Bowel Cancer Screening and Prostate Cancer Testing Community Session: 7 November, 2022

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Date of Activity: 7th November 2022

Report originally published: 14th June 2023

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Background

The Imperial Patient Experience Research Centre (PERC) is a core facility of the Imperial Biomedical Research Centre (BRC) that has been established to improve healthcare experiences for patients, their families, and healthcare professionals. One of PERC's key areas of focus is on public involvement and engagement in healthcare research. The centre provides advice, guidance, and support to researchers on involving the public in research and has been successful in establishing relationships with underrepresented and under-served communities in Northwest London.

PERC recognises that involving a diverse range of patients and members of the public in research is essential for ensuring that research is relevant, meaningful, and useful for improving healthcare experiences and outcomes for all. PERC's efforts to establish relationships with underrepresented and under-served communities in North West London have been crucial in engaging a more diverse range of patients and members of the public in research. By working closely with these communities, PERC is aiming to ensure that research is tailored to their specific needs and priorities, and that their voices are heard in healthcare decision-making.

Approach and purpose

Healthwatch Brent (HWB) carried out a survey in the Brent area, with the aim of better understanding the way the residents felt about health screening. The results demonstrated that 68.18% of the public who took the survey did not know what types of health screenings were available to them from the NHS. 54.17% of the responses stated they did not attend appointments, as they did not know what screenings were available. Furthermore, the residents who took part felt that they did not have enough information about prostate cancer testing (20%), and bowel cancer screening (17.8%) and abdominal aortic aneurisms (22 %) (**Appendix 7**). As a result, PERC and HWB co-produced an event with the aim of giving the residents of Brent a better understanding of the health screening/testing processes for prostate and bowel cancer, and where to seek further support. As abdominal aortic aneurism testing is undertaken by an external third party to the NHS we only focused on cancer screening for this event.

Event overview and agenda

The event was held in the Chalk Hill Community Centre in Brent on 7th of November 2022. The hall was open to the public and registration started from 5:30pm with refreshments and drinks being catered by an independent café based in the community centre. There were hot drinks and sandwiches served.

There were information stalls (**Appendix 2**) at the event coordinated by Healthwatch Brent from different organisations that offered support and research for prostate and/or bowel cancer within the Brent community.

There were Imperial researchers/clinicians present who wore white t-shirts with the Imperial BRC logo so they were identifiable to the community and had name badges saying what health area their research covered so attendees would know who they were speaking to.

The event was split into two sections;

1) bowel cancer screening and

2) prostate cancer testing

Both sessions were followed by Q&As as shown in the agenda (Appendix 1).

The first session focused on prostate cancer testing within the NHS and began with an introduction by an individual with lived experience of prostate cancer. Following this, clinicians and specialists discussed the disease in detail, explaining the testing processes and outlining the next steps if results were positive. This segment concluded with a Q&A session, allowing members of the public to engage with the panel of experts.

The subsequent session addressed bowel cancer screening, presented by Benezeer Siddique and Andrew Prentice from St Mark's Hospital. Their presentation was followed by another Q&A session, providing attendees the opportunity to ask questions and receive information directly from the specialists.

Speakers

Bowel Cancer speakers

- **Benzeer Siddique**: Health Improvement Specialist at St Marks hospital, presented NHS Bowel Screening program
- Andrew Prentice: Health Improvement Lead, at St Marks hospital, presented NHS Bowel Screening program

Prostate Cancer Speaker

- Alfred Samuels: Individual with lived experience of prostate cancer. Alfred was known to both PERC and Healthwatch Brent.
- <u>Dr Shah</u>: Consultant Urologist in diagnostics and therapeutics for prostate cancer at the Imperial College Healthcare NHS Trust, presented on prostate cancer testing in the NHS
- Ivan Adzawoloo-Andersson: Advanced Nurse Practitioner (<u>Urology</u>) at Imperial College Health NHS Trust, also presented on prostate cancer testing in the NHS
- **Heather Bhola-Stewart:** Advanced Nurse Practitioner (<u>Urology</u>) at Imperial College Health NHS Trust, presented Prostate Cancer testing with the NHS, and what different courses of treatment would look like if the results of the test was positive.

