

**Learning from COVID-19: British South
Asian perspectives on developing
culturally appropriate health information
resources**

June 2021



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1. Introduction

COVID-19 has had a disproportionate affect on British South Asian communities, and highlighted the urgent need for culturally appropriate health information. Written and multimedia information was produced at pace during the pandemic, amidst an absence of guidance on how best to develop culturally sensitive public health messaging for COVID-19 (1). Prior to the pandemic, there was a lack of culturally relevant information about long-term conditions that disproportionately affect South Asians. The July 2020 Scientific Advisory Group for Emergencies (SAGE) report on public health messaging for ethnic minority communities recommended qualitative engagement work with minority groups to understand how government messages around COVID-19 were received and their impacts (2).

Learning from, and building on, the significant financial and community initiatives made during the pandemic is vital to improving health outcomes for ethnic minority groups and reducing health inequalities (3). To address this, we conducted five online community engagement workshops with British South Asian communities to learn about people's views and experiences of COVID-19 health messaging, and lessons for developing health information resources for South Asian groups post-Covid. This report, funded by University of Oxford, is a starting point for research into co-producing health information for South Asian communities. It focuses on COVID-19, and a case study on type 2 diabetes.



2. COVID-19 health messaging for British South Asian communities

Throughout the pandemic, there has been an urgent need for evidence-based information about COVID-19 in South Asian languages, and in formats that can be easily accessed by people who do not read a South Asian language. To meet this need, short culturally relevant videos were produced at pace in a range of languages and topics, including hand hygiene, social distancing, lockdown, vaccines, and government guidance on community and religious events. Videos were produced by South Asian health professionals, BBC Asian Network, University of Leicester Centre for Ethnic Health Research, South Asian Health Foundation, AskDoc and many others, and disseminated via their websites and social media platforms (4).

Recommendations for developing a tailored health communication strategy for ethnic minority communities included: co-producing and pre-testing health messages that personalise experiences and target specific community beliefs (motivation); delivering messages by credible sources that community members trust (opportunity); and using language that retains cultural context and meaning to increase understanding (psychological capability) (5). Recommendations also included developing tailored health messages at pace because delays can leave a gap that can be filled by misinformation (6); and using community engagement and partnerships to understand the responses and needs of the target community (7).

Recommendations for health communication about COVID-19 vaccine uptake highlighted the importance of (i) multilingual, non-stigmatising communications with ethnic minority communities; (ii) community engagement so that health messages were sensitive to local communities; and (iii) engagement with trusted sources who could recommend and offer vaccines (8). The January 2021 SAGE report stated that using educational videos in multiple languages can increase awareness, and that health messages need to be co-designed and shared with individuals within family and communities networks to influence health behaviours within families (8). Misinformation can cause anxiety, highlighting the need for clear, honest, sensitive and non-judgmental information (9).

3. Culturally sensitive health information about long-term conditions

Limited previous research on health information for British South Asian communities has emphasised the need for information to be made available mainly via video, rather than leaflets, because of issues around literacy (10, 11). Culturally sensitive educational videos for South Asian communities have been produced on biologic medications in rheumatoid arthritis (Kumar et al 2018)]; coronary artery disease (aimed at Bangladeshi women); and insulin treatment for South Asian patients with type 2 diabetes (interactive DVD) (12). This research showed statistically significant improvement in knowledge after watching the resources, and changes in patient attitudes and understanding (10). Researchers concluded that short films providing health information for South Asians can improve patient experience and consultations between health professionals and patients (12). Lack of culturally appropriate information can result in fear of Western medicines, leading patients to seek advice on traditional medicines (11). The effectiveness of the educational video on coronary artery disease led researchers to conclude that similar videos on other conditions could be produced for South Asian communities, particularly about conditions associated with stigma such as mental and sexual health. British South Asians with type 2 diabetes, who took part in recent research about text messages to support medication use, also highlighted the need for health information in audio and video formats because it can be understood by all community members regardless of literacy levels (13).



