

Readiness Tool Data



NewSTEPs

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Limitations

- Just a reminder that these data are based on what 32 states submitted.
 - Most have not started to get ready to bring on these 3 conditions.
 - When we look at timing we typically only 1-5 states who have a start and stop date.



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Pompe Overview

Where States Are at in Based on Readiness Tool Data – Phase 2

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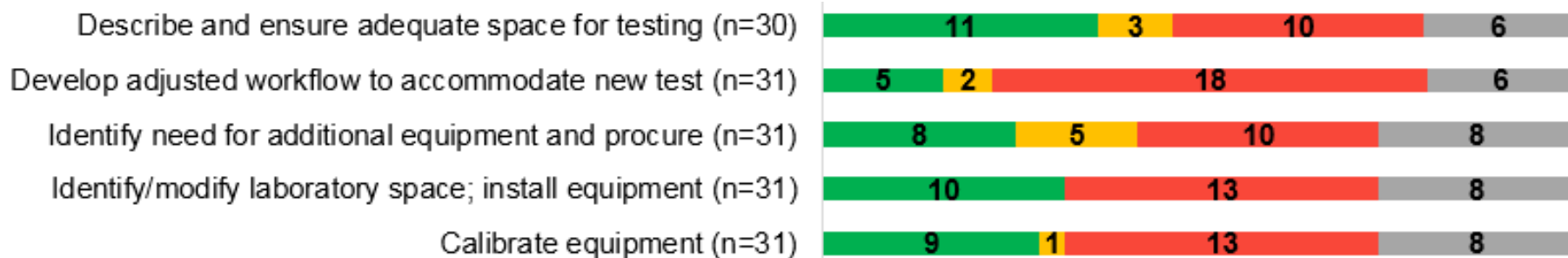
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Phase 2: Lab Facility/Infrastructure Readiness

■ Completed ■ Started ■ Not Started ■ NA

Pompe (n=33)

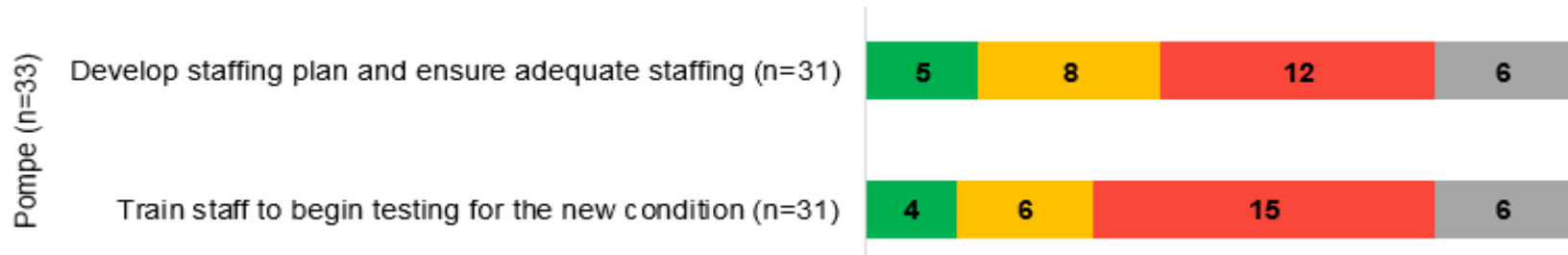


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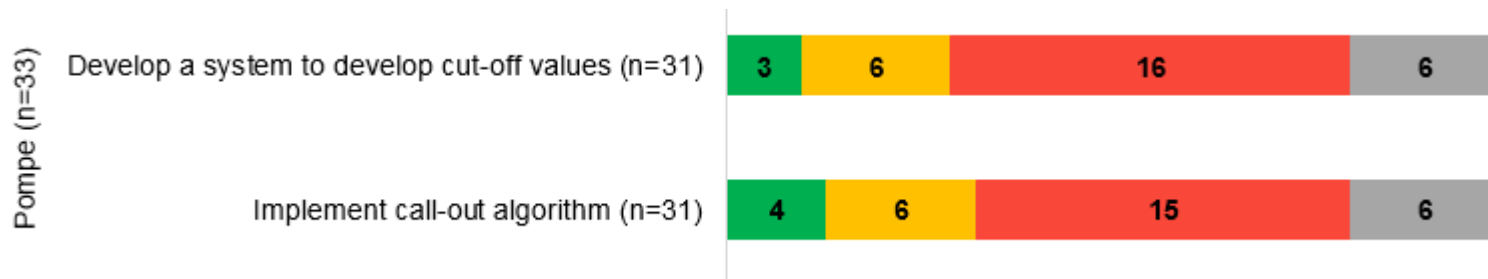
Phase 2: Lab Staffing Readiness

■ Completed ■ Started ■ Not Started ■ NA



Phase 2: Lab Reporting Readiness

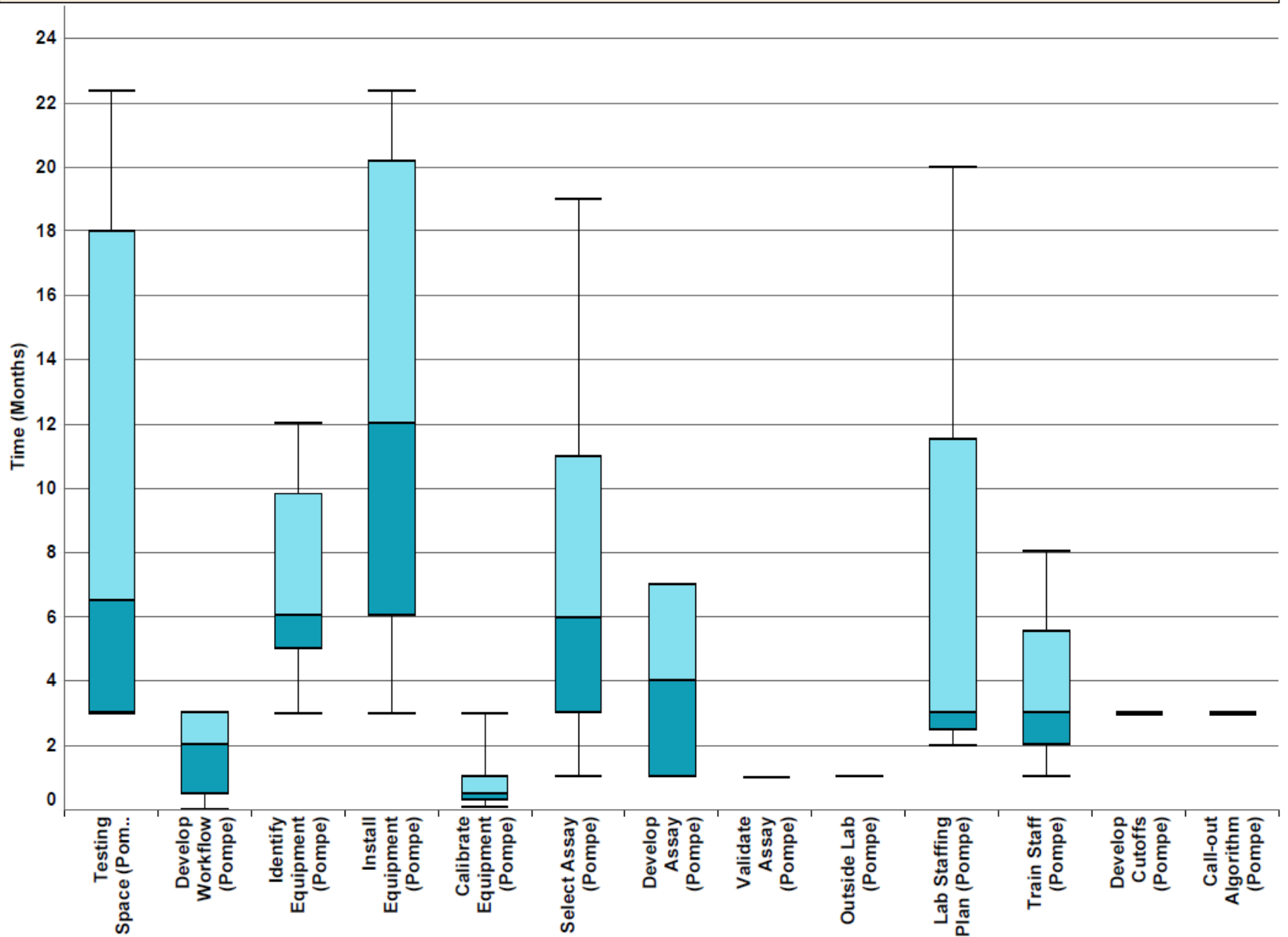
■ Completed ■ Started ■ Not Started ■ NA