Event materials

Imperial BRC branded tote bags were left on chairs for members of the public. The tote bag contained:

- $\circ \quad \text{A pen}$
- o A VOICE flyer
- $\circ~$ A card to write questions or comment to be handed up in the Q&A
- \circ $\;$ A feedback form for completion and deposit into boxes on way out

People were asked to write on Post-it notes about *"Tell us what matters to you about bowel cancer and prostate cancer?"*. Unfortunately, we did not receive any feedback on this wall.

We provided colouring in materials for children on a table at the back of the hall however no children attended the event.

The PERC stall had the option for people to sign up to the PERC Mailing list.

Attendee recruitment

The event was attended by 12 members of the public from a range of backgrounds (**Appendix 6**) for demographics of those who attended.

A flyer (**Appendix 3**) (with a QR code to the Eventbrite registration page) was created and displayed around the community centre where the event was held, and Healthwatch Brent shared the event using their community networks in Brent. The PERC team shared the event with their mailing list. No demographics were collected during registration. 55 people registered to attend on Eventbrite.

Outcomes of Event

Although there were limited members of the public in attendance, PERC made important community connections with organisations including:

- **Brent Health Matters:** work in collaboration with Health and Social care services, voluntary sector services and voices from communities in Brent to reduce health inequalities.
- Harrow Association of Somali Voluntary Organizations: an independent not- for -profit organisation that is dedicated to supporting ethnic minority residents in Harrow.
- Somali Advice and Forum of Information (SAAFI): multi-award-winning community-based organisation set up by British-Somali mothers in Brent from refugee background for positive integration.

Engaging with these organisations has resulted in improved relationship building within the Brent community. Following this event PERC was invited as guests, speakers, and stall holders to several other events within the Brent community such as sessions on diabetes, mindfulness and wellness, breast cancer, Brent autism awareness event, health educators day, carers rights day and international women.

At the event, we also established a new community relationship by connecting with a community leader from the Emmanuel Parish Church. As a result, PERC received an invitation to participate in a subsequent event on January 29th, 2023, which focused on raising awareness about prostate cancer within the Afro/Caribbean community and PERC is currently seeking to facilitate further health literacy sessions with this community.

Feedback forms

The feedback about the event was collected via a feedback form (**Appendix 4**), and the results were collated (**Appendix 5** and **6**).

The majority (7/12) of attendees had an excellent experience at the event. Some (4/12) attendees rated their experience as good, and one rated it as average.

All attendees responded "Yes" when asked if they would be interested in attending similar events in the future.

The list of healthcare topics provided as topics for future sessions suggests that attendees are interested in a variety of healthcare issues. Menopause and women's health, cancer prevention and education (including breast, testicular, penile, and prostate cancer), nephron/kidney disease, heart disease, diabetes and mental health, Vitamin D, gut health, and digestive issues were among the topics mentioned. These findings may be useful in determining the direction of future health literacy sessions, as they reflect the concerns and interests of the audience.

Learnings

The turnout for the event was limited in numbers. There was a National Rail strike on the day, and the weather was cold with heavy rain which may have impacted the attendance levels. Very few Imperial prostate cancer and bowel cancer researchers attended which would have been a good

opportunity for them to engage with the public. There was also a technical difficulty with the sound system during the session which affected the sound quality of the presentations and meant the video of the bowel cancer patient who had pre-recorded a video could be played.

