

Persons with Lived Experience of Early Psychosis or Schizophrenia and Family Members

National Surveys

SSC ™

SCHIZOPHRENIA
SOCIETY OF CANADA

SCS ™

SOCIÉTÉ CANADIENNE
DE LA SCHIZOPHRÉNIE

Supported by
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Survey Development

- Contextual focus:
 - Positive, negative, and cognitive symptoms
 - Side effects of antipsychotic medications
 - Recovery
- Survey question resources:
 - Recovery Assessment Scale
 - Self Evaluation of Negative Symptoms
 - Subjective Scale to Investigate Cognition in Schizophrenia
 - The Glasgow Antipsychotic side Effect Scale

Survey Design and Testing

- SurveyMonkey online platform
- Eligibility :
 - Self declared person with early psychosis/schizophrenia and self-declared family members
 - 18 years of age or older living in Canada
- Pre-test was undertaken
- Review by AbbVie and Schizophrenia Society of Canada
- Engagement with organization and networks

Persons with Lived Experience Survey

Family Members of Persons with Lived Experience Survey

Survey Open: July 8, 2021 to August 6, 2021

Surveys Completed
N=239

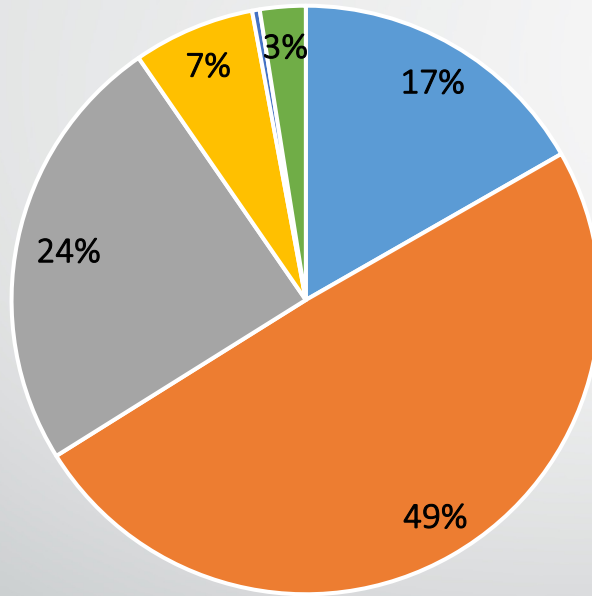
Average Time to Complete
10.1 Minutes

Surveys Completed
N=121

Average Time to Complete
8.2 Minutes

Persons with Lived Experience Survey

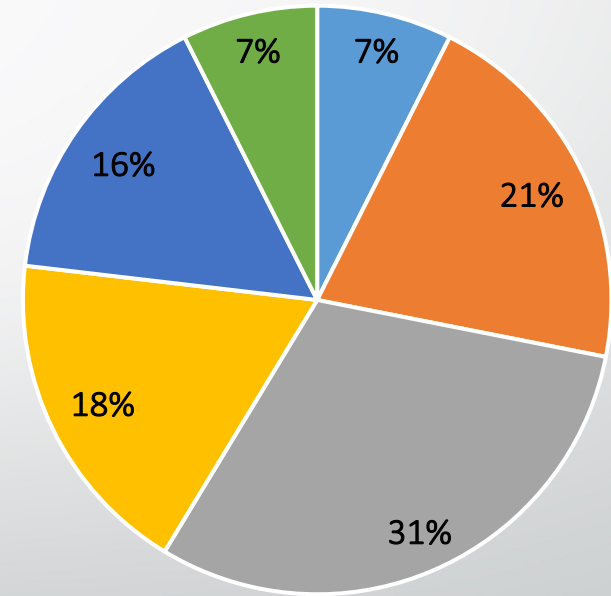
Age of Survey Respondent



- 18-24 years old
- 25-34 years old
- 35-44 years old
- 45-54 years old
- 55-64 years old
- 65 or older

Family Members of Persons with Lived Experience Survey

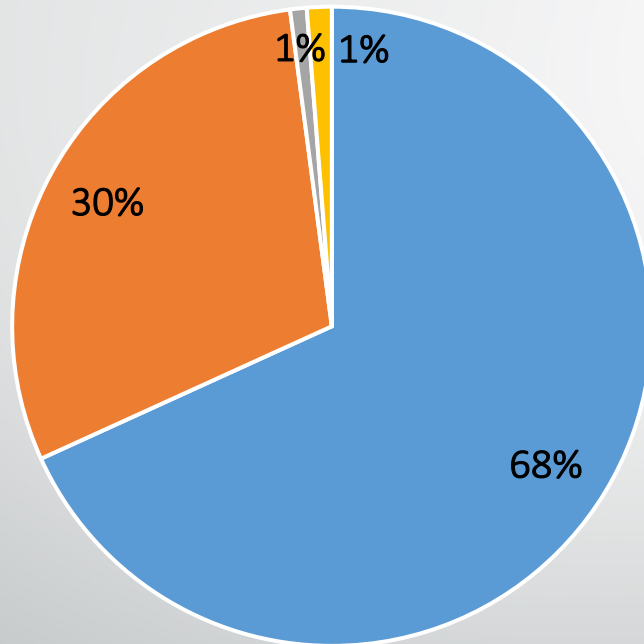
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Persons with Lived Experience Survey

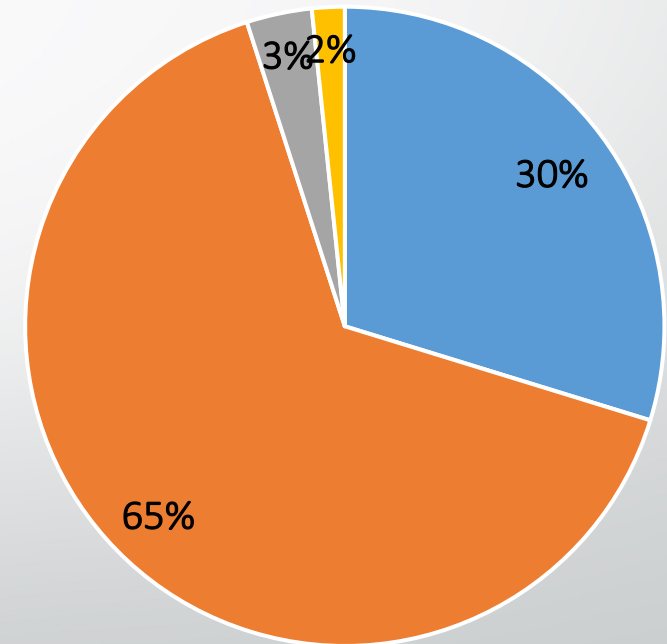
Gender of Survey Respondent



Male Female Other Prefer not to answer

Family Members of Persons with Lived Experience Survey

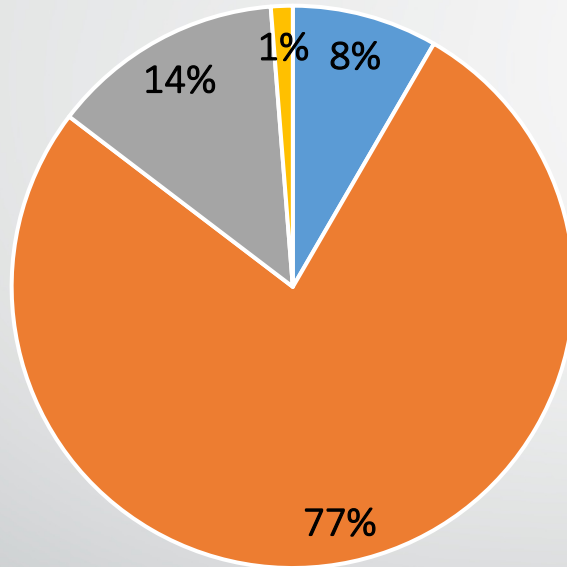
Gender of Survey Respondent



Male Female Other Prefer not to answer

Persons with Lived Experience Survey

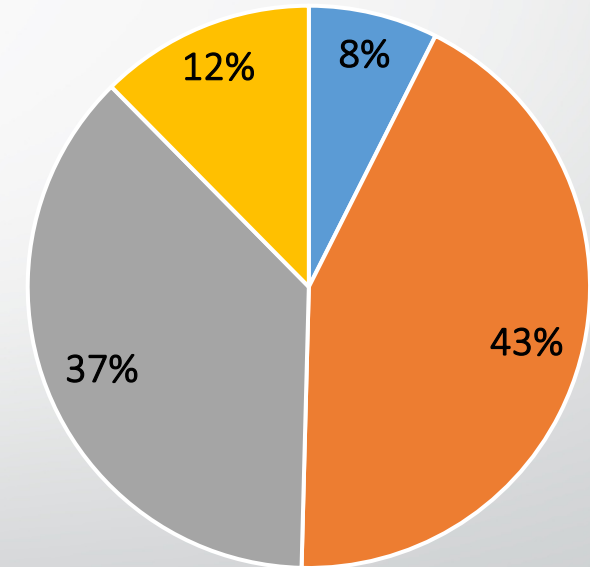
Residence of Survey Respondent




- Psychiatric Facility / Crisis Stabilization Unit
- With Family
- Community Setting (Not with Family)
- Prefer not to answer

