



OMS Patient Registry – Natural History Study

Details on OMS Onset to Date – August 20, 2017

Disclosures:

NORD has provided a five year grant to The OMSLife Foundation to develop the Patient Registry

The OMS Registry is stored in a NORD database and follows all the standard practices of a medical database

All surveys, graphs, reports, etc... are approved by Hummingbird IRB

The charts represent simple graphs and analytics with minimal amount of data - Detailed data analytics will be forthcoming in the future once we acquire more data!!!!

Special thanks to **NORD** for providing a grant to develop the OMS patient registry and

The **Board of Directors at OMSLife Foundation** for funding the additional expenses associated with the OMS patient registry

Special thanks to our Project Team:

Brooke D'Souza

Christy Dennis

Kellee Miller

And our **Medical Advisory Team:**

Dr. Wendy Mitchell

Dr. Mark Gorman

Dr. Tim Lotze

Dr. Marc Tardieu

Dr. Anne Berg

Discussion on first impressions of the Registry Data....

The issue:

We need a cure for OMS!!!

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What if we really need consistent application of diagnosis, treatment, and therapies for many OMS warriors?

Discussion on first impressions of the Registry Data....

The issue:
We need a cure for OMS!!!

What if we have the cure and need consistent application of diagnosis, treatment, and therapies?

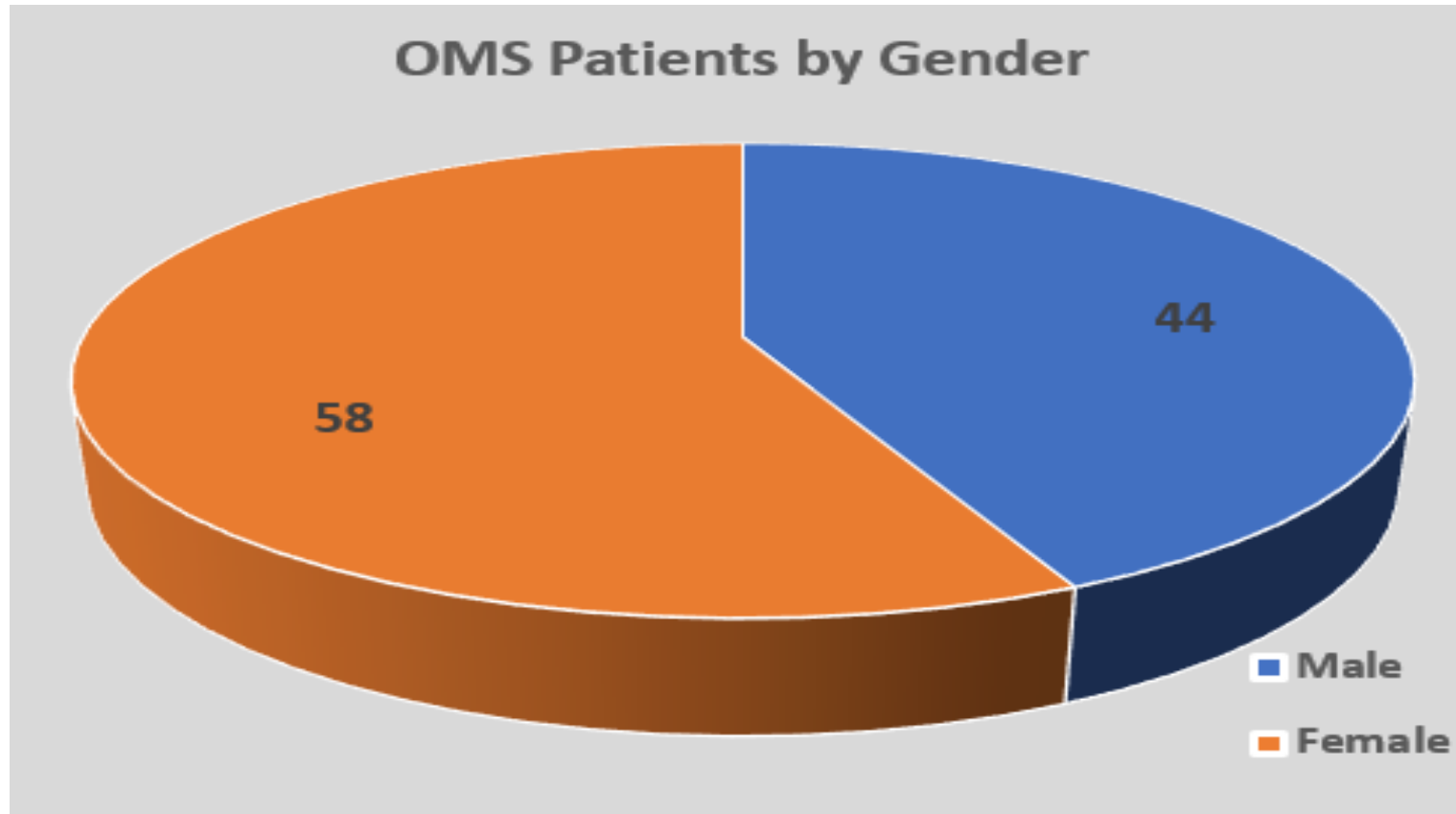
Collecting data over a long period of time can help us see trends in quality of life. That is the purpose of a patient reported registry

So let's look at some of the initial findings....

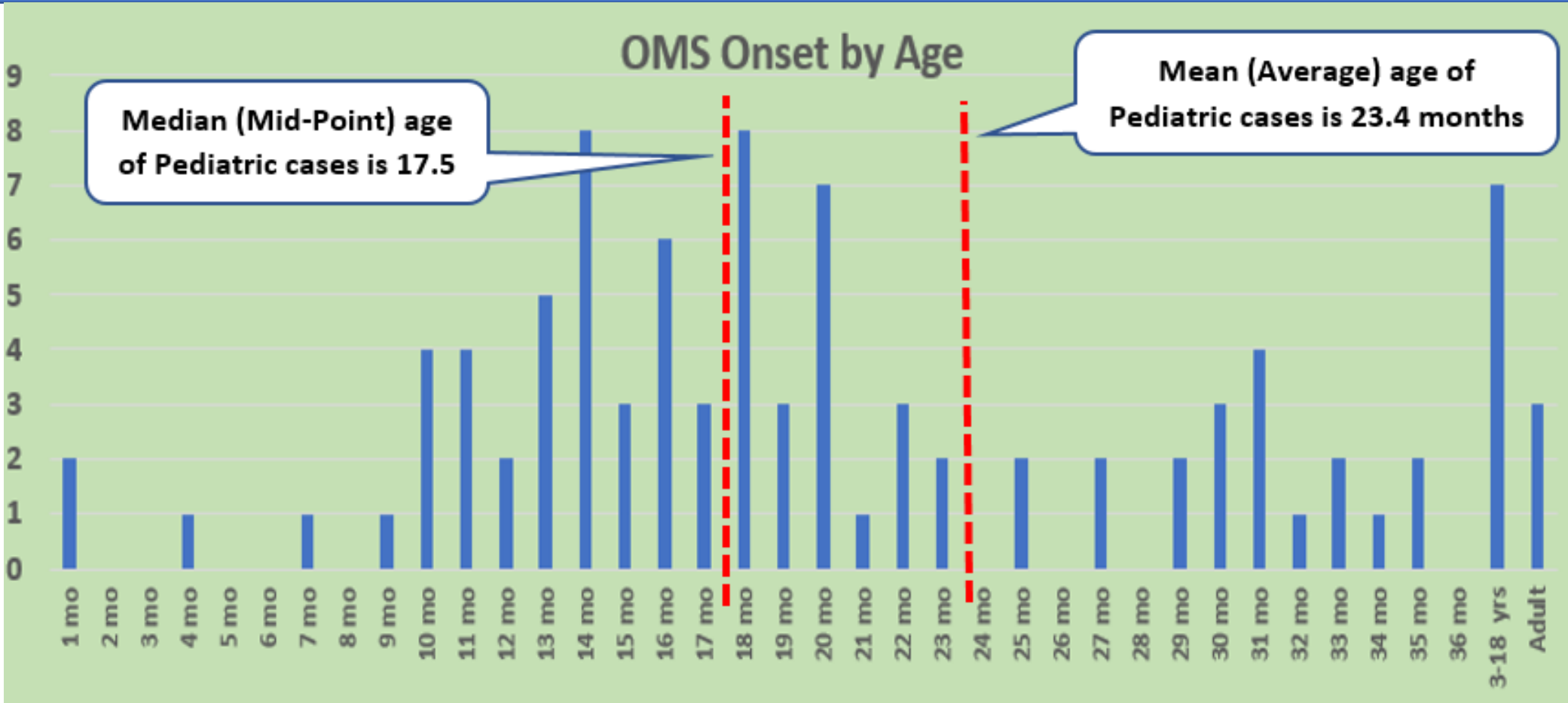
Question 1: What is the gender of the OMS Patients? -102 responses

