



WSS Foundation
Wiedemann-Steiner Syndrome Foundation



WSS Data Collection Program

Wiedemann-Steiner Syndrome
Data Progress Report - November 2023

Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report

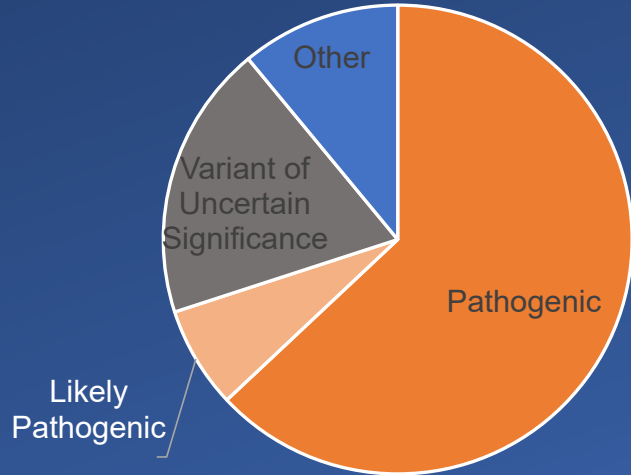
Patient Locations Across the Globe

This report reflects the enrollment and completed surveys of **178 individuals** diagnosed with WSS between the launch of the program on September 1, 2022 and November 20, 2023.

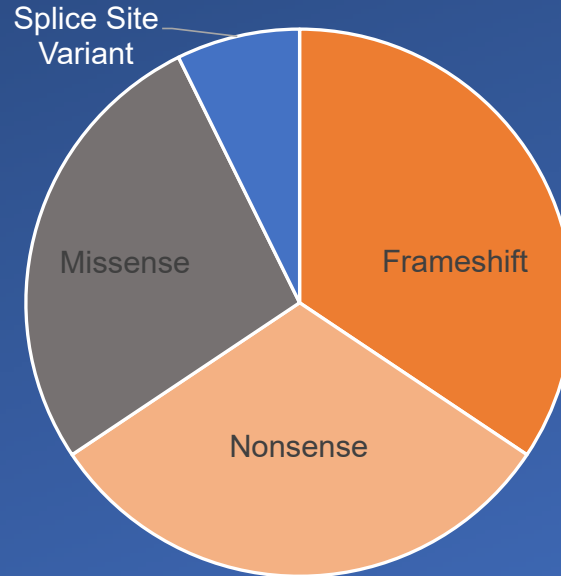


Percentage KMT2A Mutation Types Reported

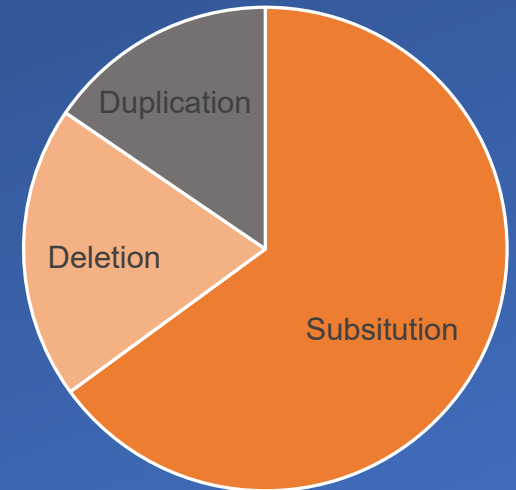
Sequence Classification



Protein Consequence



Sequence Variant Type

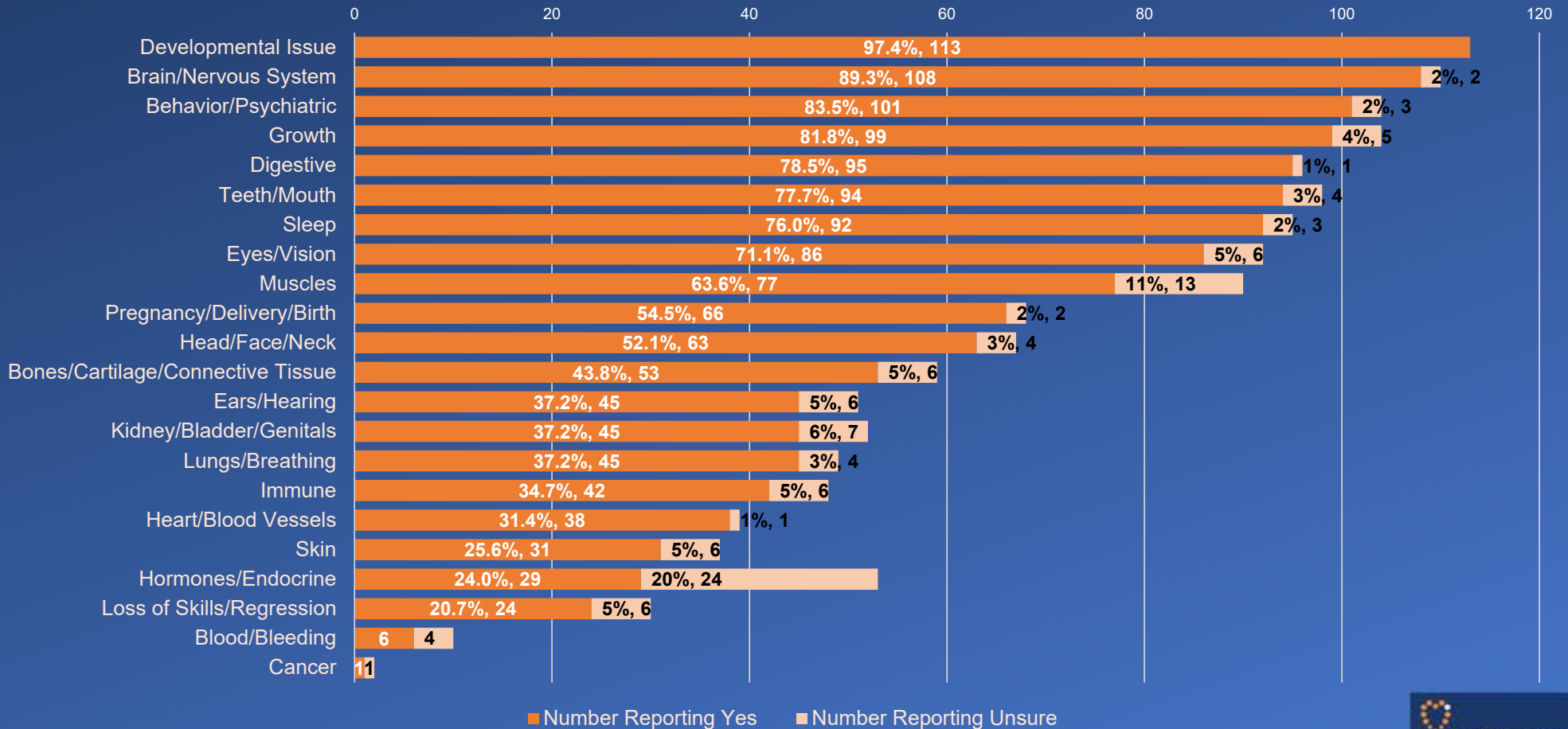


Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Overview of Reported Issues

Of 121 respondents, how many reported having issues in each of the following domains?

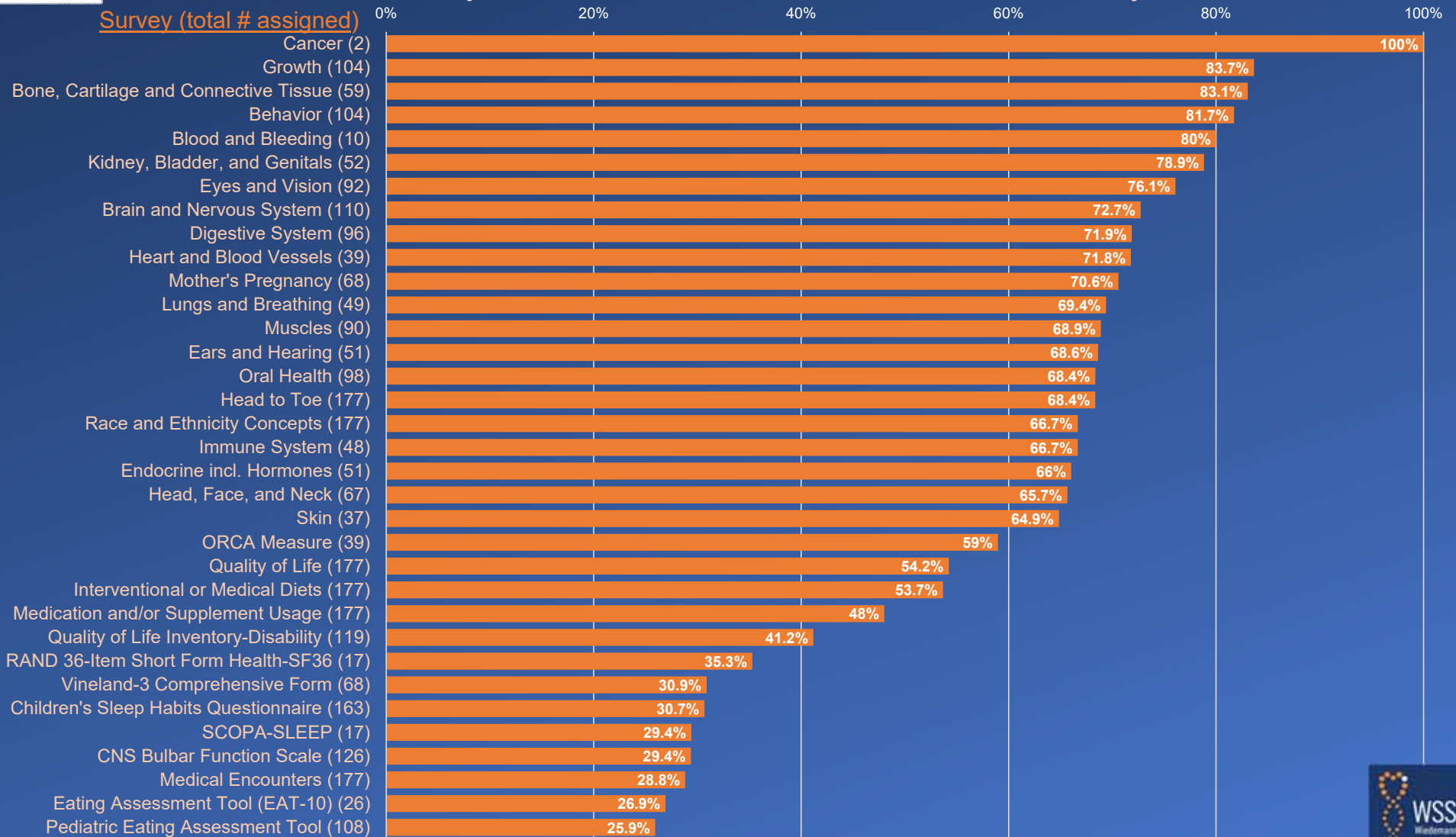


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

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Completion Rate of Relevant Surveys



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Most Common Concerns with Development

