

# Understanding uptake of cervical screening amongst South Asian women in Ontario, Canada: A concept mapping study

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# Today

- Cervical screening amongst South Asian women in Ontario, Canada
- Using concept mapping:
  - to **identify experiences** in the lives of South Asian women living in Ontario that shape their decisions to get screened for cervical cancer
  - to **uncover how participants think** about these experiences in terms of importance and ease to address, to better encourage cervical screening
  - to **identify impactful action items** to encourage cervical screening

\*In this study, South Asian identity refers to those that self-identify with a South Asian ancestry (i.e., not necessarily of South Asian birth). South Asian ancestry can include the following countries: Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, Sri Lanka. This also includes people who can trace their origins back to South Asian countries, such as Indo-Guyanese people. South Asian refers to ancestry and includes those that have immigrated to Canada and those that were born in Canada.

# Cervical screening amongst South Asian women in Ontario

- South Asian women have the lowest rates of cervical cancer screening among major ethnic groups in the Ontario, and a higher burden of cervical cancer.
  - 2015 study: adjusted odds ratio of screening for South Asian women compared to non-immigrant women in urban primary care practices in Ontario, was 0.61 (95% CI 0.59–0.64) patients.
  - 2010 study: screening rates were lowest among women from South Asia when compared to the referent group (Canadian-born women and immigrants who arrived before 1985) (adjusted rate ratio 0.81, 95% CI [0.80–0.82] among women aged 18-49 years, adjusted rate ratio 0.67 [0.65–0.69] among women aged 50–66 years).

# Concept Mapping

- Concept mapping (CM) is a collaborative method that is driven by a conceptualization process that produces visual representation of ideas and their interrelationships.
- The result of this method is a conceptual framework that reflects how a group views a particular topic, including priorities around addressing that topic.
- CM can help a group: solve a problem; articulate a need or desire; or come up with a plan or develop an intervention

# Concept Mapping Study

How do the lives and experiences of South Asian women living in Ontario shape their decisions around getting screened for cervical cancer?

- South Asian women eligible for cervical screening
- People who work at organizations that serve South Asian women
- Peers
- Healthcare providers with South Asian patients

**CERVICAL CANCER SCREENING**  
Amongst South Asian Women

For more information, please contact our research team at **Kimberly.Devotta@mail.utoronto.ca**

We need your knowledge and experience!

We are doing a research study to learn about your thoughts and experiences around cervical cancer screening amongst South Asian people in Ontario. We are interested in hearing from South Asian people who are eligible for cervical screening in Ontario, and this includes anyone with a cervix including cisgender women and transgender people.

**Are you...?**

- Between the ages of 21 and 70
- A woman who identifies as South Asian
- Have been sexually active
- Living in the Greater Toronto Area

**What does participation involve?**

- If you are eligible for the study, you will be asked to participate in an in-person or on-line activity where you will answer a question about cervical screening. You may be contacted to participate in future rounds.
- All information will be kept private and confidential. Your identity will not be shared with anyone outside of the research team.

**Would you be compensated for your time?**  
Yes, participants will be compensated with a \$30 honorarium for each round they participate in.

This study has been reviewed by the Research Ethics Boards of the University of Toronto (REB#43281)

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DALLA LANA SCHOOL OF PUBLIC HEALTH

Participate in a brainstorming session about **CERVICAL SCREENING**  
Amongst South Asian Women

For more information, please contact our research team at **Kimberly.Devotta@mail.utoronto.ca**

We need your knowledge and experience!

We are doing a research study to learn about your thoughts and experiences around cervical cancer screening amongst South Asian people in Ontario. We are interested in hearing from people in the community who work with or provide care for South Asian women.

**Participants include:**

- Peers
- People who work at organizations that serve South Asian women in the GTA
- Healthcare providers with South Asian patients.

**What does participation involve?**

- If you are eligible for the study, you will be asked to participate in an in-person or on-line activity where you will answer a question about cervical screening. You may be contacted to participate in future rounds.
- All information will be kept private and confidential. Your identity will not be shared with anyone outside of the research team.