Family Members of Persons with Lived Experience Survey

Residence of Family Member

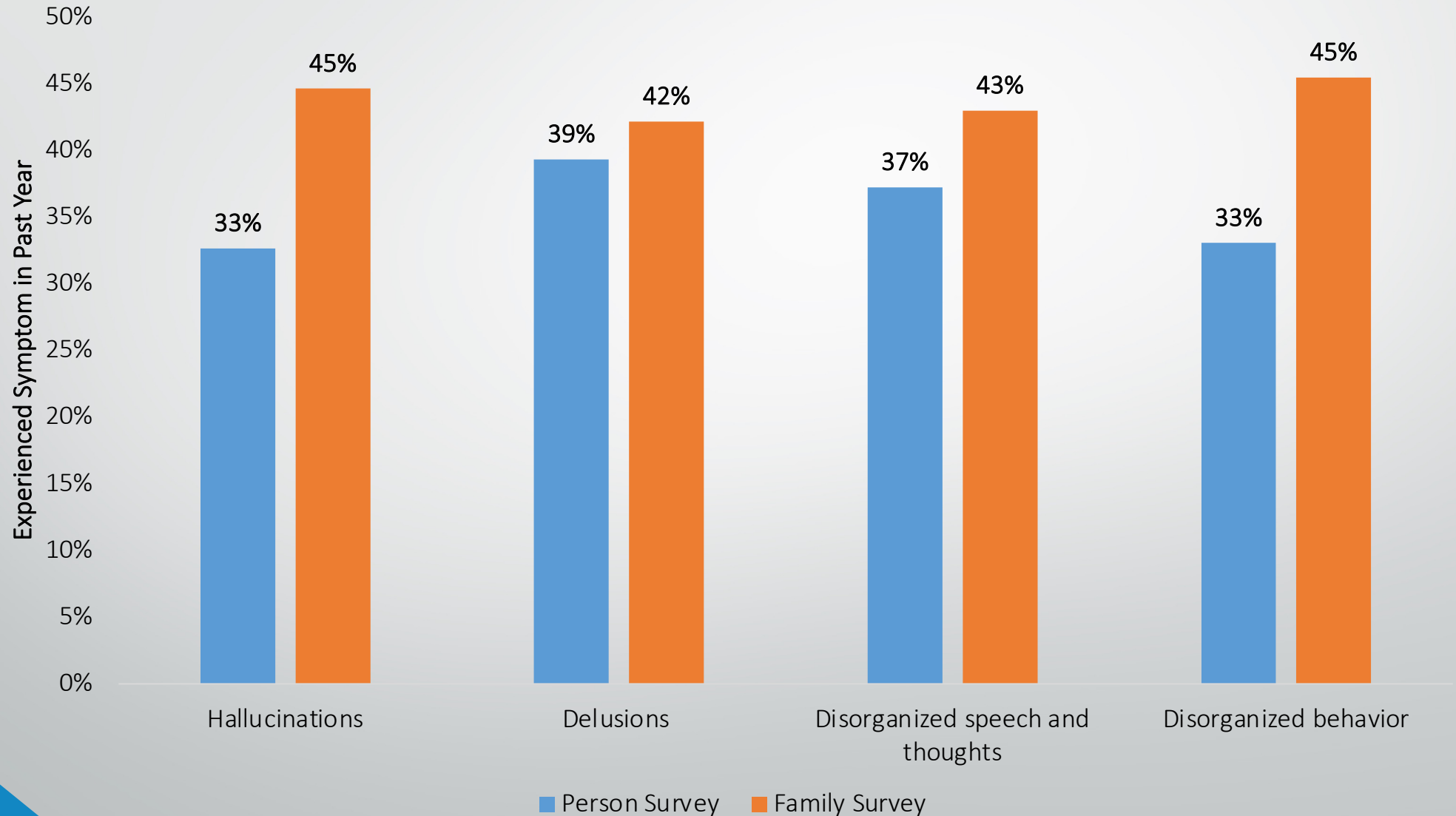


- Psychiatric Facility / Crisis Stabilization Unit
- With Me
- Community Setting (Not with me)
- Prefer not to answer



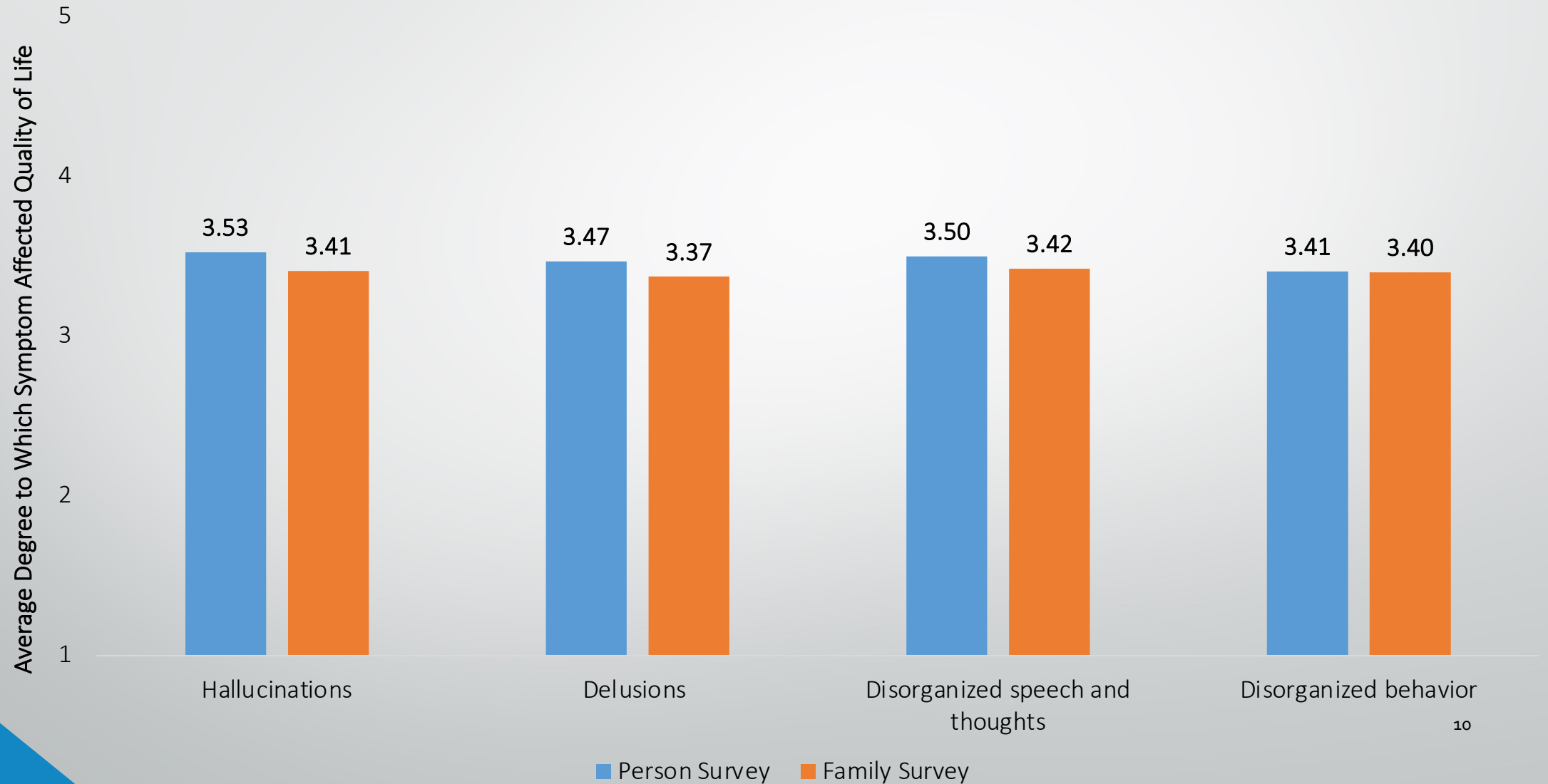
Positive, Negative, and Cognitive Symptoms

Experienced Symptom in the Past Year (Positive Symptoms)

