Health Data Basics Survey Results

733 total responses

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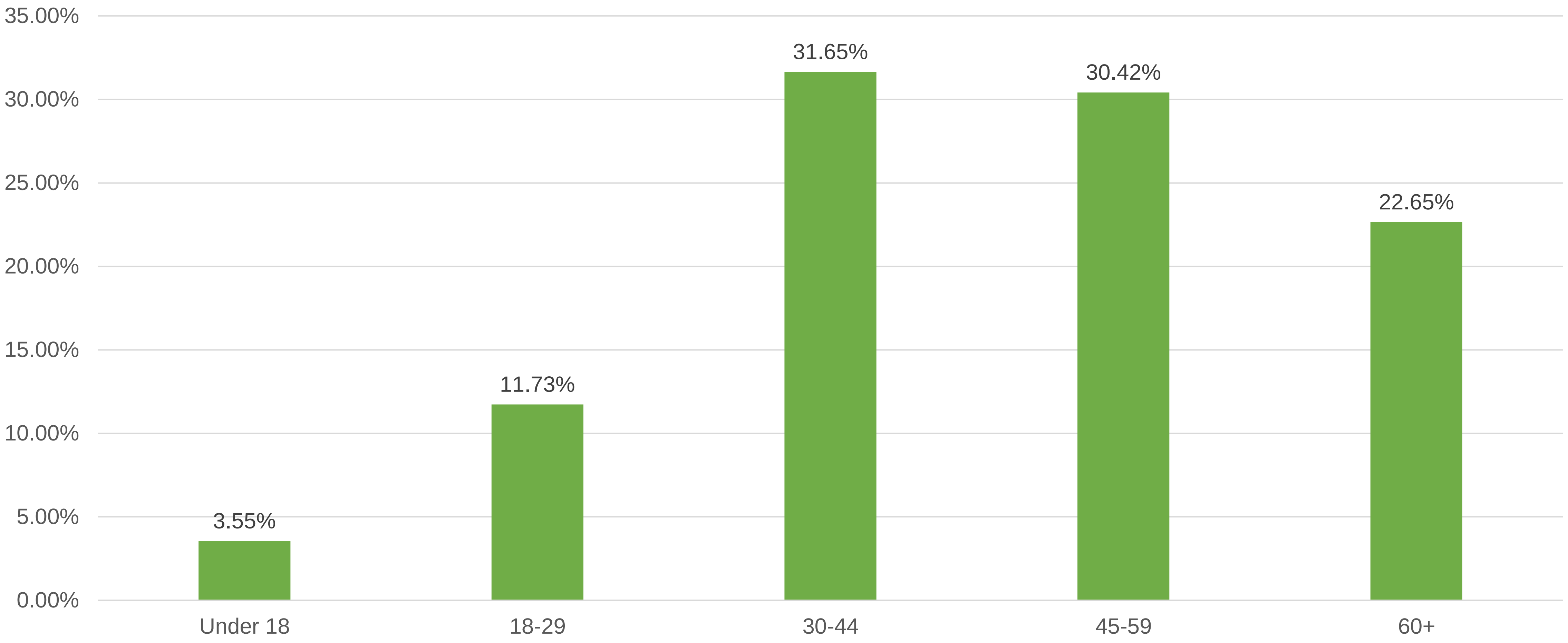
DEMOGRAPHICS

What is your age?



Other Demographics

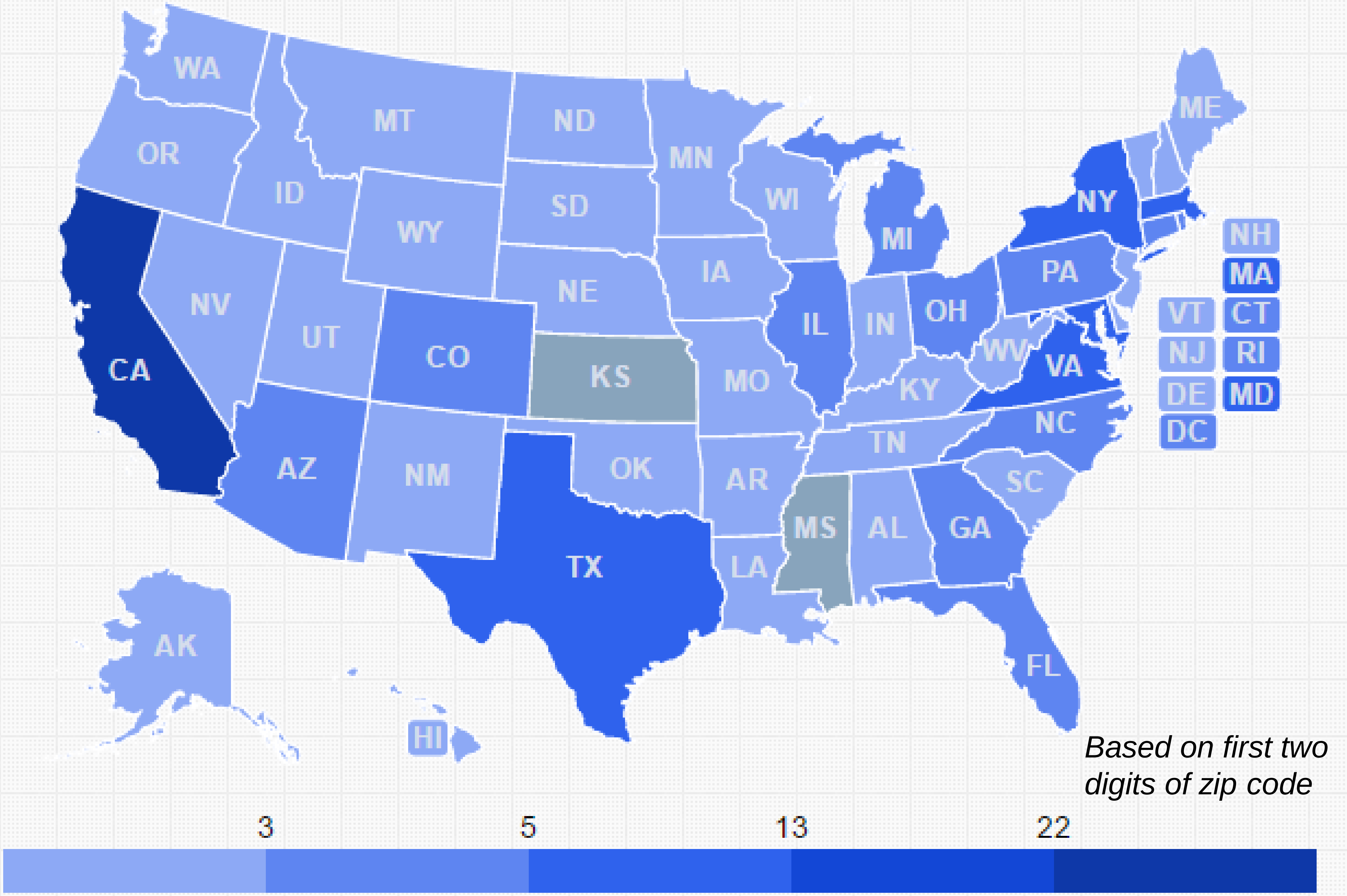
Do you live in the United States?

- *YES – 89.63%*
- *No – 10.37%*

Which gender do you identify as?

- *Female –77.58%*
- *Male – 21.46%*
- *Transgender – 0%*
- *Non-binary – 0.41%*
- *Prefer not to answer –0.55%*

Geographic Reach


WA
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NC
VA
WV
PA
NY
ME
NH
MA
VT
CT
NJ
RI
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AK
HI
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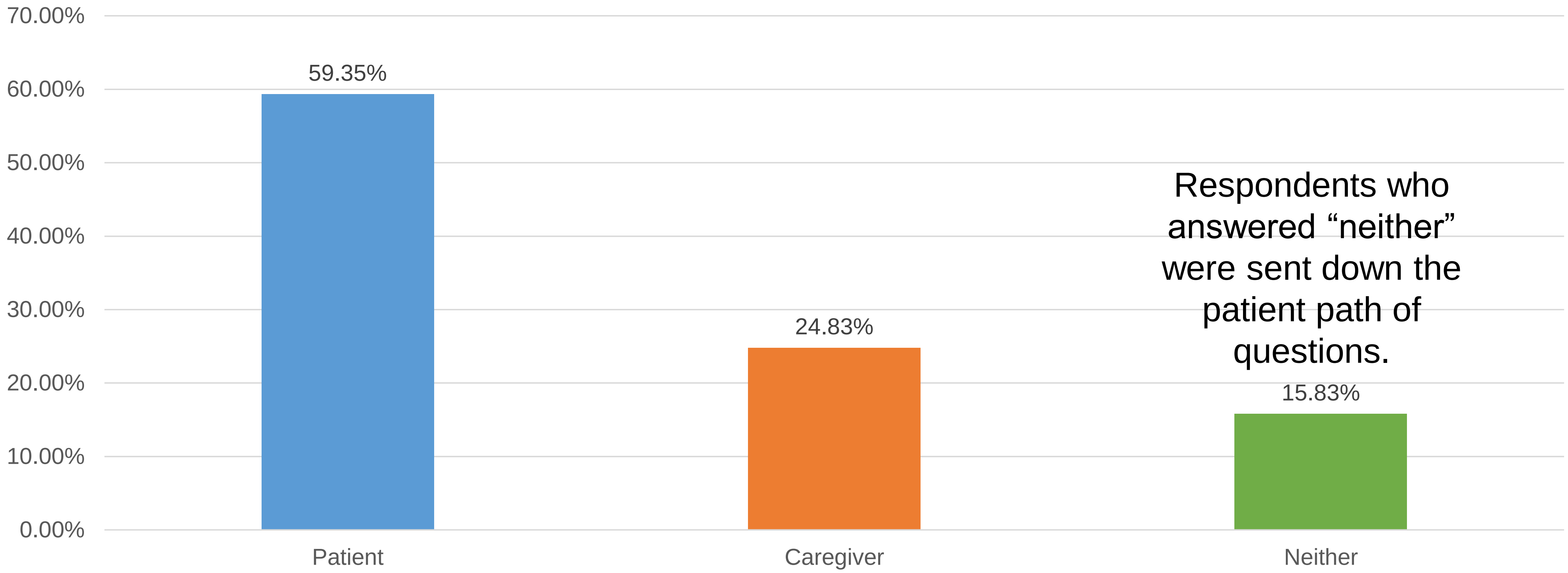
5
13
22

Based on first two digits of zip code

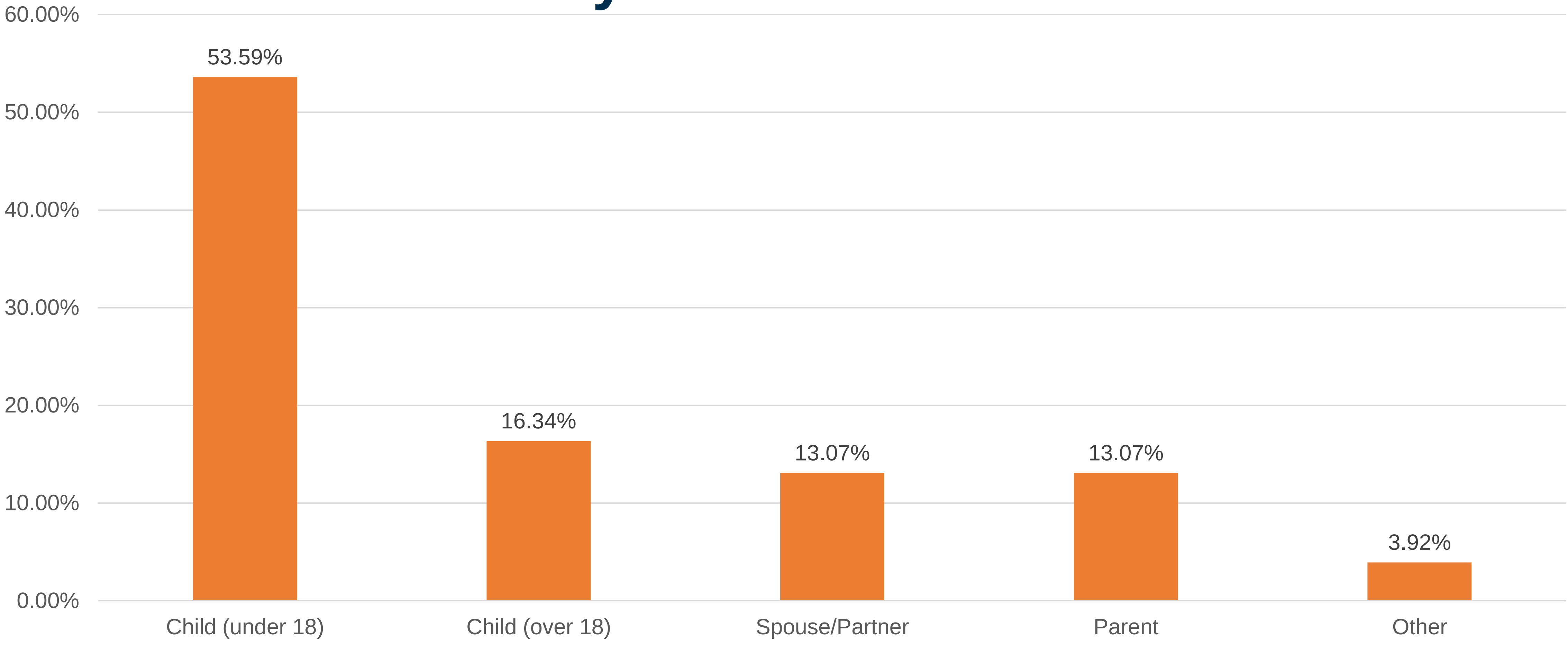
Do you identify yourself primarily as a patient or caregiver?



Respondents who answered “neither” were sent down the patient path of questions.

Patient (a person living with one or more health conditions that requires ongoing medical attention or support from healthcare professionals)
Caregiver (a person with caregiving responsibilities for another person with a health condition)

As a caregiver, you may care for more than one person. For this survey, please select one category that best describes your current situation:



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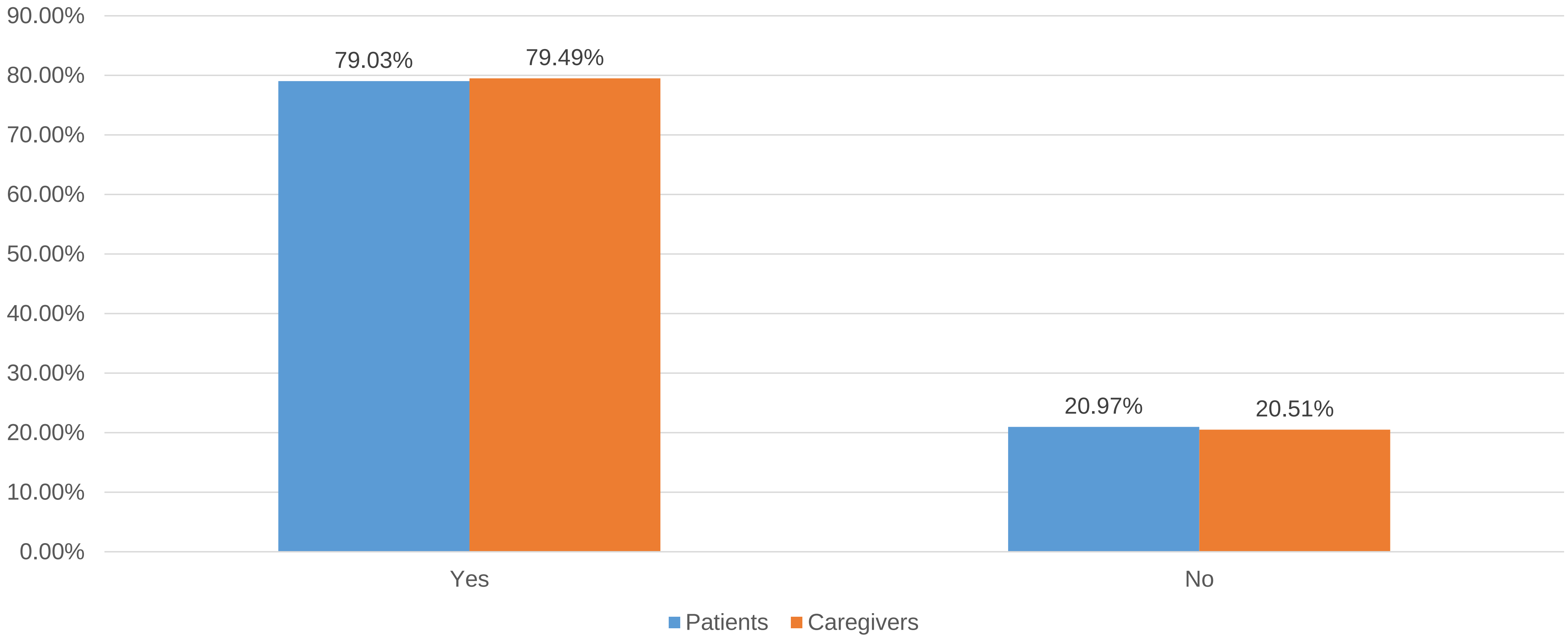
Caregivers & HIPAA

As a caregiver, do you have the necessary permissions (medical power of attorney and/or HIPAA authorization) to access the health data of the person you are caring for?