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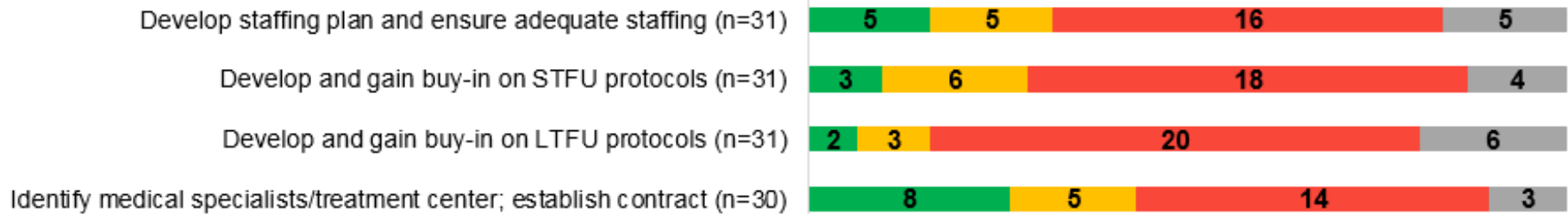
Pompe Phase 2: Time to Complete Lab Logistics



Phase 2: Follow-up Readiness

■ Completed ■ Started ■ Not Started ■ NA

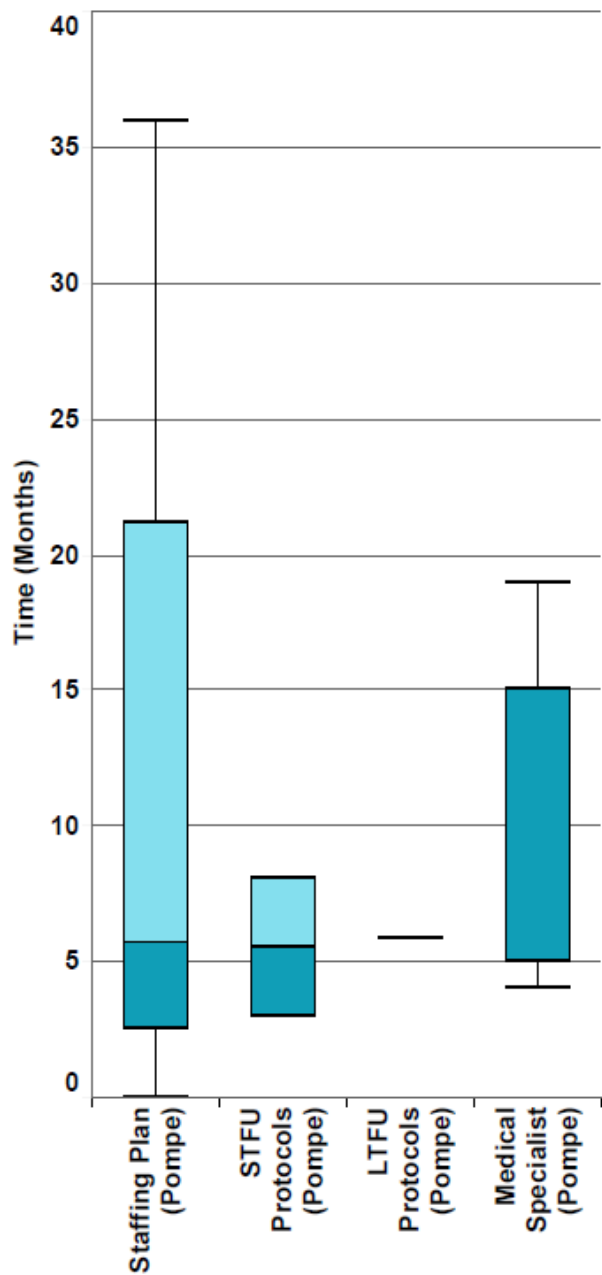
Pompe (n=33)



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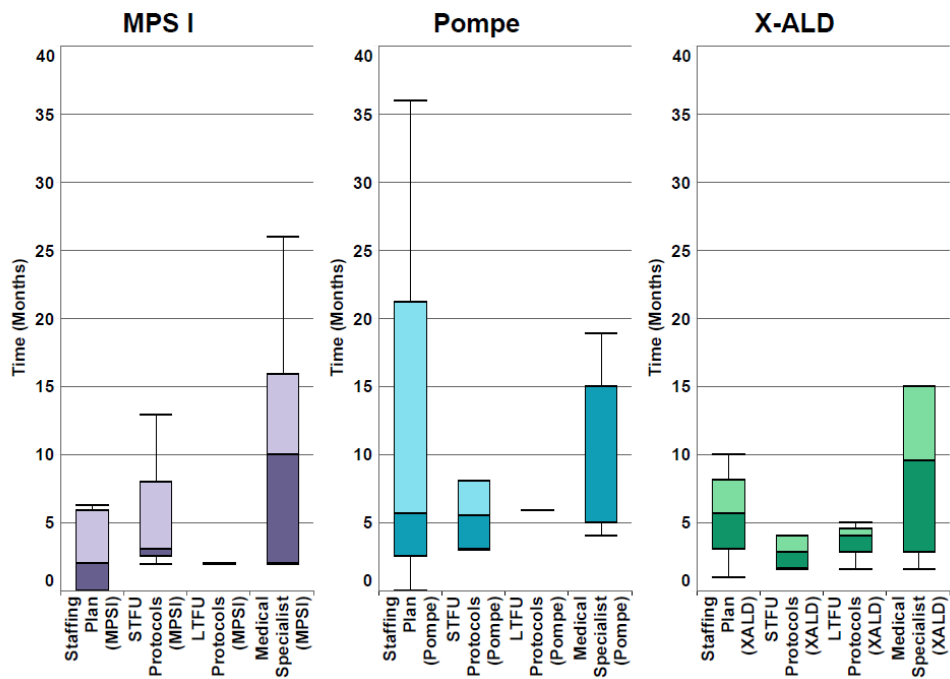
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Pompe



Time to Complete Follow-Up Logistics – Pompe

Phase 2: Time to Complete Follow-up Logistics



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MPS I Overview

Where States Are at Based on Readiness Tool Data – Phase 2

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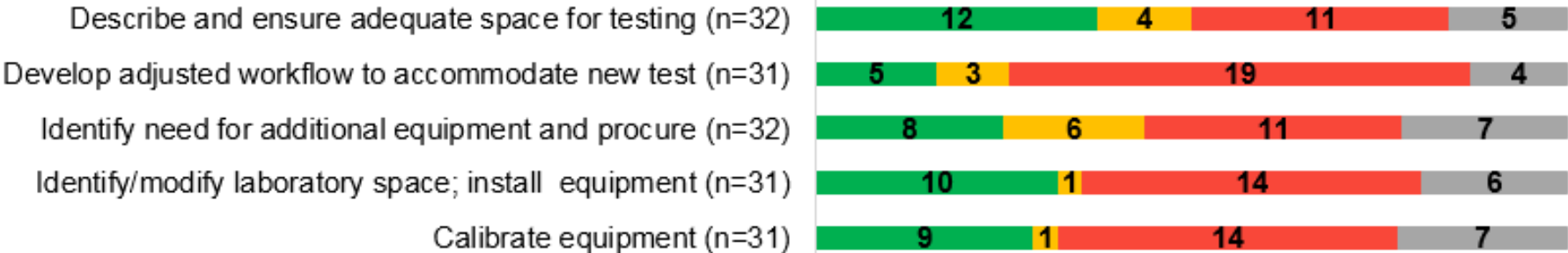
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Phase 2: Lab Facility/Infrastructure Readiness

■ Completed
 ■ Started
 ■ Not Started
 ■ NA

MPSI (n=32)



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Phase 2: Lab Staffing Readiness

■ Completed ■ Started ■ Not Started ■ NA

MPS I
(n=32)

Develop staffing plan and ensure adequate staffing (n=32)