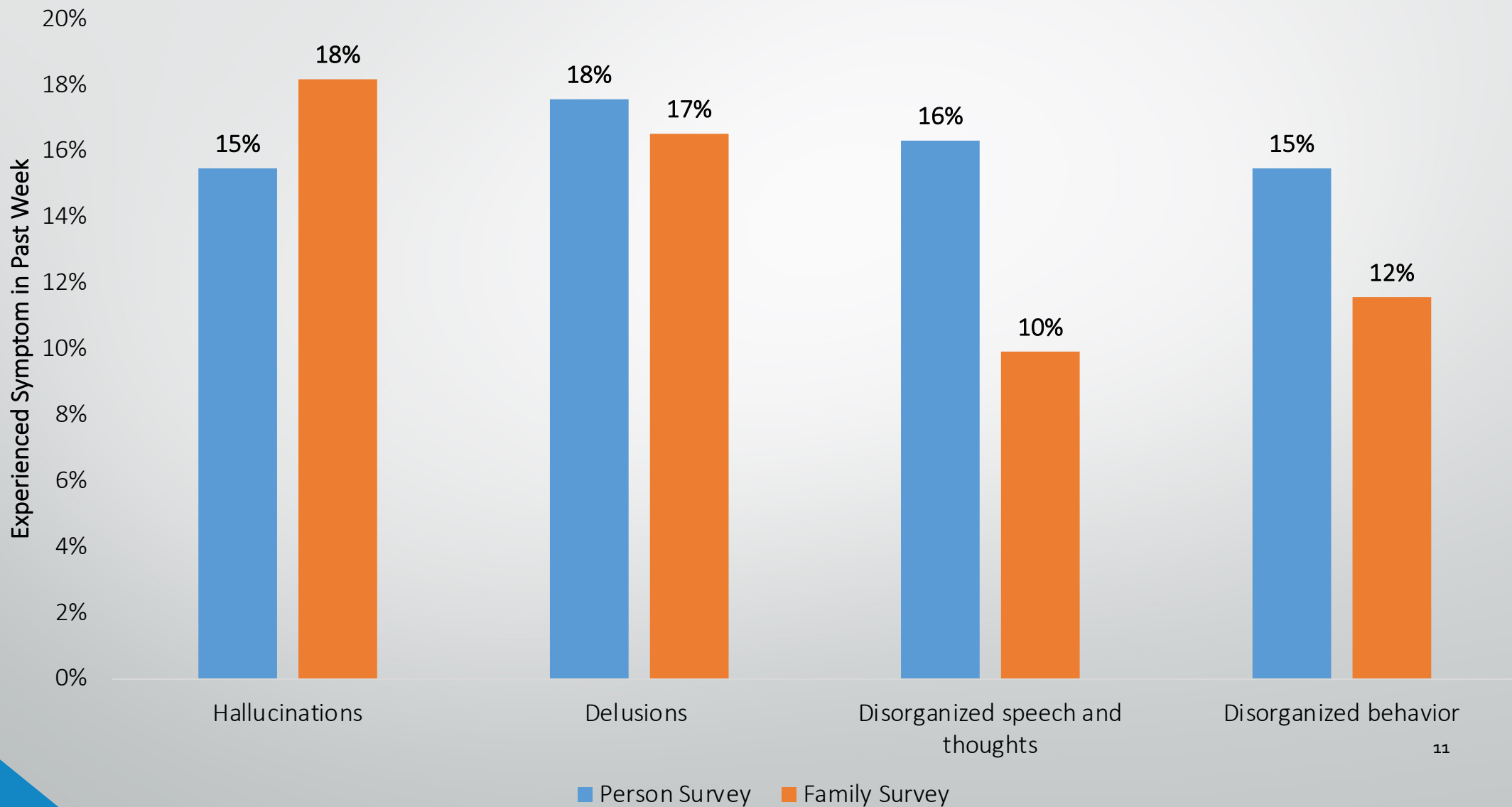


Degree to Which Symptom Experienced in Past Year Affected Quality of Life

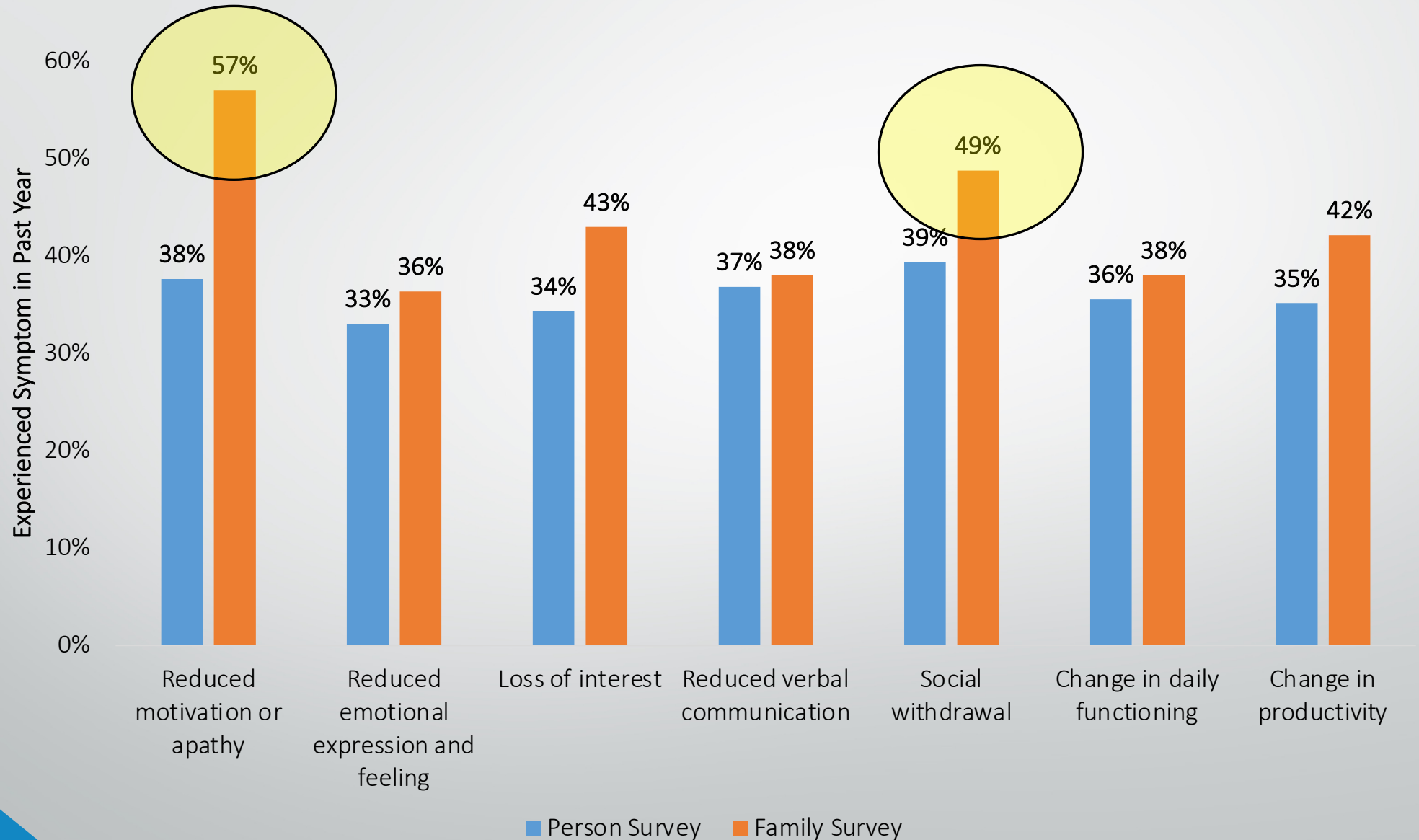
(1=Hardly at All; 2=Mildly; 3=Moderately; 4=Greatly; 5=As Worse as I can Imagine)
(Positive Symptoms)



Experienced Symptom in Past Week and Impacted Quality of Life (Positive Symptoms)



Experienced Symptom in the Past Year (Negative Symptoms)