- *Yes – 88.89%*
- *No – 7.84%*
- *I don’t know – 3.27%*

ACCESSING HEALTH DATA

Have you ever tried to get and/or look at your medical record(s) or other health data?



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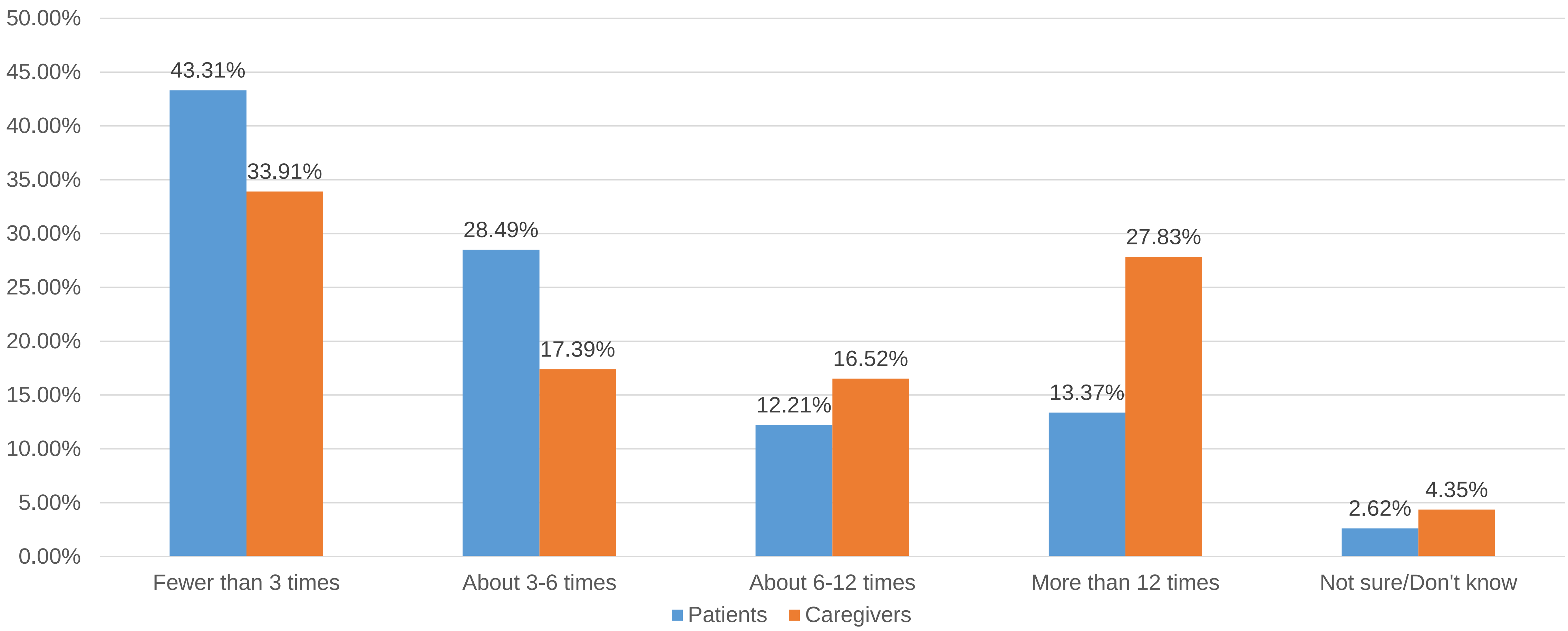
How many times did you get copies of or look at your health data over the last 12 months?



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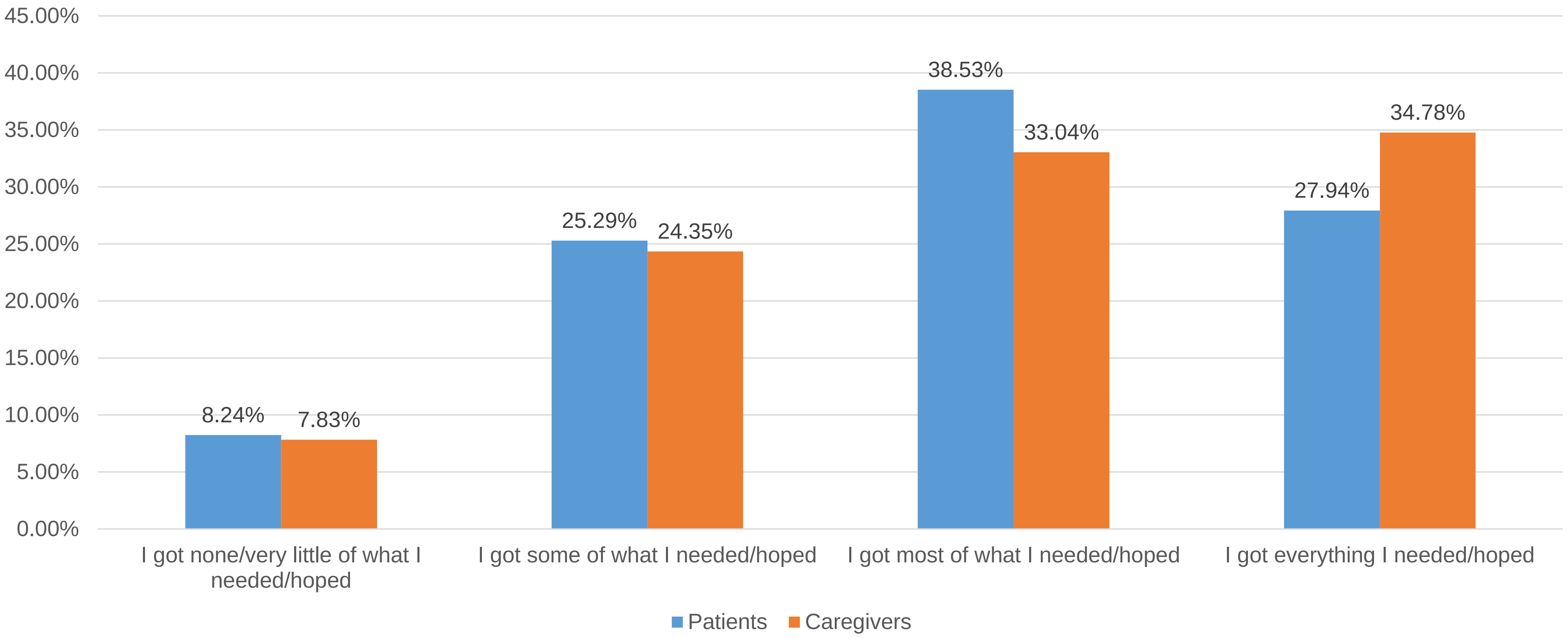
How successful were you?



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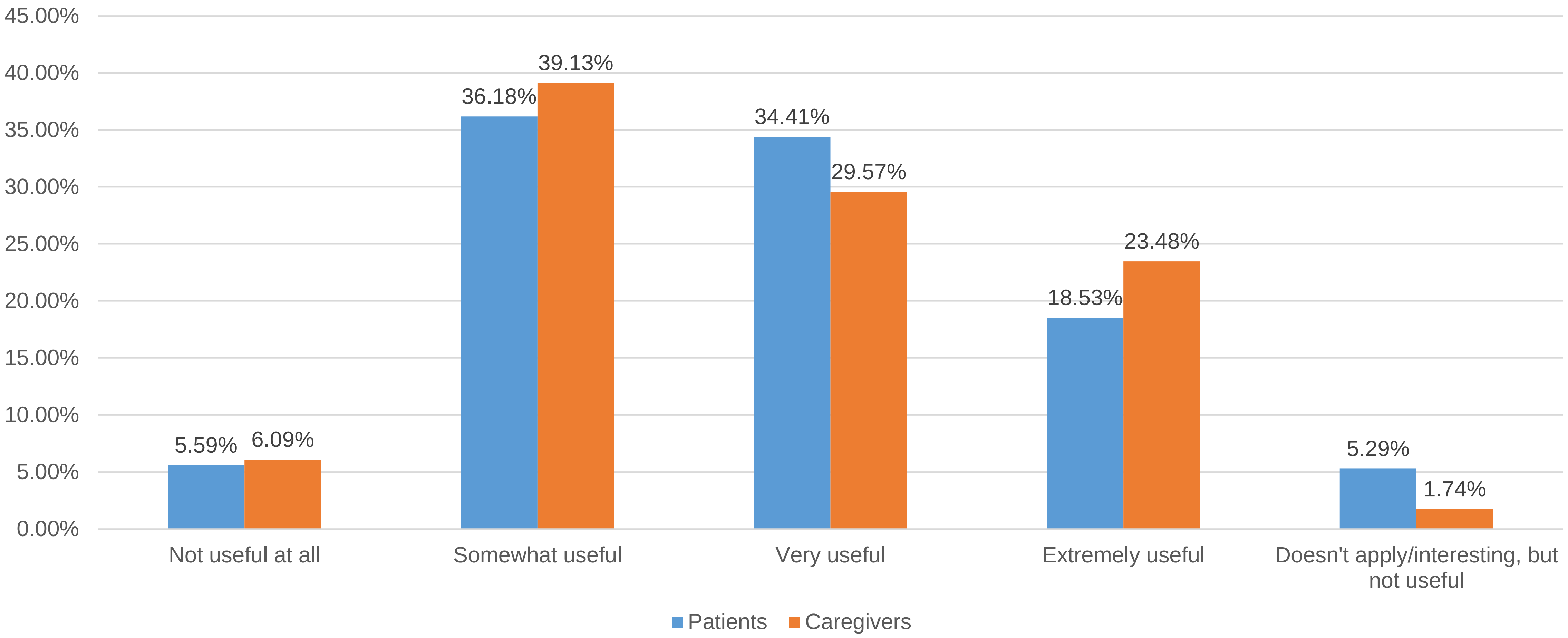
How useful did you find the health data that you accessed?



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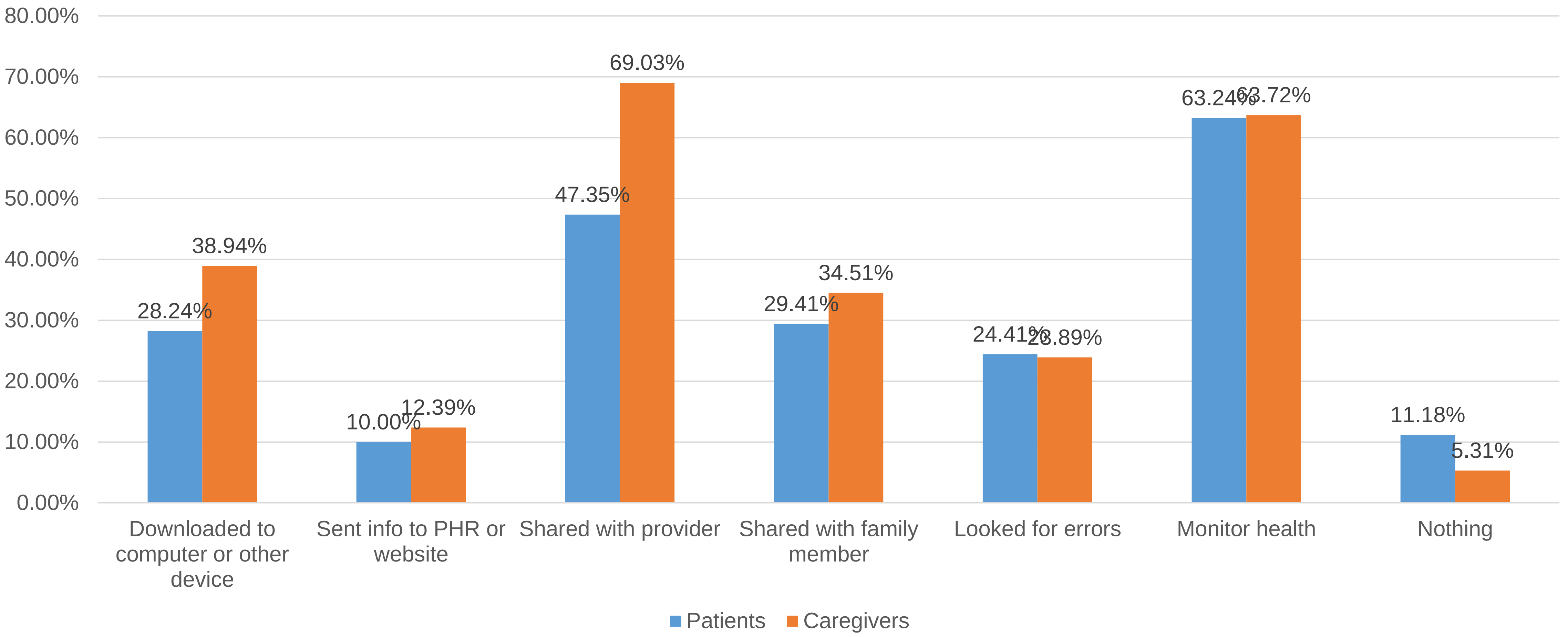
What did you do with your health data? Check all that apply.



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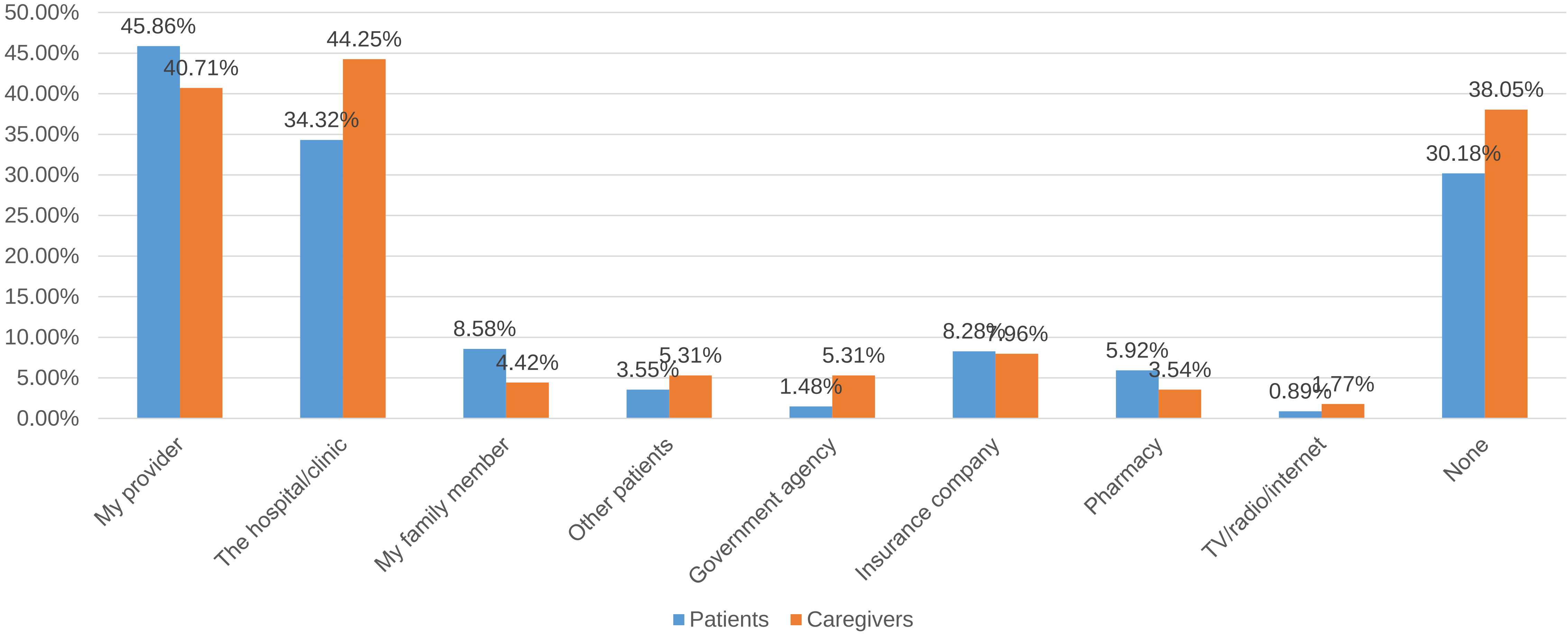
Did any of these sources help you figure out how to access your health data? Check all that apply.