Train staff to begin testing for the new condition (n=31)



Phase 2: Lab Reporting Readiness

■ Completed ■ Started ■ Not Started ■ NA

MPS I
(n=32)

Develop a system to develop cut-off values (n=30)



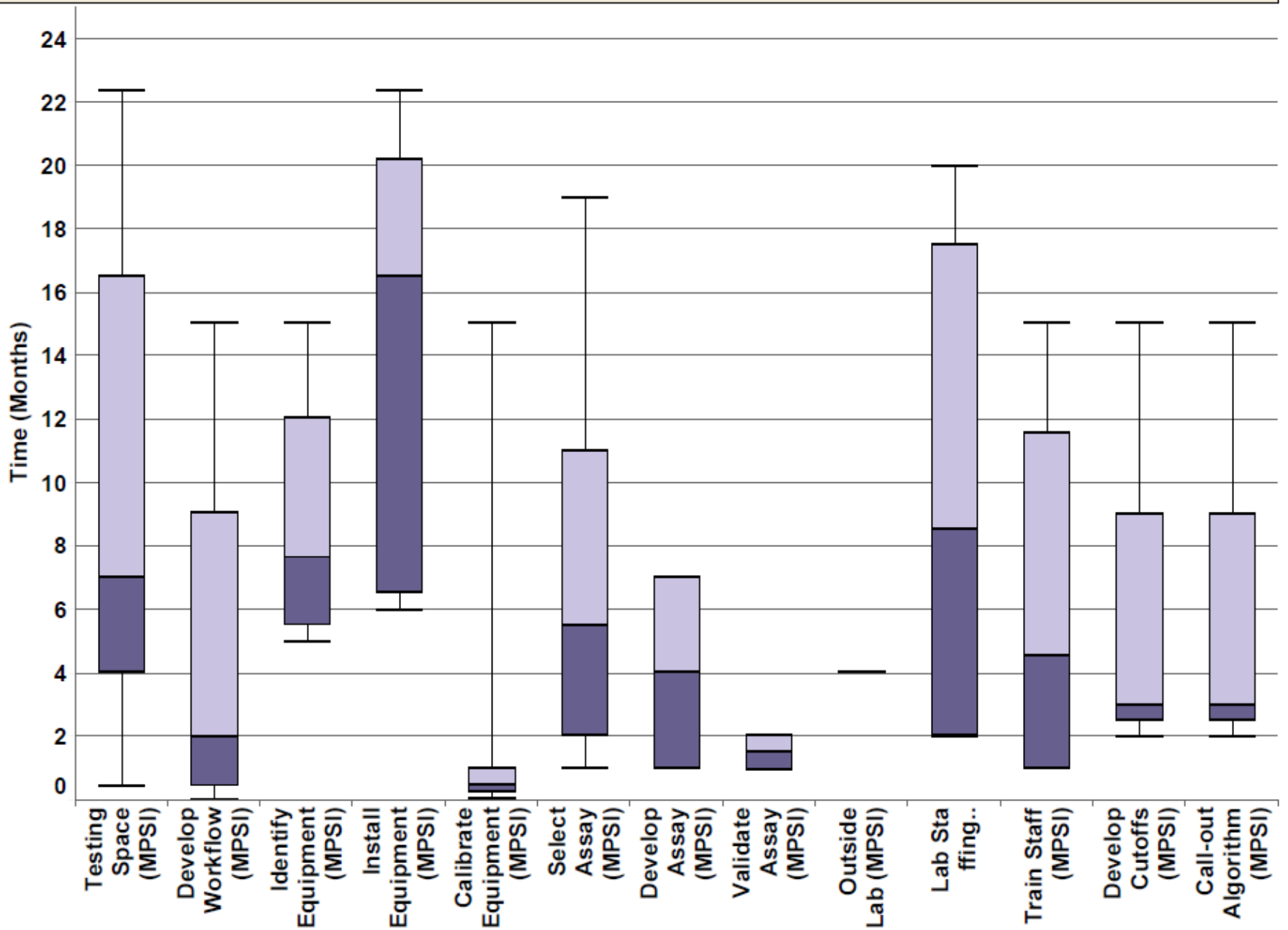
Implement call-out algorithm (n=32)



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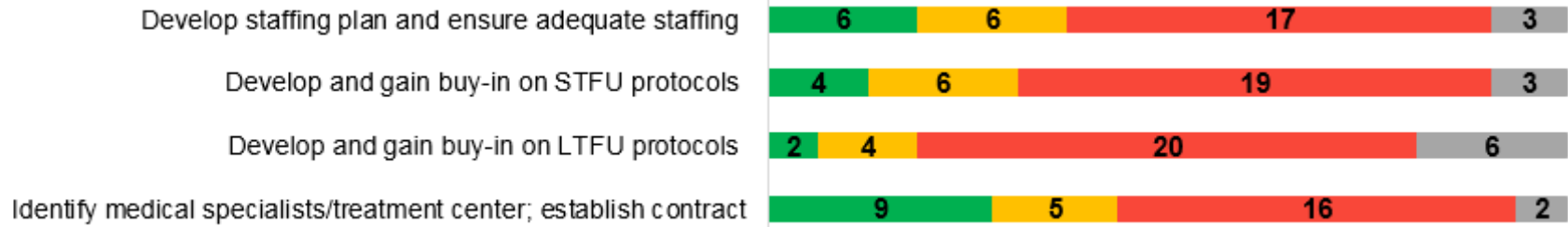
MPS I Phase 2: Time to Complete Lab Logistics



Phase 2: Follow-up Readiness

■ Completed ■ Started ■ Not Started ■ NA

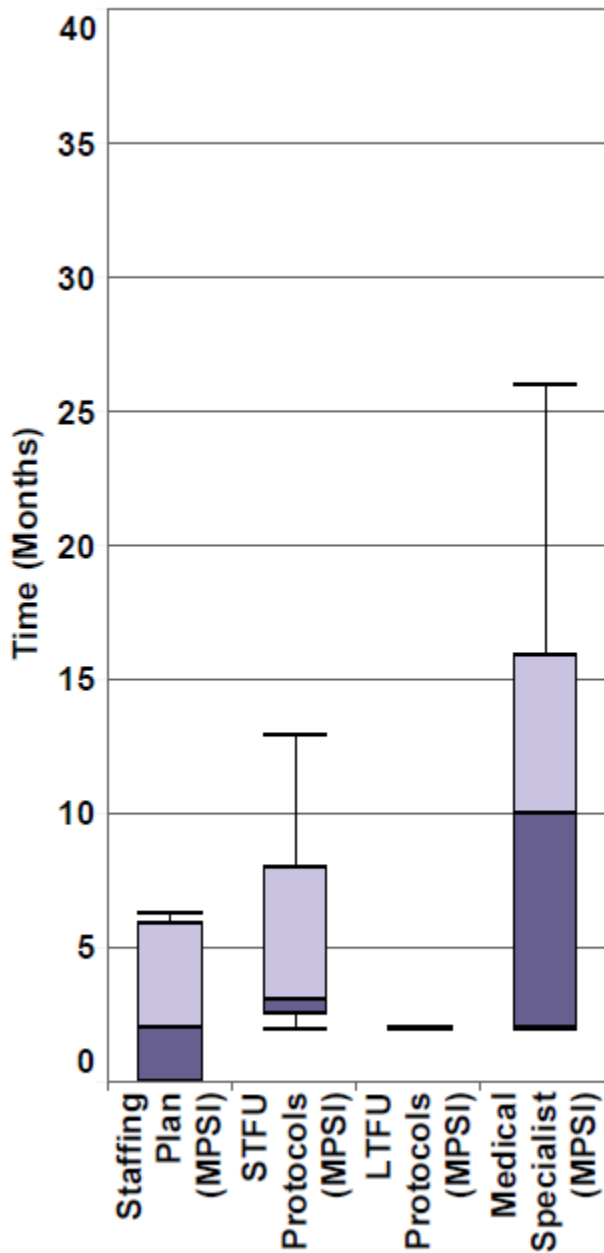
MPS I
(n=32)