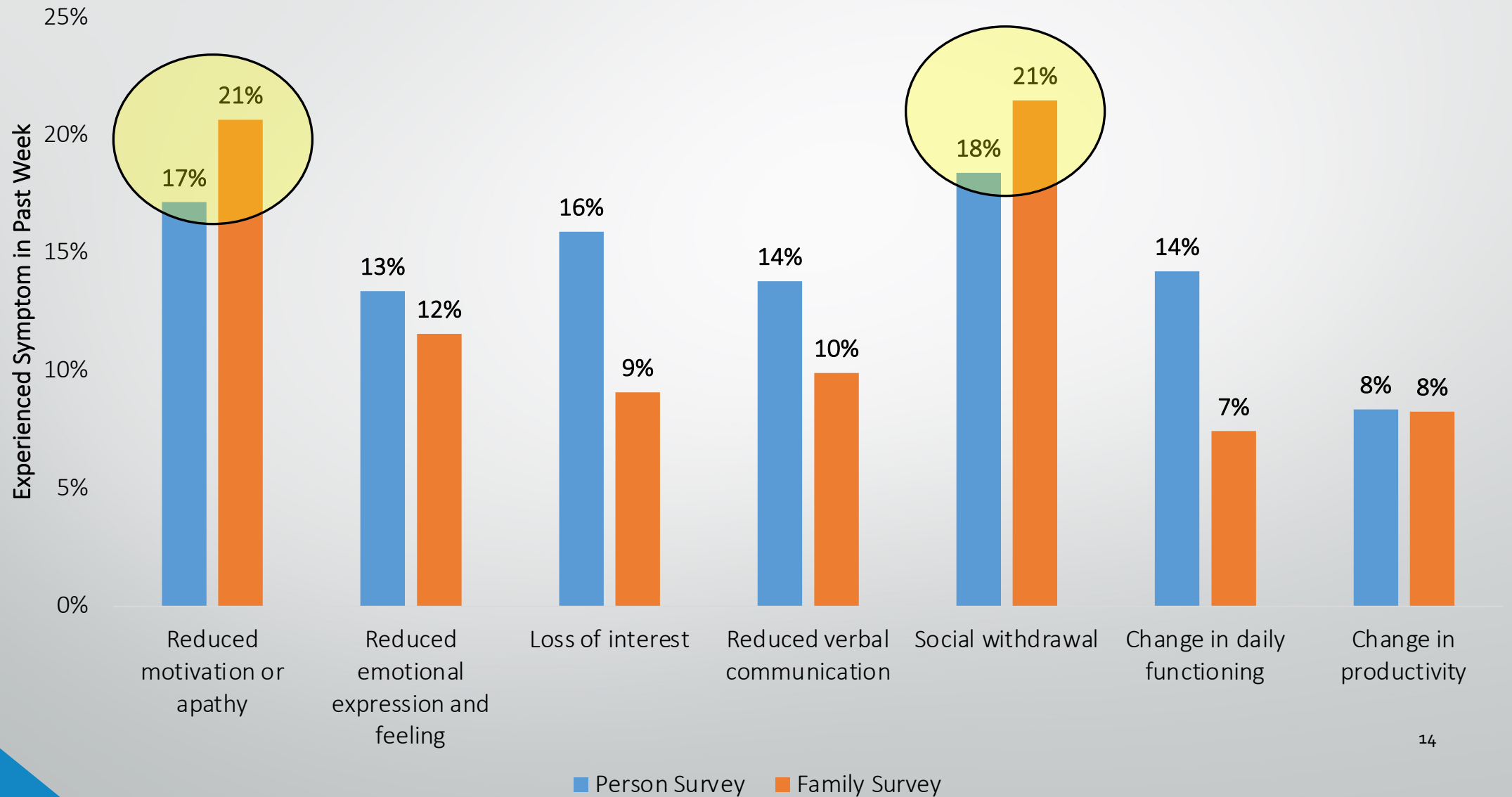


Degree to Which Symptom Experienced in Past Year Affected Quality of Life

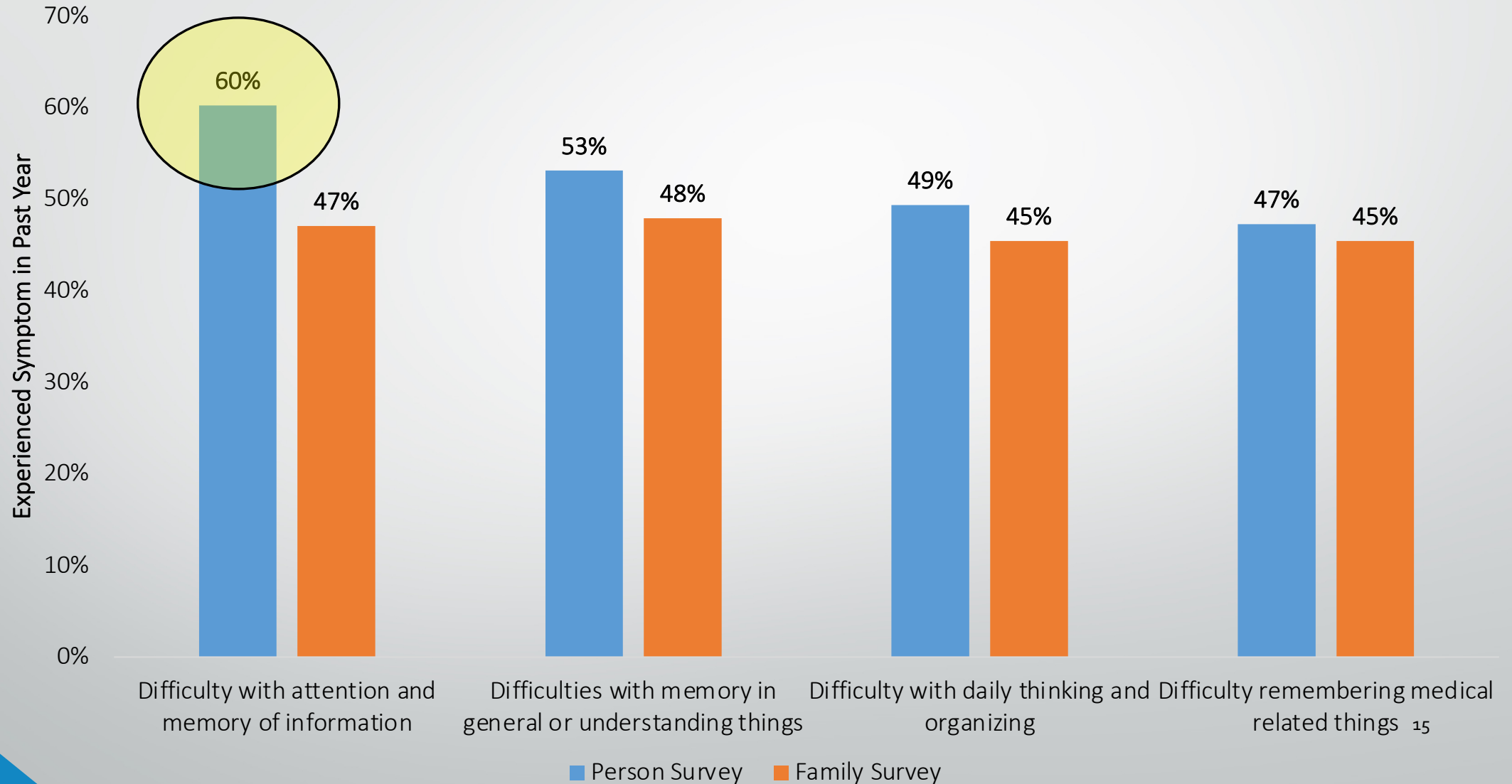
(1=Hardly at All; 2=Mildly; 3=Moderately; 4=Greatly; 5=As Worse as I can Imagine)
(Negative Symptoms)



Experienced Symptom in Past Week and Impacted Quality of Life (Negative Symptoms)



Experienced Symptom in the Past Year (Cognitive Symptoms)



Degree to Which Symptom Experienced in Past Year Affected Quality of Life

(1=Hardly at All; 2=Mildly; 3=Moderately; 4=Greatly; 5=As Worse as I can Imagine)

(Cognitive Symptoms)

Average Degree to Which Symptom Affected Quality of Life



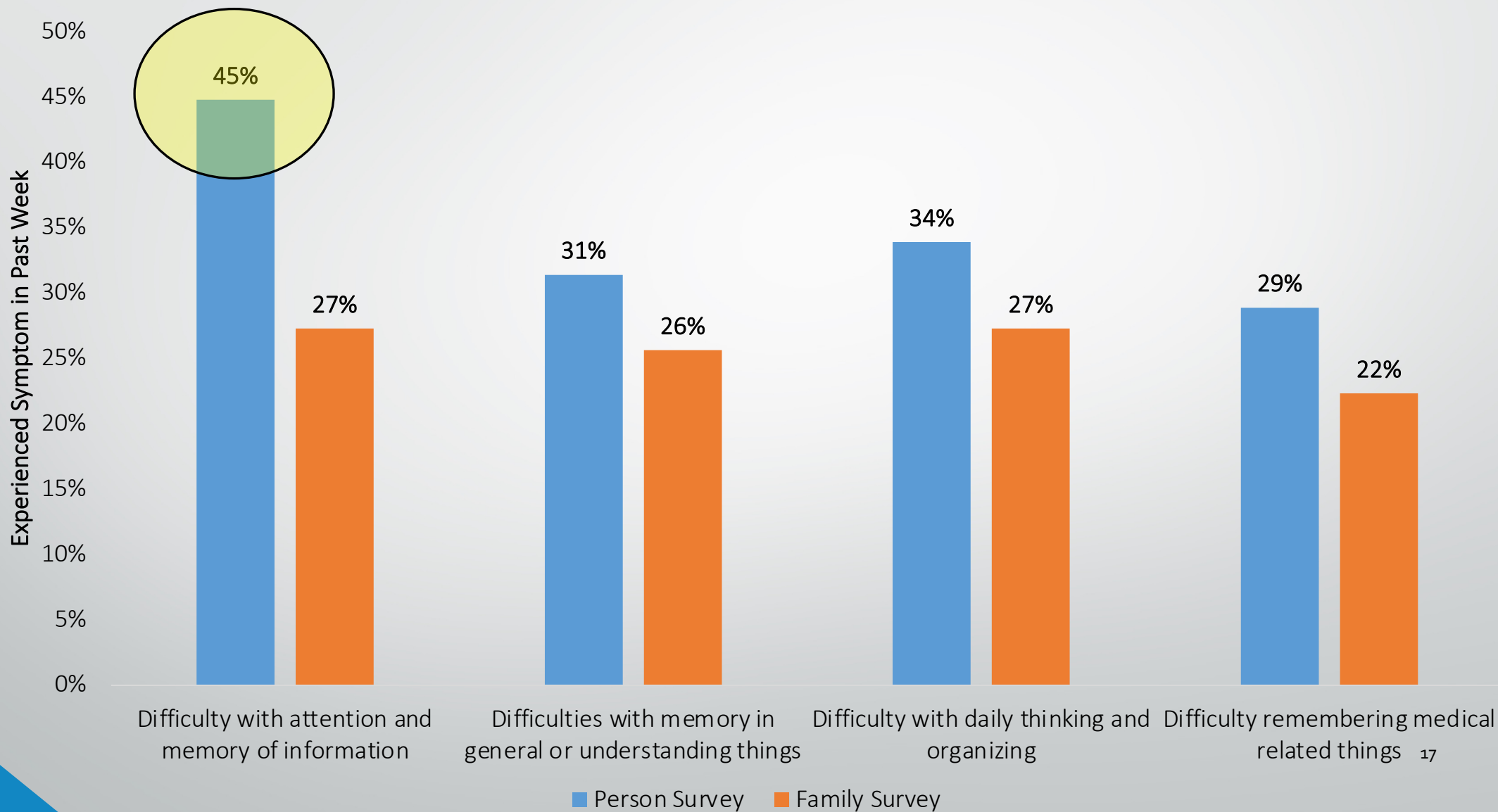
Difficulty with attention and memory of information