4. Community engagement workshops

There is a dearth of research into the best ways of developing health information for British South Asian communities. We conducted five online community engagement workshops between February–March 2021 with Indian Punjabi Sikh, Indian Gujarati Hindu, Pakistani Muslim, and Bangladeshi Muslim communities. We aimed to discuss views on COVID-19 health messaging and on developing educational resources for long-term conditions (e.g. type 2 diabetes). These PPI workshops were exploratory and aimed to provide a starting point for future research into optimising health information for South Asian populations.

Recruitment and participants

- Working with community organisations in Leicester, we recruited a diverse sample of participants from a range of age groups, educational and occupational backgrounds, literacy levels and fluency in English. Participants included those who were familiar with using video communication platforms such as Zoom and people who used it for the first time after training from our community partners.
- Participants were recruited from community networks by Nasima Miah, Ebrahim Ali, Sonal Bhavsar and Gurpreet Grewal-Santini. Verbal informed consent was obtained from all participants. The Bangladeshi workshops were facilitated by Nasima Miah, Ebrahim Ali and Suman Prinjha. The Punjabi Sikh workshop was facilitated by Gurpreet Grewal-Santini, Nasima Miah and Suman Prinjha. The Gujarati workshop was facilitated by Sonal Bhavsar and Suman Prinjha.
- 50 participants took part in five community engagement workshops. Participants included people in paid employment, retirees, students, those living with type 2 diabetes (T2D), and people who had family or relatives with T2D.
- Some participants were born in the UK while others had migrated to England. Most were living in Leicester but the workshops also included people from Nottingham, Coventry, Loughborough, and Rochdale. Workshops were conducted in English, Bengali-Sylheti, Punjabi and Gujarati, and lasted around 1.5 hours.

		Participants
Workshop 1	Bangladeshi Muslim men	09
Workshop 2	Bangladeshi Muslim women	10
Workshop 3	Punjabi Sikh men and women	11
Workshop 4	Pakistani Muslim men and women	10
Workshop 5	Gujarati Hindu men and women	10
Total		50



5. Views on COVID-19 health messaging

The first part of each workshop involved a discussion of participants' views on COVID-19 health messaging, including accessibility, sources of information, impacts and concerns.

The main themes were:

- multiple sources and formats
- trust
- distrust
- information overload
- mental health

Multiple sources and formats

1. Participants accessed information about COVID-19 from a wide range of sources depending on levels of literacy and fluency in English. This included:

- television news in English
- South Asian TV news channels and radio stations
- online national newspapers
- local free newspapers
- government and local council websites
- leaflets in community languages produced by local organisations
- community figures and leaders
- family and community members (including children fluent in English; zoom self-help group for type 2 diabetes)
- social media
- NHS website
- emails from employers / universities

2. Participants accessed information in written, audio and visual formats in English, Punjabi, Urdu, Bengali-Sylheti, and Gujarati. Those who spoke little or no English accessed information via Whatsapp, social media and Asian TV channels. They also had information about COVID-19 translated for them by their children or other family members, including 'mainstream' television news. The illness or death of people they knew was also a source of experiential knowledge.

3. Some participants were aware of the COVID-19 videos produced by health professionals "circulating" on social media, but felt that these were often not disseminated on the most commonly used platforms by British South Asians: Whatsapp and Facebook. Instagram was also used by a few people. Participants recommended that such videos should be shared on all social media platforms to have as wide a reach as possible, and be shared "again and again" for those who had missed them first time around.

4. The availability of information in a range of formats and from various sources enabled all workshop participants to access different types of information – official, unofficial and experiential. Some people felt that information in South Asian languages provided by community leaders or organisations would have been helpful. Others praised the videos that were sent to them from faith centres (e.g. Mosques) in community languages, aimed at those who could not speak English. A few participants would have liked information about COVID-19 in South Asian languages to have been reported after mainstream television news and felt that, in its absence, they and others watched videos in community languages sent to them by friends and family on Whatsapp.

"I got news from the BBC but I also watched the Bangla news as well to reinforce my understanding of the BBC news. I listened to community pillars, figures. I also spoke to family members, my children, they also shared news information with me."

