

Health Insurance Literacy and Profile Experience of Persons and Families Impacted by Fibrodysplasia Ossificans Progressiva

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INTRODUCTION

Fibrodysplasia Ossificans Progressiva (FOP) is an ultra-rare, progressive, and permanently disabling disorder of extraskeletal ossification. FOP is characterized by episodic flare-ups and irreversible heterotopic ossification in muscles, tendons, and ligaments, which often results in a permanent loss of mobility, decreased quality of life, and a shortened lifespan.

AIM

The aim of this study was to determine the health insurance profile, health insurance literacy, current medical and dental care, and burdens of access in persons impacted by FOP residing in the US. An analysis of health insurance profile and health insurance literacy is presented here.

METHODS

Study Design

This mixed methods non-interventional study was conducted between September 2024 and March 2025 with individuals diagnosed with FOP and their caregivers.

- Information about the study was shared with affected individuals known by the IFOPA and affected individuals who had opted into the EnCompass[®] database.¹
- After signing informed consent and providing documentation or attestation of disease, subjects filled out a survey and elected to participate in a follow-up 1-hour telephone interview.

Measures

- To measure health insurance literacy, participants were administered the Assessing Americans' Familiarity with Health Insurance Terms and Concepts questionnaire, which was previously administered to the general population by Hammel and colleagues.²
- The percent who answered each question correctly was captured and compared to those in the general population.²
- Questions were added which addressed issues encountered with contemporary rare disease therapies. These questions were developed independently with input from affected individuals and disease experts.
- Participants were also asked questions which evaluated their health insurance literacy and to self-rate their abilities to seek insurance information, their document literacy, and their cognitive abilities to apply insurance knowledge.

RESULTS

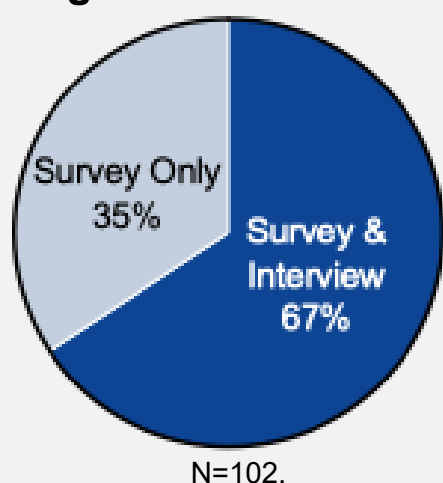
Participants

- 102 participants from 34 states completed the survey, representing 46% of the known patient population in the US
- 67 completed a follow-up interview
- Most participants had government-based plans only

Table 1. Participant Demographics

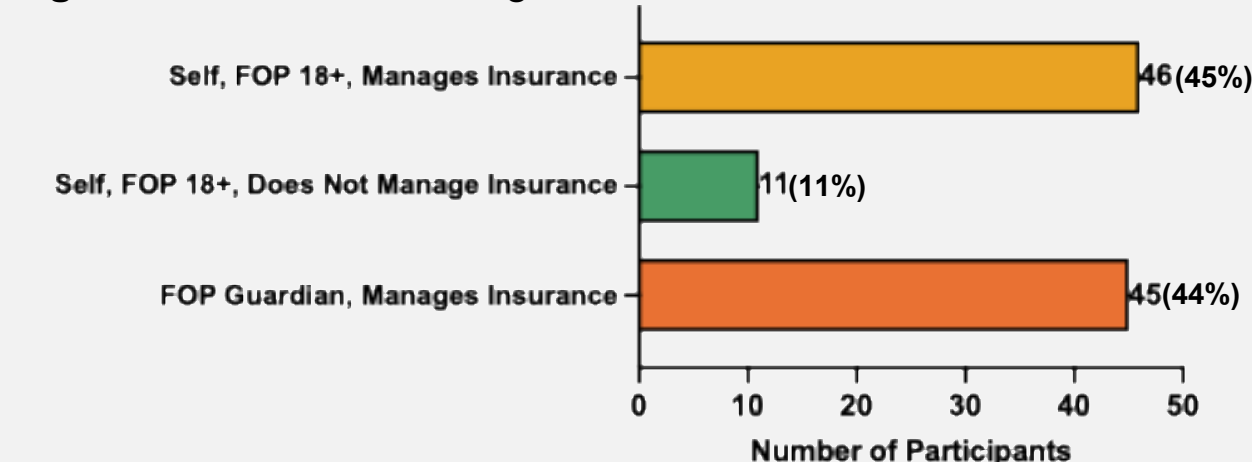
Study Participants N=102	
Sex, n (%)	
Male	45 (44)
Female	57 (56)
Age, mean (range)	27.4 (2-66)
Ethnicity, n (%)	
White	80 (78)
Asian	8 (8)
Black/African American	6 (6)
Hispanic/Latino	6 (6)
American Indian/Alaska Native	1 (1)
No answer	1 (1)
Payor type, n (%)	
Government only	42 (41)
Private only	39 (38)
Private + government	19 (19)
Uninsured	2 (2)