Difficulties with memory in general or understanding things

Difficulty with daily thinking and organizing

Difficulty remembering medical related things

Experienced Symptom in Past Week and Impacted Quality of Life (Cognitive Symptoms)

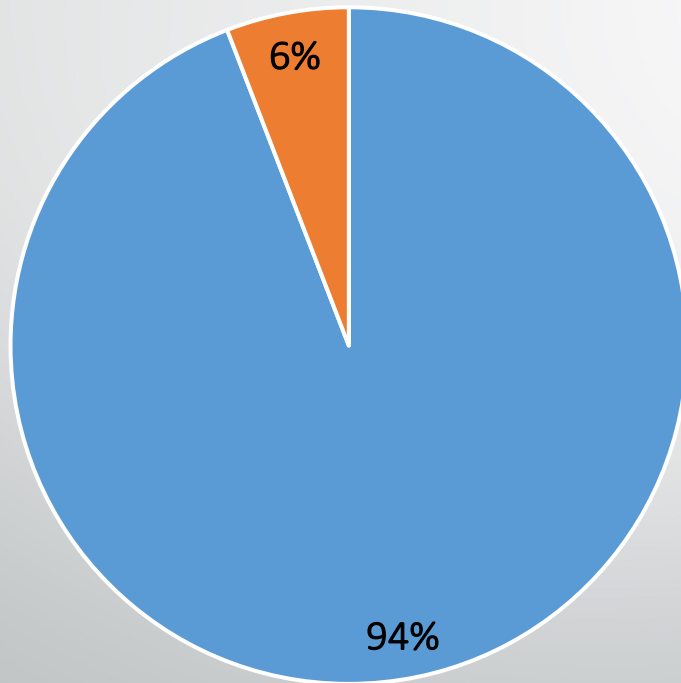




Medication Use and Side Effects

Persons with Lived Experience Survey

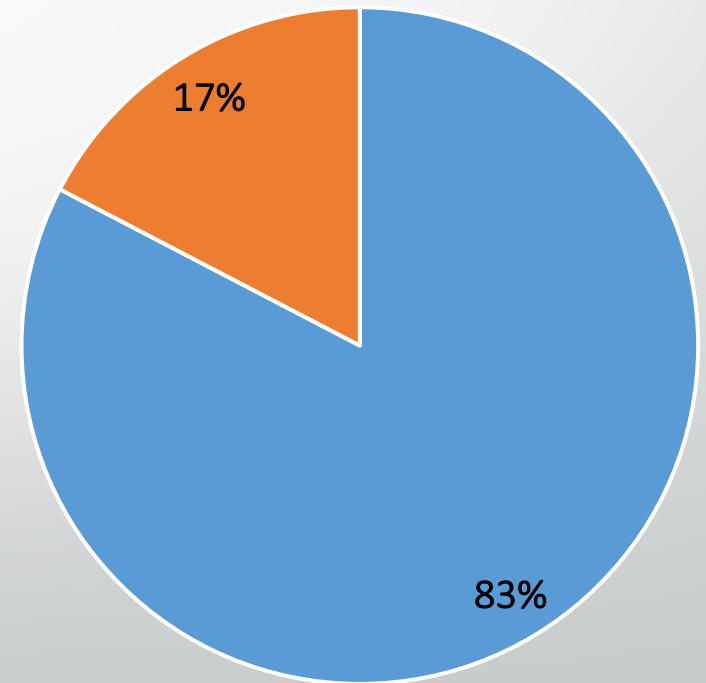
Take medication for early psychosis or schizophrenia?



■ Yes ■ No

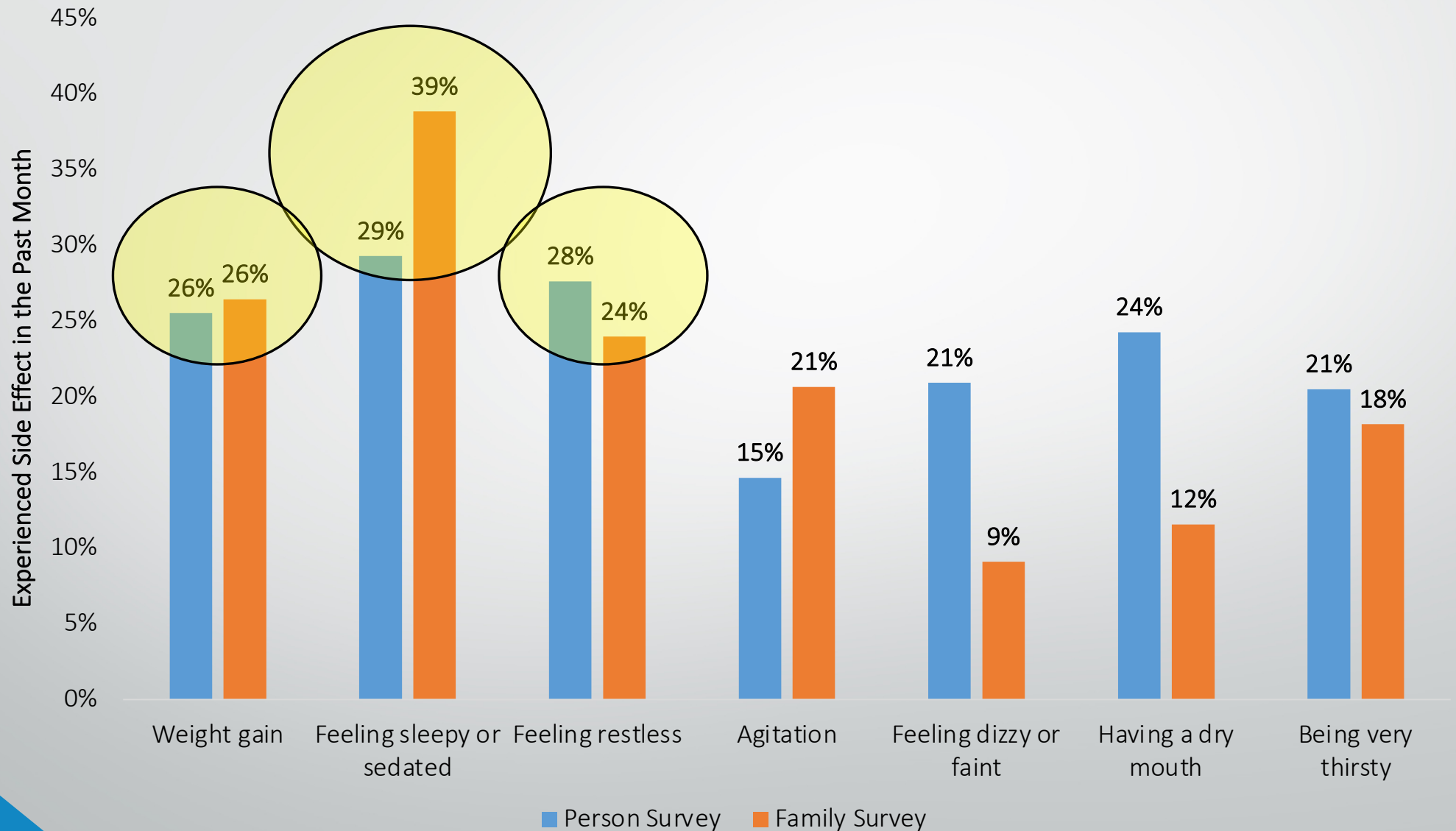
Family Members of Persons with Lived Experience Survey

Does your family member take medication for early psychosis or schizophrenia?