Appendix 1: Agenda

- **5:30pm**: Doors open, food served, stands open
- **6-6:05pm**: HWB/PERC complete introductions for the event
- 6:05-6:10pm: Person with lived experience of bowel cancer speaks
- 6:10-6:25pm: St Marks presents on bowel cancer and screening
- 6:25-6:40pm: Q&A for bowel cancer screening
- **6:45-6:50m:** Person with lived experience of prostate cancer speaks
- 6:50-7:05pm: Imperial College NHS Trust presents on prostate cancer testing
- 7:05-7:20pm: Q&A on prostate cancer
- **7.20pm-8pm**: Opportunity for attendees to mingle with presenters and clinicians, and visit stalls

Appendix 2: Stall holders

- 1. Brent Health Matters
- 2. ORCHID (prostate cancer charity)
- 3. Healthwatch Brent
- 4. Patient Experience Research Centre (Imperial College)
- 5. St Marks Hospital
- 6. North West London CCG
- 7. Macmillan

Appendix 3: Event Poster

The following poster was used to advertise the event



NIHR | Imperial Biomedical Research Centre



Community cancer awareness evening

7 November, Chalkhill Community Centre (Wembley) from 5.30pm



Appendix 4: Event Feedback form

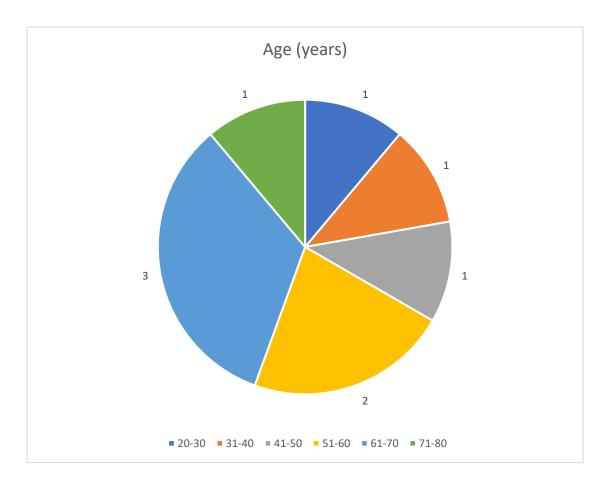
	FEEDBACK FORM - Healthwatch Brent an mperial Cancer Aware Event - 7 November 20 questions below or scan ss the online feedback form	nd ness 🥂 🗎
	you rate your experience at this	event? (please circle)
Ver	y bad Bad Average Good	Excellent
	attend future events like this jus (please tick) Yes No Idon't k	ŕ
3. What other future sessi	healthcare topics would you like ons?	to hear about at
l am also ha	opy to share my	
age	No, thanks Sure, it's:	
ethnicity	No, thanks Sure, it's:	
gender	No, thanks Sure, it's:	
postcode (first section only)	No, thanks Sure, it's:	
	in hearing about future o oout healthcare topics? As	