58 Girls – 57%

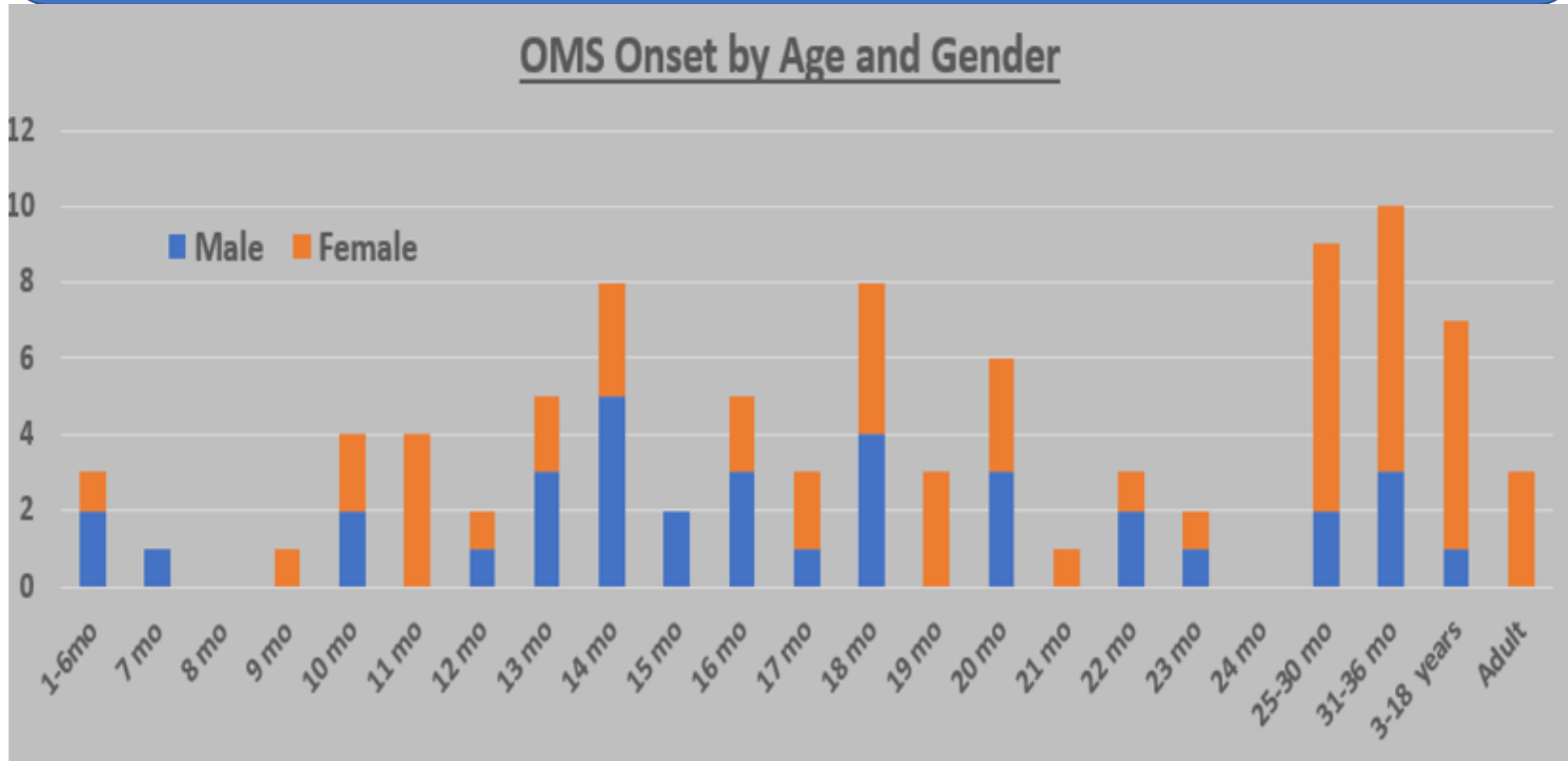
44 Boys – 43%



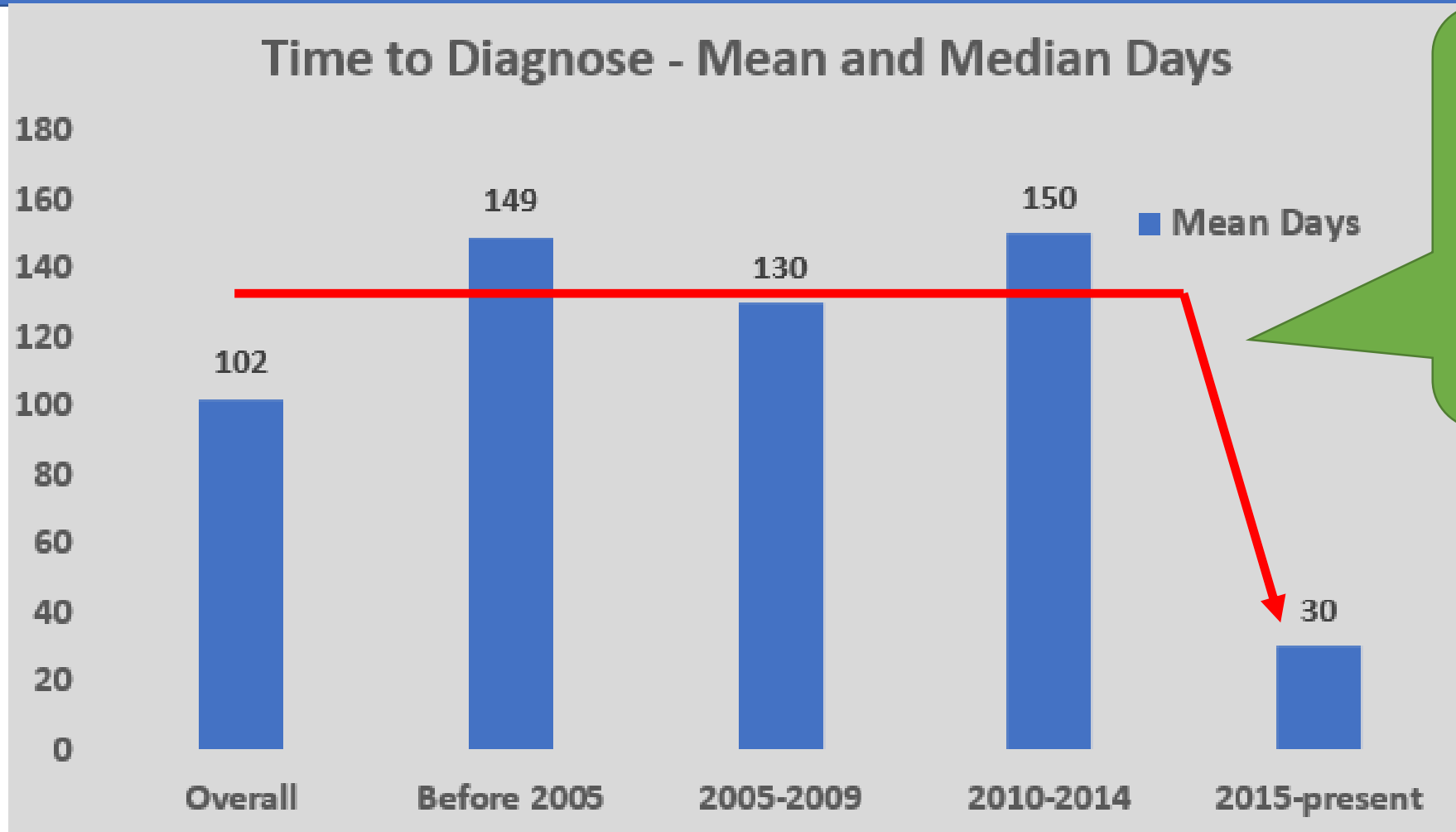
Question 2: What was the age of the patients at onset of OMS? - 93 responses



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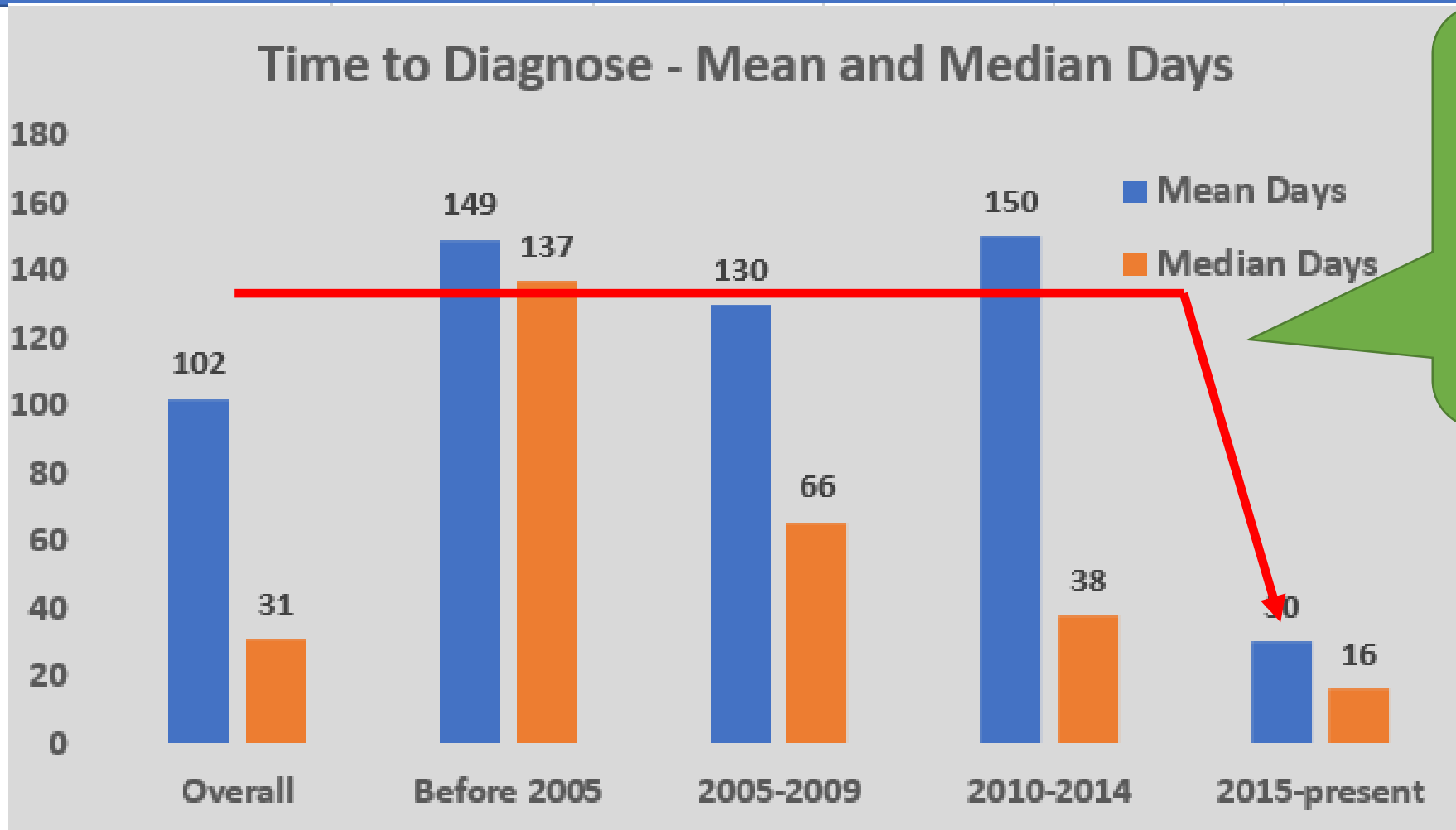