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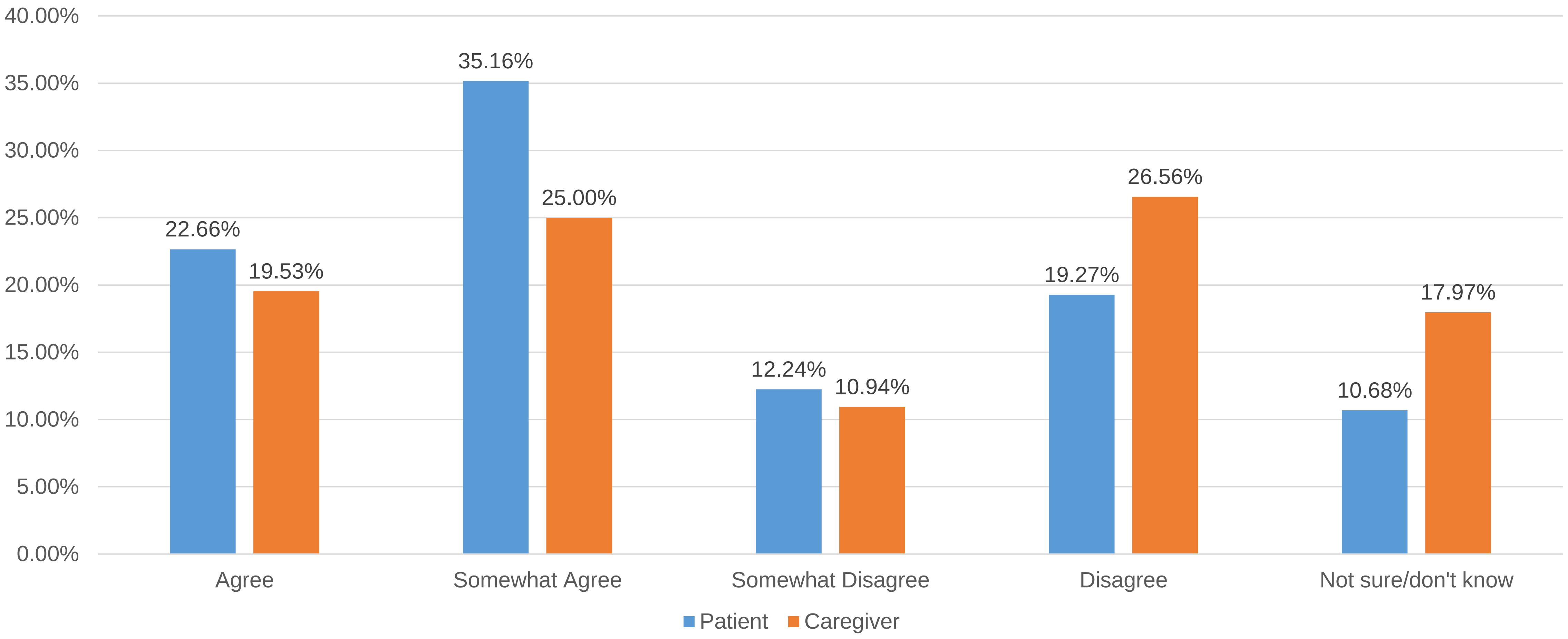
How much do you agree with the following statements?

It is easy to access my/their health data online



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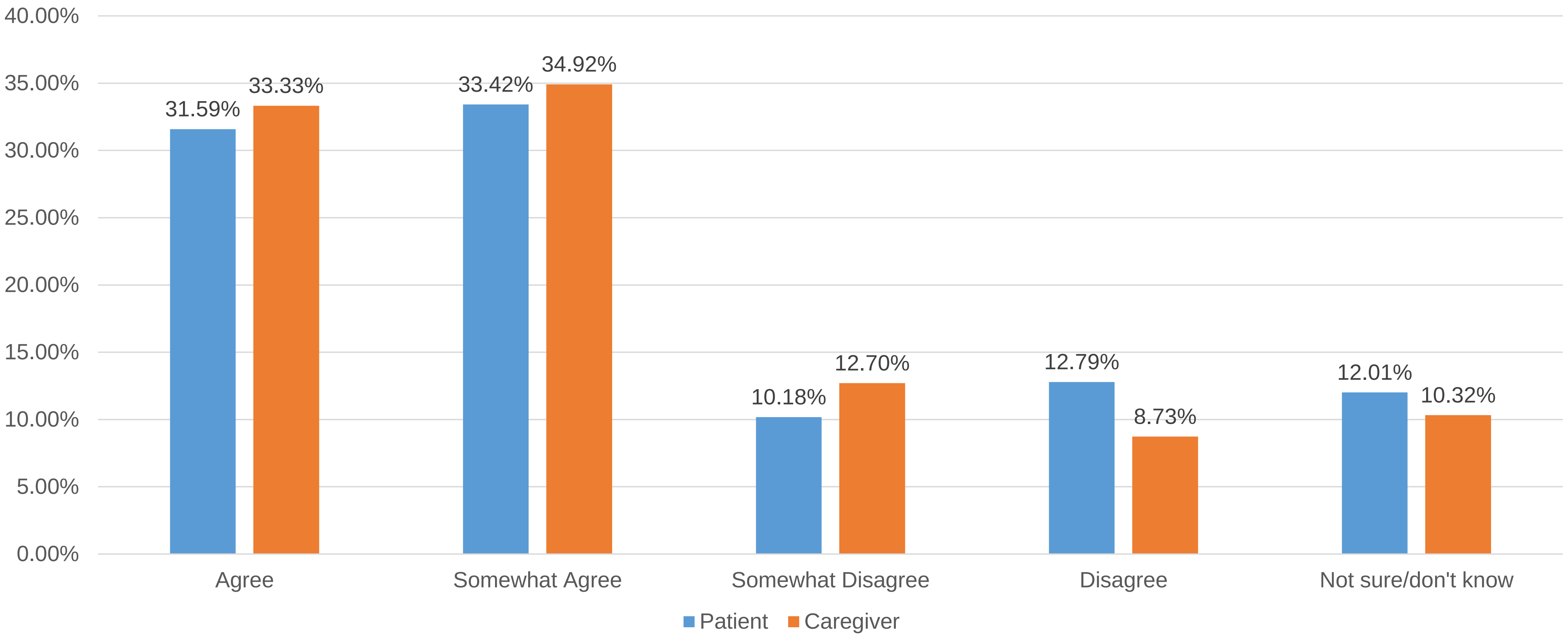
How much do you agree with the following statements?

I could access my/their medical record if I wanted to



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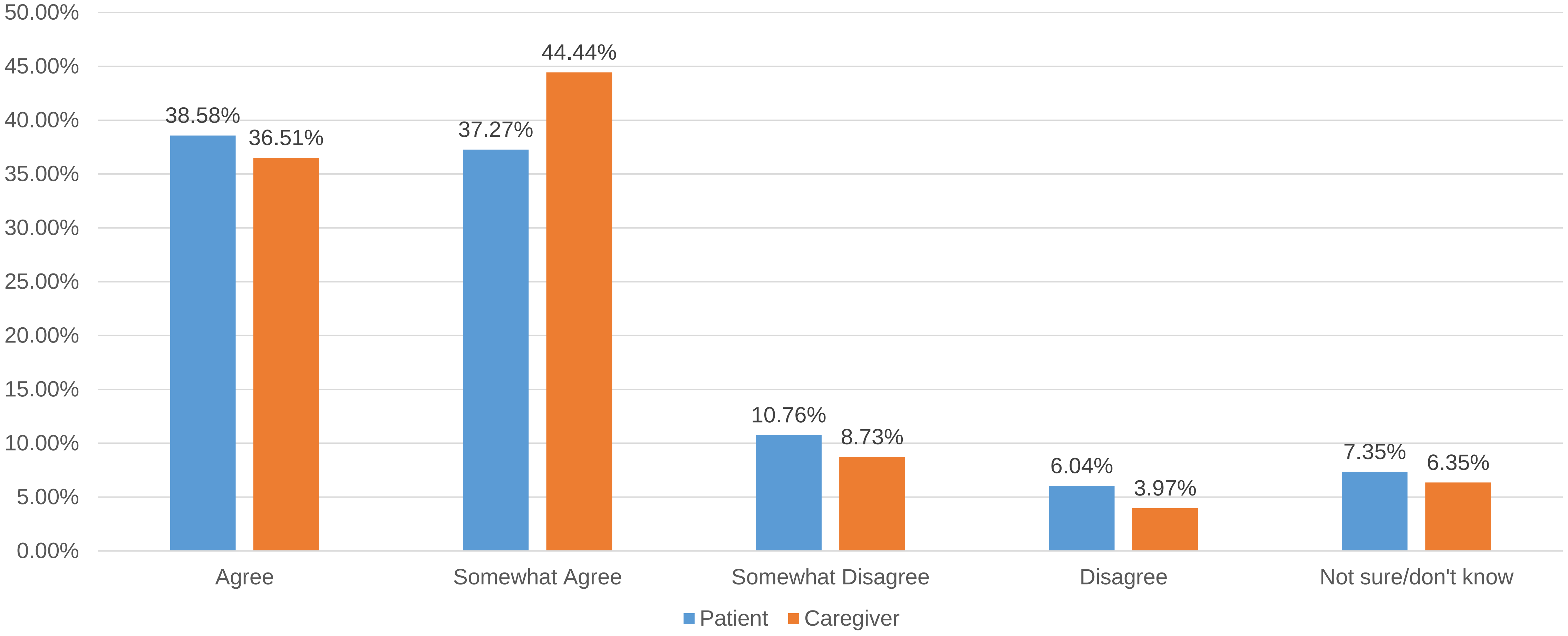
How much do you agree with the following statements?
My/their health data is useful to me even if it is incomplete



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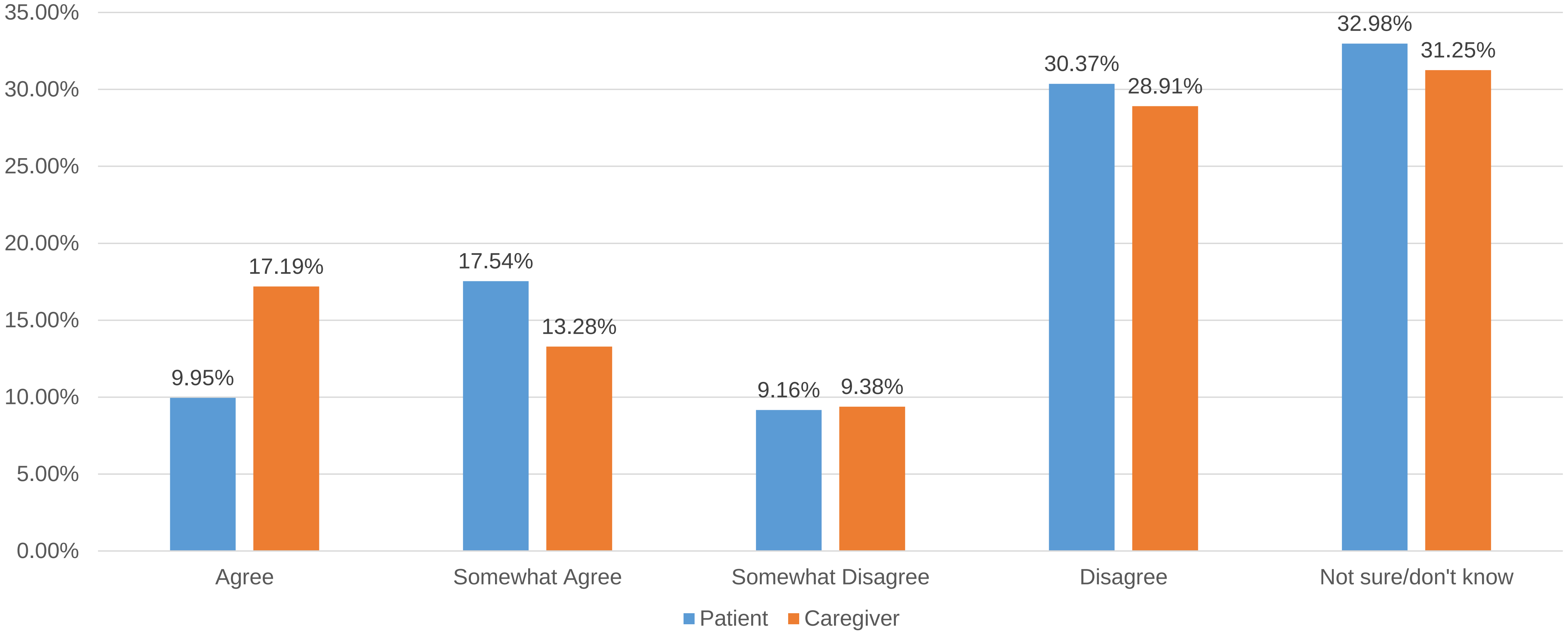
SHARING & USING HEALTH DATA

How much do you agree with the following statements?

If I wanted to know with whom my/their health data had been shared, I would be able to find out



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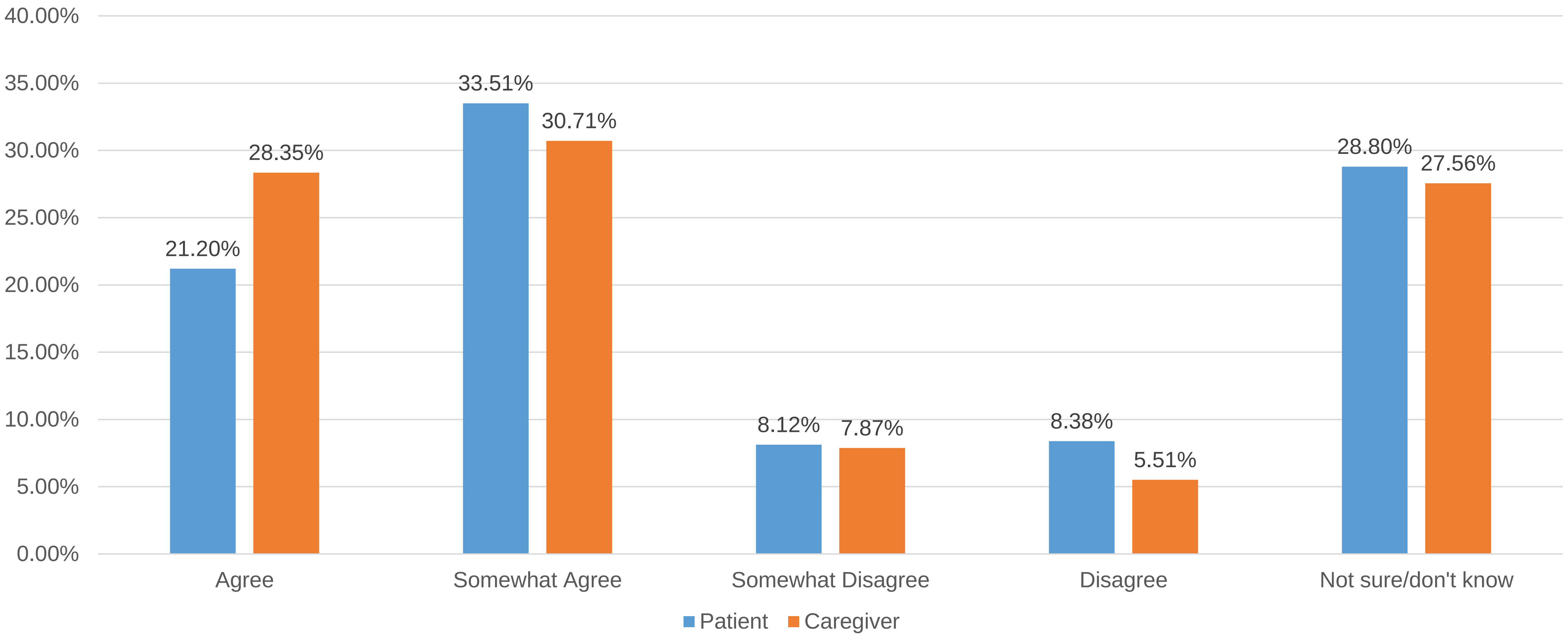
How much do you agree with the following statements? **Safeguards are in place to protect my/their health data from being misused**



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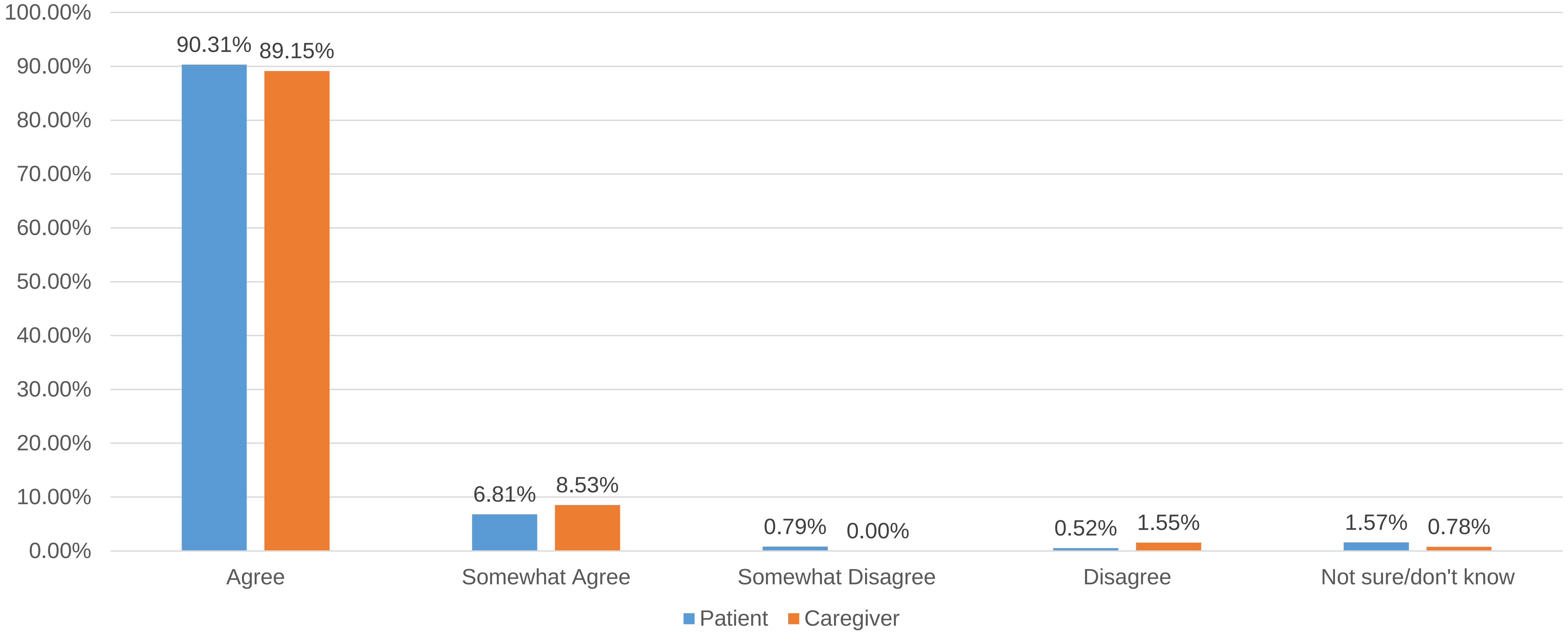
How much do you agree with the following statements?

