Health Insurance Literacy in Myotonic Dystrophy Type 1 (DM1), An Interim Report

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BACKGROUND

- DM1 is a progressive, inherited disorder, with multisystem clinical manifestations caused by mis-splicing of key genes (i.e., a spliceopathy) resulting in loss of muscle function and CNS symptoms (e.g., fatigue, excessive sleepiness, cognition)
- There are no FDA approved treatments for DM1, however new therapies are in development
- To optimize access the DM1 community has an urgent need to understand their health insurance benefits
- Dyne Therapeutics and the Myotonic Dystrophy Foundation (MDF) are conducting a study to examine health insurance literacy and the burdens of access experienced by individuals diagnosed with DM1 and their caregivers. The outcomes of this research will be used by Dyne and the MDF to design programs and inform other work intended to support families with DM1

OBJECTIVES

- To better understand the health insurance literacy and health insurance profile of individuals diagnosed with DM1
- To better understand burdens faced by individuals affected by DM1 as they seek access to care, medications and assistive devices to address their condition
- To create a baseline dataset to benchmark future progress, and inform family support and education programming in DM1

METHODS

- The study includes about 100 people with DM1 or their caregivers
- This interim report reviews responses collected as of March 13, 2025
- Participants answered 10 health insurance knowledge questions from the Kaiser Family Foundation (KFF) survey[1]
- Their responses were compared to the general U.S. population and grouped by whether they manage their own insurance

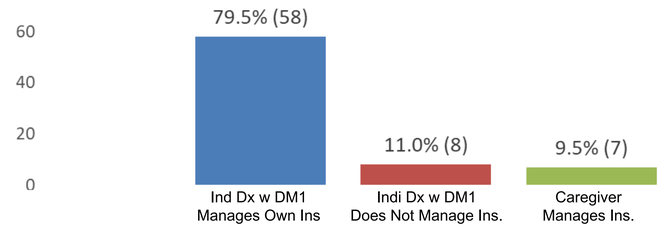
Figure 1. Questions Summary from KFF [1]*

*Acess QR code for full question set

Q1. Definition, health insurance premium
Q2. Payment of health insurance premium
Q3. Definition, health insurance deductible
Q4. Copay calculation for in hospital stay
Q5. Definition, annual out-of-pocket limit
Q6. Definition, health insurance formulary
Q7. Definition, provider network
Q8. Question re: in-network providers for hospital stay
Q9. Out-of-pocket calculation for out of network lab tests
Q10. Question re: appeals for claim denials

DEMOGRAPHICS

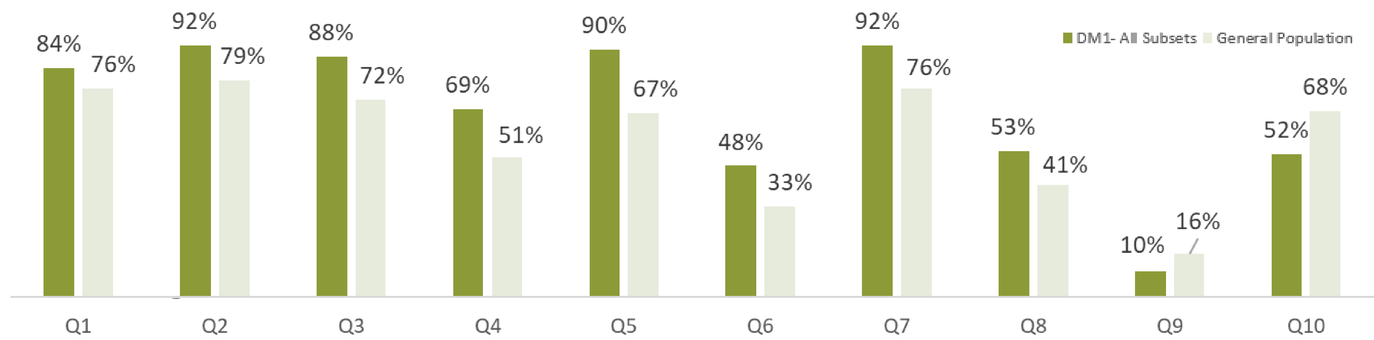
Figure 2. Participants to Date, n=73



- Data from 73 participants was analyzed. Most (79.5%) participants were individuals diagnosed with DM1 who manage their own insurance. Individuals diagnosed with DM1 who do not manage their own insurance (11.0%), as well as caregivers (e.g. spouse or parent) who managed the insurance of the individual diagnosed with DM1 were also included (9.5%) (Figure 2)
- There was a representative sample of participants from across the United States, but clustered in some states, due to family members affected

