

## The Specific Carbohydrate Diet (SCD) Survey 2020



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# TABLE OF CONTENTS

Background.....2

Survey Sample Demographics .....3

SCD Background .....7

SCD Life.....11

APPENDIX: Survey Result Charts.....13

## BACKGROUND

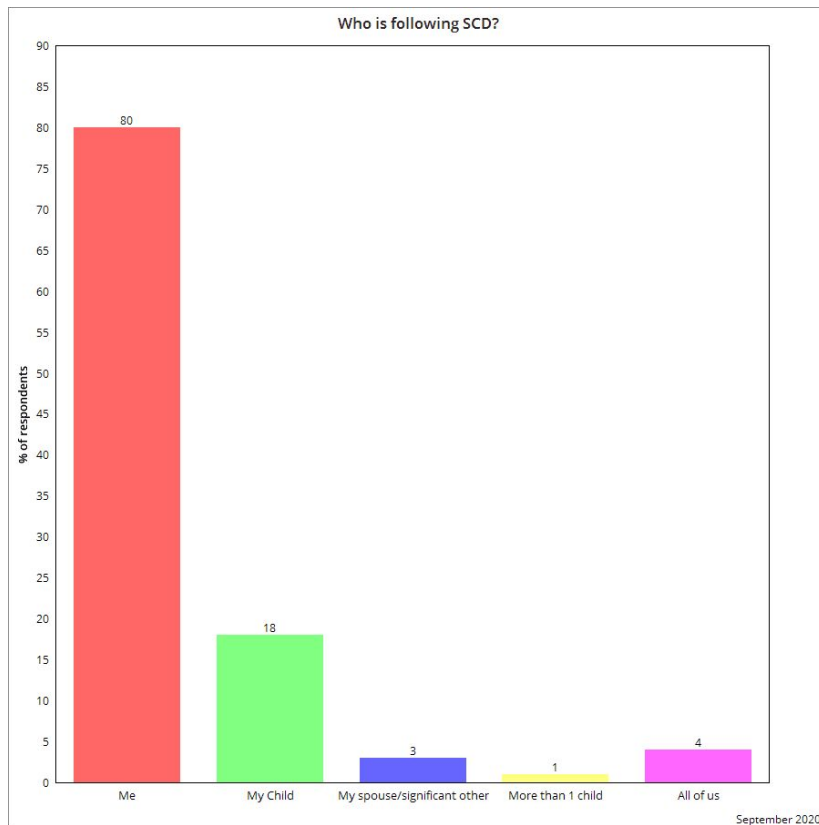
From July through September 2020, the Specific Carbohydrate Diet Association collected 846 anonymous responses via Facebook and Instagram about “SCDers”, or people who have incorporated the diet into their lives, and we estimate the population size of people who follow SCD to be 1,000,000. The estimated margin of error in our sampling is +/-3%.

The Specific Carbohydrate Diet (SCD) Survey gives people who follow the SCD an opportunity to compare life experiences by compiling individual responses to represent an entire SCD Community. The Survey gives the SCD Community insight on how others have incorporated SCD in their lives, their successes and challenges and the effectiveness of the SCD as a treatment tool for the treatment of diseases that originate or directly impact the gastrointestinal tract. As we undertake future surveys, we will refine the variables inherent in surveys to provide more details and transparency. We hope you will gain valuable information from the survey results.

Throughout this report, the term “SCDers” is used to describe the sample.

***The content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.***

## Survey Sample Demographics



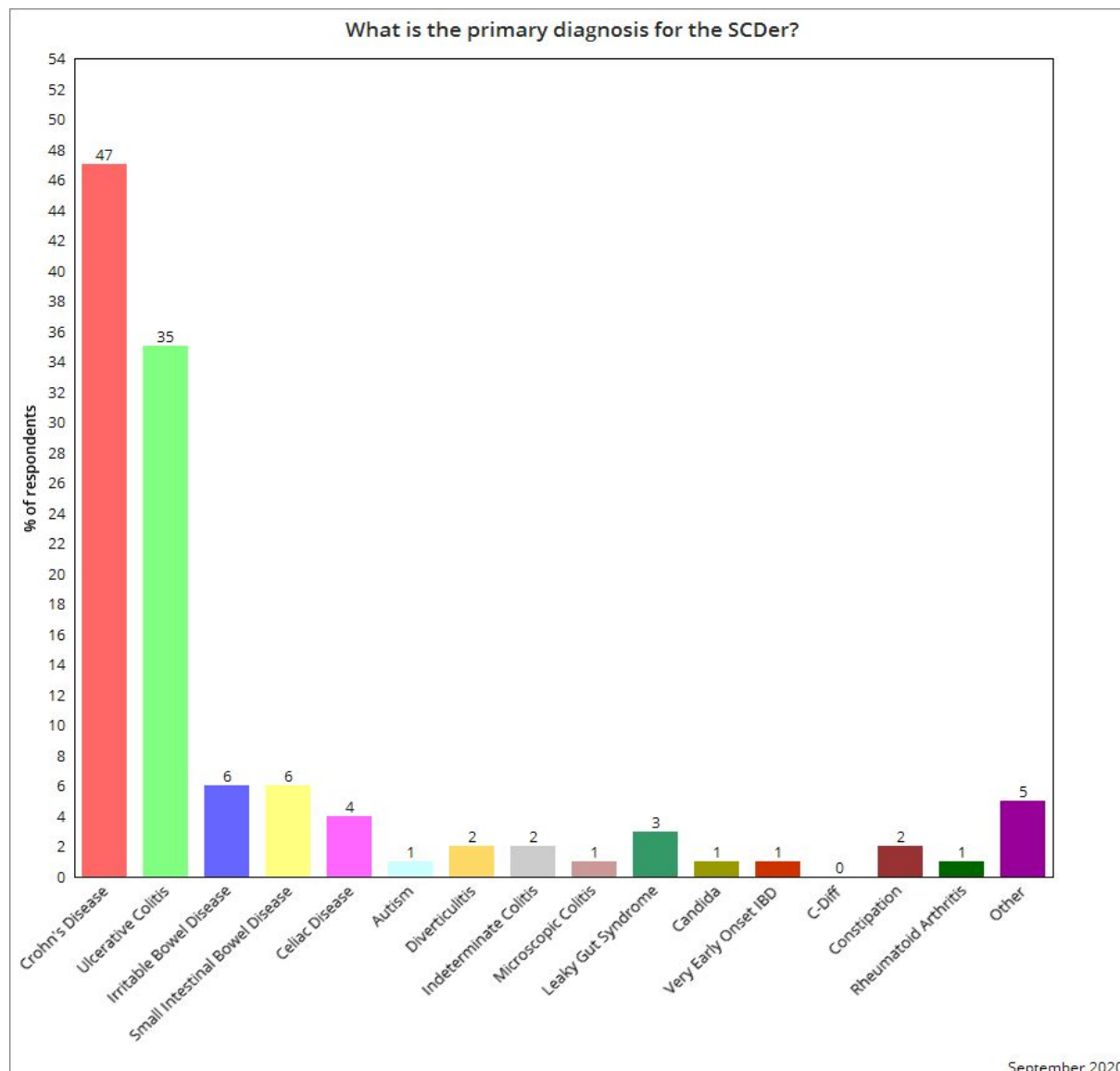
### ***Who is on the diet?***

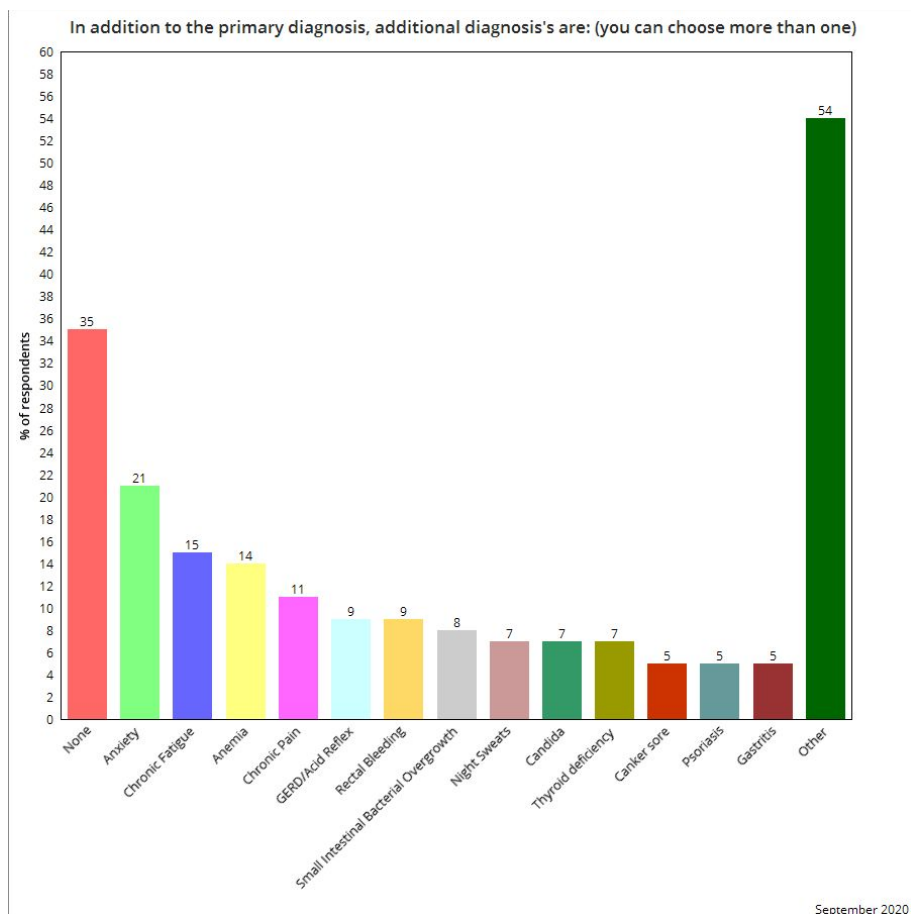
The majority of survey respondents (80%) are following the SCD diet for themselves. One-third of survey respondents consider themselves a supporter or caregiver of someone following the SCD diet (see *charts 26 and 27*). Eighteen percent are following SCD for one child. Three percent are following SCD as a spouse, partner or significant other. One percent are following SCD with more than one child, while 4% are following SCD as a family unit.

Two-thirds (65%) of SCDers are married and about a fifth (19%) are single (cite chart 32).

### **Why do you follow the SCD?**

The majority of respondents (91%) have an IBD diagnosis, specifically Crohn's Disease (47%), Ulcerative Colitis (35%), early onset IBD, indeterminate and microscopic colitis (1% each) and unspecified IBD (6%). Six percent have been diagnosed with small intestinal bowel disease, 4% with celiac and less than 3% each for autism, diverticulitis, leaky gut, candida, c-diff, constipation and rheumatoid arthritis. Five percent have listed "other", in which the individual responses were less than 1% each to be recorded as significant.





### ***Are their additional diagnoses?***

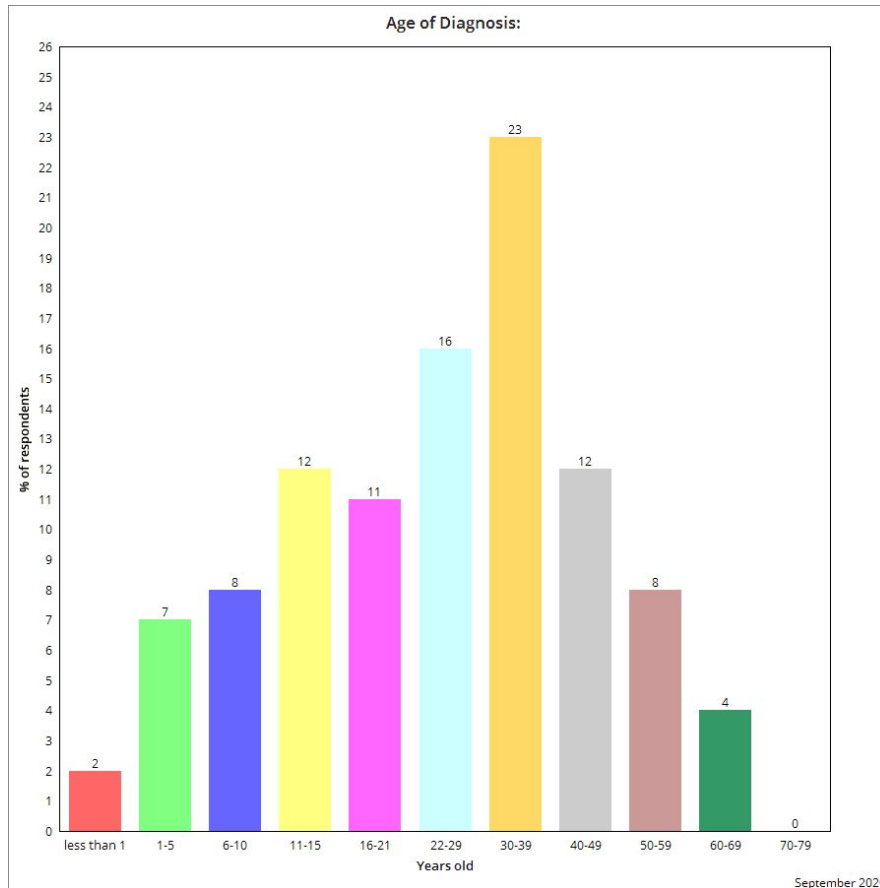
Thirty-five percent do not have any secondary diagnosis. Of those specified, 21% say they have been diagnosed with anxiety. Fifteen percent have chronic fatigue and 11% have chronic pain. Fifty-eight percent of those with secondary diagnosis report anemia (14%), GERD/acid reflux (9%), rectal bleeding (9%), small intestinal bacterial overgrowth (SIBO, 8%), candida

(7%), canker sore and gastritis (5% each). Seven percent report night sweats. Seven percent report thyroid deficiency. Five percent have been diagnosed with psoriasis. Fifty-four percent recorded "other" in which the individual responses were less than 1% each to be recorded as significant.

One-third (35%) report no secondary diagnoses.

### ***How many doctors did you visit to find your primary diagnosis?***

One third of respondents (30%) were diagnosed by the first doctor they saw for their symptoms. One third (30%) were diagnosed by the second doctor they visited. Forty percent had visited more than two doctors; 17% saw three doctors, 8% saw four, 4% saw five, 4% saw six and just 1% saw seven, but a full 5% report they required being seen by eight or more doctors to receive a diagnosis. Two percent say they did not see a doctor at all. (See chart 29)



***What are survey respondents' current ages and how old were they when diagnosed?***

The majority of respondents are adults, followed by young adults and seniors and children in equal proportions. Nearly two-thirds (59%) of respondents are adults between the ages of 30 and 59; 18% are 30-39, 23% are 40-49 and 18% are 50-59. Seventeen percent are young adults; 8% are 16-21 and 9% are 22-29. Fifteen percent are seniors; 12% are 60-69 and 3% are over

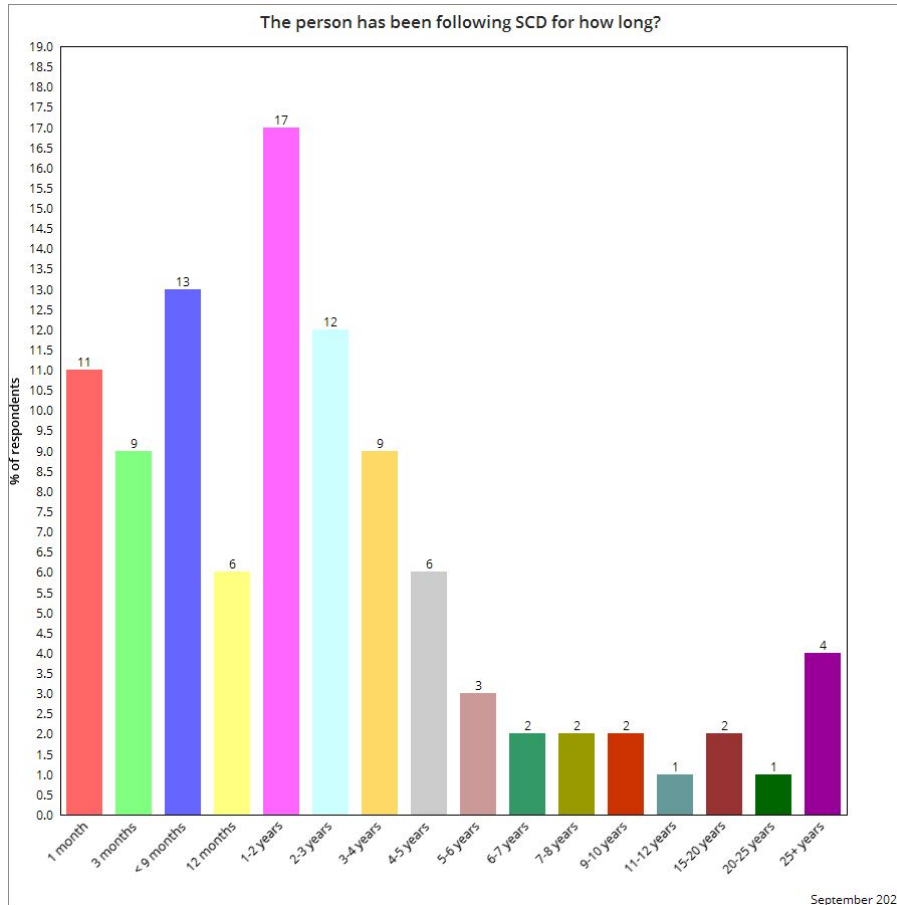
70-years-old. Fifteen percent are children; 8% are 11-15, 5% are 6-10 and 2% are younger than five-years-old.

More than half were diagnosed as adults (cite chart 4); 23% were diagnosed in their 30s followed by 16% in their 20s and 12 percent in their 40s. Forty percent of respondents were diagnosed as a minor/child; 11% at ages 16-21, 12% at 11-15, 8% at 6-10, 7% at 1-5 and just 2% were diagnosed before the age of one. Twelve percent were over the age of 50 at the time of diagnosis; 8% were in their 50s and 40 percent were in their 60s. No respondents were diagnosed in their 70s or later.

***What is the current disease status?***

The vast majority of SCDers report mild or moderate disease states; 28% say their symptoms are mild and 24 percent report they are moderate. A full third report that they are symptom free (20%), in clinical remission (14%) or histologic remission (2%). Five percent report severe disease. (See chart 28)

## SCD Background



### ***How long did it take for SCDers to see results?***

The majority of respondents are relatively new or brand new to the SCD diet. Thirty-nine percent have been on the diet for less than a year (cite chart 5); 11% for just one month, 9% for three, 14% for less than nine months and 6% for a full year. Nearly a third (27%) have been on the SCD diet for one to five years; 12% for two to three years, 9% for three to four years and 6% for four

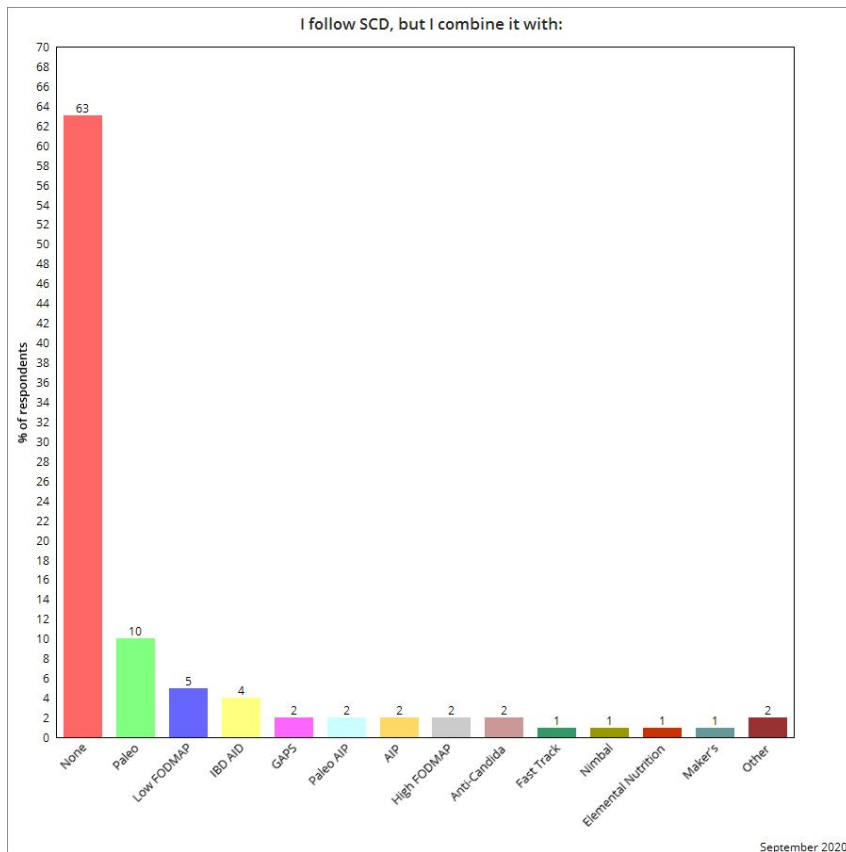
to five years. Nine percent have been SCD for five to 10 years. Four percent have been on the diet for 11 to 20 years. Four percent have been on the diet for 25 years or longer.

