#Endometriosis Influencers on Instagram: Who are they and what are they posting?

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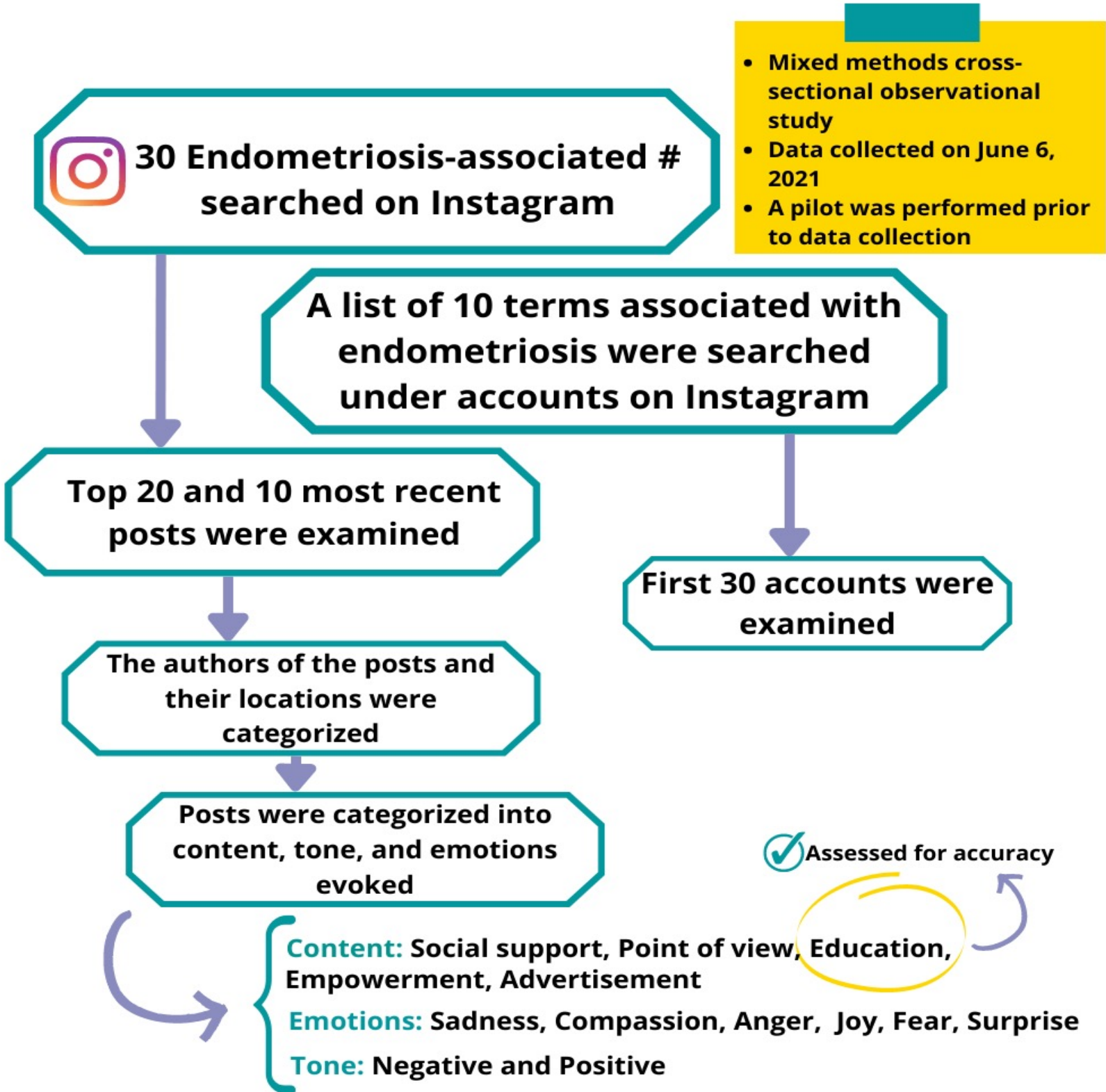
BACKGROUND

- Endometriosis affects 10% of women and those assigned female at birth aged 15 to 44 years old[1].
- Symptoms are painful menses, pelvic pain and subfertility.
- Endometriosis is a chronic inflammatory condition fraught with diagnostic and therapeutic challenges.
- Consequently, patients with endometriosis have turned to social media for health information and expression of their disease.
- Literature demonstrates the benefit of social media in improving patient health knowledge, communication and empowerment[2].
- Instagram is a popular social media platforms with 1 billion active users[3].
- Instagram allows its users to post photos with captions to a public audience and search relevant content through hashtags and likes.

OBJECTIVE

To examine endometriosis-related hashtags and accounts on Instagram including the authors of the posts and what common themes, tones, and emotions emerge from the content being posted.