Question 3: What was the length of time to correctly diagnose OMS? – 90 responses



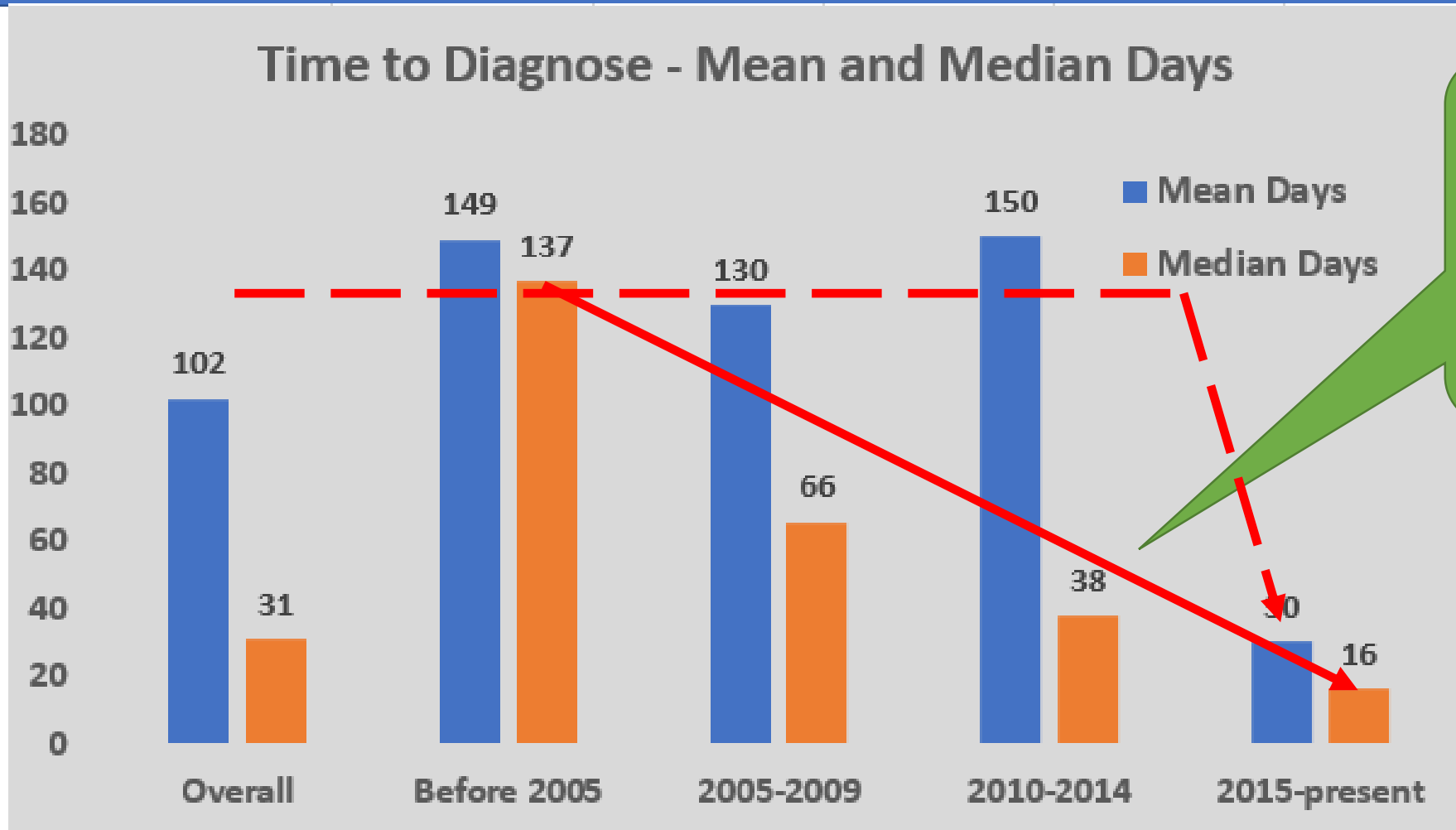
What happened after 2014 to create the dramatic drop in time to diagnose OMS?

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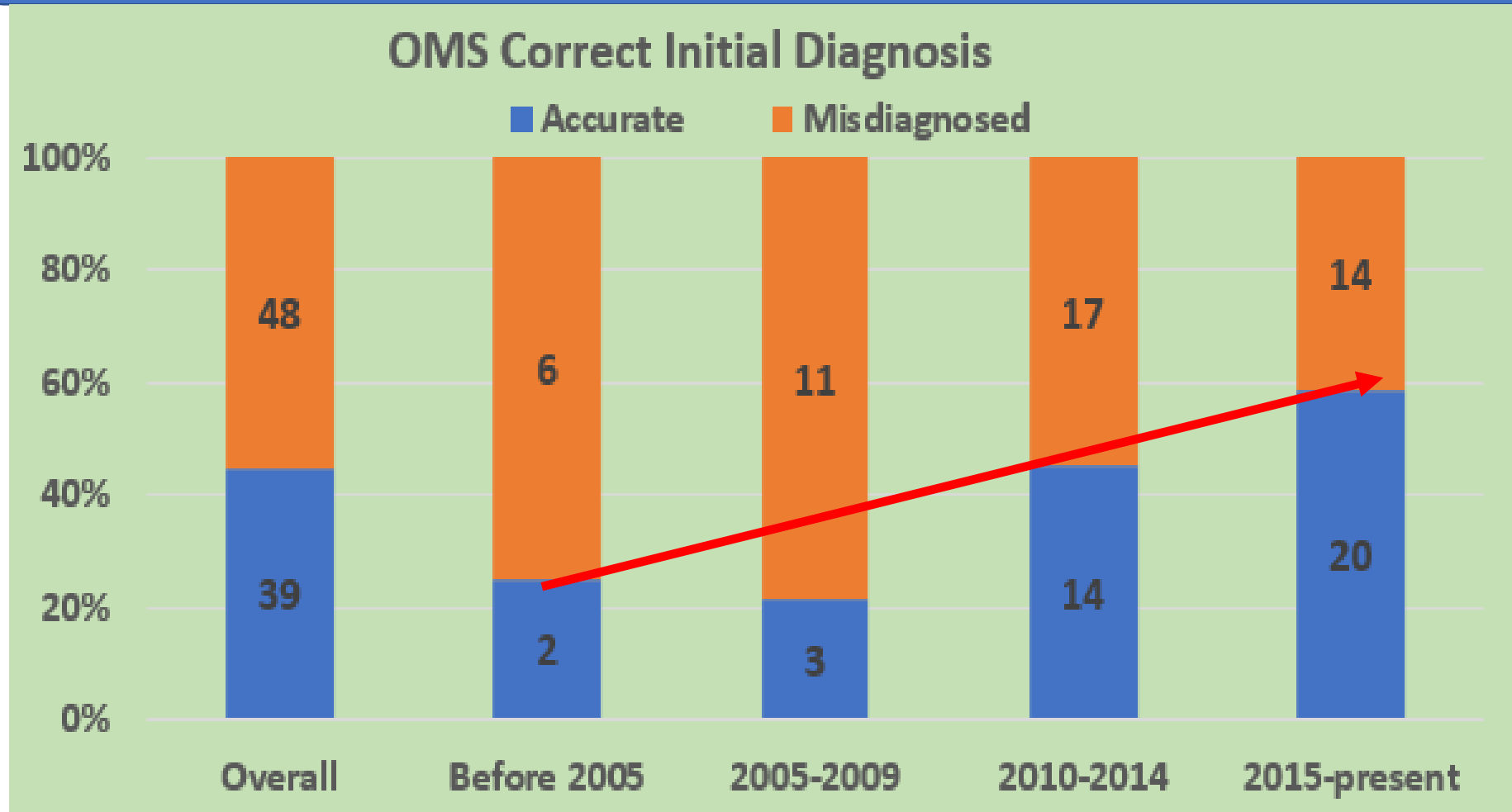
What happened after 2014 to create the dramatic drop in time to diagnose OMS?

Question 3: What was the length of time to correctly diagnose OMS? – 90 responses



The median shows steady dramatic improvement during each time period

Question 4: Was the initial diagnosis correct? 87 responses



So what does that have to do with Outcomes???

What factors determine a patient's long term quality of life?

Treatments?

Therapies?

Time to Diagnose OMS?

Severity Scores?