Seventy nine percent of the respondents saw results within the first three months of starting the diet, with a full quarter (25%) reporting results within the first week, while 43% had positive results within the first month. Nearly a fifth (19%) reported results in the first three months. Six percent reported results within the first year, 93% had positive results within the first 2 years while (and) 7% are still awaiting results after two years. (See chart 7)

Compliance to SCD guidelines varies. Forty percent of respondents say that although they eat an SCD compliant diet 76-90% of the time, they are not 100% compliant (cite chart 8). Nearly an equal amount (39%), however, report 100% compliance. Only a fifth of respondents say they are less than 76% compliant with SCD.

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Two-thirds (63%) follow only the SCD diet only. Five percent combine it with the low-FODMAP diet, 4% with IBD-AID and the other 4% autoimmune-paleo (AIP) diet. Less than one to two percent of each of the following diets were also reported.

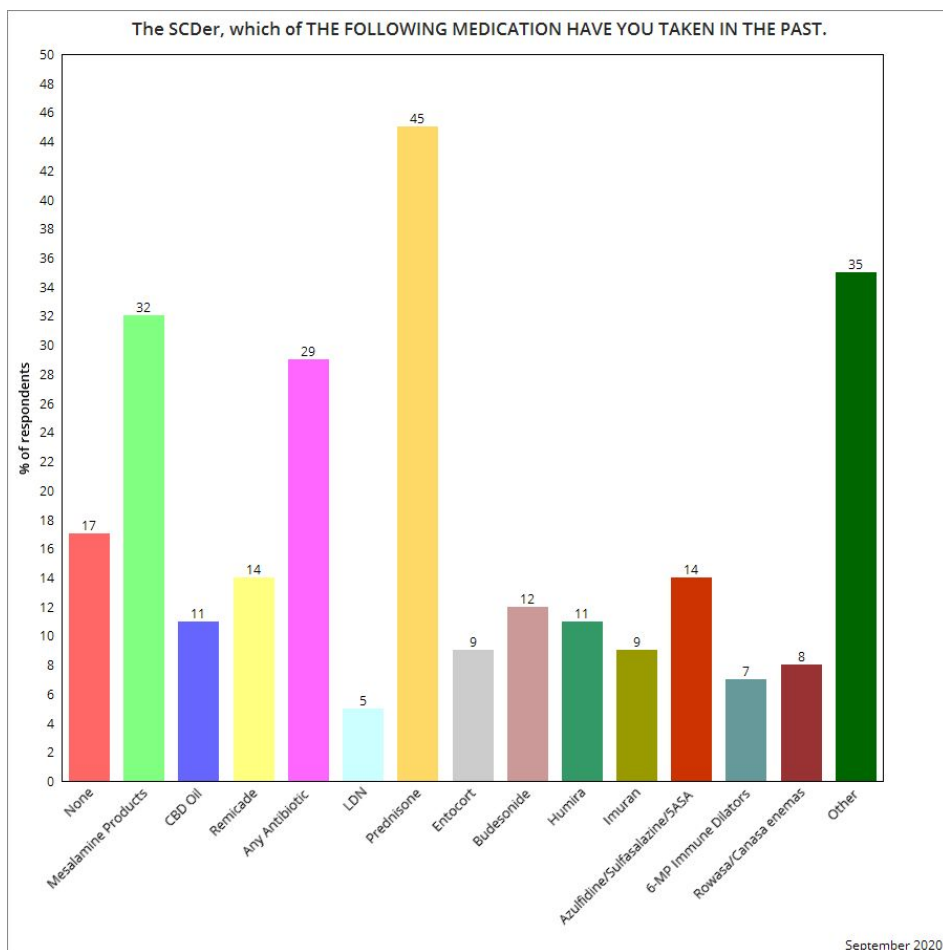
Eighty-one percent of SCDers say they eat all SCD foods they can tolerate. Eight percent do not consume beef and one percent do not consume poultry. Four percent are vegetarians, with a quarter of those being vegans. Three percent follow kosher guidelines. Three percent do not eat fish or seafood.

Three quarters of SCDers eat mostly organic foods (76%). Ten percent eat strictly organic and 5% avoid just the “dirty dozen”. Nine percent never eat organic foods. (See charts 14,15)

Six percent of respondents do not eat nuts. Of those that do, 86% eat almonds, 72% coconut, 67% cashews, 56% peanuts, 52% walnuts, 51% pecans, 26% hazelnuts, 25% macadamias, 15% brazil nuts and 7% chestnuts. (See chart 16)

### **What pharmaceutical treatments are SCDers using or have tried in the past?**

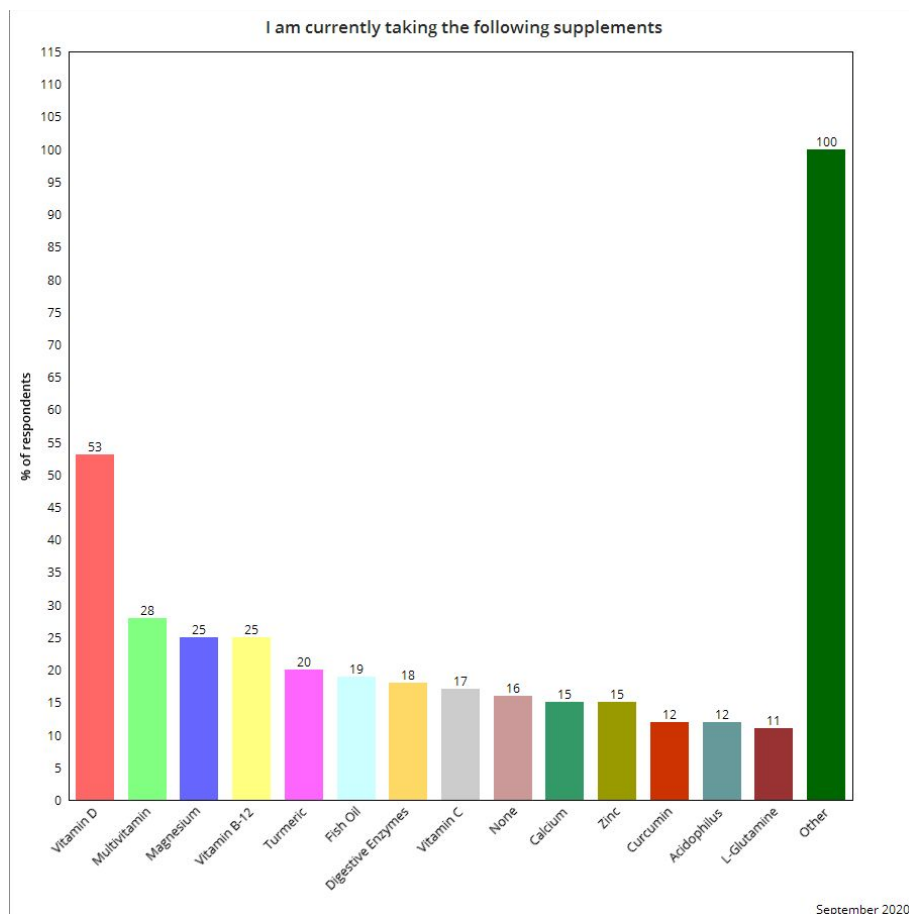
Forty seven percent of the respondents do not use medications, while 16% do not use supplements (See *chart 12*). Forty-five percent report past use with prednisone and; 14% remicade, 11% humira and 9% imuran. Thirty-two percent have used mesalamine products. Twenty nine percent have used antibiotics (any). Fourteen percent have used 5-ASA. Seven percent have used 6-MP. Seven percent have used 6-MP.



Currently, nearly half (47%) of respondents are using SCD to treat their condition without the assistance of prescription medication. One-fifth (21%) are taking mesalamine and another fifth (18%) report unspecified "other" prescription medications recorded other in which the individual responses were less than 1% each to be recorded as significant. (See *chart 11*)

Less than five percent each reported current prescription use of low-dose naltrexone, Humira, prednisone, Entyvio, Imuran, Stelara, 5-ASA, 6-MP and hormone therapy.

Although 14% reported they are using medical cannabis of any kind (7% hemp/CBD products only), cannabis is not considered a prescription drug.



### ***Is the SCDer currently using supplements?***

Over half of respondents (53%) are taking supplemental vitamin D. Nearly a third (28%) are taking a daily multivitamin. Other (popular) supplements among respondents included: Magnesium (25%), vitamin B-12 (25%), turmeric (20%), fish oil (19%), digestive enzymes (18%), vitamin C (17%), calcium (15%), zinc (15%), curcumin (12%), acidophilus

(12%) and l-glutamine (11%).

Sixteen percent of respondents report no supplement use. In addition to the listed supplements, respondents reported additional supplements, designated as other. Future surveys will expand on the responses since one hundred percent of respondents recorded "other" in which the individual responses were less than 1% each to be recorded as significant.

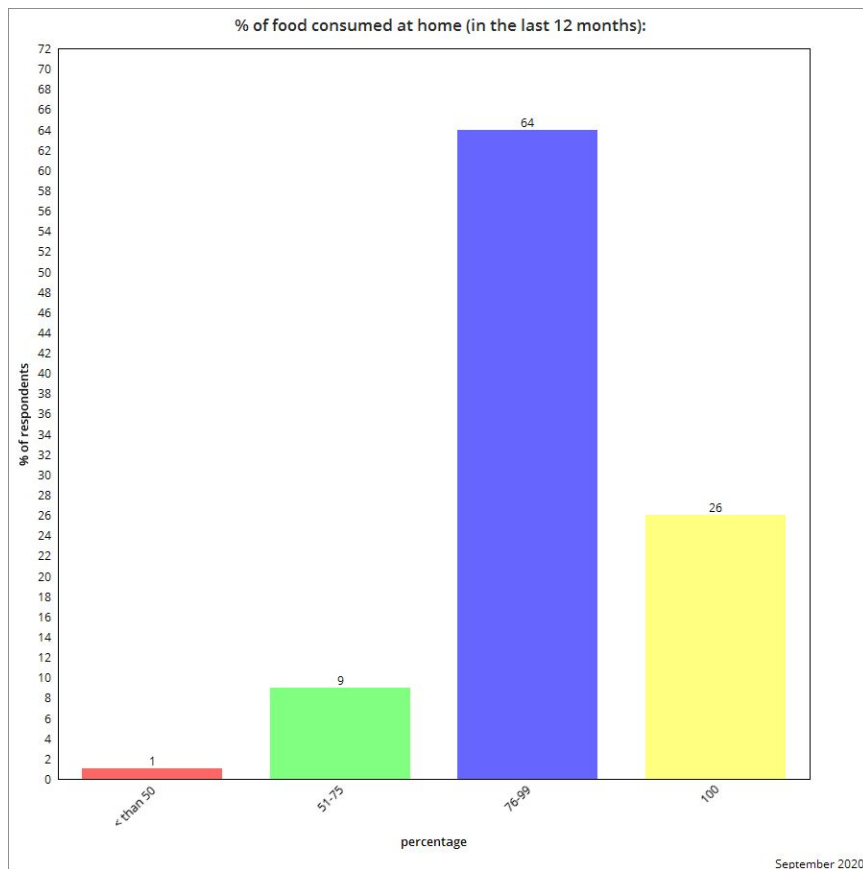
### ***Have the SCDers used supplemental tests?***

Nearly half (46%) recorded not using any alternative testing. A quarter (26%) have taken food allergy tests, 20% food intolerance tests and 15% IgG. About a fifth (18%) have done DNA sequencing; 9% have done genetic testing through 23andMe and another 9% unspecified genetic testing. Thirteen percent have been tested for parasites. Nine percent have had fecal fat testing. (See chart 31)

## SCD Life

### ***Do SCDers have guidance and support?***

Twenty five percent say their doctors or naturopaths are taking an active role in their care with the SCD. Fourteen percent see a nutritionist (cite chart 23). Twenty percent see a naturopath. Twelve percent report seeing a psychologist, therapist psychiatrist or counselor for their care (See charts 21, 22, 23 & 25). Nearly 10% report that they do not have the support of their friends and family (See chart 17). Thirty percent report they are going against medical advice by following the SCD.



### ***How much food is consumed at home?***

Nearly a quarter of respondents exclusively currently consume their food at home (26% cite chart 9). Sixty-four percent prepare 76-99% of their meals at home. In the last year, 28% report preparing all their food at home and 64% prepared their food at home 76-99% (See chart 10).

### ***What are the biggest challenges to implementing and maintaining SCD?***

Over half (54%) have challenges finding ready made foods and half (51%) report have challenges when they travel. Another half (49%) report social gatherings to be a significant challenge. Other challenges recorded are; trouble finding a variety of foods to eat (31%), lack of medical support (22%), emotional wellbeing (18%), peer pressure (12%), employment/career (12%), school and inability to afford food (11% each). (See chart 33)

Nearly a fifth (19%) cite challenges with the illegal/legal list, 17% challenges of how to follow SCD and 17% that have challenges shopping for legal foods. Twelve percent report no challenges.

### **Complications of Diagnosis**

*What complications of the disease has the SCDer experienced?*

(Only) 3% of respondents are treating an abscess (cite chart 19) and 5% are treating a fistula (cite chart 18).

*Has the SCDer required surgery to treat their diagnosis?*

Fourteen percent have required surgery to treat their disease (cite chart 20).

### **Research**

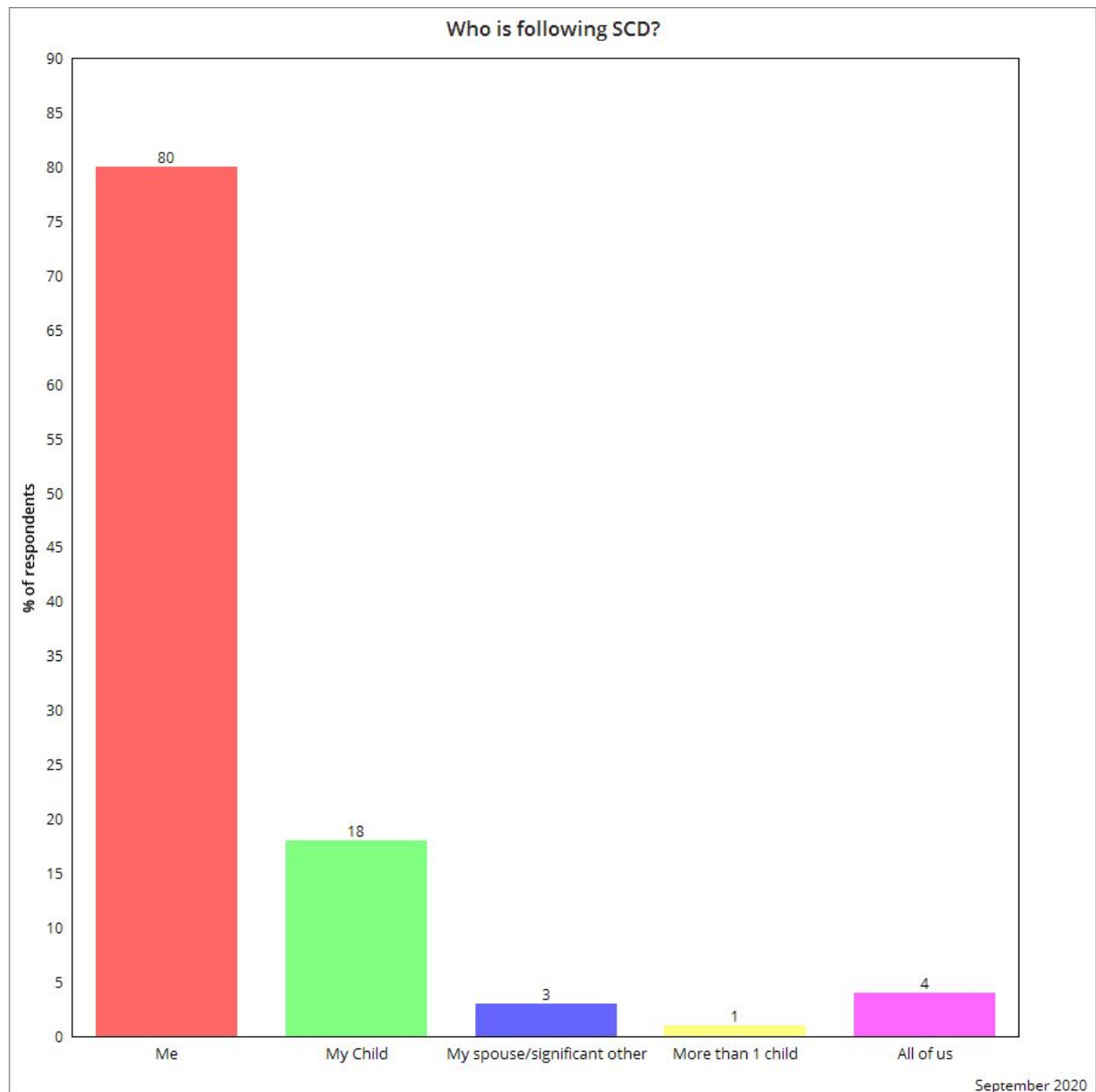
*Are you currently participating in a clinical study?*

Only 1% (cite chart 30) are participating in a clinical study.