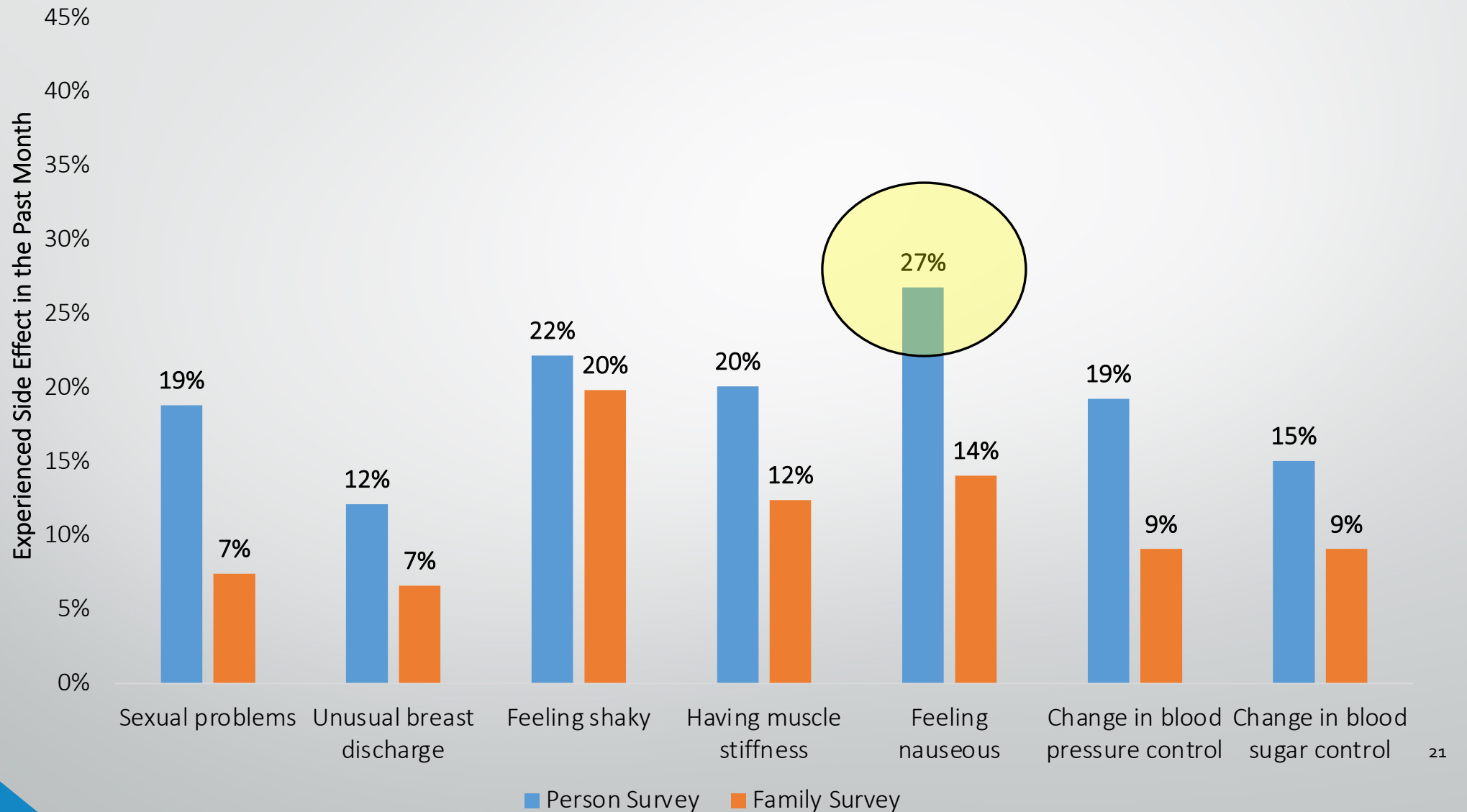


■ Yes ■ No

Experienced Side Effect from Medication over the Past Month



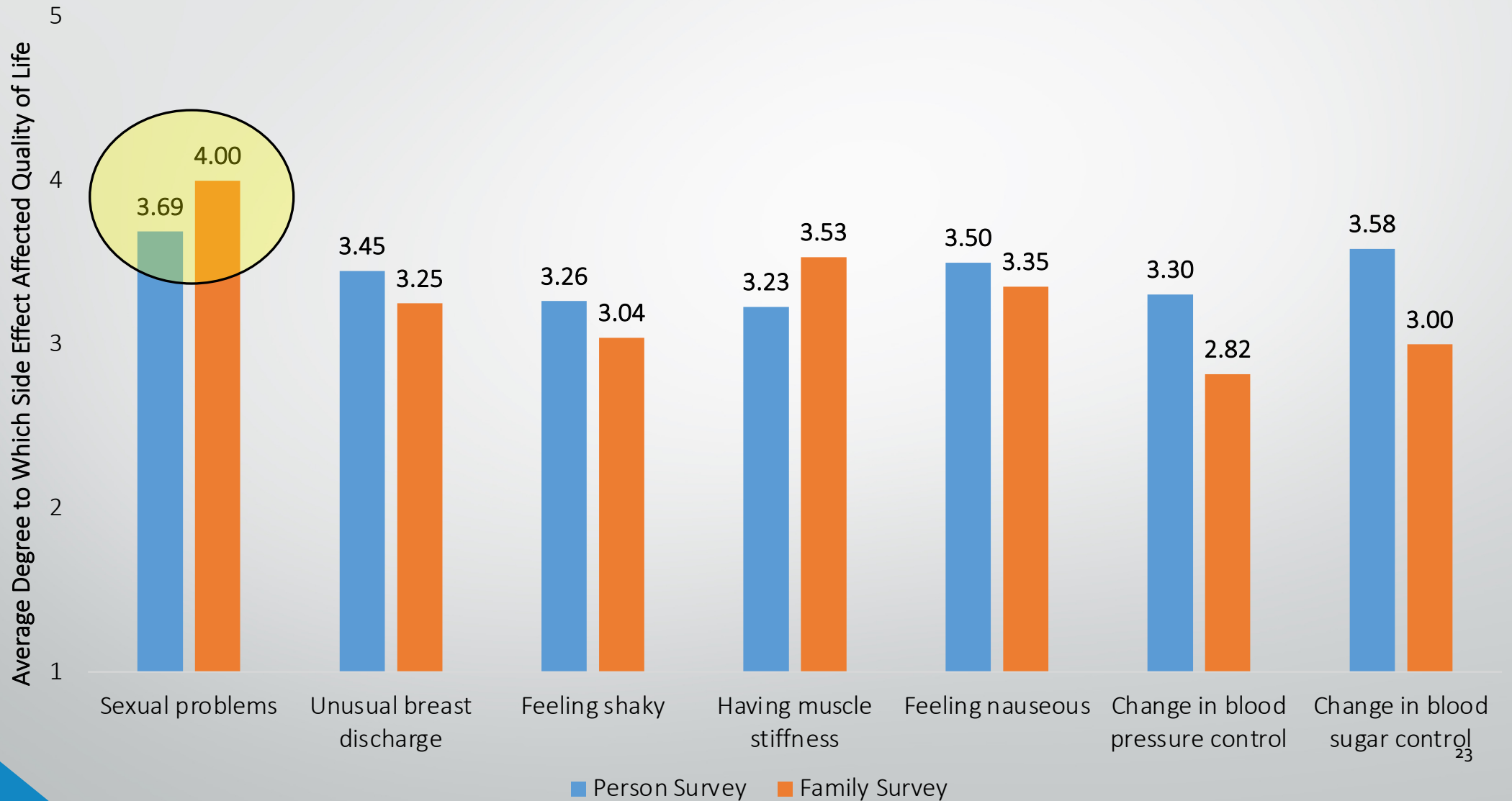
Experienced Side Effect from Medication over the Past Month



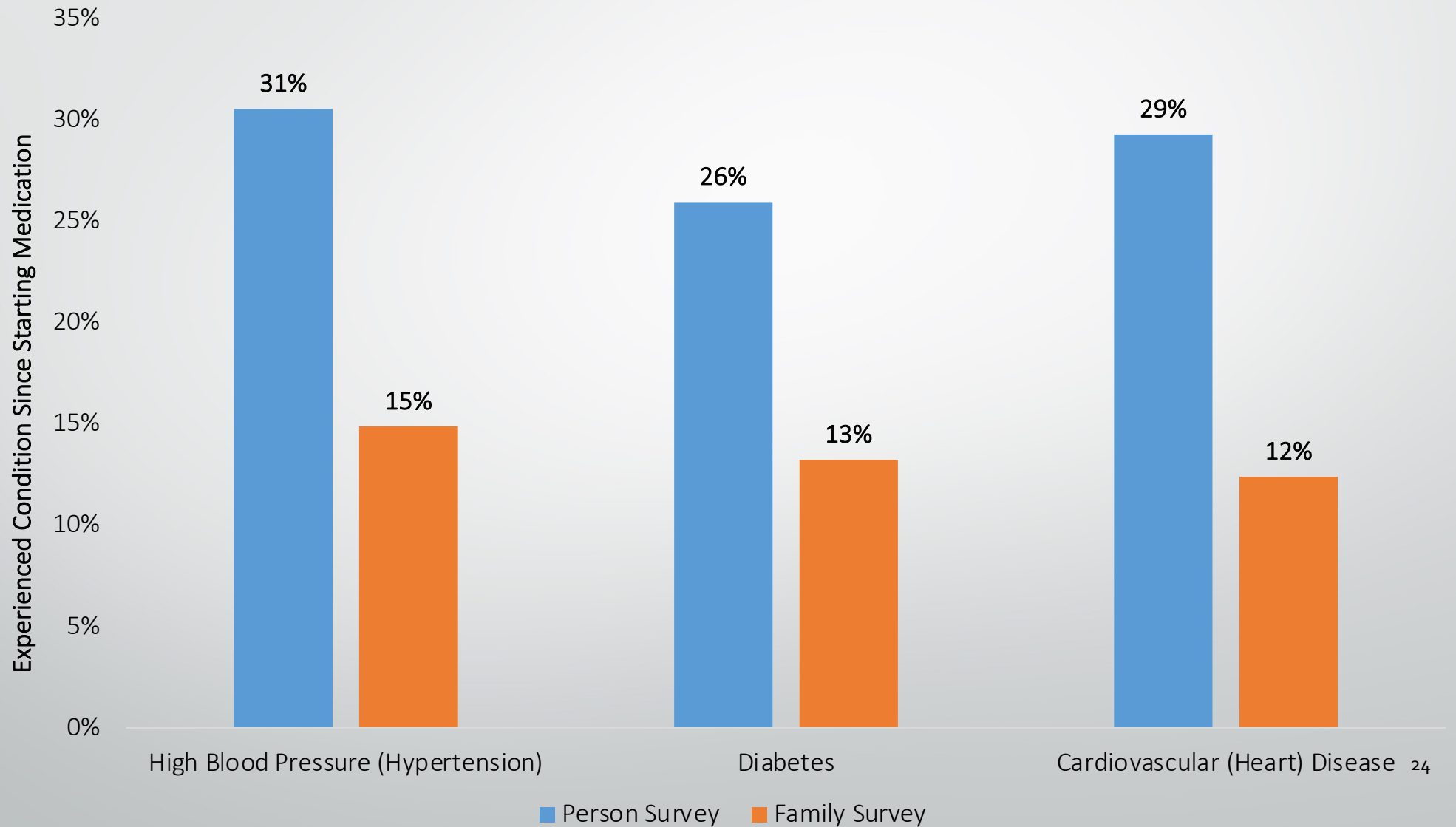
Degree to Which Side Effect Experienced in Past Year Affected Quality of Life (1=Hardly at All; 2=Mildly; 3=Moderately; 4=Greatly; 5=As Worse as I can Imagine)