Figure 1. Data Sources



- Most participants were adults managing their own insurance or parents/caregivers of person diagnosed with FOP and managing insurance (80% of these participants represented a minor)

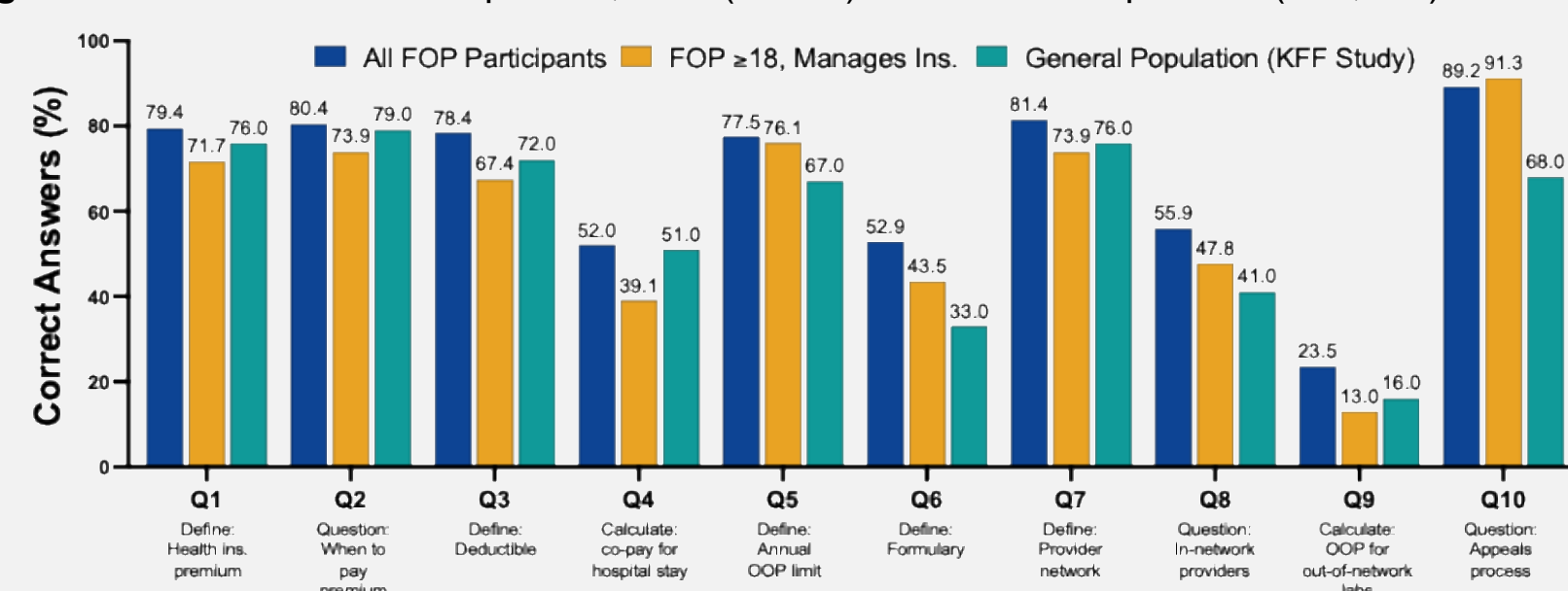
Figure 2. Insurance Management



Health Insurance Literacy

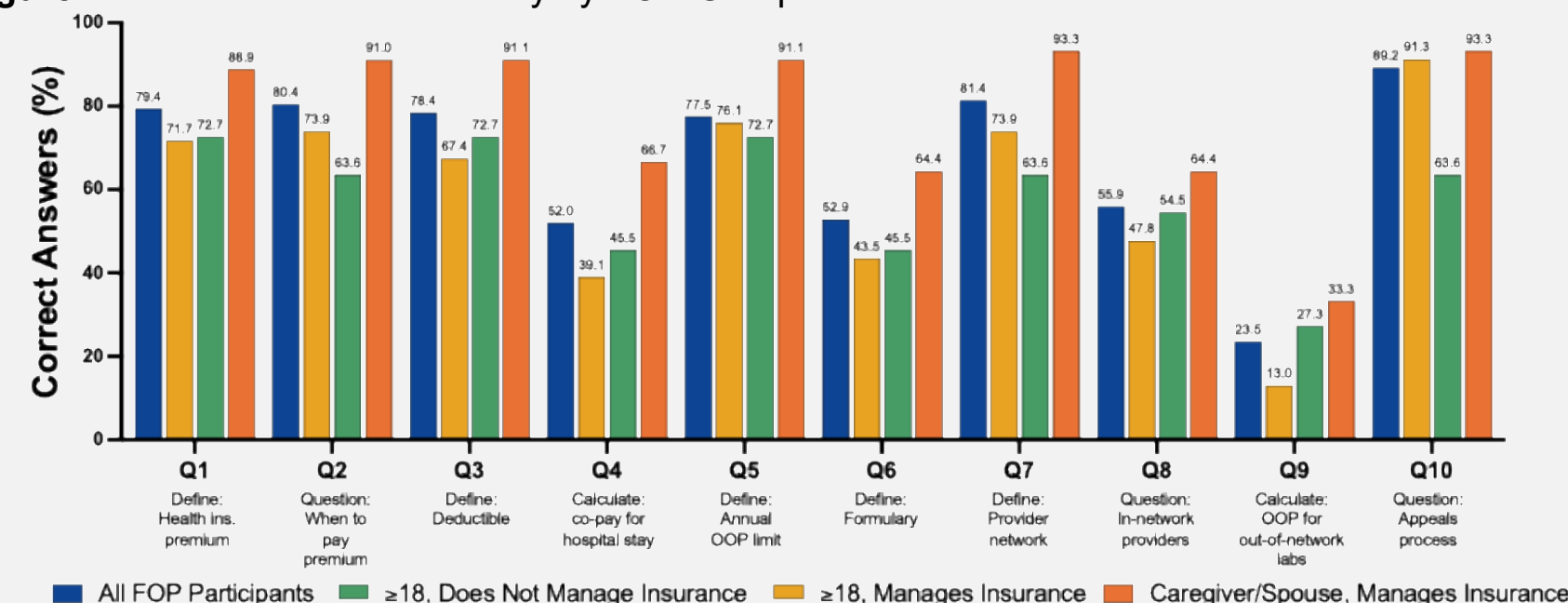
- The FOP study population scored better than the general population² in understanding and navigating health insurance, particularly when defining terminology. Both groups scored lower on questions related to pragmatic issues such as calculation of expenses.

Figure 3. Percent Correct Responses, FOP (n=102) vs. General Population (n=1,292)²