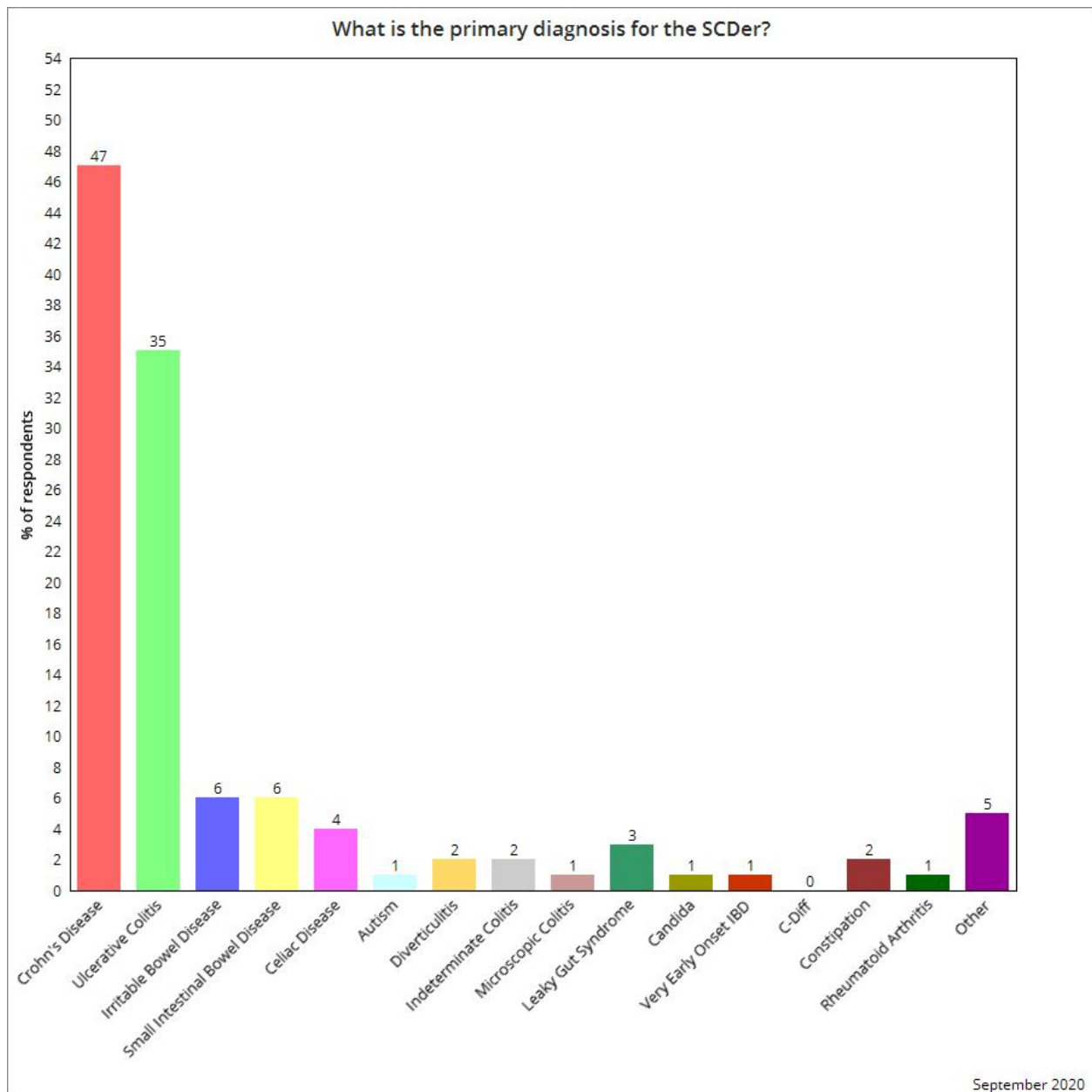
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## APPENDIX A: SURVEY RESULT CHARTS