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## 1. BRAINSTORMING

At least 44, and at most 72, people participated and generated 210 ideas that became 45 unique statements related to the prompt: *One thing about the lives and experiences of South Asian women that influence their decision, in a positive or negative way, to get screened (i.e., a Pap test or HPV test) for cervical cancer is...*

## 2. SORTING

22 people participated in independently sorting the statements into piles based on their own perceptions of the meanings

## 3. RATING

45 people participated in rating the statements in terms of **EASE** and **IMPORTANCE TO ADDRESS**

## 4. MAP INTERPRETATION

9 people participated in a group exercise of reviewing, discussing and confirming the concept mapping results

\*Participants did not have to participate in all the activities\*

# Participants

- **Service Users:** self-identify as South Asian, and is or has ever been eligible for cervical screening in Ontario (at least 21 years of age, has been sexually active, has a cervix).
- **Service Providers:** in a role that works or serves South Asian women, and a self-screen to gauge their familiarity with cervical cancer screenings amongst South Asian women. This included primary care providers, allied health, hospitalists, health promoters, community organizers, settlement service workers and more.



What did participants say?

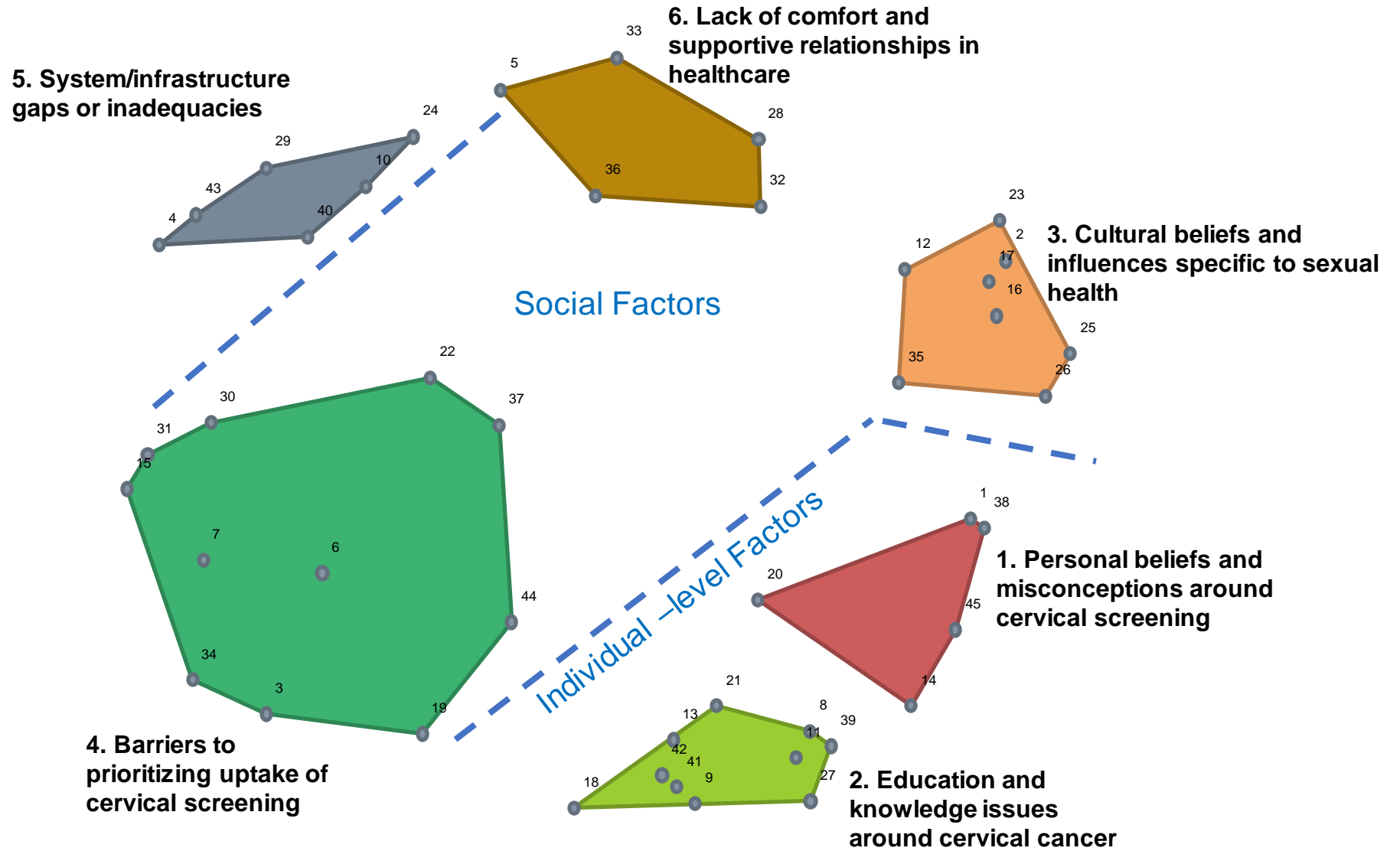
## Statement

1. The belief that you should not "touch" things or go under the knife (meaning any medical procedure) because it brings more harm than good
2. Cultural expectations or pressures that the idea of "modesty" prevents women in the South Asian community from getting screened for cervical cancer.
3. Women do not go to the doctor unless they are having an issue
4. Appointments are not available at times that are convenient for patients
5. Women do not feel comfortable with their healthcare provider
6. Lack of access to cervical cancer screening information shared by trusted sources
7. Pap test appointments are viewed as time consuming
8. Women believing that a Pap test can lead to an infection
9. A woman's lack of understanding and education around cervical cancer
10. Needing to communicate with healthcare providers in English is a barrier for South Asian women to be screened for cervical cancer
11. If a woman believes that cervical cancer is not a severe condition, this can discourage them from getting screened
12. Men in South Asian households make decisions about females getting screened
13. Education about cervical cancer is needed for men in South Asian households
14. A woman's belief that cervical cancer screening is not necessary if you have only had one sexual partner