NewSTEPS

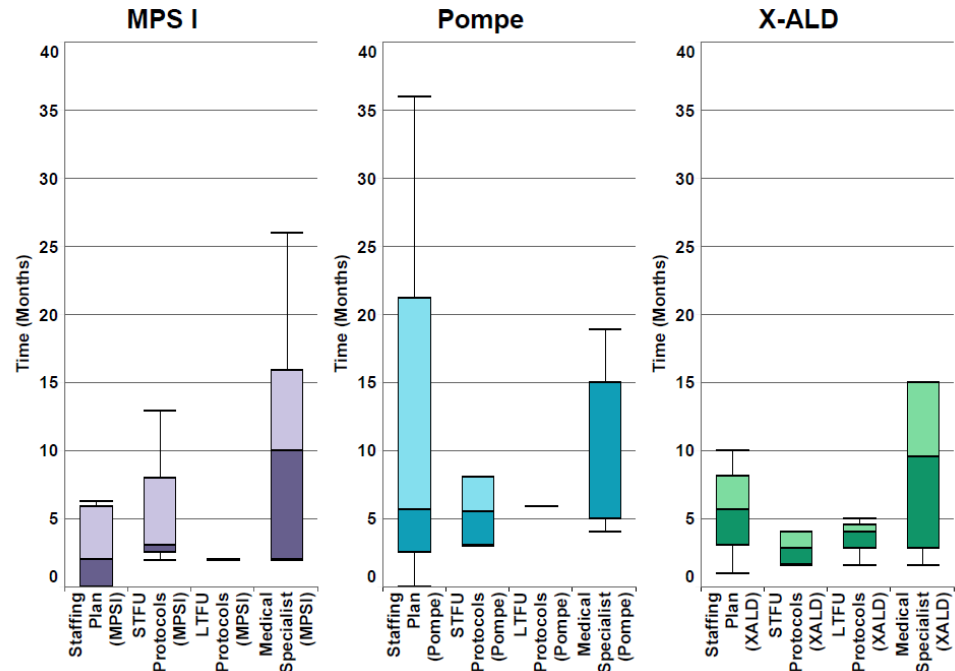
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MPS I



Time to Complete Follow-Up Logistics – MPS I

Phase 2: Time to Complete Follow-up Logistics



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X-ALD Overview

Where States Are at Based on Readiness Tool Data – Phase 2

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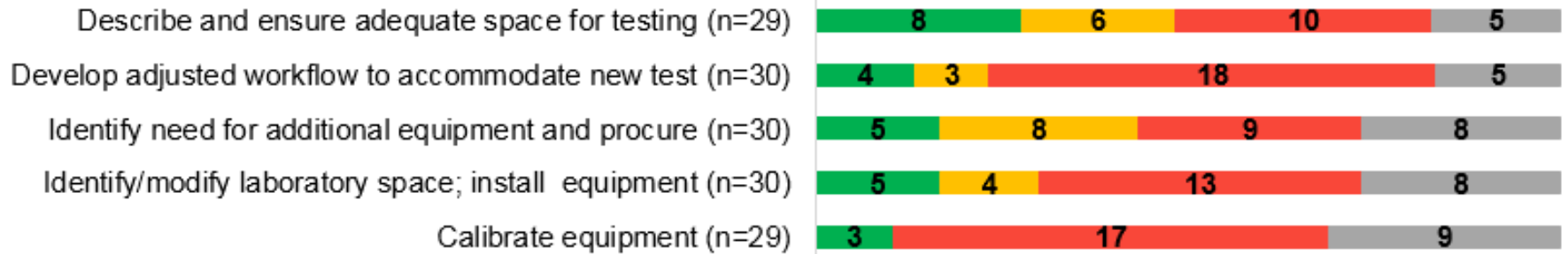
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Phase 2: Lab Facility/Infrastructure Readiness

■ Completed
 ■ Started
 ■ Not Started
 ■ NA

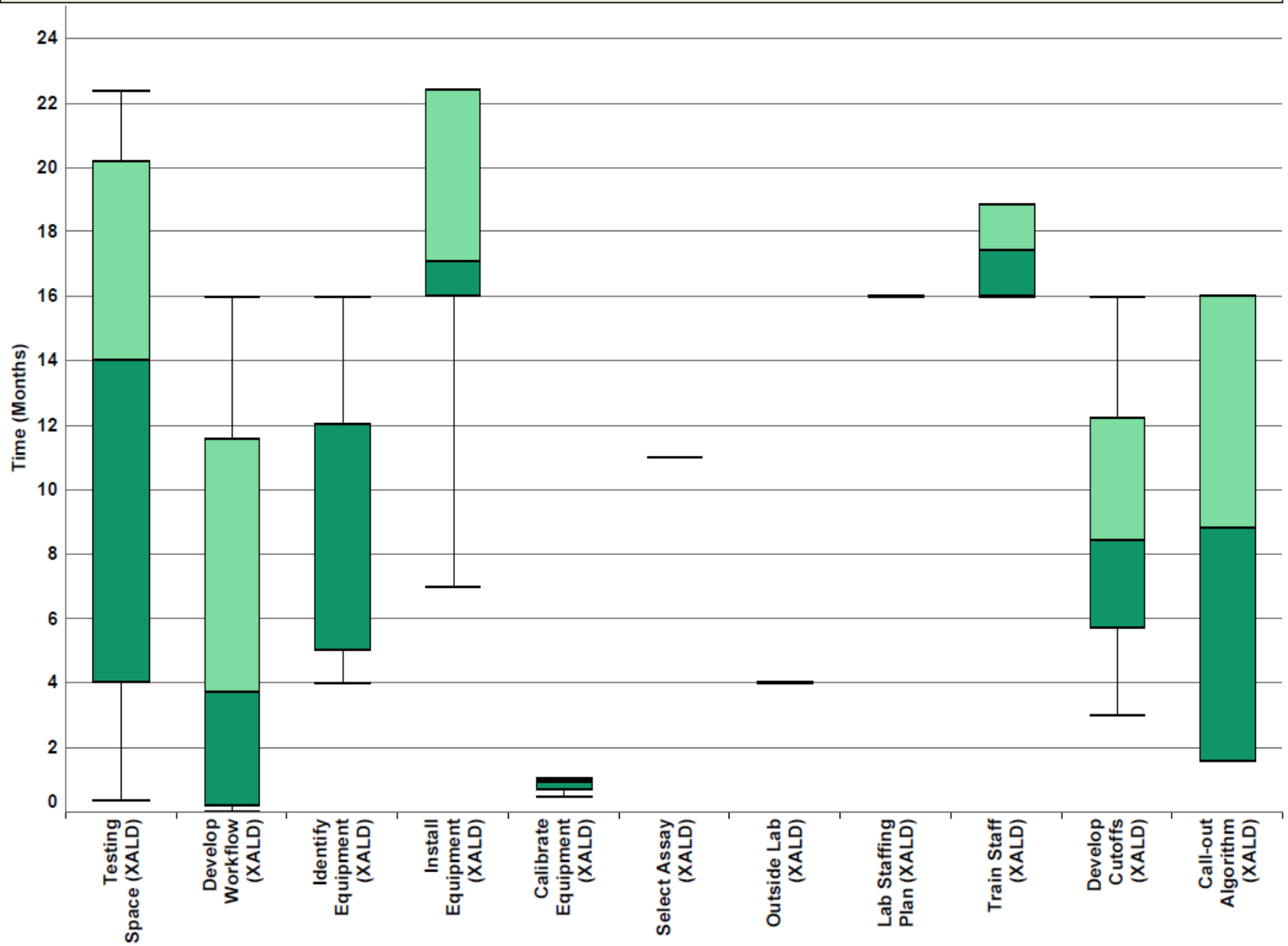
xALD
(n=30)



NewSTEPS

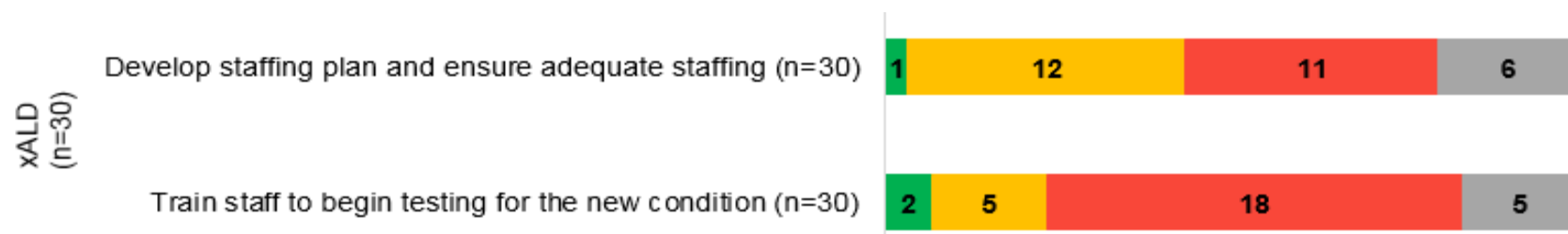
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X-ALD Phase 2: Time to Complete Lab Logistics