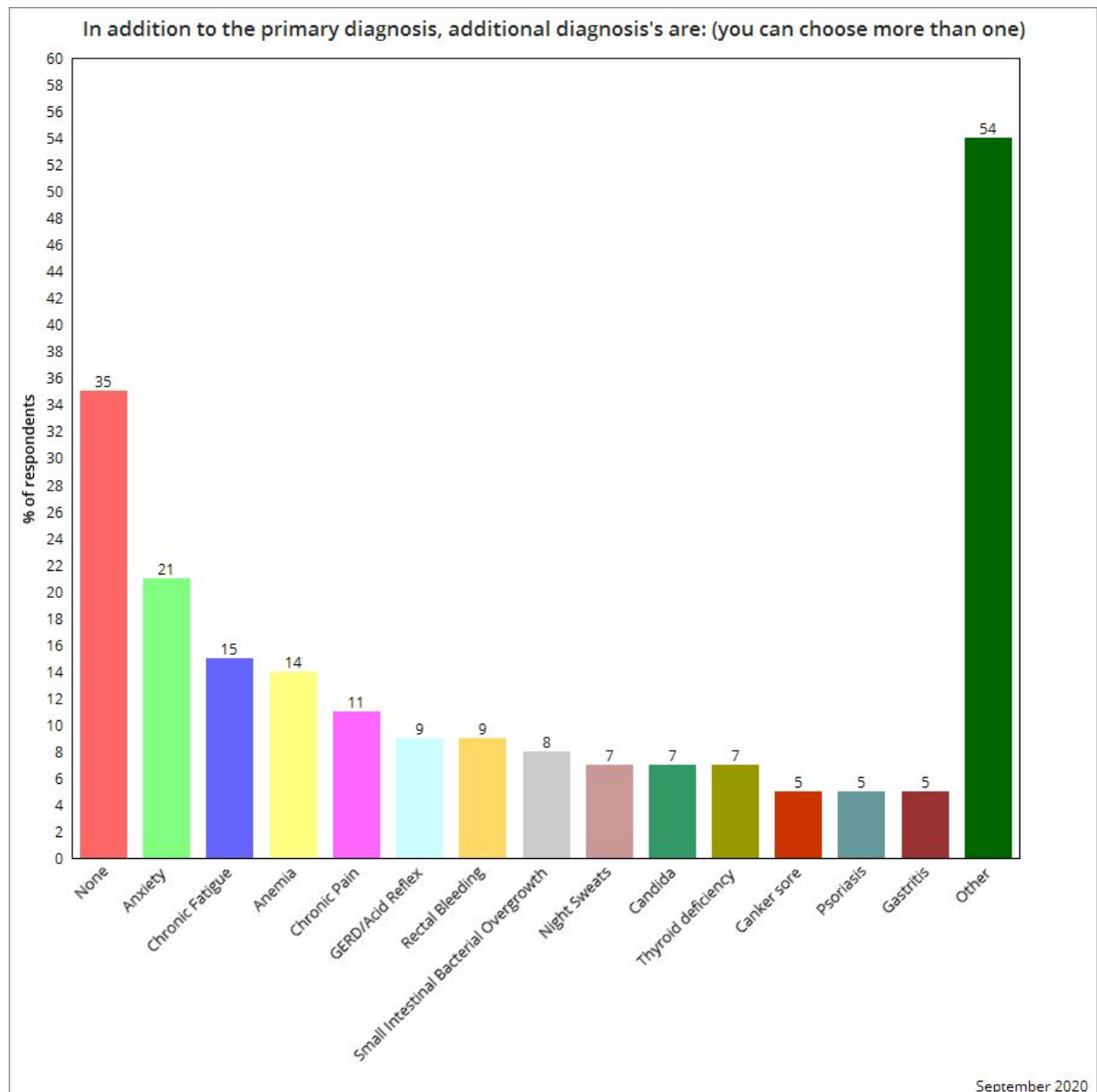
CHART 0



**CHART 1**

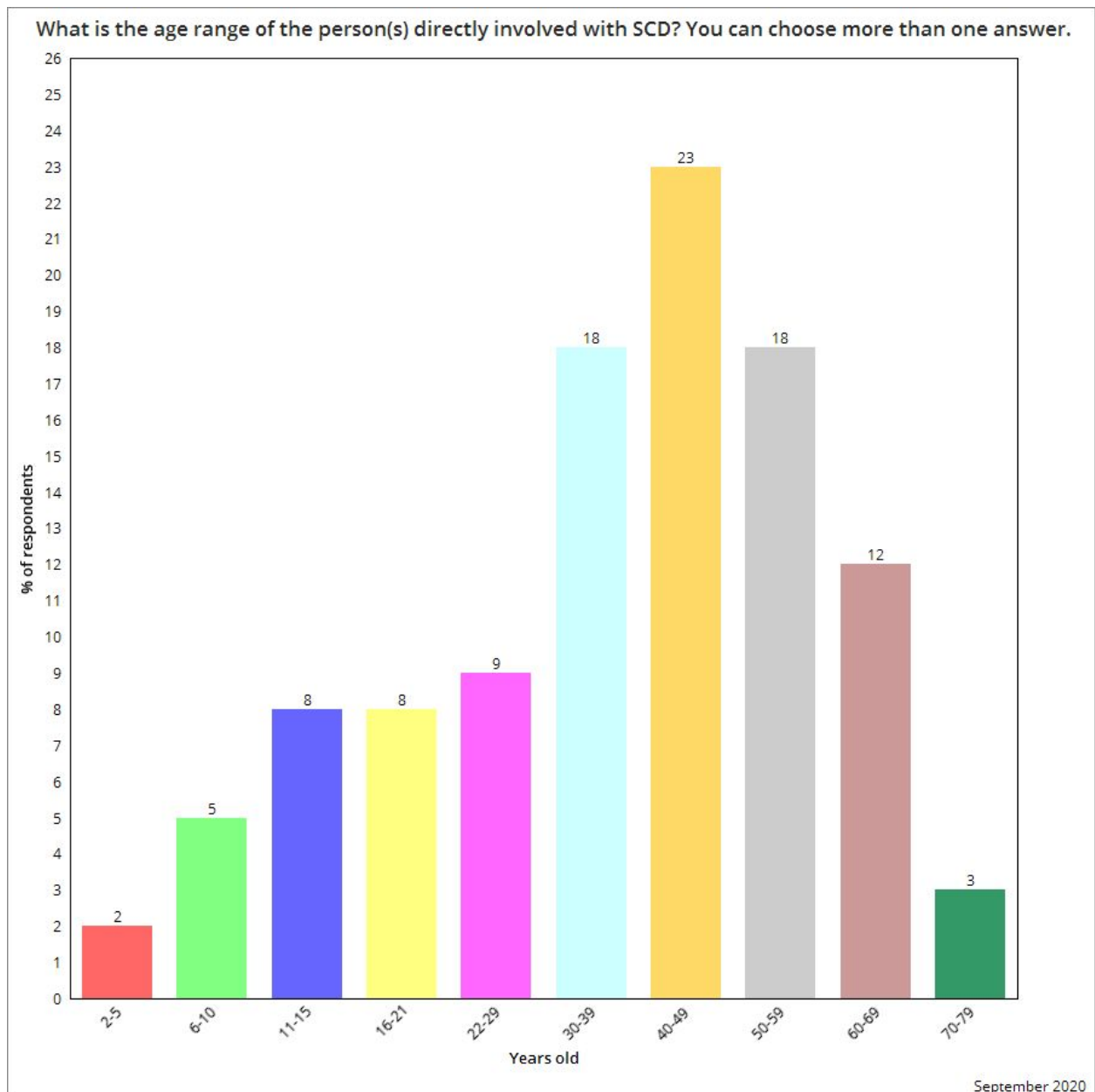


**CHART 2**

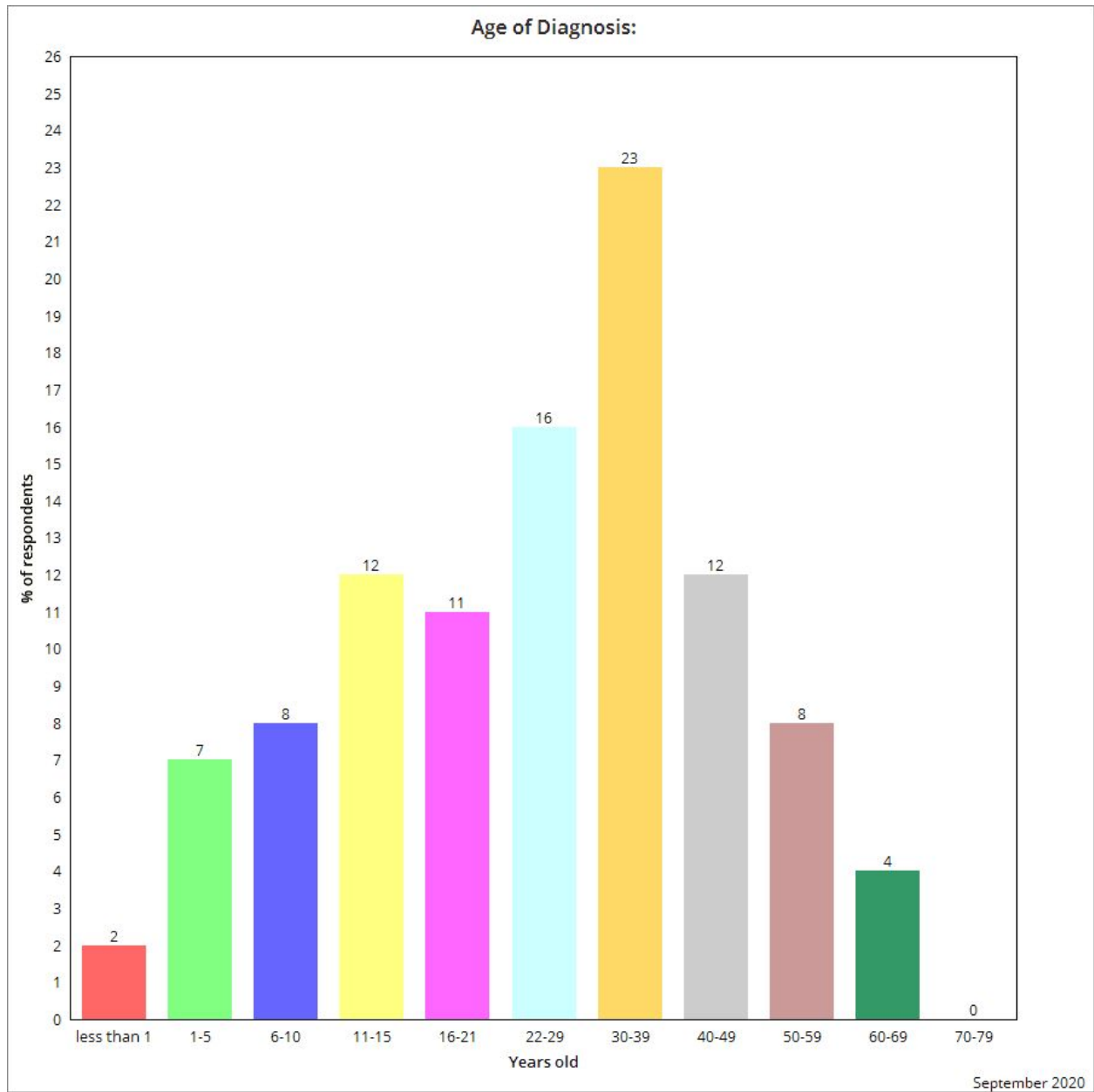




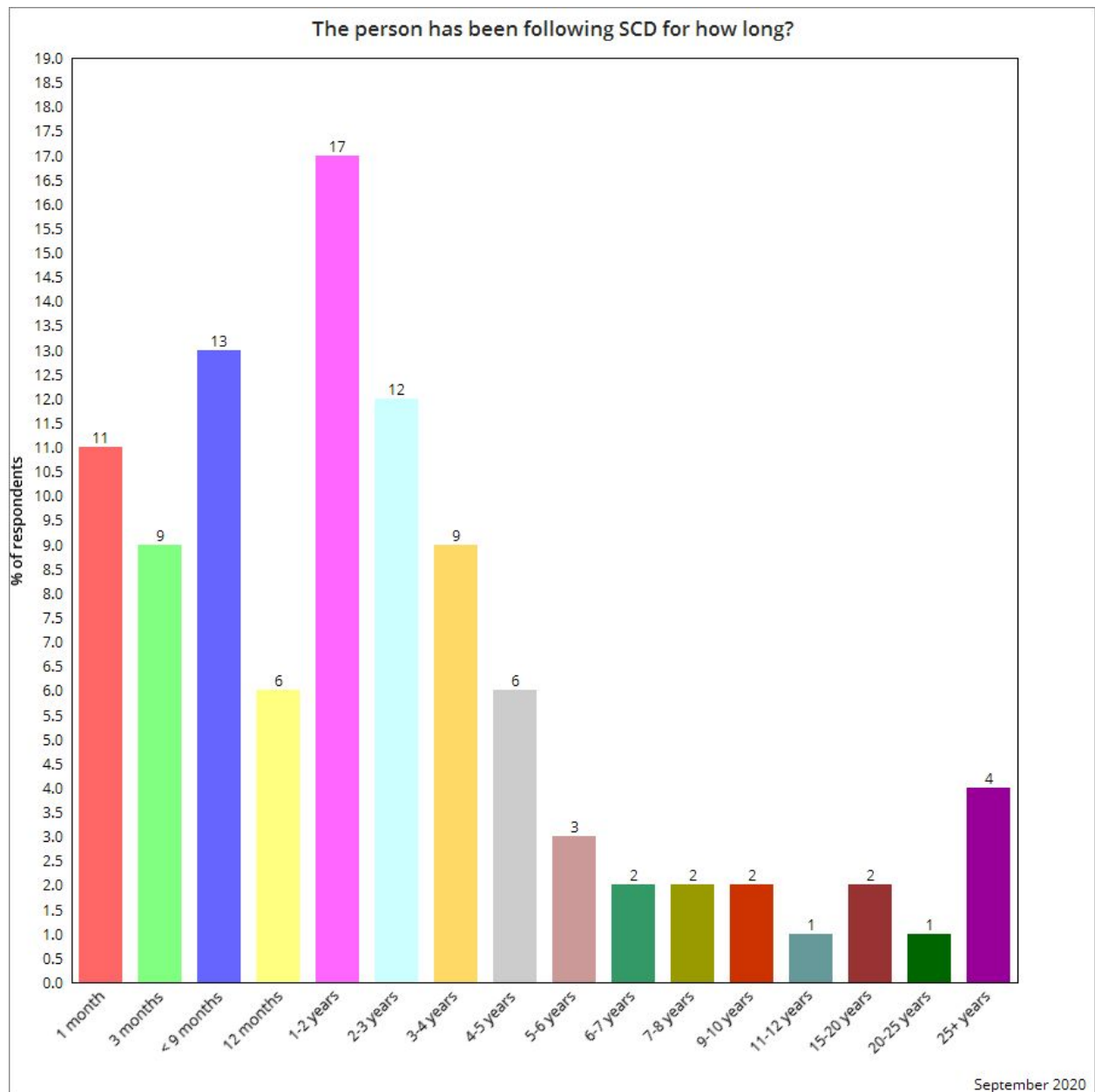
**CHART 3**



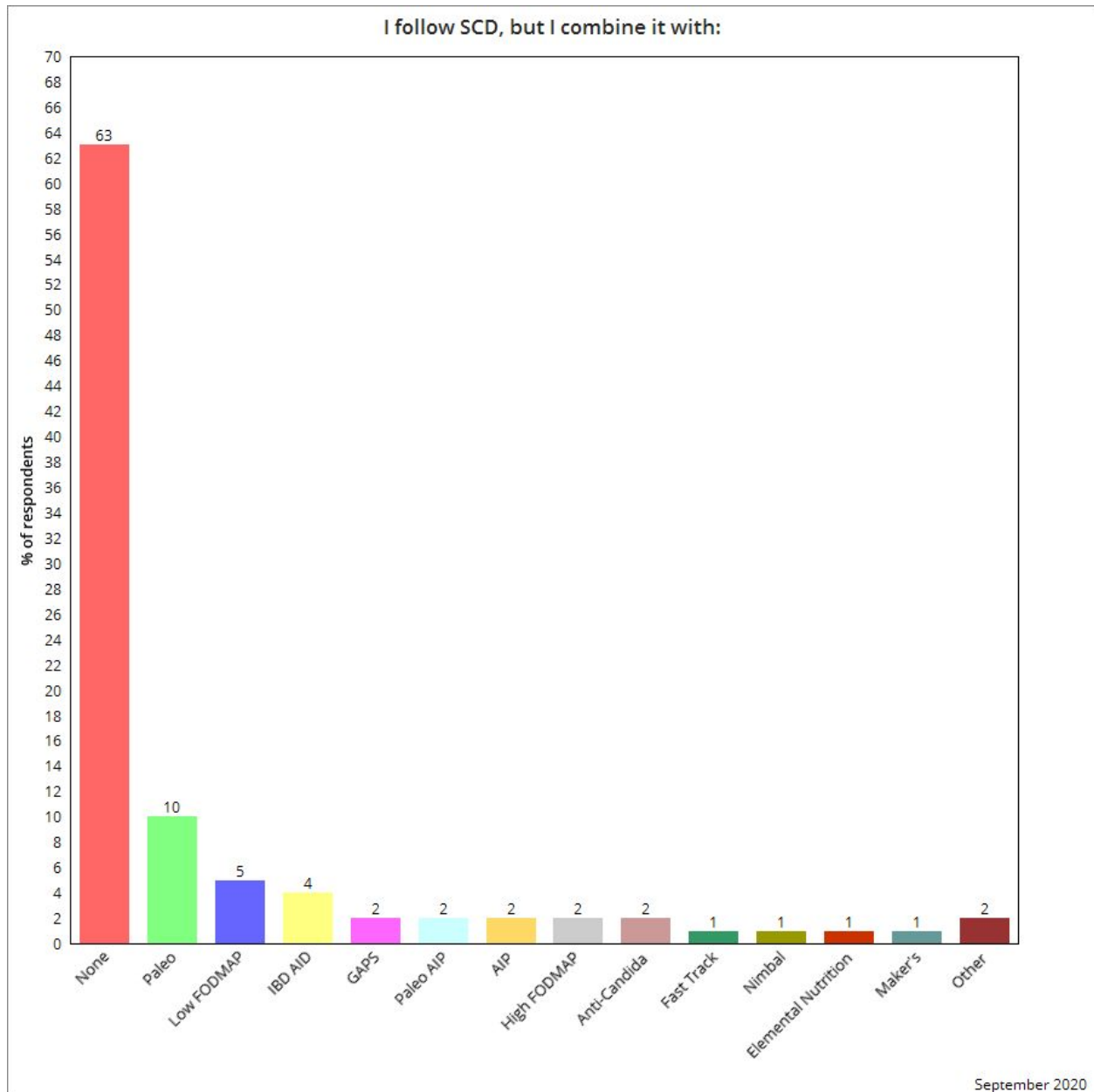
**CHART 4**



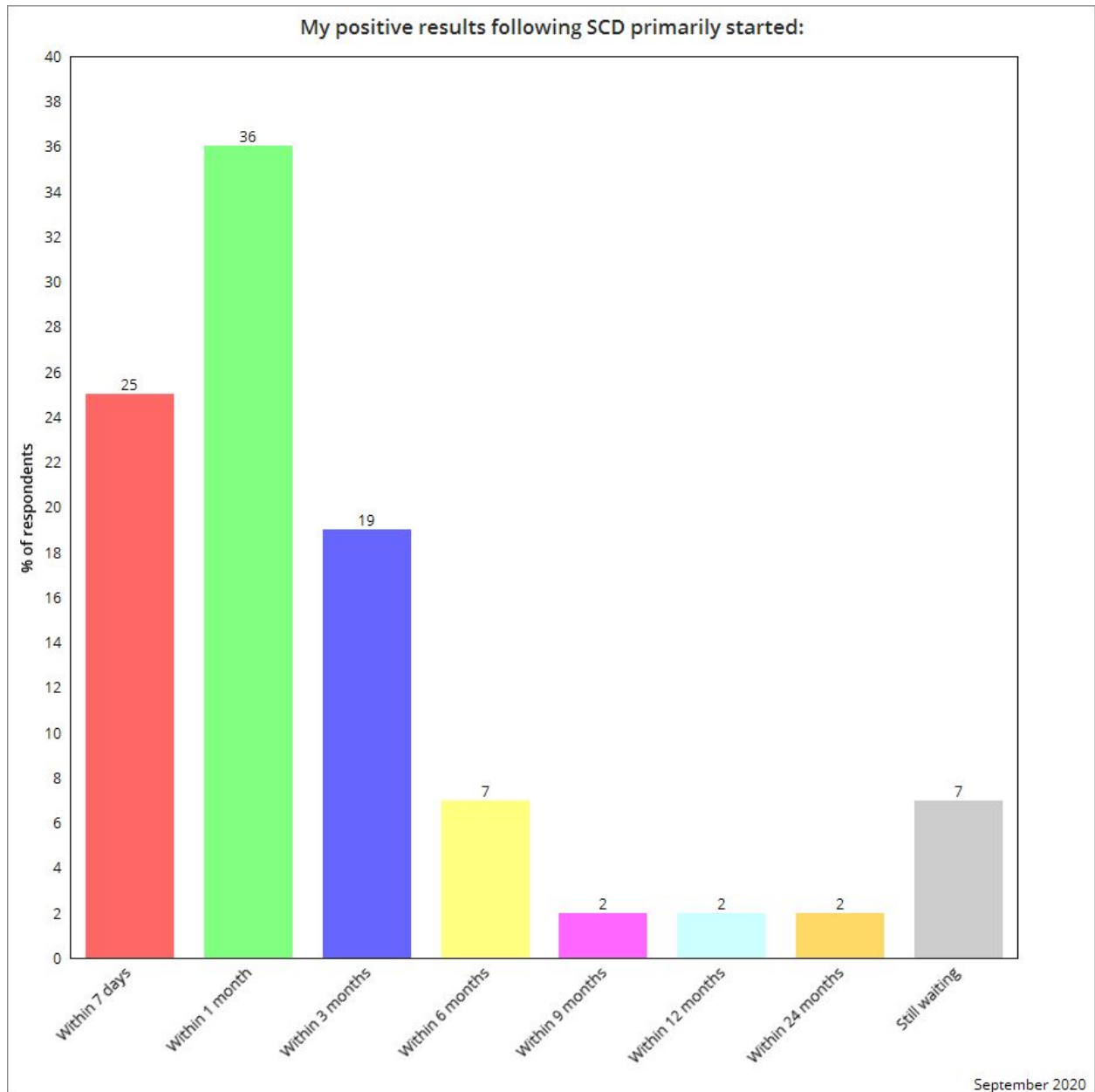
