**The G Word Transcript**

**The Muslim Census**

**Aman:** Hi, my name is Aman Ali, and I'm a community ambassador at Genomics England and you are listening to The G Word podcast. My role at Genomics England is a very interesting one; as a Community Ambassador, my role is to engage Muslim communities in the UK and their engagement with Genomics England. And today we're going to be talking about a very interesting subject – we're going to be looking at the attitudes towards health and medical research within Muslim communities. Joining me today, I have two wonderful ladies from Muslim Census, an independent organisation committed to collecting representative data to highlight the issues faced by Muslim communities, who will be helping us to understand more about this subject. So joining me today, I've got Zaynah Asad, who is a Muslim Census Project Manager and has a background as an economist, also Mai Shehab who's a Researcher at Muslim Census, who has got an educational background and a master's in surgery and is currently a fourth-year medical student as well, so she's got a lot on her plate. Welcome to Mai and Zaynah, how are you guys doing today?

**Zaynah:** We're doing well, thanks, how are you?

**Aman:** Likewise, doing very well. It's amazing to have you both on the podcast, really happy to see both. First of all, guys, tell me a bit more about Muslim Census and about the work that you guys do at Muslim Census.

**Zaynah**: Muslim Census is an independent organisation; we basically aim to reduce data gaps in the Muslim community by collecting data on Muslims through surveys. We were set up about two years ago following on from the COVID-19 pandemic, when, as you're probably aware, ethnic minorities were disproportionately represented in the cases and deaths, which led to our co-founder study to dig into this a bit more, dig into what data is there actually available on ethnic minorities and specifically Muslims.

**Aman:** I think, similarly, my work at Genomics England started around COVID as well. One of the reasons why we got in touch with Muslim Census was there a partnership between Genomics England and Muslim Census to understand the attitudes that Muslims have towards medical research. One of the reasons was, there was a COVID study done, which was looking at why, disproportionately, people from ethnic minority backgrounds were having more severe symptoms when it came to COVID. We thought that it's really important that we engage Muslim communities in research, which is conducted around genomics, for many reasons, which we'll probably go into a bit later. But we really wanted to understand what attitudes they have, and so we came up with this study that Muslim Census very kindly led for us on. Mai, I want to ask you, tell us a bit about the context of this study that we collaborated together on.

**Mai:** It was actually really encouraging from our side to see that Genomics England reached out to us to do the study, because I think it's quite well known that ethnic minorities are really underrepresented in health research. So, this is nice to see that there's a proactive effort to try and understand the attitudes towards healthcare research amongst Muslims. I'm going to hand this part over to Zaynah and then I'll follow up.

**Zaynah:** As Mai said, ethnic minorities, or ethnically diverse people, whatever term you prefer, have been massively underrepresented in genomic datasets and research. One study found that about 90% of studies only include white European individuals, which is 16% of the world's population. So obviously, these studies are kind of missing about 84% of the world's population. And so, applying the findings of these studies can be quite dangerous, because they're not really representative. And so basically, we wanted to understand the reasons why there is this lack of representation, and there are studies on different ethnic minority groups, which have found that ethnic minorities tend to have different views about genomics, and are maybe less engaged with health research. So, we wanted to find out if this was true for the Muslim community, who are made up of many different ethnic groups, but there is this preconception that Muslims’ beliefs might influence how they engage with health research and health professionals. So, we just wanted to dig into that.

**Mai:** Yeah, I think Zaynah touched on a really important point about why Muslims, because it's very easy to think of Islam as a religion; how come you're targeting Muslims? And I think for a lot of Muslims, if not most, Islam is sort of a lifestyle for its followers. And by that lifestyle, Muslims then make decisions on pretty much everything. Therefore, something like a study like this allows us to see whether decisions are linked to religion, or culture, and the best way to sort of dispel any misconceptions and encourage Muslims to take part in research. If the limiting factor is religion. And again, like Zaynah said, the more diverse the research, the more reliable it's going to be for the population and it's going to allow for better patient care. I think this is a huge thing amongst Muslims to sort of pitch into.

**Aman:** You make a really excellent point there about kind of the diverse data leading to better treatments, and better health outcomes as well. Zaynah, you mentioned right at the beginning, what percentage of most genetic studies focused on white European population?

