

ACROCOVID: an international survey on care for acromegaly during the COVID-19 era



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INTRODUCTION

- Acromegaly is a rare chronic condition with a prevalence ranging between 2.8 and 13.7 cases/100,000 people.¹
- Management of acromegaly requires a multidisciplinary team of health care professionals (HCPs).
 - Access to HCPs may be limited under pandemic conditions

OBJECTIVE

- To assess the effect of the COVID-19 pandemic on the management of acromegaly from the perspective of HCPs and people living with acromegaly.

METHODS

- Surveys were drafted by a team including people living with acromegaly and HCPs, and were available online as Google Forms (<https://docs.google.com/forms/u/0/>).
- Four surveys were conducted (patient, endocrinologist, neurosurgeon, specialist nurses).
 - Here we present the data from endocrinologists and people living with acromegaly
 - Surveys were conducted in English, with Spanish and French translations for people living with acromegaly
 - The surveys went live on the 23 June, 2020, and the data cut presented herein is from 13 July, 2020
- The data are presented descriptively.
 - To view the full surveys please use the following QR code:



RESULTS: ENDOCRINOLOGISTS

- Endocrinologist demographics are shown in **Table 1** and **Figure 1**.

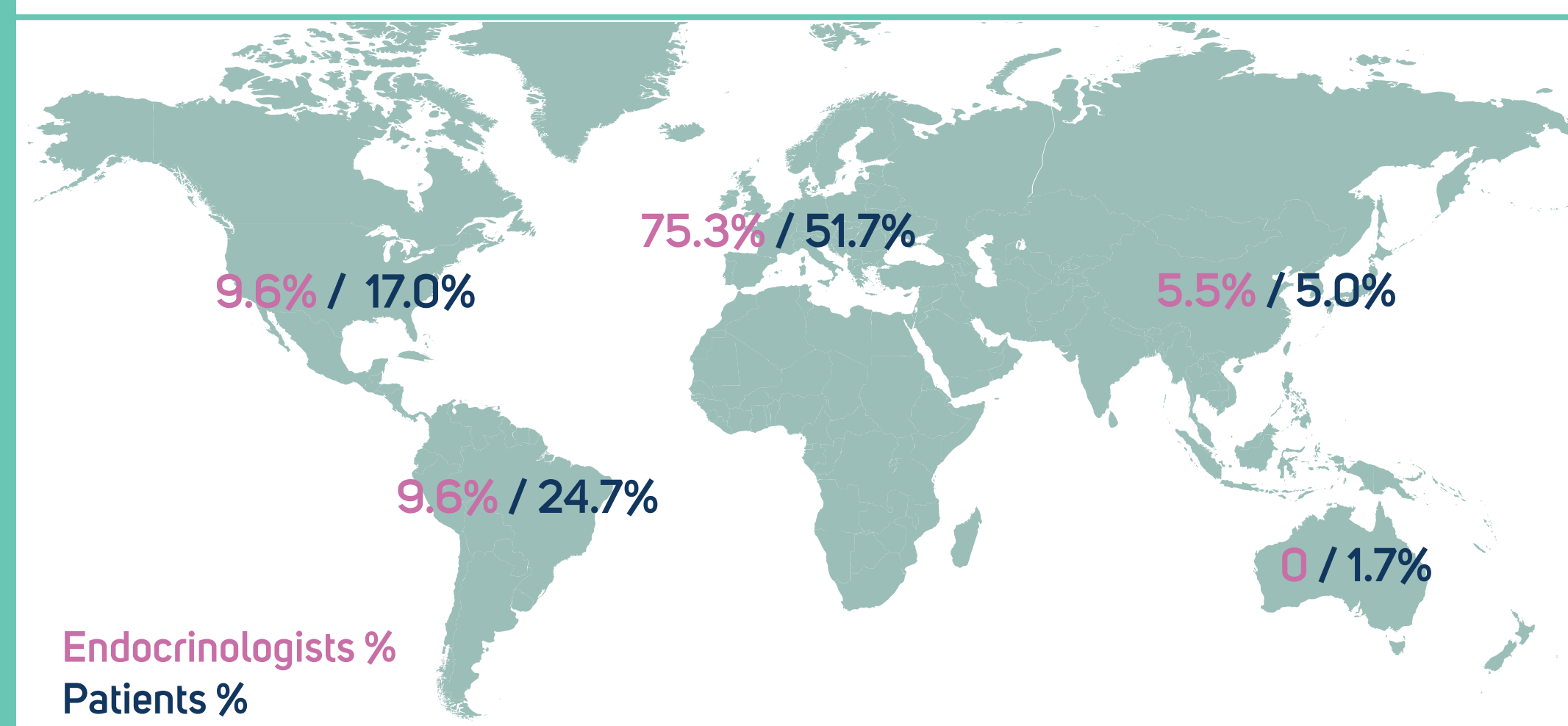
Table 1. Respondent demographics

	Endocrinologists (N = 73)	Patients (N = 182)
Female	43 (58.9)	130 (71.4)
Male	30 (41.1)	52 (28.6)
Age^a		
<30	NA	15 (8.2)
31–40	NA	24 (13.2)
41–50	NA	46 (25.3)
51–60	NA	63 (34.6)
61–70	NA	27 (14.8)
>70	NA	7 (3.9)
Number of years since diagnosis with acromegaly^a		
<1 year	NA	20 (11)
2–3 years	NA	29 (15.9)
4–5 years	NA	25 (13.7)
6–10 years	NA	37 (20.3)
11–15 years	NA	30 (16.5)
>15 years	NA	41 (22.5)
Practice type^b		
General endocrinology	31 (42.5)	NA
Pituitary centre	42 (57.5)	NA
Number of patients with acromegaly under ongoing care^b		
1–20	20 (27.4)	NA
21–50	14 (19.2)	NA
51–100	19 (26.0)	NA
≥100	20 (27.4)	NA

All data are presented as n (%).

^aIncluded in patient survey only, ^bIncluded in endocrinologist survey only; NA, not applicable.

Figure 1: Regional distribution of respondents

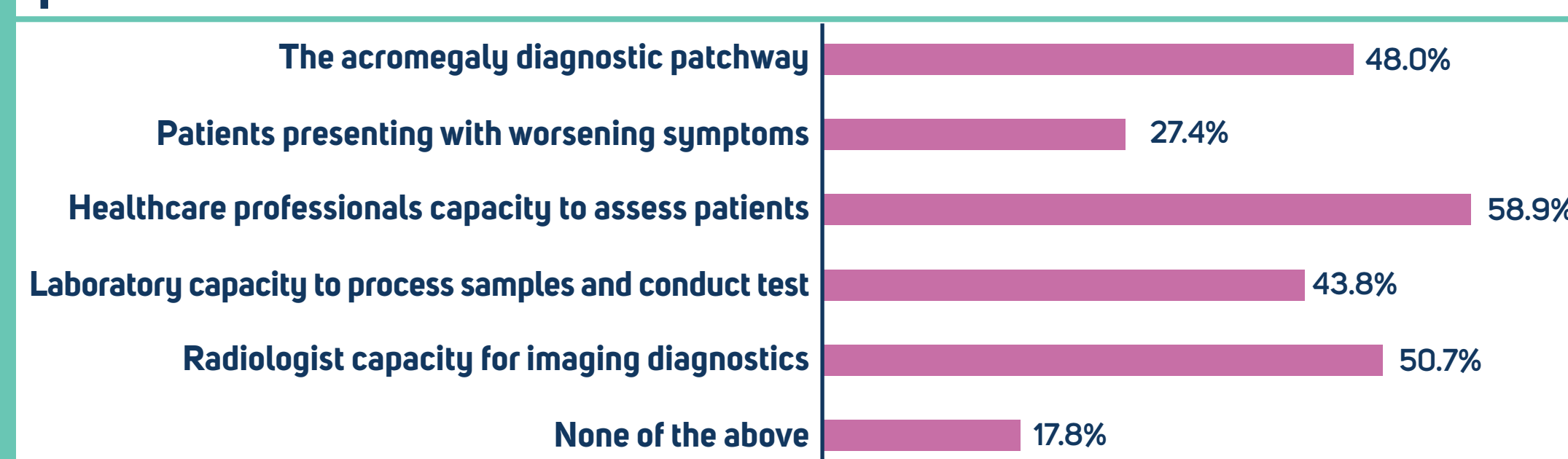


Endocrinologists: N=73; Patients: N=182.

