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Health Insurance Profile and Health Insurance Literacy (HIL) in Myotonic Dystrophy Type 1 (DM1)

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BACKGROUND

- Myotonic dystrophy type 1 (DM1) is a rare, progressive, genetic, neuromuscular disorder in which a spliceopathy caused by CTG repeat expansions in the myotonic dystrophy protein kinase (*DMPK*) gene drives heterogenous multi-system manifestations (muscular, central nervous system [CNS] and non-muscular) resulting in substantial disease burden and early mortality[1–5]
- No disease-modifying therapies are available, limiting treatment to symptom management[4]
- The burden of managing the complexity of the disease and a wide range of symptoms requiring utilization of increased services result in a decreased quality of life[4,6]
- Multidisciplinary care is rarely received in a comprehensive manner, and individuals often encounter healthcare silos[7–8]
- Better understanding of health insurance benefits will optimize access for individuals living with DM1

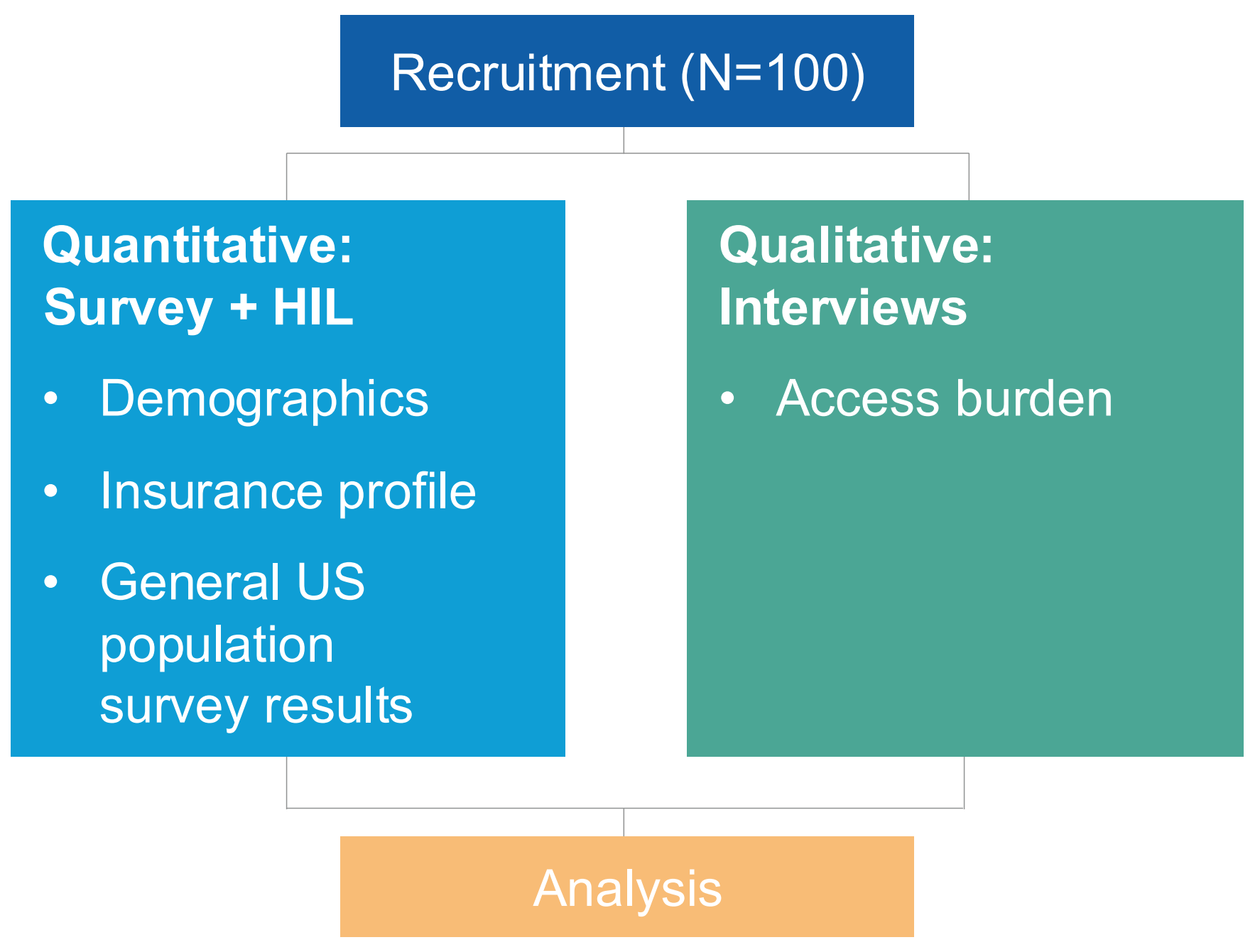
OBJECTIVES

- To understand the health insurance profile, health insurance literacy (HIL), and burdens of access experienced by individuals in the United States (US) diagnosed with DM1
- To create a dataset to benchmark future progress to inform family support and educational programming in DM1

METHODS

- This mixed-methods, non-interventional study was approved by the Western International Review Board – Copernicus Group (WCG IRB) and conducted in the US between February and mid-April 2025
- One hundred individuals living with DM1 or caregivers of individuals living with the disease were recruited through Engage Health's EnCompass® database, the Myotonic Dystrophy Foundation (MDF), and the National Registry of Myotonic Dystrophy (Figure 1)
- The 2014 Kaiser Family Foundation (KFF) survey was used to assess familiarity with health insurance terms and concepts among the general US population and participants in this study and the responses were compared[9]
- Additionally, participants completed interviews to identify and prioritize access burdens, allocating 100 points across their top three to indicate impact. Qualitative data were analyzed in MAXQDA 2020 (VERBI Software, 2019)

Figure 1. Study Design



Recruitment (N=100)

Quantitative: Survey + HIL
- Demographics
- Insurance profile
- General US population survey results

Qualitative: Interviews
- Access burden

Analysis

HIL, health insurance literacy.

RESULTS

Demographics and Health Insurance Profile

Figure 2. Participant Distribution (N=100)

