Research Paper on How Blood Borne Viruses Testing Can Become More Accessible and Acceptable for Ethnic Minorities in Aberdeen

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1. Introduction

In recent years Aberdeen became a truly multicultural city with one in six residents being born outside the United Kingdom. The prevalence of blood borne viruses (BBV) around the world varies among countries. Some members of ethnic minorities are coming to Aberdeen from countries of high risk. BBV treatment is important because effective medicine are now available and treatment should be started as soon as possible to prevent long-term damage. In order to provide treatment patients need to be identified through testing. This research aims to see how BBV testing can be more acceptable and accessible to ethnic minority communities.

This report is divided into five main parts. In the first two parts, research methods and participants are presented. Later in parts three and four results are discussed and finally recommendations are made to make BBV testing more acceptable and accessible to ethnic minorities in Aberdeen.

2. Methodology

The research was conducted over the period of a few months. Initial questions were asked during the GREC/NHS Feedback Day in November 2015, when 81 members of ethnic

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minorities took part in these focus groups. These data were analysed and the initial report was prepared in January. The initial findings influenced the main methods of the research, which included the survey on BBV (52 participants), a focus group with community stakeholders (9) and the in-depth interviews (9).

The survey attempted to explore how culture and religion may influence the health choices of participants. Secondly, participants were asked where they would like to receive more information about the BBV. Also, people who took BBV testing were asked to describe their experience. Results from the survey helped to shape up questions for the in-depth interviews.

Initial focus groups aimed to check participants' knowledge on the subject and allowed them to suggest how awareness could be raised around the issue.

A community stakeholder focus group and interviews allowed in-depth discussion on the BBV, especially around experiencing any barriers and approaches to make testing more acceptable and accessible among ethnic minorities. Interviewees were recruited from survey participants.

Intensive notes were taken during the focus groups discussions and interviews were recorded, and transcribed. Later, all data were analysed by themes in the CATMA (Computer Aided Textual Markup & Analysis).

3. Participants

The tables below show the data from the monitoring forms on participants. Firstly, personal data are given on interviewees (Table 1), language in which the focus groups were conducted (Table 2) and the detailed information on survey participants (Tables 3, 4 and 5).

Participants in in-depth interviews					
Ethnicity	Gender	Age	Student	How long in the UK	Religion
Bengali	Female	25-30	Yes	1 and half year	Hindu
British	Female	30-35		24 years	Atheist
Arab	Female	30-35		4 years	Muslim
French	Female	30-35		5 years	Atheist
Italian	Female	20-25	Yes	3 and half year	Catholic
Polish	Female	35-40		4 years	Catholic
Lithuanian	Female	25-30		3 years	Orthodox
Italian	Male	40-45		8 years	Catholic
Venezuelan	Male	40-45		3 years	Catholic

Table 1

Focus Groups	
Language used in the focus group	**Number of participants**
Urdu	10
Lithuanian	12
Arabic	20
Romanian	3
English (including Polish, Slovak, German)	12
Russian (Latvians)	17
English (Stakeholders)	9
Chinese	7
Total	90

Table 2

Ethnicity Division in Survey			
Nepalese	2	Latin American	1
British	4	Scottish/Polish	1
Scottish	6	Hungarian	1
English	2	Other	4
European	3	Romanian	1
Indian	3	Venezuelan	1
Bangladeshi	3	Ukraine	1
Spanish	2	Chinese	1
Arab	1	Asian	2
Mediterranean	1	African	3
Estonian	1	Swedish	2
Malaysian	1	Polish	5
Total	52		

Table 3

Religion in the Survey	
Atheist	8
Catholic	8
Christian	11
Protestant	4
Hindu	3
Other	2
Islam	4

Table 4

Gender Division in the Survey	
Female	37
Male	15

Table 5

4. Analysis

Results are divided into the themes which were identified in the interviews. These are: participants' knowledge of BBV, their testing experience, and how culture and religion may shape people's perception on BBV. The discussion is led by quotes from the interviews and it is supported by data from survey and focus groups.

A. Participants' Knowledge of the BBV

In the pilot study participants were asked if they are aware what BBV are; 60% of them answered yes. However, there was an issue if the measure was a right one as this question was asked in the focus group and the answer was not anonymous. Therefore, a similar question was asked in the survey.