Participant in Bangladeshi Muslim men's workshop

"I think at the start of the pandemic I relied heavily on news sources. Like I said, it was just a matter of picking out the more credible sources....A lot of my information did come from work as well, so working for [name] healthcare trust, you know the daily emails that we were getting at the time. And then of course the city council emails that were coming through too."

- Participant in Bangladeshi Muslim women's workshop

"Some news I got from radio and WhatsApp and some other programmes. Also in our Wednesday diabetes self-help group meeting.... And my son and daughter also, they share lots of information."

- Female participant in Gujrati Hindu workshop

"The TV news is the most important because they talk about COVID a lot. Secondly, from radio I can understand it in my own language, for example Sabras radio and Sanksar radio. They provide news in my language. That's the best one in our community....Overall, we get information from Facebook and WhatsApp and news and radio etc."

- Female participant in Gujrati Hindu workshop

"From my experience I think there are two platforms that are very active at the moment, one is Facebook, another is WhatsApp....I myself have seen Dr. [name] video but after that I couldn't find it anywhere....You have to actually, you know, run it for many times so that people can see because, once you miss that, maybe if you run it many times, then people might see that soon. This is why I said that these sorts of clips are not circulating enough on social media."

- Participant in Bangladeshi Muslim men's workshop

Trust

1. Many people reported trusting the information that they had accessed, including daily news briefings on television, information from health professionals (some of whom were family or friends that worked in the NHS), local councillors, and information disseminated by employers or universities.

"What's been helpful is obviously the news briefings which come from the government. You know, they've been quite good at updating the public with the daily briefings. "

- Participant in Bangladeshi Muslim men's workshop

"Where I get information from is, first of all I go to the sources of the government, Gov.UK. I go to the local authority, like the city council website to get information that I really need. And if, for example, I'm travelling, let's say to Manchester, I'll try to go into maybe the city council of Manchester to get the information from their website also, to find out what the situation is over there, okay. And apart from these sources, I try to also get some information from, directly from friends who are doctors, consultants, who are maybe working in hospitals and they're quite trustworthy.....So when we talk directly to somebody that we really trust, like a consultant who is working in the hospital, you are, I believe you are able to get that information straight away instead of just, you know, going around and around to pages and PDFs and documents and missing information. So those are the main two sources of information I use: government website, local authority website, and consultants."

- Participant in Bangladeshi Muslim men's workshop

"I used the Gov.UK website a lot because the Gov.UK website allowed me to look up specific bits of information as and when I needed it rather than being bombarded with it. For instance regarding, I don't know, wedding attendees, how many you could have. I could put that into the search website in the Gov.UK website and I could get that specific information. And then also through work, so as a councillor we're privy to a lot of the local figures and a lot of the local information. ."

- Participant in Bangladeshi Muslim women's workshop

"I get all my information from [name of mainstream TV channel] because that is all I watch. And I've not gone anywhere else to find any information. I have literally believed everything that I've seen on the [television news]. Going from like having any messages on WhatsApp and the phone, I actually don't read any of them. I just delete them because I prefer not to watch anything that I get sent on my phone. I'll just watch the news. But I believed, I've believed what they've said because they don't know anything more than I know. We're all in it together, that's how I look at it, that whatever information is coming out from them is what they've just found out as well "

- Female participant in Punjabi Sikh workshop

Distrust

1. Some people reported feeling unsure or confused about what to believe at the start of the pandemic, and how their views changed as they learnt more about the severity of the situation and the illness or death of people they knew.
2. Conflicting or contradictory health messages, and misinformation on social media, often led to a distrust of information, as well as to confusion, overwhelm and disengagement. Information from different sources with contradictory messages led some participants to question which sources were genuine.
3. A few people noted that information on the South Asian TV channels that they had watched sometimes seemed to differ to that on mainstream British TV, leading them to question what to believe.
4. Participants were aware of the plethora of fake news and misinformation on social media, including on videos shared with them via Whatsapp. Some stopped engaging with social media stories, deleting videos sent to them without watching them because they found them "scary" or "too negative". Misinformation included denial of the existence of COVID-19 as well as the treatment of it using natural foods or herbs.
5. Some people questioned the trustworthiness of news reported in mainstream media because of the negative portrayal of South Asian communities.
6. Participants also felt confused by information that stressed the seriousness of COVID-19 on the one hand, and the behaviour of other people on the other, who were seen to be flouting guidelines or rushing to book holidays.