Let's look at OMS Severity Scores

Stance:

- 0: standing and sitting balance normal for age
- 1: mildly unstable standing for age, slightly wide based
- 2: unable to stand without support but can sit without support
- 3: unable to sit without using hands to prop or other support

Gait:

- 0: walking normal for age
- 1: mildly wide-based gait for age, but able to walk indoors and outdoors independently
- 2: walks only or predominantly with support from person or equipment
- 3: unable to walk even with support from person or equipment

Arm/hand function

- 0: normal for age
- 1: mild, infrequent tremor or jerkiness without functional impairment
- 2: fine motor function persistently impaired for age, but less precise manipulative tasks normal or almost normal
- 3: Major difficulties in all age-appropriate fine motor and manipulative tasks

Opsoclonus

- 0: none
- 1: rare or only when elicited by change in fixation or "squeeze test"
- 2: Frequent, interferes intermittently with fixation or tracking
- 3: Persistent, interfering continuously with function and tracking

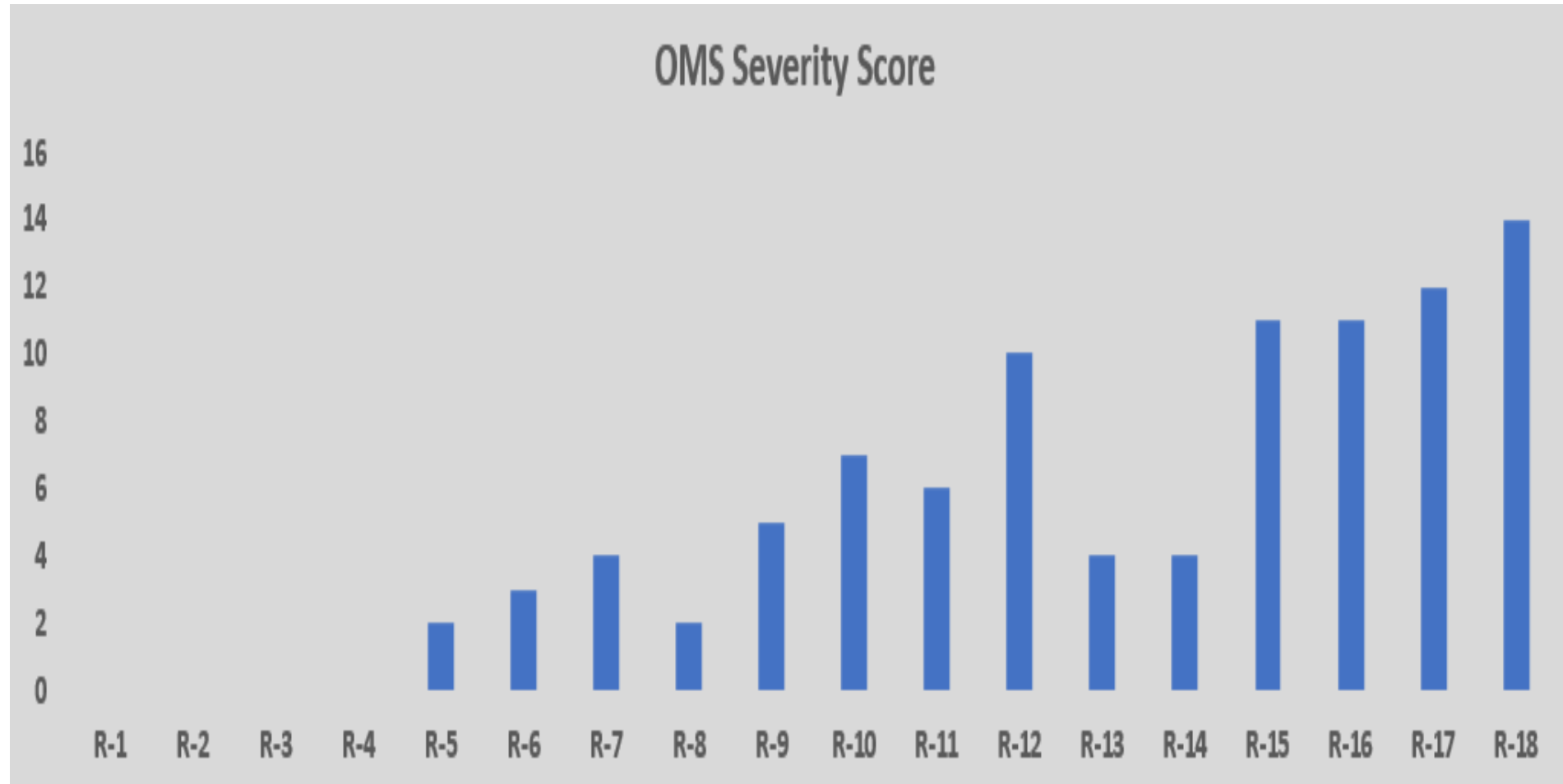
Mood/Behavior

- 0: normal
- 1: mild increase in irritability but consolable; and/or mild sleep disturbances
- 2: irritability and sleep disturbances interfering with child and family life
- 3: Persistent severe distress

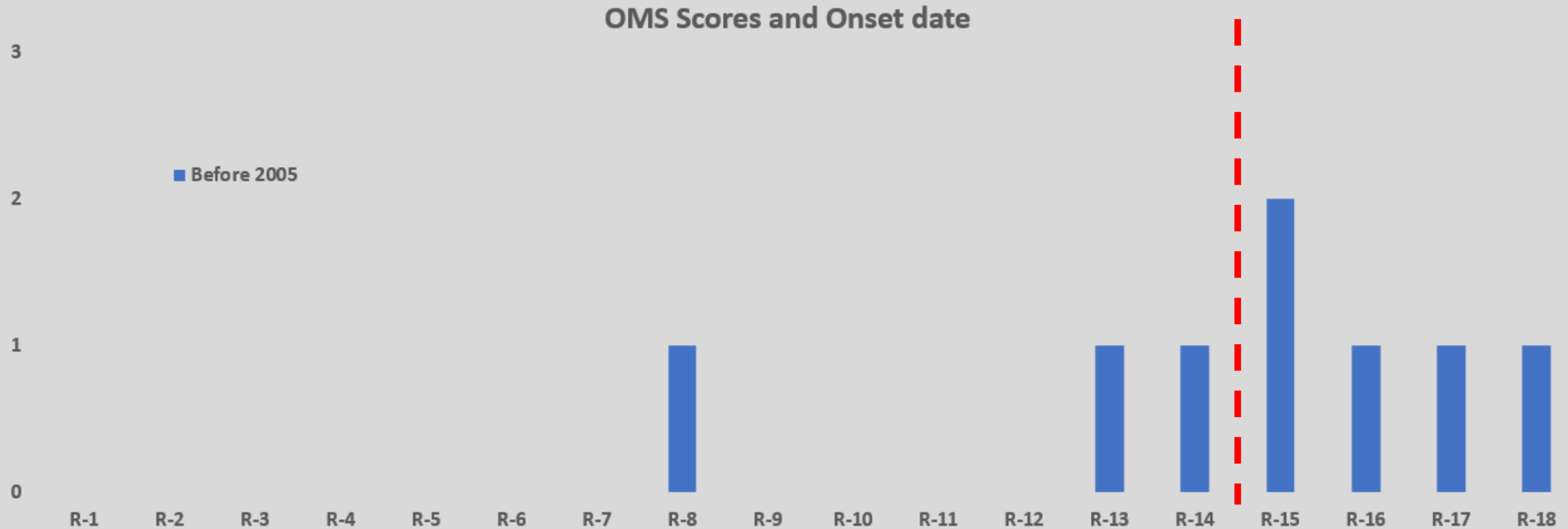
Speech

- 0: normal for age, no loss
- 1: mildly unclear, plateaued in development
- 2: loss of some words or some grammatical constructs (i.e. from sentences to phrases) but still communicates verbally
- 3: severe loss of verbal communication and speech.

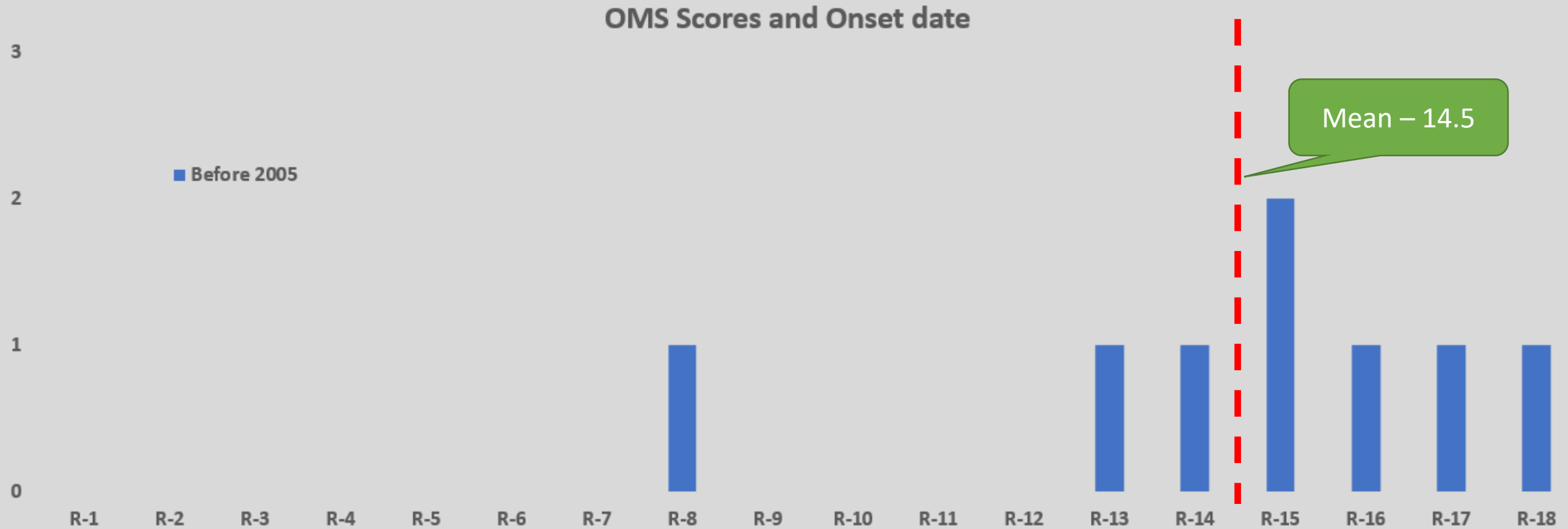
Question 7: What is the OMS Severity Score? 95 responses



