

# Caregiver perceptions of effects of the COVID-19 pandemic on health care access and management for children with inherited metabolic diseases: a cohort analysis

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## Rationale and objective

### Rationale

- The COVID-19 pandemic has changed health care delivery; many changes are anticipated to continue in the future
- Children with IMD often have high health care needs.
- Effects of the pandemic on healthcare for this population are unknown

**Objective:** Describe the impact of the COVID-19 pandemic on health care access + management for children with inherited metabolic diseases (IMDs)

## Methods

**Design:** cohort study on family health care experiences

**Participants:** parents ("caregivers") of children ≤12 years of age diagnosed with an IMD

**Recruitment:** through 11 participating Canadian pediatric metabolic clinics

**Data collection:** From Dec 2020 – Apr 2022, we invited caregivers to complete one cross-sectional, online, intake questionnaire which included questions on pandemic effects on child health, healthcare experiences, family IMD management, and family well-being

**Analysis:** Descriptive statistics of data received to date; preliminary findings presented

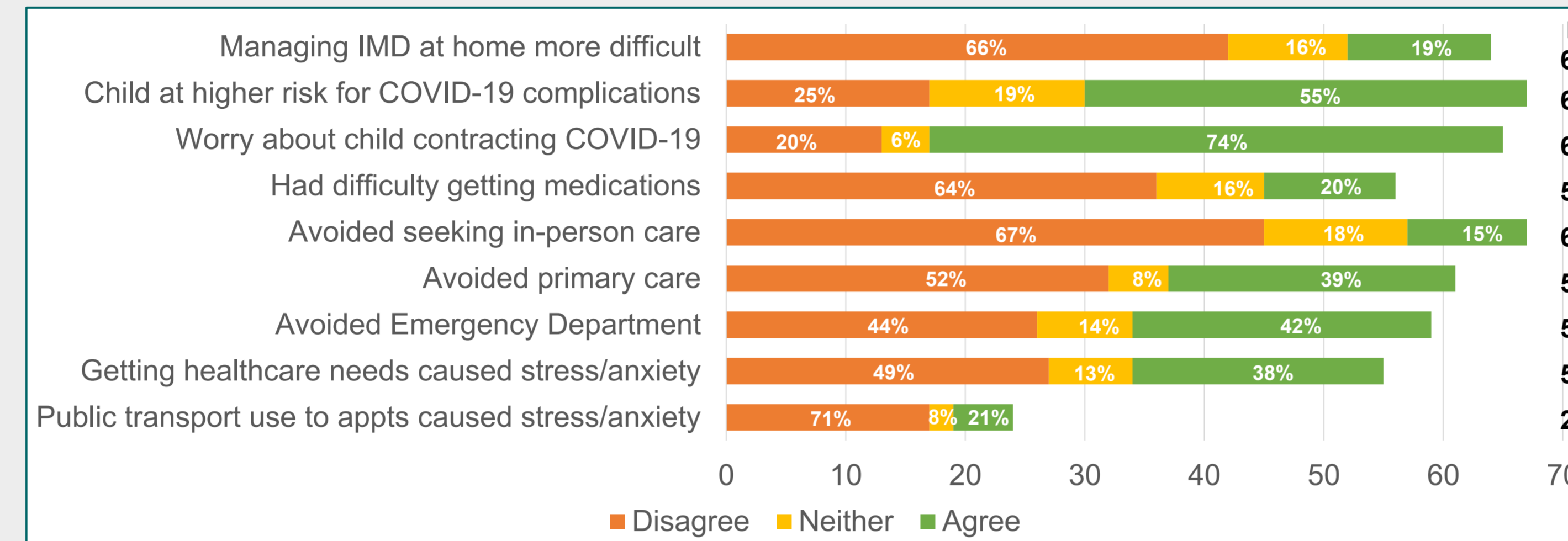
## Results: participant characteristics

| Table 1. Respondent (N=68) |           | n (%)                     |           |
|----------------------------|-----------|---------------------------|-----------|
| Relationship, mother       | 60 (88.2) | Residence                 |           |
| Highest education          |           | Ontario                   | 37 (54.4) |
| Sec. school diploma        | 14 (20.6) | Alberta                   | 11 (16.2) |
| College/vocational degree  | 15 (22.1) | New Brunswick/Nova Scotia | 12 (17.6) |
| University degree          | 39 (57.4) | British Columbia          | 4 (5.9)   |
|                            |           | Other                     | 4 (5.9)   |

| Table 2. Child (N=68) |           | n (%)                  |           |
|-----------------------|-----------|------------------------|-----------|
| Age, years            |           | IMD                    |           |
| 0 – 3                 | 27 (39.7) | Amino acid disorders   | 16 (23.5) |
| 4 – 6                 | 20 (29.4) | Urea cycle disorders   | 8 (11.8)  |
| 7 – 9                 | 14 (20.6) | Organic acid disorders | 4 (5.9)   |
| 10 – 12               | 7 (10.3)  | Fatty acid disorders   | 21 (30.9) |
| Sex, female           | 39 (57.4) | Other                  | 19 (27.9) |