**CHART 5**



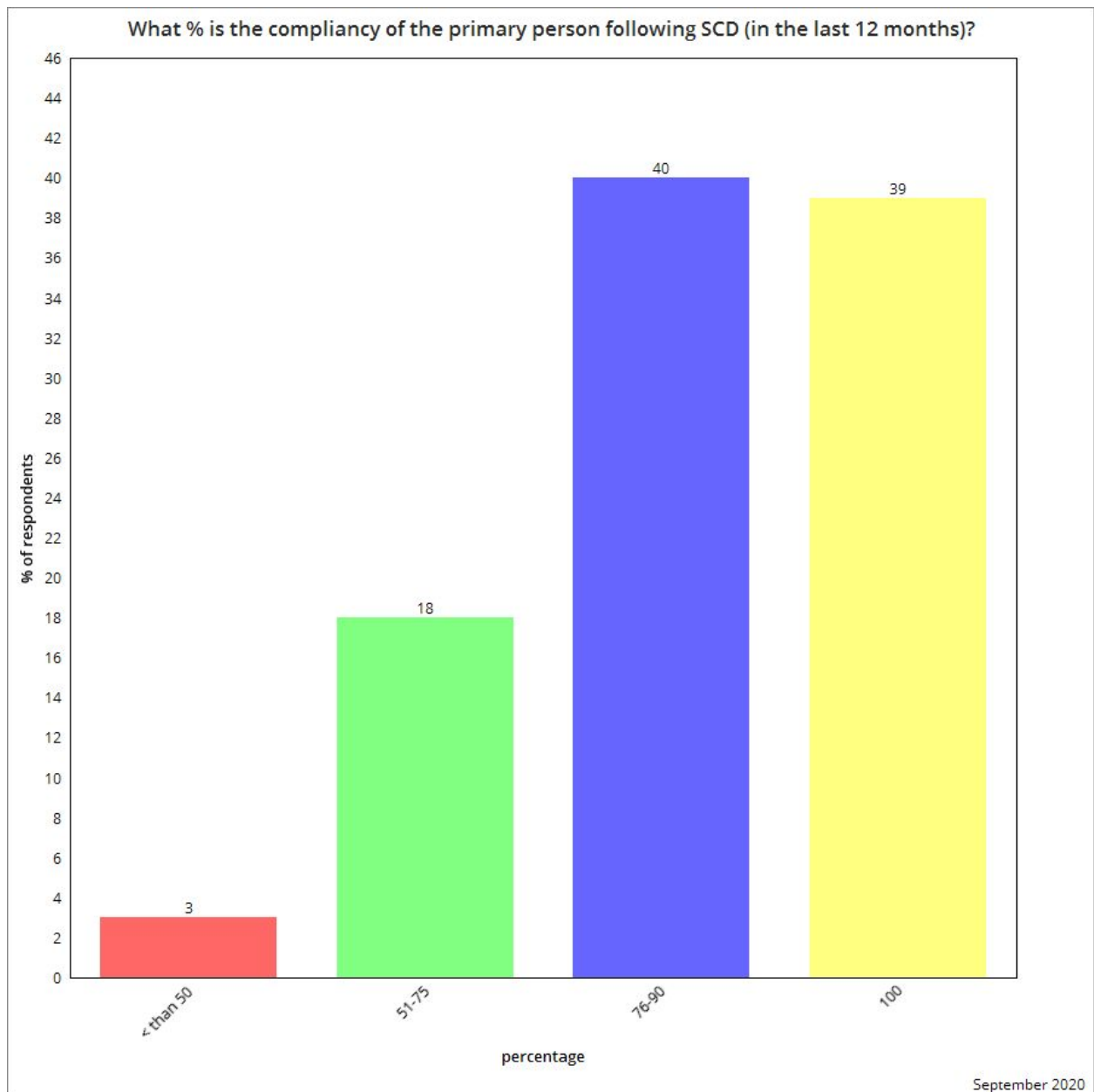
**CHART 6**



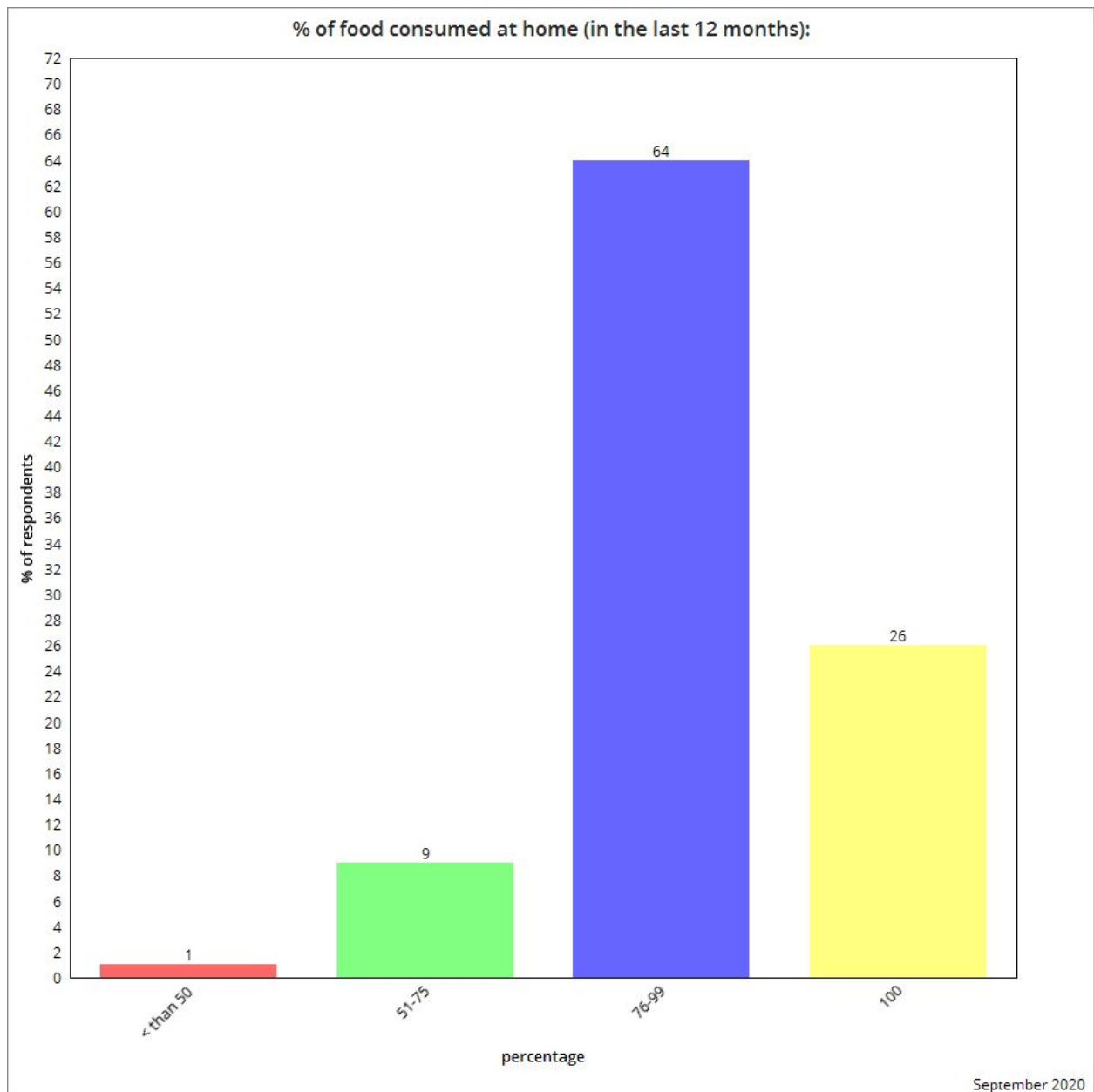
**CHART 7**



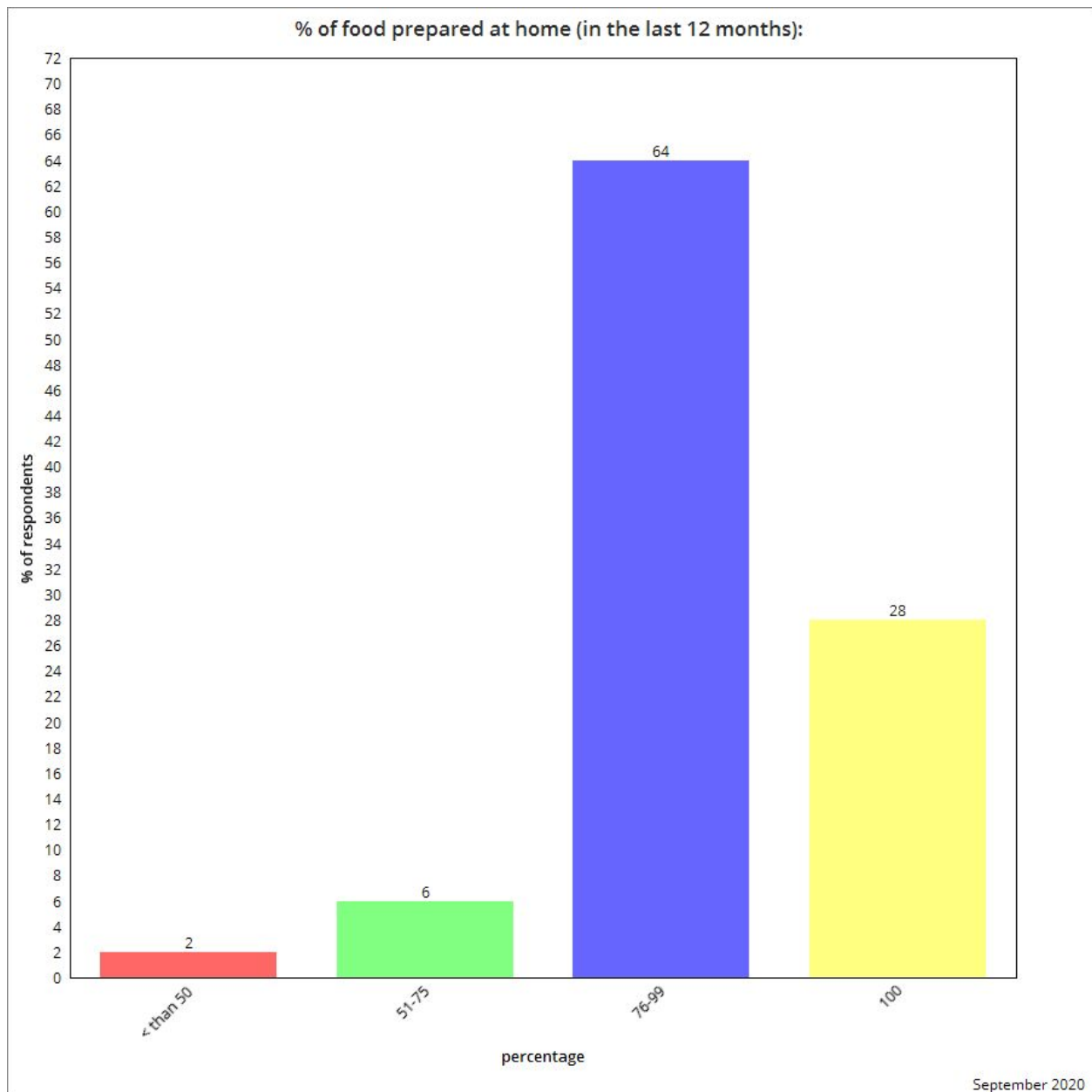
**CHART 8**



**CHART 9**

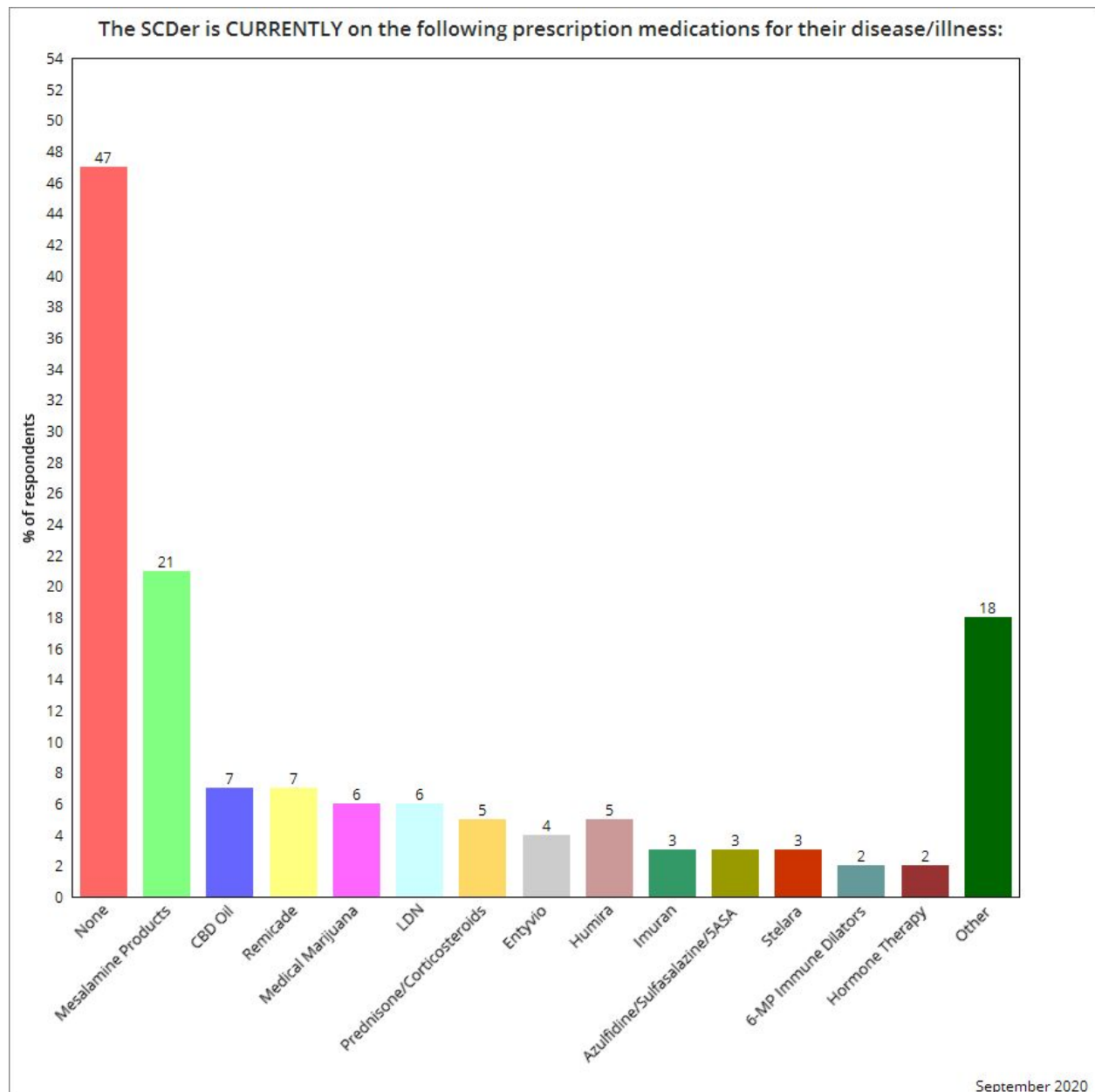


**CHART 10**

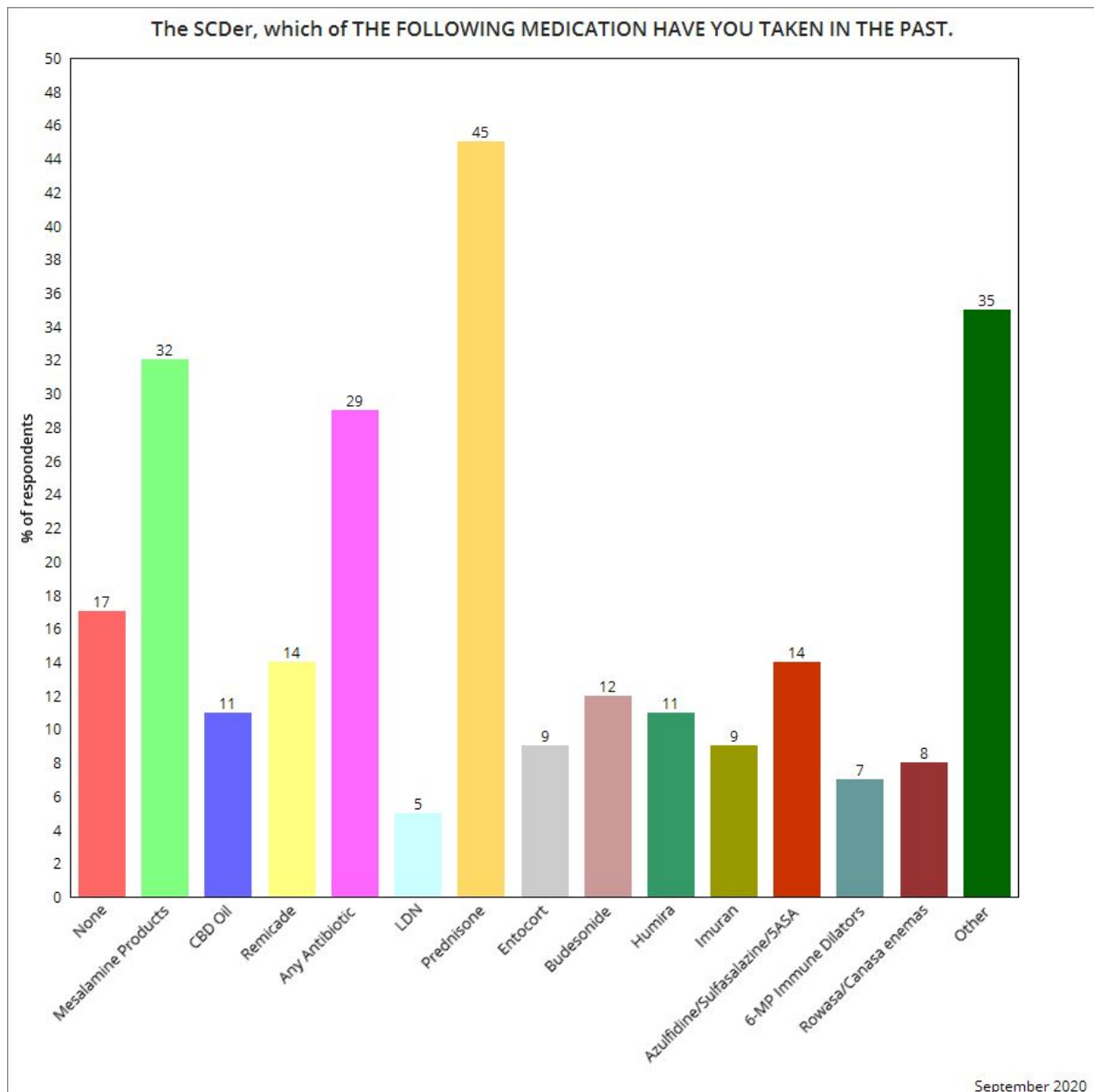




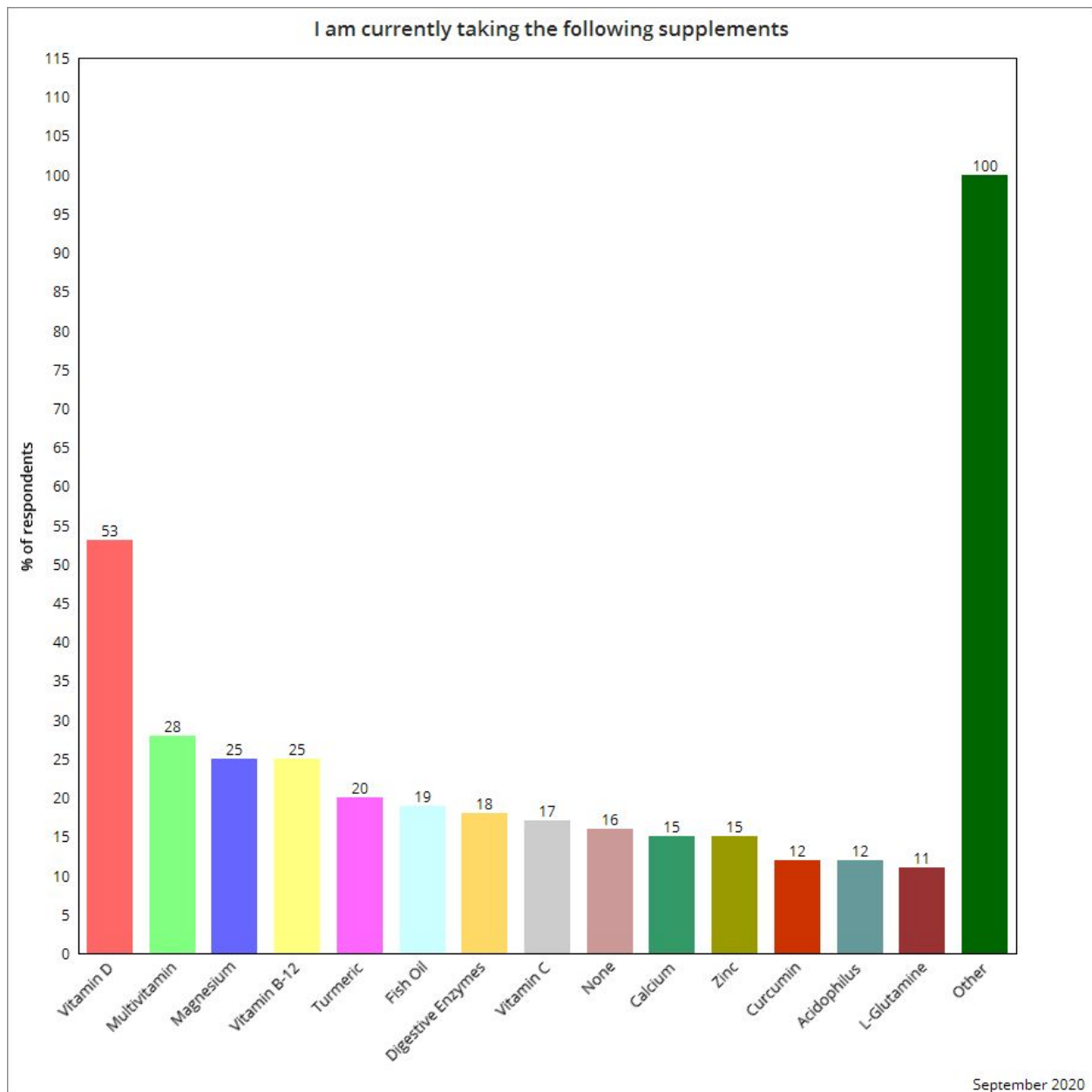
**CHART 11**



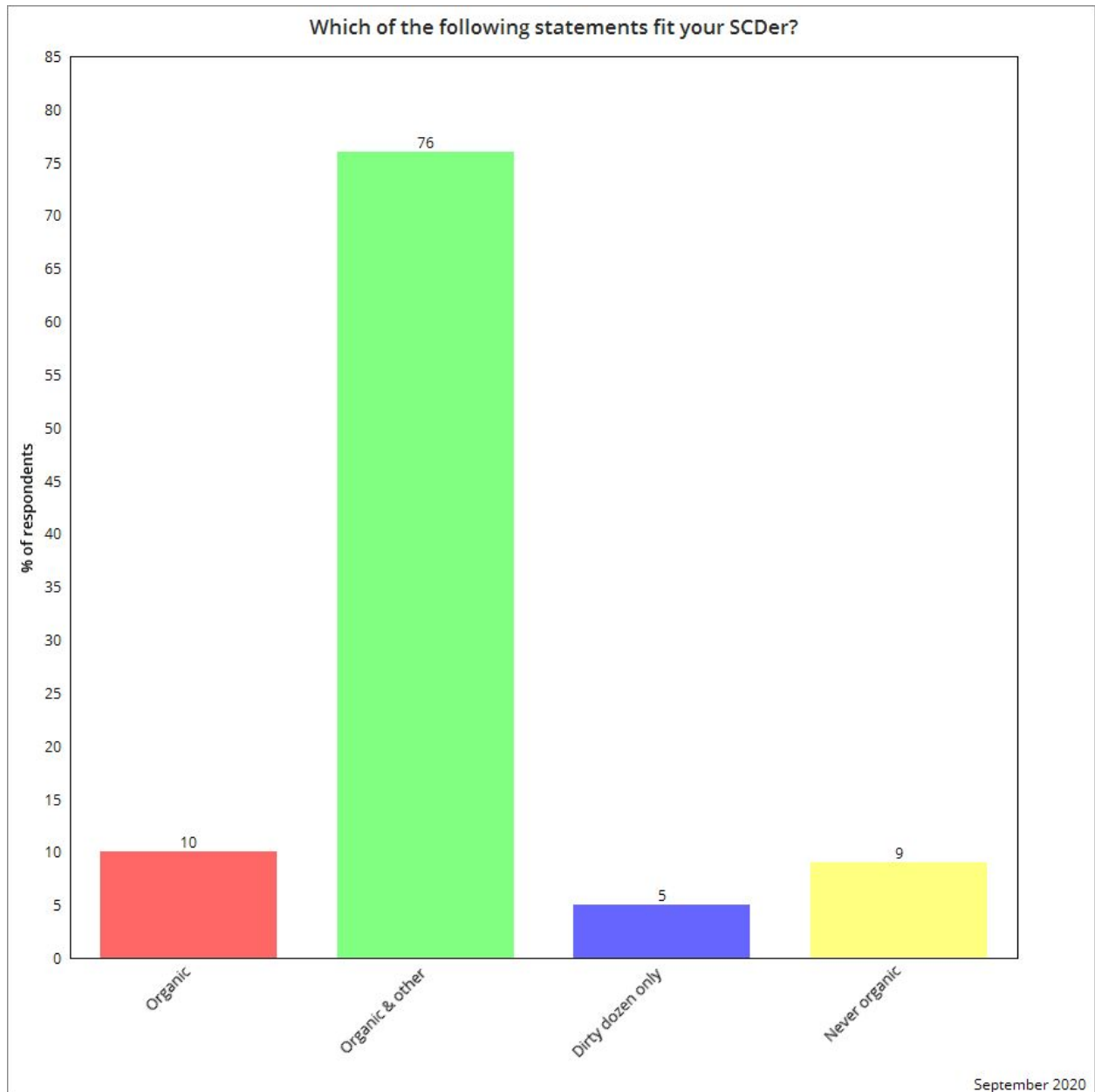