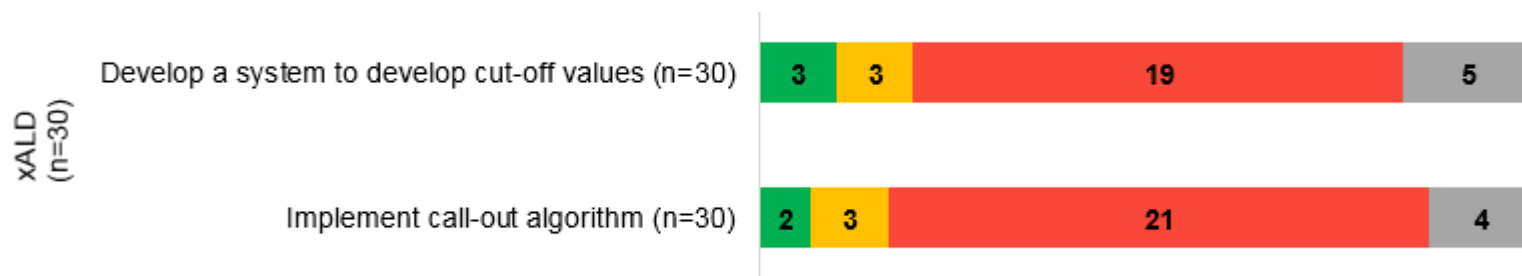
Phase 2: Lab Staffing Readiness

■ Completed ■ Started ■ Not Started ■ NA



Phase 2: Lab Reporting Readiness

■ Completed ■ Started ■ Not Started ■ NA



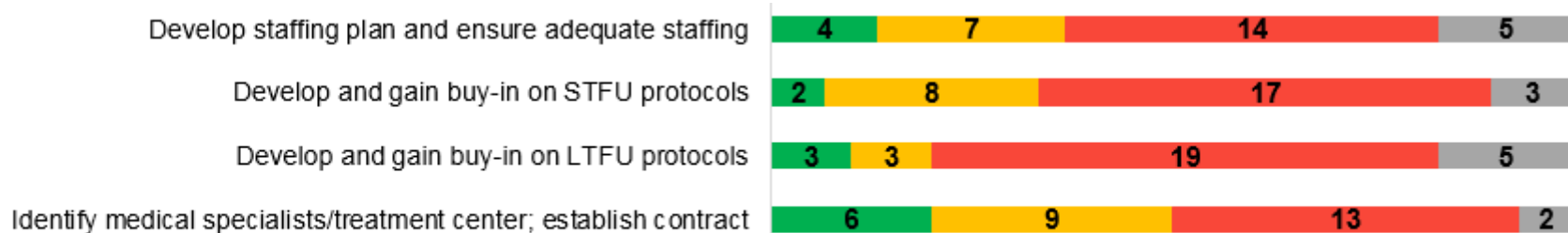
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Phase 2: Follow-up Readiness

■ Completed ■ Started ■ Not Started ■ NA

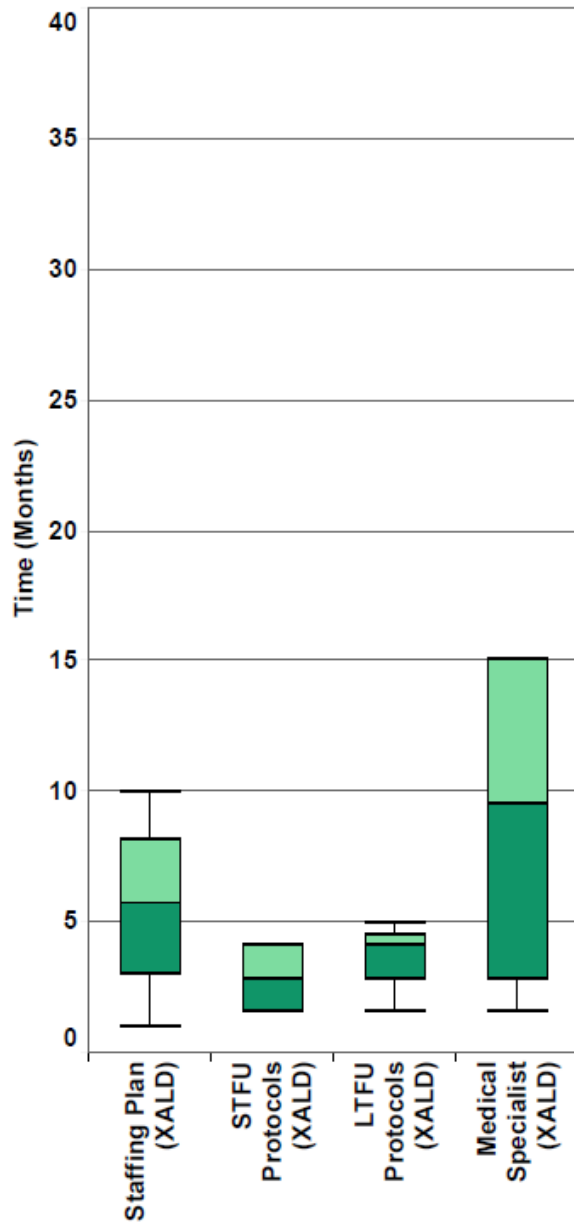
XALD
(n=30)



NewSTEPS

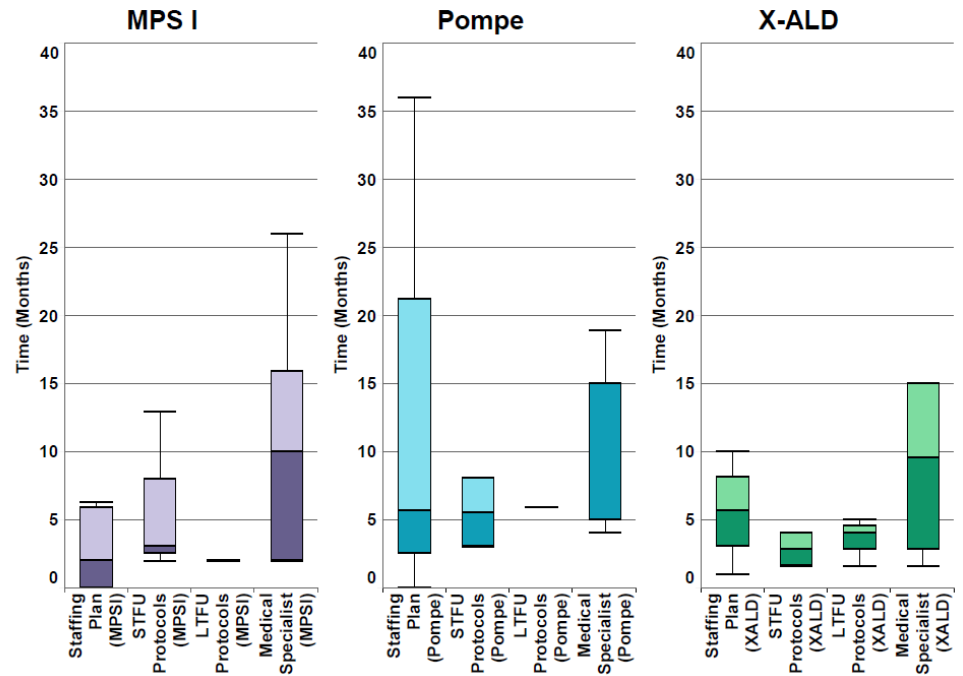
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X-ALD



Time to Complete Follow-Up Logistics – X-ALD

Phase 2: Time to Complete Follow-up Logistics



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Overview of Phase 1 - Legislation/Mandate Stage

