

Do rare disease patients have access to the information they need to make informed healthcare decisions?

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Methods (Part 1)

Time-limited internet search



30
minutes



3
members of the public took part

Rare

- Usher syndrome
- Primary immuno-deficiency
- FOP

Common

- Type 2 diabetes
- Bipolar disorder
- HIV

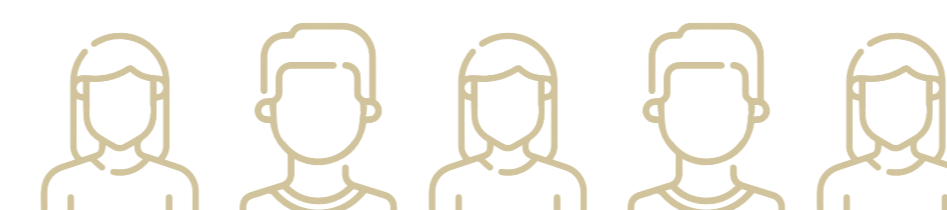
FOP: fibrodysplasia ossificans progressiva; HIV: human immunodeficiency virus

Methods (Part 2)

Patient representatives survey



20 patient representatives were sent a survey on 24th September 2021



10 patient representatives responded



8 survey questions

- Multiple response options
- Free-text boxes
- 5-point Likert scale

Topics covered:

- Access to necessary information
- Barriers to access
- Most useful formats of information

Objective

Access to clear, accurate information helps patients make informed healthcare decisions.¹

We aimed to identify barriers to health-related materials for patients with rare diseases.

Methods

Part 1) Three members of the public conducted a 30 minute internet search to retrieve pre-determined information about two assigned diseases, one rare and one common. The format and understandability of the information found was reported.

Part 2) A survey was distributed to patient representatives to determine patient experiences accessing disease and treatment information and the format of these materials.

Conclusions

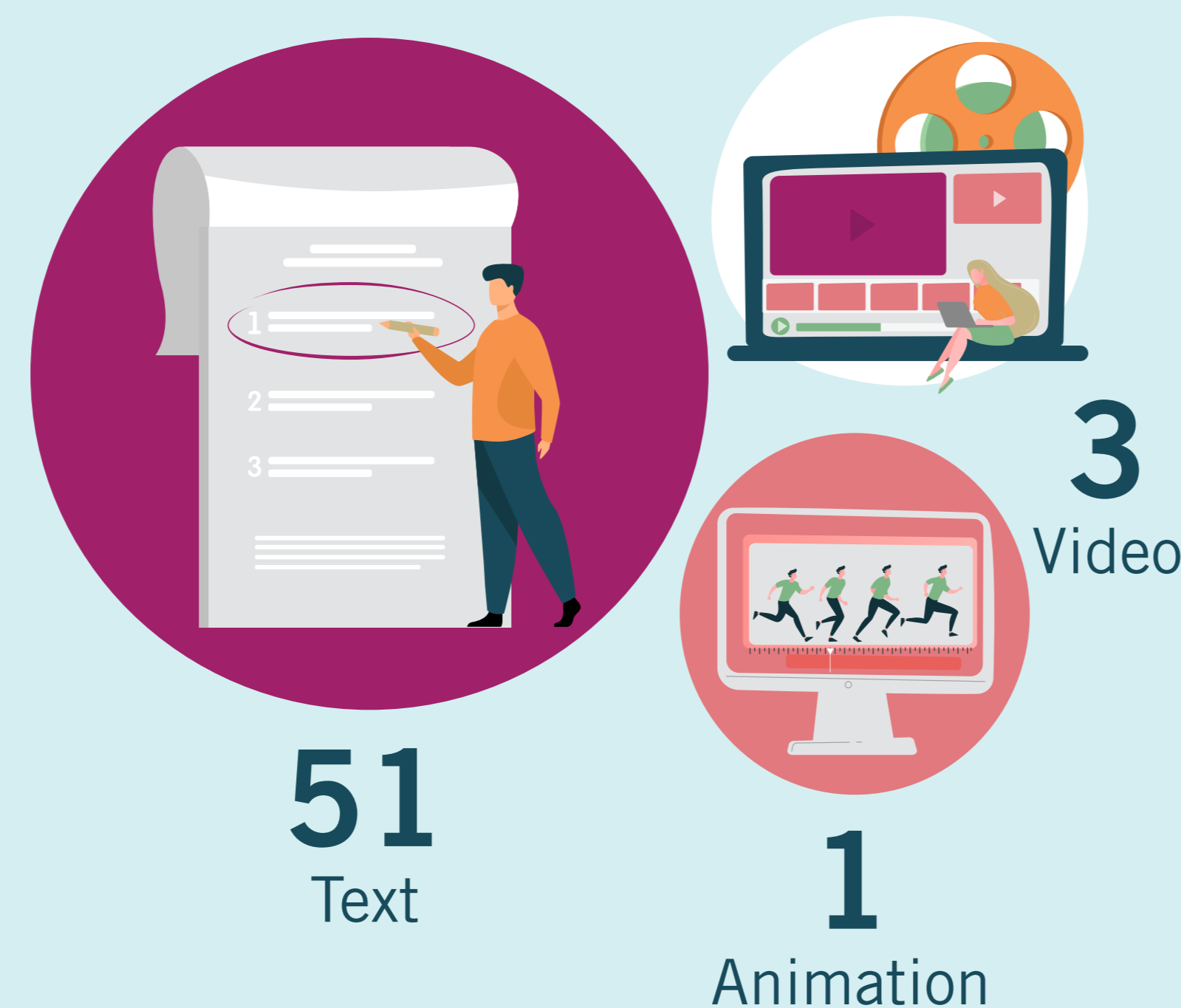
Patient representatives reported that most patients actively sought information about their diseases and that visual formats were particularly useful.