Endocrinologists perspective on COVID-19 and the acromegaly diagnostic and treatment pathway

- More than half of respondents (n = 42; 57.5%) accessed advice on treatment of patients with acromegaly during the COVID-19 pandemic.
- 37 respondents (50.7%) agreed or strongly agreed that the COVID-19 pandemic had negatively affected their ability to maintain patient relationships:
 - 39 (53.4%) reduced contact
 - 4 (5.5%) only allowed urgent visits
 - 1 (1.4%) suspending services entirely
- 58 (79.5%) indicated that patients had approached them regarding being at increased risk from COVID-19.
 - 33 (45.2%) reported that their patients had sought their advice on disease management during the pandemic
 - 46 (63.0%) reported that patients sought advice regarding medical therapy
 - Just 8 (11.0%), 11 (15.1%), and 14 (19.2%) proactively advised on general health measures, acromegaly management, and medical therapy, respectively
- Effect of the COVID-19 pandemic on diagnostic pathway is shown in **Figure 2**.

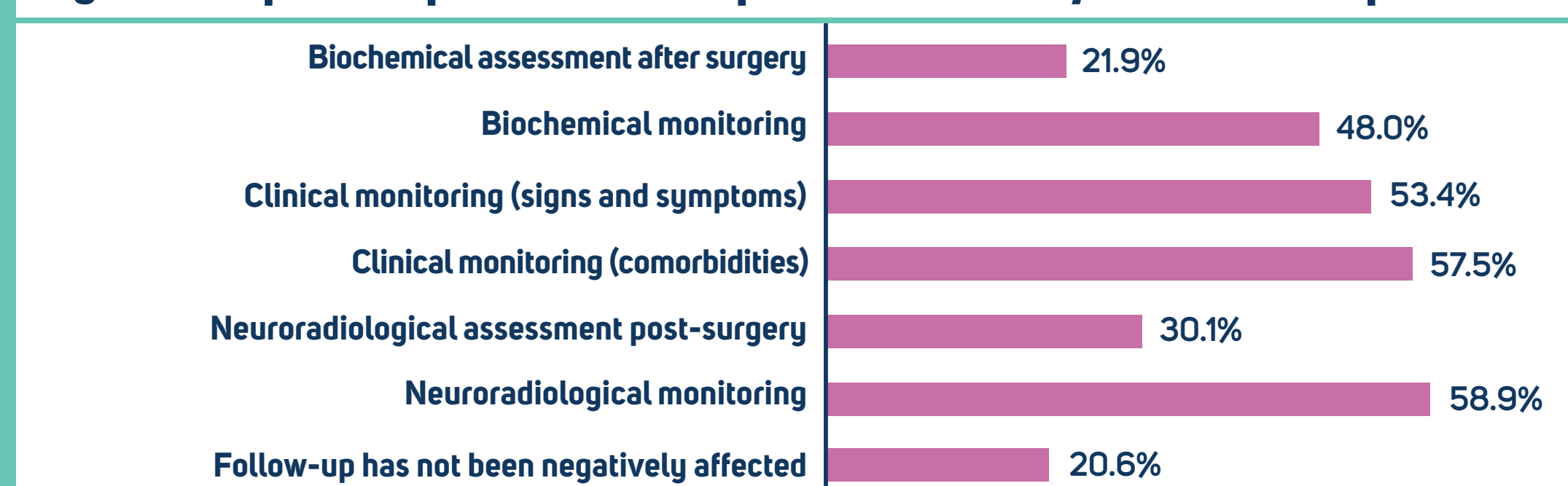
Figure 2: Aspects of patient management most affected by the COVID-19 pandemic



Data indicate percentage of respondents reporting a negative effect in each specific area of patient management.