**CHART 12**



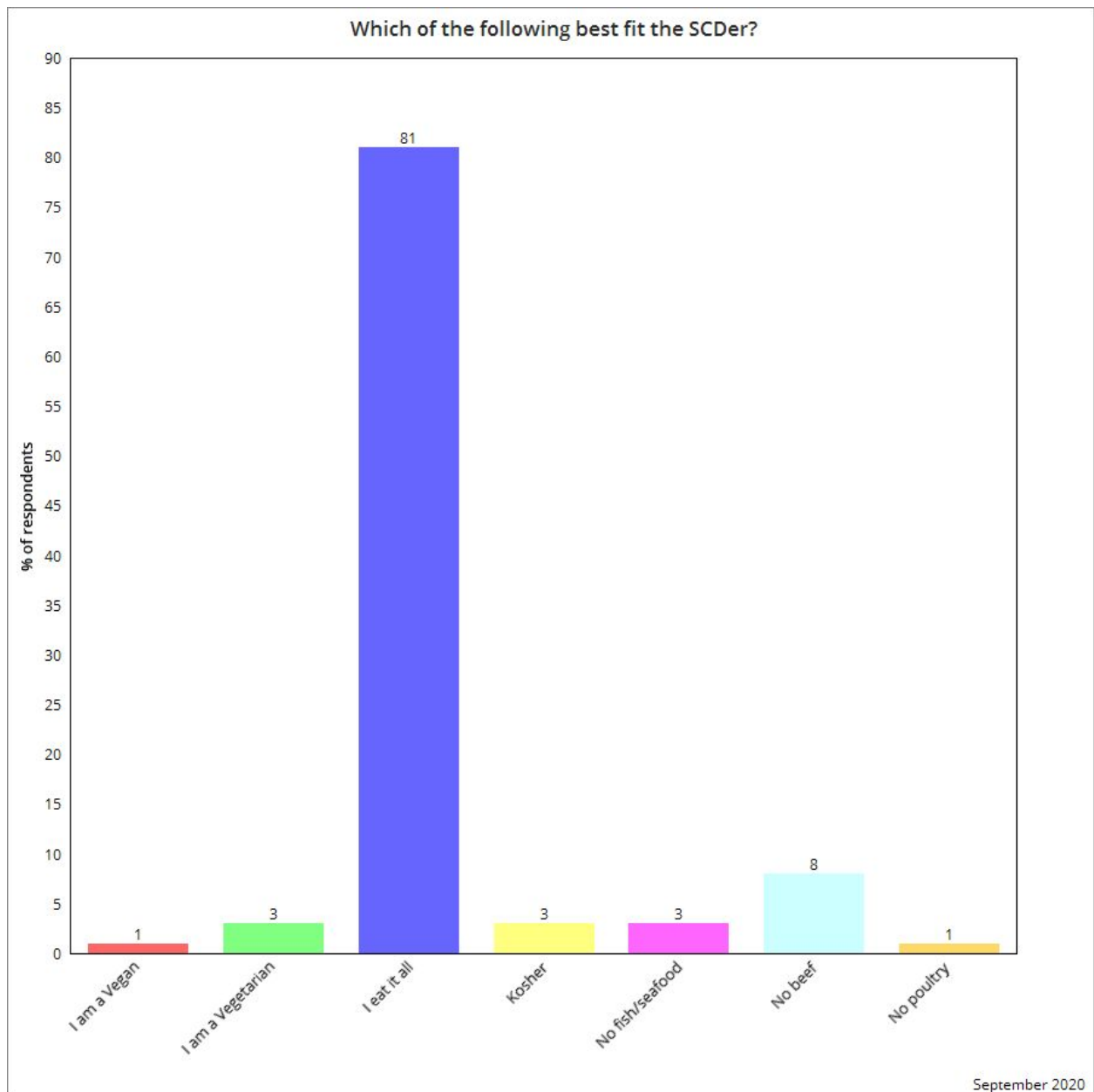
**CHART 13**



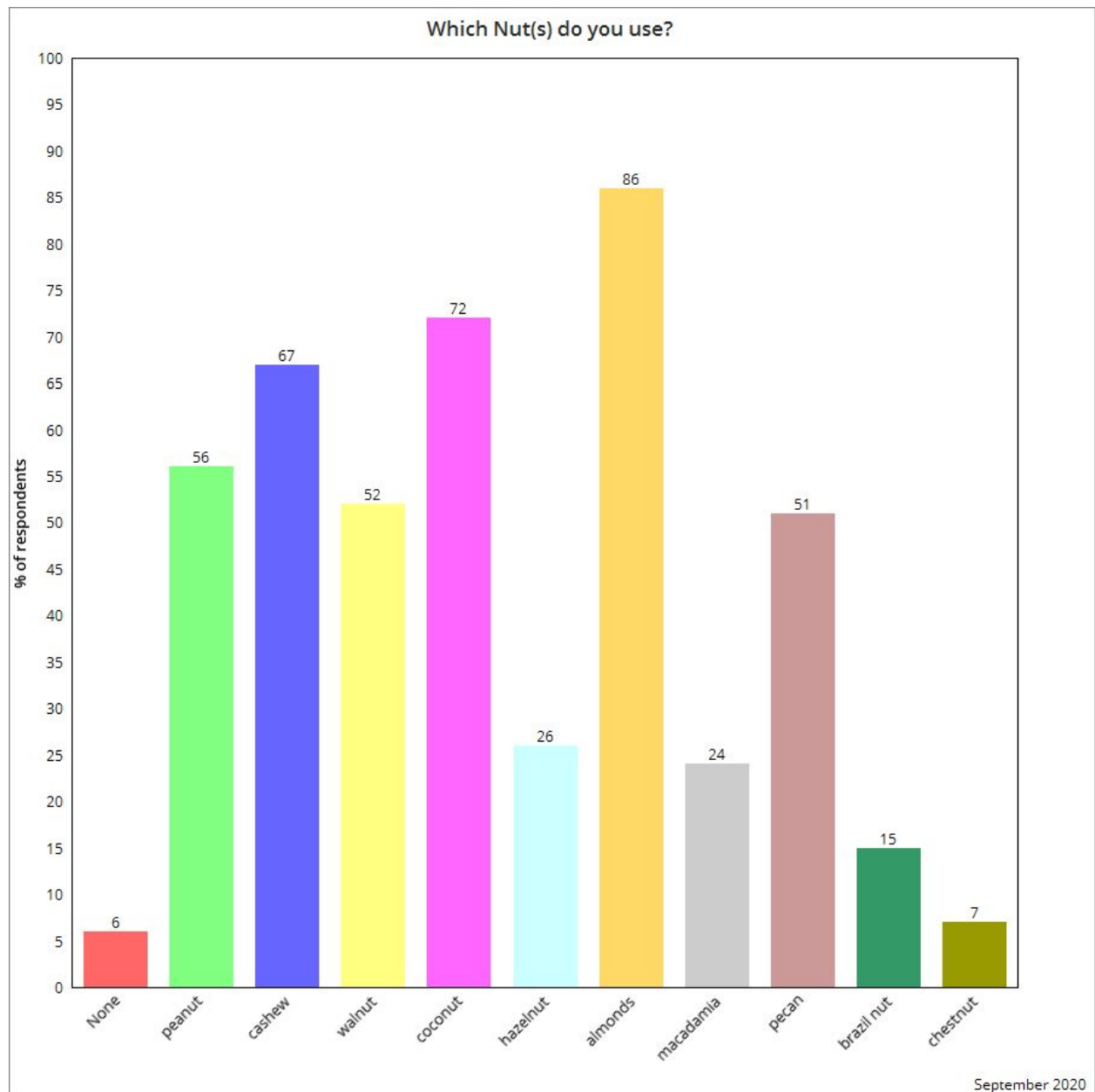
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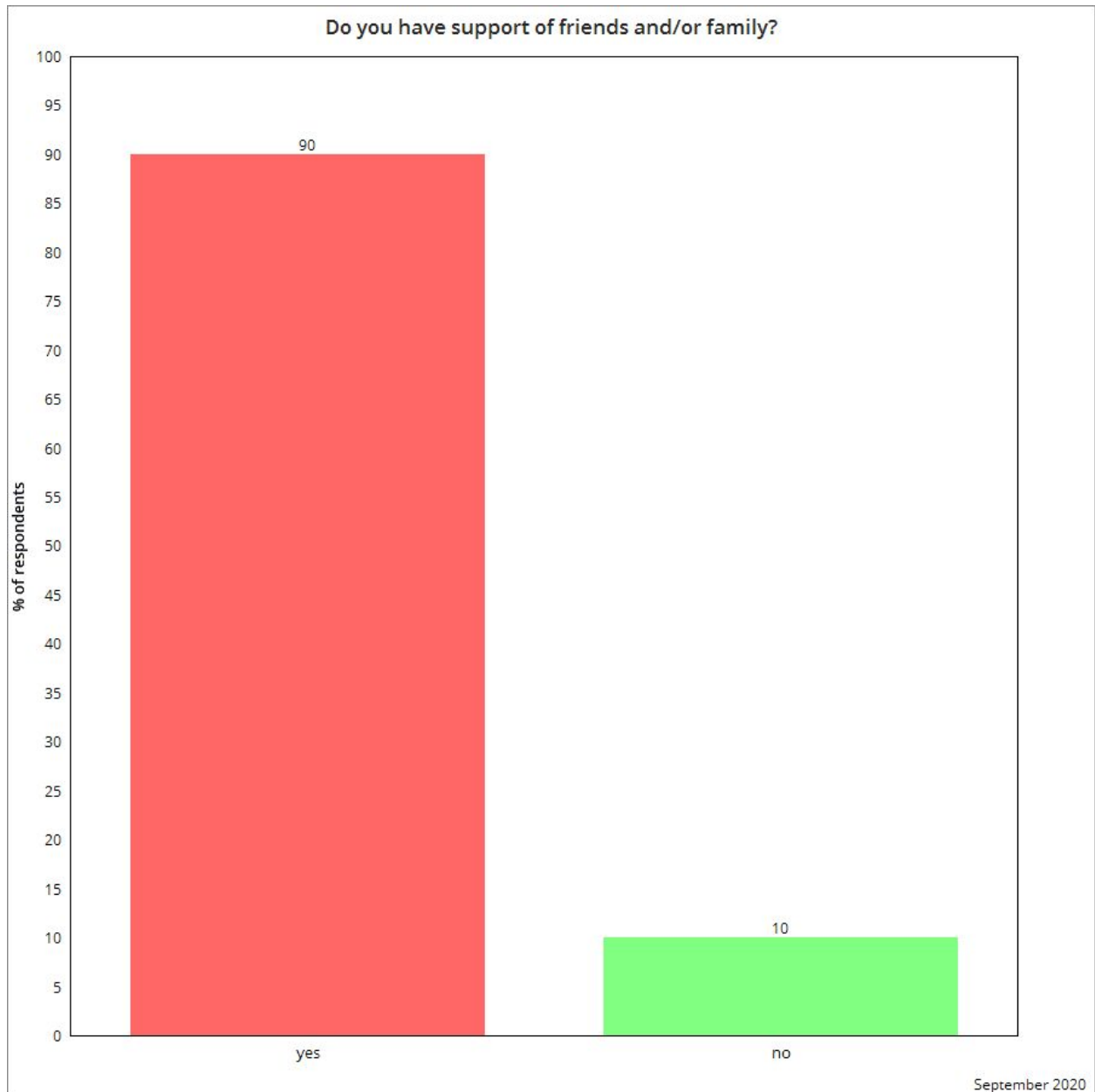
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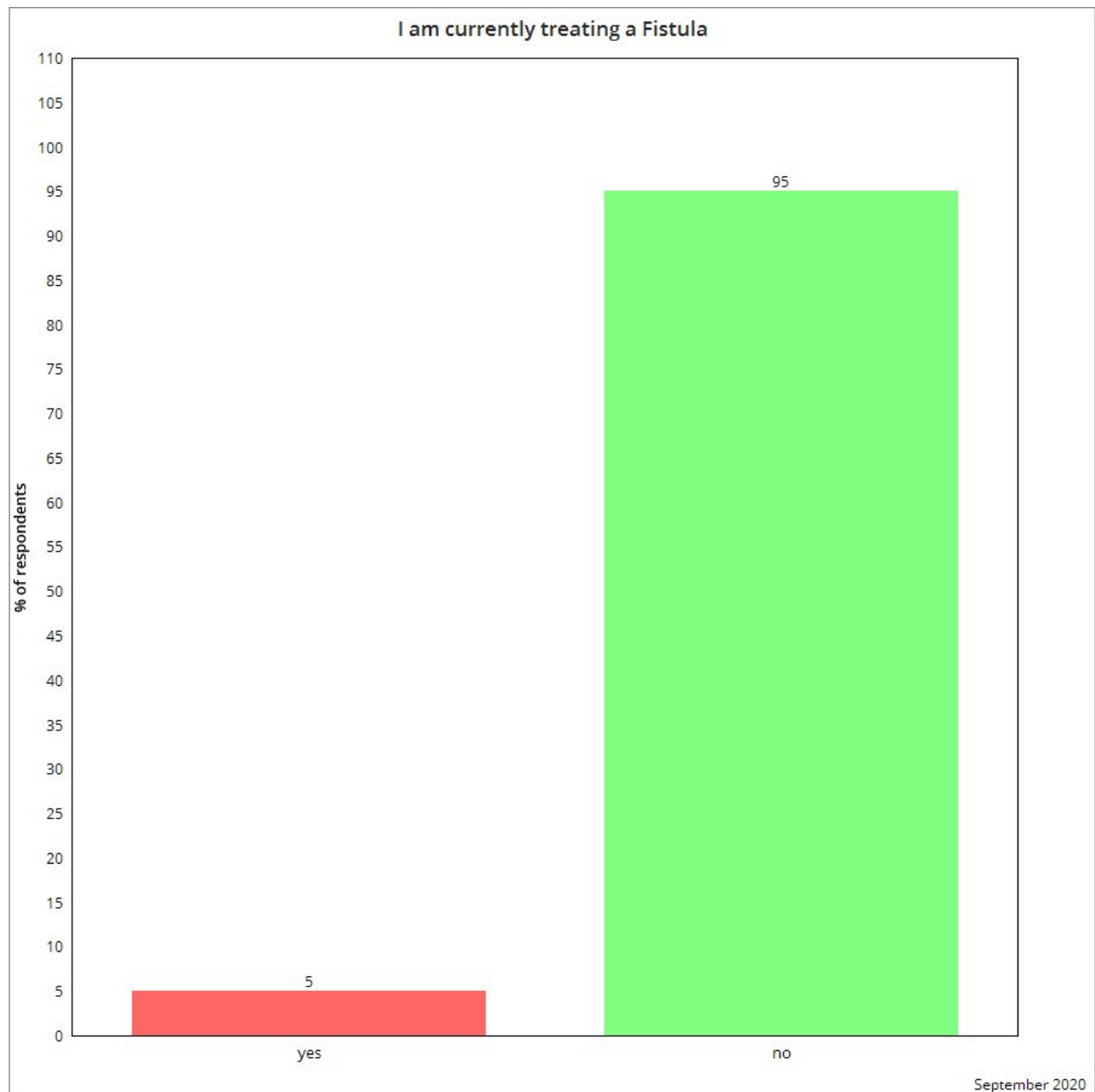
**CHART 16**