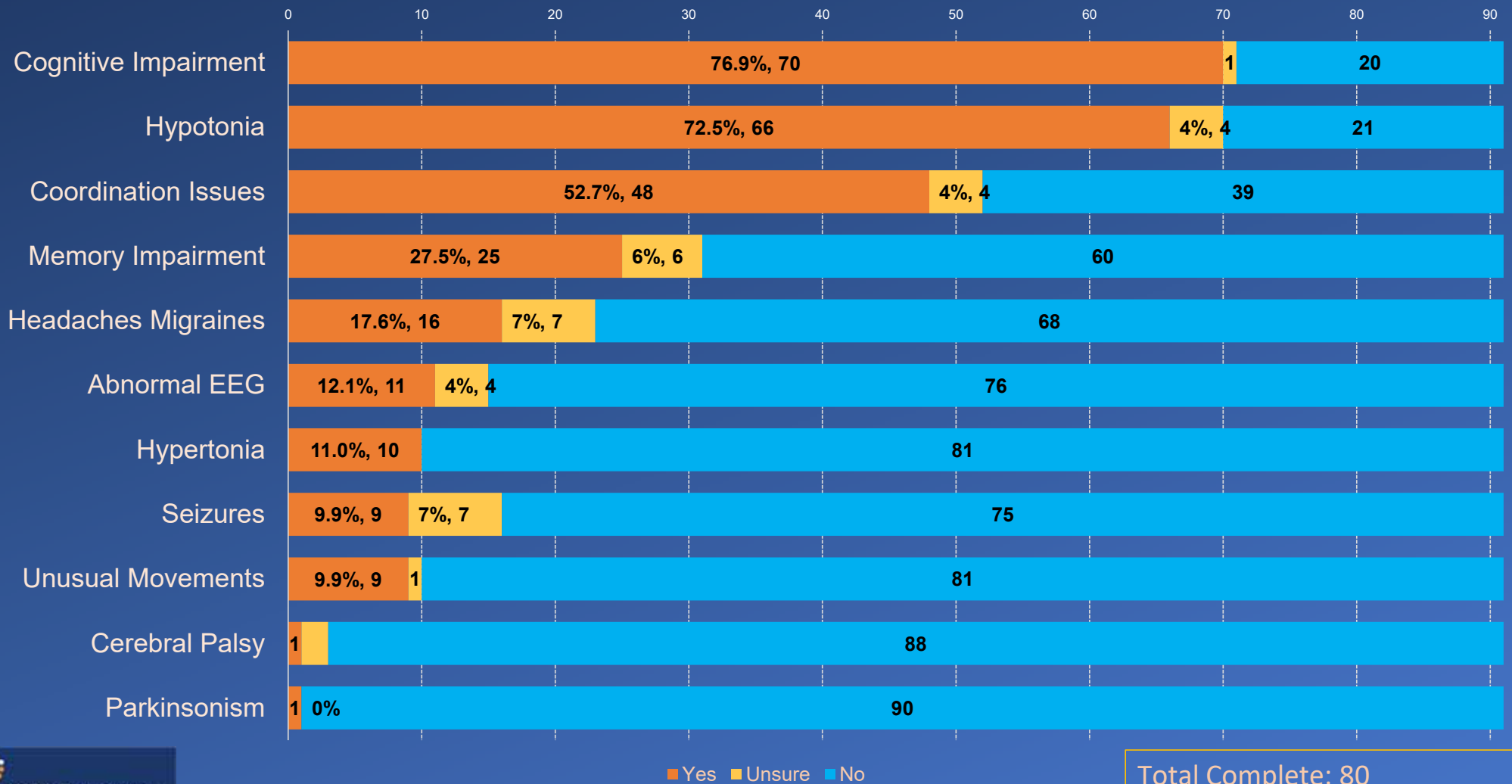


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

November 2023 Report



Symptoms reported in Brain and Nervous System Domain



■ Yes ■ Unsure ■ No

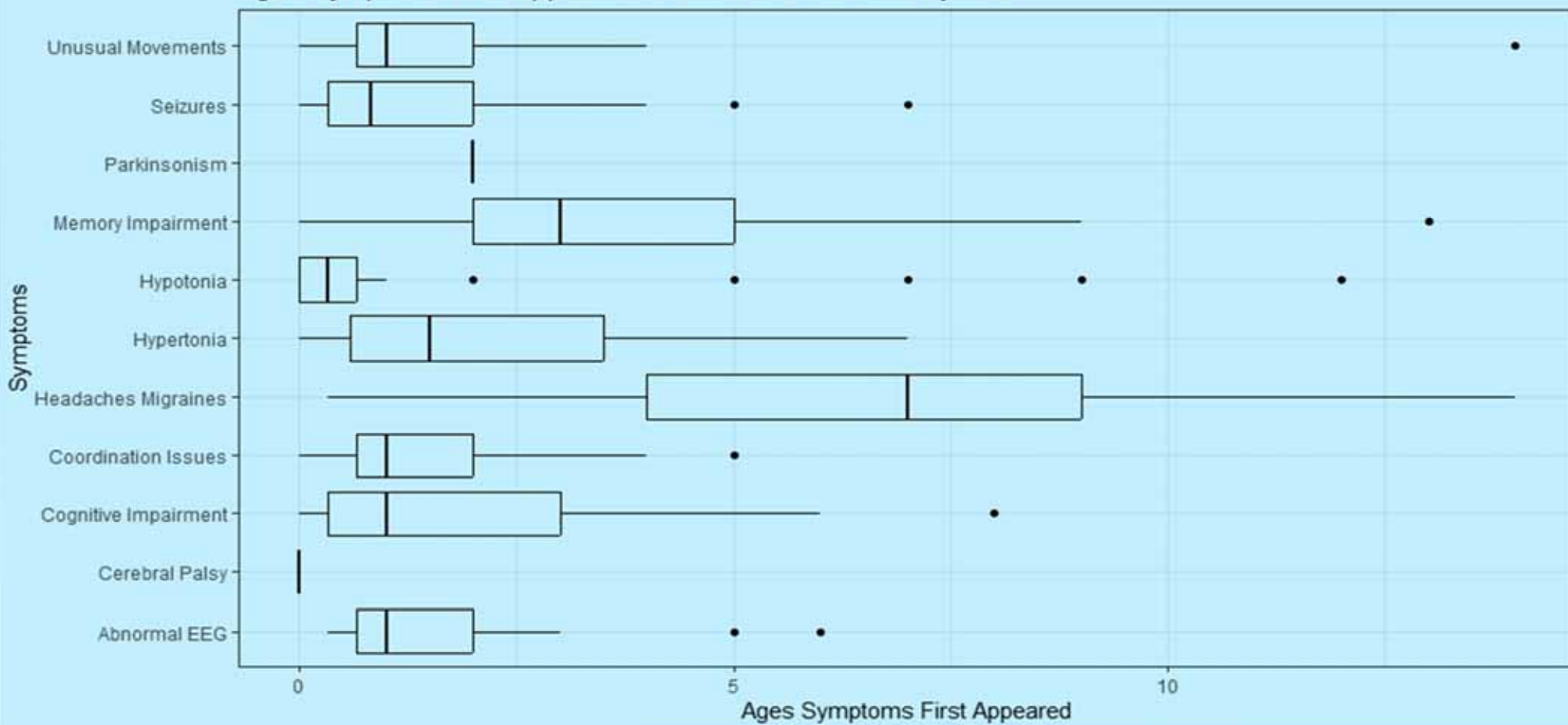
Total Complete: 80
 Surveys still Needed: 30



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Ages Symptoms First Appeared in Brain and Nervous System

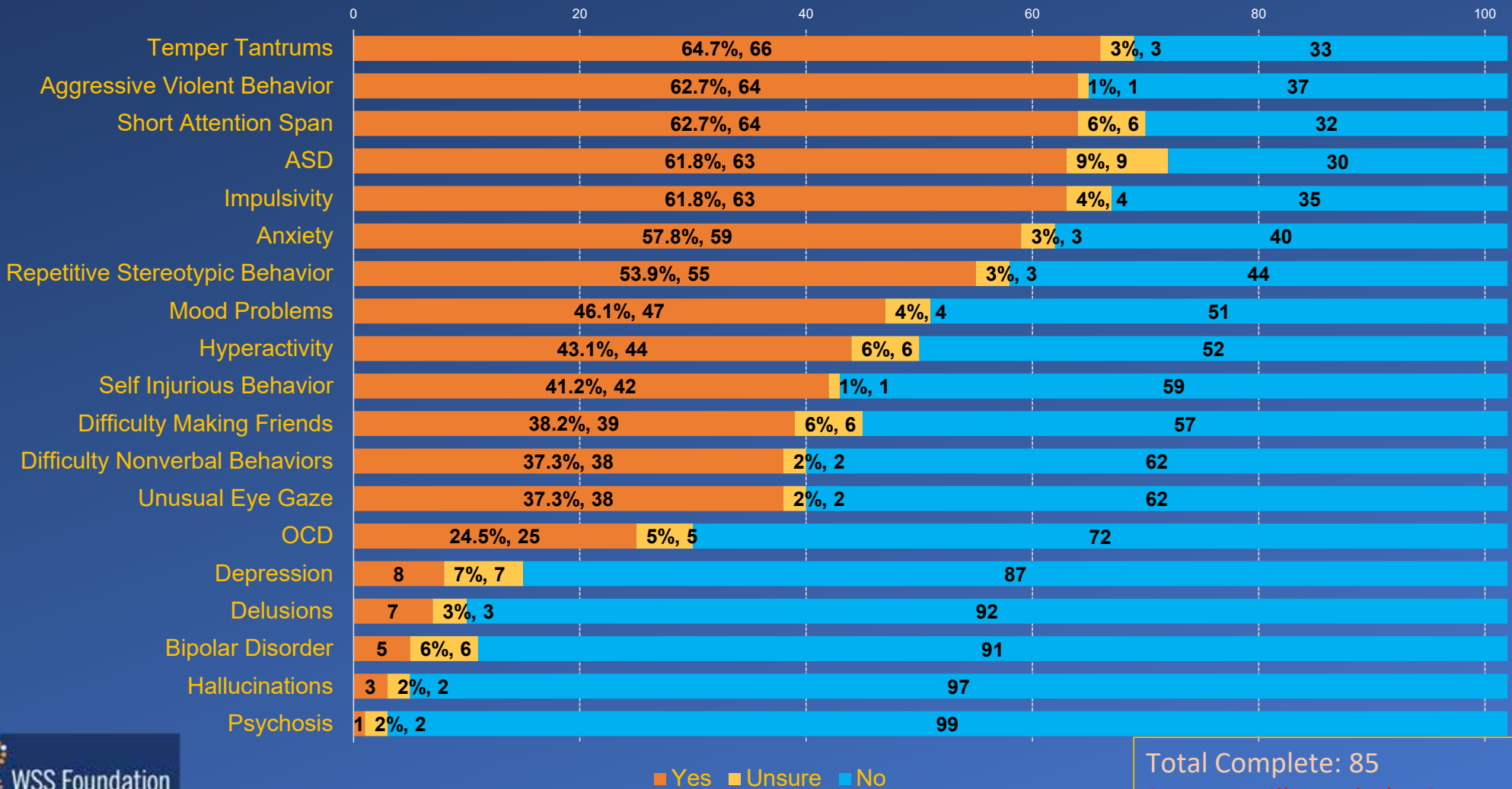


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

November 2023 Report



Symptoms reported in Behavior Domain



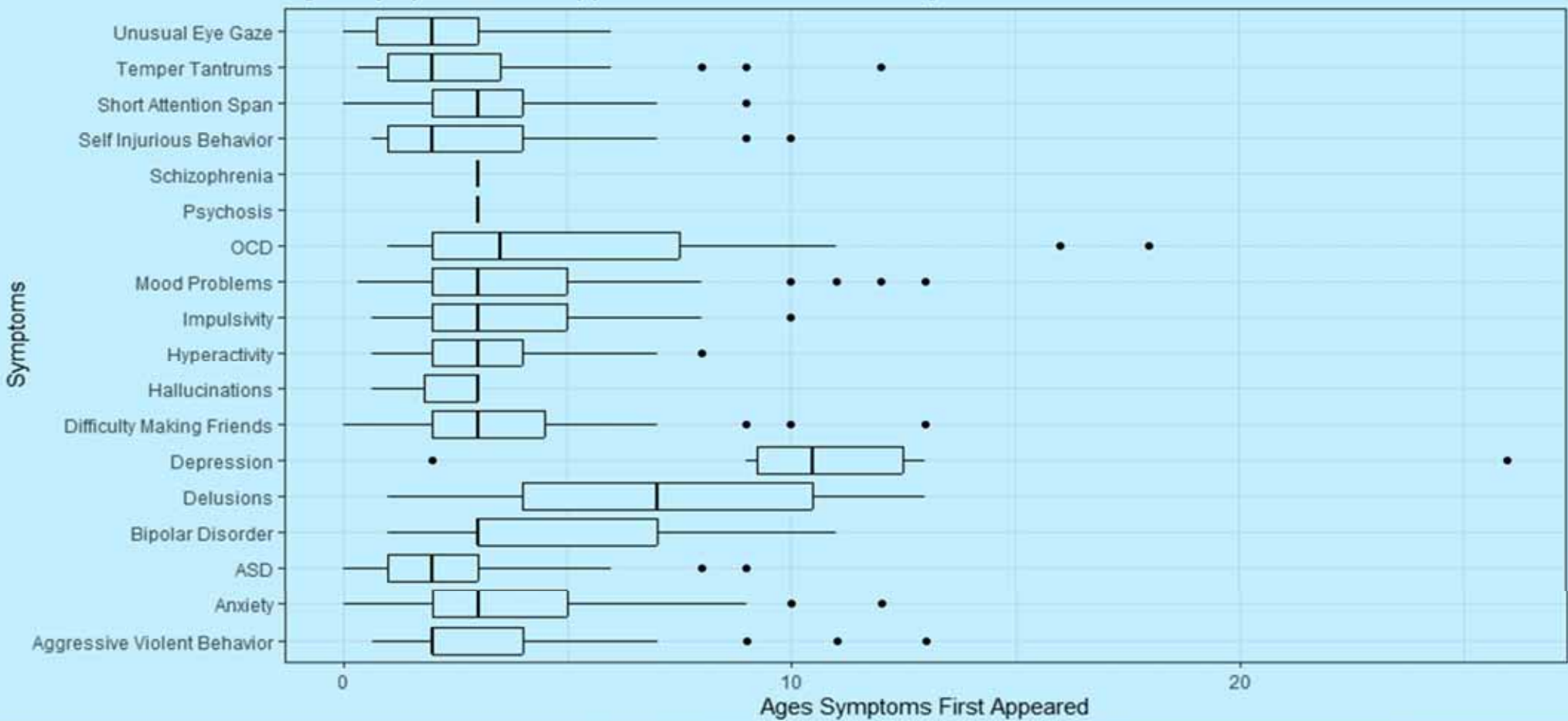
Total Complete: 85
 Surveys still Needed: 19



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



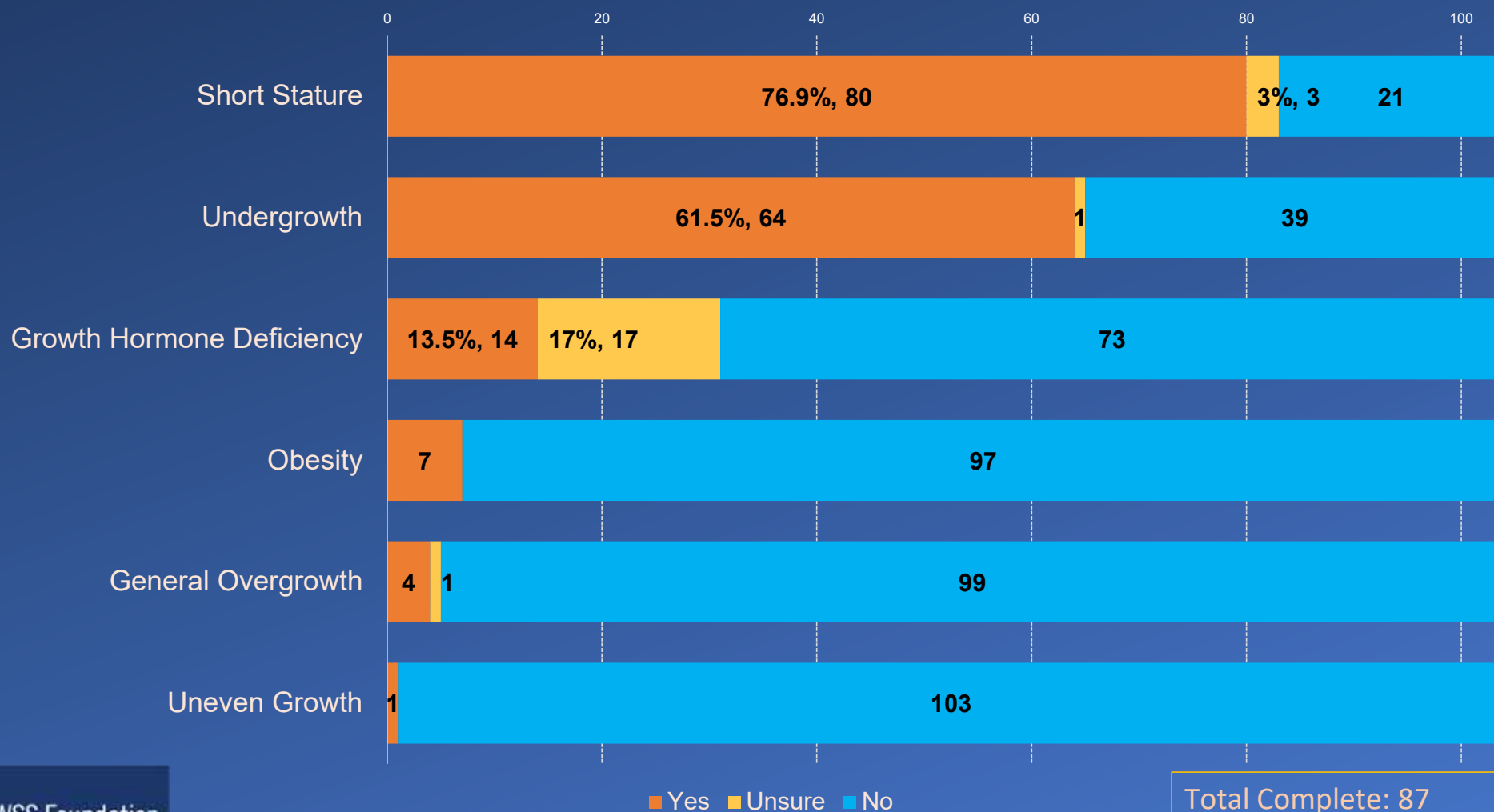
Ages Symptoms First Appeared in Behavior and Psychiatric Domain