METHODS

- 30 Endometriosis-associated # searched on Instagram
  - Mixed methods cross-sectional observational study
  - Data collected on June 6, 2021
  - A pilot was performed prior to data collection

- A list of 10 terms associated with endometriosis were searched under accounts on Instagram

- Top 20 and 10 most recent posts were examined
- First 30 accounts were examined

- The authors of the posts and their locations were categorized

- Posts were categorized into content, tone, and emotions evoked — Assessed for accuracy

Content: Social support, Point of view, Education, Empowerment, Advertisement
Emotions: Sadness, Compassion, Anger, Joy, Fear, Surprise
Tone: Negative and Positive

RESULTS

Total hashtags: 770 , 59.4% (n=457) were related to endometriosis
Total accounts: 227, 92.1% (n=209) were related to endometriosis

Table 1: Location of posts

Location	Hashtags % (n)	Accounts % (n)
USA	21.2 (97)	5.7 (12)
UK	20.4 (93)	9.1 (19)
Australia	11.8 (54)	7.2 (15)
Canada	8.1 (37)	1.4 (3)
Germany	5.5 (25)	1.0 (2)
Other/Unknown	33.0 (151)	75.6 (158)

RESULTS

Table 2: Author of posts and activity level

	Hashtags % (n)	Accounts % (n)	# posts in June (mean)	# of likes per post in June (mean)
Patient	57.1 (261)	60.3 (126)	14.4	481.2
Healthcare Provider	21.0 (96)	2.9 (6)	16.0	536.7
Organization	3.1 (14)	9.1 (19)	18.0	188.7
Other/Unknown	20.0 (86)	29.7 (58)	--	--

Figure 1: Content of hashtag posts

- Social support **38%**
- Point of view **27%**
- Education **18%**
- Empowerment **12%**
- Advertisement **5%**

Objective and accurate: 68.5% (n=98)

Subjective and non-accurate: 31.5% (n=45)
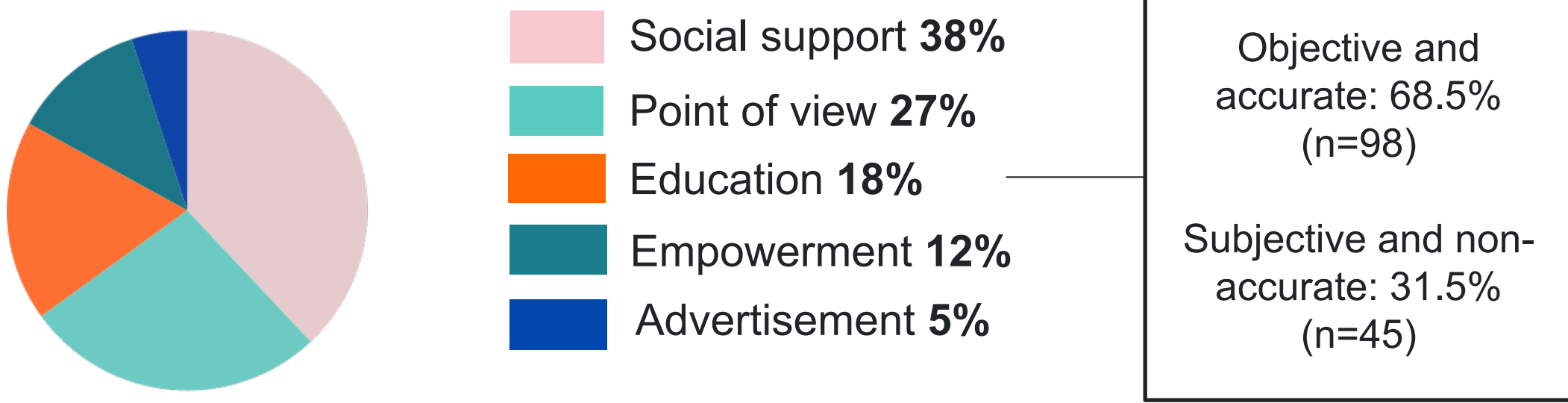
Figure 2: Tone of hashtag posts