15. Women need reminders to know when they are due for cervical cancer screening
16. Negative cultural beliefs behind gynecologist visits leads to South Asian women feeling shame when booking appointments.
17. South Asian women are not comfortable to discuss their sexual history
18. Not enough media coverage of cervical cancer screening within the South Asian community
19. Pap tests can feel painful
20. Women may view a Pap test as a dirty procedure where you may bleed afterwards
21. Preventative care is not well understood by South Asian women
22. Prior negative experience with a Pap test discourages South Asian women from getting screened
23. South Asian women may be worried about their family finding out they are sexually active
24. Not having a healthcare provider of a similar cultural background makes intimate tests such as a Pap test, uncomfortable
25. Sex is a taboo topic amongst South Asians
26. Any tests related to sex can be considered dirty
27. Women believe that if they have an HPV vaccine, they do not need to be screened for cervical cancer
28. Women may be shy to have an examination in that area of their body
29. Foreign trained physicians may not encourage their patients to do cancer screening, as preventative care may not have been common in their home countries.
30. South Asian women may prioritize looking after their families over their own health
31. South Asian women may be too busy with their jobs or careers to take care of their own health
32. Lack of support from family members to go and get screened
33. Lack of support from friends to go and get screened
34. Women are afraid to find out if they have cancer
35. Cervical cancer screening is not openly discussed in the South Asian culture
36. Women may be uncomfortable with going to the doctor in general
37. Women hear other women share negative experiences about getting a Pap test
38. The belief that if a cervical cancer diagnosis is your fate or destiny, there is no reason to get screened
39. Belief that you only have to worry about cervical cancer if you have a problem with your menstruation
40. Family doctor does not encourage cervical cancer screening during appointment
41. Women may not know what a Pap test involves
42. Women may not know the purpose of a Pap test
43. Women do not have a family doctor
44. South Asian women will only get screened when symptoms arise
45. South Asian women won't get screened because they think they cannot get cervical cancer.

# Sorting Activity

- In the sorting activity, participants were asked to provide their perceptions on the similarity between the items in the main list of statements.
- The purpose of this was to identify how participants view the interrelationship of the ideas.