**Zaynah:** 90%.

**Aman:** That represents 16% of the global population?

**Zaynah:** Yeah.

**Aman:** It's almost like if you think about a slice of pizza, we're only literally understanding one slice of that entire picture. So, I guess one of the really big motivations we had is we want to shine a light on that 84% - the rest of the population as much as we can. Obviously, we won't be able to send all of that picture, but engaging with Muslim communities allows you to understand quite a significant portion of that big piece of what we're talking about as well. So, we decided upon doing a study. So how did we actually understand attitudes that Muslims had towards health research and medical research? How did we go about doing that?

**Mai:** So just a little disclaimer, before we go into it, we actually ended up surveying around 1,000 Muslims. And now we know, speaking of the little slice of pizza that we currently have, this is also a little slice of the Muslim population. And we're aware it doesn't reflect on attitudes of all Muslims. But this is a really good starting point we found for us to be able to help Genomics England to understand health research in our population group. Zaynah was the Project Manager on this, so I'm going to let her talk about how we did it, and then we can talk about results and that kind of thing.

**Zaynah:** Yeah, sure. Thanks, Mai. So yeah, we basically conducted the research through an online survey, which was then ran to our subscriber base and our social media channels. So as Mai says, over 1000 Muslims living in the UK responded to the survey. And, obviously, that's not every Muslim in the UK, but we did weigh the data by age, gender and ethnicity to make sure that our sample was representative of the Muslim community as a whole, as per the 2011 census data. Of course, it is true that Muslims who are already interested in this stuff might be more likely to fill it out. But we think, given the sample size, given that we've wasted the data, we're confident that this can provide a viable insight into the attitudes of Muslims. And as I said, it's a useful starting point to inform engagement with Muslims.

**Aman:** Fantastic. So, what did we learn from those 1,000 people that took place in the study?

**Mai:** So, some of our key findings were that 86% of Muslims found health research to be very important, and 50-60% said they'd be willing to participate if asked. However, it was quite interesting to see that only 22% of respondents had actually previously taken part in health research, even though there was this big sort of commitment to wanting to take part. And only 4% of those had taken part in genetic research, which is kind of a little bit more understandable, because it is a bit more niche than health research in general.

**Aman:** Yes, so that's really interesting. So that's basically telling us lots of Muslims would be interested, because they see it as very important, but many of them haven't had the chance maybe, or what are some of the reasons you feel that people haven't taken part in research?

**Mai:** Yeah, I think it shows there’s sort of a little bit of a gap between those carrying out the research and the community. And there's sort of a need for community engagement projects to fill that gap and reach out because there is a willingness there to get involved. Maybe it's just the information isn't reaching the Muslim community.

**Aman:** And you mentioned information, information is a really key point there. Because I think one of the things that was explored within the study was information seeking behaviours of Muslims. And so, what did we learn about that, in particular?

**Mai:** So, this was actually another quite interesting thing that we found when we looked into our data, in the number crunching. And we found that Muslims are actually very similar to the rest of the population in terms of where they seek their healthcare information, with 73% saying that the NHS is their go-to source for medical information. So it just shows that it’s the most trusted one. And I think this, again, highlights that although there does need to be community engagement projects, we also can't look past the importance of mainstream, just using the NHS and the resources that are already available to us.

**Aman:** Fantastic. I mean, I know, for example, I always go to Google and then I'll type in something and then I’ll go to the NHS website, as the first link I'll look at, and I probably won't look at anything else, and then if there's something, some information available on there, then I'll access it. But I know that my parents, they probably wouldn't do the same. They probably would ask me to find out something or they’d call the GP. They love going to the GP because we have an open surgery at 11 o'clock in the morning, which apparently isn't the case around the country. Usually you have to wait two, three weeks for an appointment. But there is that difference, isn't it? And was there a difference that we saw between generations or kind of people with different backgrounds? Or was it the same across the board when it came to Muslim demographics?

**Mai:** That's actually quite good that your GP has that option, that’s quite nice to hear. So, we also found that the older, I'm not sure we have the exact numbers, but the older population tend to go to friends and family more, whereas the younger population tend to go online. And I think it's one of those where it's where trust is built. So, the older population is just used to and trusts friends and family, whereas we are a lot more comfortable sort of online. So that's our number one source of information. Zaynah, is there anything you want to add on that?