However, most readily available online resources were text-based and were less accessible in the rare disease space.

Our findings demonstrate a clear unmet need for accessible healthcare information in the rare disease community.

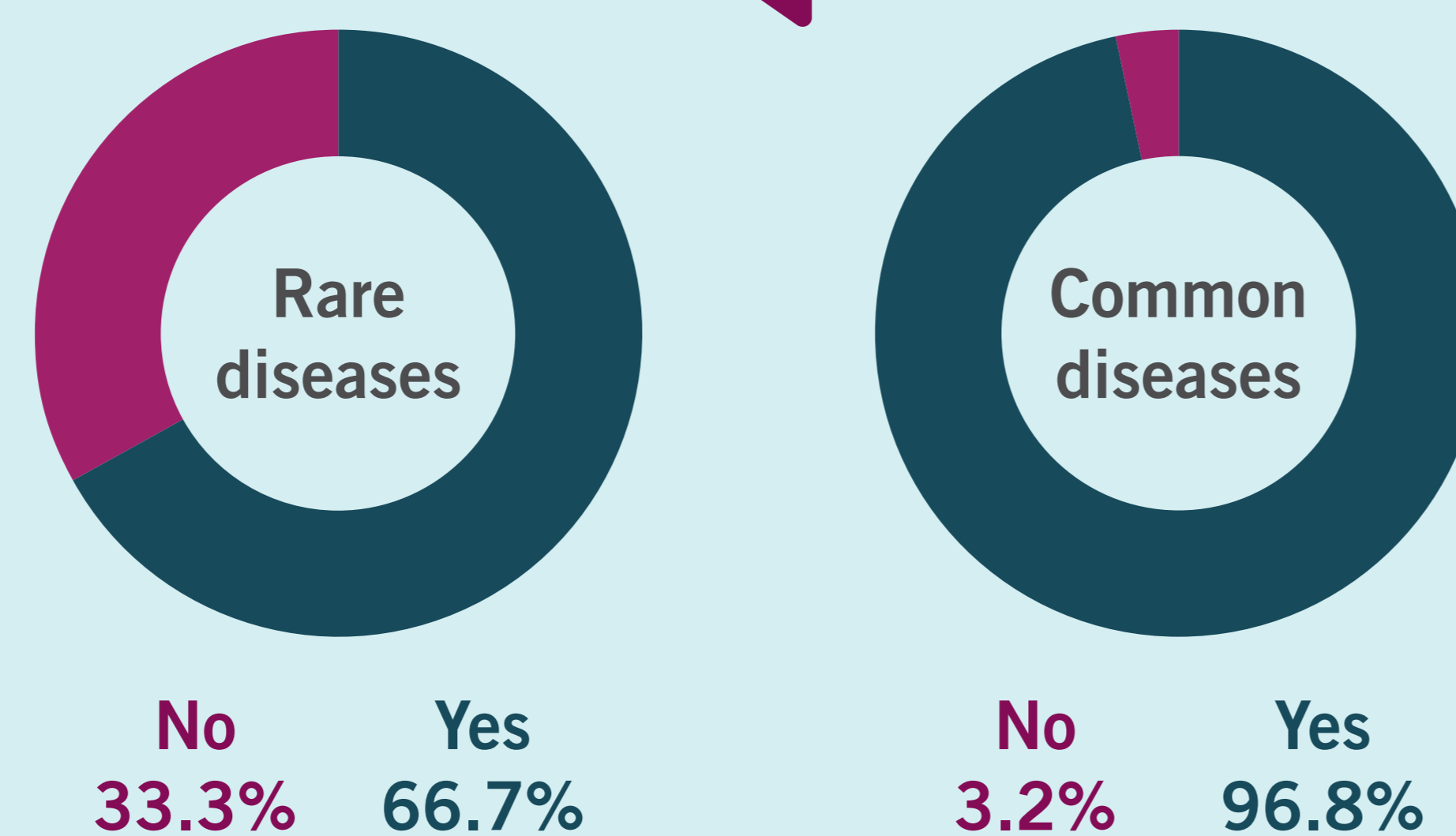


Results (Part 1)



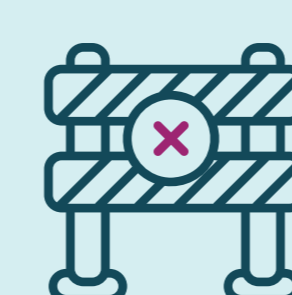
Of the information found, **text** was the most readily available format of patient materials

Were you able to easily access, read and understand the information that you found about the disease?