The main source of information came from, basically from social media because I don't watch too much TV. And at the beginning I felt like this is just fake, when initially the virus had come from one city. At that time I thought that this is just a normal thing, it's not that big an issue. When the thing came to this country, and I saw many people who died actually here, then I felt that it is something. And that's the main thing that changed my mind. "

- Male participant in Pakistani Muslim workshop

"Even when the information is coming through very reliable sources, you still doubt them, even the government. What the government tells us, it's difficult to believe really that they are really telling us the truth, and they're only giving us selective information. Maybe they have their agenda behind it. But that still keeps you wondering whether this is true, whether it's not true. So this is where I am, kind of a confused person after having all that information, after having a lot of information, after having processed a lot of information, still the real truth seems to be somewhere away which is not in front of us, which we don't know."

- Male participant in Punjabi Sikh workshop

"I think there's a little bit of conspiracy going on. And I still feel that we're not in the full picture. And I feel myself that, yeah it's got better slightly but there's gonna be a twist. So I don't know. I'm not a hundred percent confident but however, I mean I think it's just one of these things that you've got to make sure that you, you know, follow the rules. And obviously it's affecting everyone's mental health as well."

- Female participant in Punjabi Sikh workshop

"Then it was issues like it's the Black community, the Pakistani community maybe, and they were looking to us, at Bangladeshis. And I think that was unfair for social media to blame the Bangladeshi communities because obviously they have more underlying conditions. And I think it was unfair to target, you know obviously it's the government and social media, they just want to tell the people, they just want to blame that part and blame someone. "

- Participant in Bangladeshi Muslim women's workshop

Sometimes the Asian TV programmes, they're giving different types of information. The people there are confused about it, what is right and what is wrong. So I think if any community leaders, if they can translate the information into Bangla, then our community people can understand....Not all the people in my community can understand English, so they're using WhatsApp. So sometimes some people share different kinds of links. It was fake news but the people, they panic. So I think if our community leaders translated important videos from English, it would be good for our community. "

- Participant in Bangladeshi Muslim women's workshop

"They can clearly manipulate stats [statistics] to suit what narrative they want kind of thing because, for example, they were saying that there was high Covid rates in Leicester....Everyone was looking down on Leicester kind of thing. And then if you looked at the actual results, yeah the levels were high because testing was high. But it was also community cases, it wasn't community hospital cases....So from what I started off, believing everything they say, it's got to the point where a lot of us are quite fed up and don't really believe anything that's coming out now."

- Male participant in Punjabi Sikh workshop

Information overload

1. Participants discussed being "inundated" with information, "hooked on the news 24 hours a day", and feelings of fear and uncertainty particularly at the start of the pandemic. The large volume of information on television, social media, and from family and friends led, over time, to a sense of fatigue, overload or overwhelm in some.
2. Some people felt that the information they accessed was "scary", including videos that they perceived as too negative. Some limited what they watched to protect against an overload of information, while a few stopped watching television news completely.

"We've had loads of information left, right and centre through videos, through paper work, you know, and all sorts of things. And I've been involved in translation work as well, so I've done a lot translation around Covid, you know, the kinds of instructions in different languages and all that. So from that point of view, all I can say is that, information-wise, we have been inundated, right, loads of it."

- Male participant in Punjabi Sikh workshop

"I work for the city council so we did get quite a lot information firsthand because, as we work in adult social care, a lot of the sort of like initial information had to be applied instantly. For example, like social workers that were working in care homes and things, things like PPE and things like that, they have to be almost imminently, you know the information had to be given out straight away. But again, because it's been such a long time and it's almost coming up to a year now, it gets to the point where you get so much information and a lot of the time it's quite overwhelming."