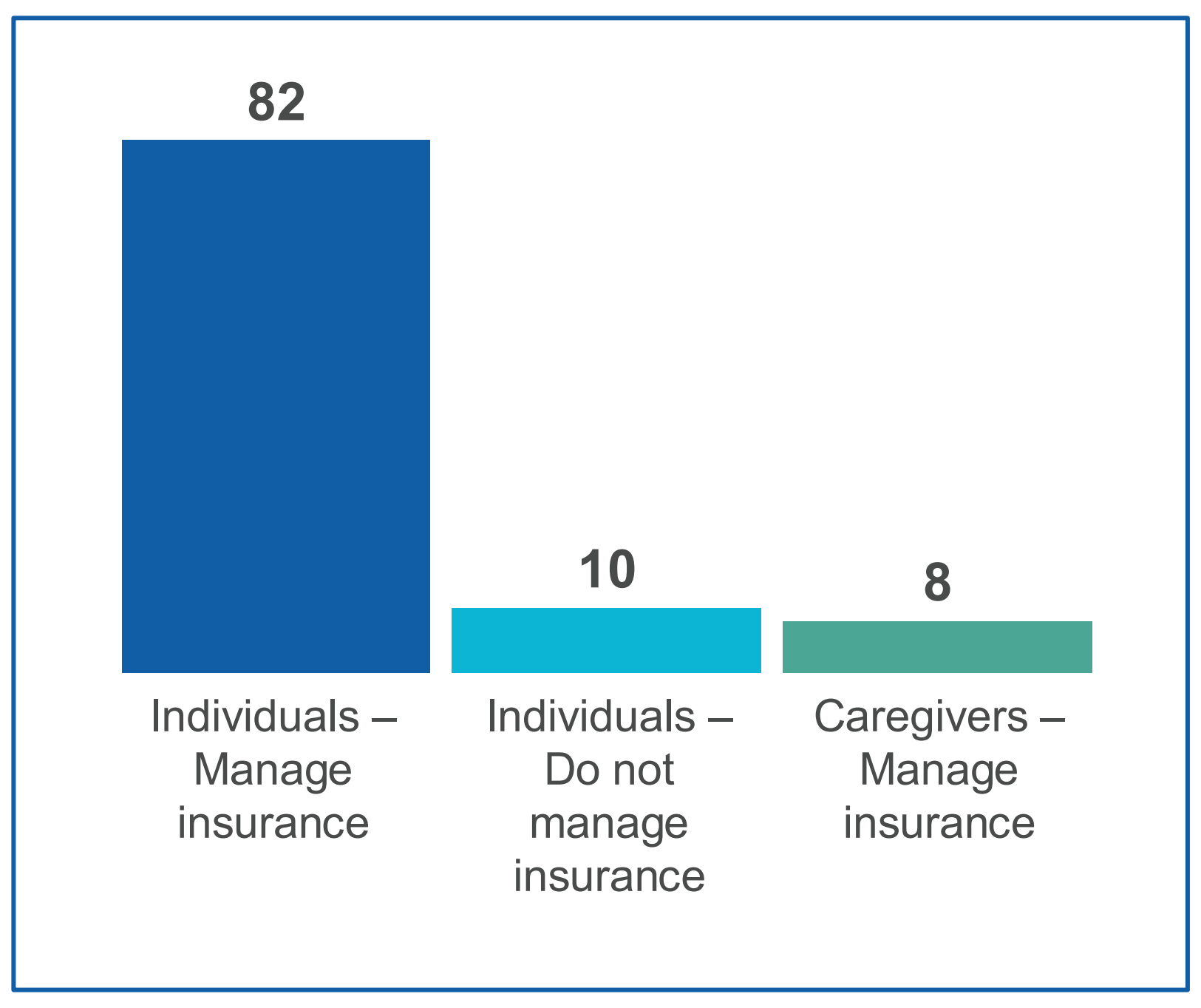