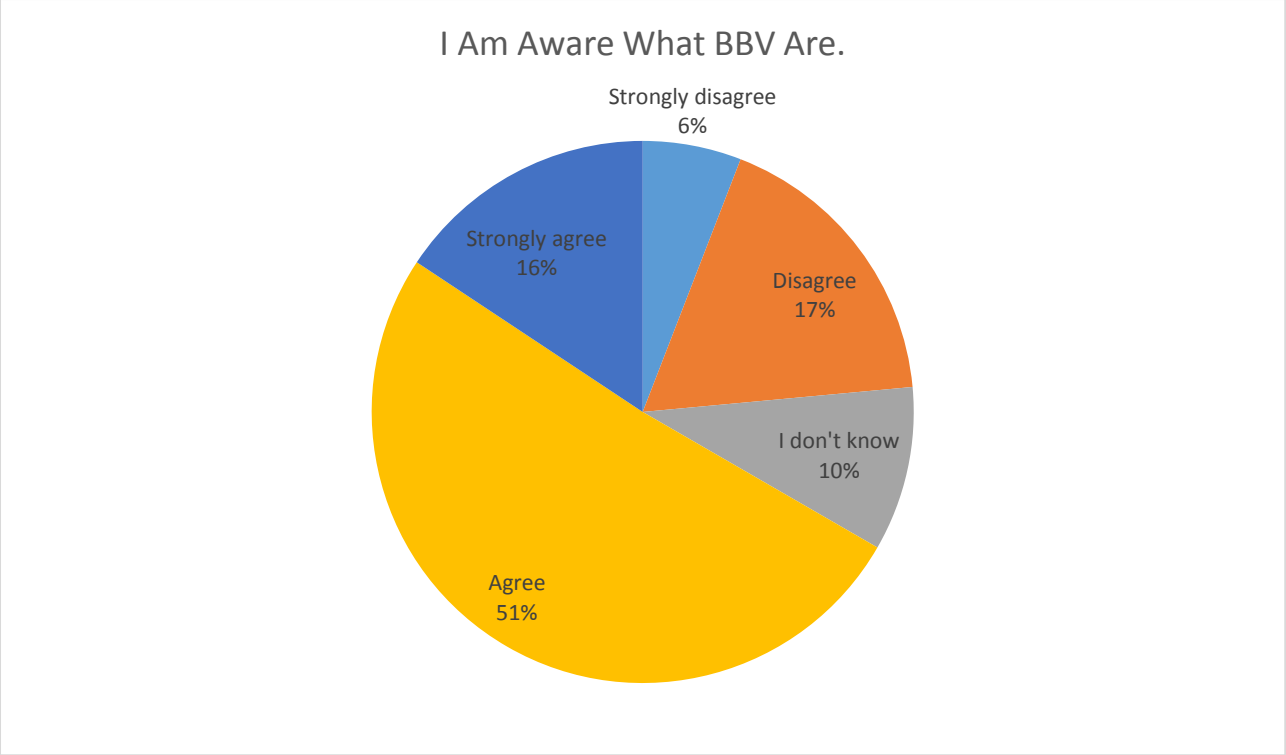

Figure 1

67% of participants agreed or strongly agreed with this statement. Therefore, it seems that the majority of participants know what BBV are. Nevertheless, when the same people were asked if they are aware what Hepatitis B, C or HIV/AIDS is, then their knowledge is much higher. The average result is presented in the table below.

Term	**How well participants know the term from 1 to 5, where 1 is low and 5 is high.**
BBV	3
Hepatitis B	3.25
Hepatitis C	3.27
HIV/AIDS	3.96

Table 6

During the in-depth interviews people's knowledge was tested in a different approach as they were asked if they can say what BBV are.

There are viruses or diseases… which by definition… you bear in your blood… (French female)

In fairness I have very vague idea. I would believe it's something you get when you are injured and your blood is exposed to whatever … (Lithuanian female)

They are a kind of virus, which can be transmitted through blood in humans… but I suppose it is not limited to humans (Italian female)

Others were able to name some of them, but three interviewees thought that Hepatitis A is one of them.

Participants have a vague understanding what BBV are however they are not able to give a straight forward answer, which is not surprising as they are not specialists. Nevertheless, their understanding of the subject increases when the jargon is not used and plain English is used. Many members of ethnic minorities speak English, but may still think in their mother tongue. When some words do not have a direct translation in their mother tongue, participants may not understand it. The Lithuanian participant spoke in this way about this issue:

I: Oh no, no I was aware of Hepatitis its just didn't record directly to me like blood borne viruses a few more diseases to it .

R: So do you think it will be confusing for ethnic minorities to use it?

I: Yeah I would say so yes because in fairness the specific word one of the things Okay well I adopted quite few of Scottish and English… years I've been around but there are quite a few people I know who really stayed here long time like Polish, Lithuanian, Latvian, Estonian, Russian even who are still struggling even after five, eight years well they obviously get to certain level of talking and understanding but there is always things that they cannot really figure out unless you have a vocabulary with you all the time, most of them don't.