Where States Are at Based on
Readiness Tool Data

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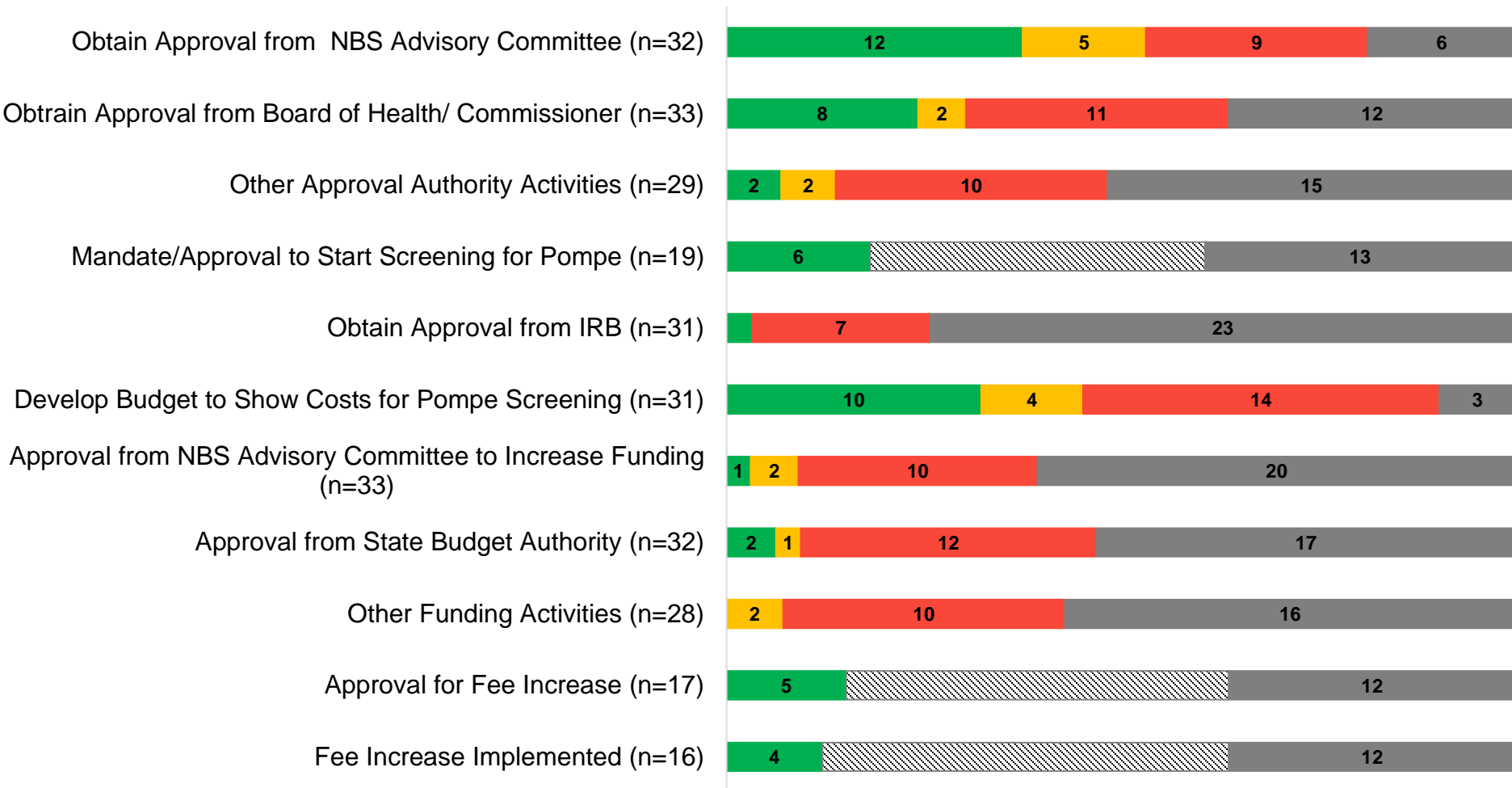


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Status of Phase 1 Activities for Pompe (n=33)

■ Completed ■ Started ■ Not Started ■ NA

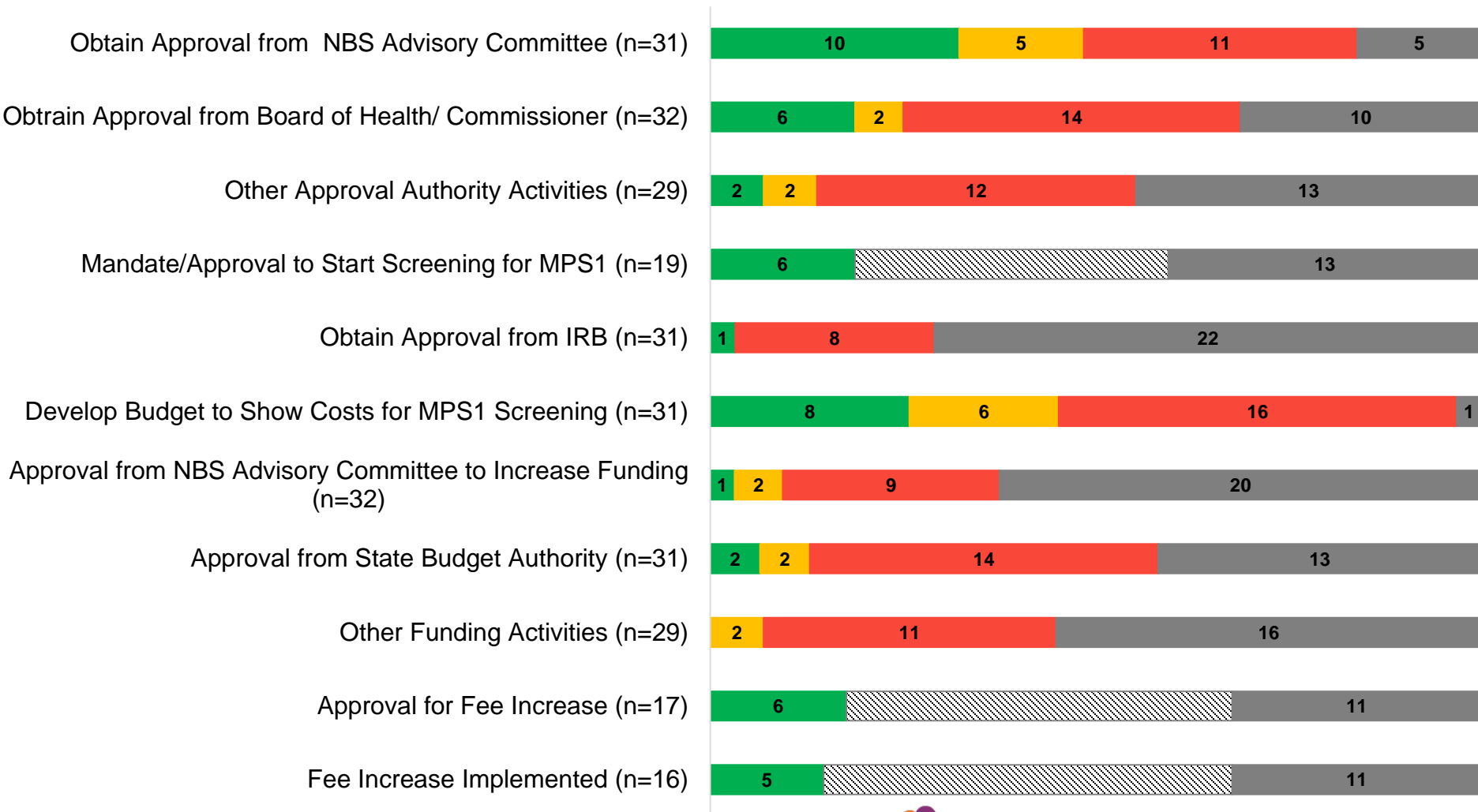


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Status of Phase 1 Activities for MPS I (n=32)