**Zaynah:** I’ll just echo what Mai has said, that there was kind of a generational difference, and that younger Muslims were more likely to go online. I think there was also a bit of a generally generational difference in that younger Muslims rated health research as more important than those older than them. And so, I think that there are generational gaps, but I think, yeah, the younger Muslims are a useful avenue to kind of maybe influence older generations to do online research.

**Aman:** I think that's a really important point. Because I think, especially with community engagement, especially my work with Genomics England as a Community Ambassador is to engage with Muslim communities, and I'm thinking, okay, what this research is telling me is that if I want to get through to the older generation, those who may not be so tech savvy, those who may not be familiar with kind of knowing that even just a website exists where you can find out lots of information about different health related issues, that, okay, if I want to target them, then I should target younger people, their children or their nephews or nieces. And then through them, I'll be able to engage the older generation. So that was a really useful insight for me personally, from the perspective of kind of organising community engagement. It's not a case where I have to go directly and figure out ways how am I going to get to the older generation – actually, the conduit for it is the younger generation itself. So, moving on a bit to try and understand what motivates Muslims to take part in research because we've established that most Muslims view health research as very important, and most – well just over half – said that they would participate if they were asked, but we know that we have this gap; that only 22% have taken part in generic health research, and even fewer when it comes to genomic/genetic research. So, what did we understand in terms of what motivates Muslims to take part in research?

**Zaynah:** This was one of the things we looked into in our study. And actually, most Muslims said that they were more likely to take part in research if they were familiar with the institution conducting the research, which I think really links to this whole idea of trust and transparency – that when Muslims talked about where they went for information, the reason they went to the NHS was because they trusted the NHS and it was reliable. So, I think this is quite a theme that we're seeing throughout the research. And that yeah, Muslims are more likely to seek information and also take part in research from institutions that they're familiar with. And then the kind of second factor was, if the study benefited the development of medicine in society more broadly, and the kind of across the piece, Muslims tended to select factors based on positive collectivist outcomes as opposed to individualistic reasons, which I think makes sense to me and anecdotally, in the Muslim community, that is a strong sense of community. So, I do think it makes sense that what we're seeing in the findings is that Muslims want to take part in research, kind of because of societal reasons, because of the community. And some felt that they had a duty to benefit their community. This was something that was mentioned quite a lot in our kind of open text answers, this idea of duty and supporting society more widely.

**Aman:** I think that was another really crucial insight that we got from the study is that the motivation of collectivist kind of reasoning for taking part in research. Often, if someone was to ask me, okay, well, what would make you take part in research? And I think, okay, how would I personally benefit? What would I directly get from taking part? And that would motivate me personally, but from this study, it showed that a lot of people, actually, are more concerned about their community, and also future generations as well. And I think one of the big things, the penny dropped for me a couple of weeks ago, is that taking part in genetic research in particular is saving lives for the future. So it's not a case where you might directly benefit. The treatments may not be created in your lifetime for breast cancer or prostate cancer or any other kind of genetic related diseases that exist out there. But it's a case where it's a duty that people have mentioned, it's almost been a reminder to make sure that I've got my motivations correct in that it might be my future generation, my children, my children's children who benefit from me taking part in research now. And that was a really kind of poignant moment, that reflection that I had. I don't know, maybe if Mai or Zaynah, if you had any anything to add to that?

**Zaynah:** Oh, yeah, definitely, I guess I was going to make a more broad point of it fits into this area. But I think one thing, if we’re talking about kind of the reasons for taking part, it's important to reflect that Muslims aren't just a homogenous group; that there are different ethnicities, we've already seen differences in generations. For example, Black, African and Caribbean Muslims were the least likely to take part, with about 21% of them willing to take part in health research, compared to 56% of Muslims overall, and there have been other studies that have shown there is less willingness amongst Black, African and Caribbean individuals to take that in health research, due to racism and other factors. So I think it's important to kind of look at, obviously, look at these findings and statistics, and what Muslims are saying, but also recognise there are differences within the community and that needs to inform our engagement as well and how we look at what motivates Muslims to take part in research, because there are different communities within the community.