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report

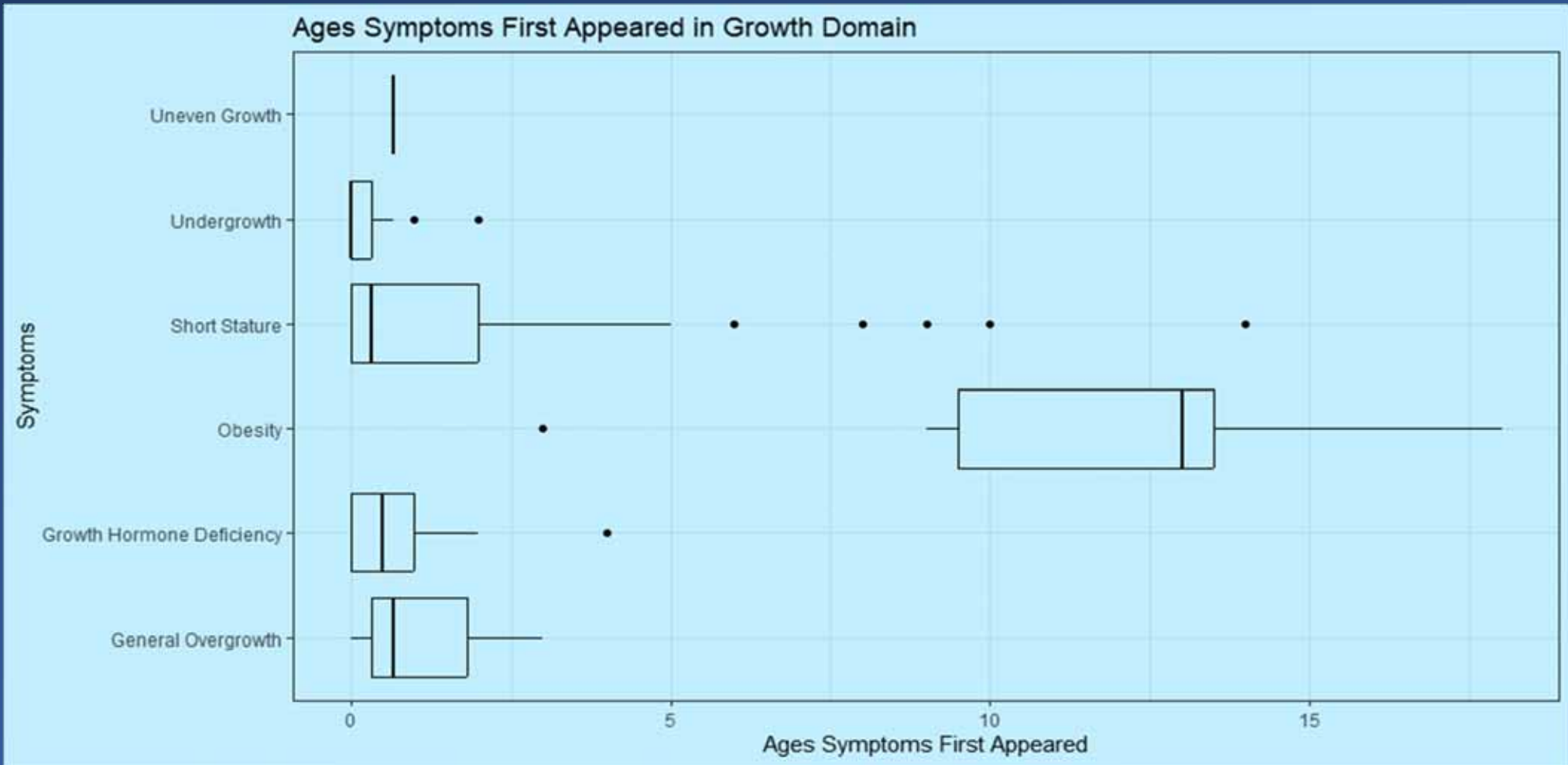


Symptoms reported in Growth Domain



Total Complete: 87
Surveys still Needed: 17

Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report

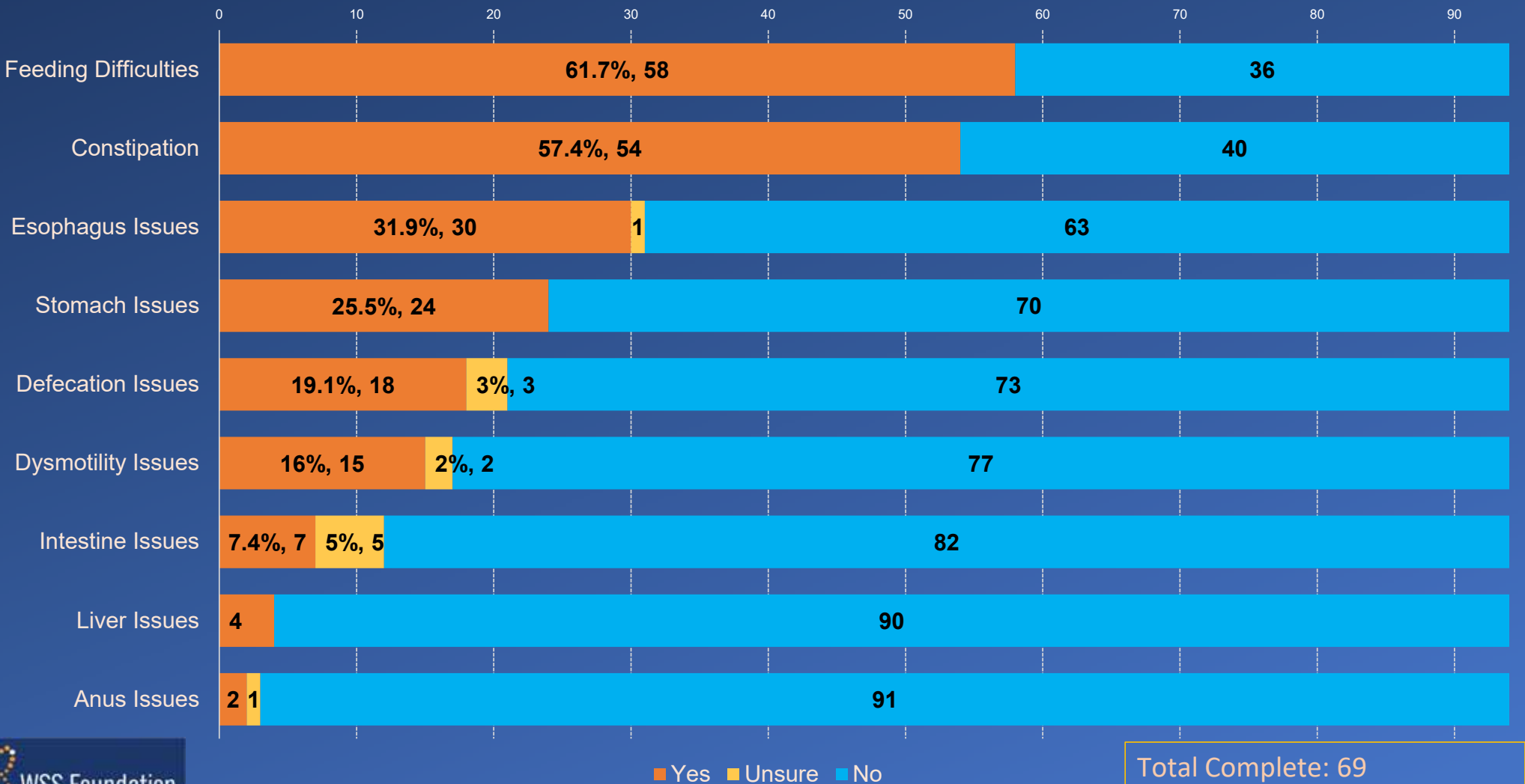


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

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Symptoms reported in Digestive System Domain



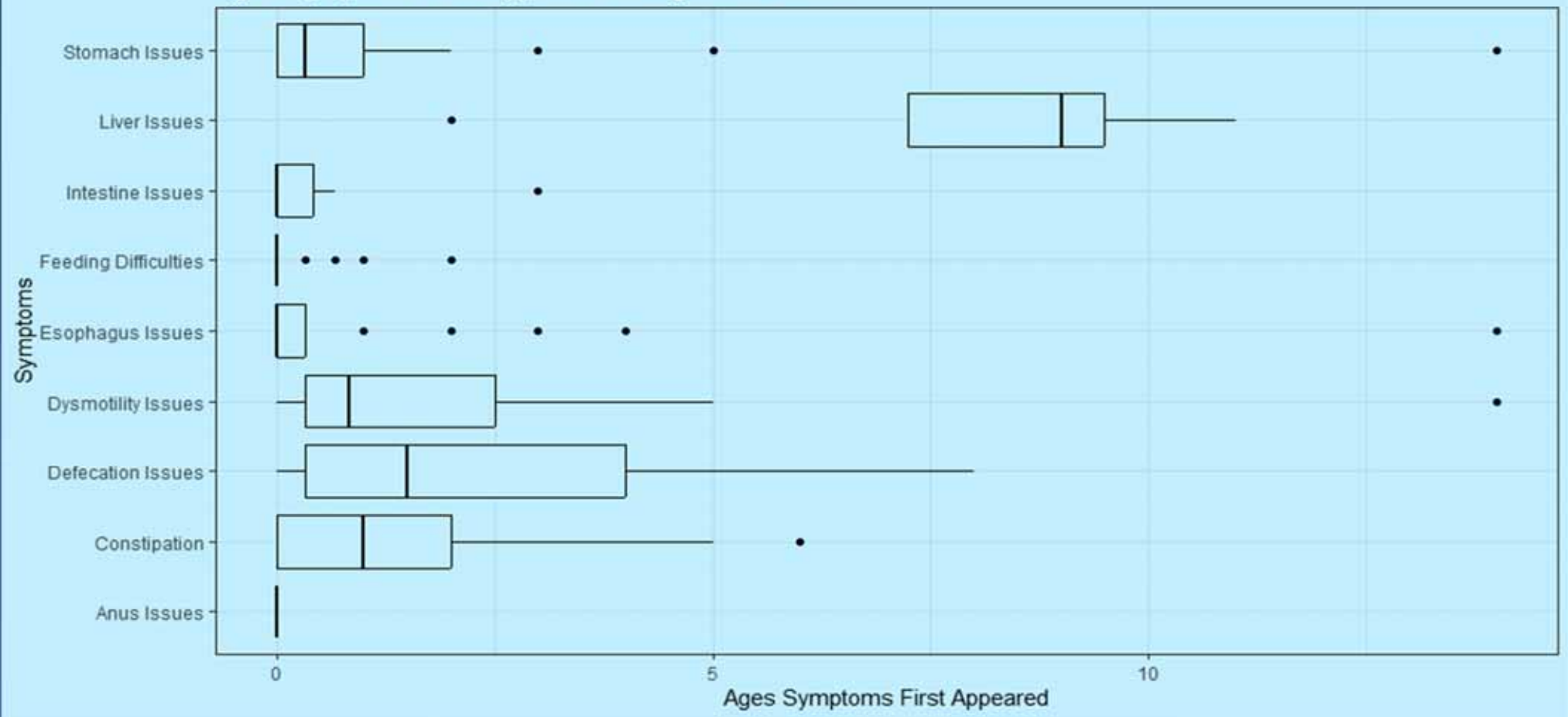
■ Yes
 ■ Unsure
 ■ No

Total Complete: 69
 Surveys still Needed: 27

Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Ages Symptoms First Appeared in Digestive Domain

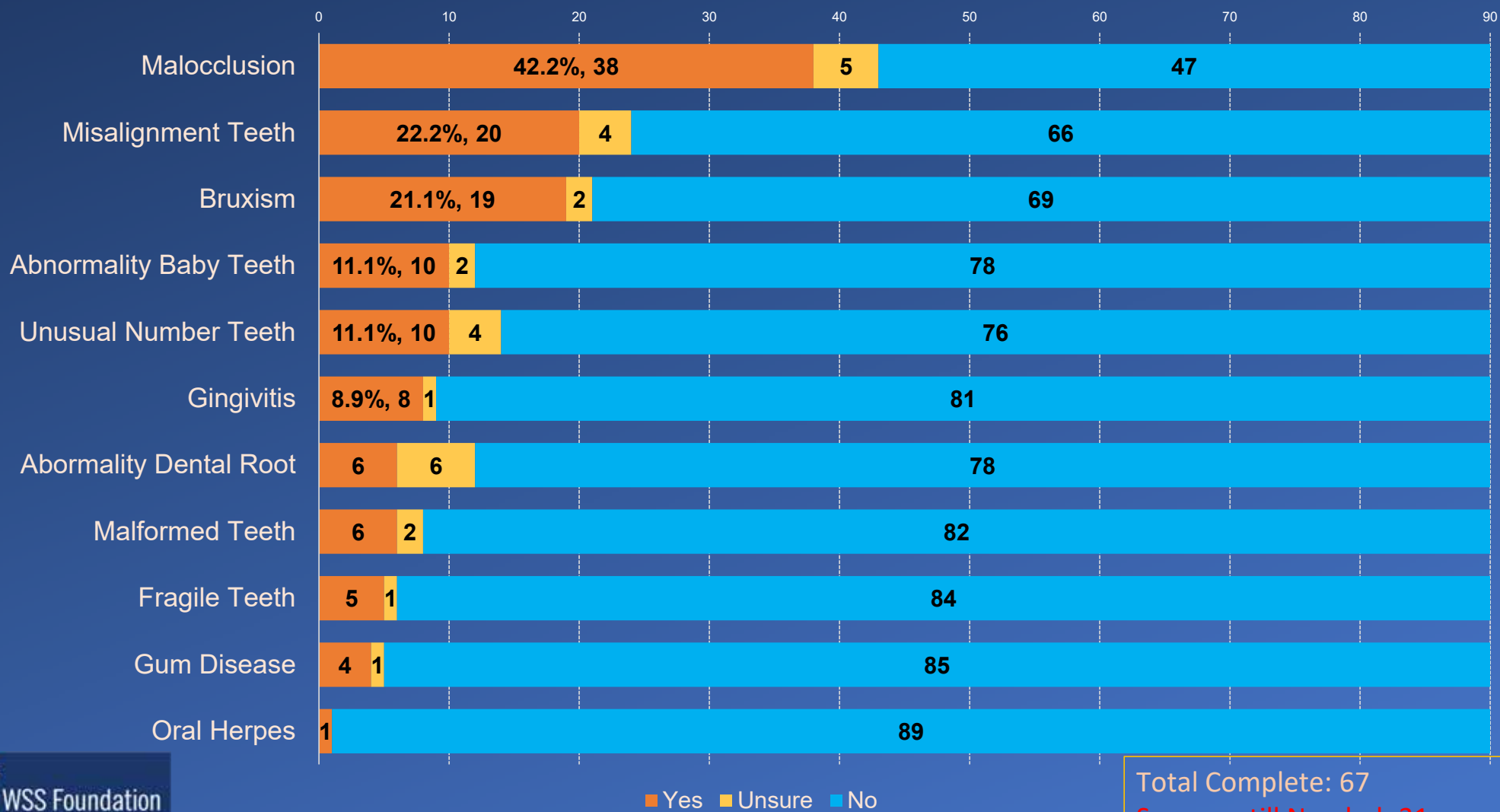


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

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Symptoms reported in Oral Health Domain