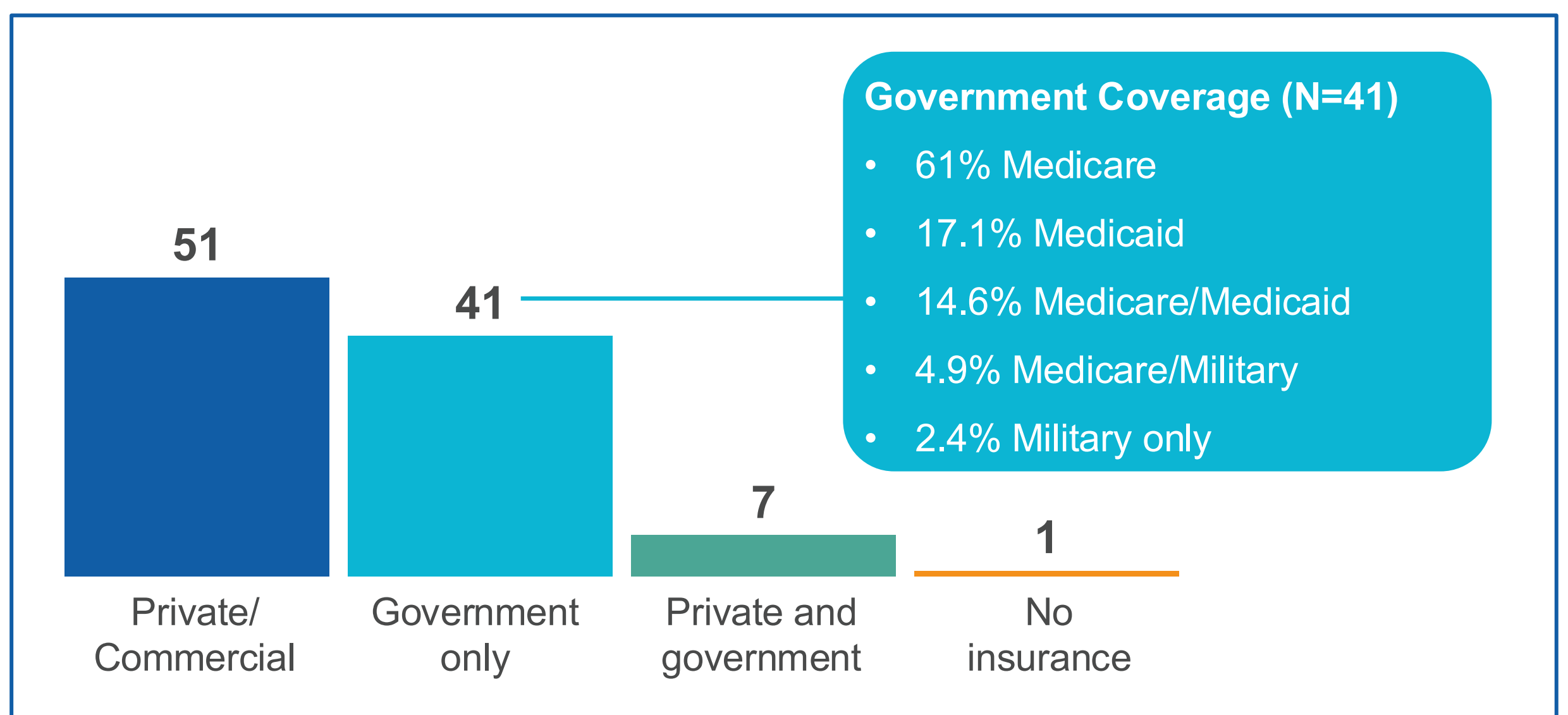