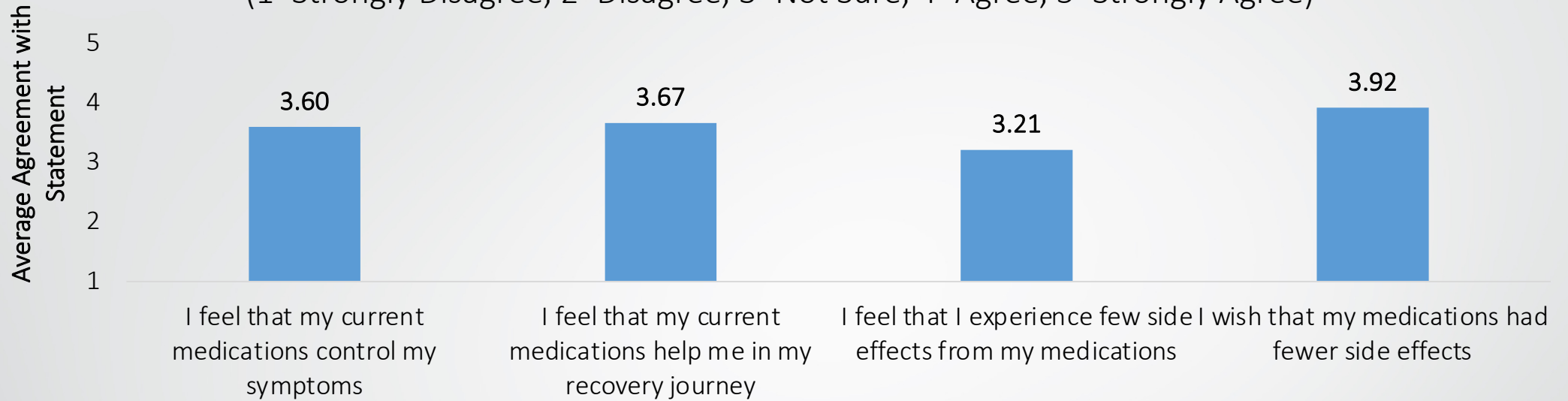
Degree to Which Side Effect Experienced in Past Year Affected Quality of Life (1=Hardly at All; 2=Mildly; 3=Moderately; 4=Greatly; 5=As Worse as I can Imagine)



Experienced Condition Since Starting Anti-Psychotic Medication



Degree to Which Person Respondent Agreed with Statement (1=Strongly Disagree, 2=Disagree, 3=Not Sure, 4=Agree, 5=Strongly Agree)



Degree to Which Family Respondent Agreed with Statement (1=Strongly Disagree, 2=Disagree, 3=Not Sure, 4=Agree, 5=Strongly Agree)

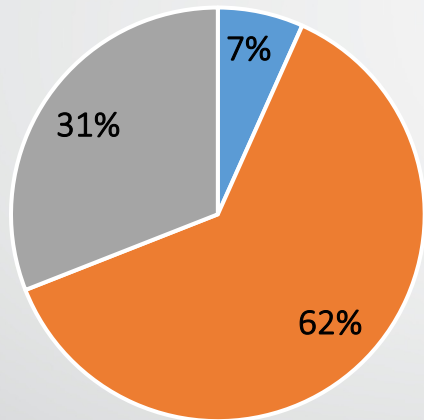




Recovery Journey

Persons with Lived Experience Survey

How do you feel you are currently doing in your personal recovery?
1=I am struggling in my recovery
10=I consider myself in recovery, living a full and meaningful life

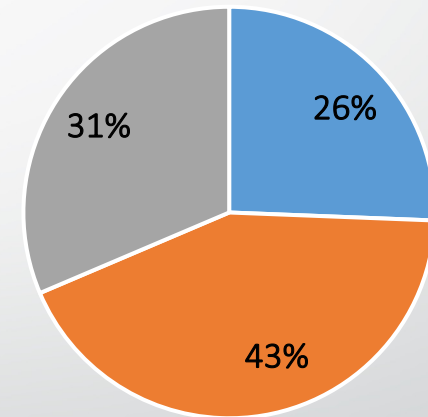


■ 1 to 3 ■ 4 to 7 ■ 8 to 10

Average Score
6.6

Family Members of Persons with Lived Experience Survey

How is your family member doing in their personal recovery?
1=They are struggling in their recovery
10=I consider them to be in recovery, living a full and meaningful life