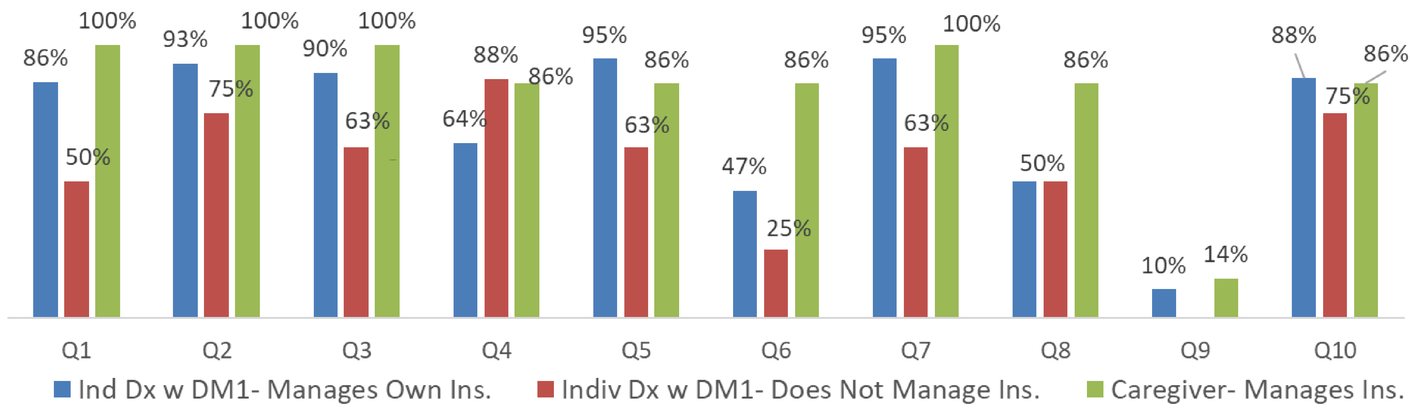
HEALTH INSURANCE LITERACY

Figure 3. Correct Answers for DM1 Community vs. General Population, n=73



- In this interim analysis, participants scored higher (average was 67.7%) than the general population sampled by KFF (average was 57.9%) (Figure 3)
- The only two questions for which DM1 participants scored worse than the general population were related to provider networks and appeals
- Like the general community, those affected by DM1 had difficulty calculating out of pocket costs

Figure 4. Correct Answers for DM1 Community Based on Insurance Management, n=73



- Within the DM1 community, caregivers (e.g. parents or spouses) who managed insurance scored higher than individuals diagnosed with DM1 who managed their own insurance (Figure 4)
- Both groups scored higher than individuals diagnosed with DM1 who did not manage their own insurance

SUMMARY

Interim findings suggest that individuals with DM1 and caregivers may have greater healthcare insurance knowledge than the general population, likely due to their frequent use of medical services and assistive devices.

- **Opportunities exist for industry and patient organizations to help address challenges related to healthcare access and understanding out-of-pocket costs for new treatments**
- **Final results will serve as a benchmark for future studies and guide family programming initiatives to better support the DM1 community**

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DISCLOSURE INFORMATION. Dr. Novack, Dr. Kerr, Ms. Beaverson and Dr. Dugar, are current or past employees of Dyne Therapeutics Inc. and may hold Dyne stock and/or stock options. Dr. Skinner, Dr. Stevenson, and Dr. Rohrwasser are employees of the Myotonic Dystrophy Foundation. Ms. Melchior and Ms. Jackson are employees of Engage Health, Inc., who conducts research for a variety of biopharmaceutical clients.

REFERENCES

1. Mira Norton, Liz Hamel Follow @lizhamel on Twitter, and Nov 2014. "Assessing Americans' Familiarity with Health Insurance Terms and Concepts." *KFF*, 12 Nov. 2014, https://www.kff.org/health-reform/poll-finding/assessing-americans-familiarity-with-health-insurance-terms-and-concepts/.

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