# Cluster Map



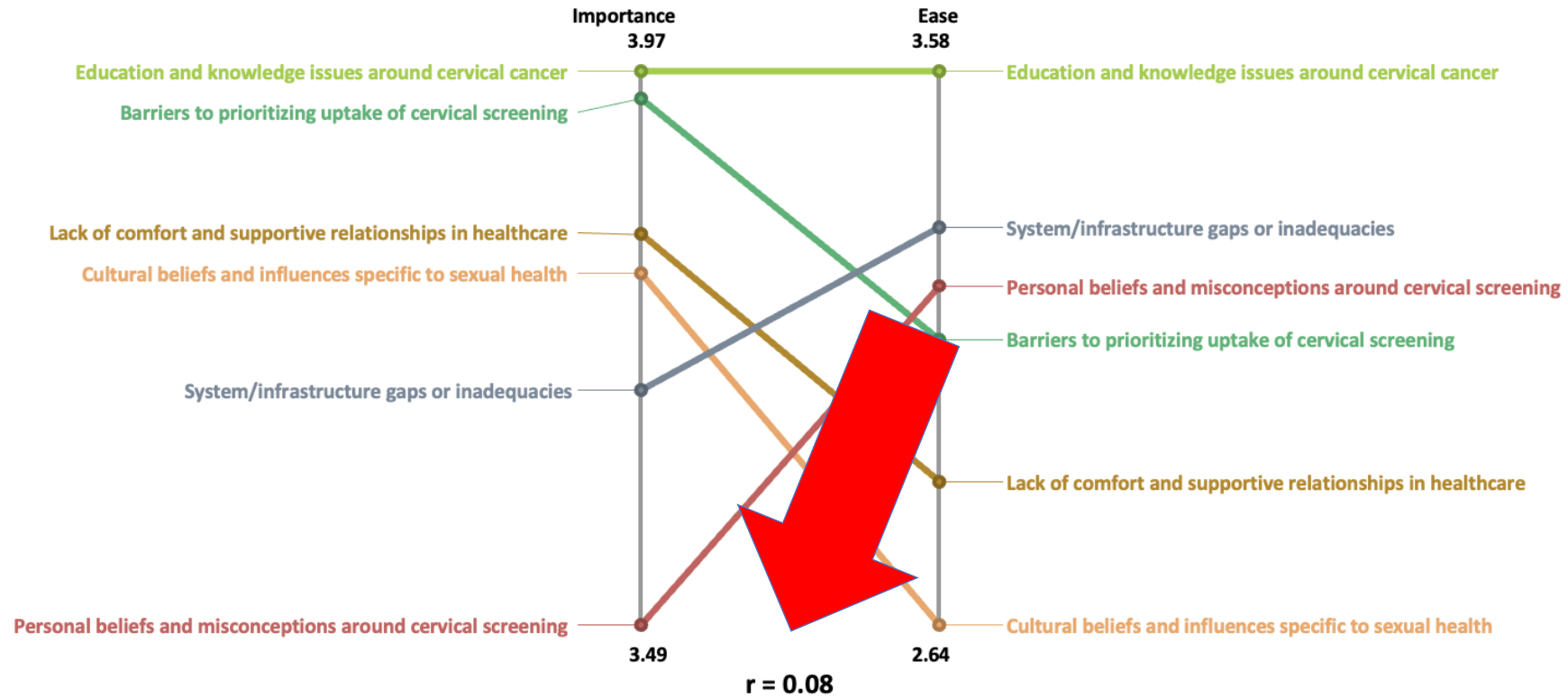
0.2780 Stress Value

How did participants value these statements?

