

One Percent or More: Outreach, Acceptance, and Representation

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1. Introduction

A central question facing the United Kingdom (UK) charity STAMMA (also known as the British Stammering Association), and any organisation supporting people who stammer, is, “Who is our audience?” For STAMMA, the answer is “people who stammer” (or stutter), but a second, inherent, question is, “How many adults stammer?” Such information is critical for planning outreach efforts, establishing the need for services, and judging the success of educational or support programs.

Several large-scale population-based studies have explored the prevalence of stammering (see Bloodstein et al., 2021, for discussion). The majority have focused on children; relatively few prevalence studies have incorporated adults in their populations. Previous studies have yielded a range of answers to how many adults stammer, dependent on age. The rates reported cluster around 0.7%, though a 1% average prevalence rate is commonly cited by authors (Bloodstein et al., 2021).

1.1. Listener-based vs. Speaker-based Judgements

A challenge facing previous research on the prevalence of stammering is a consistent reliance on *listener-based judgements* of whether a person stammers. That is, prior studies have determined a person's stammering status based on what *other people* hear in their speech. Often, this involves a minimum number of certain observable speech disfluencies (e.g., at least 3% “stuttering-like disfluencies,” such as part-word repetitions, prolongations, or blocks; see Bloodstein et al., 2021). Certainly, the presence of observable stammering is one aspect of the condition, although it is not the only consideration (Tichenor & Yaruss, 2019). Moreover, through strategies such as changing words or avoiding speaking situations (Constantino et al., 2017; Douglass et al., 2018; Murphy et al., 2007) or even fluency-enhancing strategies (Tichenor et al., 2022), many people who stammer may not allow their stammering to be observed by listeners. They may also exhibit fewer (or more) disfluencies in a particular situation due to the inherent variability of stuttering (Constantino et al., 2016; Tichenor & Yaruss, 2020). As Yairi and Ambrose (2013) pointed out, “in individual screening, people who exhibit mild stuttering or show considerable fluctuation in their stuttering, may, by chance...go undetected, a phenomenon we have encountered in initial evaluations as well as follow-ups” (p.73).

Whether stammering is reported by a speaker or observed by a listener, the emphasis on overt behaviors raises the possibility that prior studies have *underestimated* the percentage of people who experience sensations that are commonly associated with stammering. This is increasingly likely in light of recent findings that covert aspects of stammering are extremely common in people who stammer (Tichenor & Yaruss, 2019). If we consider the possibility that adults have had more time than children to develop and experience negative consequences of stammering, and to develop the motivation and the skill to hide their stammering, it may be that prevalence studies in adults are more susceptible to underestimation than studies in children. (That said, there is certainly evidence that children and adolescents may also utilise strategies to prevent a listener from seeing or hearing a moment of stammering (Jackson et al., 2019).

To fully understand the true prevalence of stammering, particularly in adulthood, studies should consider not only the production of observable speech disfluencies but also the internal perceptions that people report about their own speech. To date, however, no studies of the prevalence of stammering have considered internal states, such as the sensation of “loss of control” (Perkins, 1990), feeling “stuck,” or being “unable to move forward in speaking,” even though these terms accurately describe how adults who stammer experience the moment of stammering (Tichenor & Yaruss, 2019).

To address this issue, STAMMA has commissioned public surveys annually since 2018 to investigate how many adults stammer in the UK, and to explore whether *speaker-based* rather than *listener-based* perspectives might bring greater understanding of the true prevalence of stammering.

2. Method

2.1. Participants

The number of participants completing STAMMA’s survey over the past four years is presented in Table 1.

Table 1. Survey Participants per Year and Date Range for Completion

Year	No. of participants	Date range for survey completion
2018	1,974	6 th -7 th November 2018
2019	2,018	19 th -20 th December 2019
2020	2,022	11 th -13 th December 2020
2021	6,302	19 th - 23 rd November 2021

2.2. YouGov Polling

Questions posed by STAMMA were included in online ‘omnibus’ surveys conducted by *YouGov* (<https://yougov.co.uk>). YouGov is a polling agency whose data is regularly referenced by the international press. Although this type of public polling presents some challenges, including the complexities of defining stammering, it can draw responses from a broader cross-section of society, rather than just clinical populations.