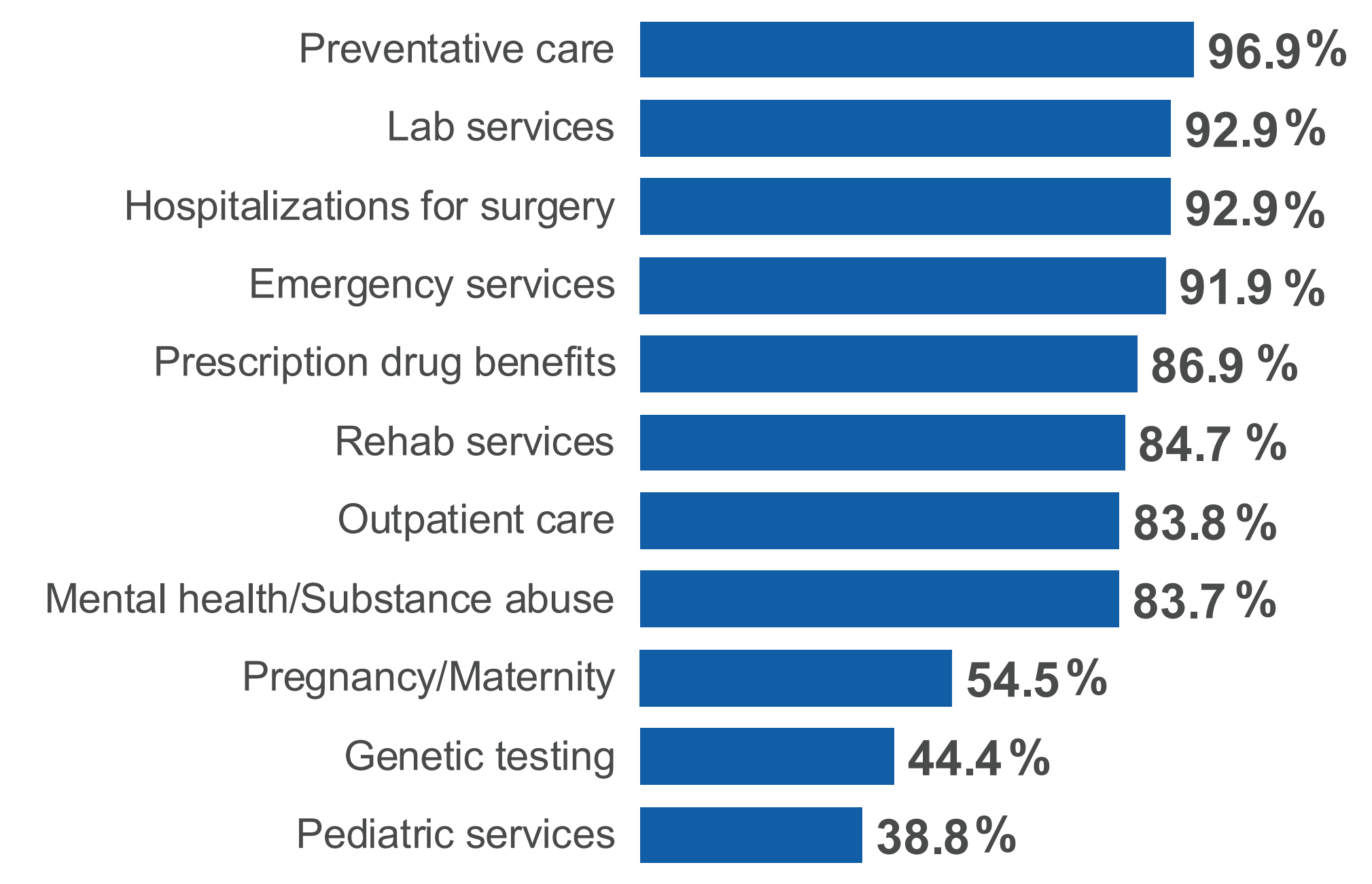
Figure 3. Insurance Coverage (N=100)*



Government Coverage (N=41)
- 61% Medicare
- 17.1% Medicaid
- 14.6% Medicare/Medicaid
- 4.9% Medicare/Military
- 2.4% Military only

*23% of insurance plan type responses were corrected to ensure accurate allocation of responses into the insurance categories.