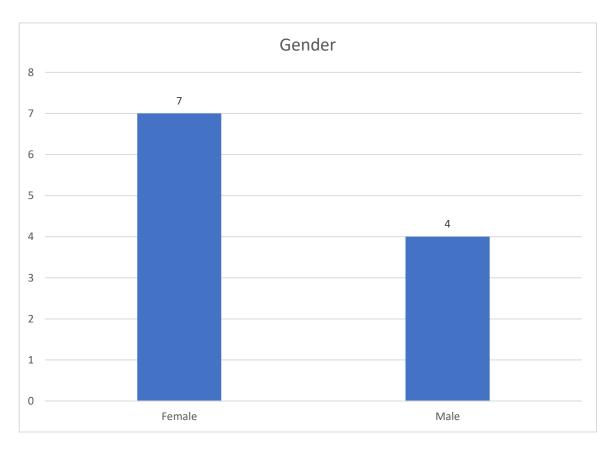


Appendix 5: Attendee feedback

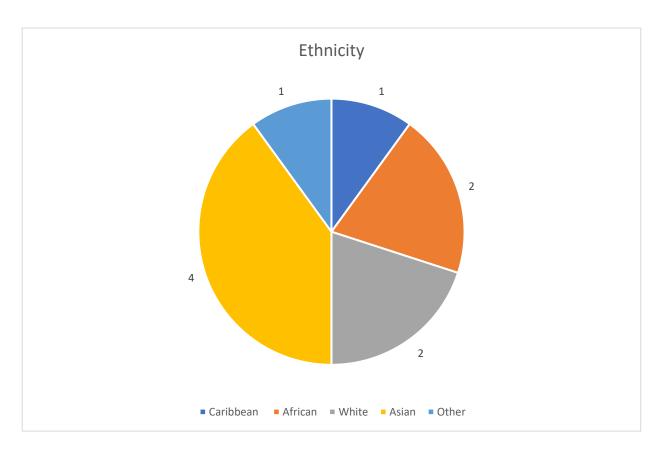


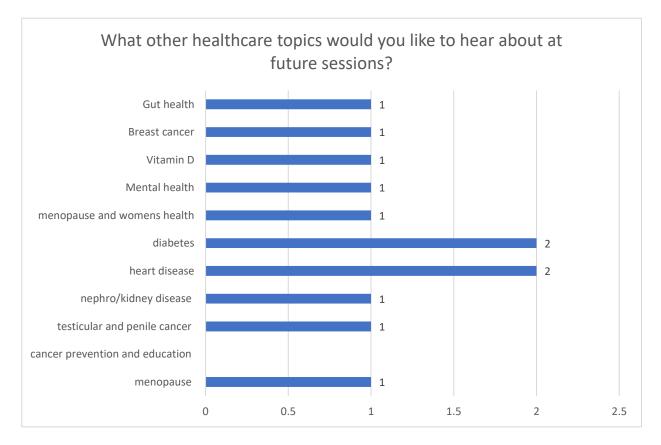






DOI: <u>10.25561/105142</u>



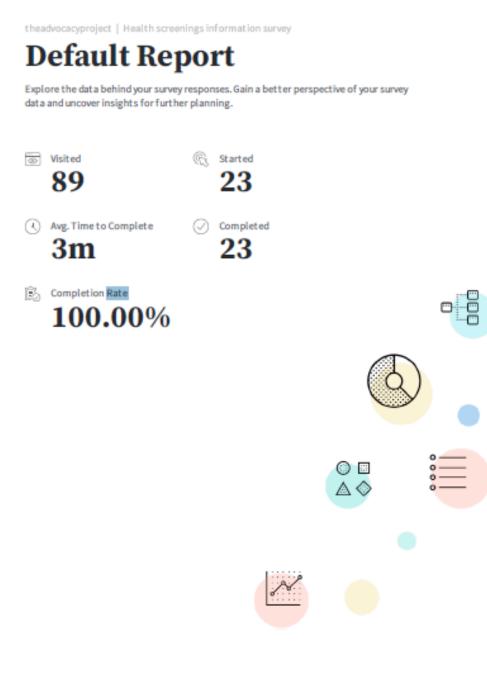


Appendix 6: Attendee demographics

Table 1: Demographic characteristics provided in feedback forms (N=12)

Characteristics	n (%)
Age (in years)	Mean (range)
53 (25-80)	
Age groups (in years)	
18-24	0 (0.0)
25-34	1 (10.0)
35-44	0 (0.0)
45-54	1 (10.0)
55-64	3 (30.0)
65 – 74	2 (20.0)
75+	2 (20.0)
Prefer not to say	1 (10.0)
Gender	
Female	6 (60.0)
Male	3 (30.0)
Prefer not to say	1 (10.0)
Ethnic group	
White	3 (30.0)
Black/African/Caribbean/Black British	2 (20.0)
Asian/Asian British	2 (20.0)
Mixed/Multiple Ethnicity	1 (10.0)
Other	2 (20.0)
Postcode (first section only)	
НА	1 (10.0)
HA7	2 (20.0)
NW6	1 (10.0)
HA7	2 (20.0)
НАО	1 (10.0)
НА9	2 (20.0)