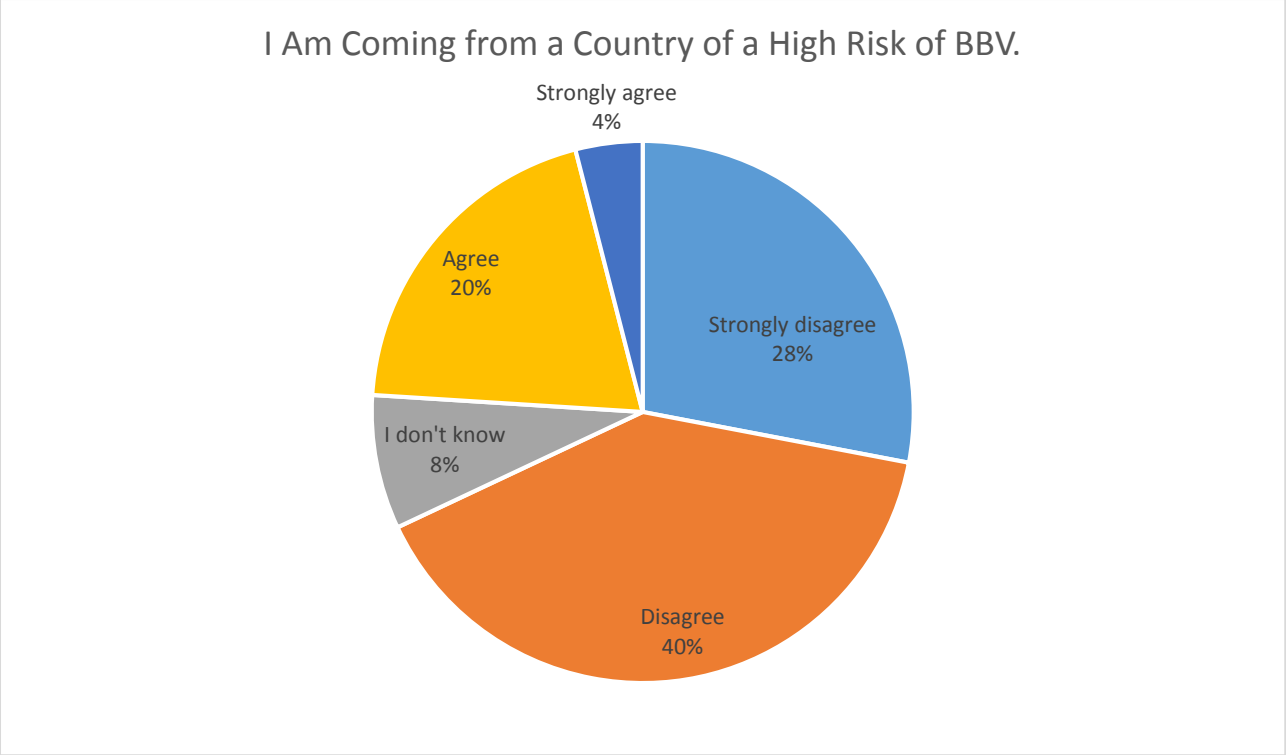

Figure 2

Last but not least, in the survey participants were asked if they think that they are coming from a country with a high risk of blood borne viruses. In the graph above, one can see the answers from participants who are actually coming from countries of high risk. It shows that 68% of them disagree or strongly disagree with this statement. Clearly, participants are not aware of the prevalence of BBV in their home countries.

B. Religion

One may presume that people's religion may influence their approach to their health issues. In the survey, participants answered four questions regarding their religiosity. It was open only to people who specified their religion. The average answer is presented in the table below. The scale is from 1 to 5, where 1 is strongly disagree and 5 is strongly agree.

Religiosity Questions	
My religion shapes my daily routine	2.65
I ask for advice from my spiritual leader on medical matters	1.9
I am active in my religious congregation	2.77
I read religious magazines and newsletters	2.34

Table 7

Religion does not seem to have a big influence on the choice of health treatment or participants' approach to health. However, as the sample is small, it is not possible to specify if there are any differences between various religions. The relation of religion and health was further discussed in the interviews.

R: [interviewing participant identifying as Catholic] Does Catholic religion intervene with health decisions?

I: I don't think, I don't think I mean they are Catholic but in a close group probably the one very close to the church but no they must be minority but no. you know about the pope and the latest statements I think I mean there is a clear distinction between what is religion and what is health and so probably like many years ago like forty or fifty years ago maybe, Yes, there would be issues but now no. (Italian male)

A similar answer was given by a Hindu person who was asked if culture or religion has influence on Hindu medical choices. She answered "*cultural background has a lot of influence*" and later added that religion has almost no influence in her society on this kind of choices.

C. Culture

As well as religion, culture is considered to have an influence on medical choices of people. It was already pointed out that culture is more influential than religion. However, a longer discussion is required to see how one's cultural background may influence possible testing. In order to do it, the home country influence will be discussed, and then culture in general.

Home country influences people's perspectives as one of the interviewees pointed out:

it depends… especially how you were educated in your own country and how it is discussed in your own country. (Female French)

Moreover, some people grew up in more traditional environments and did not speak about such topics at home.

I: yes, it is. In spite of that we go forward and develop… we understand that our parents did not meet this function… but they still repeat what was before.
(Female, Polish)

Later, a Polish participant spoke that she had to challenge herself to speak with her daughter about sexual health and it was not easy. There is a need to provide advice to parents on how to deal with and approach these issues, especially if they did not have a role model before.

Often it happens that people do not get enough information and do not expect some services which are offered.

Yes that's the thing, there are so many things which must be explained to students, even contraception… so many myths about… so many nonsense and people believe it and they take it for granted (Lithuanian female)

Therefore, it may be necessary to approach members of various ethnic minorities.in slightly different ways. When participants were asked if BBV are a taboo topic to speak with their family or friends they said:

I: No no… it is a healthy topic…. We speak everything…. With my wife… even my daughter… not problem at all.
(Venezuelan male)

Maybe it depends on generation… maybe now younger generations are a bit more open (French female)

Taboo Questions	
Topics around my body and hygiene are taboos for me.	1.78
I can speak about blood borne viruses with my partner.	4.16
I can speak about blood borne viruses with my family	3.92
Speaking about drugs is a taboo for me.	1.78

Table 8

The above table shows participants' average answers on the questions regarding taboos. The scale is from 1 to 5, where 1 is strongly disagree and 5 is strongly agree. It seems that people feel confident to speak about their body or drugs, as well as about BBV with their family or partners; with a slightly higher score for partner than family.