Abbreviations: HCP: healthcare professional.

Results (Part 2)

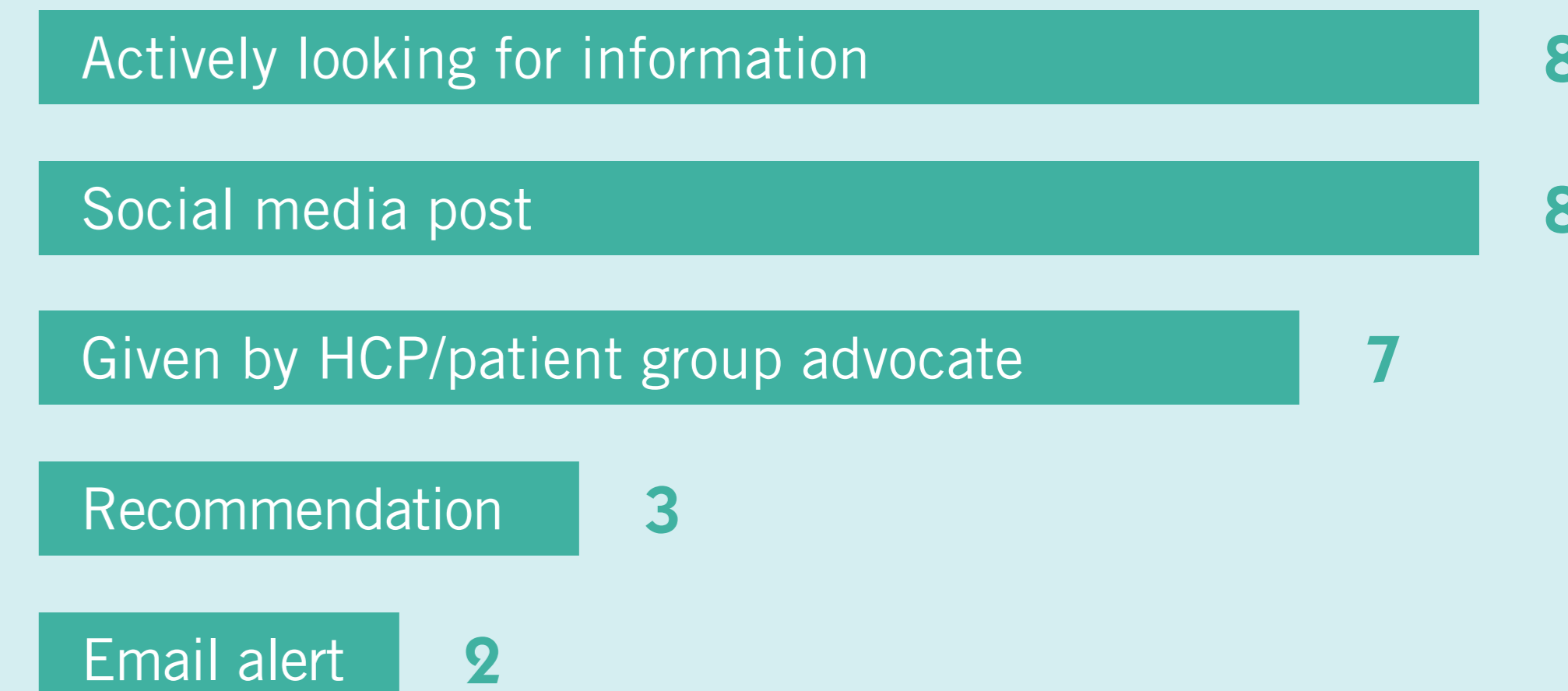


80% of patient representatives felt patients do not have access to the information they need about their disease

When considering the format of materials, what has been particularly useful for patients?



When considering materials that patients have engaged with over the past six months, what led them to those resources?



What is the biggest barrier preventing patients from accessing the materials or information that they need about their disease, medication or day-to-day advice?

“ Learning difficulties [may] impact on the individual’s ability to access appropriate information ”

“ Lack of specialist support for the unique challenges ”

“ Lack of understanding [about] the disease from HCPs ”

“ Patients don’t know where to look, [or] it hasn’t yet been written ”



References

1. Department of Health. The UK Strategy for Rare Diseases, 2013: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/260562/UK_Strategy_for_Rare_Diseases.pdf.

Author Contributions

Substantial contributions to study conception/design, or acquisition/analysis/interpretation of data: SM, EP, JS, CW, SJC; Drafting of the publication, or revising it critically for important intellectual content: SM, EP, JS, CW, SJC; Final approval of the publication: SM, EP, JS, CW, SJC.

Disclosures

SM: Employee of Costello Medical when research was conducted; EP, JS, CM and SJC: Employees of Costello Medical.

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