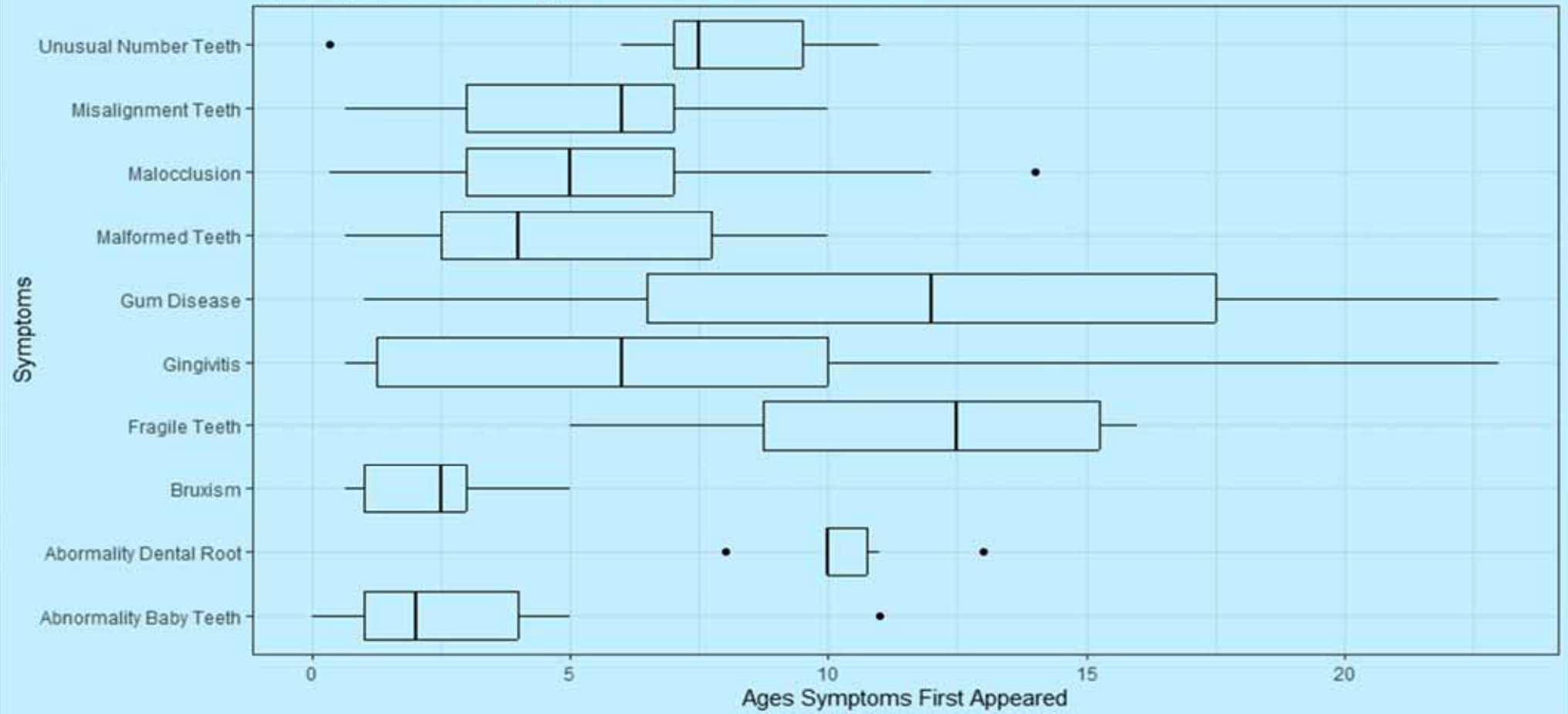


Total Complete: 67
 Surveys still Needed: 31

Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Ages Symptoms First Appeared in Oral Health Domain

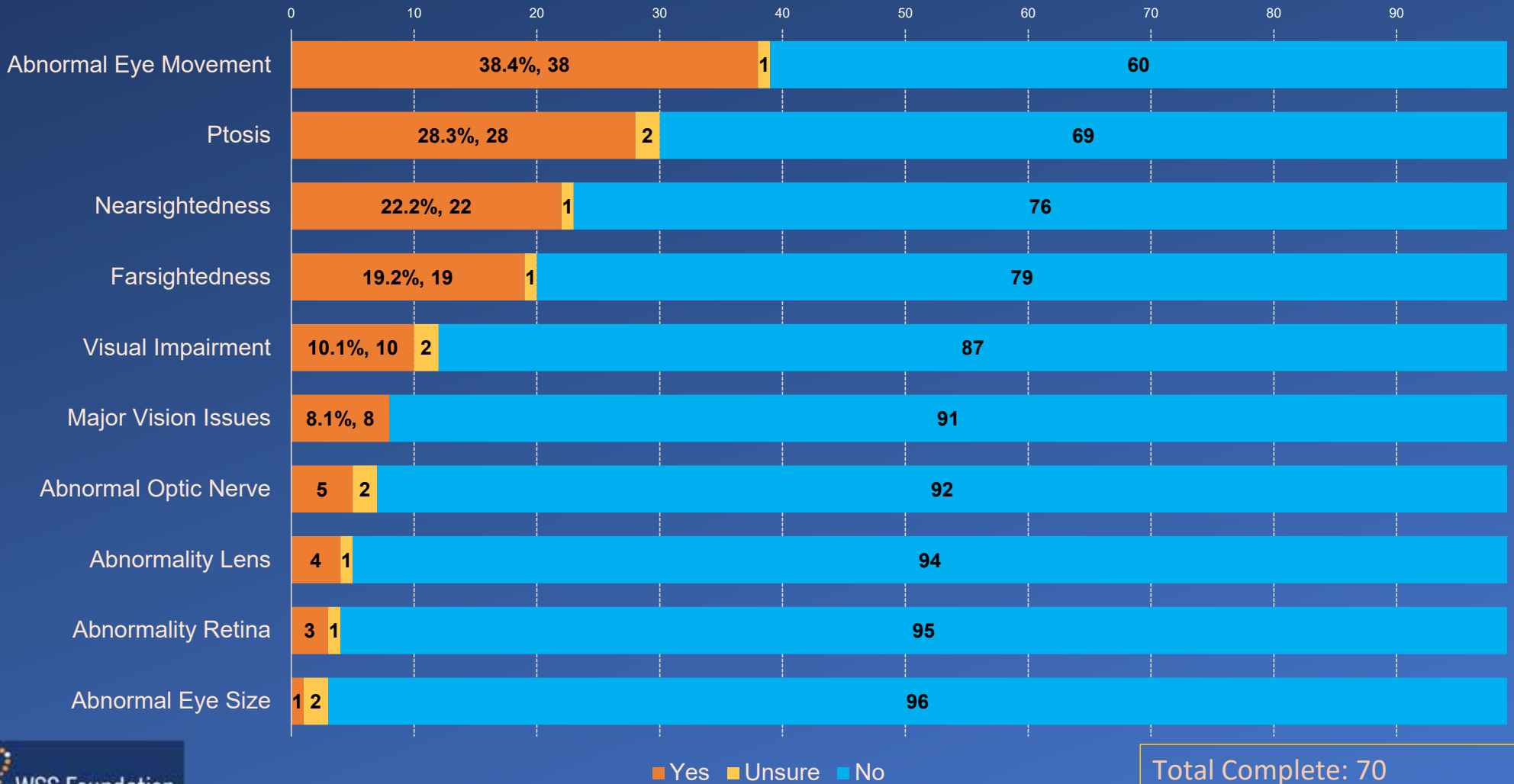


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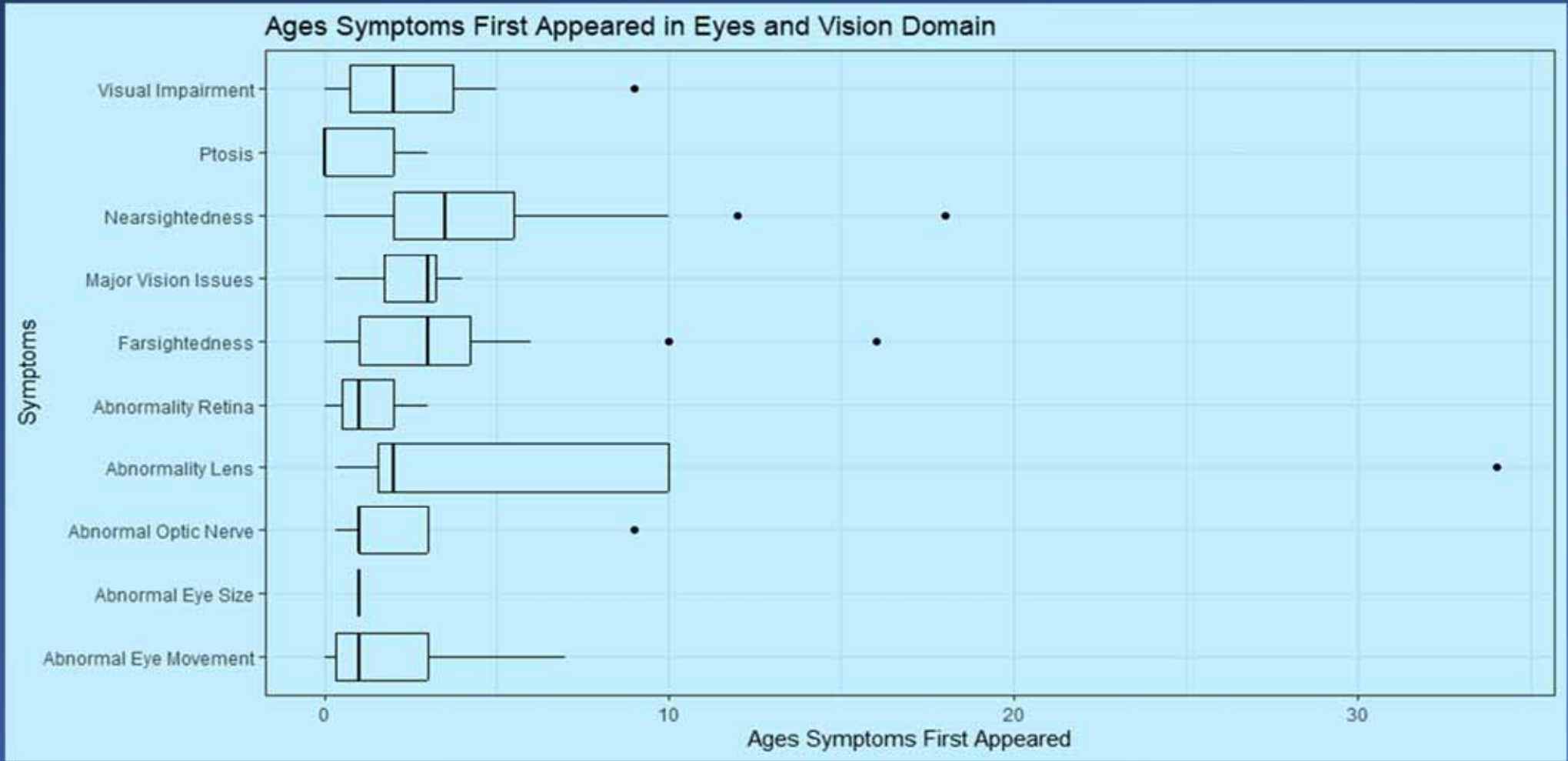
Symptoms reported in Eyes and Vision Domain



Yes Unsure No

Total Complete: 70
Surveys still Needed: 22

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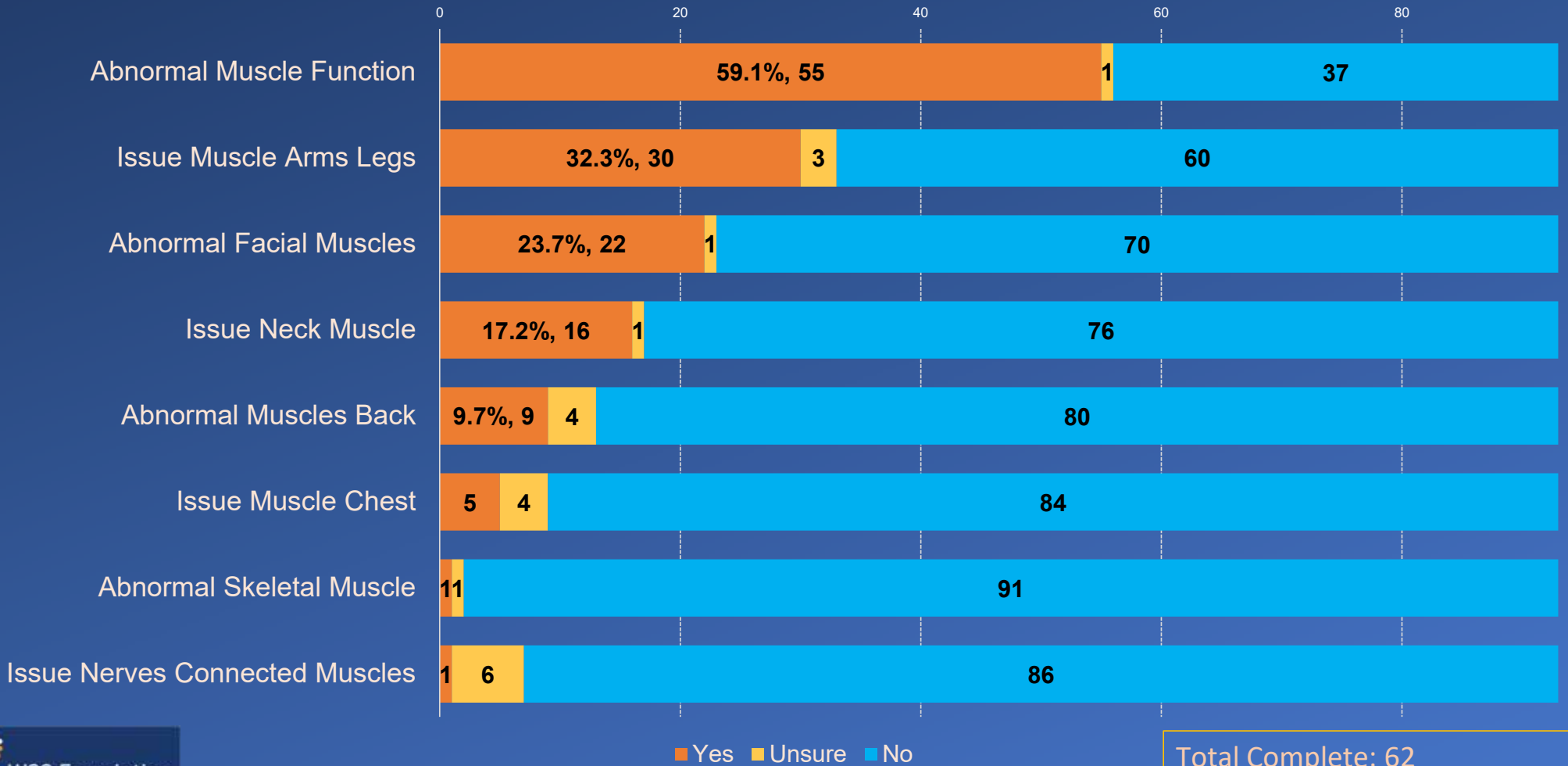