Last but not least, it is essential not to generalise based on the culture or country as people may come from various parts of a state, such as rural or urban areas, and this division may shape their perceptions.

I come from the capital right and I am still from a much more modern society and I'm not against pre-marital things or anything but if you go to a village part even the Southern part of India it's much more conservative (Bengali, female)

D. Testing Experience

In the survey participants were asked if they ever took BBV testing; 16 of them answered positively to this question. Then they were asked to rank their satisfaction from 1 to 10, where 1 was not satisfied at all and 10 was very satisfied). The average results was 8.8. Moreover, the comments were positive.

"clear information, approachable staff, prompt answers"

"very professional"

"Written results offered."

Similar results appeared in the in-depth interviews:

R: Coming back to the testing, were you happy with it?

I: The exam, the blood, yeah absolutely very fast like one minute. So they just take blood and done. (Italian Male)

It can be argued that testing is provided at the high standard. However, participants are not aware how long testing takes; only 10% of participants thought it takes only a minute.

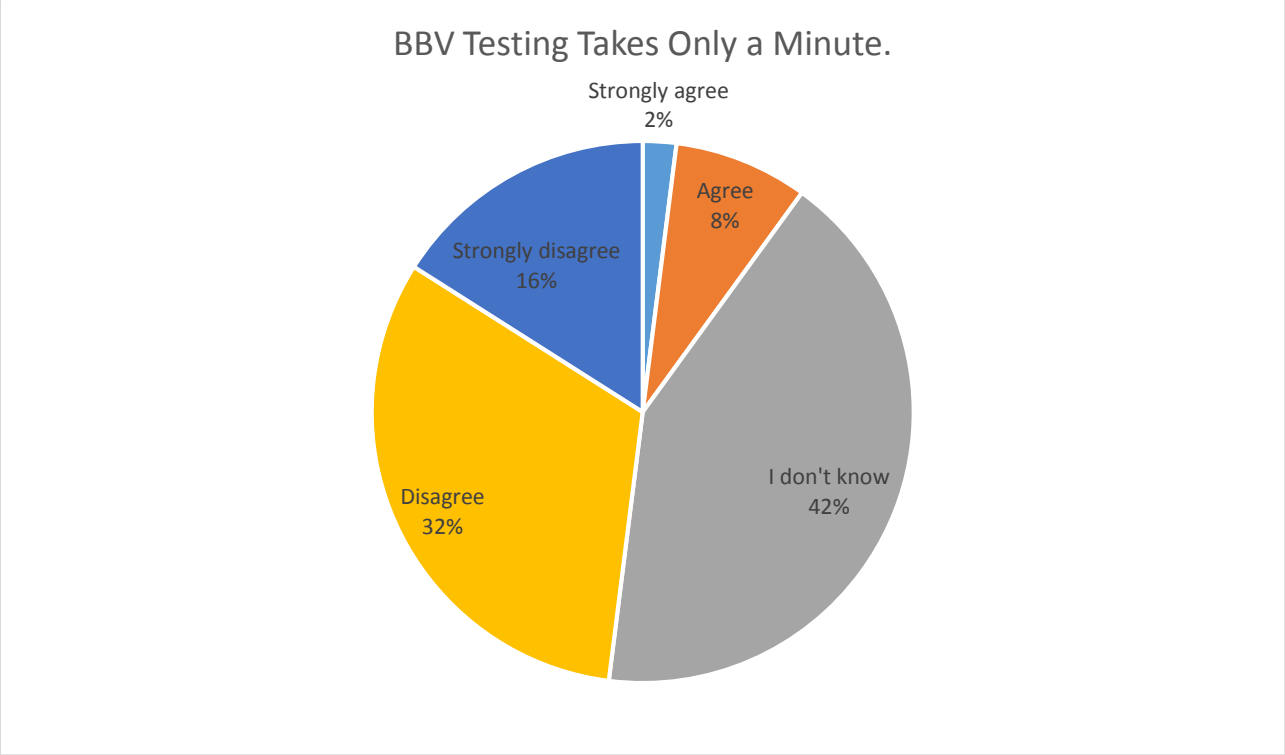

Figure 3

5. Raising Testing Uptake

The main aim of this research was to see how BBV testing can be more accessible and acceptable to ethnic minorities. It was challenging to speak with people about how to improve services.

R: Okay so do you have any suggestions how to change it? How to improve it?

I: I can't perhaps because how can I explain that? It's like we people who be like scared from you, people started saying that if you pass on something like that, you prefer not to say it. (Arab, female)

This part has been divided into three subparts: how to approach in general, how to reach students and how to offer testing.

A. General

In the survey participants were asked to rank from first to fifth choice how they would prefer to learn more about NHS services and their respective answers are summarised in the table below.