- Participants who managed insurance for an affected child had the highest scores, followed by affected adults who managed their own insurance.

Figure 4. Health Insurance Literacy by FOP Group



Interview Insights: Patient Needs

- In qualitative interviews, there were 131 mentions of resources/services that would be helpful, spanning 32 different categories.
- Participants most often expressed a desire for services for insurance education/coordination



Services for insurance education/coordination
33 mentions



Resources for disease information & education
12 mentions



List of FOP-experienced HCPs and/or dentists
12 mentions



Financial assistance
12 mentions



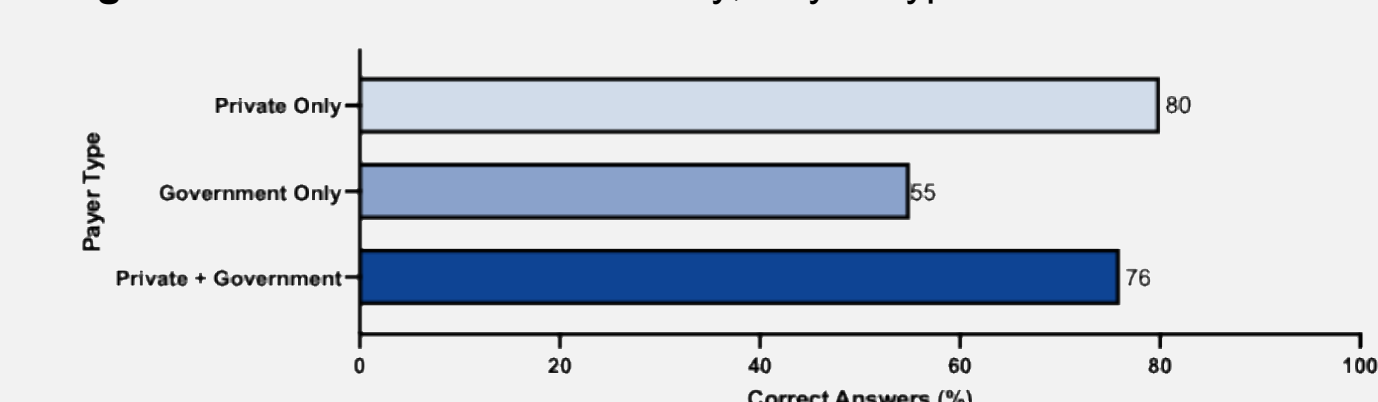
Help with navigating/awareness of available resources
10 mentions