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

November 2023 Report



Symptoms reported in Muscles Domain



■ Yes
 ■ Unsure
 ■ No

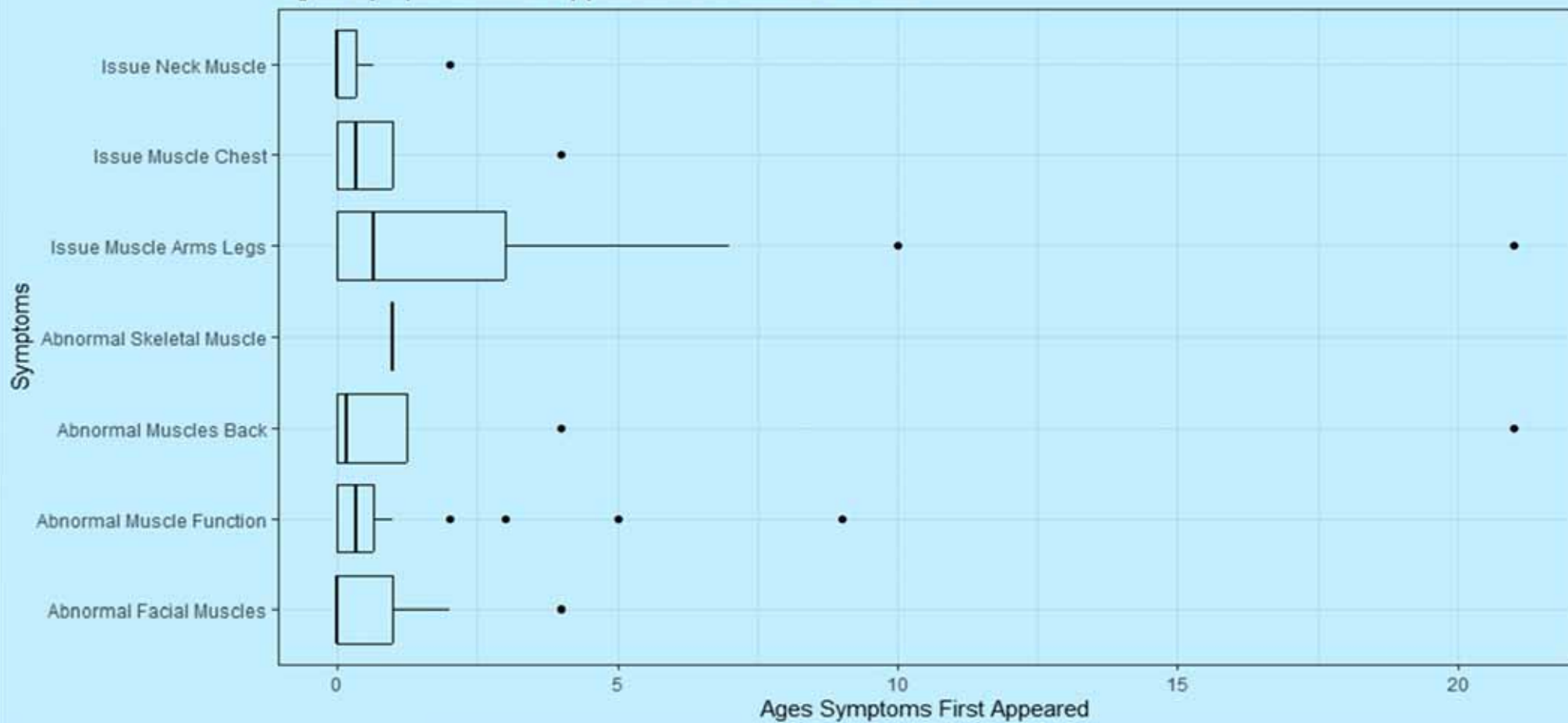
Total Complete: 62
 Surveys still Needed: 28



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Ages Symptoms First Appeared in Muscles Domain

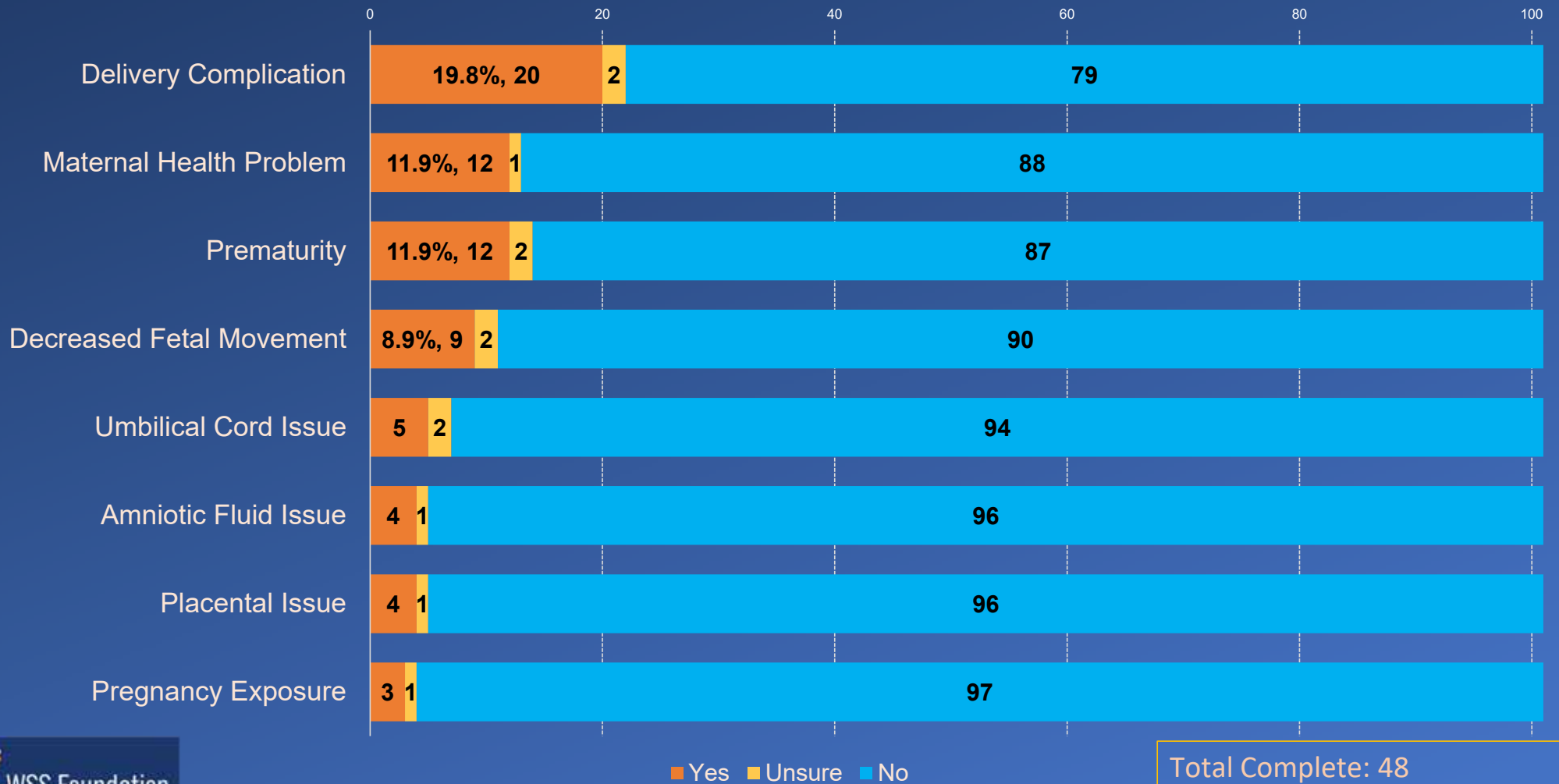


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

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Symptoms reported in Mother's Pregnancy Domain



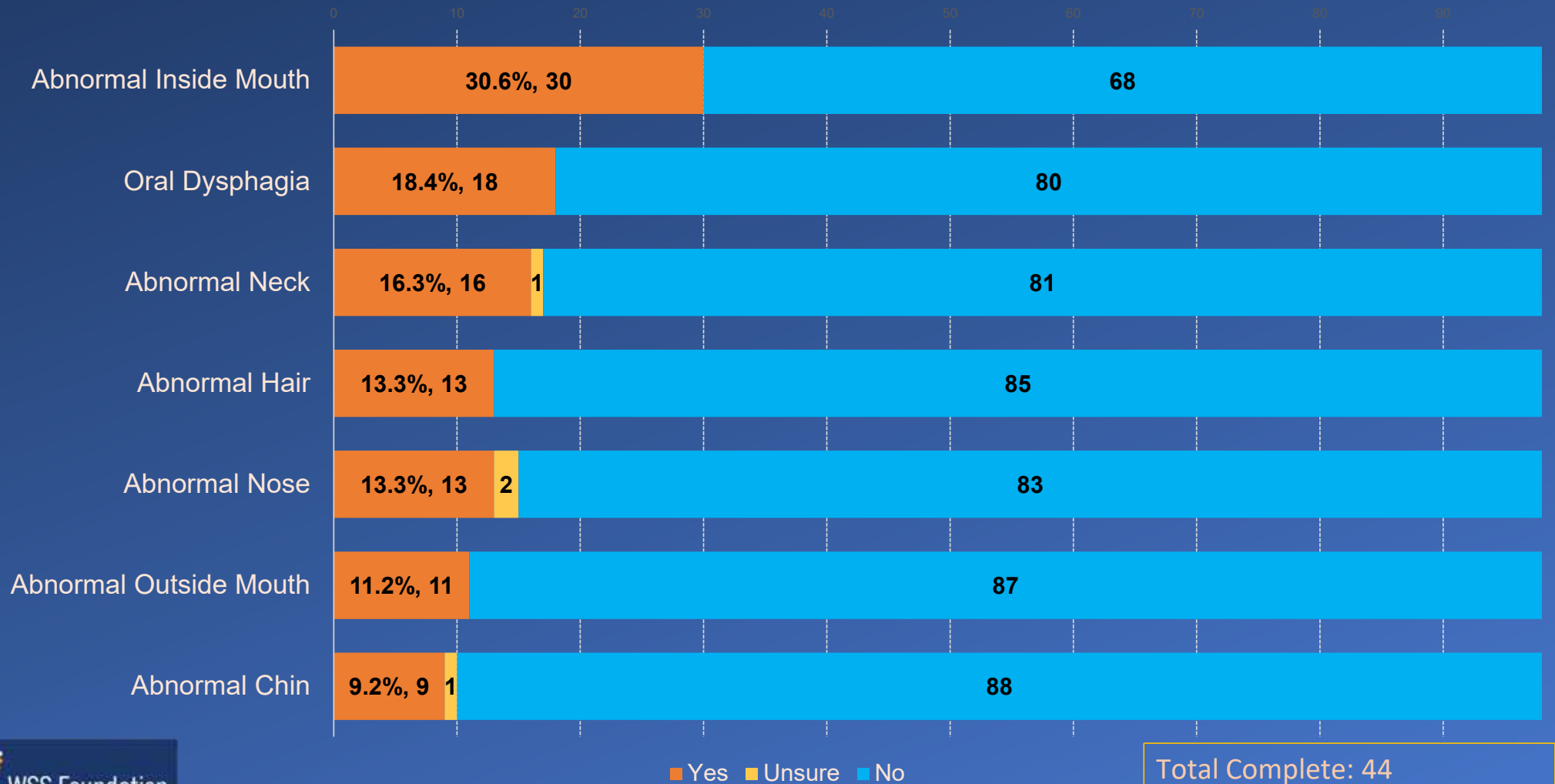
■ Yes ■ Unsure ■ No

Total Complete: 48
Surveys still Needed: 20

Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Symptoms reported in Head, Face, and Neck Domain



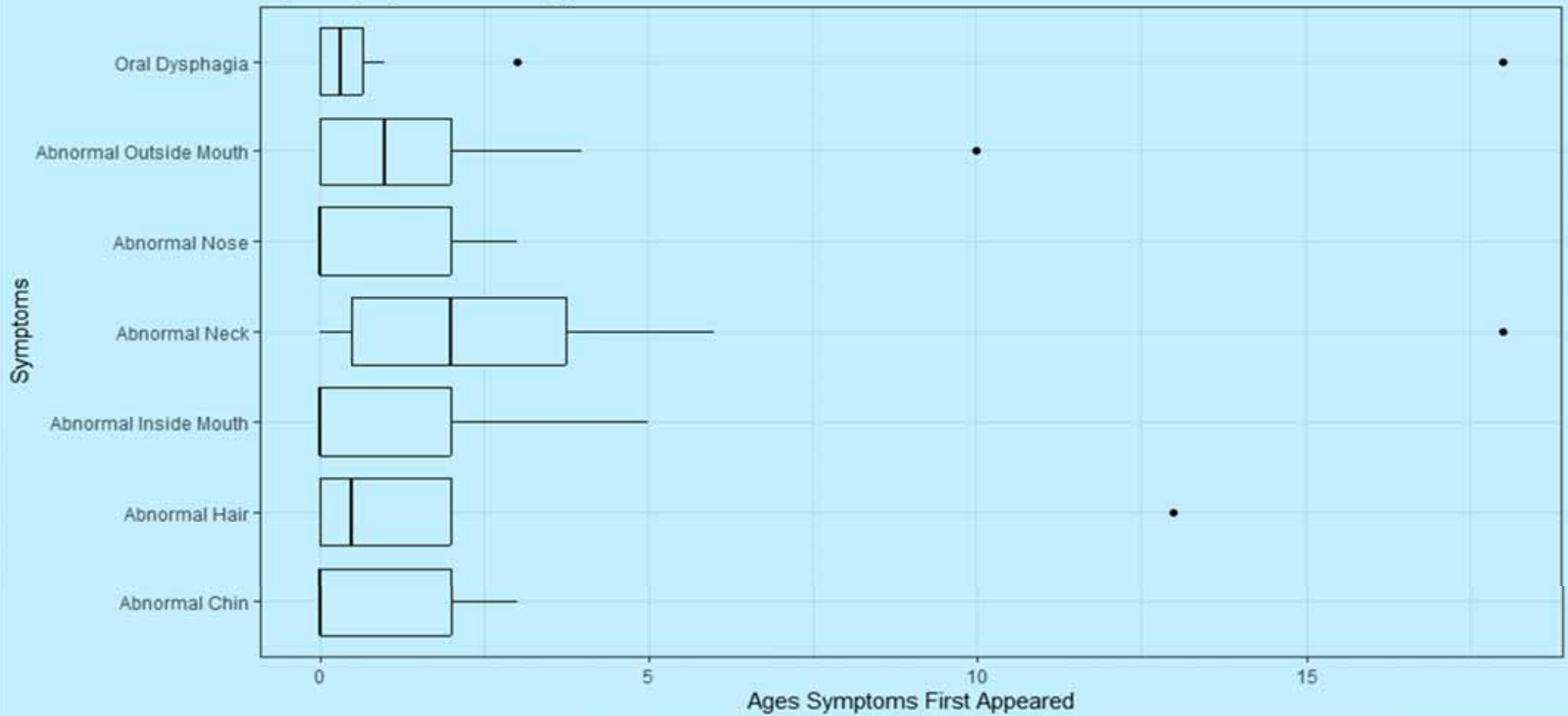
■ Yes ■ Unsure ■ No

Total Complete: 44
Surveys still Needed: 23

Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Ages Symptoms First Appeared in Head, Face, and Neck Domain