	First Choice	Second Choice	Third Choice	Fourth Choice	Fifth Choice
Website	52%	6%	9%	10%	0%
App	4%	15%	0%	19%	62%
Leaflet	11%	44%	26%	14%	10%
GP	23%	24%	43%	5%	10%
Healthpoint	11%	12%	22%	52%	19%

Table 9

The majority of participants prefer to learn more about the NHS from the Internet. The second most popular option is GP with 23%. It seems that participants were not really interested in App as 62% would choose it as the fifth choice. Second least popular option was Healthpoint

with 52% of participant choosing it as fourth option. Last but not least, leaflets were less popular in the first round of voting both with website and GP.

With the development of digital technology, leaflets became less popular. However, leaflets still play an important role.

I am not sure what I would prefer… a leaflet may be good. Because even if you speak with your GP and you… I don't know… have some mental blockade or you don't want to speak about it. At least leaflets leaves you alone and gives some information. (French Female)

Leaflets can be distributed to patients during the GP visits so they have extra information available to read if they wish to learn more. In the case of ethnic minorities it may be especially important as English is a second language to them and they may not feel confident to ask what they would consider "silly" questions.

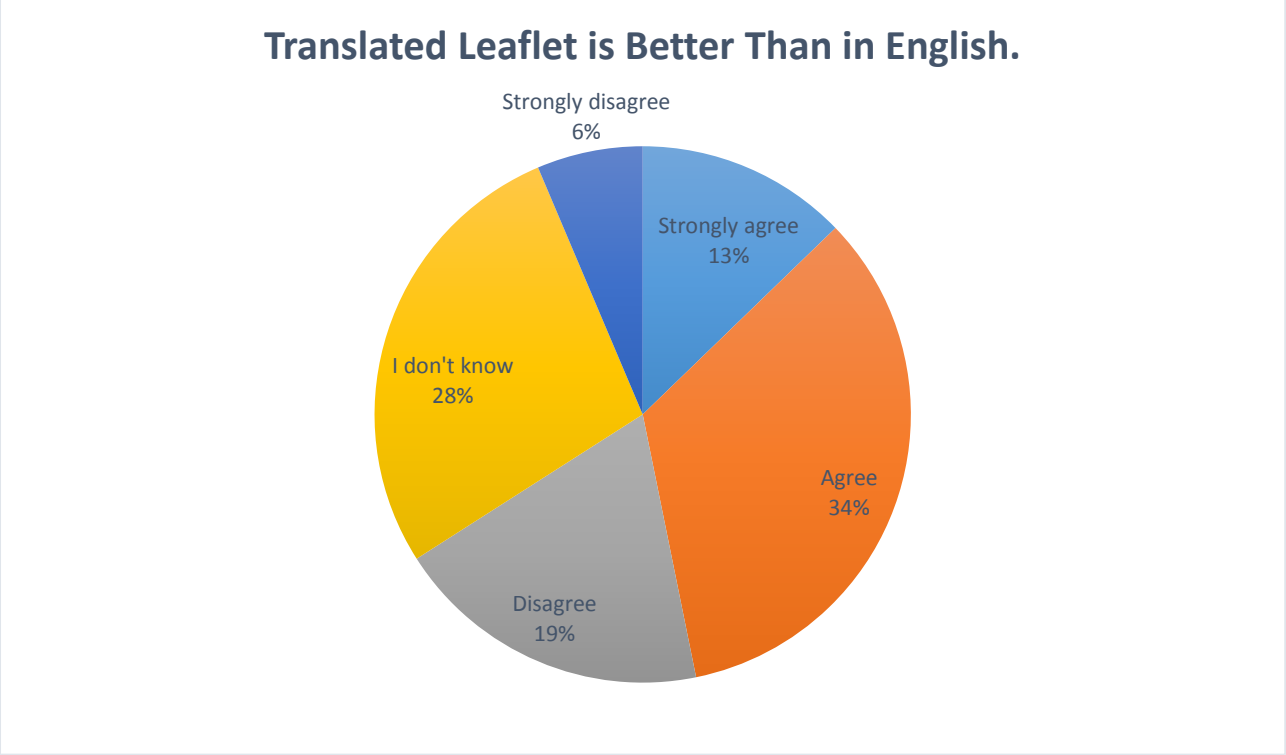

Figure 4

Also, 47% of participants prefer translated leaflet rather than one in English.

Think the best way is to send into this environment people with wide knowledge …. And I think this should be their role to provide a reliable information… the worst thing is when they (religious people) receive partial information which may be interpreted in a wrong way… what else… sharing more information at schools… here should be more.

(Polish, female)

The Polish lady spoke about the danger of providing only partial information. People who come to speak about BBV should have good understanding of it. Some work is already done in the city in a form of free BBV training organised by NHS. What is more, the stakeholders focus group pointed out the need to show that it is worthwhile for targeted groups to learn about BBV. Nowadays, everyone tries to reach members of the public so this task is mostly challenging, but there are a few ways to do it.

The Venezuelan participant suggested the use of social media. Moreover, the Arab participant added that the Muslim minority in the city checks local pages for the Muslim community on a regular basis.