# Rating Activity

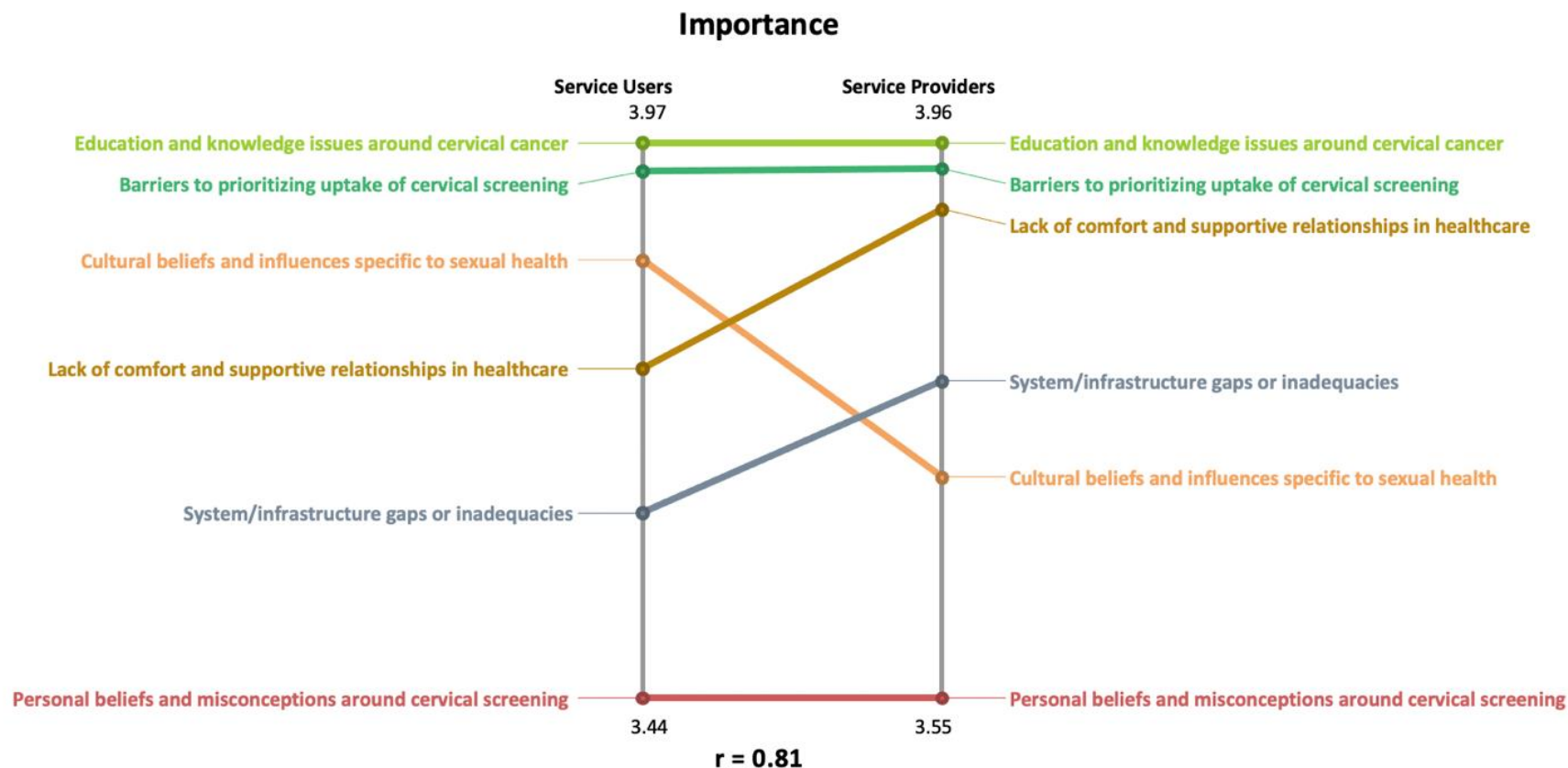
- Participants were asked to rate on a 5-point scale, all 45 statements based on these two questions:
  - How much do you agree or disagree that **REMOVING OR FIXING THIS BARRIER** would improve cervical cancer screening participation amongst South Asian women? (**IMPORTANCE**)
  - How **EASY** do you think it is to solve or address this issue so that South Asian women will be encouraged to participate in cervical cancer screening? (**EASE**)