- Negative **53%**
- Positive **45%**
- Neutral **2%**

Figure 3: Emotion of hashtag posts

- Sadness **27%**
- Compassion **23%**
- Anger **18%**
- Joy **17%**
- Fear **12%**
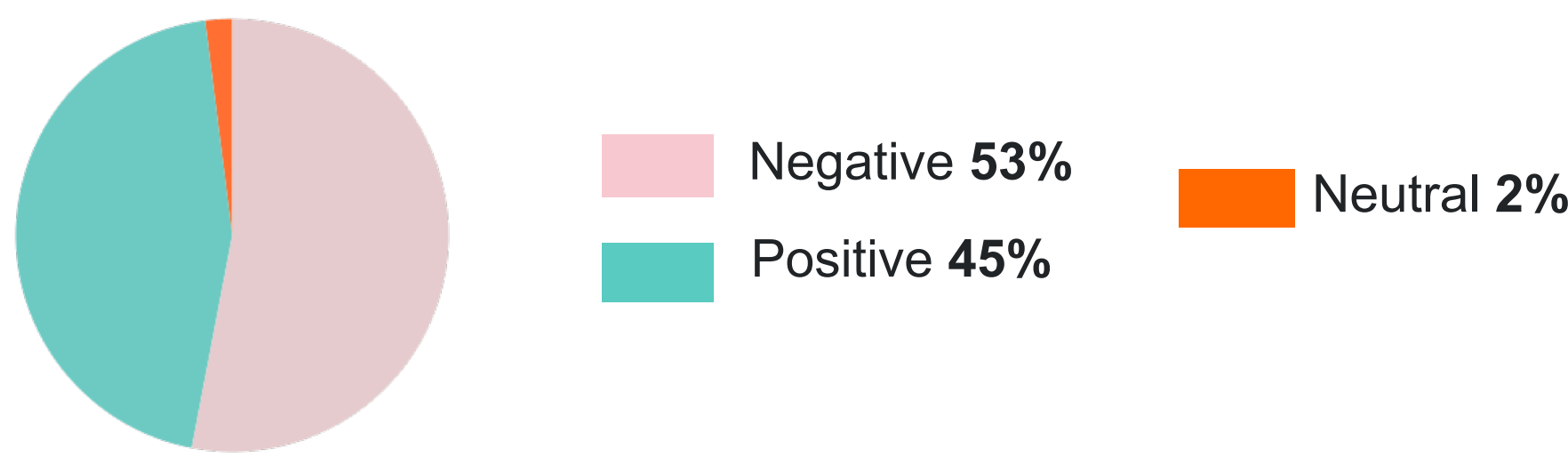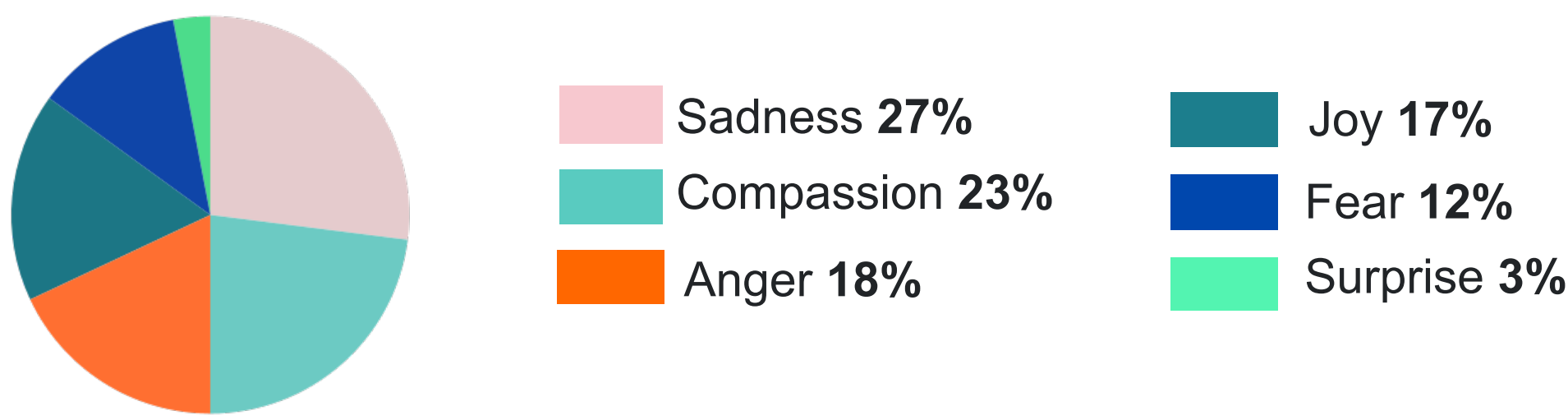- Surprise **3%**

CONCLUSIONS

- From our results, there is a greater prevalence of patients posting on Instagram about endometriosis which is similar to other studies[4].
- Most of the posts are patients providing social support and telling their stories about their experience with endometriosis in a personal narrative.
- Most commonly the posts conveyed a negative tone and portrayed sadness, which is not surprising because endometriosis is a chronic pain syndrome.
- For the most part the information on Instagram is generally accurate when compared to evidence based information, however, accuracy is likely to increase with more healthcare providers were posting on Instagram about endometriosis
- Although there are fewer healthcare providers on Instagram, they are active users and obtain more likes on average compared to patients speaking to the potential reach Instagram has to a wide audience of patients

REFERENCES: 1) Zondervan KT, Becker CM, Missmer SA. Endometriosis. Longo DL, ed. N Engl J Med 2020;382:1244-1256. **2)** Benetoli A, Chen TF, Aslani P. How patients' use of social media impacts their interactions with healthcare professionals. 2018. **3)** Chen, J. Social media demographics to inform your brand's strategy in 2020. 2020. Webpage:https://sproutsocial.com/insights/new-social-media-demographics/. Accessed November 15, 2020. **4)** Sinha R, Shibata R, Patel A, Sternchos J. Social Media in Minimally Invasive Gynecologic Surgery: What Is #Trending on Instagram? Journal of Minimally Invasive Gynecology, (2021), 1730-1734, 28

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