Completed Started Not Started NA

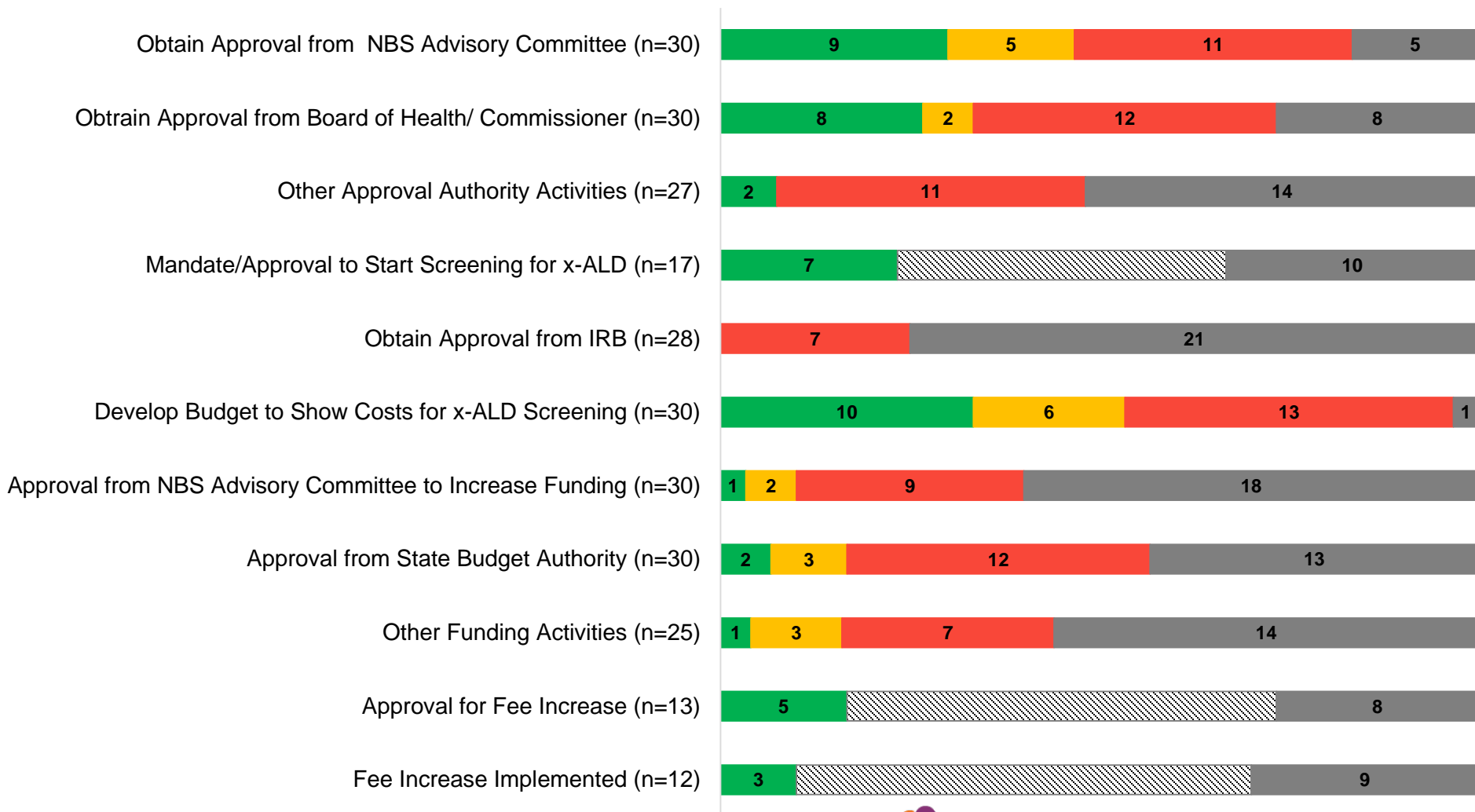


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Status of Phase 1 Activities for x-ALD (n=30)

■ Completed ■ Started ■ Not Started ■ NA



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Phase One

4 states

Approval/Authority To Screen MPS1 (12-36 months)

4 states

Fee MPS1 (5 to 49 months)

4 states

Total Phase 1 MPS1 (5 to 54 months)

2 states

Approval/Authority To Screen Pompe (12 to 18 months)

4 states

Fee Pompe (5 to 21 months)

4 states

Total Phase 1 Pompe (5 to 21 months)

4 states

Approval/Authority to Screen X-ALD (6 to 13 months)

3 states

Fee X-ALD (5 to 21 months)

2 states

Total Phase 1 X-ALD (5 to 21 months)



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Overview of Phase 3 - Education Activities For the New Disorders

Where States Are at Based on Readiness Tool Data

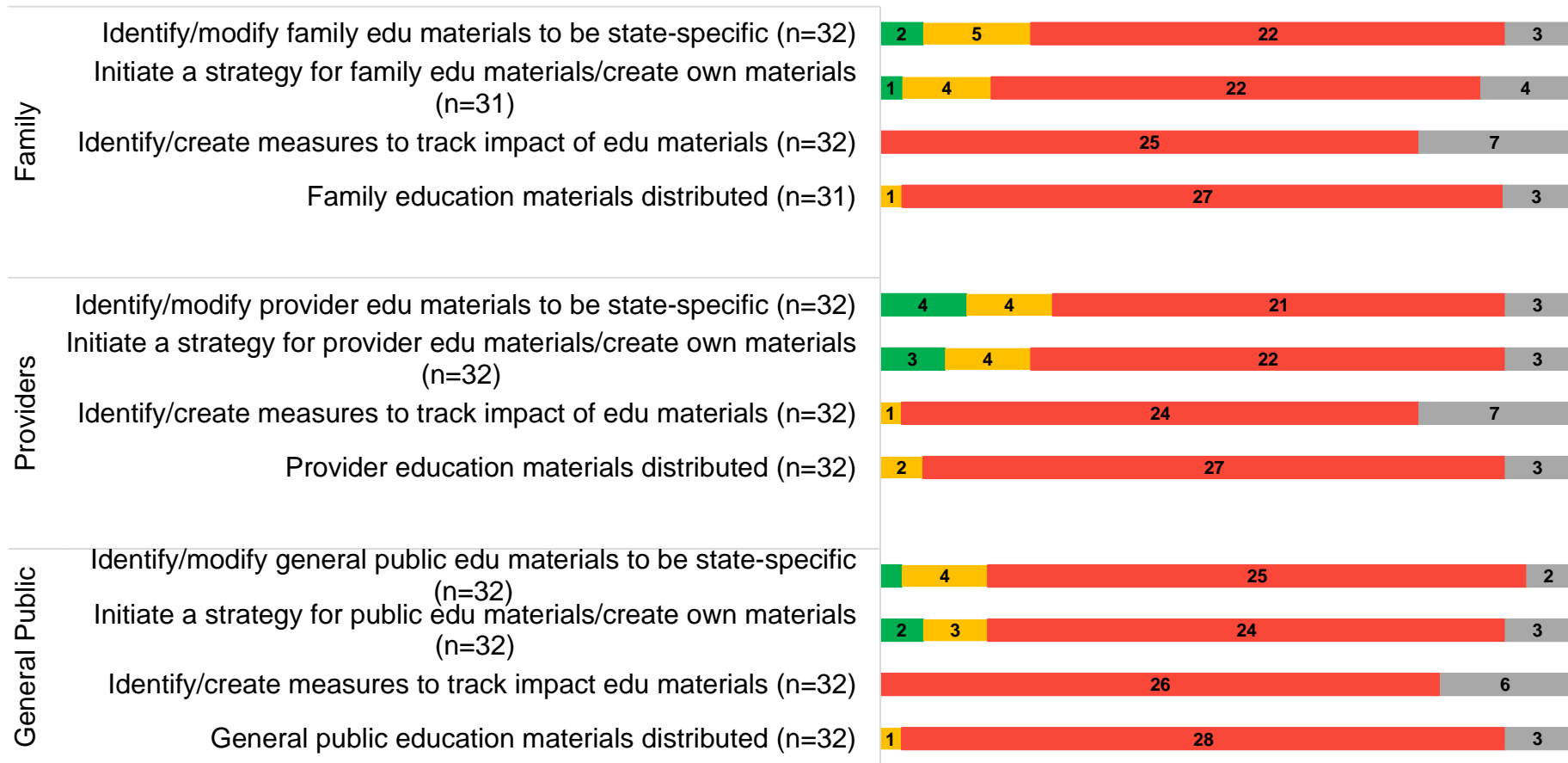
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MPS I-Phase 3: Status of Education Activities (n=32)