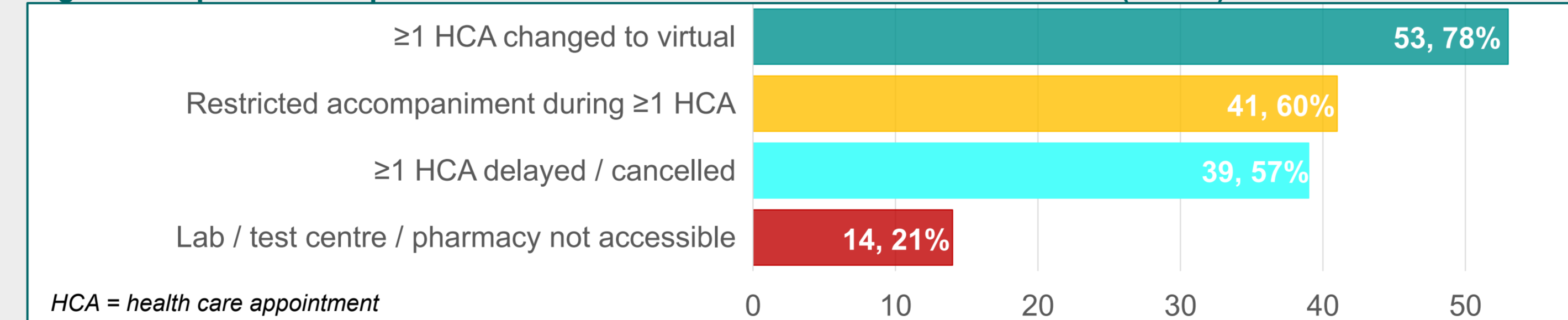
## Preliminary results

Figure 1. Caregiver experiences and concerns about child health and health care during the pandemic (N = 68)



- Most participants (**52, 81%**) did not find managing their child's IMD at home more difficult compared to pre-pandemic (c. March 2020) (Figure 1).
- Although a majority of caregivers worried about their child contracting COVID-19 (**48, 74%**), a minority avoided seeking in-person health care during the pandemic (**10, 15%**).
- A majority of participants (**37, 55%**) viewed their children as at higher risk for COVID-19 complications compared to other children.
- There was greater concern about the Emergency Department and primary care, with approximately **40%** avoiding those places ≥1 time during the pandemic.

Figure 2. Impacts of the pandemic on healthcare access for children with IMD (N = 68)