Appendix 7: Health Screening survey feedback from Health Watch Brent



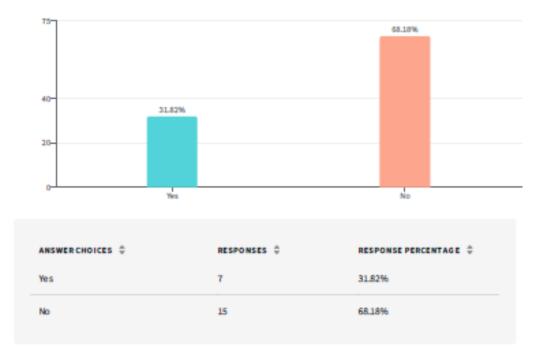
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Made with 刻 SurveySparrow

QUESTION 01 | YES ORNO

Do you know what types of health screening are available to you from the NHS?

Answered: 22 Skipped: 1

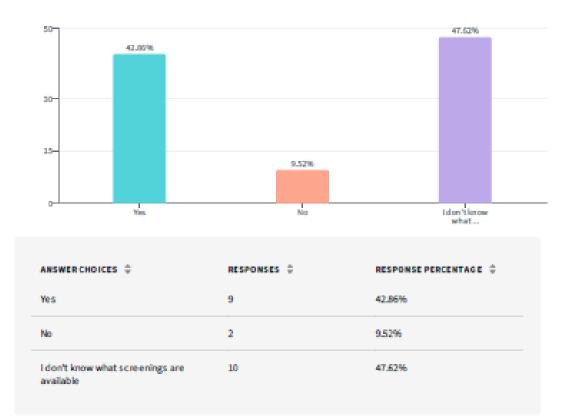


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QUESTION 02 MULTIPLE CHOICE

Do you attend the screenings recommended for your age and gender?

Answered: 21 Skipped: 2



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QUESTION 03 | MULTIPLE CHOICE

If you don't attend, what are the reasons for this? (You may choose multiple reasons)

Answered: 23 Skipped: 0

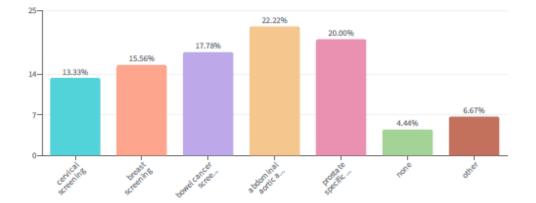


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QUESTION 05 | MULTIPLE CHOICE

Which of these areas would you like more information about? (You may choose multiple options)

Answered: 21 Skipped: 1



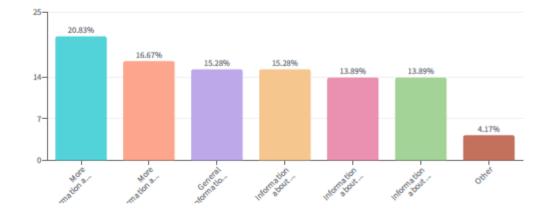
ANSWER CHOICES 🌲	RESPONSES 👙	RESPONSE PERCENTAGE 🍦
cervical screening	6	13.33%
breast screening	7	15.56%
bowel cancer screening	8	17.78%
abdominal aortic aneurysm (AAA) screening	10	22.22%
prostate specific antigen (PSA) screening	9	20.00%
none	2	4.44%
other	3	6.67%

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QUESTION 07 | MULTIPLE CHOICE

What type of information would you like about health screenings? (You may choose multiple options)

Answered: 22 Skipped: 1



ANSWER CHOICES 🌲	RESPONSES 🌲	RESPONSE PERCENTAGE 🌐
More information about what is available for my age/gender	15	20.83%
More information about what is available for my family	12	16.67%
General information about what happens during screenings	11	15.28%
Information about how to book a screening	11	15.28%
Information about what happens during a particular screening	10	13.89%
Information about screenings for particular conditions	10	13.89%
Other	3	4.17%

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What type of information would you find useful?