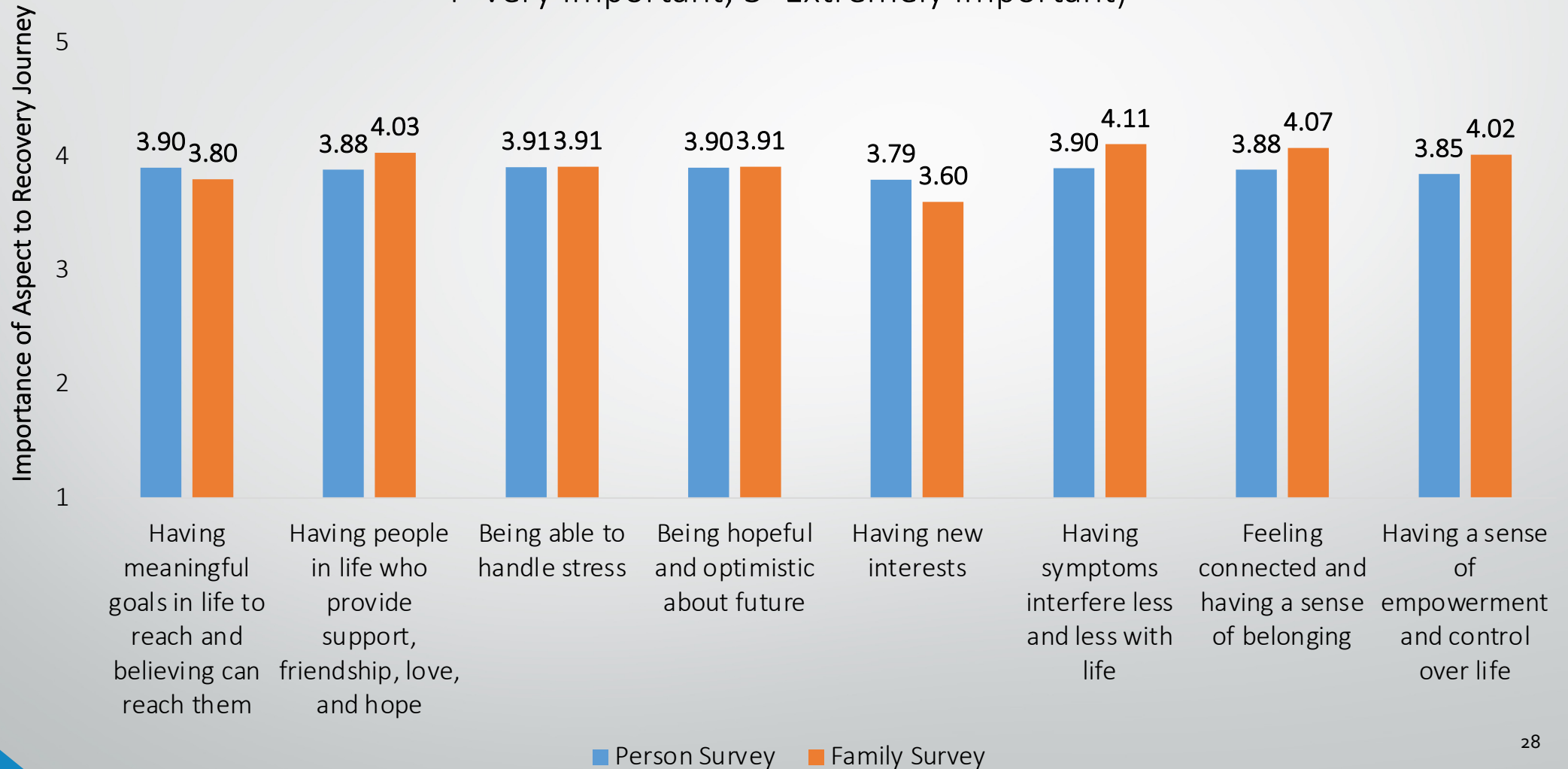


■ 1 to 3 ■ 4 to 7 ■ 8 to 10

Average Score
5.9

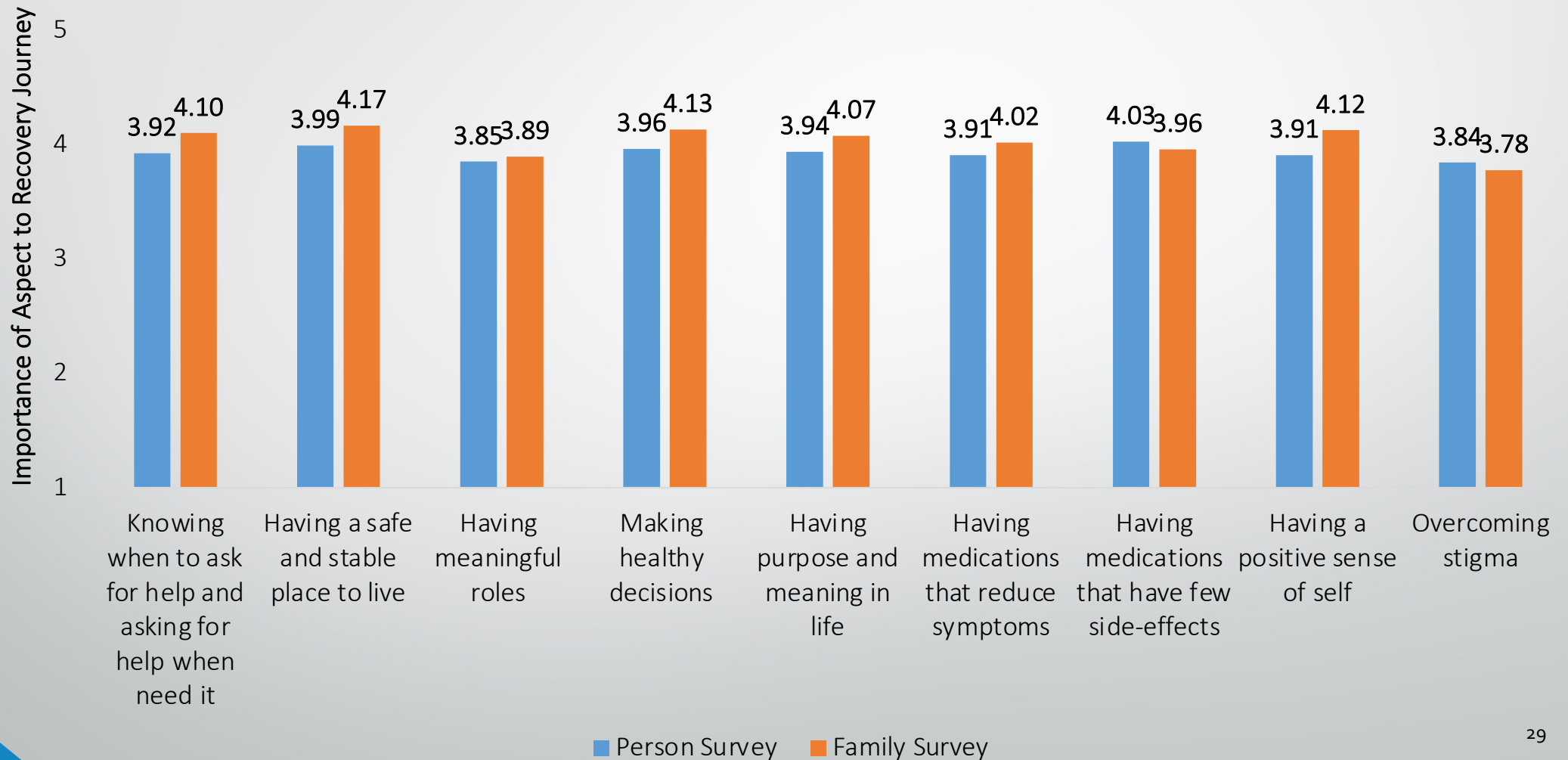
How Important Each Aspect is to Recovery Journey

(1=Not at all Important; 2=Slightly Important; 3=Moderately Important; 4=Very Important; 5=Extremely Important)

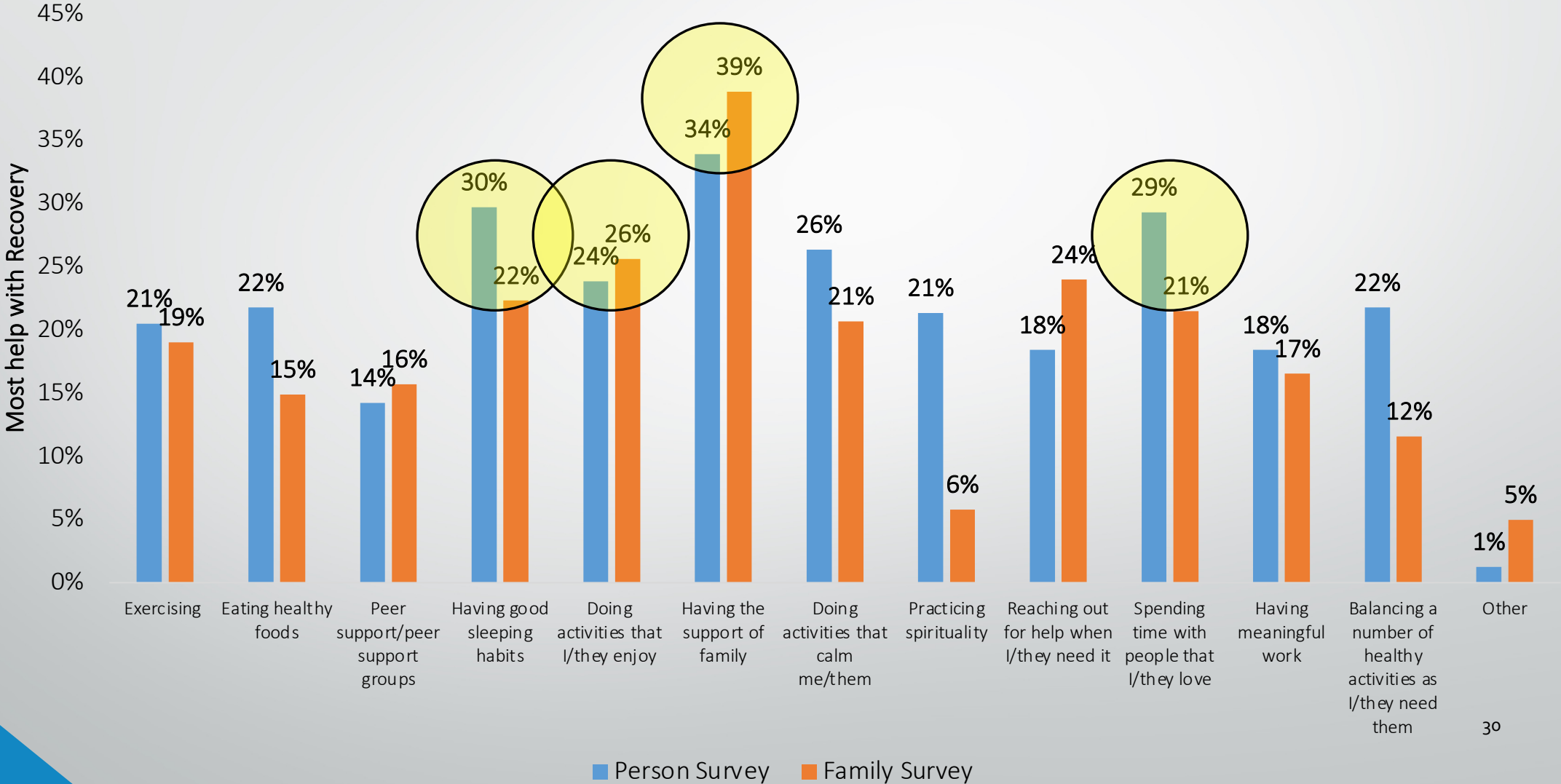


How Important Each Aspect is to Recovery Journey

(1=Not at all Important; 2=Slightly Important; 3=Moderately Important; 4=Very Important; 5=Extremely Important)



Please indicate up to three things that you feel most help with the personal recovery journey



Key Discussion Points: Symptoms

- Most recognizable symptoms of early psychosis or schizophrenia are positive symptoms
- Negative symptoms and cognitive symptoms may contribute more to poor functional outcomes and quality of life than positive symptoms
- Limited success to date of antipsychotic medications treating negative or cognitive symptoms
- Important to consider the use of psychosocial interventions in conjunction with antipsychotic treatment

Key Discussion Points: Side Effects


- Feeling sleepy or sedated most frequently reported side effect
- Hypertension/high blood pressure and diabetes reported as side effect
- Survey results consistent with existing research
- Very real concerns underscore the need for continued research

Key Discussion Points: Recovery

- Most hopeful news in schizophrenia research is in the field of psychosocial rehabilitation and recovery
- Recovery **PHILOSOPHY** of mental illness and the medical model can be complementary and can be used together
- Results demonstrate the importance of having medications (with few side effects) and the importance of the many aspects of recovery
- Despite side effects and symptoms and the reported impact of these on quality of life, respondents reported progressing in recovery or were in full recovery

Concluding Remarks

- National surveys have confirmed previous research findings and have done so within a current, Canadian context
- Quality of life continues to be significantly impacted for people with early psychosis and schizophrenia.
- Continue to be many unmet needs related to broadly accessing therapies and supports that have been shown through evidence to have positive impacts on negative and cognitive symptoms
- Listening to and understanding individuals' personal experiences will authentically allow us to continue to work toward improved treatments that will support recovery and a better quality of life



Thank you very much!
Questions?