- Participant in Bangladeshi Muslim women's workshop

"I've seen so many videos like on YouTube, everywhere. You just turn the television on, or the mobile on, and you just see the videos and what is happening in China. And yes it was scary, I just stopped it because you can't, it's, you can't believe it seriously when you see these videos. It's just rumours and I seriously stopped it. It was in the beginning, it was the first or second week, and then I just decided no, you can't believe all of these things, no. And then it was just the television. And seriously after half a year or one year, I just stopped television as well because it's just too much news."

- Participant in Pakistani Muslim workshop

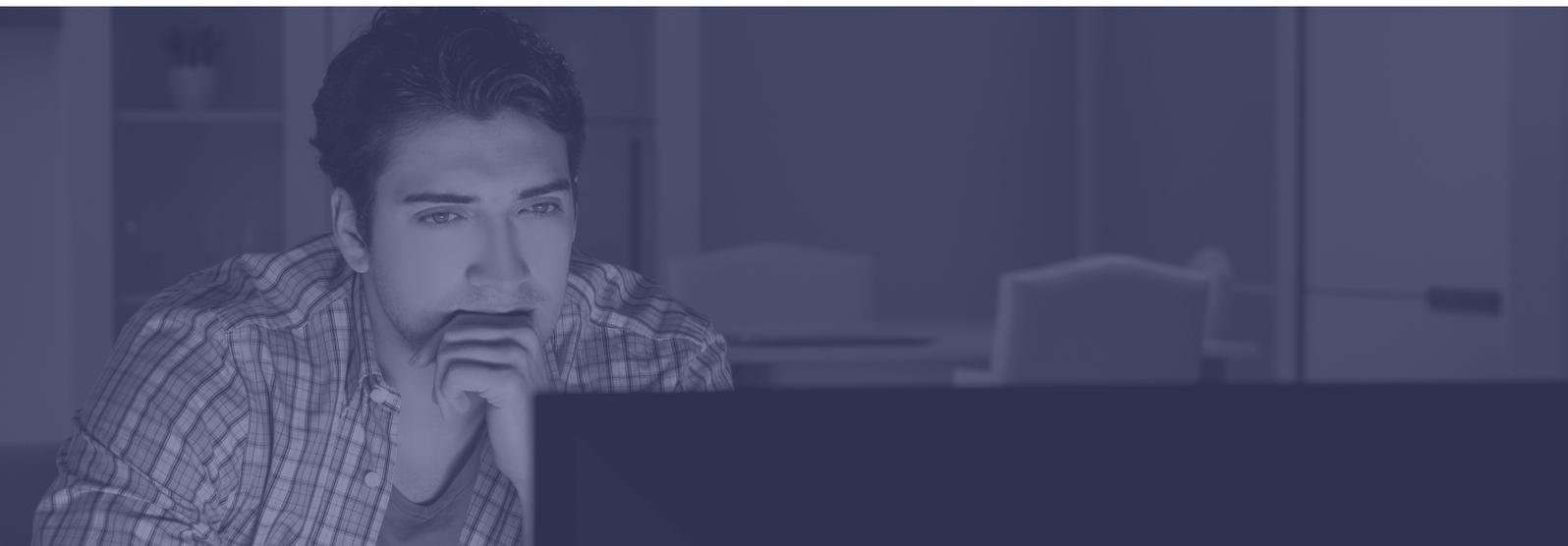
"Initially I started off with a lot of broadcast news but I weaned myself off of that. And I've just decided to choose which, where I get the information from, relying totally on official sort of sources rather than, you know, Whatsapp videos or whatever because I know there's a lot of misinformation and scaremongering through Whatsapp videos and social media. So I've stayed away from social media as much as possible.."

- Participant in Bangladeshi Muslim women's workshop

SP: "Have you seen any videos [about COVID-19] on social media? "

Participant: "No, I haven't really, no. There's so many, I think there's, I don't know if it's me or not but I find there's a lot of information overload. So, you see, you get a lot of videos, a lot of things being circulated, and maybe I've just been busy recently but I don't necessarily watch them all. So it's busy, and literally every other minute you're getting videos on WhatsApp from all these different groups so which ones do you....some of them are a few minutes long and you just don't have the time to look at them all. ."