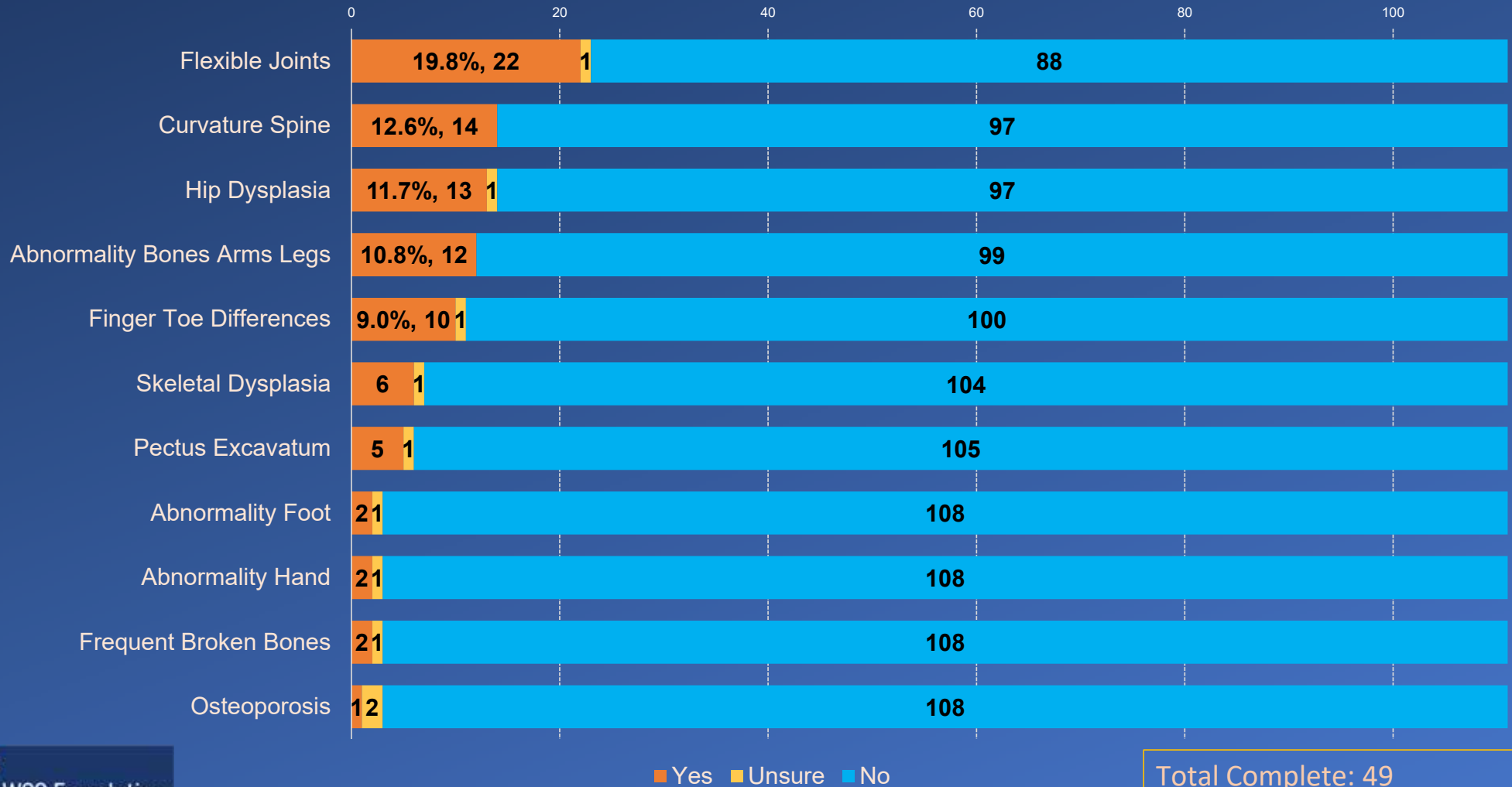


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

November 2023 Report



Symptoms reported in Bones Domain



■ Yes ■ Unsure ■ No

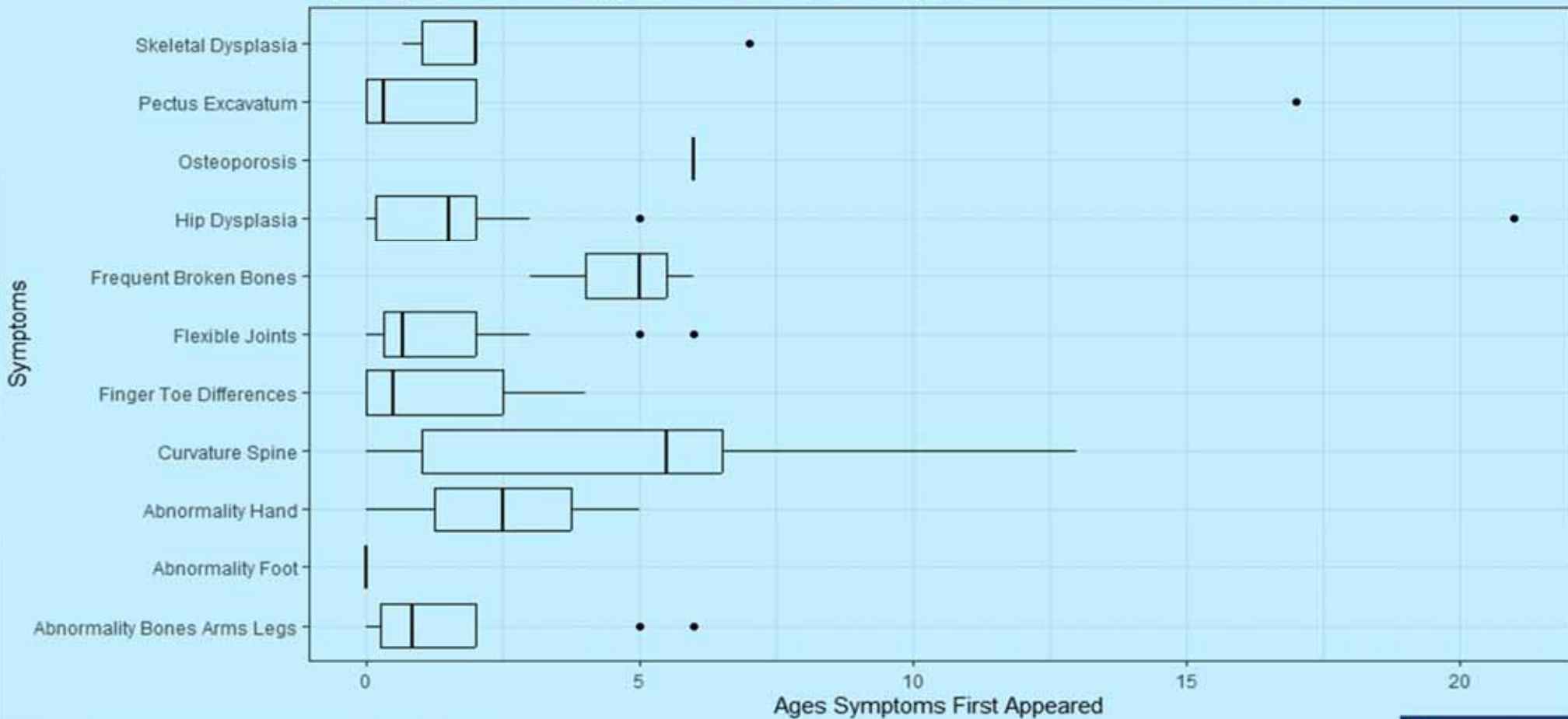
Total Complete: 49
 Surveys still Needed: 10



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



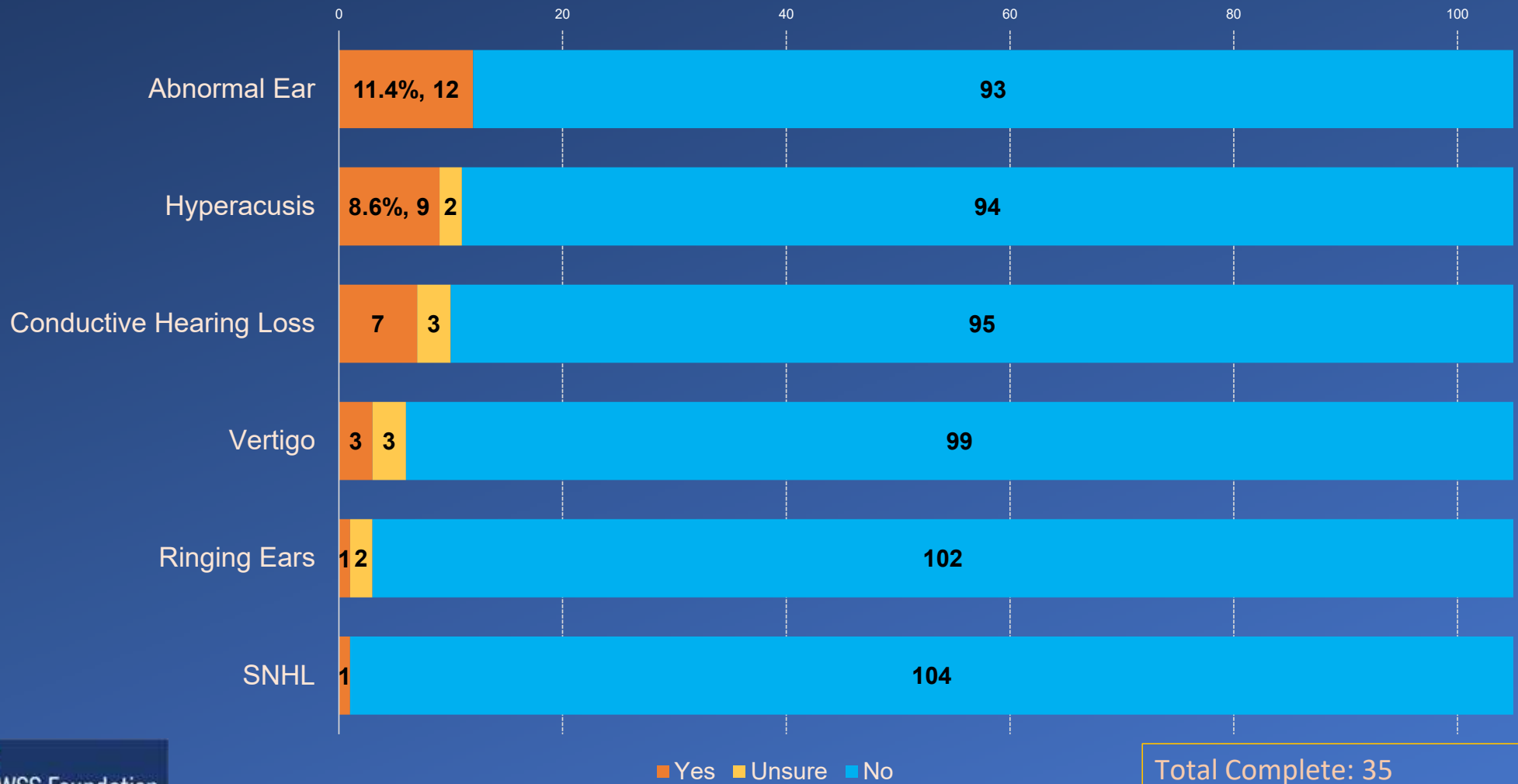
Ages Symptoms First Appeared in Bone, Cartilage, and Connective Tissue Domain



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Symptoms reported in Ears and Hearing Domain