I should be able to see all of my/their health data, including everything in my/their medical records.



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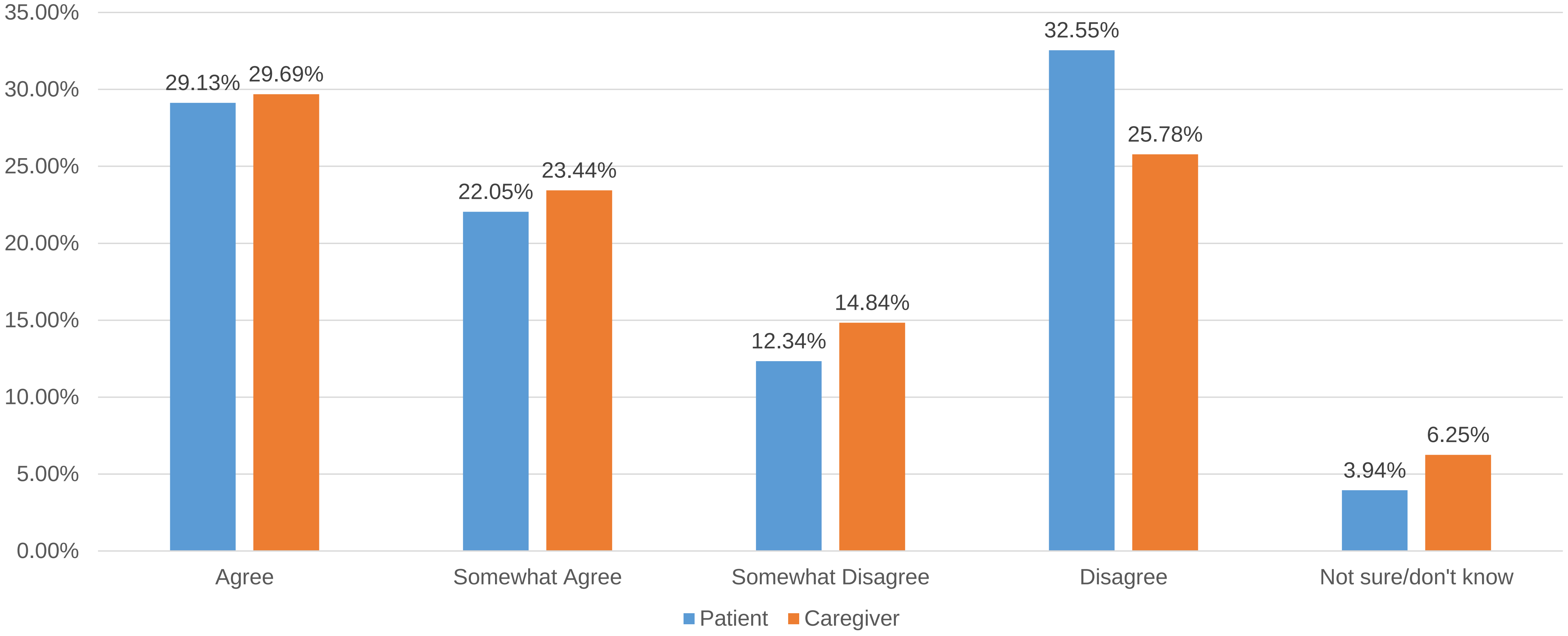
How much do you agree with the following statements?
As long as my/their health data is anonymized (can't be tracked back to me/them) I would be okay with it being shared without my permission



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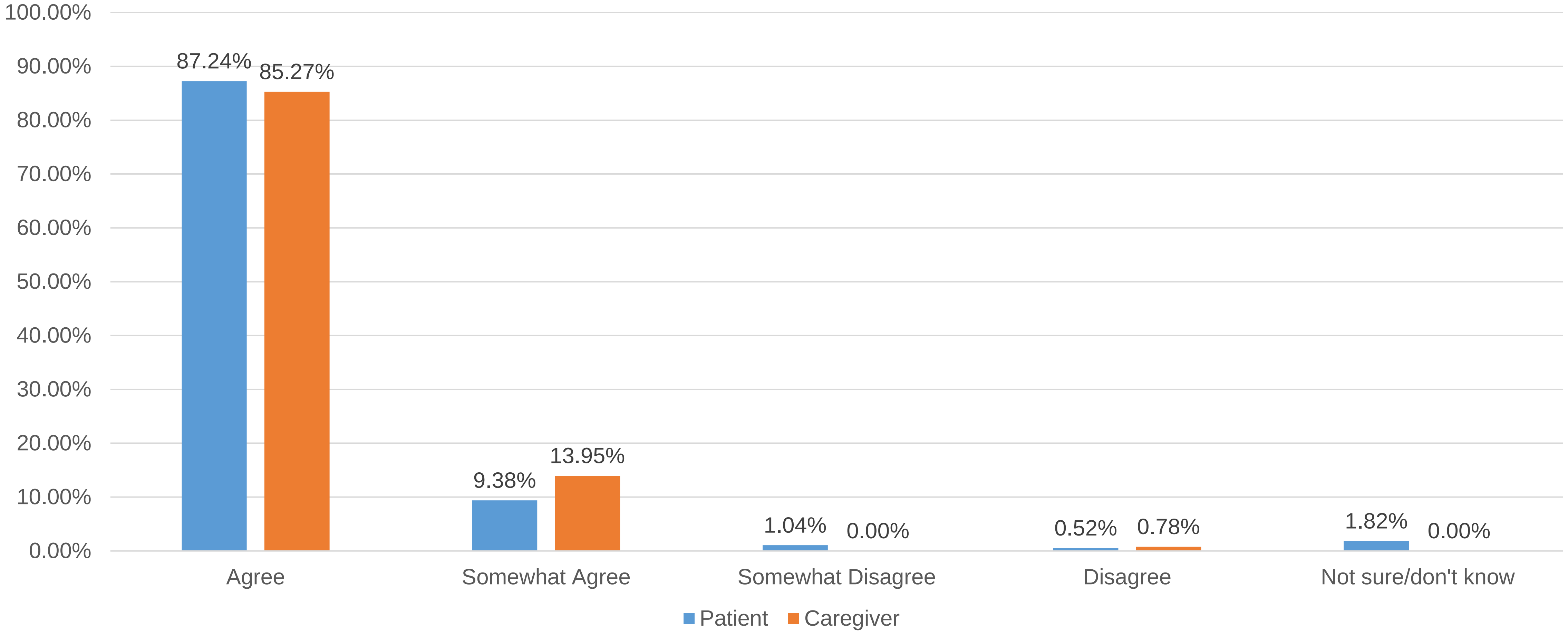
How much do you agree with the following statement?

I should be able to share my/their health data, including their medical records, with any of my/their providers (or other members of my/their care team/others caring for them).



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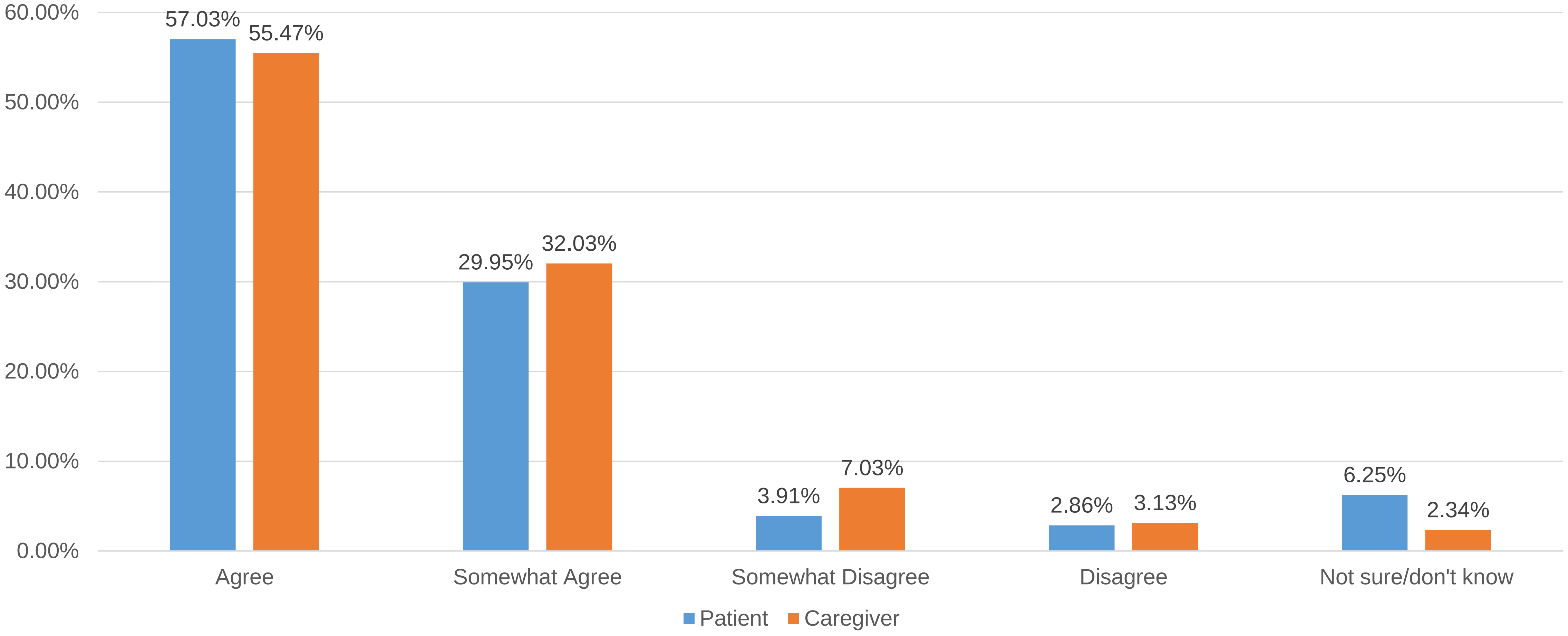
How much do you agree with the following statements?

There are benefits to people/public health when organizations involved in health care share health data about individuals, including me.



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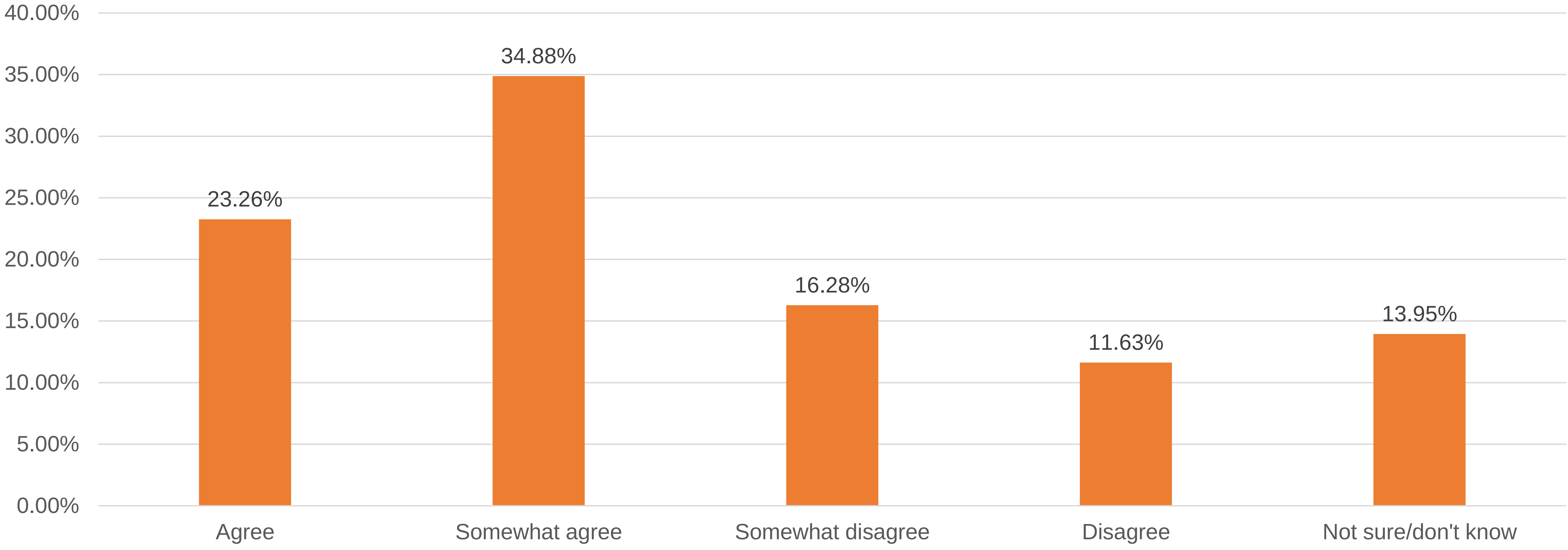
Caregiver Response: How much do you agree with the following statement?

Laws get in the way of my having access to their health data to help them with their care.



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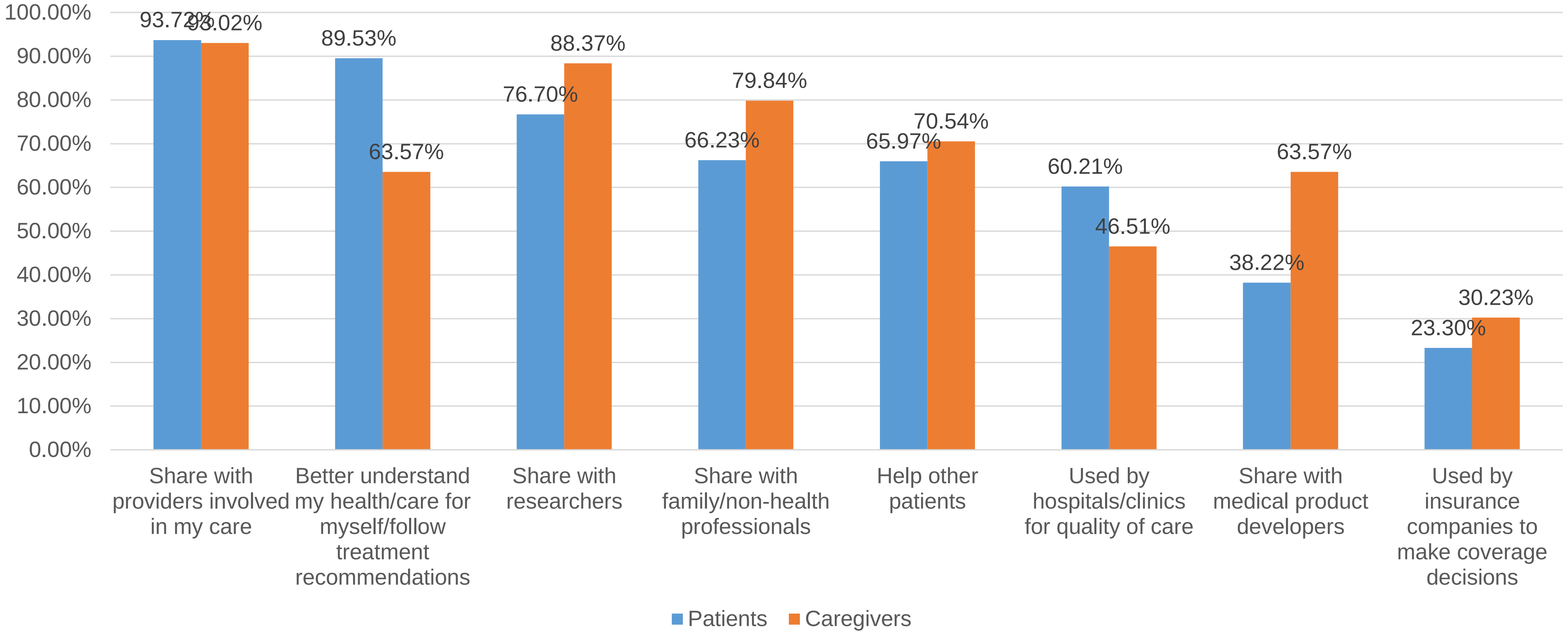
If you had access to all of your health data and it was complete and accurate, how would you prefer to use it? Check all that apply.