Figure 4. Services Covered by Health Insurance (N=99)

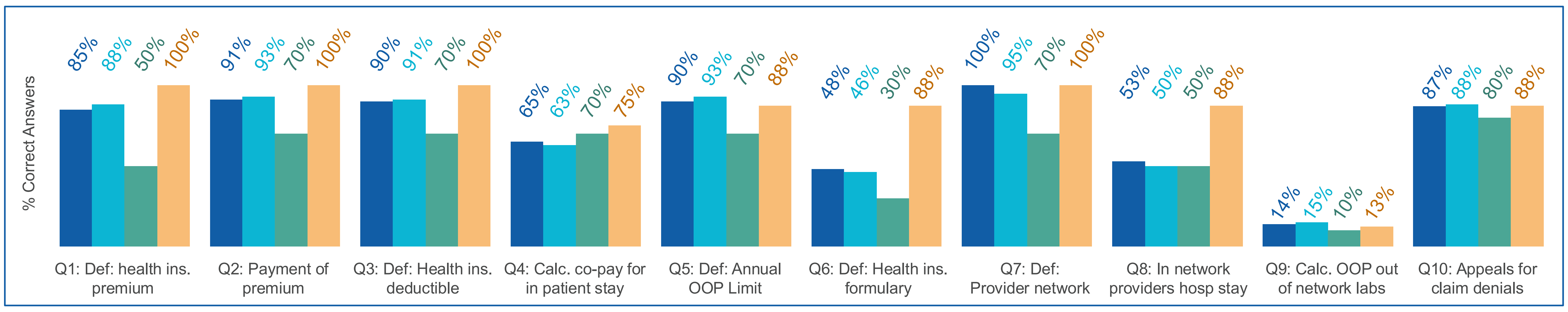


- Mean co-pay was $92.53 among the 66 participants who reported their highest individual co-pay for a supportive medication
- 93% did not participate in any co-pay support, reduced co-pay, or free drug program
- 45% did not require a specialist referral