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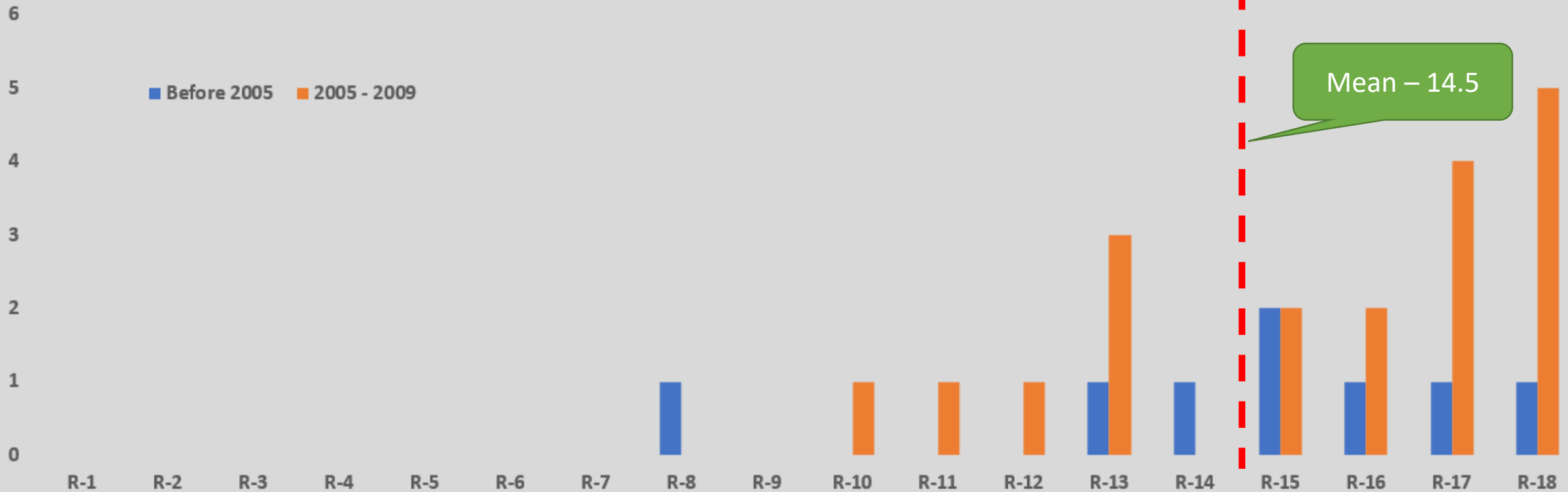


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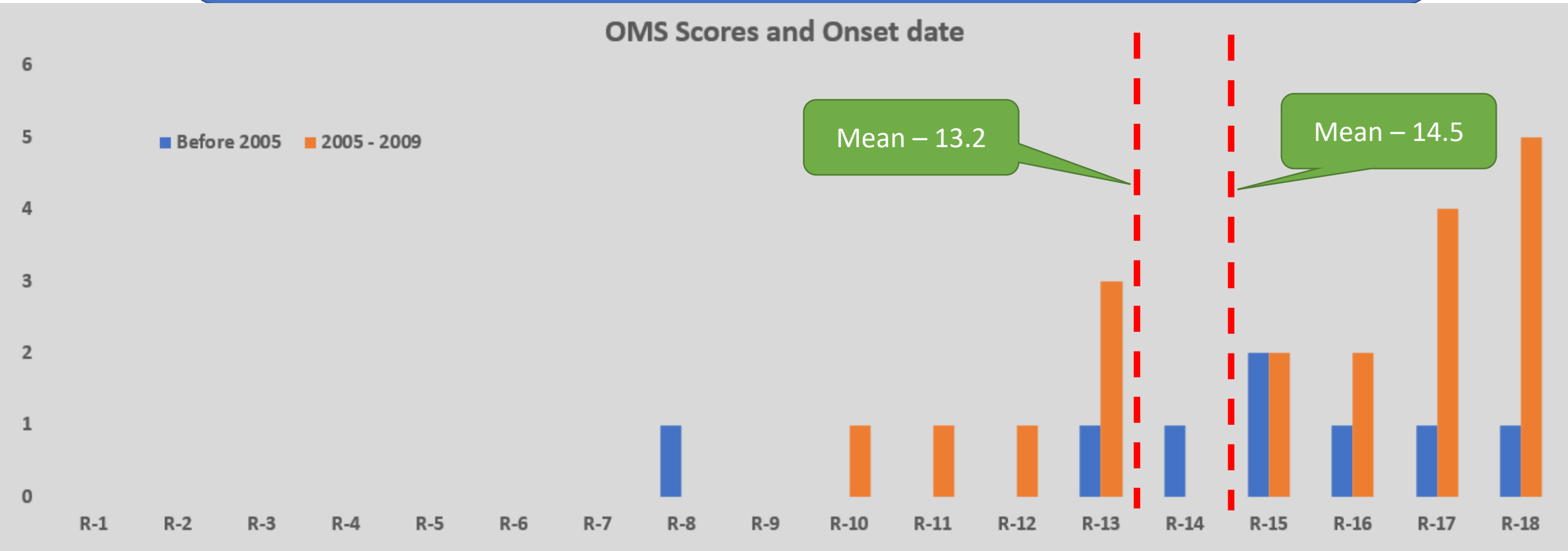


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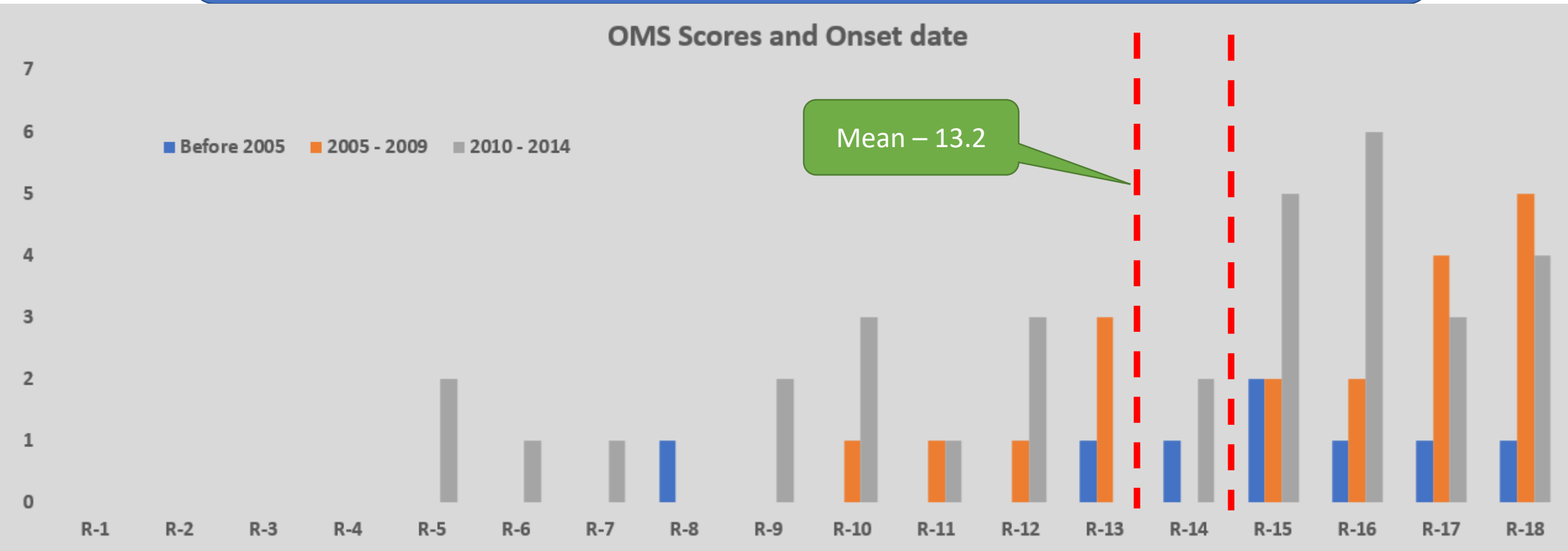
OMS Scores and Onset date