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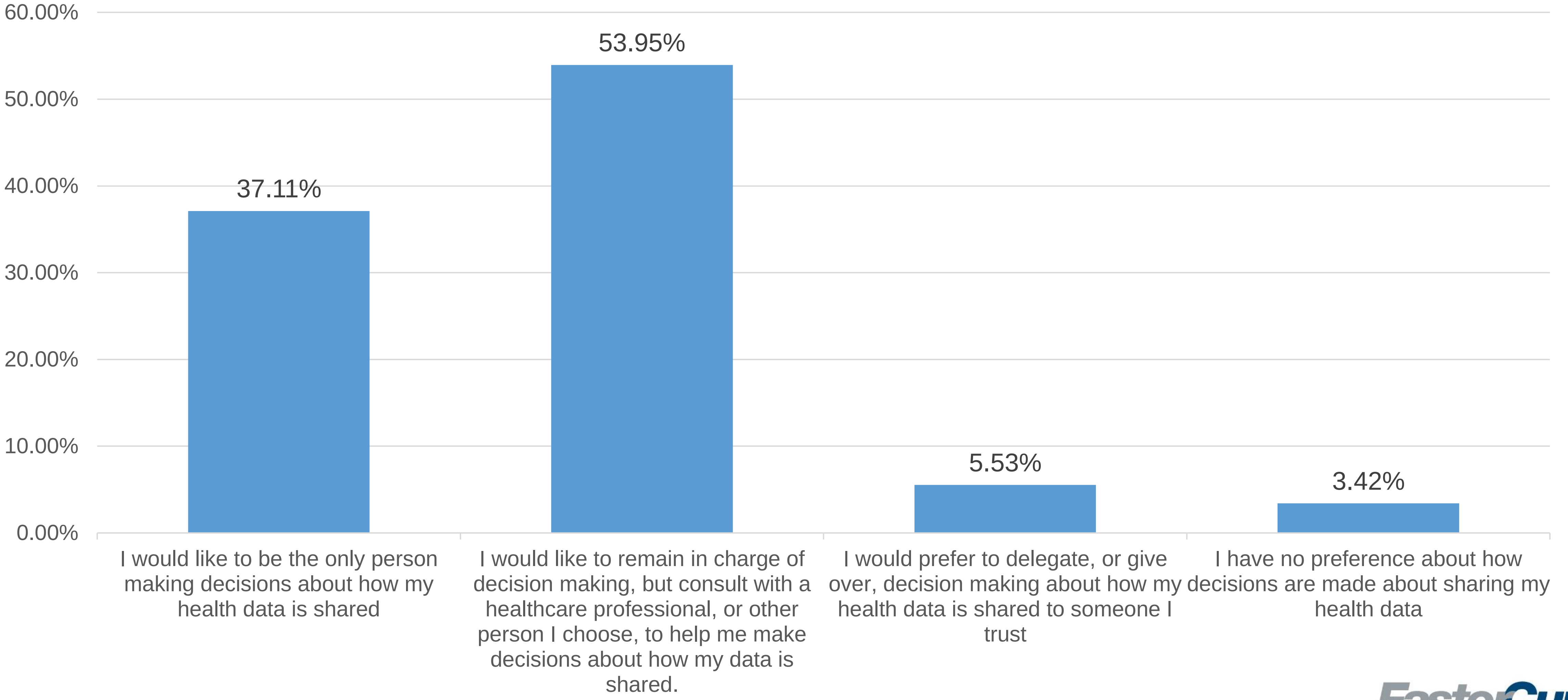
Patient Responses: How would you prefer to make decisions about how your health data is shared?



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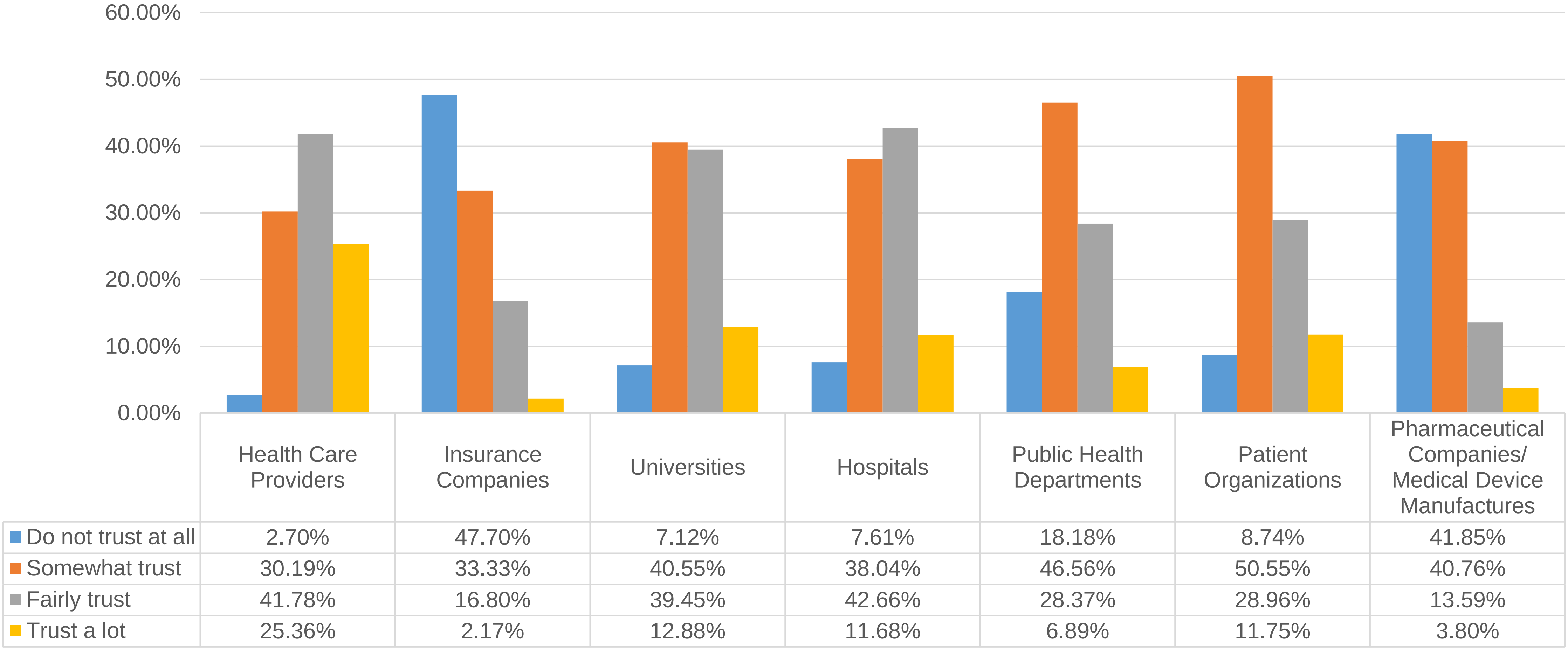
TRUST

Patient Responses: How much do you trust the following organizations to manage how your health data is shared with the system?



	Health Care Providers	Insurance Companies	Universities	Hospitals	Public Health Departments	Patient Organizations	Pharmaceutical Companies/ Medical Device Manufactures
🟦 Do not trust at all	2.70%	47.70%	7.12%	7.61%	18.18%	8.74%	41.85%
🟧 Somewhat trust	30.19%	33.33%	40.55%	38.04%	46.56%	50.55%	40.76%
◼ Fairly trust	41.78%	16.80%	39.45%	42.66%	28.37%	28.96%	13.59%
🟨 Trust a lot	25.36%	2.17%	12.88%	11.68%	6.89%	11.75%	3.80%

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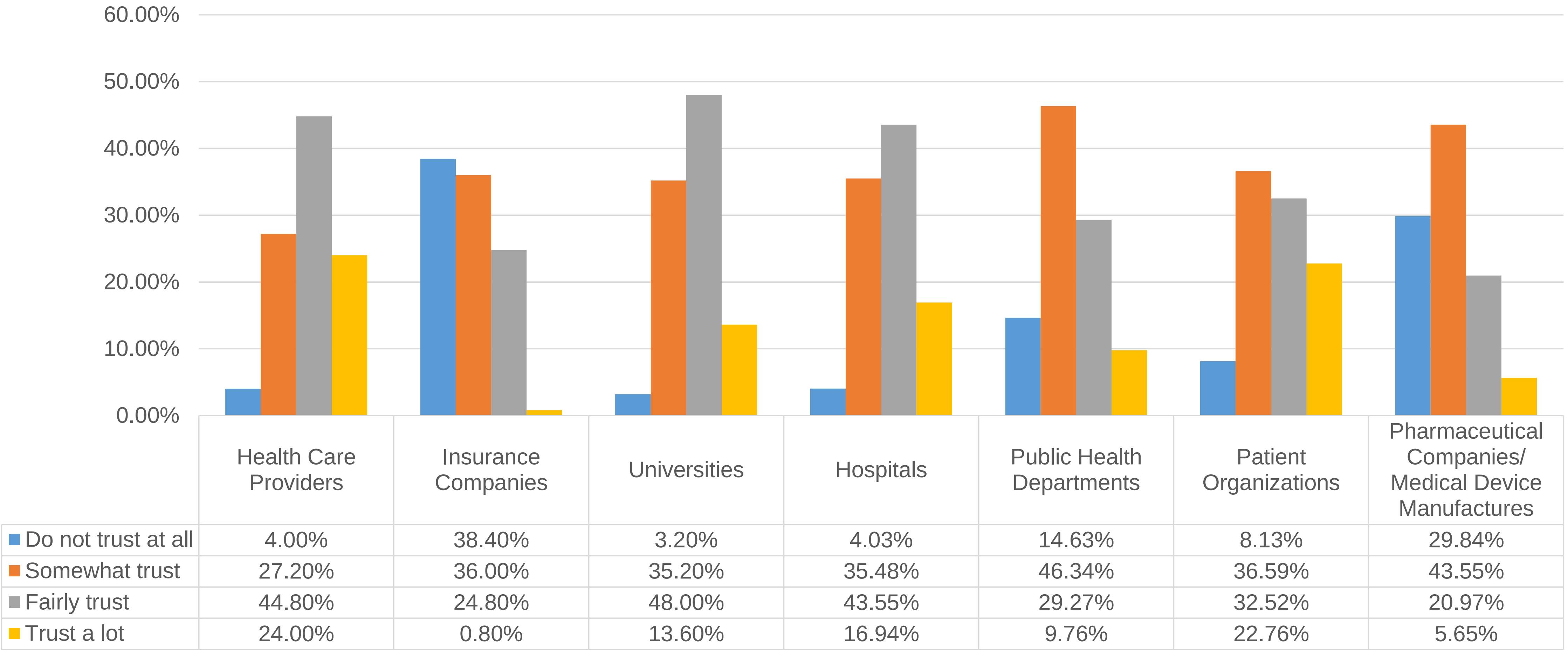
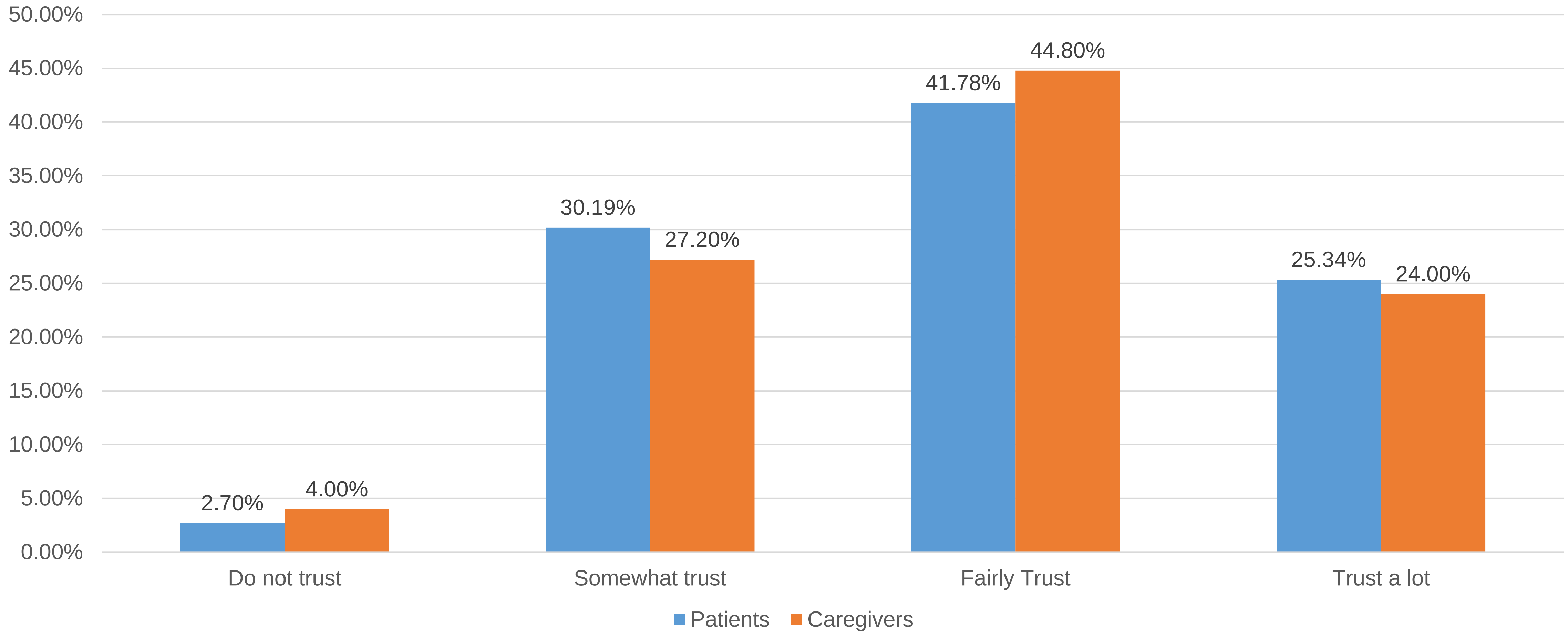
Caregiver Responses: How much do you trust the following organizations to mange how their health data is shared within the system?