- Effect of the COVID-19 pandemic on patient follow-up practices is shown in **Figure 3**.

Figure 3: Aspects of patient follow-up most affected by the COVID-19 pandemic



Data indicate percentage of respondents reporting a negative effect in each specific area of patient management.

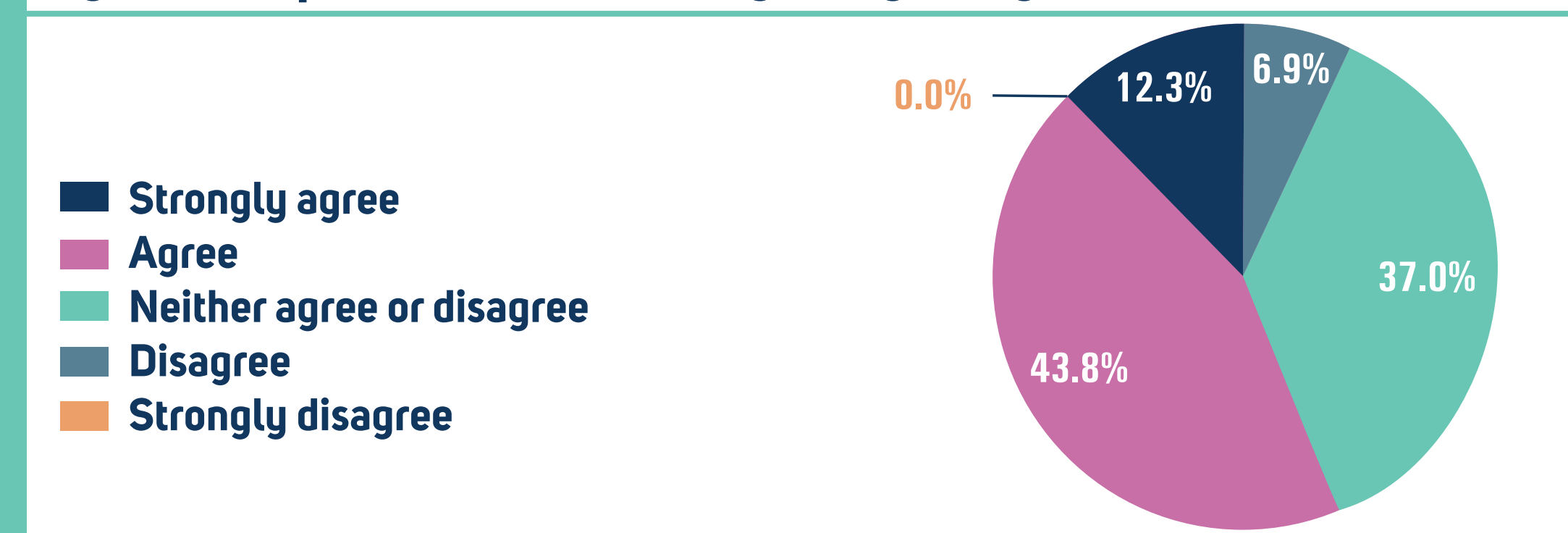
- When treating uncontrolled patients:
 - 27 (6.7%) respondents delayed or cancelled a change in treatment
 - 33 (45.2%) respondents used remote communication to assess the urgency of treatment
 - 29 (39.7%) respondents managed a dose or treatment change as normal
- 8 (11.0%) respondents recommended delaying monthly somatostatin analogue treatment to reduce risk of infection.

- 37 (50.7%) respondents agreed or strongly agreed that self/partner-administered somatostatin analogue injections were of increased importance.
 - 25 (34.3%) recommended this treatment option
- 24 (32.9%) respondents delayed surgery due to a lack of testing provision and 42 (57.5%) due to a lack of surgical provision.