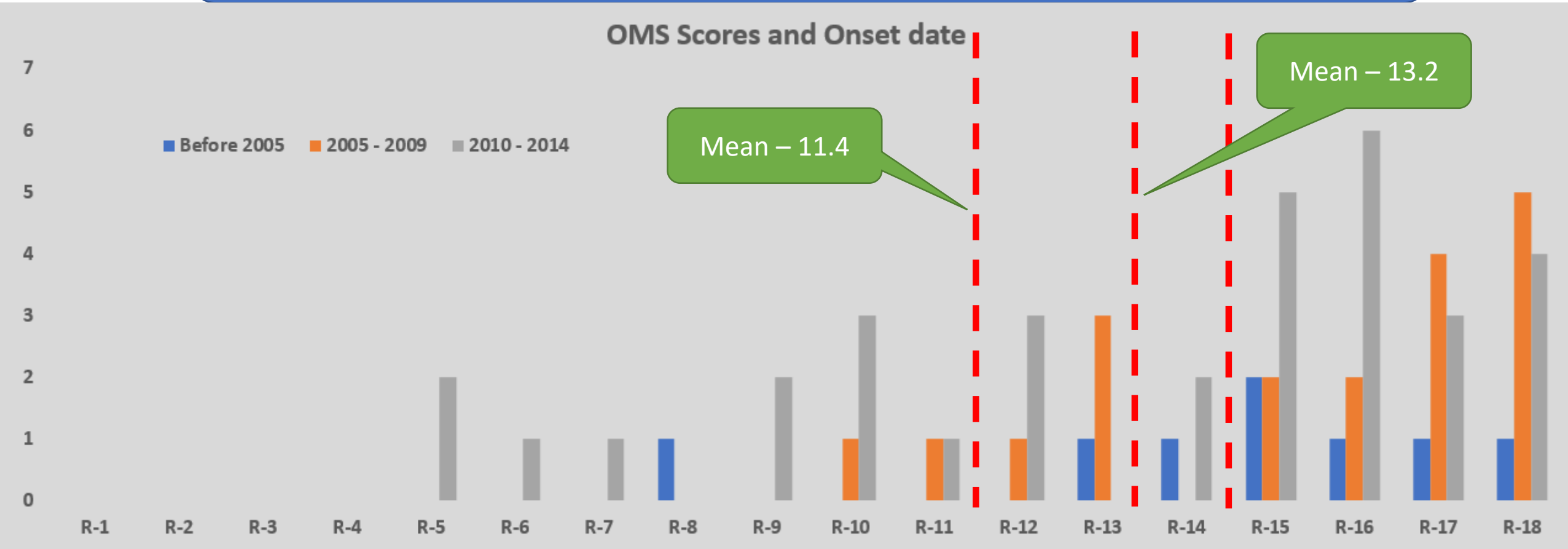
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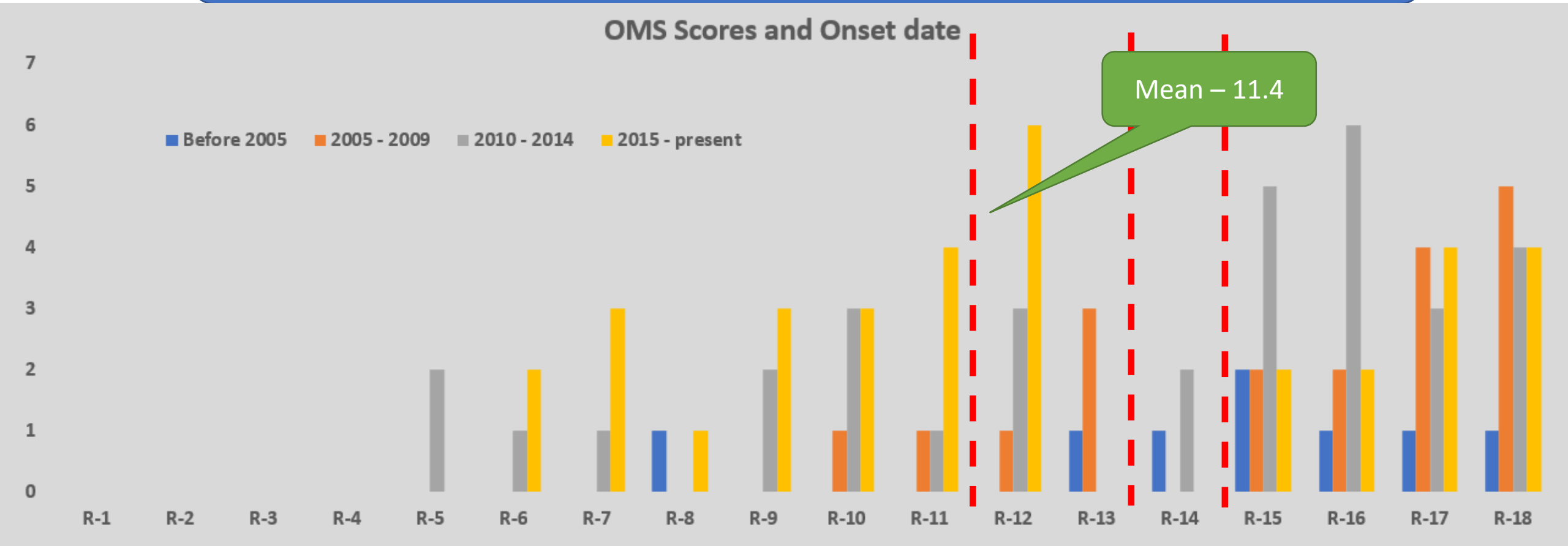
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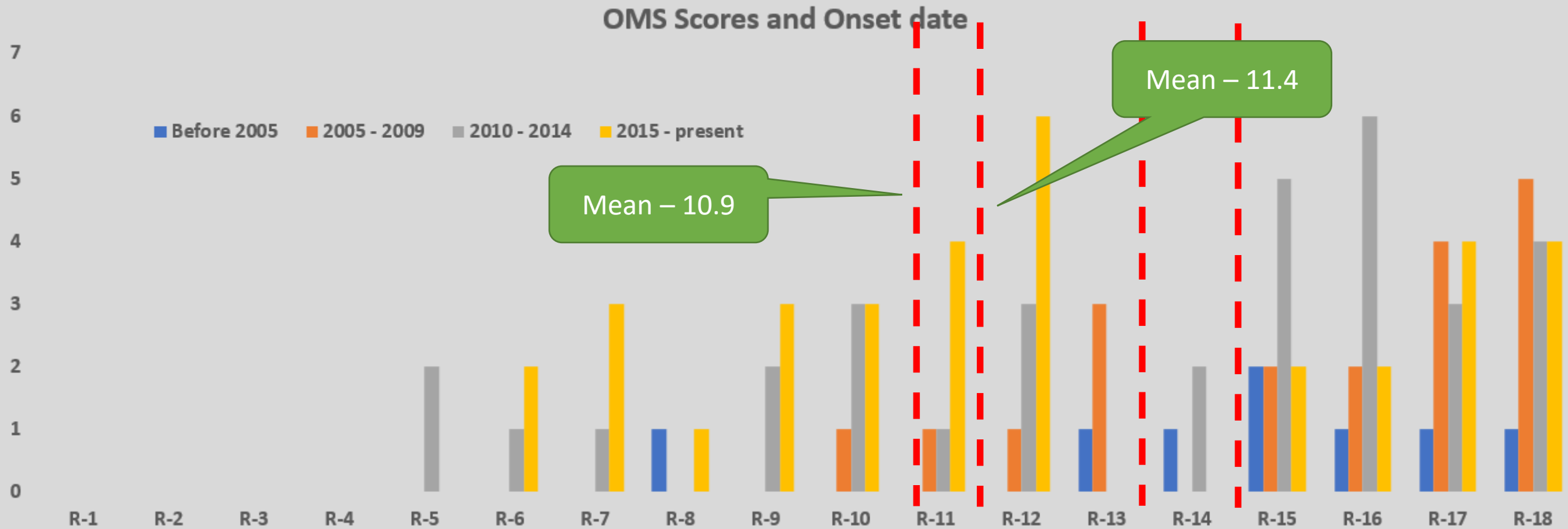
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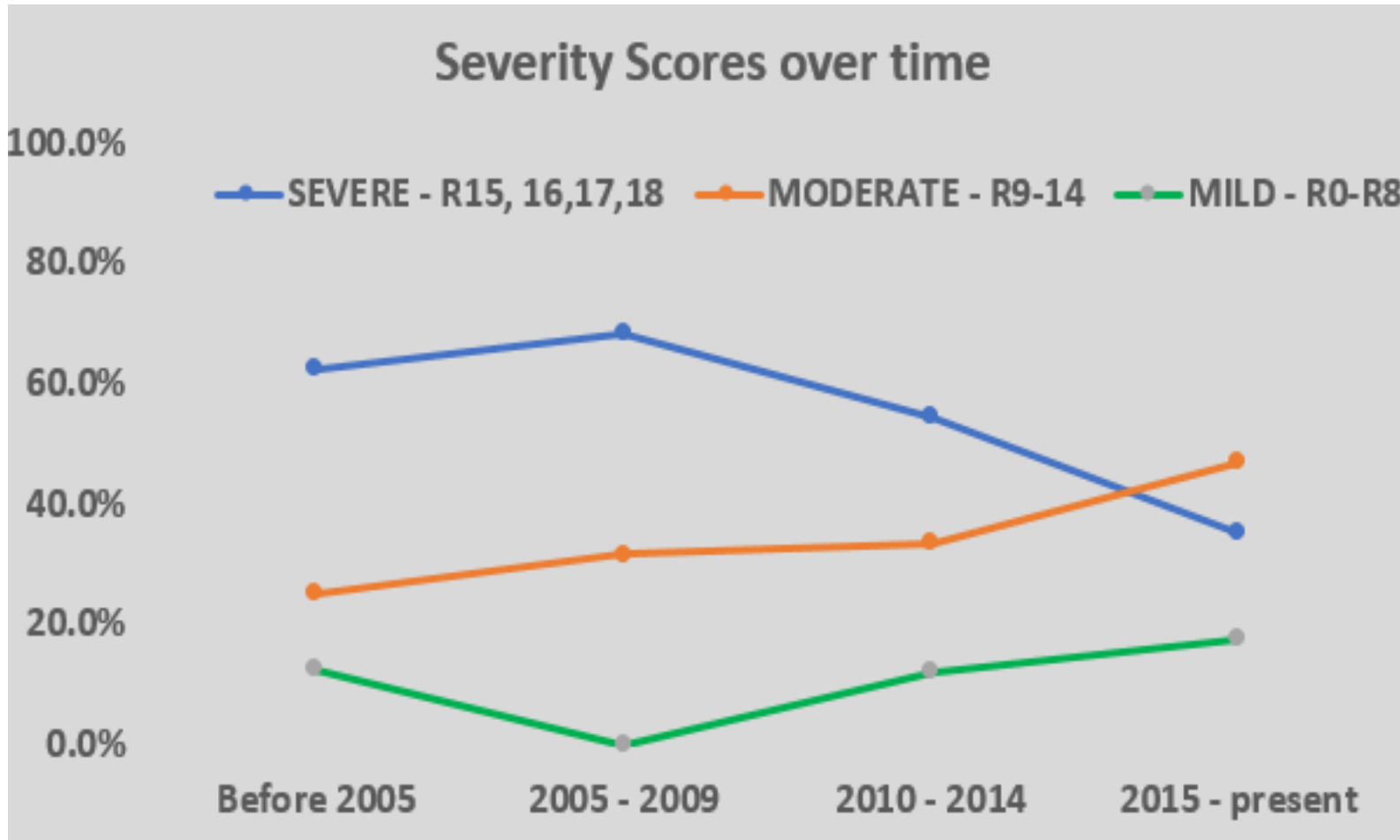
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And what should we consider regarding therapies???