Health Insurance Literacy

- Compared with the general US population survey responses, there were shared gaps in understanding cost-related concepts
- Individuals with DM1 that do not manage their insurance have the largest gaps across all questions

Figure 5. HIL Survey Responses: DM1 Participants (N=100) vs. General US Population (N=1292)



Calc, calculated; Def, definition; Hosp, hospital; Ins, insurance; OOP, out of pocket.

Burden of Access

Figure 6: Relative Burden of Access to Healthcare Across All Participants (N=100)

Burden of Access Theme	Weighted Score	Burden of Access Theme	Weighted Score
Process to get: care and services	31.89	Process to get: devices and equipment	2.8
Insufficient coverage: care and services	9.33	N/A	2
Not covered: care and services	8.54	Process to get: general coverage	1.95
Time I spend: care and services	8.45	Delay in getting: devices and equipment	1.78
Process to get: treatments and medications	6.65	Delay in getting: treatments and medications	1.75
Delay in getting: care and services	5.95	Insufficient coverage: devices and equipment	1.38
Insufficient coverage: general coverage	5.3	Insufficient coverage: treatments and medications	1.31
Not covered: devices and equipment	2.9	Fear: general coverage	1.15
Not covered: treatments and medications	2.89	General knowledge: resources	1.05
Fear: treatments and medications	2.83	Fear: care and services	0.1

- Most participants reported navigating the process to obtain care and services as the primary burden
- Coverage-related challenges ("insufficient coverage" and "not covered") were also key contributors to the burden of healthcare access
- 30% of participants reported difficulty identifying knowledgeable healthcare providers

STUDY LIMITATIONS

- Modest sample size may not be fully representative of the broader DM1 population
- Participants were recruited through patient advocacy groups and registries which may represent individuals who are more informed about their disease
- Comparator population based on a historical assessment of health insurance literacy in the general US population, therefore limiting ability to control for differences in demographics or methodology
- Qualitative findings are based on self-reported experiences and may be subject to recall bias

CONCLUSIONS

- Individuals with DM1 demonstrated health insurance literacy comparable to the general US population with shared gaps in understanding cost-related concepts
- While most participants were covered by health insurance, access burden was driven primarily by system complexity, coverage limitations, and challenges identifying knowledgeable providers
- Targeted education and support will be essential to ensure access to emerging therapies and clinical care

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DISCLOSURE INFORMATION

The research was sponsored by Dyne Therapeutics and conducted in conjunction with the MDF. Engage Health drafted the survey and interview guide in conjunction with Dyne and the MDF, fielded the study and performed all analyses. Interviews were conducted by Engage Health personnel trained in the collection of qualitative information. The DM1-ActivC and the MAASTRICHT UMC+ "DM1-ActivC Calculation Tables" were licensed from Prof. Dr. I.S.J. Merkies and Prof. Dr. C.G. Faber, from the School for Mental Health and Neuro Sciences MHeNS, part of the Maastricht University. The MDHI was developed by Heatwole and colleagues and was licensed from the University of Rochester, Rochester, New York. Deidentified patient-level data was provided to staff from the University of Rochester, who performed all calculations related to the MDHI data. MAXQDA 2020 was utilized through a license obtained from VERBI Software, GmbH. The insurance plan type was reviewed and categorized by Jennifer Shumsky of JLS Consulting, based on the plan name. AD and KB were employees of Dyne Therapeutics, Inc. at the time the study was conducted.

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