**Aman:** Exactly, there's no such thing as a Muslim community, is there? It's loads of communities who come together and make supposedly the Muslim community – you've got Muslims from South Asian backgrounds, you've got Muslims from Arab descent, you've got Muslims from North Africa, mainland Africa, you've got Muslims from all around the globe. And the demographic is very, very diverse, not just different beliefs but different kind of cultures. And you're right, if there's going to be any engagement, it can't be a case of, oh, we're going to engage the Muslim community in one way and that's going to fit all of them and everyone's going to respond equally. Zaynah, you mentioned a really important point there, and Mai can help as well, is that we've spoken a bit about what motivates people to take part, but what, and you mentioned, you alluded to it a bit, as to what makes people not want to take part in your health research. What did we understand in regard to that?

**Mai:** I just wanted to add one more point regarding the different ethnicities and communities within the Muslim community. The biggest thing I noticed from this study was it's not a one glove fits all approach, and the importance of sort of realising what works for different communities and different ethnicities and cultures within our larger community. And I'm going to come to your point about what maybe deters Muslims away from healthcare research. And, so we found that the biggest thing that pushes them towards it is if there's sort of trust with that organisation, and if that organisation is transparent, so it makes sense that on the flip side, if there's no trust with that organisation, that’s sort of the thing that pushes Muslims away. And another thing was Muslims really value ethics being taken highly into consideration, which sort of, it makes sense in the community that we live in. I'm going to let Zaynah build on this one.

**Zaynah:** Yeah, sure. So another reason for wanting to take part in research was that if it had been reviewed by the ethics committee to make sure that those kind of ethical values were there. In terms of what pushes Muslims away, most have concerns about the risks of taking part in research, whether that’s health risks, and a lot also felt that they didn't know enough about what is involved in health research. But there were differences and reasons given by different ethnic groups. So, a majority of Arab Muslims and Indian Muslims would not trust that those doing the research would have their best interests at heart. And Pakistani Muslims, or Muslims from mixed or English ethnicities, felt uninformed about health research procedures. So, I think it just, this just highlights the need for engagement and education within the Muslim community. Because if a big part is that people felt they don't know enough about what's involved in health research, they don't know enough about health research procedures, I think kind of making sure that Muslims are educated on these things and doing that kind of outreach could be really useful.

**Mai:** Yeah, I think also, another thing we saw in our study is that older Muslims said their lack of time is the number one reason that they're not participating. So, I think another way to sort of tackle that is just to highlight the importance of health research, so that dedicating time towards it is something that's taken more as a priority.

**Aman:** I’ll share an example here. I mean, one the ways that we, myself assisted Genomics England in its COVID-19 study was I realised we need to make it easier for some communities to get involved. Number one, like Zaynah mentioned, they don't know how to get involved or what's involved. That was the first challenge, and then the second challenge was making it easy for them. Because there might be a time cost, you might have other things during the day and that fits low in terms of your priority, in terms of your agenda for the day. So, one of the things that we did was, wherever the study was travelling across the country to recruit participants, I would find a local mosque. And on a Friday, I'd encourage you to do the stall on a Friday or on the weekend. And I'd say, on the Friday, I'm going to get the local mosque to make an announcement that this study is taking place. And we want people to take part in the research. And just say that literally around the corner is where you can take part – there’s a designated store, or there's a hotel or venue that's been booked just around the corner from the mosque, literally on your way out, you can take part. And I think that led to an uptick in people taking part in research studies in that COVID-19 study. So, I think, two excellent points there that we need to make it very clear how it is that they can get involved, and announcement did that. And the second, make it easy for them. We know that a lot of Muslims, not majority, maybe, but a lot of Muslims do attend Friday prayers. And that's an excellent way to engage Muslim communities in the UK.

But just going back to kind of understanding a bit more about why we focus on Muslims, because people might be wondering, why is it that this one community or communities have been focused on. Actually, this Ambassador programme that I'm a part of, I'm just focusing on Muslim communities with a long term view. But there's other community ambassadors focusing on other groups within the UK as well. But just to focus, just for a moment, on the Muslim communities in the UK, Muslim community demographics, Zaynah can you shed light on what that demographic looks like in the UK, because you mentioned the census data from 2011, and that census has just been repeated last year, and we're looking forward to more data coming out, and we don't know what the answers are yet. But what are the demographics like in the Muslim community in the UK?