Well translated leaflets would probably be the best option because obviously if it's in your language and obviously it's made sure that the native speaker has reviewed before it was published (Lithuanian female)

However, there are plenty of ethnic minorities and many of them speak various languages, there is a difficulty to choose languages which should be available

But everyone is from different culture so there would be no perfect recipe for those [posters/booklets] (Lithuanian female)

Thus, there is no clear answer; the choice should be made upon the target group.

The community stakeholder group suggested to do work around World Hepatitis Day to raise awareness without causing fear among members of the community. There is a need for a positive approach. The examples of a positive approach include the work of the BBV nurse, who comes to local events and speaks to people about BBV and offers testing. As part of the cooperation, the nurse joined GREC's Heath Link Worker on a number of events, including the African Women's Conference, offering testing to participants.

In conclusion, it is necessary to show an example of a positive approach within the NHS; this quote comes from the person who works in the NHS:

I've been working with ethnic minority communities so through that time I've been fortunate enough to get to know people and develop natural links with people (Female, British*)*

B. Students

There are 27,000 students studying in Aberdeen, coming from all over the world. Often, they are not aware what services are available. As the majority of students are young people, who tend to access information in a different way, there is a need to understand this group more. Even the most obvious services for locals, can be a surprise for newcomers. Students can be relatively easily accessed through universities. Ideas proposed by participants included more materials during freshers week and local student events, and leaflets available in the student accommodation.

At uni, there was a class or whatever, not a conference but rather a discussion at uni. My partner attended and he was really surprised that apparently in the UK, maybe not here but in Scotland definitely you can request free condoms for free at university, whatever size you need and he was oh my God, I don't have to buy these things anymore. WOW, you were here for two years and you just learnt now.

(Lithuanian female)

Students can be approached in the same way as any other group plus through fresher's week and e-mail as each student has to check on a regular basis their university email address.

Well there is always obviously an option of e-mail of course. Because Like I myself try to stick to e-mails. (Bengali, Female)

C. Offered Testing

In order to understand people's views on being offered testing, each interviewee was asked if they would accept testing if offered by their GP. All of them answered yes. The second question was if they would change their mind if learnt that only their particular ethnicity was targeted. These questions were asked to participants who came from both high and low risks countries. Their answers were:

R: Okay, but let's say that your GP would offer you the testing, would you accept it?

I: Yes

R: Okay

I: Yep

R: You wouldn't feel discriminated?

I: No-no

R: they offer it because you are from India

I: no-no-no

R: Okay

I: It's just.. I mean in fact I'll take it very encouragingly saying that they're concerned about that (Indian female)

The opposite view was expressed by other participants:

R: So if your GP would offer you a testing, would you take it?

I: Yes, sure.

R: What would happen if you would find out that they offer it to you because you are Italian?

I: (silence for a few seconds)… then… I would probably not agree.

R: Would you feel discriminated?

I: Yes,

R: So what about if it is not Italian but because you are a member of an ethnic minority, non-British?

I: Exactly the same, I would feel discriminated. (Italian female)

Would you take it if your GP offers? What if you know they offer only for Arabs, would you feel discriminated?

I : Yeah. for Arabs you feel discriminated, but for everyone it's okay. Because if for everyone if we do. (Arab female)

There are mixed feelings among participants regarding targeting of ethnic minorities. It may happen that a decision to target members of ethnic minorities may backfire and people will not take testing. It shows that there is a need to reassure participants that any actions are taken for their benefit and that they are not being tested because of their ethnic background.