	Health Care Providers	Insurance Companies	Universities	Hospitals	Public Health Departments	Patient Organizations	Pharmaceutical Companies/ Medical Device Manufactures
🟦 Do not trust at all	4.00%	38.40%	3.20%	4.03%	14.63%	8.13%	29.84%
🟧 Somewhat trust	27.20%	36.00%	35.20%	35.48%	46.34%	36.59%	43.55%
⬜ Fairly trust	44.80%	24.80%	48.00%	43.55%	29.27%	32.52%	20.97%
🟨 Trust a lot	24.00%	0.80%	13.60%	16.94%	9.76%	22.76%	5.65%

How much do you trust the following organizations to mange how their health data is shared within the system? **Health Care Providers**



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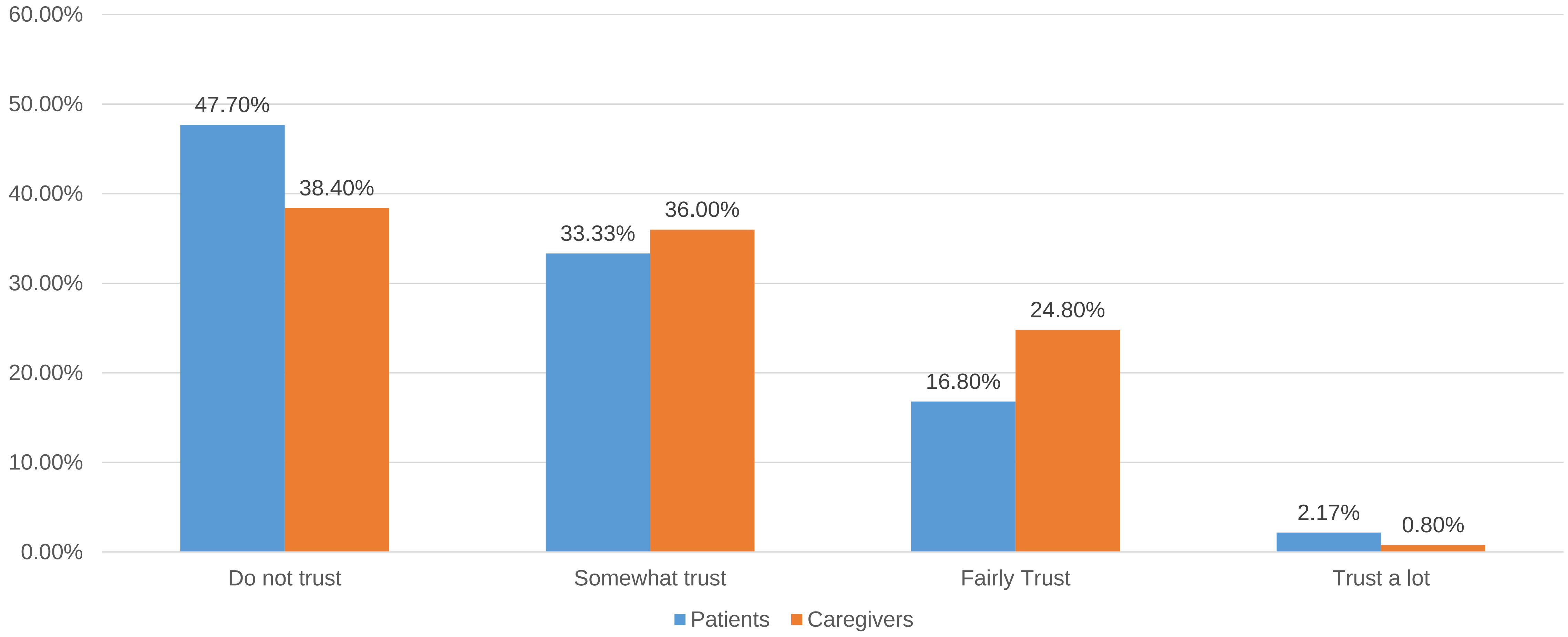
How much do you trust the following organizations to mange how their health data is shared within the system? **Insurance Companies**



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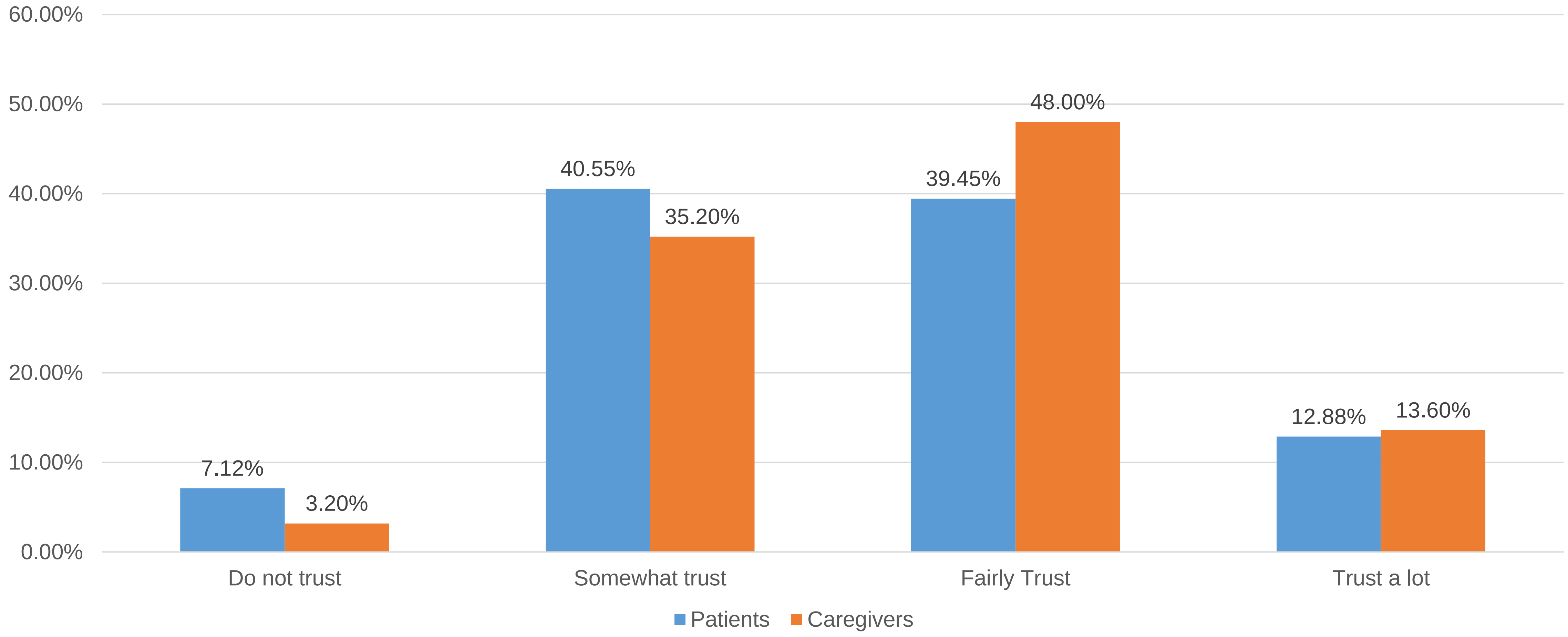
How much do you trust the following organizations to mange how their health data is shared within the system? **Universities/academic medical centers**



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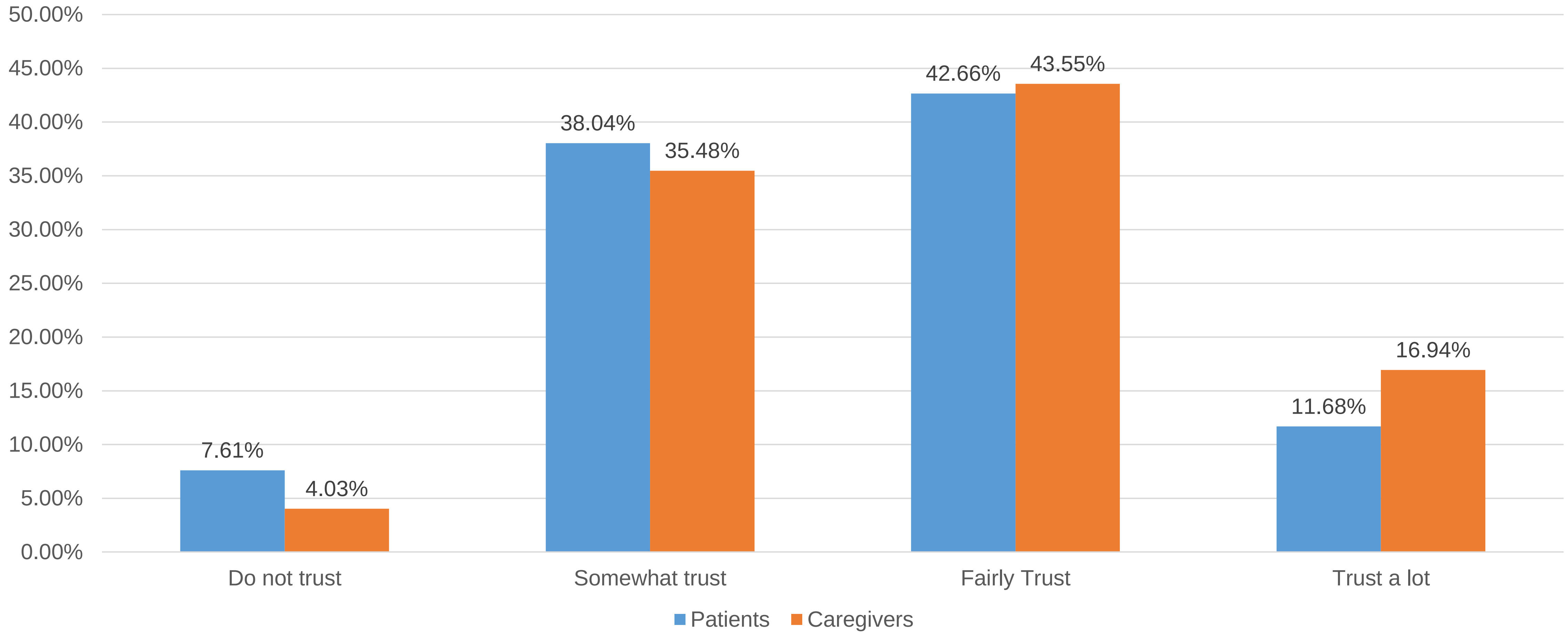
How much do you trust the following organizations to mange how their health data is shared within the system? **Hospitals**



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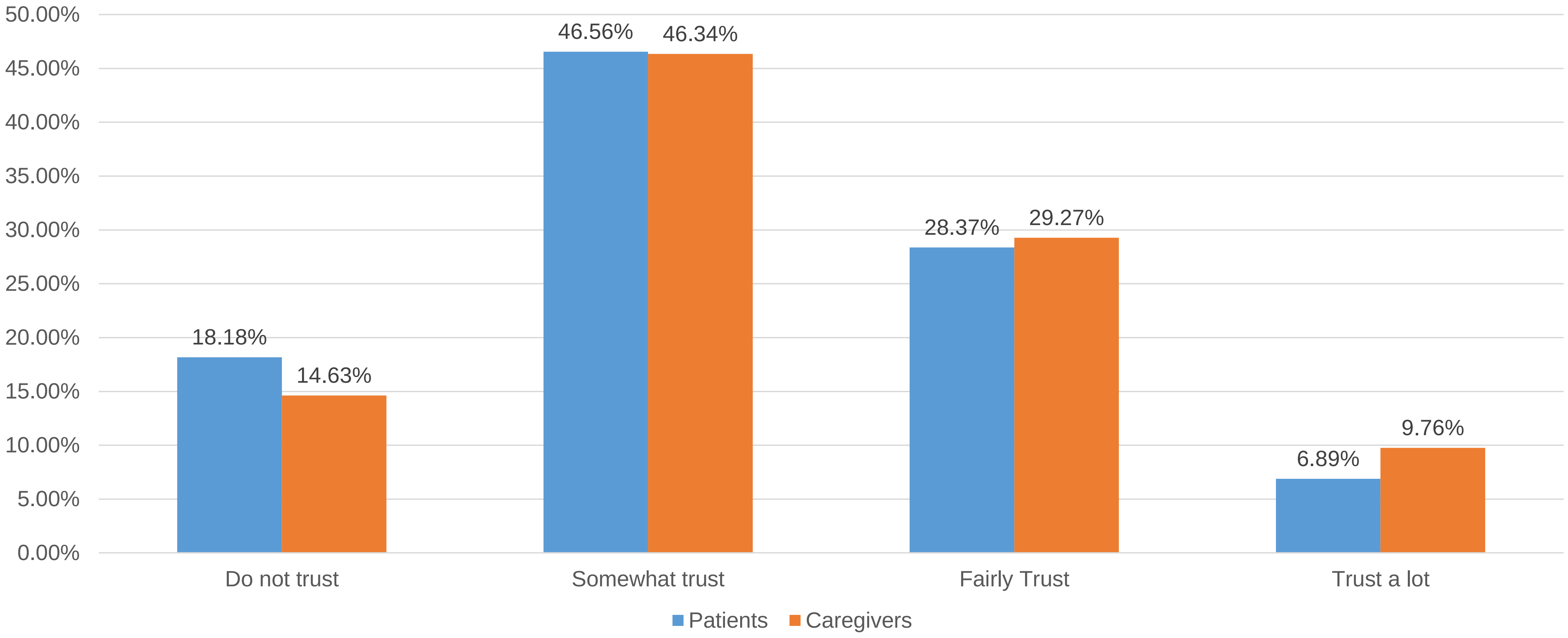
How much do you trust the following organizations to mange how their health data is shared within the system? **Public health departments**



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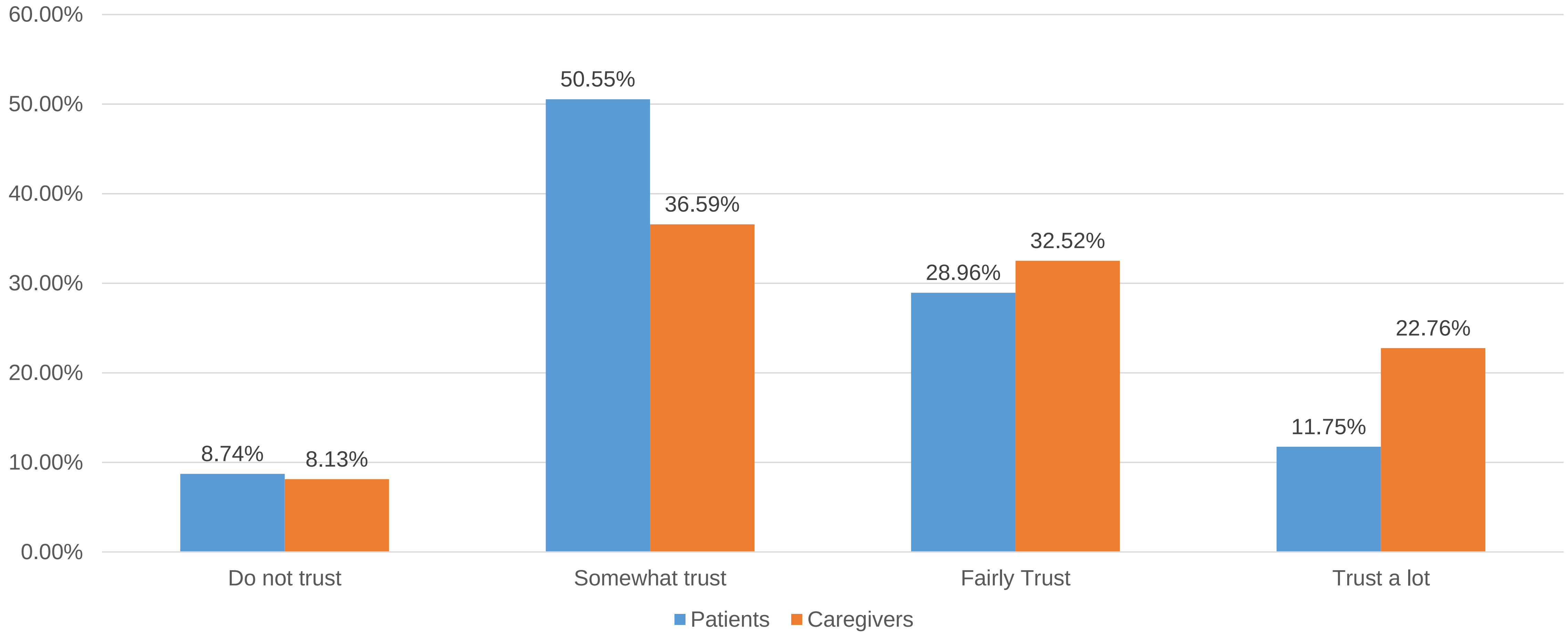
How much do you trust the following organizations to mange how their health data is shared within the system? **Patient organizations**



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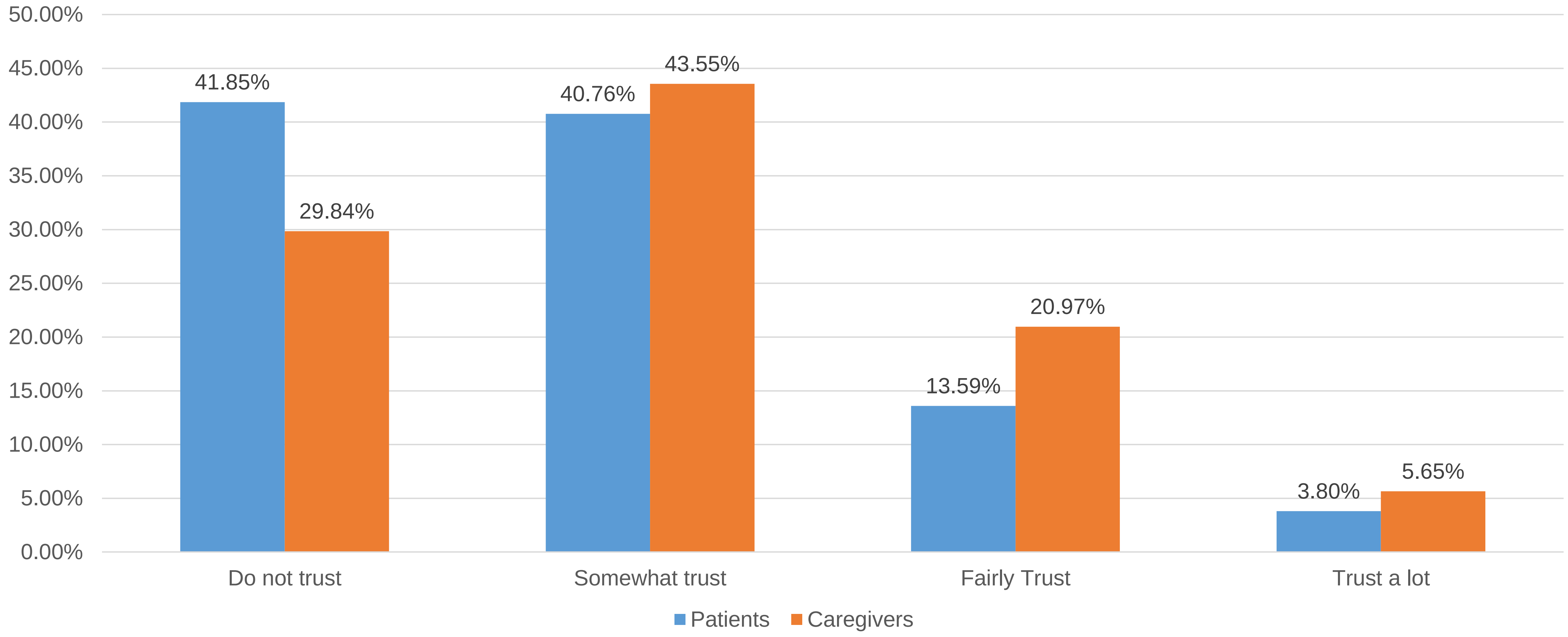
How much do you trust the following organizations to mange how their health data is shared within the system? **Pharmaceutical companies/medical device manufacturers**