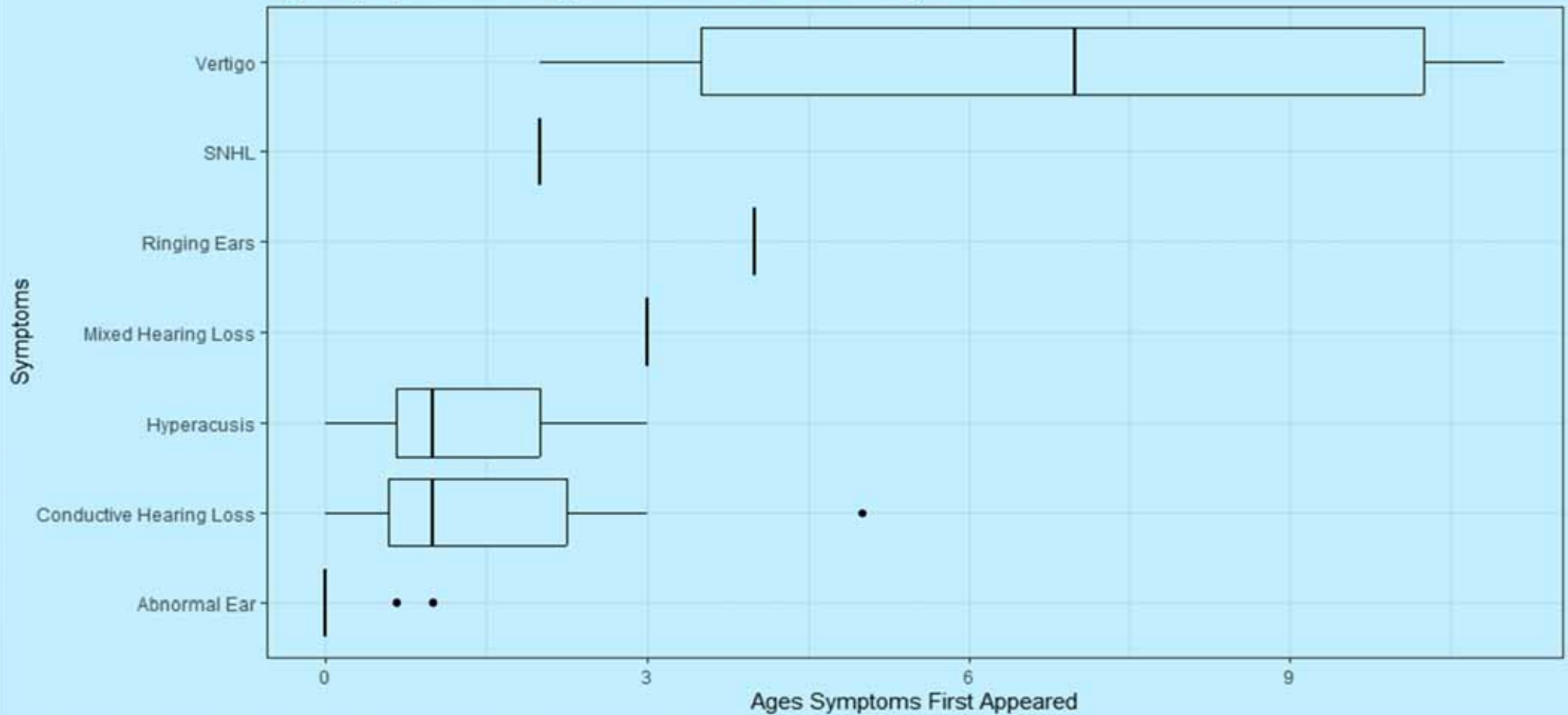


Total Complete: 35
Surveys still Needed: 16

Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



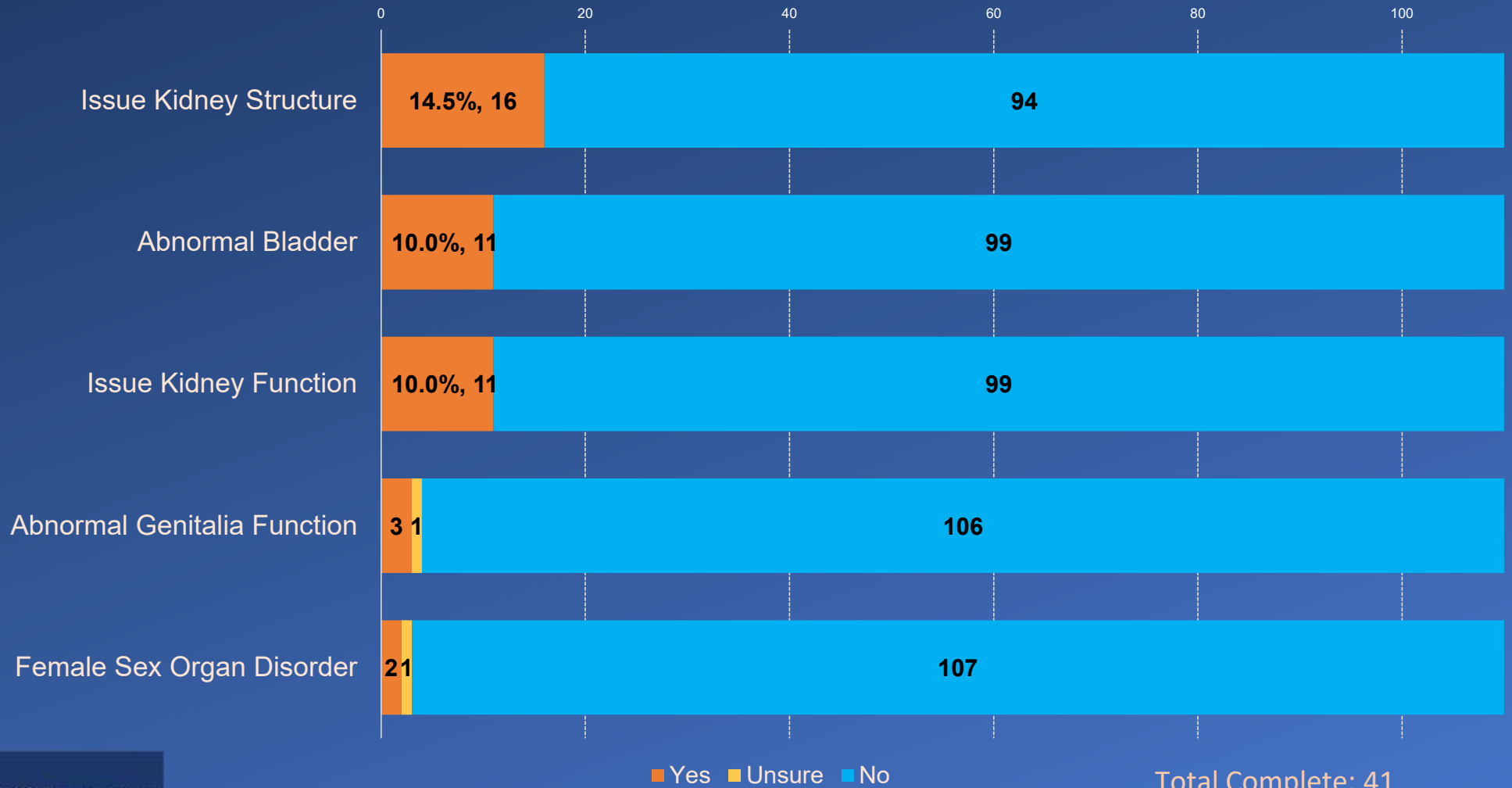
Ages Symptoms First Appeared in Ears and Hearing Domain



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Symptoms reported in Kidney, Bladder, and Genitals Domain



■ Yes ■ Unsure ■ No

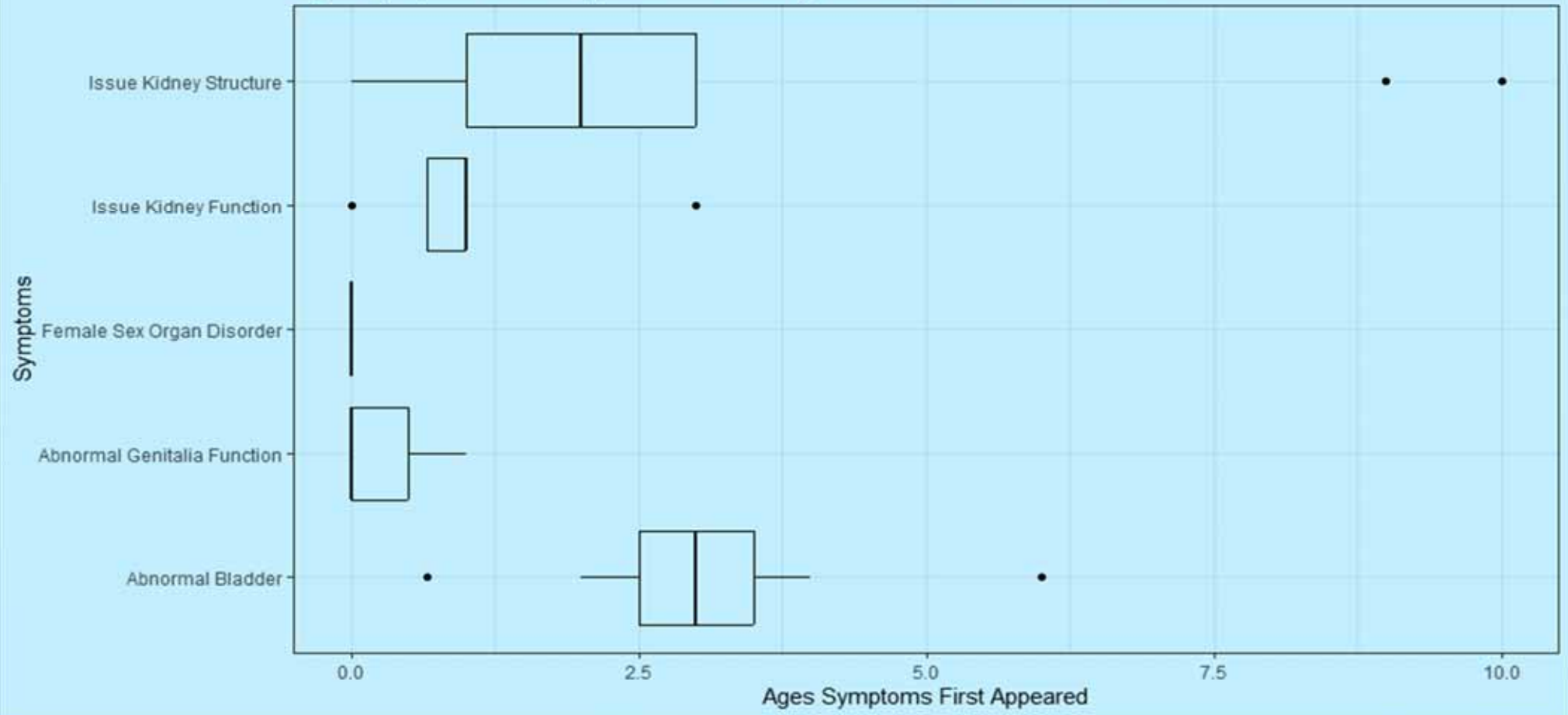
Total Complete: 41
Surveys still Needed: 11



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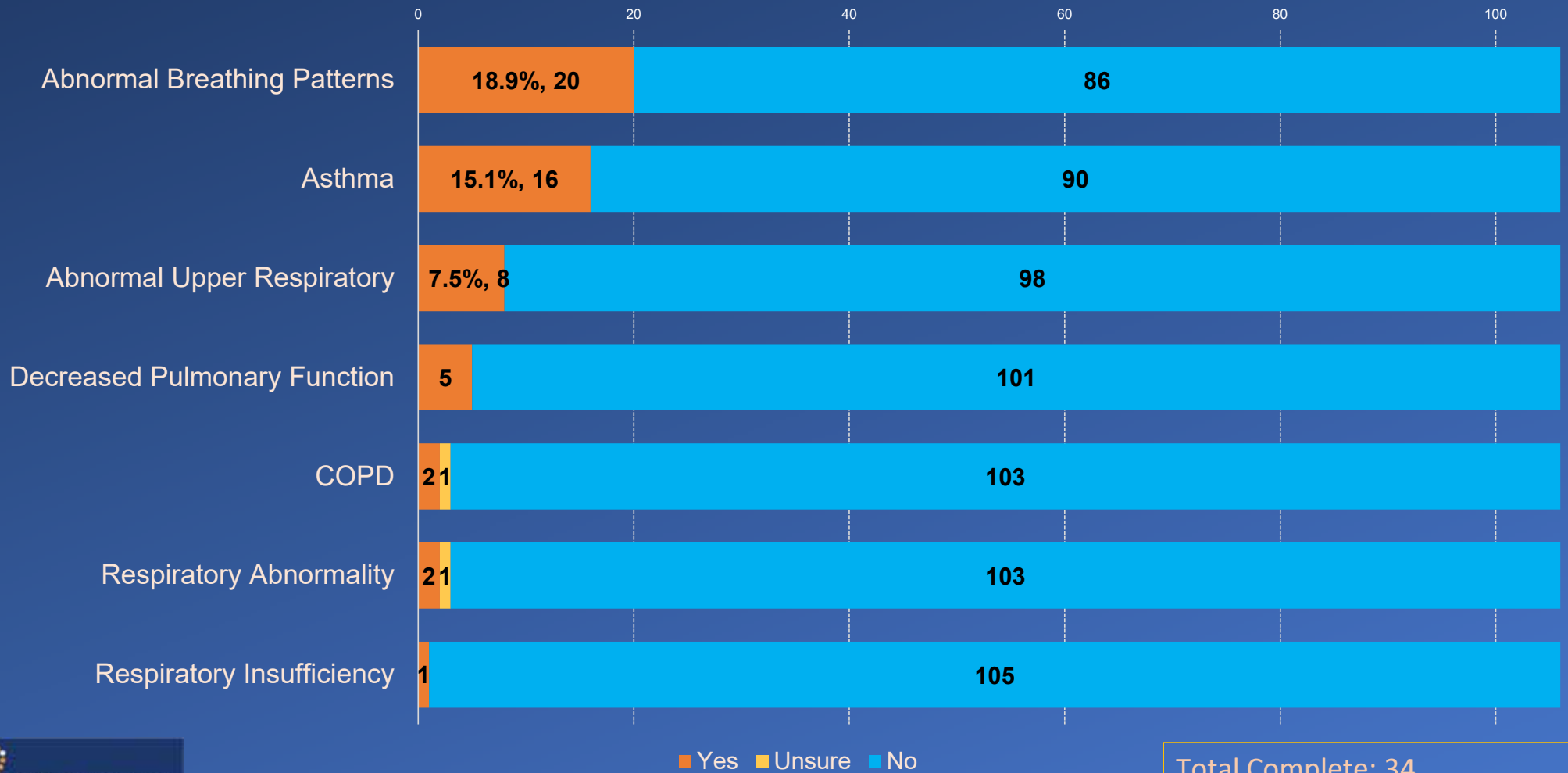
Ages Symptoms First Appeared in Kidney, Bladder, and Genitals Domain



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



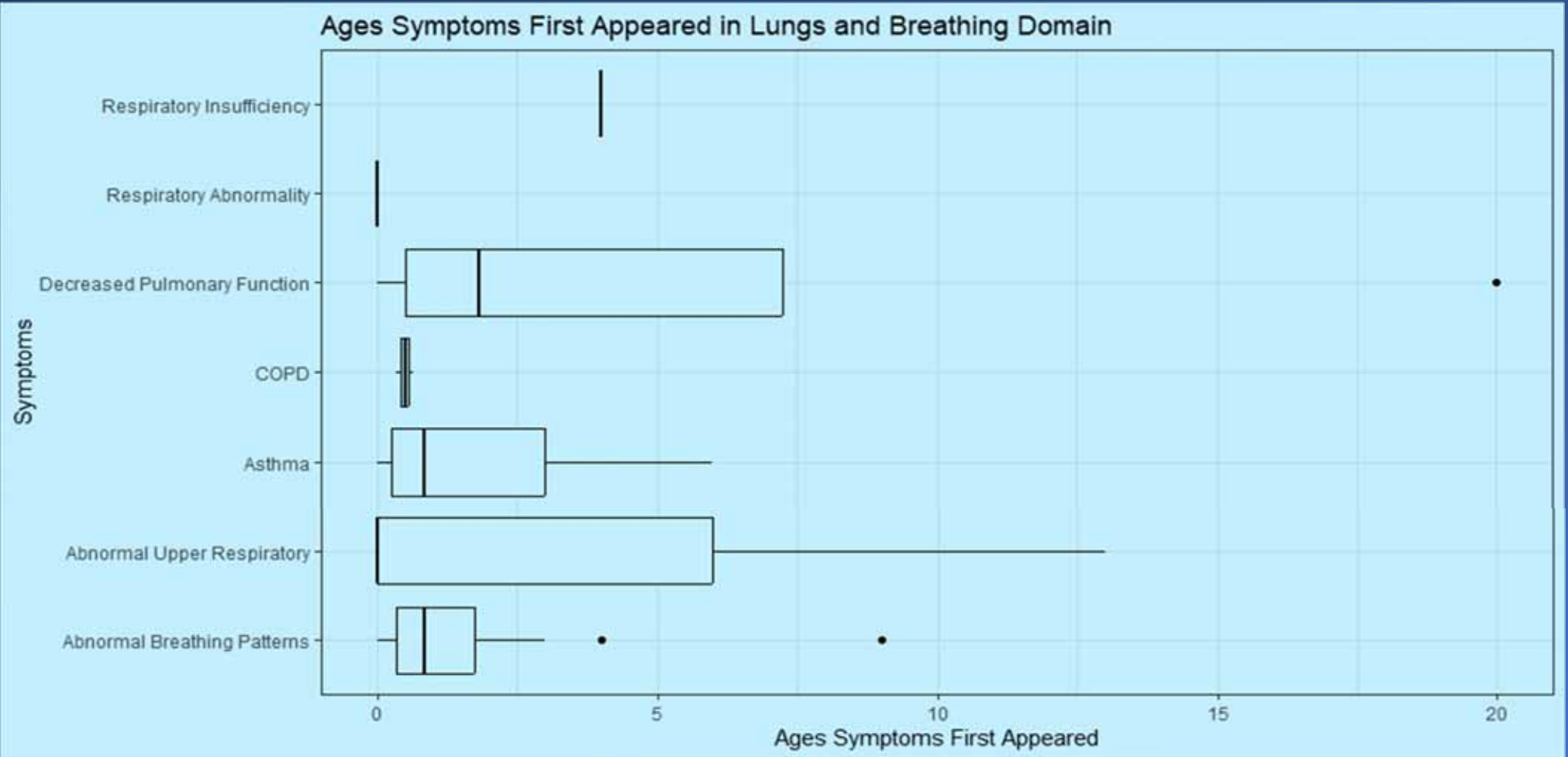
Symptoms reported in Lungs and Breathing Domain