**Zaynah:** Sure, I think there's a mix of Muslim demographics in the UK. I think there's definitely a majority from a South Asian background, but there's also Black, African and Caribbean Muslims. There's Arab Muslims, there's a small minority which are from a white Caucasian background. So there's really just like, a huge mix of ethnicities within the UK.

**Aman:** And with that ethnic diversity being prevalent within the Muslim community, what potential does that have for Muslim engagement in health research?

**Zaynah:** I think it basically means that if you're kind of getting more Muslims to participate, just by default, you're getting a huge mix of different ethnic backgrounds to participate, just because the fact that the Muslim community is so diverse. Obviously, it does mean that we need to think about how we engage with Muslims, because there are so many ethnic backgrounds, as we've talked about, it's not a one size fits all approach, there needs to be nuance. But I think it basically means that if you engage with Muslims more, if Muslims participate in more, you're capturing many different ethnic groups.

**Aman:** And that has a global impact, right? I mean, I know that Genomics England, the treatments that they are looking to innovate, are not only going to benefit communities in the UK, but globally as well. And in order for those treatments, like you mentioned right at the beginning, for them to be most appropriate, or kind of most effective for global populations, having data from Muslim communities who come from South Asian backgrounds, from African backgrounds, from other backgrounds as well, and Arab communities as well, you get insight into those geographic areas around the globe as a result. And then, hopefully, whatever treatments that we might kind of innovate in the UK can be not only of a benefit to people in the UK, but globally as well. And that for me, there's a huge potential there, and a huge motivation for me, in particular, to engage Muslim communities in health research. I don't know, Mai, having a medical background, is there any insight you have on that?

**Mai:** Yeah, I agree. I think increasing engagement in healthcare research is one thing, genetic research is up and coming. The more your population is representative of the actual population, the more we’ll be able to study gene variants and understand the effect of diseases, and how it will outcome different patients, because, yeah, we might understand how a certain disease work, but we won't know how it works, and presents in different ethnic groups. So that's really, really important for us to understand. So, I think that's the number one thing that really excited me about this project when it came through.

**Aman:** And you mentioned, genetic research is up and coming, and it's not as well known, it's not as established as maybe health reasons to do with cancer or to do with a number of other kind of health issues. So, one of the key things that we also understood from the study was what attitudes Muslims have towards genetic research. So, I don't know if you guys want to shed a light on what we learned about that and what attitudes Muslims have towards genomics.

**Zaynah:** Yeah, sure. I think what we found was that those attitudes to health research was quite similar to the attitudes to genetic research. So, they didn't really distinguish that much between the two, kind of genetics and health separately, they kind of saw them both quite similar. And in terms of Muslims’ familiarity with the population, and I don't, with genetic research, quite have the figures to hand, but it was quite in line with the general population in terms of familiarity. So, I think that's kind of what we saw. But I think we did see that the younger generation were more likely to view genetic research as positively than the older generation.

**Mai:** Yeah, so the figures are 22% of Muslims are familiar with sort of terms related to genomics, so maybe DNA genetics, genomics. And that is, like Zaynah said, broadly similar to the general population, which is around 25%. I think the fact that it is up and coming means that maybe less people are aware of it.

**Aman:** And then more the reason to engage those communities to bridge that gap, right?

Mai: Yeah, definitely.

**Aman:** That's it. So, on the back of the amazing study that you guys did, where you really did help shed the light on some of the attitudes that Muslim communities have towards health research and internet research results. You also came up with a number of recommendations as well for how engagement can improve, and just recommendation in general. So, what were some of those recommendations that you have for Genomics England, or the wider health research environment?

**Mai**: So, I think, importantly, in our study on attitudes towards the future, over 70% of our respondents said that they were hopeful about where developments in science and technology are going. So, again, just shows a willingness to sort of learn more and participate more. In terms of recommendations, I think there needs to be some roadmap with certain stages. So, raising awareness, like you mentioned earlier on, sort of the opportunity for people to ask questions, find out the answers to them. And then the final stage is how to get involved. Like we've mentioned earlier, I think it is really important to diversify the sources and information that we provide to Muslims and in what ways we give them to Muslims, and to the community in general. Like we mentioned, only 25% know about genomics. So, again, it's not a one glove fits all approach. From the feedback that we got on this report, we got that social media infographics work for some groups, videos in different languages. Like you mentioned earlier about standing outside, on Fridays, outside mosques and sort of pointing towards people towards the right direction, so local events or mosques, university, Islamic societies. Another really nice one, I think, is personal stories. I think we've seen that Muslims are more likely to participate in research if they see it benefiting others and their local community. So, if we put out these personal stories and make them available, Muslims are more likely to sort of see exactly where this research is going. And like we mentioned, trust and transparency, so the more transparent, the more likely you are to get involvement.