- Participant in Bangladeshi Muslim men's workshop



Mental health

1. Participants noted the varied impacts of the pandemic, and pandemic-related information, on their mental health. This included the affects of economic hardship, isolation, fear, uncertainty, and the death or illness of family and community members. Some recalled how the information they had accessed had "played on their mind" and made decision-making difficult.

2. Although some people felt that talking therapies could help, no one mentioned accessing psychological support. Many stressed that there was a lack of information about COVID-19 and mental health for South Asian communities, including educational videos about isolation, loneliness, anxiety, depression, and bereavement.

"In our community, there are a lot of heart problems, blood pressure, stress too....Because of Covid there is a lot more stress, and a lot of people have lost their businesses. They've had to stay inside their homes. They've had the death of family or friends. For all these reasons, stress has been greatly heightened. "

- Male participant in Punjabi Sikh workshop

"The community is under a lot of stress in terms of economic and social hardship, and as well as, there's been a lot of illness and deaths in the community....including some of our people who have been participating in [name of community organisation]....So it's a really difficult time emotionally and mentally for people. "

- Participant in Bangladeshi Muslim men's workshop

"I'm a mother of two little children and we've had some cases as well. But it really affected families financially, economically, even health wise. And I think that everything has been restricted. Families have been through too much of a traumatic time.....So there should be certain things that at least we can support each other mentally. It really, really helps. Even talking therapy really makes a difference. "

- Female participant in Punjabi Sikh workshopp

"In my house there is no one positive so far, but we are so scared and fed up. Even my children are. Even my father-in-law has left his job. He also tells me not to go to work because I am diabetic, my immunity is low. If I go out, I will catch it quickly. Even if I cough a little in my house, then straightaway I have been asked to get checked for Covid. You do all of this. Even now we feel like we are living in depression."

-Female participant in Gujarati Hindu workshopp



6. Views on developing health information: a case study

The second part of each workshop involved discussing lessons from COVID-19 messaging and views on developing health information resources for South Asian communities, using type 2 diabetes (T2D) as an example. It included watching a 6-minute video on 'South Asian experiences of type 2 diabetes and emotional health', aimed at encouraging discussion on health education for South Asian communities. Interview clips from the award-winning Healthtalk website (www.healthtalk.org) were collated into a bespoke short film by The Dipex Charity, who has been sharing accessible health information with the general public for over 20 years. The short film included information about T2D from a South Asian health professional and clips from South Asian patients sharing their personal experiences. We asked workshop participants about their views on the educational video, including the content, length, languages, and format. The main topics of discussion included:

- need for culturally appropriate health information
- format and content of educational resources
- languages and subtitles
- patients' experiences
- dissemination

Need for culturally appropriate health information

1. Culturally relevant information for South Asian communities was seen as vital because of language barriers for those who do not speak English; because it could fill gaps in the knowledge of patients with poor access to healthcare; and because it could promote discussion about (sensitive) health issues.

2. The perceived impacts of educational videos included: improving confidence around self-management; providing a sense of control which could lead to better self-management; improving understanding; filling gaps in information provided by health professionals; instilling hope and motivation when hearing about the experiences of others; promoting communication about common conditions (such as type 2 diabetes and depression); helping to break taboos; and providing support to patients and families.

"The [example] video's quite informative. But if we do comparisons between diabetes or Covid, it does make a difference, like Covid is a new topic. It's not into our life....There are certain things [diabetes] that need more guidance...It does make the lifestyle of a person very, very different. So I think the videos, visual and audio things do make an impact on a person."

- Female participant in Punjabi Sikh workshop

"The [example] video's quite informative. But if we do comparisons between diabetes or Covid, it does make a difference, like Covid is a new topic. It's not into our life....There are certain things [diabetes] that need more guidance...It does make the lifestyle of a person very, very different. So I think the videos, visual and audio things do make an impact on a person."