Answered: 23 Skipped: 0

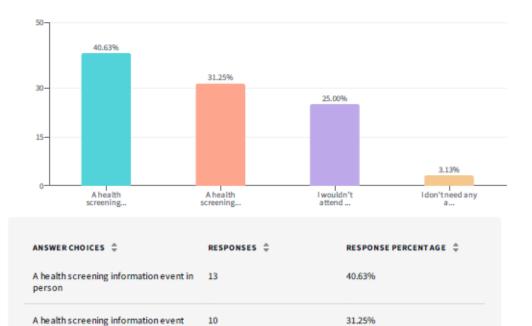
online

I wouldn't attend an event but would like 8

1

I don't need any additional information

more information such as a flyer

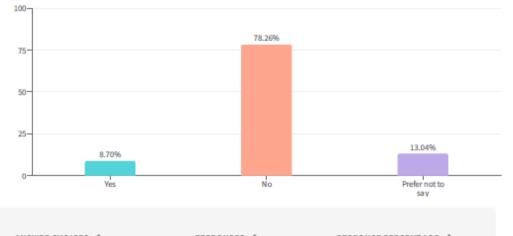


25.00%

3.13%

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ABOUT YOU	4 Questions
QUESTION 11 MULTIPLE CHOICE	
Are you a carer?	
Answered: 23 Skipped: 0	



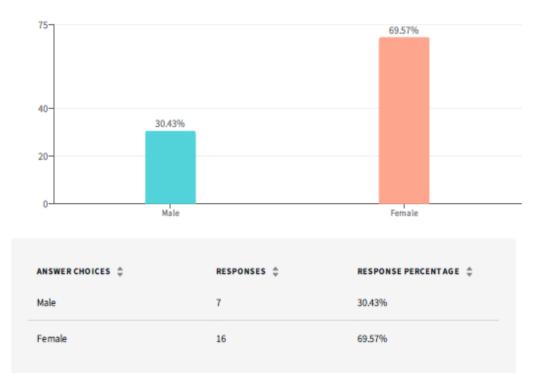
ANSWER CHOICES 👙	RESPONSES 🌲	RESPONSE PERCENTAGE 🌲
Yes	2	8.70%
No	18	78.26%
Prefer not to say	3	13.04%

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ABOUT YOU

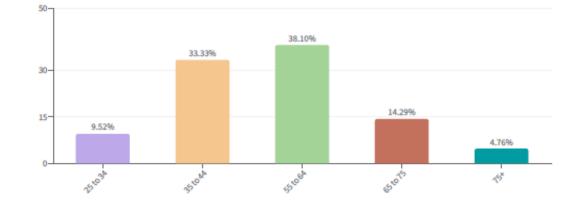
What gender do you identify as?

Answered: 23 Skipped: 0



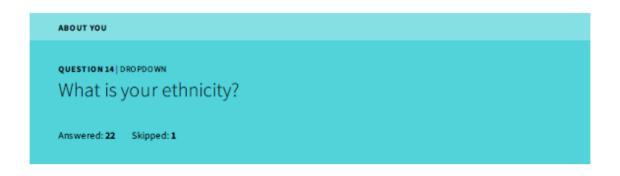
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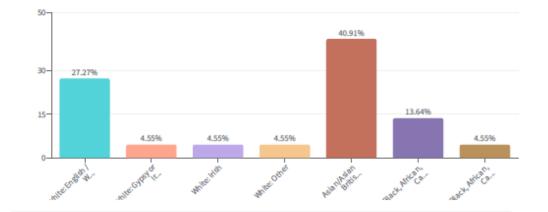
ABOUT YOU QUESTION 13 | DROPDOWN What is your age group? Answered: 21 Skipped: 1