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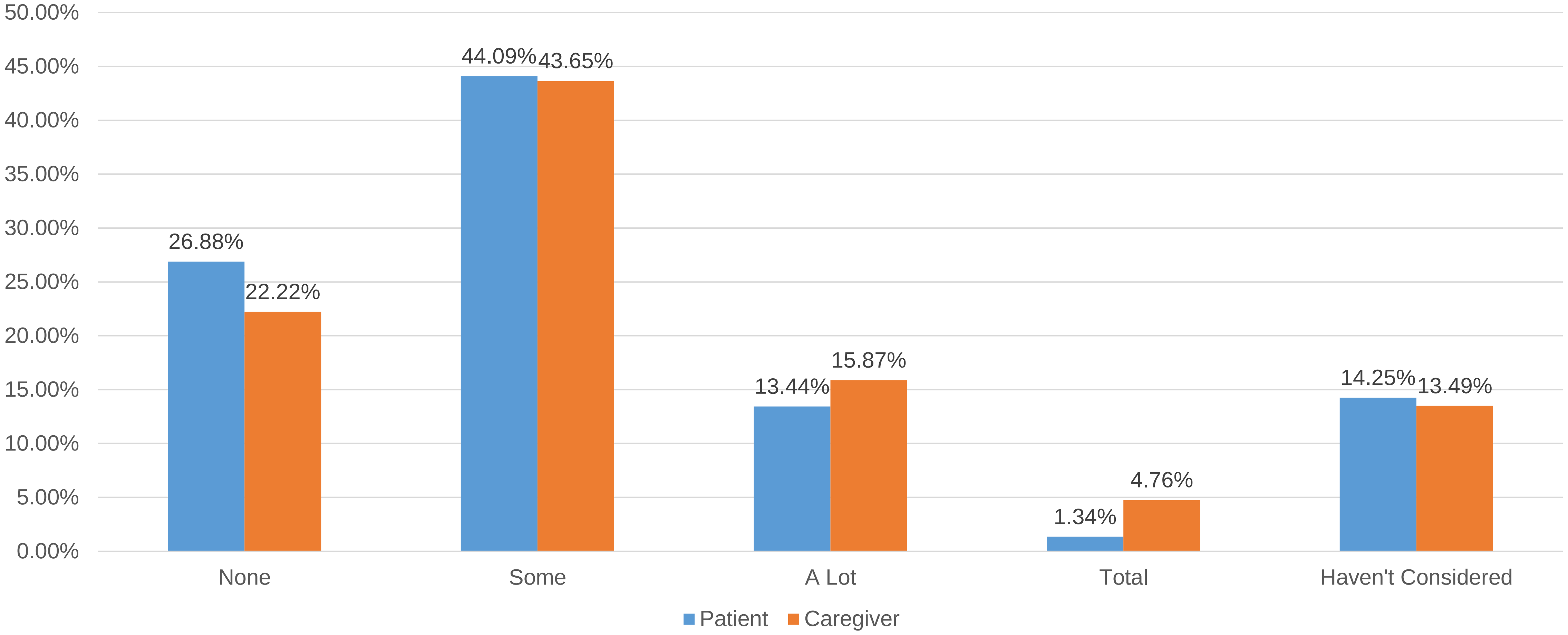
How much control do you feel you have over the sharing of your/their health data?



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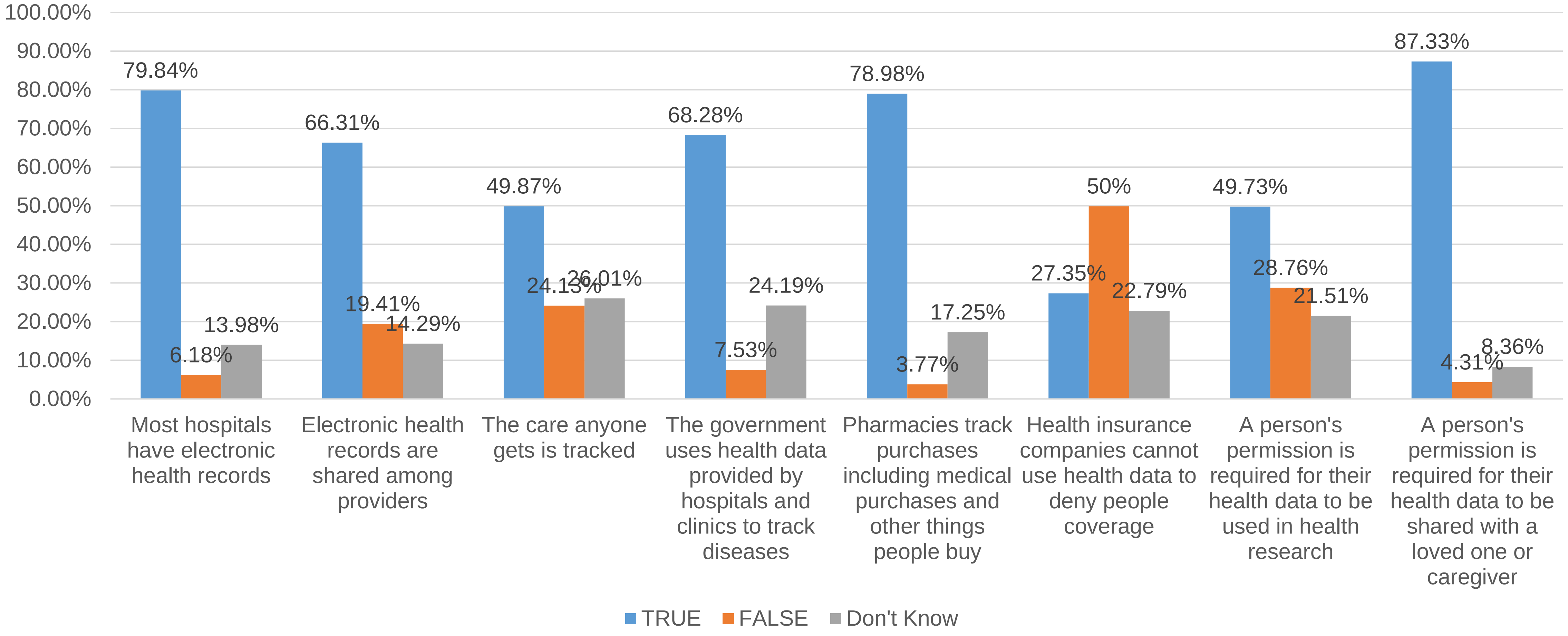
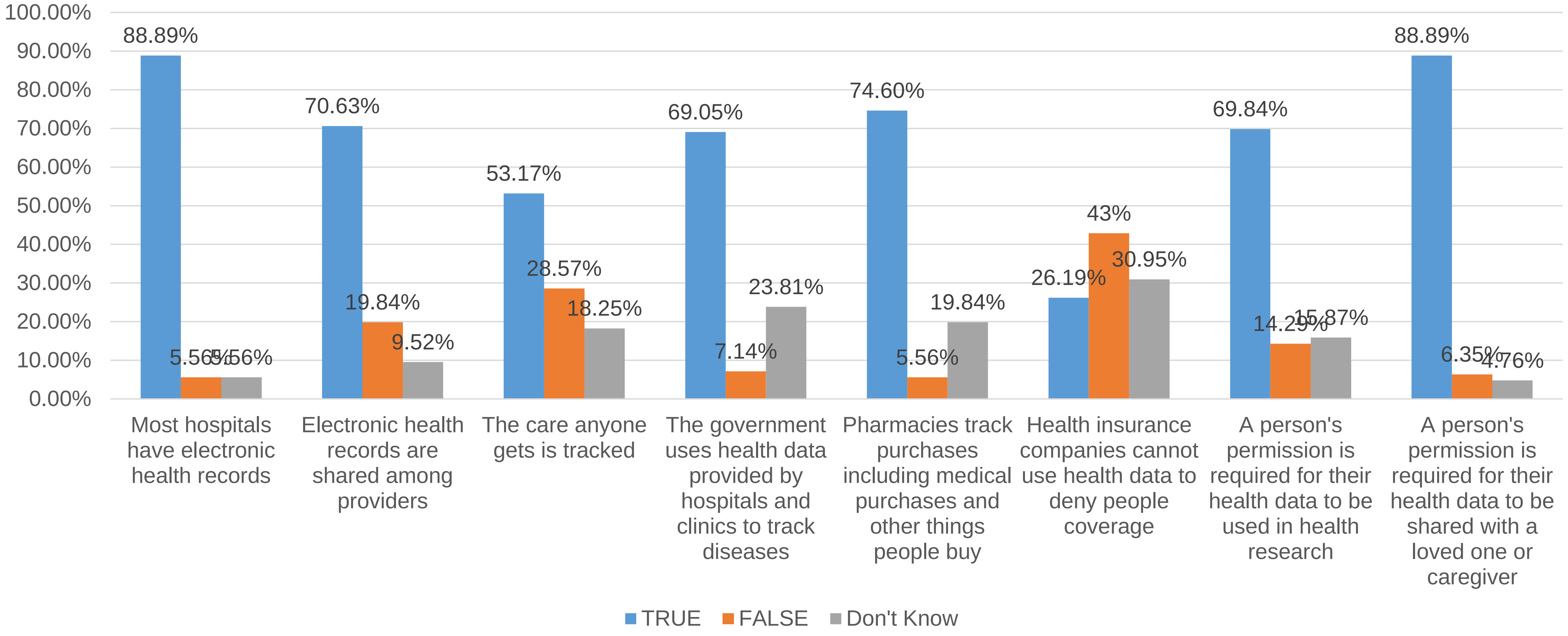
TRUE/FALSE

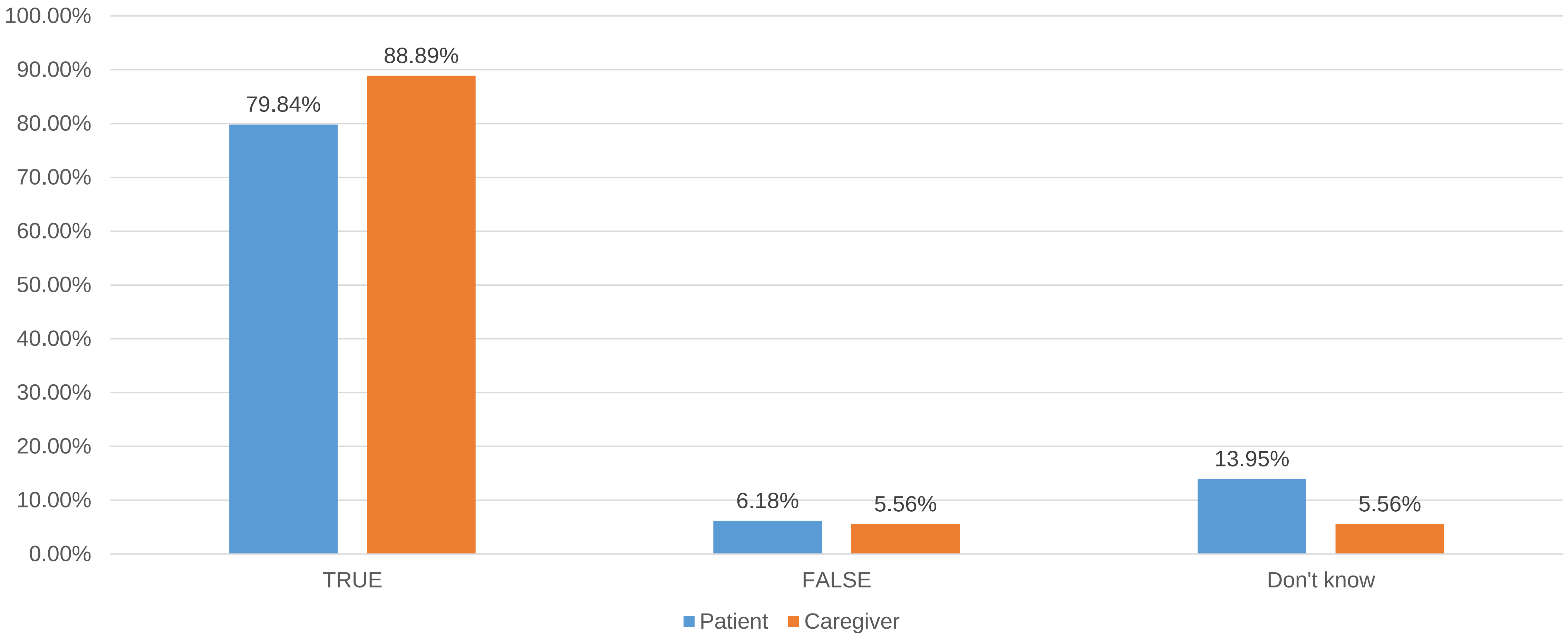
Patient Responses: What do you think of the following statements?



Caregiver Responses: What do you think of the following statements?



What do you think of the following statement:
Most hospitals have electronic health records



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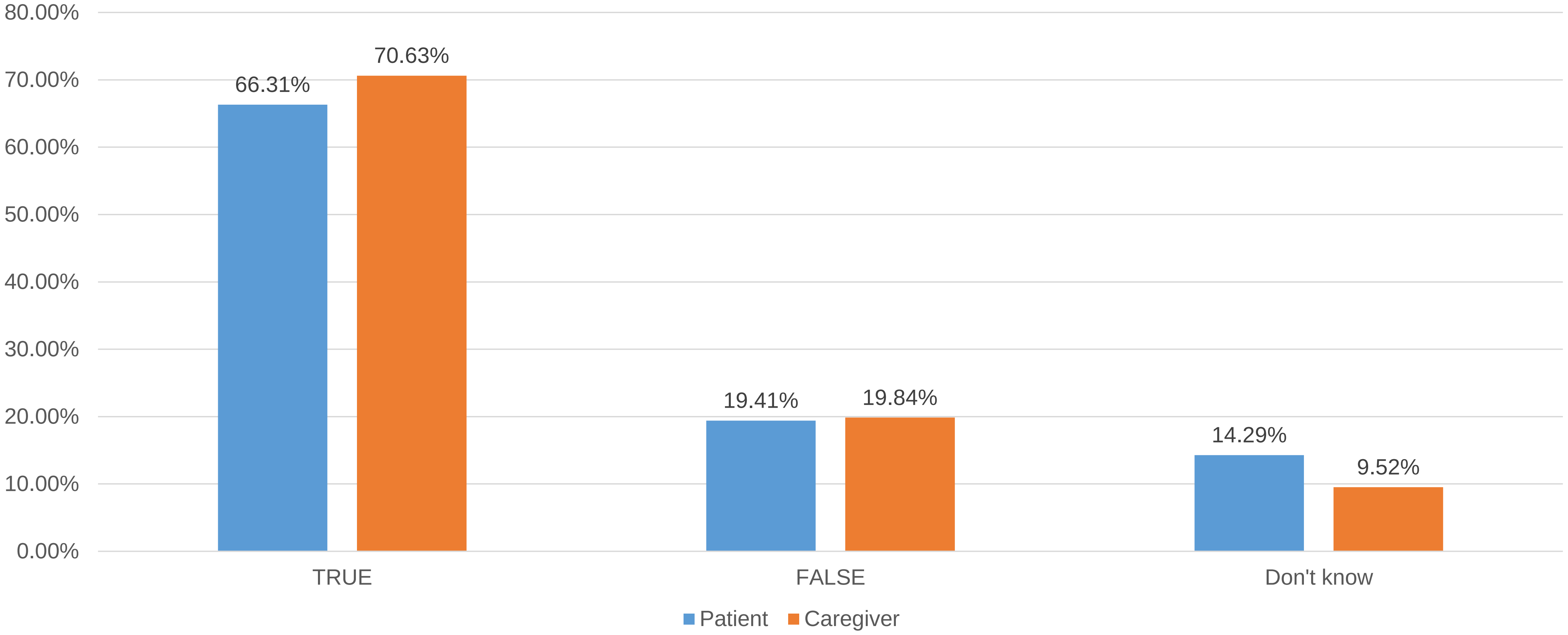
What do you think of the following statement:

Electronic health records are shared among providers (physicians, specialists, hospital systems)



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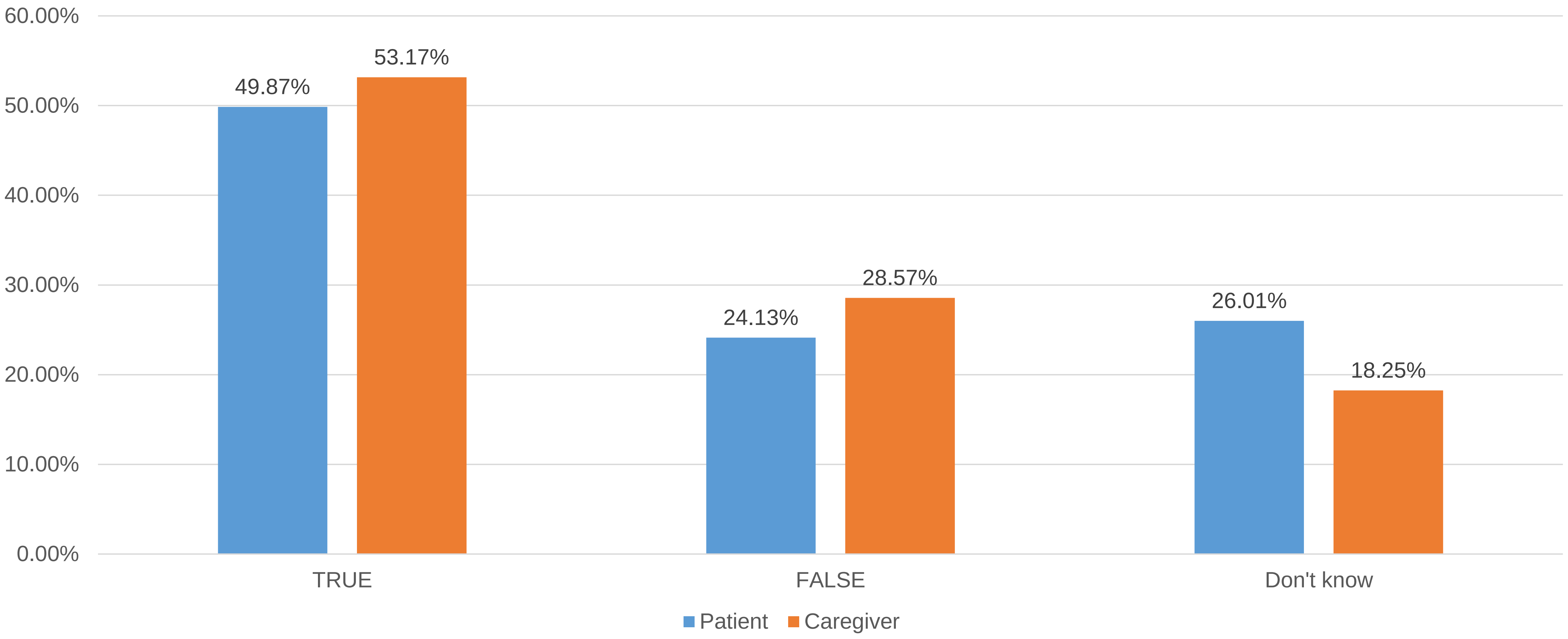
What do you think of the following statement:
The care anyone gets is tracked.



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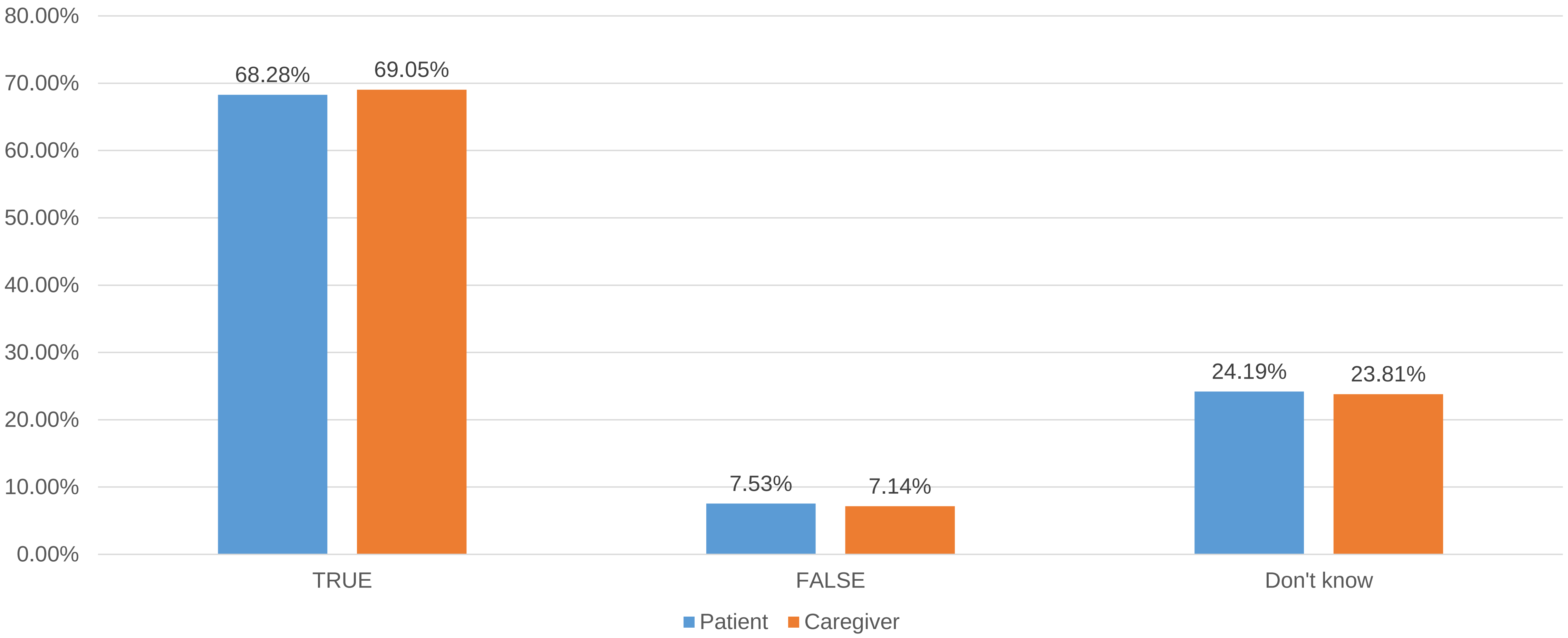
What do you think of the following statement:
The government uses health data provided by hospitals and clinics to track diseases.



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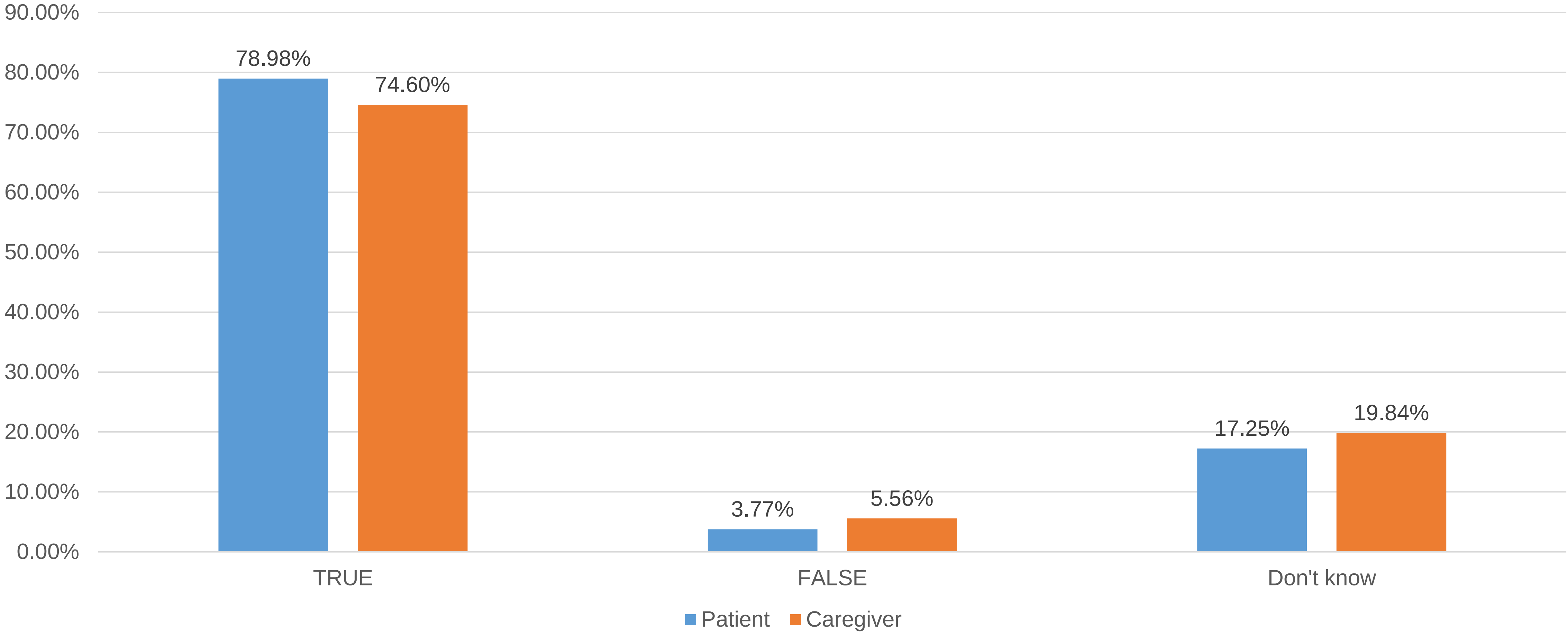
What do you think of the following statement: **Pharmacies track purchases, including medical products and other things people buy from them.**



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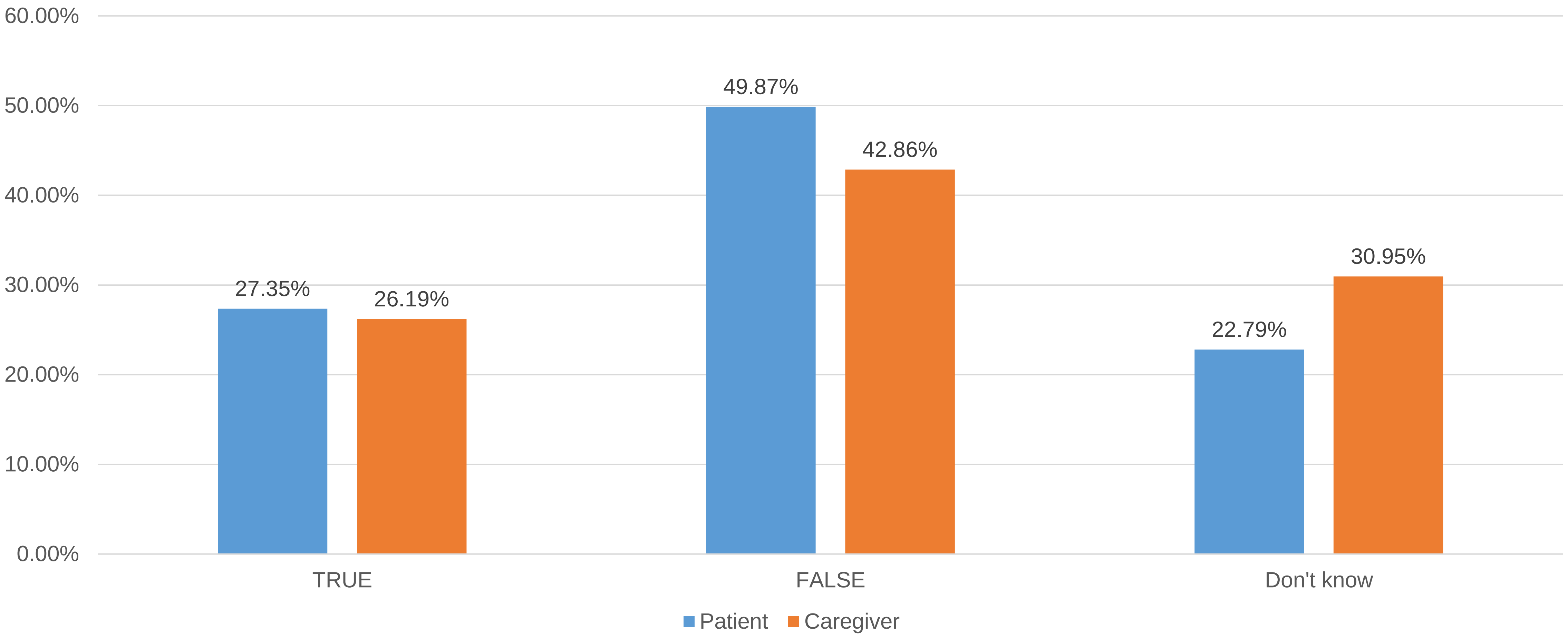
What do you think of the following statement: **Health insurance companies cannot use health data to deny people coverage.**



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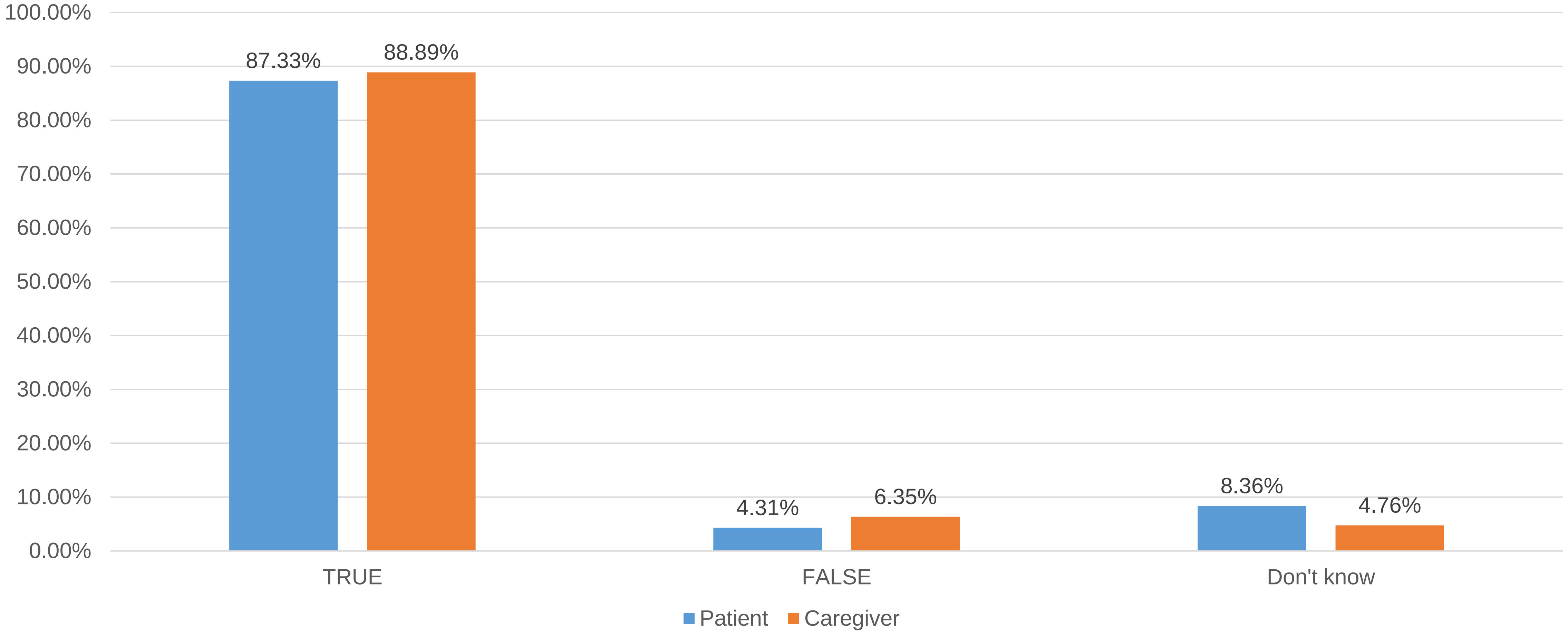
What do you think of the following statement:
A person’s permission is required for their health data to be shared with a loved one or caregiver.



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Data is knowledge.
Data is power.

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