Effect of COVID-19 on communication from the endocrinologist perspective

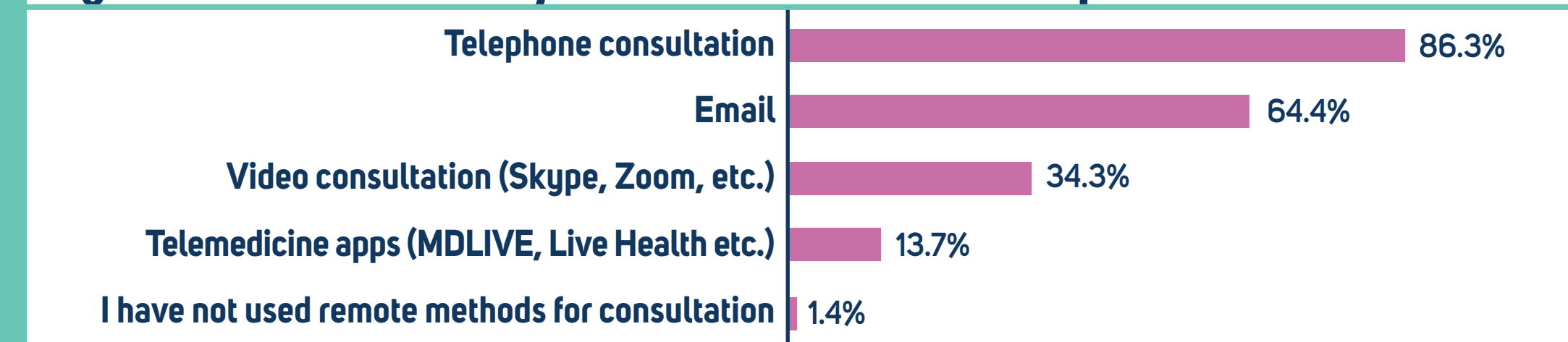
- Effect of the COVID-19 pandemic on endocrinologist communication practices is shown in **Figures 4 and 5**.

Figure 4: Proportion of endocrinologists agreeing with the below statement



Remote consultation has improved my ability to communicate with patients living with acromegaly during the COVID-19 pandemic

Figure 5: Most commonly used remote methods for patient communication



Data indicate percentage of respondents reporting having used each communication method under COVID-19 pandemic conditions. Note that each respondent was able to indicate more than one method.

- Effect of the COVID-19 pandemic on communication practices is shown in **Figures 4 and 5**.
- Remote consultations were most commonly used to discuss:
 - The condition and treatment options post-diagnosis (n = 56; 76.7%)
 - Adverse events related to treatment (n = 49; 67.1%)
 - Diagnostic consultations (n = 23; 42.5%)
 - Alternative treatment pathways (n = 26; 35.6%)
 - Training of patients/family members on somatostatin analogue or growth hormone receptor blocker treatment (n = 23; 31.5%)
- 31 (42.5%) respondents agreed or strongly agreed that specialised endocrine nurses had increased importance during the COVID-19 pandemic.
- 49 (67.1%) respondents agreed or strongly agreed that they would continue to use new methods of consultation in the presumed post-COVID-19 environment.