What factors determine a patient's long term quality of life?

Treatments?

Therapies?

Time to Diagnose OMS?

Severity Scores?

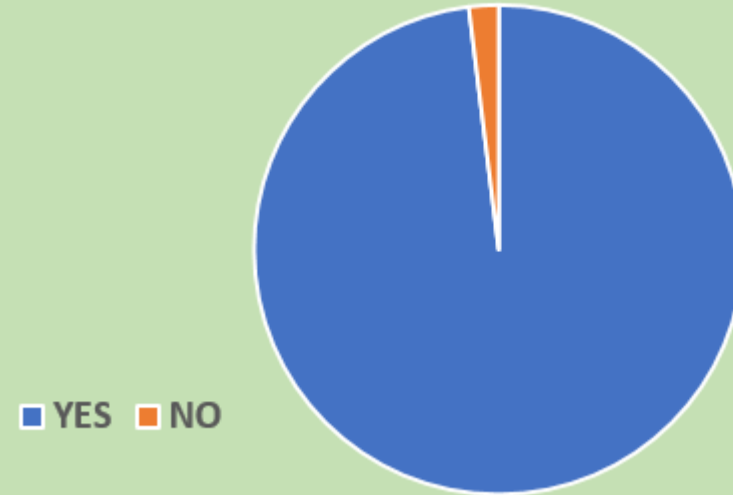


Were Therapies Beneficial???