YouGov omnibus surveys include questions from various organisations. Survey respondents are recruited via advertising and partnerships. The samples of respondents completing each survey are designed to be representative of British adults in terms of age, gender, social class, and education. YouGov has over one million UK adults available for polling, and each omnibus survey is aimed at around 2,000 participants. YouGov records socio-demographic information for all respondents and provides a small financial incentive for respondents to complete surveys.

2.2.1. Do You Stammer?

Over the four years that STAMMA has used YouGov to conduct an annual public survey, the questions have explored attitudes and understanding around stammering. In addition, the survey also asked respondents if they stammer using statements such as the one below:

By "stammering or stuttering", we mean when someone struggles to get words out, often repeats or prolongs sounds or words, or gets stuck without any sound. Sometimes this includes putting in extra sounds or words. This is different from the problems most people will commonly experience, such as the occasional hesitation or stumbling around words.

3. Results

Analyses of the data obtained from the YouGov polling are ongoing; preliminary analyses and results were presented at the 2021 Joint World Congress on Stuttering and Cluttering. Three selected examples of these preliminary analyses are presented in the sections that follow.

3.1. Prevalence of stammering

The wording of the questions and response options have varied somewhat from year to year, but results pertaining to the basic question, *Do you currently stammer or stutter?*, detailed in Table 2, reveal a consistent pattern: *More than 1%* of respondents to report that they currently stammer. This pattern is seen across all 4 years, including a total 12,316 UK respondents.

Table 2: Number of Respondents Reporting That They Stammer

Year	No. of participants	Percentage	N
2018	I currently stammer or stutter	3.1%	61
2019	I currently have a stammer or stutter	2.9%	58
2020	I currently have a stammer or stutter and do not try to hide this	2.0%	40
2020	I currently have a stammer or stutter and try to hide this	2.0%	36
2021	Stammer or stutter ONLY	1.9%	116
2021	I stammer or stutter <i>(includes respondents who reported that they ONLY stammer or stutter as well as those who indicated that they stammer or stutter AND have co-existing conditions which might also impact on their speech)</i>	2.5%	153

3.2. Gender differences

With its greater number of total respondents (n=6,302), the 2021 survey allowed for a closer exploration of demographic characteristics of those who reported that they stammer. For example, although a male:female ratio of 4:1 is commonly cited in relation to stammering in adulthood (Bloodstein et al., 2021), responses to the 2021 survey revealed a much closer ratio of close to 2:1 for those reporting that they stammer or stutter only and 3:2 for those who indicated they also had another co-existing condition which might also have an impact on their speech (see Figure 1).

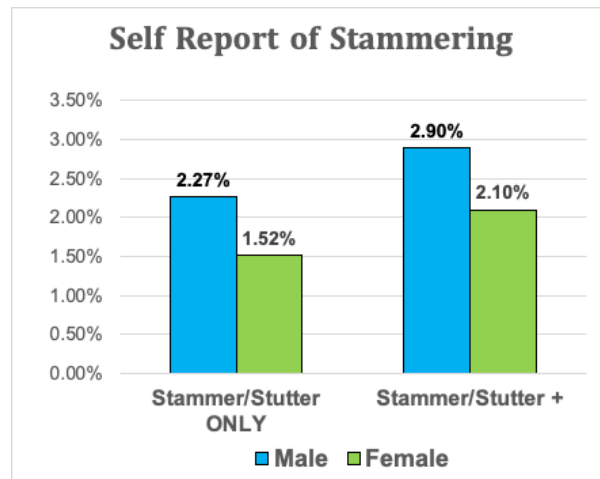


Figure 1: Male:Female ratio of respondents reporting that they stammer, comparing those reporting that their only speech related condition is stammering with those reporting that they stammer AND have a co-existing condition which might also impact their speech.

3.3. Covert aspects of stammering

A considerable number of respondents from the 2021 survey reported features consistent with covert stammering. For example, respondents who indicated that they currently stammer were asked to select behaviors from a list when answering the question, “Which, if any, of the following do you tend to do?” It is notable that 38% of respondents reported that they change words to those that are easier to say, 32% reported saying less than they want to, 30% reported trying to pick different words or avoid talking so that others will not see that they are stuck, and 25% reported that they avoid a situation altogether (see Figure 2).