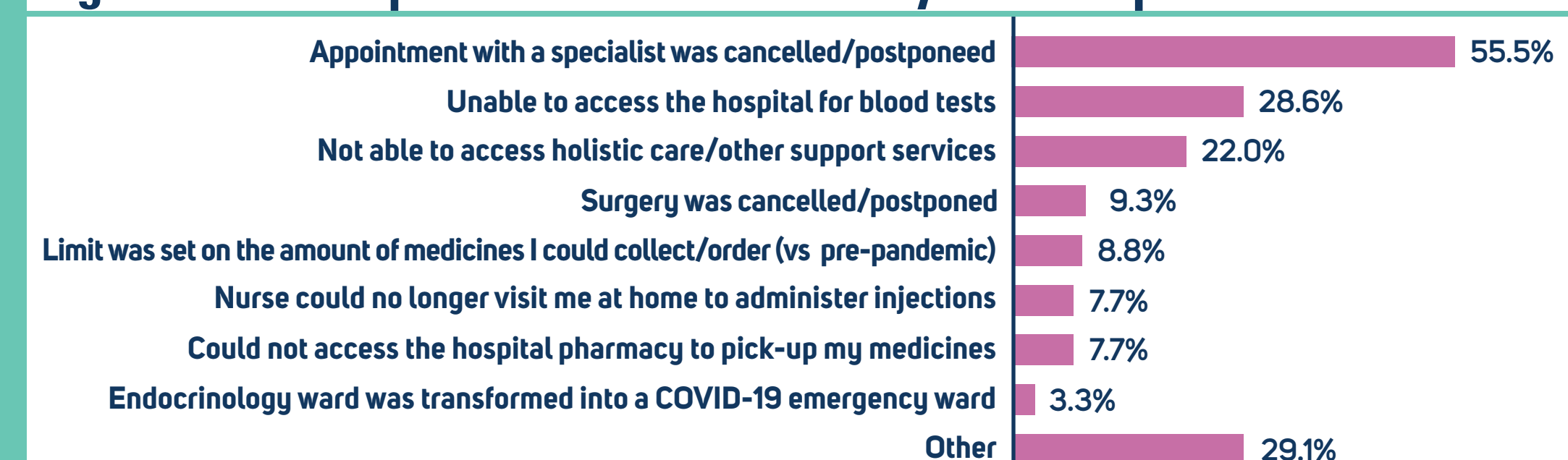
RESULTS: PATIENTS

- Demographics of people living with acromegaly are shown in **Table 1** and **Figure 1**.

Perceptions of people living with acromegaly during the COVID-19 pandemic

- 5 (2.8%) respondents had tested positive for the SARS-CoV-2.
 - 93 (51.1%) agreed or strongly agreed that the pandemic made managing their condition more challenging
- Effect of the COVID-19 pandemic on access to care is shown in **Figure 6**.

Figure 6: How has patient care been affected by COVID-19 pandemic conditions?

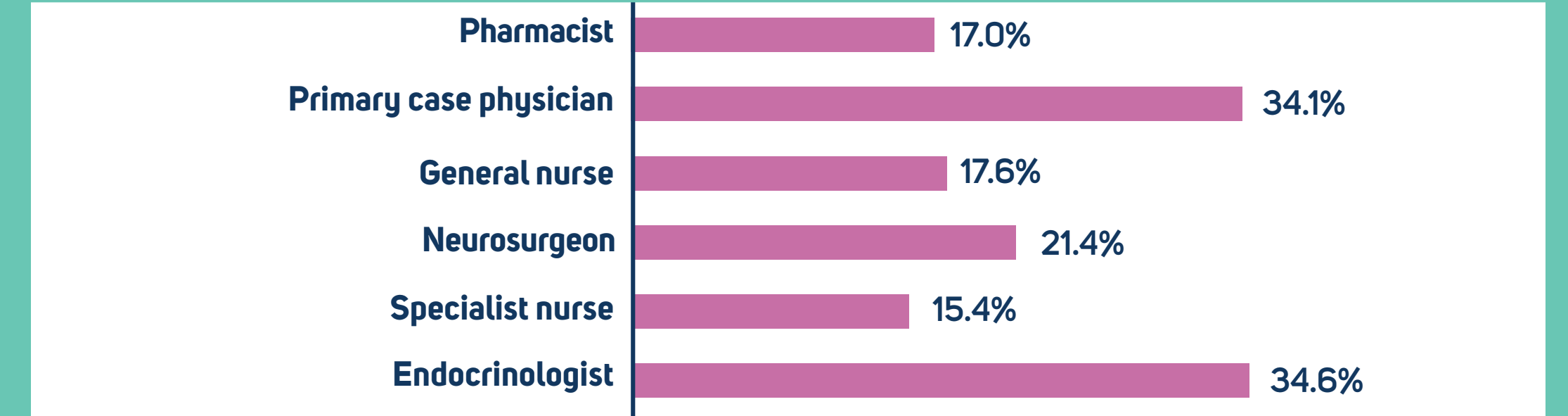


Data indicate percentage of respondents reporting a negative effect in each specific area of patient care. Note that each respondent was able to indicate more than one affected area.

- 71 (39.0%) respondents agreed or strongly agreed that the COVID-19 pandemic had affected their ability to provide samples for regular lab testing.