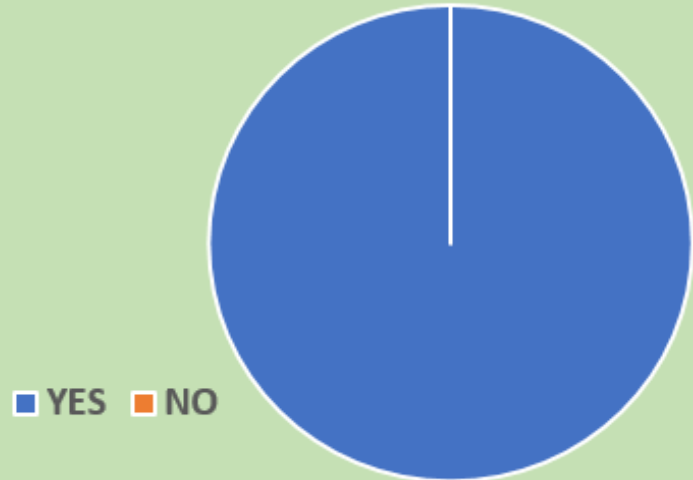
Speech Therapy was Beneficial



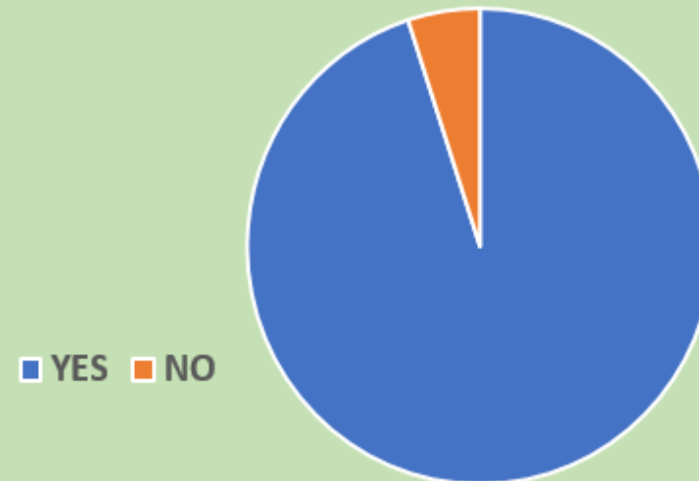
Physical Therapy was Beneficial



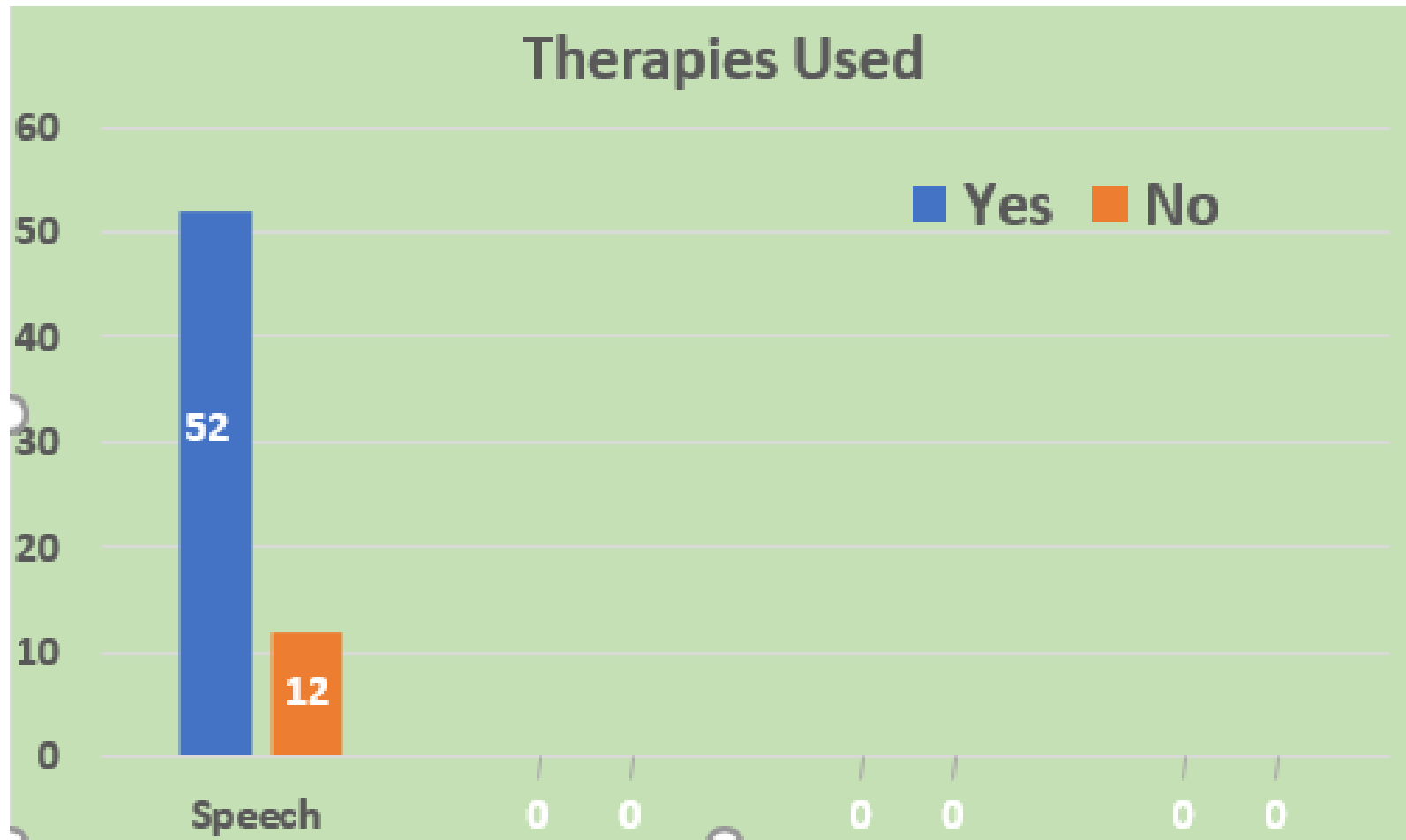
Occupational Therapy was Beneficial



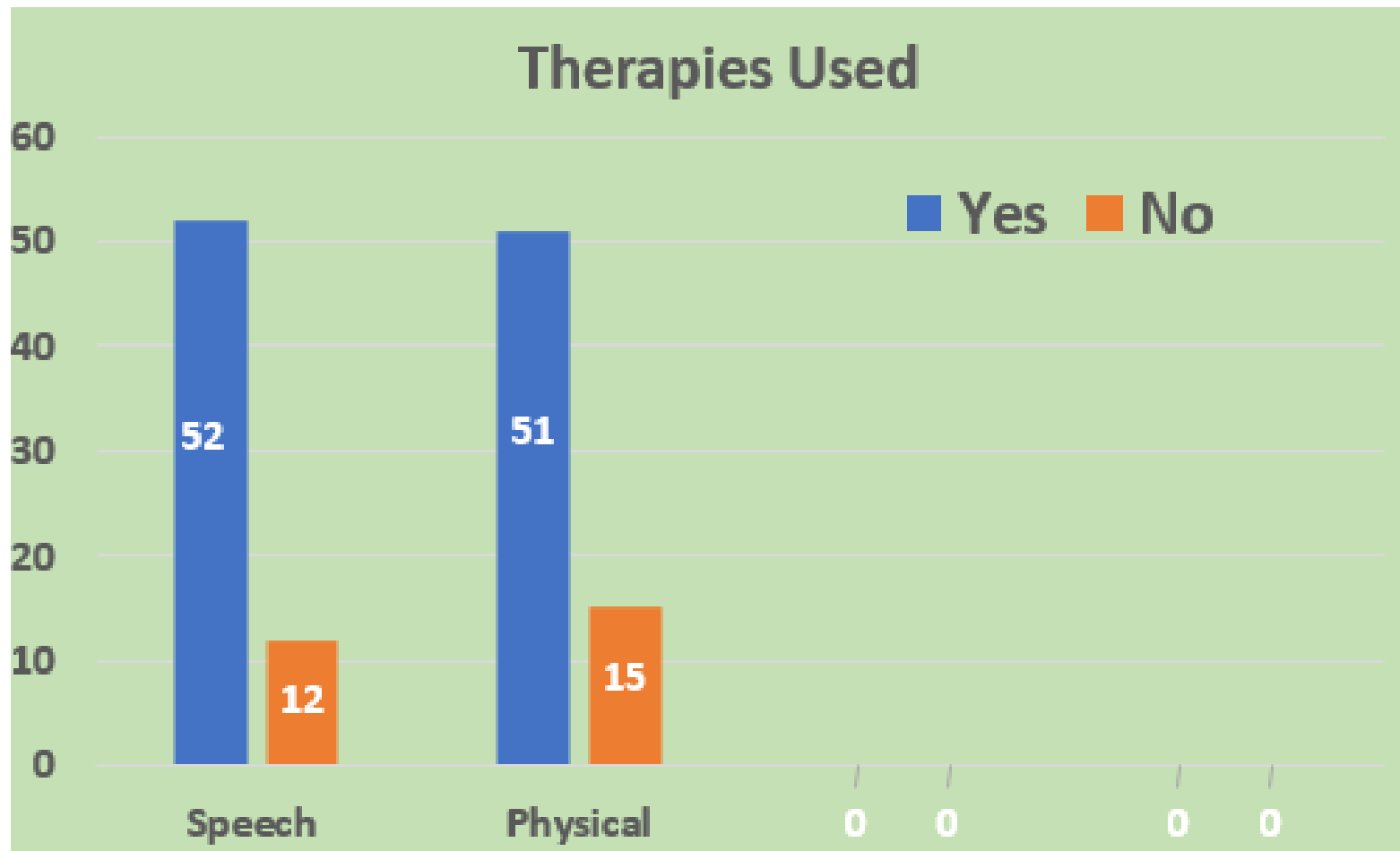
Behavioral Therapy was Beneficial



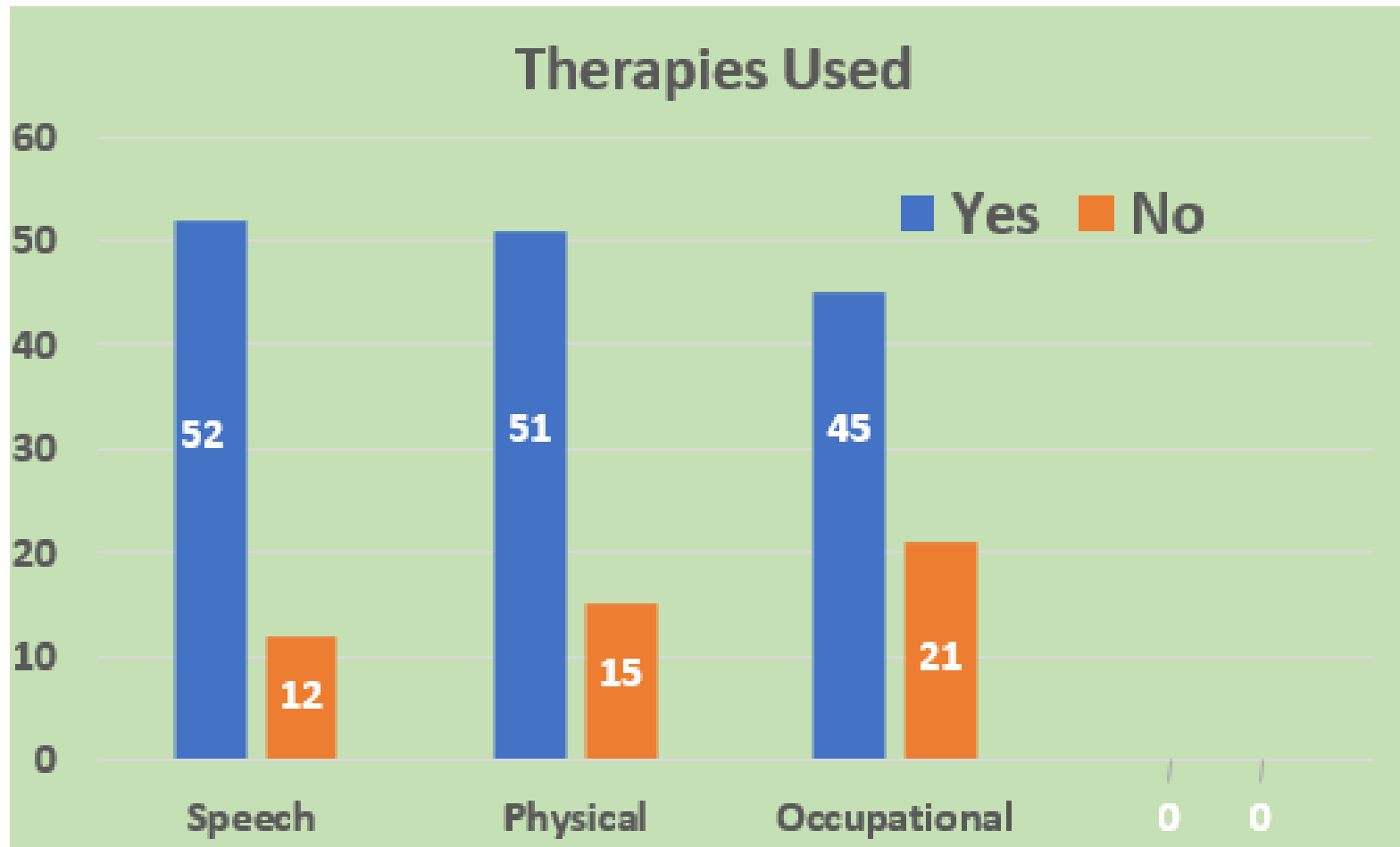
Therapies Used.....



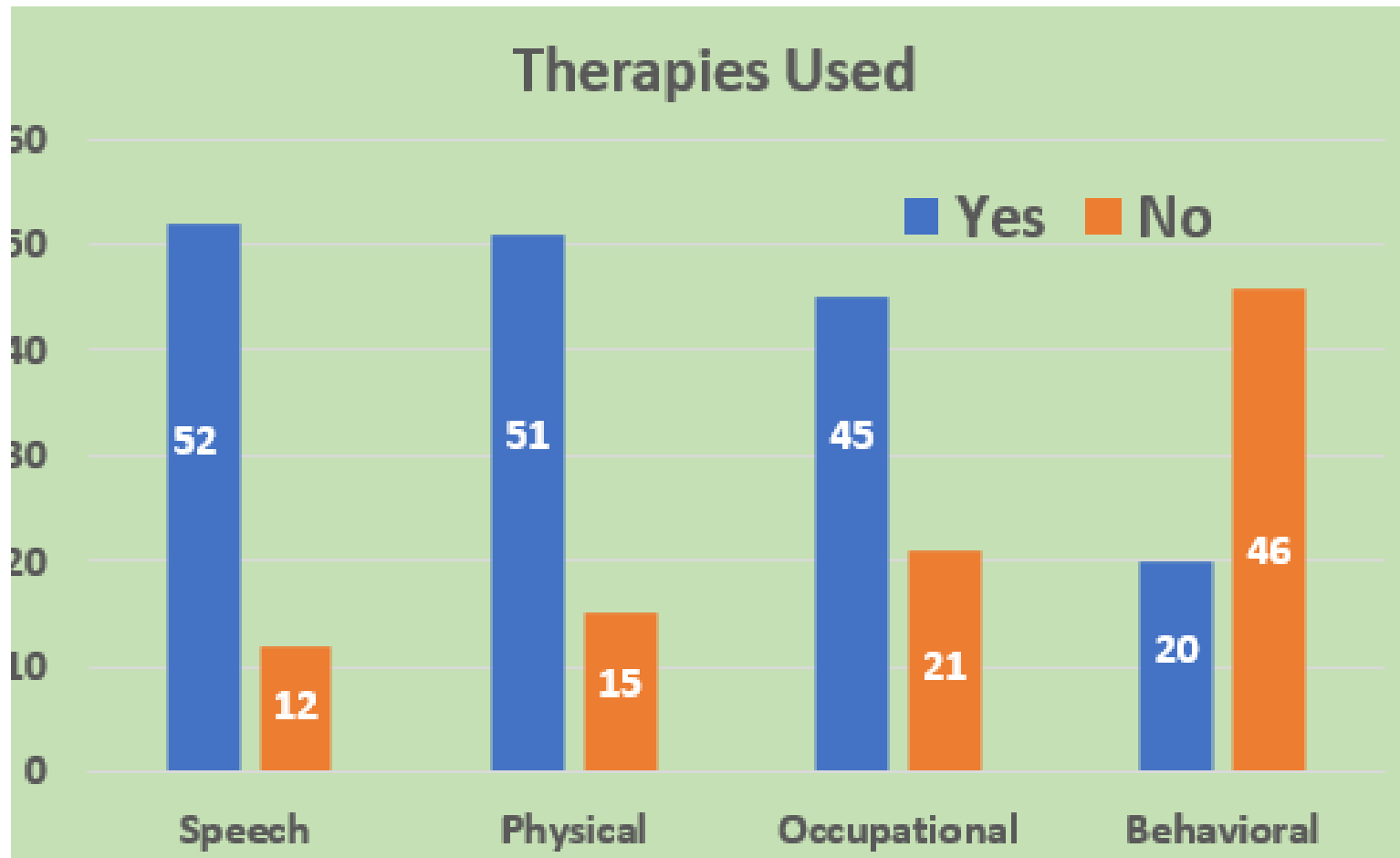
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Therapies Used.....



In closing.....

Will faster diagnosis and lower severity scores
lead to better quality of life?

Would behavioral therapies lead to better
quality of life?

Thank you!

For more information on the OMS Patient Registry – Natural History Study

To join the OMS patient Registry, go to

<https://oms.iamrare.org>