**CHART 17**

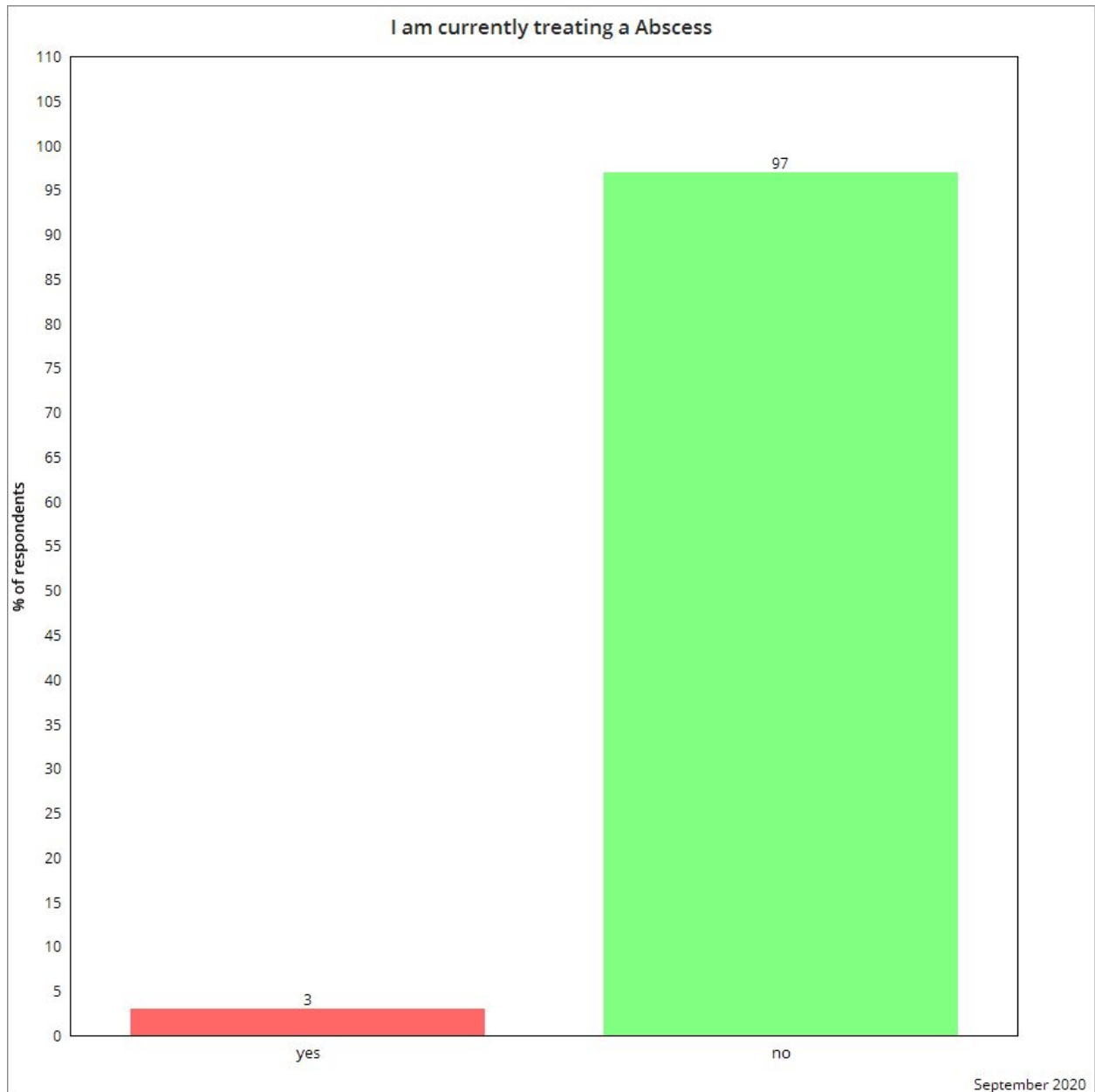


**CHART 18**

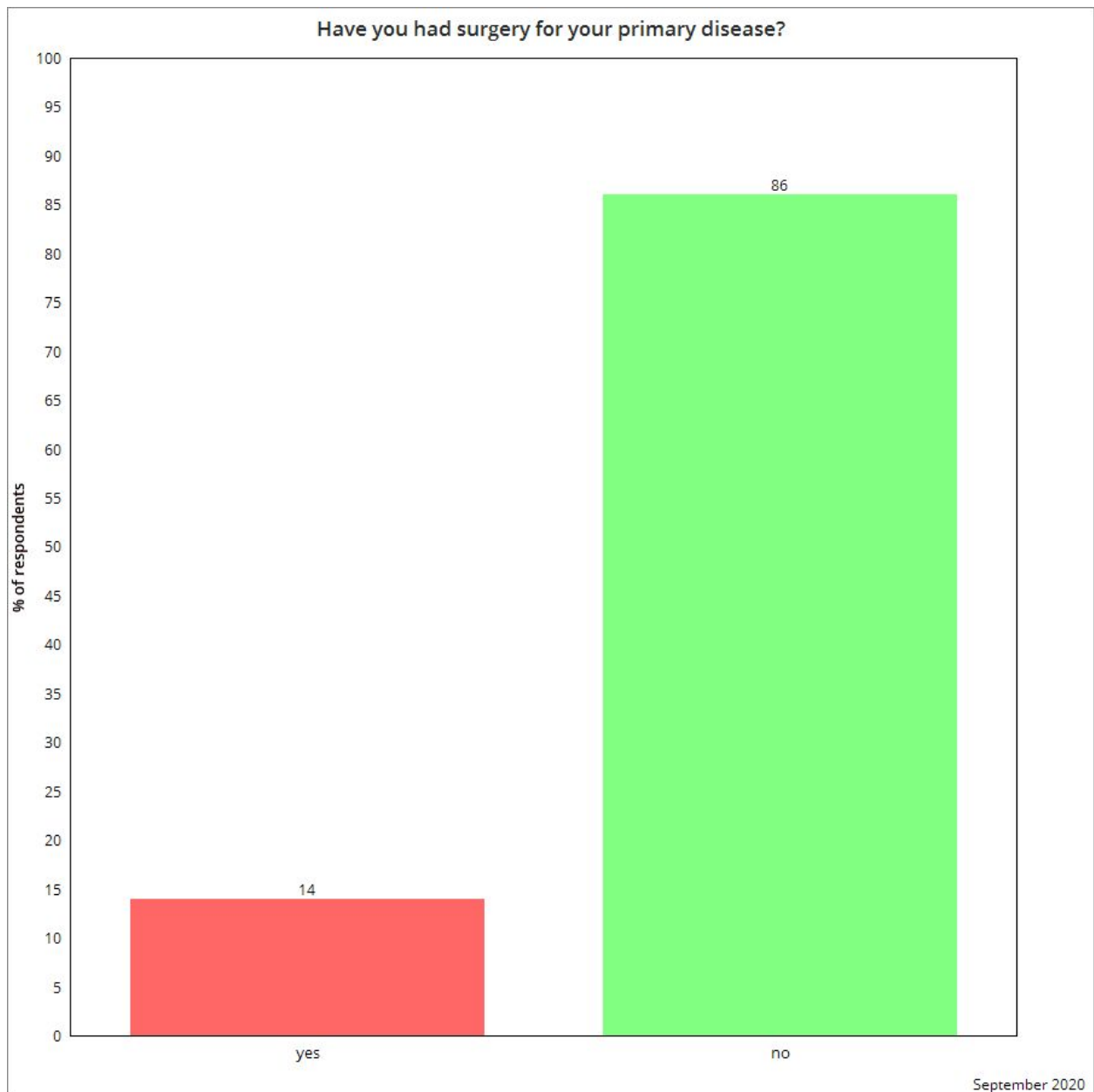




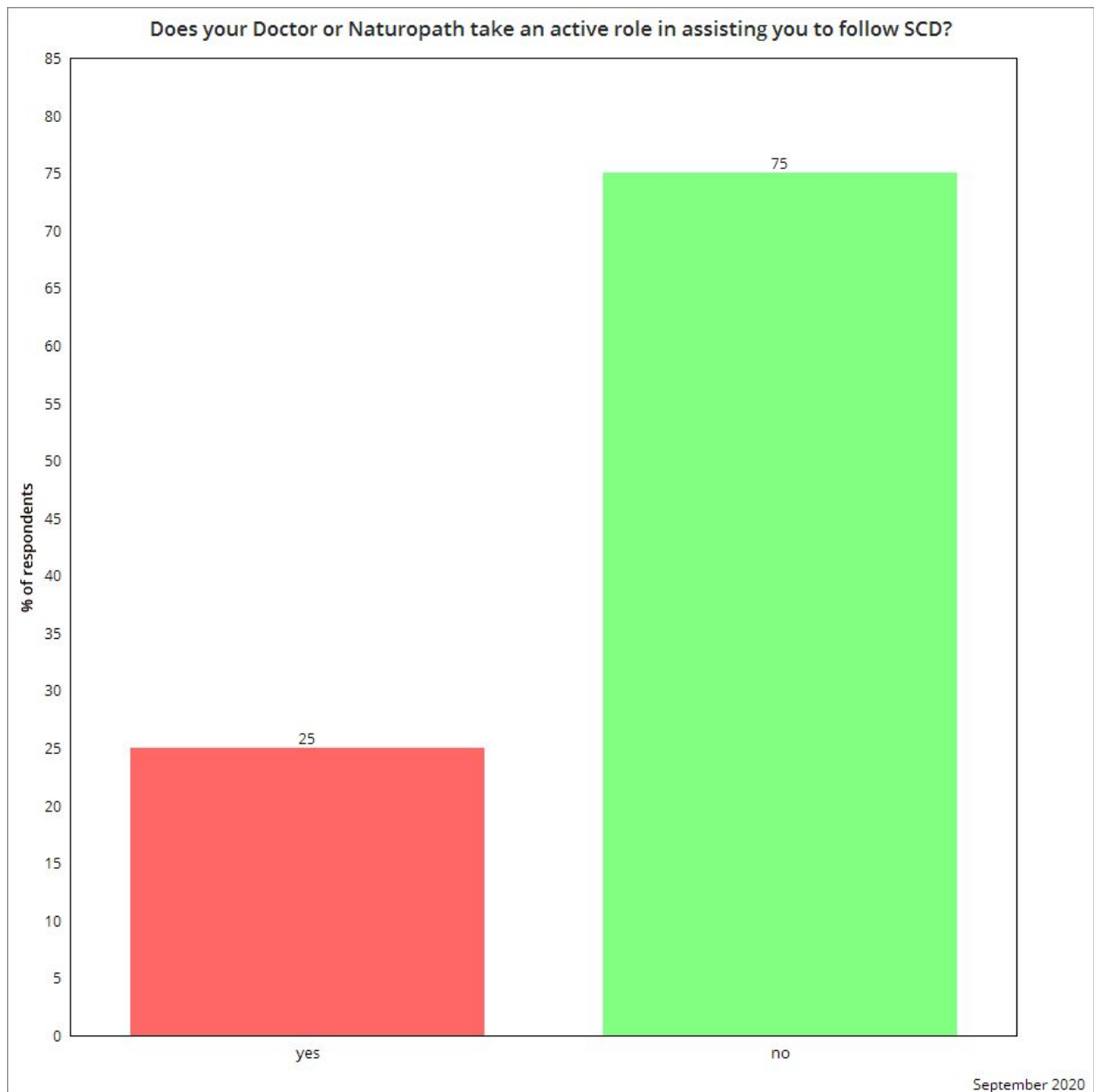
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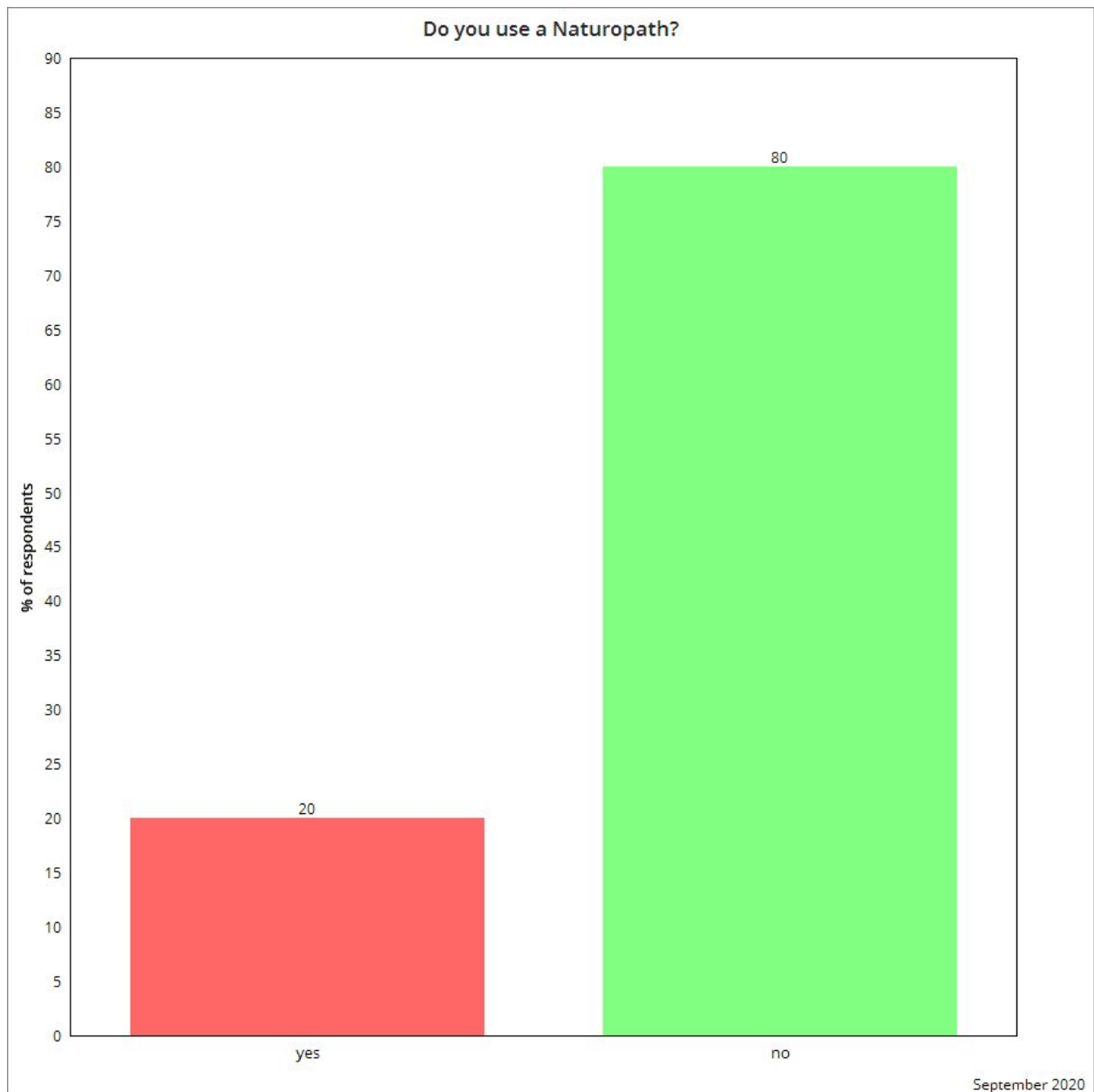
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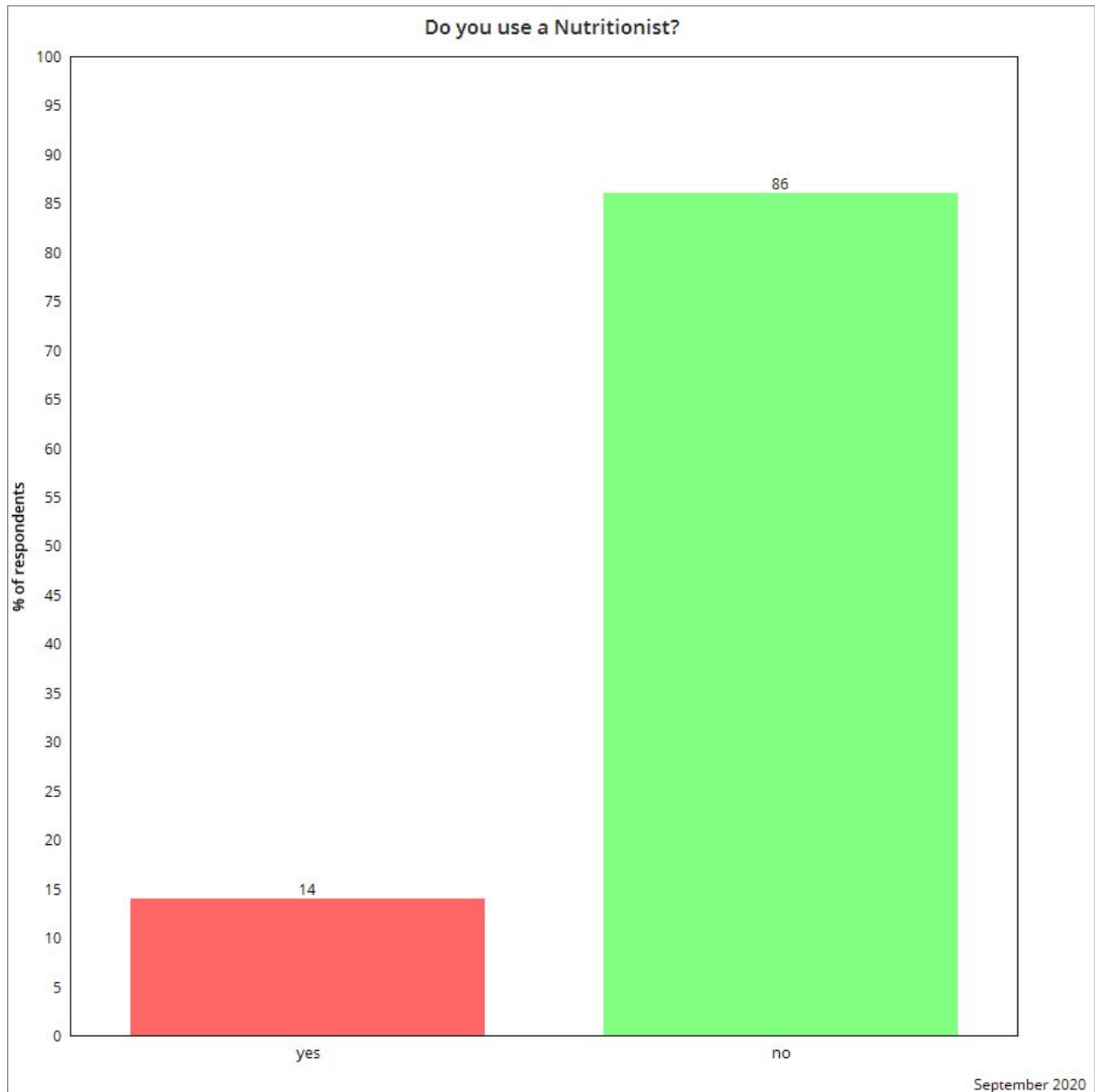
**CHART 21**