State-level resources (HCPs, dentists, coverage, programs)
8 mentions

- Participants with only government coverage answered 55% of questions correctly vs. 80% of participants with private coverage.

Figure 5. Health Insurance Literacy, Payor Type



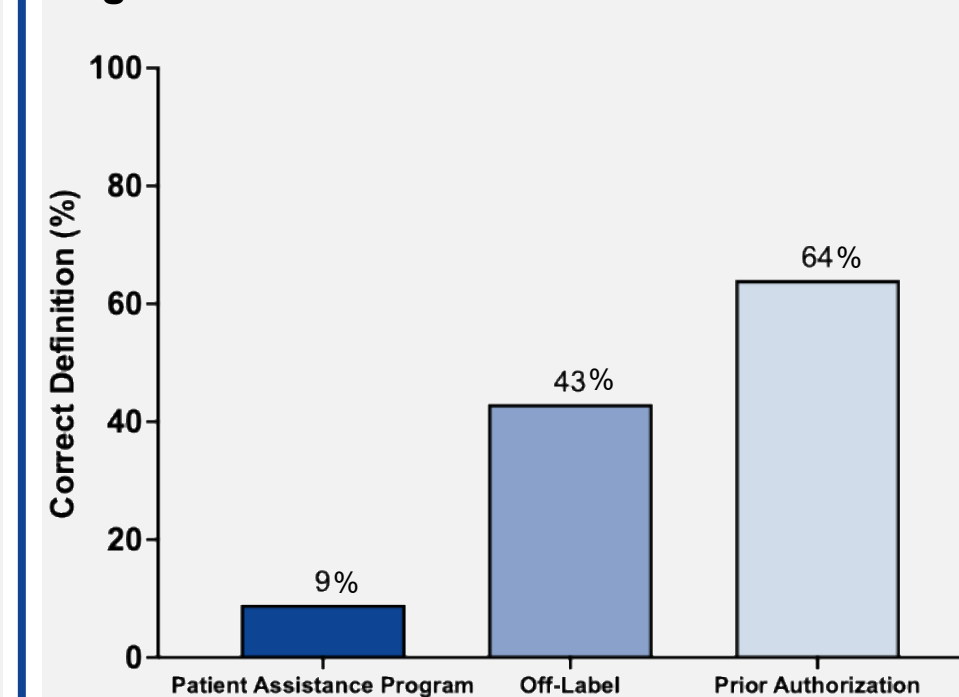
- Participants were asked to self-rate their ability to seek information regarding insurance, understand insurance documents, and their ability to apply insurance knowledge using a scale from 1 (strongly disagree) to 10 (strongly agree).
- Self-ratings indicate that people with FOP and their caregivers feel confident in their health literacy.

Figure 6. Health Insurance Literacy, Self-Rating



- When asked to describe key concepts in their own words, many interview participants provided incorrect definitions
 - Many believed a "patient assistance program" was a care coordination/overarching financial assistance service
 - Many believed "off-label use" referred to the use of a generic medication
 - Many confused the concept of a "prior authorization" with a physician referral

Figure 7. Correct Definitions n=67



CONCLUSIONS

This study provides an understanding of the health insurance profile and health insurance literacy of individuals affected by FOP in the US. Information gathered provides pragmatic insights that will help guide education and support programs.

REFERENCES AND FUNDING

- "Encompass[®]." Engage Health, 2019, www.engagehealth.com/encompass/.
- Norton M, Hamel L, Brodie M. Assessing Americans' Familiarity with Health Insurance Terms and Concepts. KFF. Published November 11, 2014. Accessed August 18, 2025. <https://www.kff.org/affordable-care-act/poll-finding/assessing-americans-familiarity-with-health-insurance-terms-and-concepts/>

This study is supported by grants from the EveryLife Foundation Rare Giving Program, IPSEN and Regeneron Pharmaceuticals.