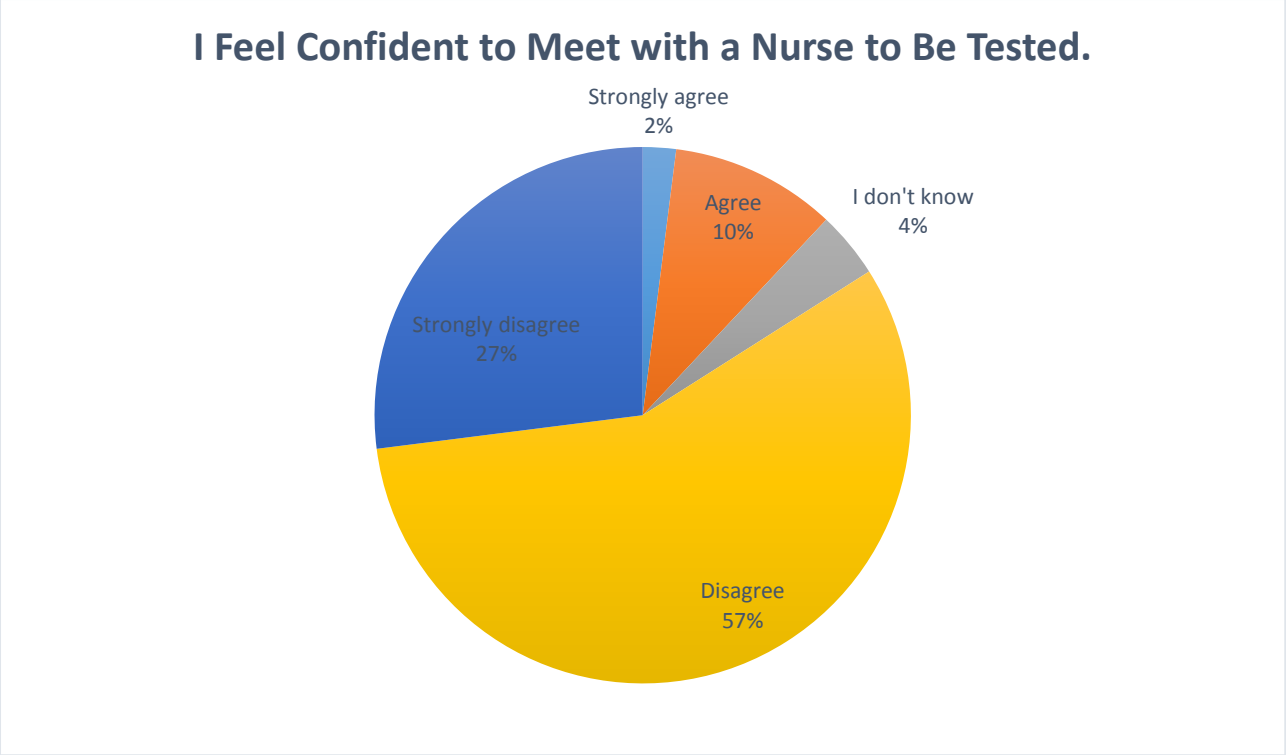

Figure 5

Last but not least participants do not feel confident to be tested by a nurse; with 84% of them disagreeing with the statement. It is opposite to the number of people satisfied with testing, thus it is again necessary to explain the process more.

6. Recommendations to Make BBB Testing More Acceptable and Accessible to Ethnic Minorities.

1) To focus more on Hepatitis B and C as people are much more aware of HIV.
2) To avoid the use of the phrase 'blood borne viruses' because members of ethnic minorities may not have an equivalent in their mother language and it risks being perceived as jargon.
3) To inform more people from countries of high risk. However, avoid the targeted testing based on ethnicity as it may have opposite effect.
4) There is no need to target religious congregation as their religion does not influence health choices as much as culture does. However, more research would be required to fully understand each single religion's influence on people's health choices.
5) To clearly explain to participants what testing looks like, how long it is; this information can be added to BBV leaflet.
6) Promote more the healthpoint as a source of health information.
7) Target every year the new student population, especially during freshers week.

Appendix

Attachment 1 Results from Focus Groups' Discussion about Blood Borne Viruses

Results from Focus Groups' Discussion about Blood Borne Viruses,

November 2015 GREC/NHS Consultations in Aberdeen

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January 2016

On Saturday 21st of November, members of ethnic minority communities in Aberdeen were invited to participate in the GREC/NHS Consultations. 81 representatives of various ethnic minorities who took part in the focus groups. Each of the participants had an opportunity to express themselves in their mother tongue as interpreters were present. One of the topics during focus groups discussion was about blood borne viruses (BBV). Participants discussed four questions regarding BBV. The first two aimed to check participants' knowledge on the subject, while the other two allowed participants to discuss how they would suggest awareness could be raised around the issue.

Participants were first asked if they were aware what blood-borne viruses are. Results are shown in the Figure 1. The majority of participants knew what BBV are. However, there is an issue of validity. It was an open question to a group and members raised their hands to answer yes or no. Therefore, some participants may have preferred to say yes to follow the lead of others or to not show lack of knowledge as some participants came with their friends, partner or family. It must be pointed out that BBV, particularly related to sexual activity, are often seen as a taboo by some cultures (Lee at al, 2010:42).

One must avoid to generalise based on a small sample. Nevertheless, some observed patters among ethnic groups are worth to mention. The least informed groups were Urdu, Russian and Chinese speakers. The most informed groups were people who sat in mixed groups and Arabic speakers.

Secondly, participants were asked if they know how to get checks. Figure 2 shows the results. The overwhelming majority of participants did not know where they can receive checks. In some groups, there were single interviewees, who answered that there were aware.

Only one out of the two mixed groups was aware where the service was available or where to search for the information. Although number were small, participants who knew little about BBV were from countries with a higher prevalence.

Finally, interviewees discussed how awareness of BBV could be raised and how uptake of testing could be increased. Almost every group pointed out that more promotion is needed. They recommended to raise awareness though media, internet, libraries, schools, universities, as well as GPs and pharmacies. Chinese participants suggested that translated leaflets would be more accessible for them. People said that they would accept testing if offered by their GP. However, they pointed out that they do not know if testing can be done without prescription from their GP or how much time testing takes. Finally, some participants pointed out that they would not only like to learn more about BBV, but other NHS services as well.

Recommendations

This short piece of research suggests some improvements and possible actions for the future:

3. 1. To make a change in the NHS leaflet (CGD 150234) on blood borne viruses from "the person doing the blood test will explain the process, when and how you will receive

the results" to include some information about how much time a test takes and to ensure individuals that it is not intrusive, and the approximate time to receive results.