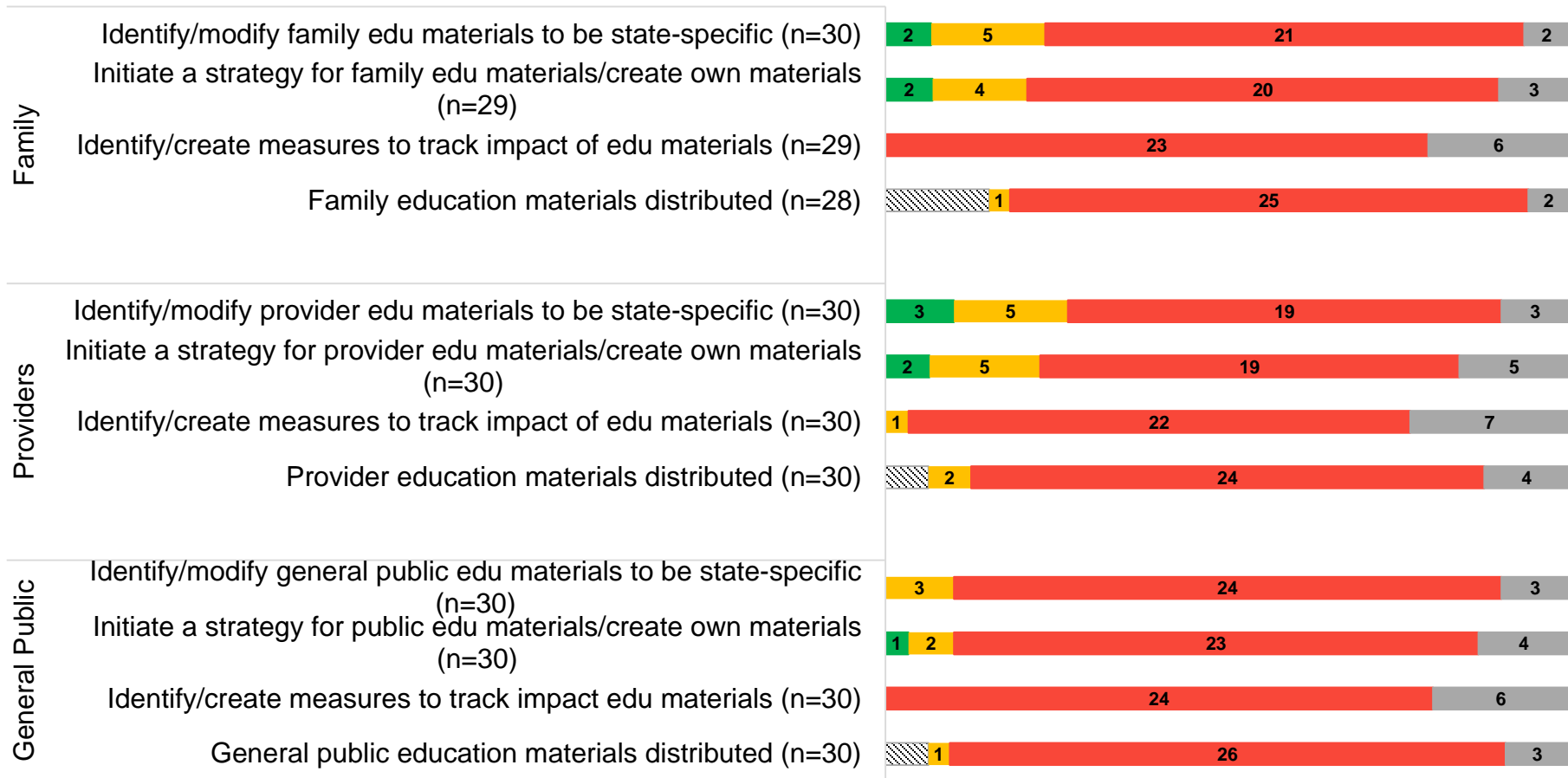
■ Completed
 ■ Started
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 ■ NA



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xALD-Phase 3: Status of Education Activities (n=30)



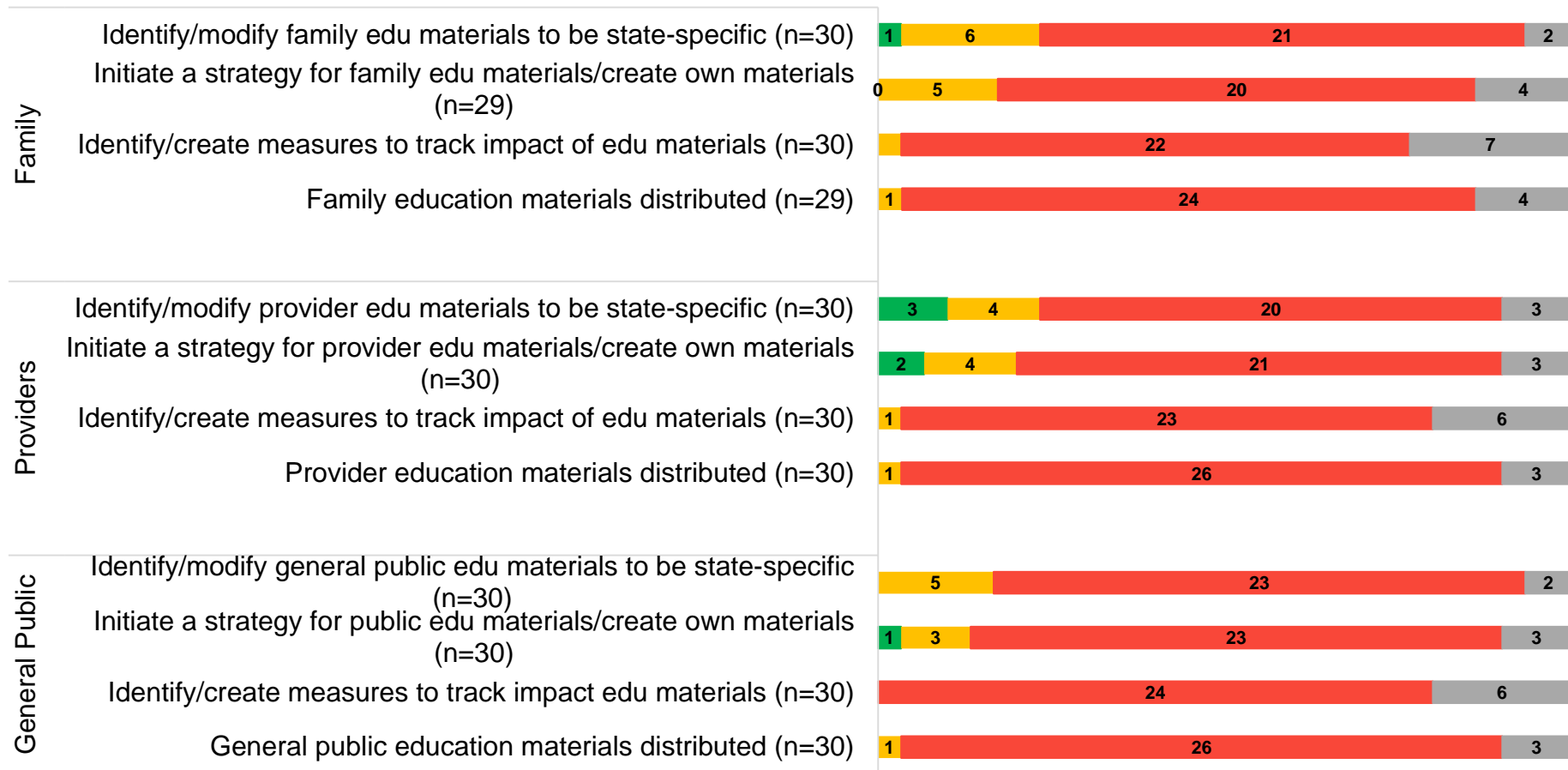
■ Completed
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 ■ NA



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Pompe-Phase 3: Status of Education Activities (n=33)



■ Completed
 ■ Started
 ■ Not Started
 ■ NA



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Thank you to Our Village

Our Meeting Planning Team

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- Tony Steyermark
- Amelia Mulford
- Rasoul Koupaei



The Data Team

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- Marci Sontag

The Logistics Team

- Kshea Hale
- Ruthanne Sheller
- Funke Akinsola



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