- Female participant in Punjabi Sikh workshop

"It is very important to share these videos as good information can be shared and people can gain experience. "

- Female participant in Gujarati Hindu workshop

"To break taboos is a big thing because in our community we have a lot of misperceptions and kind of keeping things to ourselves, not sharing with other people. I don't know how we can change people's attitudes on that....It's quite important. We need people to be open. We need people to talk about things. We need people to share with other people what they are, what problems they have....There are people who like to talk to their own people in their own language, in their own settings, and that helps a lot. "

- Male participant in Punjabi Sikh workshop

"Giving that information to someone gives them that sense of control, you know they automatically will be informed that they know how to manage themselves better. And also it's about education isn't it, you know, when you've given that information out, a person understands why they've got this particularly illness, what they can do to manage it, it's bringing that sense of control and that will in the long-term help them not only physically but also mentally as well."

- Participant in Bangladeshi Muslim women's workshop

"If we had videos like these, they could really help our communities. And if someone [a patient] talks about, like 'this happened to me and now I've come through it', that would be even more helpful because if that person can recover [from depression], then I could also get better in the same way"

- Male participant in Punjabi Sikh workshop

Format and content of educational resources

1. All participants agreed that video was an ideal format to deliver health information for South Asian communities. Participants expressed a strong preference for video over written information and emphasised the need for audio and visual information that could be understood by all community members regardless of education, age and literacy levels.

2. Videos were seen as a more engaging way of communicating health information, and people noted that such resources need to have clear image and sound, be professionally edited, be produced and disseminated by credible sources, and include content that is specific and relevant to each South Asian community.

3. Participants valued having evidence-based information from healthcare professionals, examples of patients' experiences, and information about where to find support.

4. Participants felt that short 1-2 minute videos about COVID-19 were helpful, but that longer videos were needed for chronic conditions to support people to better manage different aspects of their condition. People felt that a 30-minute educational video (e.g. on type 2 diabetes and emotional health, or other long-term conditions) would be long enough to keep them engaged and include relevant information, but that each topic covered in the resource should also be available as a stand-alone clip for those who want "short and snappy" bite-sized information.

5. A few people suggested that each 30-minute video should include key takeaway messages at the end of each short section.

6. Some people felt that the involvement of respected community figures or celebrities could enhance interest and acceptability, though others wanted experiential information from 'real' patients.

7. Information about where to find support, including helpful websites and organisations, was seen as important, particularly at the end of the film.

8. A few people suggested that music could also be included at the start of educational videos, and at other relevant points, to help make them more engaging.

9. Creative ways of communicating health information suggested by participants included producing plays, comedies, songs and poetry that contained short messages, straplines or catchphrases that would "stay in the mind". Some people suggested that rhyming poetry could also help people who have a poor memory or those living with conditions such as dementia.

"Audio-visual is the better way of communication because people can engage, people can see something practically....There are some people who can't read, who can't write, for them audio-visual is a very good way of communication"

- Male participant in Punjabi Sikh workshop

"I think we all agree that now we're living in a different sort of age where all the information out there, and people with all the abilities, like some people have low level, some people have high level, they're all getting information from online....So these sort of videos definitely, definitely will give them [patients] some confidence, to some extent greater confidence to actually manage their life. "

- Female participant in Punjabi Sikh workshop

"I definitely think video is a good idea because I don't think I could absorb any more information through reading. I don't even read short leaflets either. "

- Participant in Bangladeshi Muslim women's workshop

"I actually think that a video is a good idea because when I think of people who don't have English as their first language, I think of my parents, you know because they're Bangladeshi, Bengali is their first language. And quite often one of the things I've seen my parents respond to is someone like them, somebody similar to them, their age, their background, speaking the same language as them, speaking of their experiences. That resonates way more than a piece of paper with, you know, diabetes information. So I actually do think a video is a good idea. "

- Participant in Bangladeshi Muslim women's workshop

"We need to have more kind of catch phrases which can stick in people's minds when you say something. Or some rhythmical, some rhyme, even say a bit of poetry, a bit of a share, some kind of a thing, to develop around that topic. And songs, make some songs to insert those one or two lines of the song which can stick in people's minds for a longer time period. That can be helpful."