**Aman:** You're right. And building on that point of trust, there was quite a big concern around data and how data is going to be used. That was a big key result that came out of this study. Do you want to elaborate a bit more about what you guys learned about how Muslims feel about data and how data is going to be used?

**Mai:** We actually found that 80% of Muslims are concerned about data security. In the overall population, that percentage is a lot lower at around 25%. I think that's something that needs to be sort of rectified, before expecting the Muslim community to completely trust research. But again, like we've seen from the data, there is a willingness. I think hand in hand, something can definitely be done.

**Aman**: Yeah, I think we're definitely pushing against an open door. As one of my colleagues at Genomics England said, there's an open door here, we just need to enter that door with transparency and honesty. And also, to give that reassurance that whenever, whatever research that we're going to be undertaking, that your data will be protected and it's only going to be used in a manner in which we've got your consent for, and in an ethical manner as well. And that we need to build that trust before, and you can't just expect, oh, hey, they have the benefits for you as an individual and more importantly, you as a community. So, take part. No, that trust needs to be built, and that naturally will only occur over time. So, really, I think that's a good place to kind of bring our conversation towards a conclusion. And I want to thank Mai and Zaynah for coming on to our podcast today and shining a light on attitudes that Muslims have towards health research and medical research as well. Do you guys have any exciting new projects that you guys are working on at Muslim Census that our viewers and listeners may be interested in, maybe potentially even take part in if we have any Muslim listeners listening in?

**Zaynah:** Yeah, we've actually got a cost of living survey coming up, which is kind of looking at the impacts of the rising cost of living on the Muslim community. So that should go live in early September and we're hoping to publish the report and findings in October, so definitely look out for that. And if there are any Muslim listeners, we're also recruiting for volunteers at the moment, bit of a shameless self-plug but just though I’d mention it.

**Aman:** Fantastic. And how can people find out about the survey? Is their website they can visit or social media?

**Zaynah:** The survey will be published on our website, and also on our Twitter and Instagram pages.

**Aman:** Fantastic. So, you've heard it there guys, so if you're interested in taking part in that research, I think definitely I will be, because the cost of living is really affecting many of us. So definitely encourage people to take part in that. And also keep an eye out for the Genomics England page, the work that we're going to be doing engaging Muslim communities. It definitely is a long-term commitment, and one of the wonderful things that's really made me proud and motivated to work with Genomics England is that it's not just this one study that they've done, where what have you found out a bit of information about the community and I’m just going to leave on a shelf. On the back of this study, there's a long-term programme of engagement that's been agreed upon, which I'm going to be involved in, and other people are going to be involved in as well. And there's a long-term commitment towards improving that engagement with Genomics England and genetic research and health research in general, as well. So, definitely watch this space and keep an eye out for more engagement projects and more podcasts that we're going to be recording in regard to understanding Muslim attitudes and engagement with Muslim communities. So with that, we'll bring our podcast session to an end. Once again, big thanks to Mai and Zaynah, and also to all our listeners for joining in as well.

**Mai:** It’s been great being on your podcast, thank you for listening.

**Zaynah:** Thank you for you so much.

**Aman:** That's all for this episode. Thank you for listening to this discussion about The G Word. And for joining us on this journey to highlight and debate the implications of genomics as it comes to the mainstream of healthcare, and society. You can find out more about Muslim Census and their work by visiting muslimcensus.co.uk, or you can visit their social media handles @MuslimCensus. If you have any views on these topics or have a person in mind you would like us to interview, do write to us at podcast@genomicsengland.co.uk. Remember to subscribe to The G Word on Apple podcast, Spotify, or wherever you listen. And if you've enjoyed listening today, give us a five-star review, because it will really help us to reach out to other people who can find out about our series. We appreciate your support very much. And until the next time, I'm Aman Ali, see you on the next episode of The G Word.