# Pattern Match



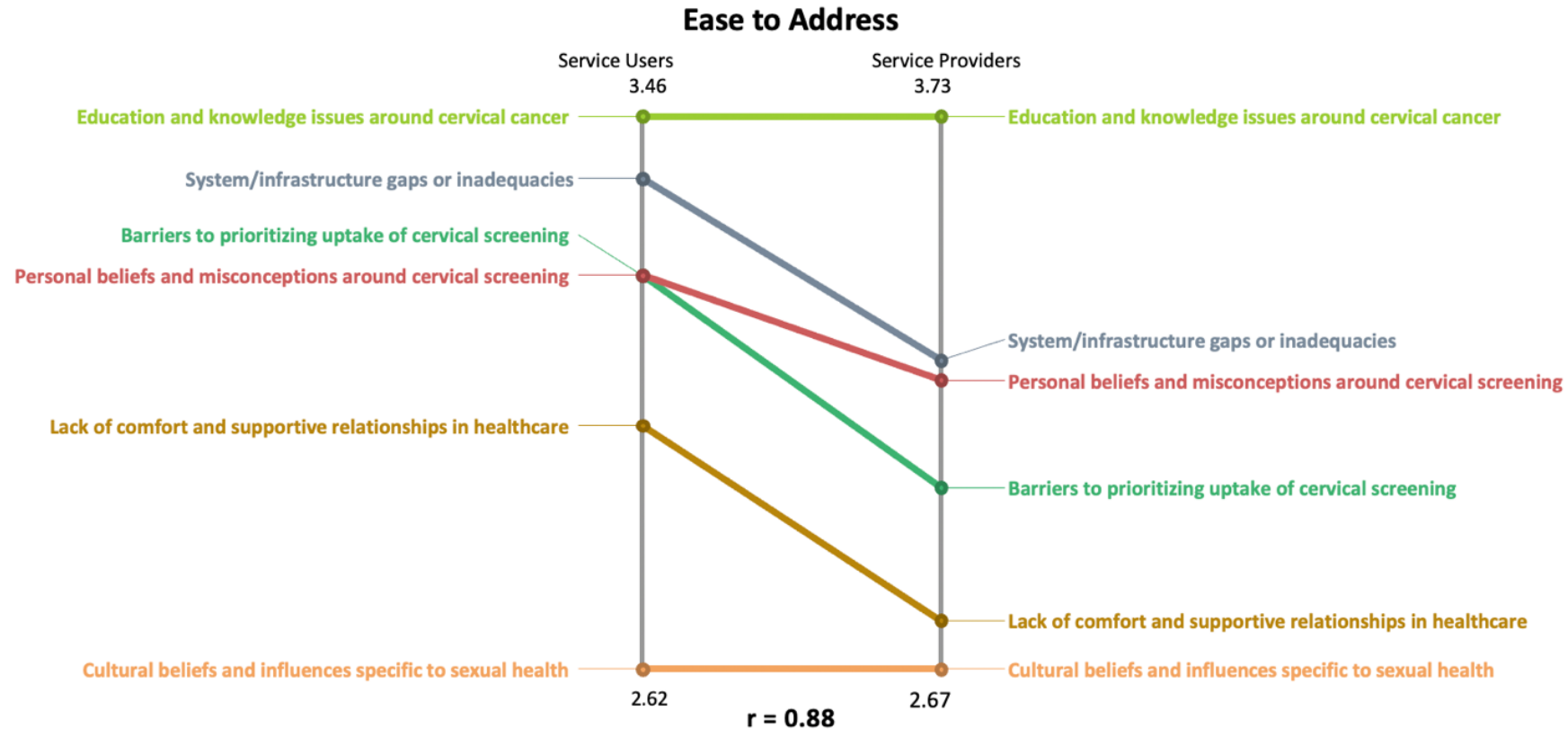
**Relative pattern match comparing average cluster ratings ‘importance’ (n=44) and ‘ease’ (n=44). These rating variables measure how important and easy to address the statements were to encourage cervical screening.**