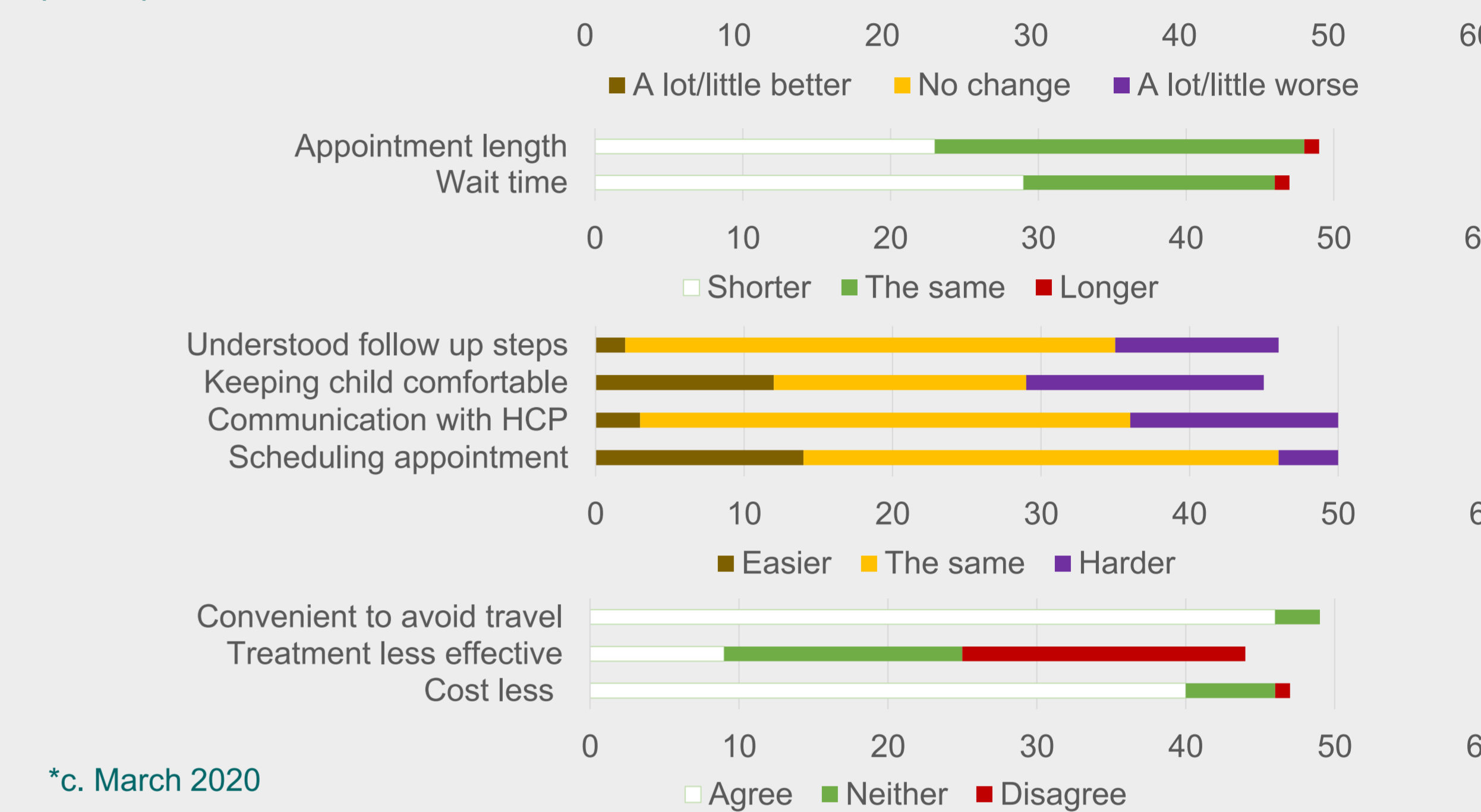
- 61 of 68 caregivers (**90%**) selected ≥1 impact of the pandemic on health care access (Figure 2).
- While many participants experienced a delay of health care, cancellation was less common (Table 3)
- Of concern, **>20%** could not access a lab, test centre, or pharmacy when needed because of reduced opening hours

Table 3. Types of health care appointments delayed or cancelled

|                             | Delayed n (%) | Cancelled n (%) |
|-----------------------------|---------------|-----------------|
|                             | <b>N = 37</b> | <b>N = 19</b>   |
| With known provider         | 29 (42.7)     | 15 (23.1)       |
| Tests/diagnostic imaging    | 12 (17.7)     | 4 (6.2)         |
| With new provider           | 9 (13.2)      | 2 (3.1)         |
| Home healthcare             | 6 (8.8)       | 4 (6.2)         |
| Health assistance at school | 4 (5.9)       | 2 (3.1)         |
| Missing                     |               | 3               |

## Preliminary results, continued

Figure 3. Caregiver ratings of virtual health care during the pandemic, compared to similar in-person care pre-pandemic\* (N = 53)



- Overall, many participants found many aspects of virtual care to be similar to those of corresponding in-person care; however, **~1/3 (31%)** of caregivers rated virtual appointments worse than in-person appointments (Figure 3, top).
- Broadly, virtual appointments tended to be shorter, caregivers waited less time to have the appointment, and they found it convenient to avoid travel and less costly than similar in-person appointments (Figure 3, second and last sections).
- However, one-quarter to one-third (**28-36%**) found it harder to communicate with the provider, keep their child comfortable, and understand follow-up steps during virtual encounters compared with similar in-person encounters (Figure 3, third section).

## Discussion

- This study was conducted with caregivers experiencing a variety of pandemic-related policies across a timespan encompassing multiple pandemic waves. Nevertheless, we identified common perspectives on changes to health care delivery for children with IMDs and their impacts.
- Caregivers were concerned about COVID-19 risk but avoidance of care was mainly in the emergency department; appointment delays were common but cancellations rare.
- Many participants appreciated some conveniences of virtual care but some experienced challenges with communication, comfort, and follow-up. Our study was online; thus our sample may be biased toward participants who have greater comfort with virtual experiences.
- Conclusion:** This study identifies areas where further study is needed, especially the various elements of virtual care that contribute to caregiver ratings. Caregiver perspectives should be considered in the design of virtual health care interventions for this population.