- Effect of the COVID-19 pandemic on access to HCPs is shown in **Figure 7**.

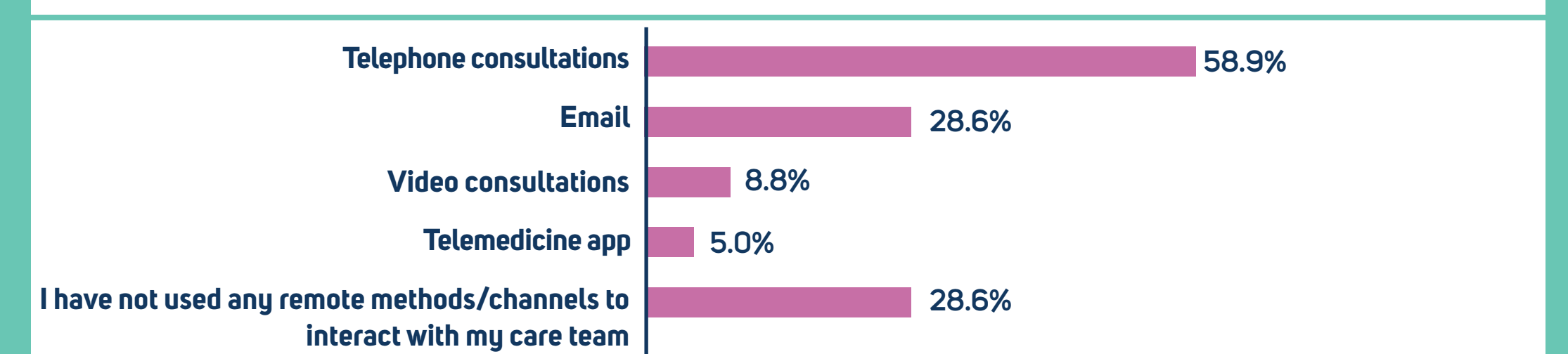
Figure 7: Have COVID-19 pandemic conditions affected patient access to members of the care team?



Data indicate percentage of respondents reporting a negative effect in each specific area of access. Note that each respondent is able to indicate more than one affected area.

- Effect of the COVID-19 pandemic on communication is shown in **Figure 8**.

Figure 8: Most commonly used remote methods for patient communication with their care team



Data indicate percentage of respondents reporting having used each communication method under COVID-19 pandemic conditions. Note that each respondent is able to indicate more than one method.

- 49 (26.9%) respondents reported limited access to injectable drug therapies.
 - 40 (22.0%) respondents reported access to care-team members who administer injectable therapies being affected
- People living with acromegaly reported increased use of:
 - Patient advocacy group materials (n = 47; 25.8%)
 - Facebook communities (n = 69; 37.9%)
 - Medical information (n = 62; 34.1%)
 - Pharmaceutical companies' websites (n = 38; 20.9%)

LIMITATIONS

- We were unable to verify the identity of the respondents.
- The results of the survey provide a limited 'snapshot' of an evolving situation.

DISCUSSION/CONCLUSION

- Endocrinologists, most of whom were treating high numbers of patients with acromegaly, reported broad negative effects from the COVID-19 pandemic on the acromegaly care pathway, but care was continued in the vast majority of cases.
- Gaps in care included a reduced ability to proceed with planned surgical procedures due to both a lack of surgical provision and limited access to pre-surgery testing.
- Remote communication was seen as a positive tool by a majority of endocrinologists; two-thirds plan to continue to utilise these methods of communication in the post-COVID-19 era.
- Self/partner-administered injection of somatostatin analogues were of increased importance under pandemic conditions for more than half of endocrinologists.
- COVID-19-specific guidance is available,^{2,3} and half of endocrinologists have accessed support.
- Effects of the pandemic on people living with acromegaly were similarly broad, with more than one-quarter of patients reporting difficulties accessing therapy.
- Endocrinologist and general-practitioner access were the most common issues for people wishing to access their care team.

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DISCLOSURES

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BMC, MM, PM & SK - none to declare