ANSWER CHOICES	RESPONSES 🗘	RESPONSE PERCENTAGE 👙	
25 to 34	2	9.52%	
35 to 44	7	33.33%	
55 to 64	8	38.10%	
65 to 75	3	14.29%	
75+	1	4.76%	

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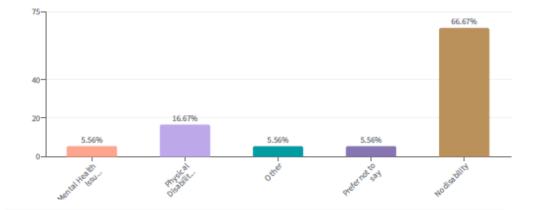
ANSWER CHOICES 👙	RESPONSES 👙	RESPONSE PERCENTAGE 👙
White: English / Welsh / Scottish / Northern Irish / British	6	27.27%
White: Gypsy or Irish Traveller	1	4.55%
White: Irish	1	4.55%
White: Other	1	4.55%
Asian/Asian British: Indian	9	40.91%
Black, African, Caribbean, Black British: African	3	13.64%
Black, African, Caribbean, Black British: Caribbean	1	4.55%

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QUESTION 15 | DROPDOWN

Do you consider yourself to have a disability?

Answered: 18 Skipped: 0



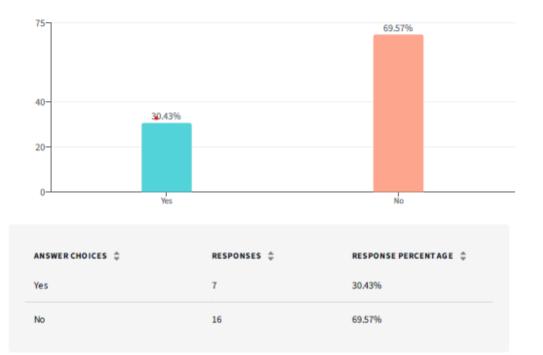
ANSWER CHOICES 👙	RESPONSES 🚔	RESPONSE PERCENTAGE $\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \$
Mental Health Issue	1	5.56%
Physical Disability	3	16.67%
Other	1	5.56%
Prefer not to say	1	5.56%
No disability	12	66.67%

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QUESTION 17 | MULTIPLE CHOICE

Do you consider yourself to have a long-term condition or health and social care need?

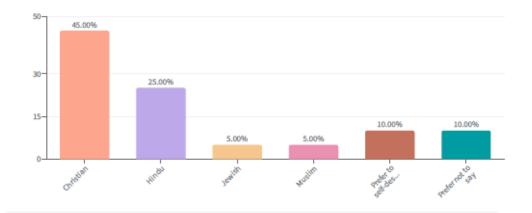
Answered: 23 Skipped: 0



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QUESTION 18 | DROPDOWN What is your religion?

Answered: 20 Skipped: 2



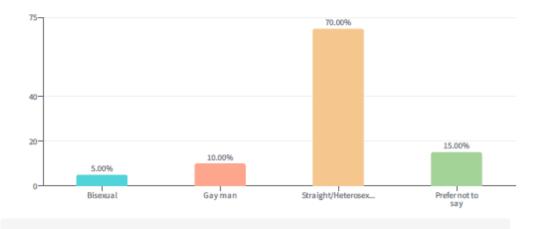
ANSWER CHOICES 🚔	RESPONSES ≑	RESPONSE PERCENTAGE ≑
Christian	9	45.00%
Hindu	5	25.00%
Jewish	1	5.00%
Muslim	1	5.00%
Prefer to self-describe	2	10.00%
Prefer not to say	2	10.00%

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QUESTION 19 | DROPDOWN

What is your sexual orientation?

Answered: 20 Skipped: 0



ANSWER CHOICES 👙	RESPONSES 🛱	RESPONSE PERCENTAGE 👙
Bisexual	1	5.00%
Gay man	2	10.00%
Straight/Heterosexual	14	70.00%
Prefer not to say	3	15.00%

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