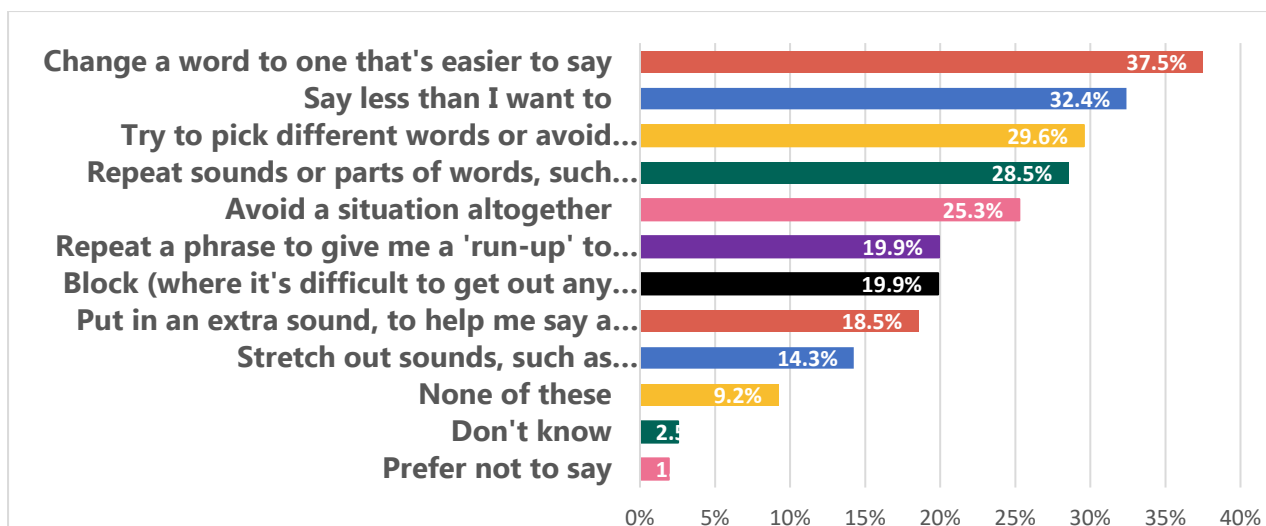


Figure 2: Responses from 2021 survey to the question “Which, if any, of the following do you tend to do?” based on all participants who indicated that they currently stammer (including those with co-existing conditions).

4. Conclusion

How many people stammer? This question seems simple at face value, but an accurate estimation of how many people stammer requires careful consideration of what stammering is and what it is not. Prior research has focused only on definitions of stammering as judged by listeners; the present research adds the perspective of people who stammer. Considering speaker perceptions of their own internal experiences in this way can help to increase the accuracy of population estimates regarding the prevalence of stammering, particularly in adulthood. Although polling has significant advantages, such as access to a large, representative sample of a population, this methodology poses its own limitations. These include self-diagnosis by respondents who may have varying understandings of the term “stammering.” A detailed definition of stammering was used within the poll in an attempt to generate a common understanding of the term, but there is still a risk that the description included features that respondents perceived to be reflective of other speech differences. In such a case, a respondent may have responded “yes” to the question “Do you stammer?” because they have a different speech pattern that shared features in common with stammering.

Accounting for the perceptions and experiences of people who self-report as being individuals who stammer yields prevalence values notably higher than the 1% figure that is commonly cited. Further research will be necessary to determine whether this higher figure actually reflects the prevalence of stammering in the broader population. Perhaps stammering, particularly in covert or apparently milder presentations, is more prevalent than has previously been believed. These self-report data also challenge the commonly accepted male-to-female sex ratio, suggesting possible differences in how stammering may be perceived by listeners for male vs. female speakers. Such findings contribute to two fundamental discussions: who decides whether a person stammers or not, and where are the boundaries between stammering and not-stammering, given the spectrum and variety of features of stammering, particularly with regard to less-overt aspects of the condition.

Analyses of the YouGov data are ongoing, and we anticipate further findings that may challenge presumptions about the characteristics of people who stammer. We encourage others to complete similar surveys in other countries to see whether the findings presented here are replicated; such research will contribute to further understanding who stammers and how they experience stammering.

Disclosures

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