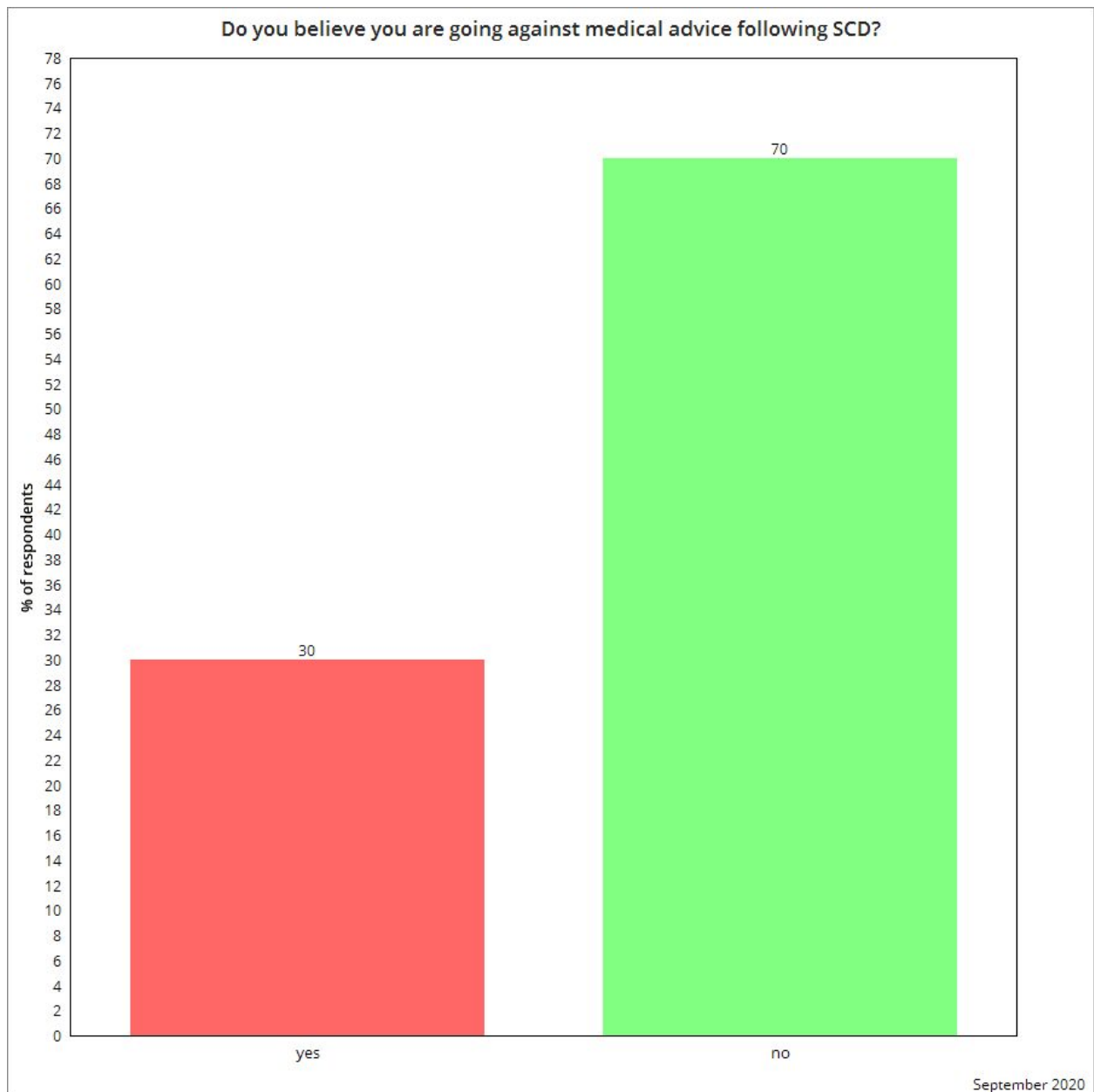
**CHART 22**



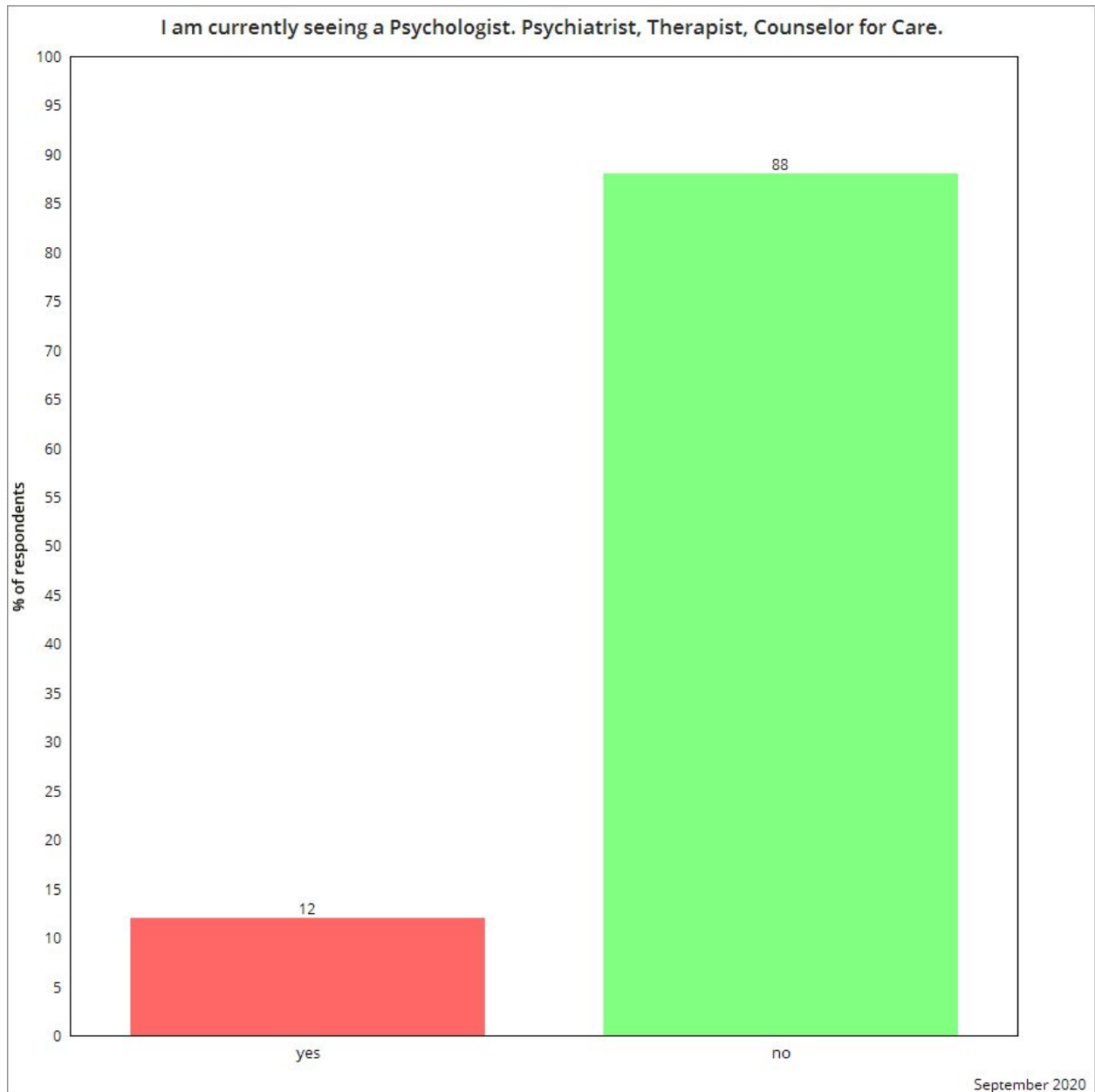
**CHART 23**



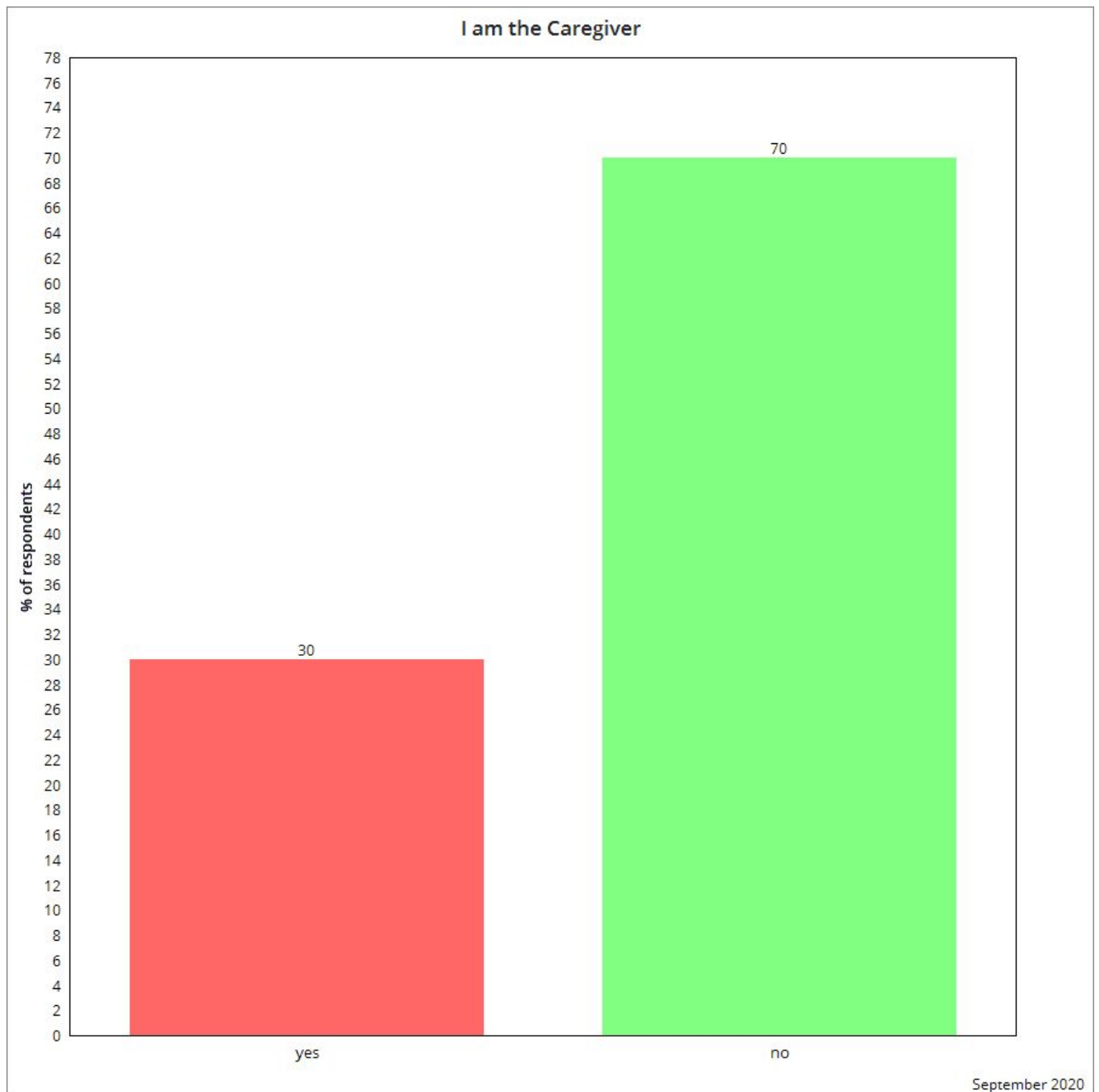
**CHART 24**



**CHART 25**

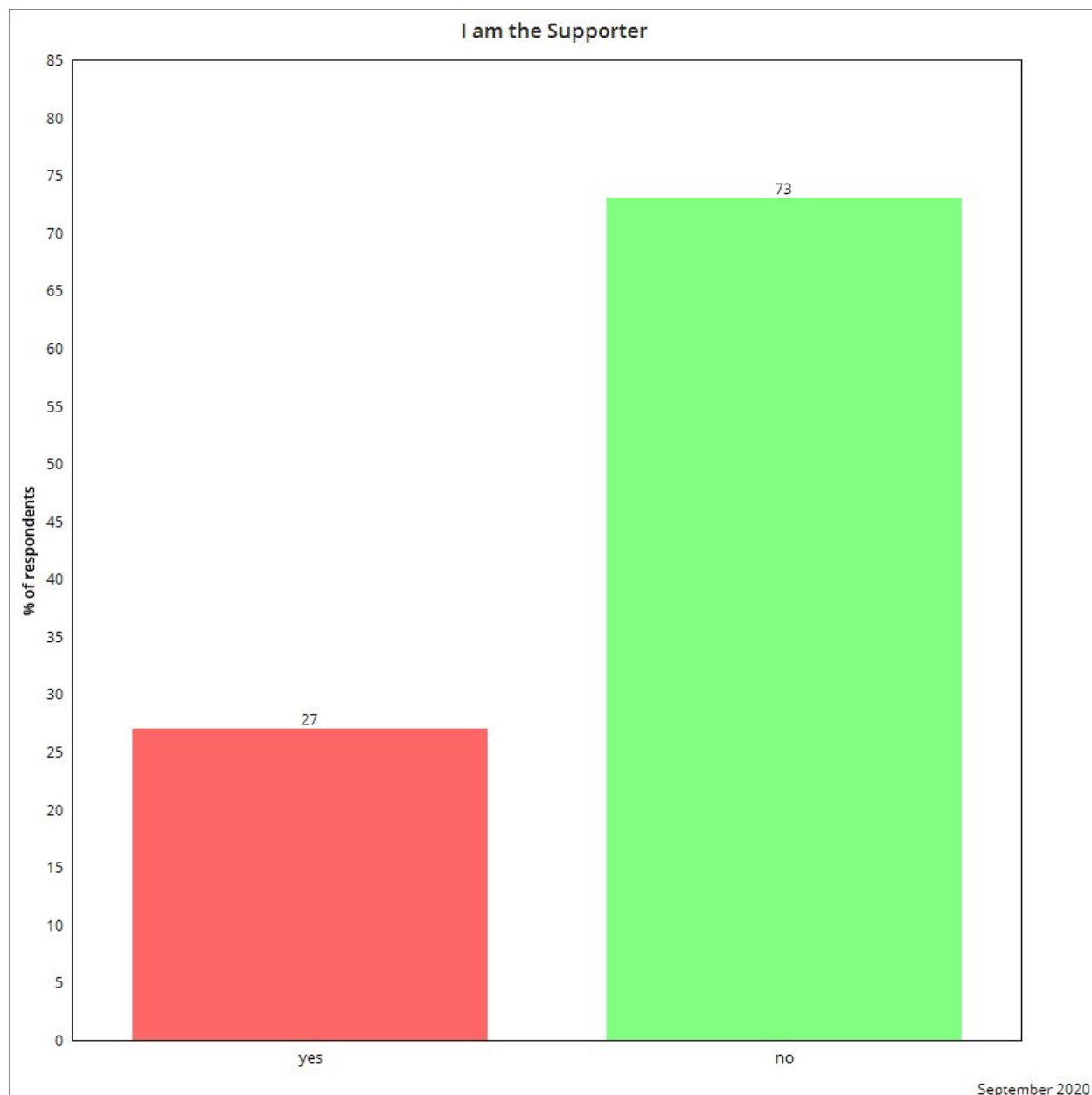


**CHART 26**

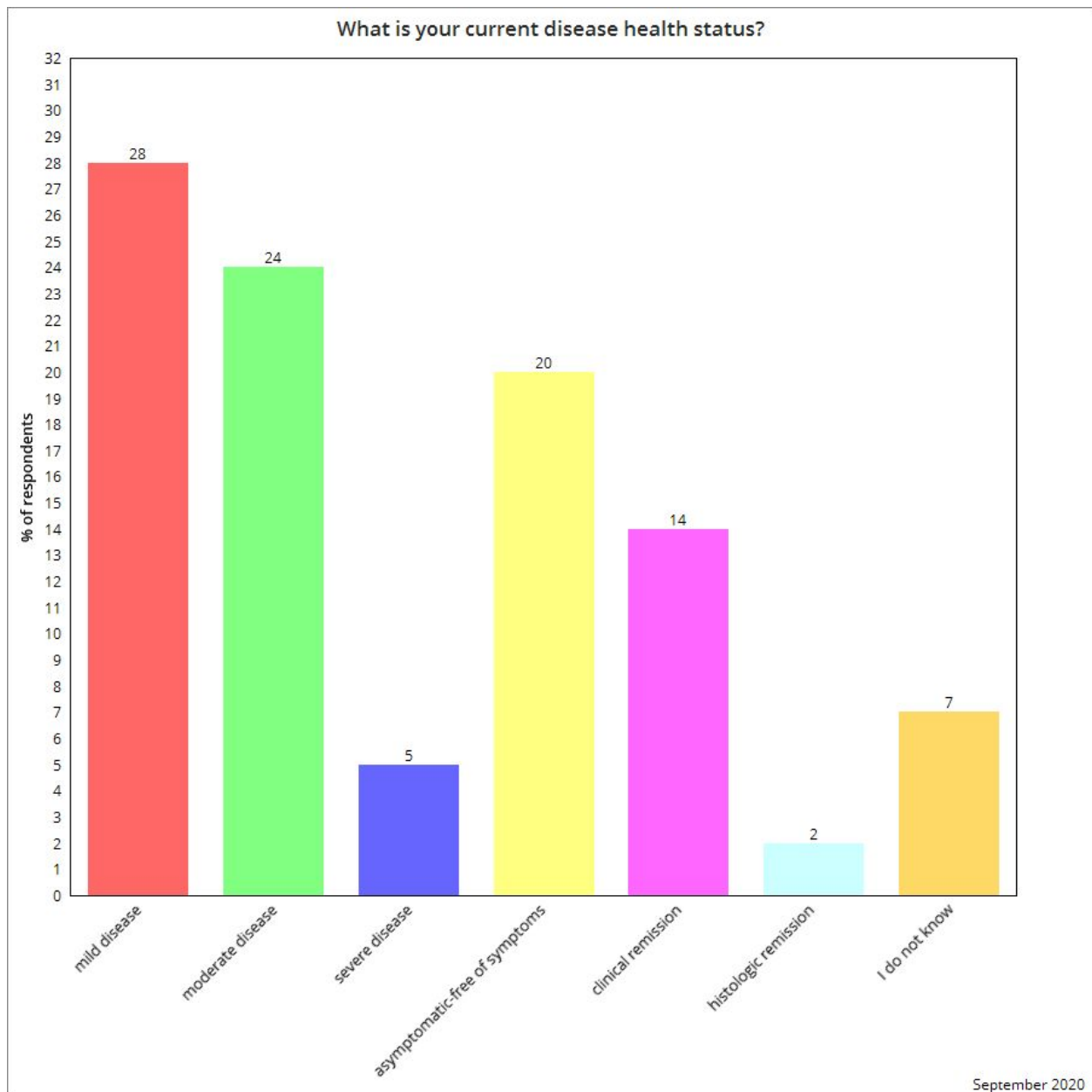




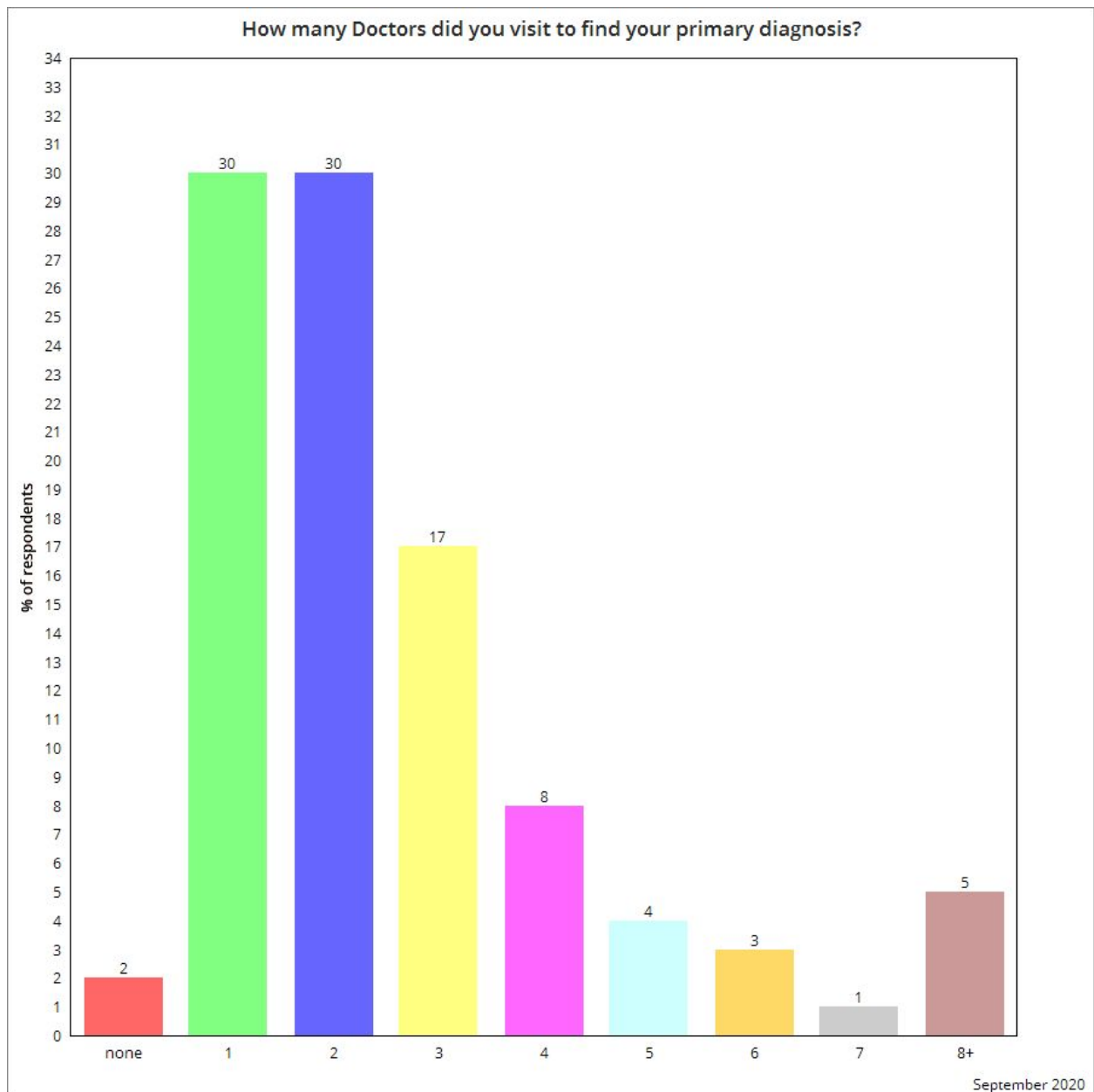
**CHART 27**



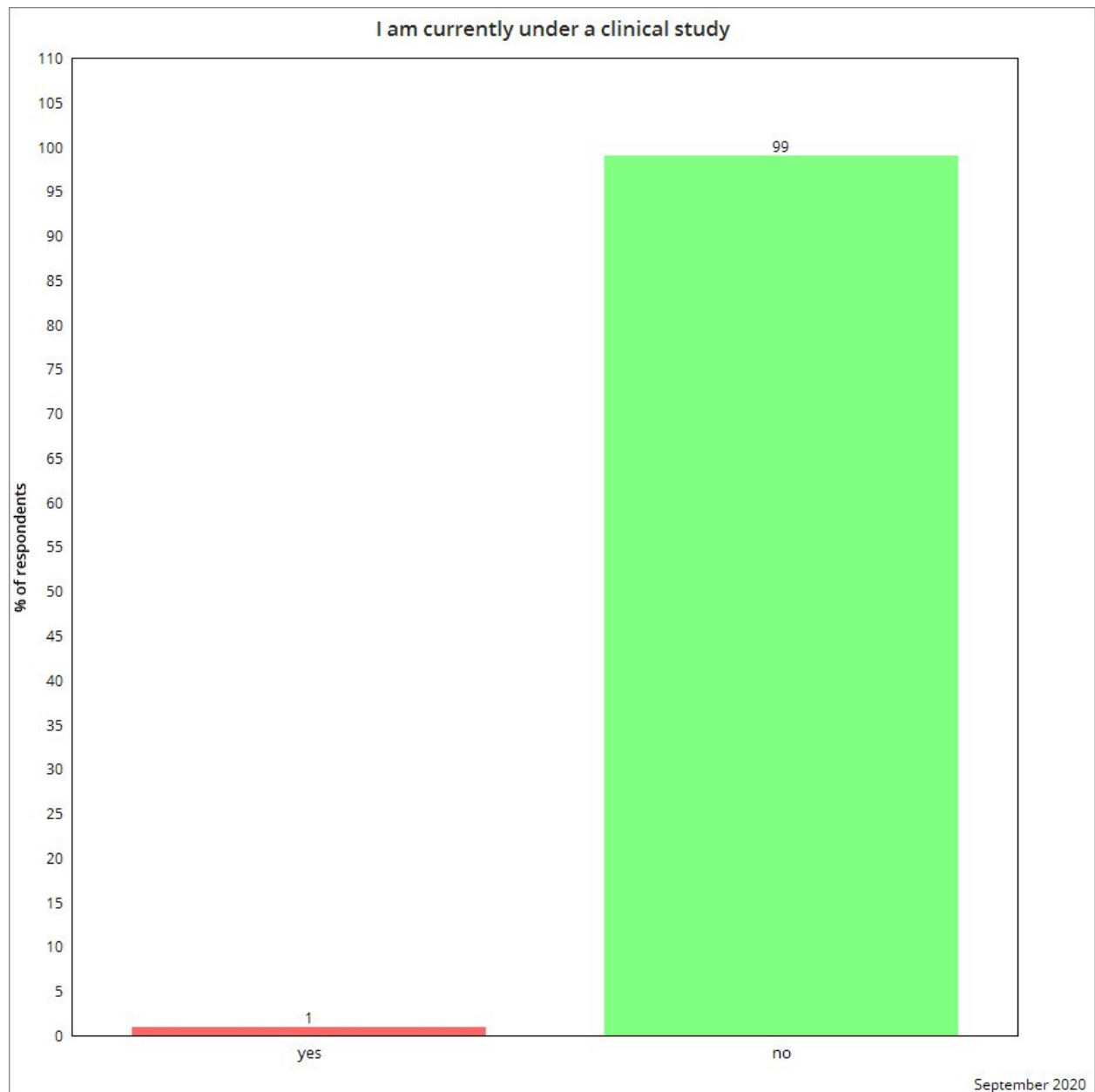
**CHART 28**



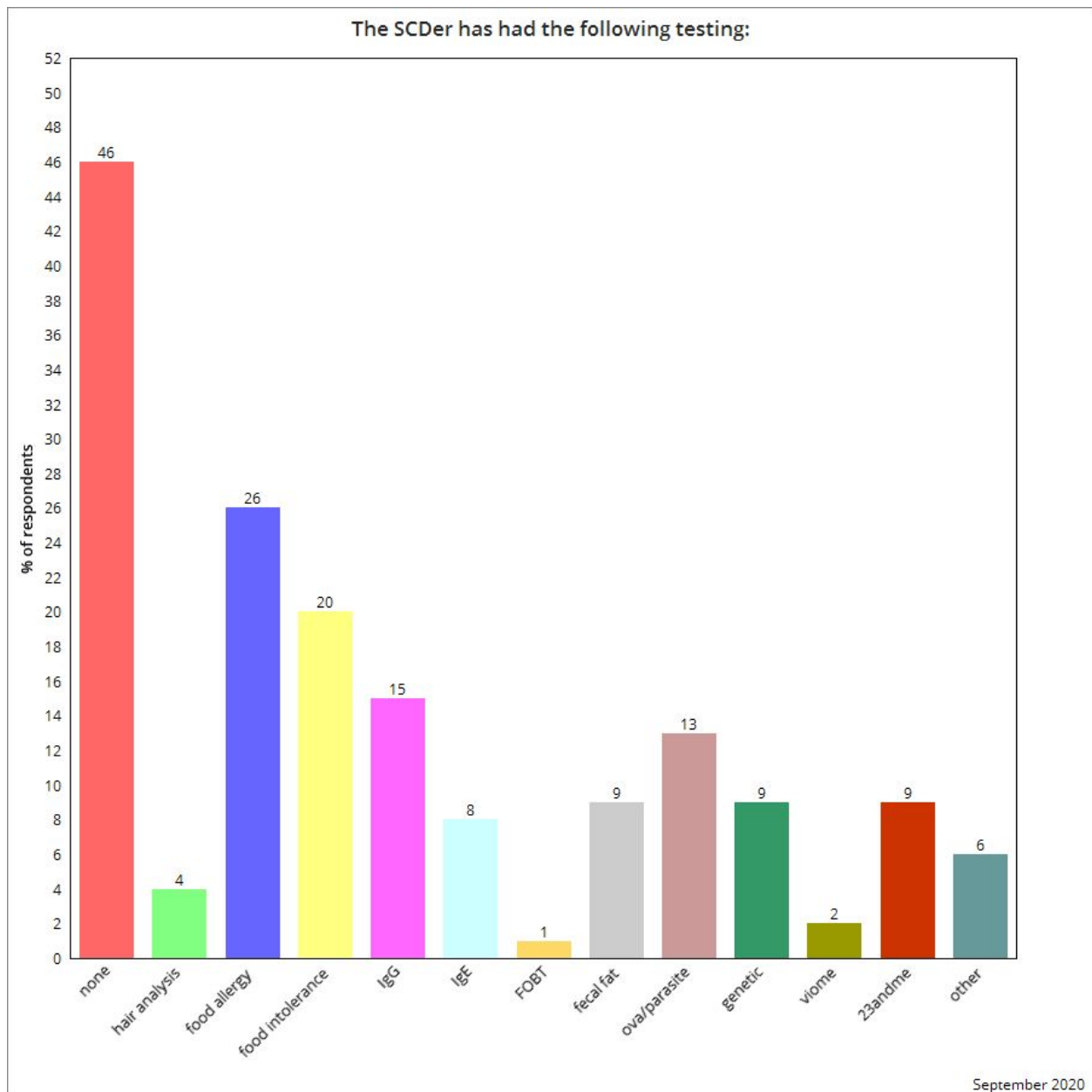
**CHART 29**



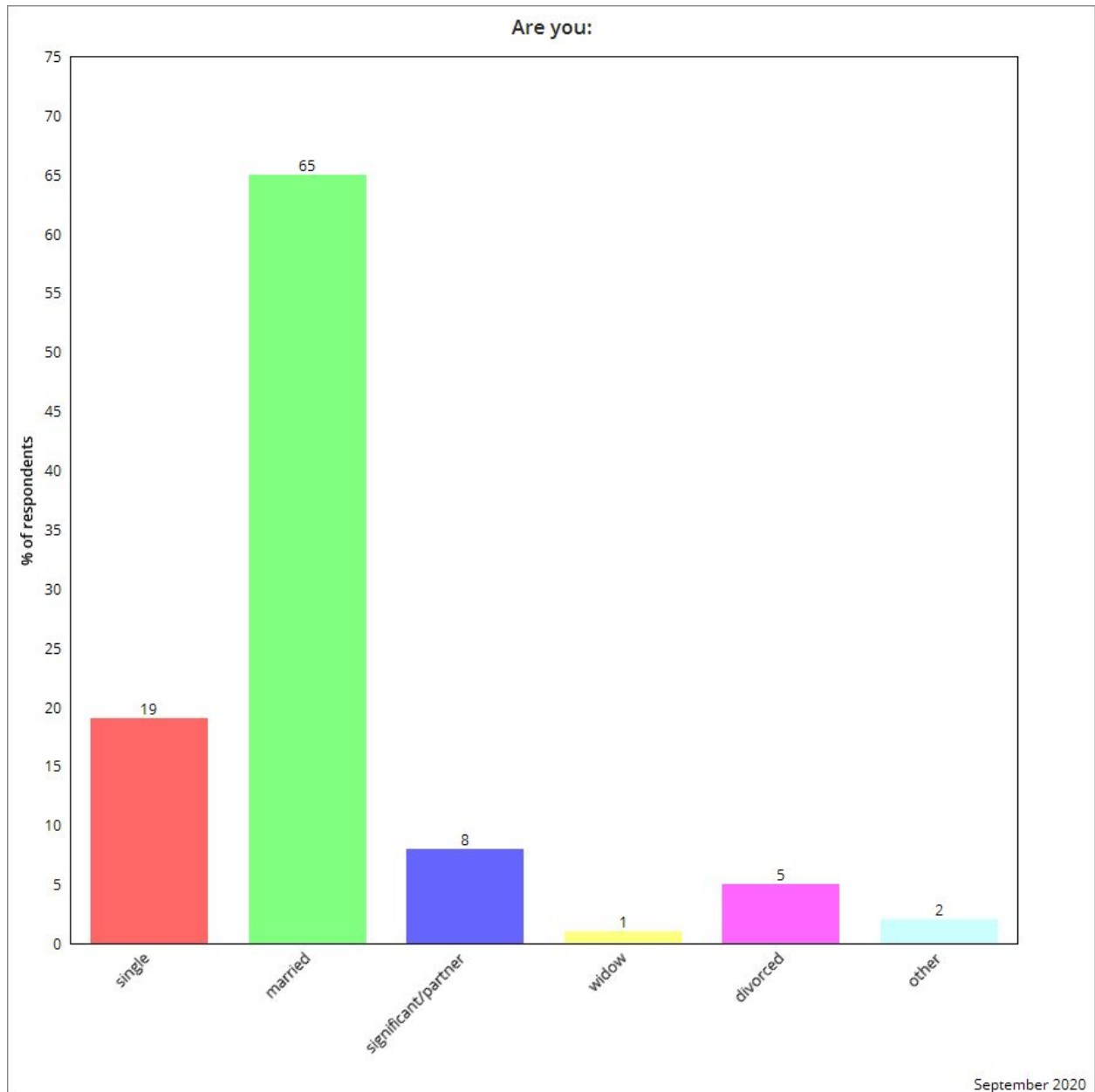
**CHART 30**



**CHART 31**



**CHART 32**



**CHART 33**