Total Complete: 34
Surveys still Needed: 15



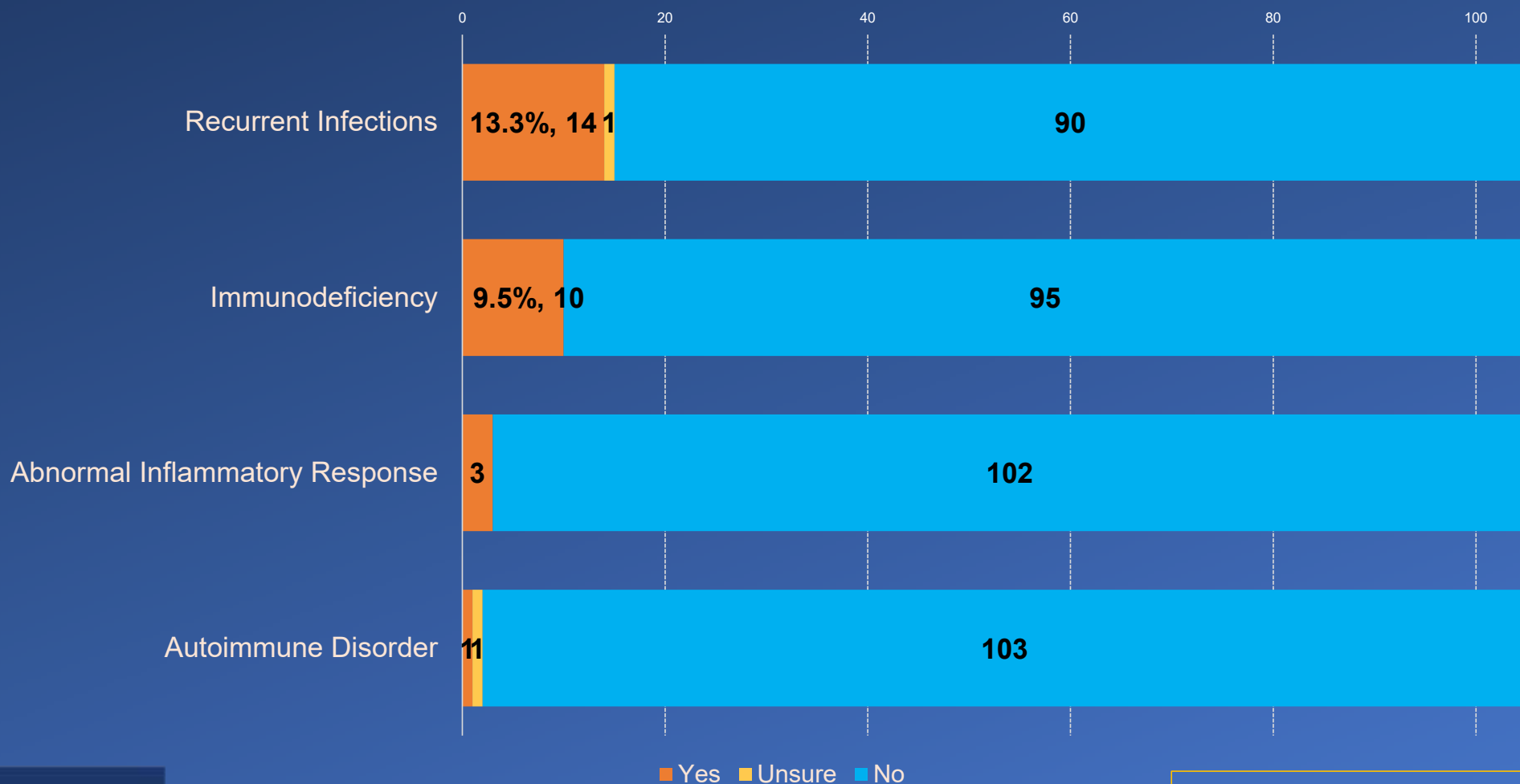
Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Symptoms reported in Immune System Domain



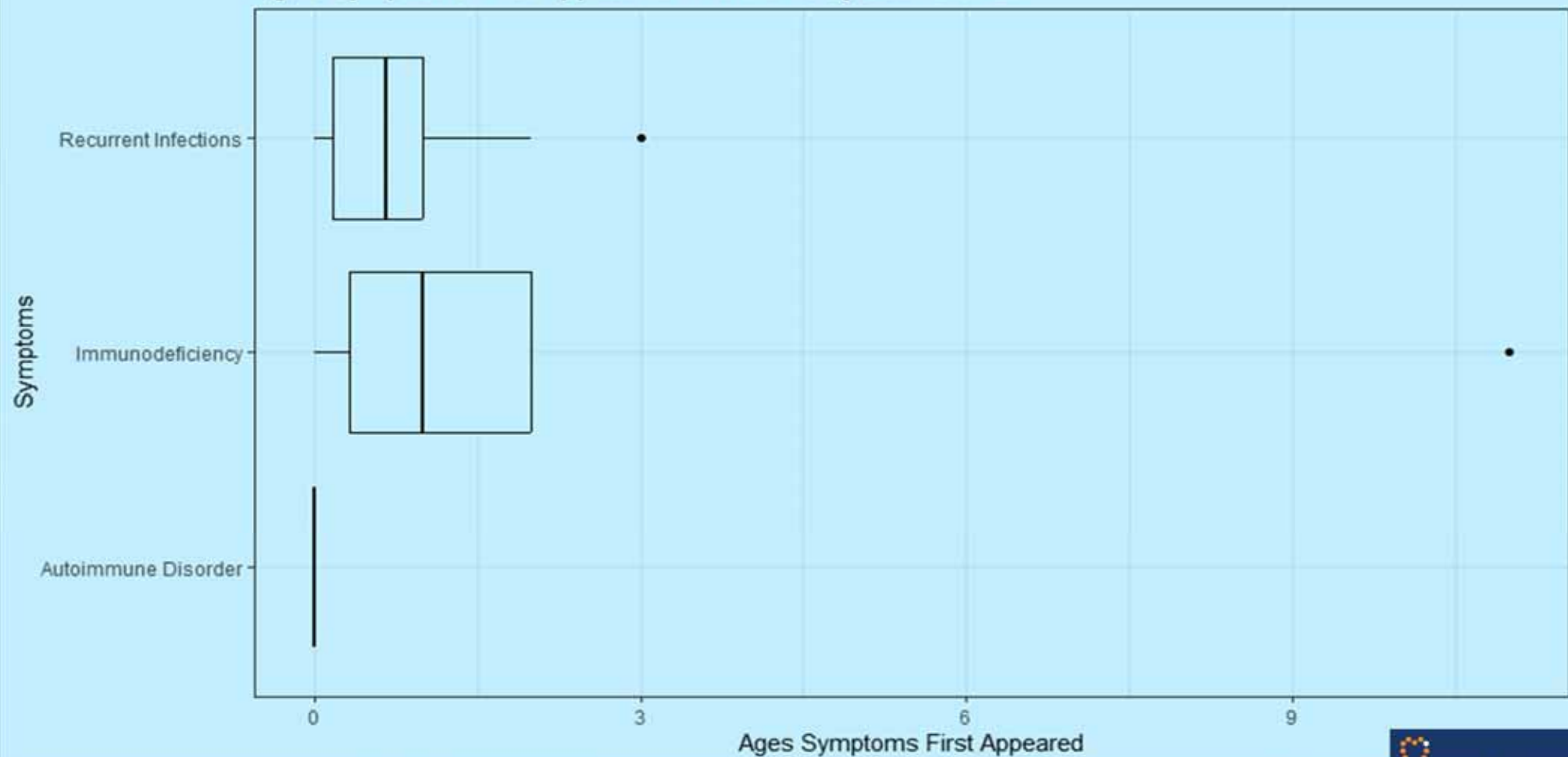
Total Complete: 32
Surveys still Needed: 16



Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Ages Symptoms First Appeared in Immune System Domain

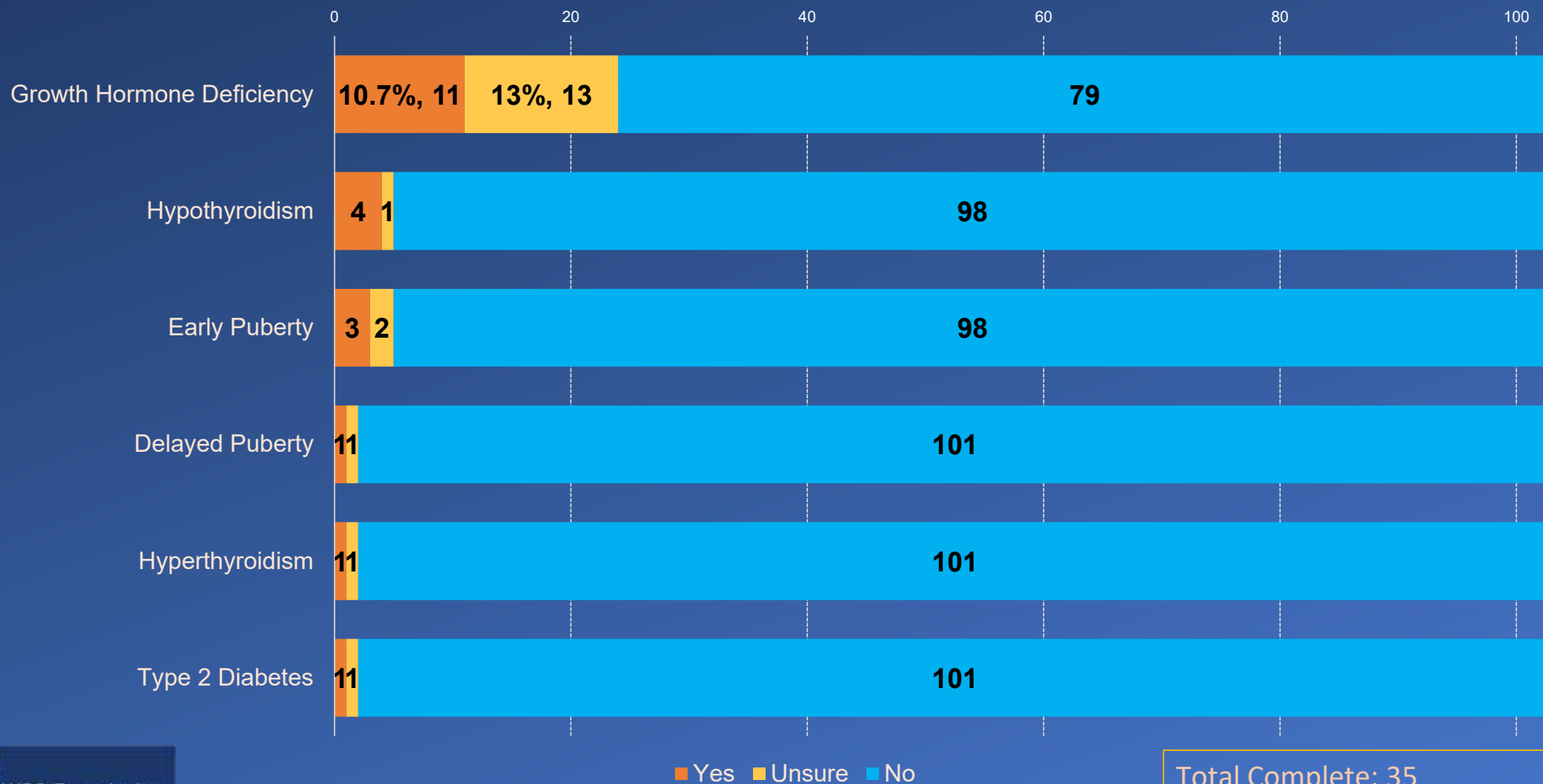


Wiedemann-Steiner Syndrome (WSS) Data Collection Program

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Symptoms reported in Hormone and Endocrine Domain

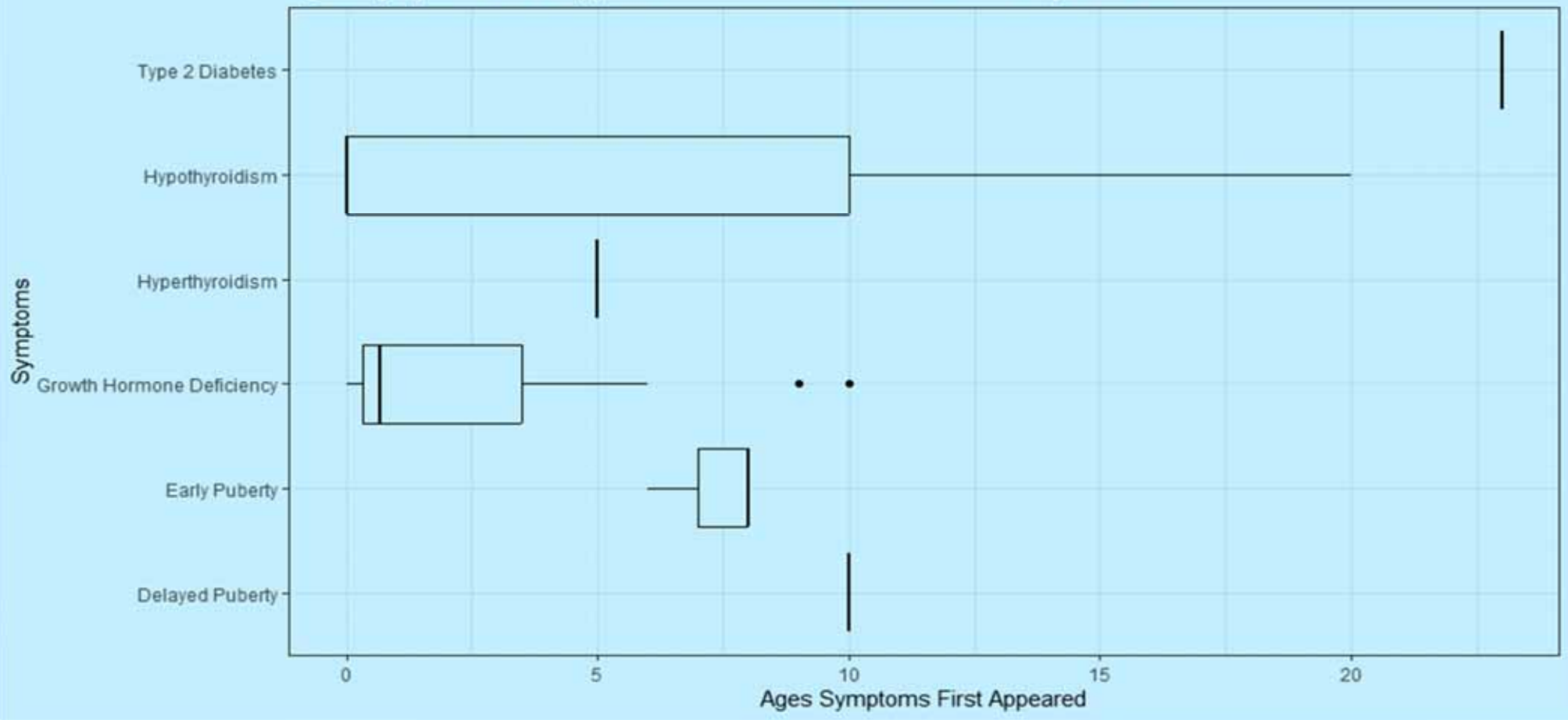


Total Complete: 35
Surveys still Needed: 18

Wiedemann-Steiner Syndrome (WSS) Data Collection Program November 2023 Report



Ages Symptoms First Appeared in Hormone and Endocrine System Domain





For more information:
www.wssfoundation.org or
info@wssfoundation.org

To participate, enroll at: wss.rare-x.org