2. In the future, it would be beneficial to ask participants, in the written questionnaire, what the blood borne viruses are. Then, they could discuss in a focus group, how they acquired this knowledge.
3. To get involved in the World Hepatitis Day on 28th of July to raise awareness on blood borne viruses and use the World Day for media coverage. There are many actions happening around the world, supported by the World Health Organisation though the World Hepatitis Day Project, more can be found on http://worldhepatitisday.org/

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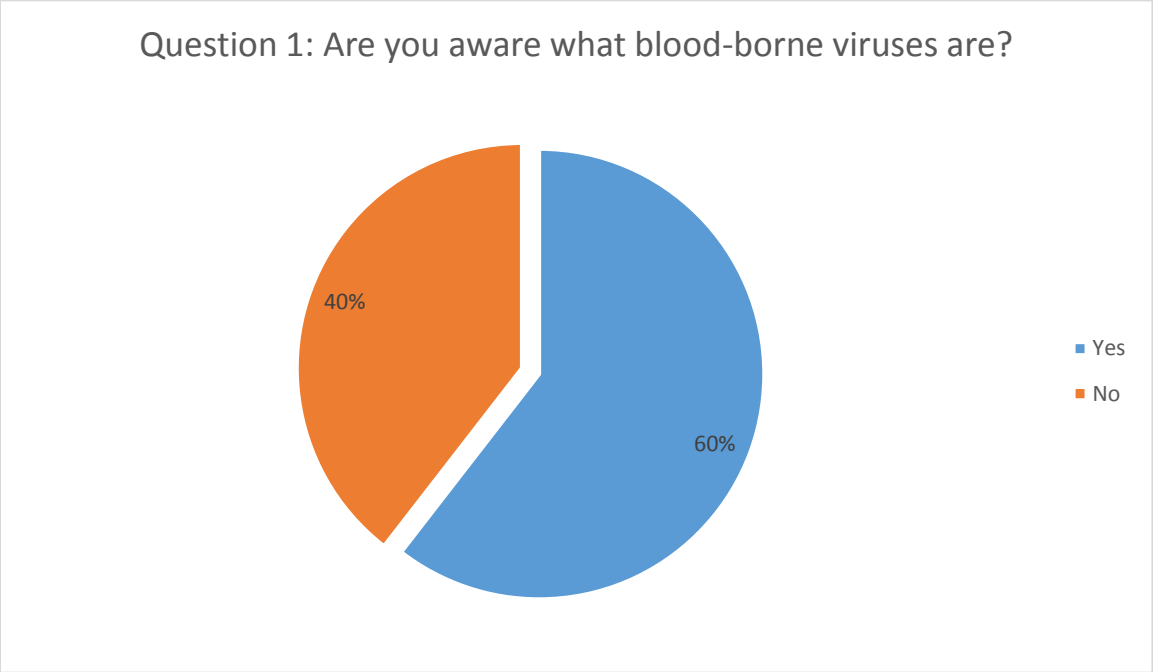

Figure 1

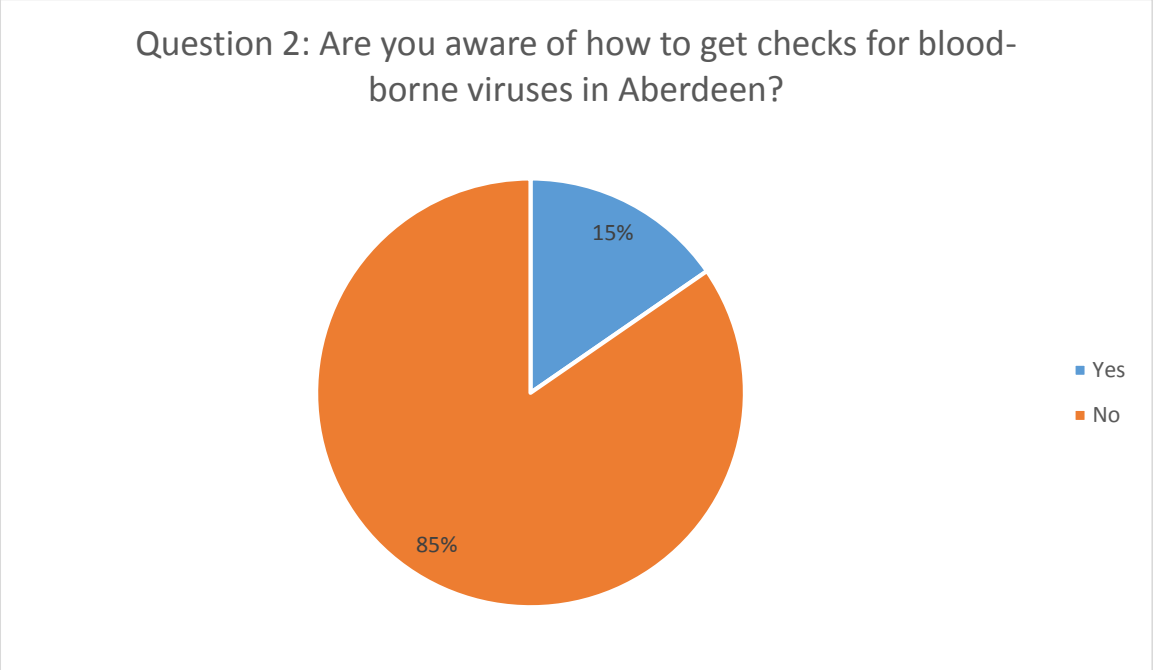

Figure 2