# Comparing Perspectives on Importance

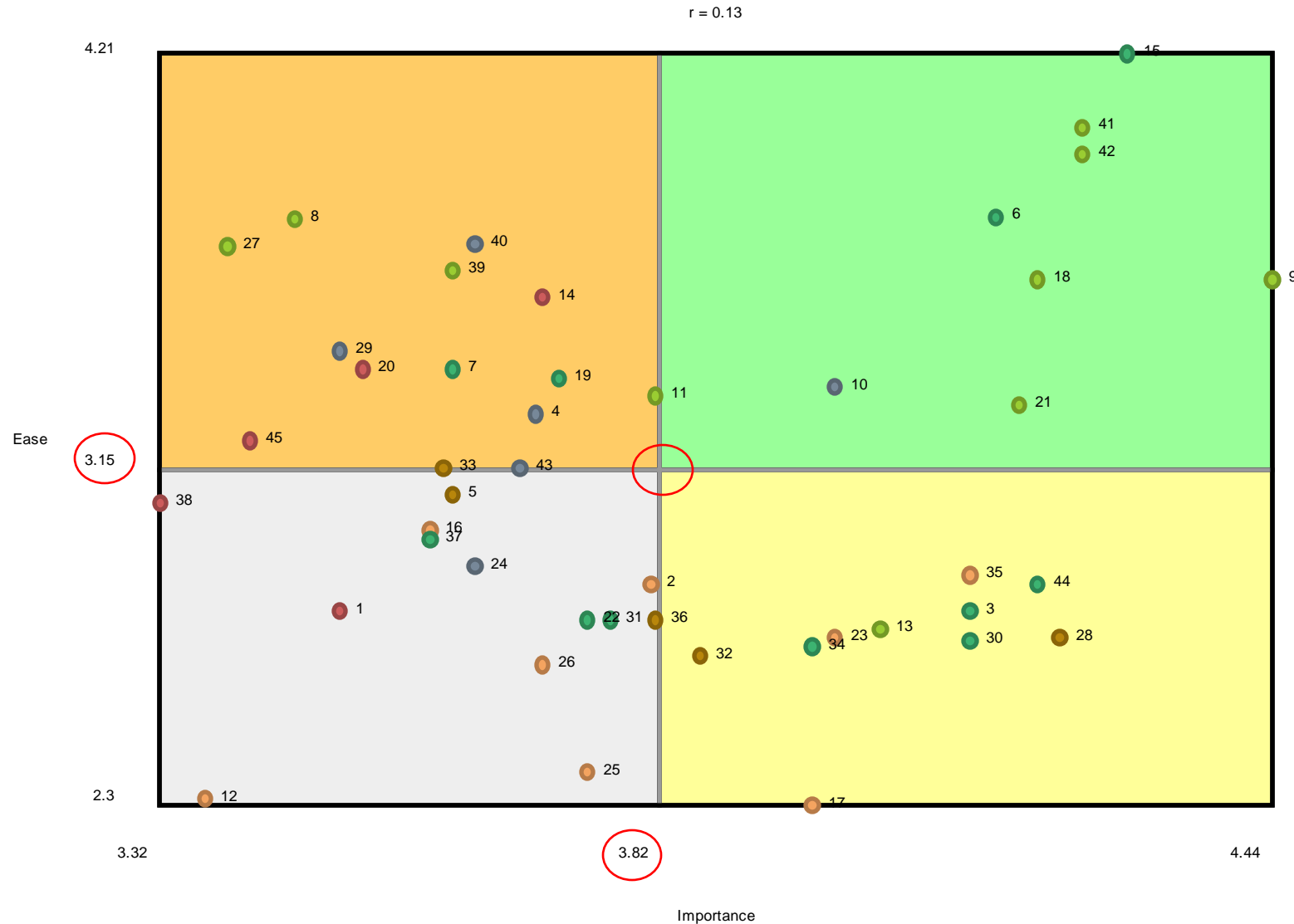




# Comparing Perspectives on Ease to Address



# Go-Zone Display at the Statement Level



← High priority for implementation

← Also high priority, but will be challenging to implement

## Most Easy and Most Important to Address: 'Go-Zone'

- 6. Lack of access to cervical cancer screening information shared by trusted sources
- 9. A woman's lack of understanding and education around cervical cancer
- 10. Needing to communicate with healthcare providers in English is a barrier for South Asian women to be screened for cervical cancer
- 15. Women need reminders to know when they are due for cervical cancer screening
- 18. Not enough media coverage of cervical cancer screening within the South Asian community
- 21. Preventative care is not well understood by South Asian women
- 41. Women may not know what a Pap test involves
- 42. Women may not know the purpose of a Pap test

# Most Important and Least Easy to Address

- 3. Women do not go to the doctor unless they are having an issue
- 13. Education about cervical cancer is needed for men in South Asian households
- 17. South Asian women are not comfortable to discuss their sexual history
- 23. South Asian women may be worried about their family finding out they are sexually active
- 28. Women may be shy to have an examination in that area of their body
- 30. South Asian women may prioritize looking after their families over their own health
- 32. Lack of support from family members to go and get screened
- 34. Women are afraid to find out if they have cancer
- 35. Cervical cancer screening is not openly discussed in the South Asian culture
- 44. South Asian women will only get screened when symptoms arise

# Summary

- The point map showed us the relationship between the different statements that were brainstormed and then sorted by participants
- The clusters showed us how people grouped/identified themes in the data
- The pattern-matches show us how the ideas are rated and differences amongst sub-groups
- The go-zones shows us what are most actionable

# Thank you!

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