combines at least these areas in one app. This leads people with type 1 diabetes to use multiple apps, which ties up time you don't really want to spend on it.

Even though people with type 1 diabetes agree on what information is important, there are slight individual differences. An app in which you could compile the information according to your personal wishes is also at the top of the wish list. This wish would be easy to fulfill. The set of relevant parameters is known and there are only minor individual differences.

A third wish is a manufacturer-independent app that makes it easier to change manufacturers without losing their data. So far, manufacturers have shown little willingness to grant free access to the data. This wish is certainly not easy to fulfill. Here, the legislator could contribute something by giving data sovereignty back to the patients.

In the future, studies should be conducted more frequently that provide insight into the daily lives of people with type 1 diabetes and put these people at the center of attention. Patients should be granted data sovereignty and it should be possible to decide for themselves who receives what information. The apps provided by the manufacturers are far from what those affected want. Therefore, the appeal goes to manufacturers to develop more user-friendly applications.

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# Appendix

Deskriptive Statistiken						
	N	Minimum	Maximum	Mittelwert	StdAbweichung	
BZ Messgerät	1025	0	1	,71	,453	
Insulinpen	1025	0	1	,47	,499	
Insulinpumpe	1025	0	1	,60	,490	
CGM System	1025	0	1	,94	,233	
Pumpentyp	1025	-88	2	-30,53	38,647	
IOB bei Pen	1025	-77	10	-38,67	41,006	
aktueller Wert	1025	-99	6	-3,89	22,537	
Trendpfeil	1025	-99	6	-8,91	32,592	
Verlaufskurve	1025	-99	6	-5,59	28,554	
IOB	1025	-99	6	-14,44	39,509	
Time in Range	1025	-99	6	-9,69	34,883	
HbA1c	1025	-99	6	-6,17	31,311	
Stoffwechsellage	1025	0	10	6,58	2,124	
Optimale App	1025	0	10	6,29	2,711	
Berechnung KH	1025	0	10	4,63	3,089	
App Integration	1025	0	10	7,64	2,759	
Vertauen in Arzt	1025	0	10	8,27	2,124	
Ernährung anpassen	1025	0	10	5,34	3,028	
App unabhängig	1025	0	10	7,29	2,449	
Social Media Nutzung	1025	0	10	6,65	3,210	
Zeit mit Apps	1025	0	10	7,27	2,910	
Sport und Blutzucker	1025	0	10	5,18	3,198	
TIR Nutzung	1025	0	10	5,31	3,183	
App anpassbar	1025	0	10	7,69	2,164	
Arztbesuche wichtig	1025	0	10	7,43	2,785	
Sportliche Aktivität	1025	0	10	5,34	2,893	
KH schätzen	1025	0	10	7,53	2,583	
App Hinweise	1025	0	10	7,38	2,307	
Zahl an Apps	1025	0	10	2,60	1,732	
Partner einbeziehen	1025	0	10	4,91	3,638	
Geschlecht	1025	1	3	1,32	,470	
Alter	1025	1	4	2,99	1,042	
Wohnort	1025	1	3	1,95	,820	
Bildungsstand	1025	1	5	3,65	1,289	
Gültige Werte (listenweise)	1025					