- Participant in Bangladeshi Muslim women's workshop

I think having a longer video [30 minutes], so that those who want to and those for whom it is really important, would be useful. But you can use like little snaps of that longer video, split it up and then, depending on which way you're getting it out, whichever method you're getting it out, you can use some of the short videos and you can use the original longer video....I think if you make one long video and then split it up, and then deliver it in small doses for those who don't want to, you know, be bombarded with the big video all at once. You can do both basically"

- Participant in Bangladeshi Muslim women's workshop

"Maybe it was just me, the clarity in the video wasn't there and the sound at times didn't seem right. That might be just the recording but it has to be really sharp and clear. "

- Female participant in Punjabi Sikh workshop

Languages and subtitles

1. Participants felt that educational videos should be available in all relevant community languages, with subtitles in English for those who do not speak a South Asian language.
2. Subtitles should be large enough to read easily.
3. Regional dialects could present difficulties and subtitles would help in these situations.
4. A few people questioned whether subtitles in community languages, as well as in English, should be available, though the majority felt that English subtitles would be sufficient. Some South Asian people can speak an Asian language but not read or write it.

"I noticed it was only English and Urdu. It should be in multiple languages, for example Gujarati, Bengali, Hindi, Punjabi, English."

- Male participant in Pakistani Muslim workshop

"The concept of having someone like my Mum or my Dad or someone of their generation speaking in their language and telling them of their experience, I think is actually really important. And I would definitely back it."

- Participant in Bangladeshi Muslim women's workshop

"I think [the videos] should be made in English, Bengali, Hindi and Urdu. If they were in different kinds of languages, people from ethnic groups can understand. Because most ethnic minority people don't understand English."

- Participant in Bangladeshi Muslim men's workshop

Participant: "My first language is probably English. So I would prefer, personally, to have some in English. I mean my Bangla's okay, you know reading's not bad but, for the younger population in the community, I think their first language is English, not Bangla."

SP: "And how about videos which are say in Bangla with the English subtitles?"

Participant: "Yeah, I think that would be very helpful."

- Participant in Bangladeshi Muslim men's workshop

"What you could do is have ones tailored. So rather than have one video with five different languages, have a video in Bengali, have a video in Punjabi, have a video in Urdu etc. And then target those communities accordingly. I think the language thing is important. "

- Participant in Bangladeshi Muslim men's workshop

"For the older Bengali community, there's not enough information out there in Bengali. For example, if I thought of my Mum, I don't think she would understand half the things that were, information that was given out in English, whereas if that communication was put out in Bengali, or if it was given out in a different way, then perhaps people could understand a bit better and a bit more....My Mum recently discovered YouTube. I think she would like a video version of that, perhaps more so than reading because she wears glasses so she's unable to, she's unable to read like small writing now. "

- Participant in Bangladeshi Muslim women's workshop

"It's about getting the message across to the communities, so we have to factor the languages as well. So I think, you know, if you target obviously the different aspects of Asian communities, like having the messages in Hindi, Punjabi, Bengali, Urdu and other such languages, then you kind of reach proportionately the wider Asian community. "

- Male participant in Punjabi Sikh workshop

Patients' experiences

1. The inclusion of patients' personal experiences, alongside evidence-based information provided by healthcare professionals, was seen as vital for many reasons. Participants valued hearing the views of other community members as these could encourage people in a similar situation to manage their health better. Educational videos could also help inform family and friends about a condition.

2. Hearing about the experiences of others was also seen as important because sharing personal stories could help break "taboos" around discussing sensitive topics (e.g. depression). People felt that hearing about others in the community who had recovered (e.g. from depression) could instil hope and promote effective self-management.

3. Participants felt that showing a wide range of experiences on educational videos was important, including the perspectives of younger people so that all age groups could relate to the information. This was especially the case for conditions such as type 2 diabetes, though participants noted that this may not be relevant for all chronic conditions.

4. Participants felt that educational videos should include tips from patients about what had helped them most. Many mentioned that people can learn much from the stories and experiences of other patients.

5. The inclusion of patients who did not want a video recording was also viewed as important, and using actors, animation, infographics and other imagery relevant to the topic when patients wanted to share their experiences but remain anonymous. Images unrelated to the topic (e.g. plants, as used in our example video) were not considered engaging. Younger participants were generally more in favour of having animation and statistical information on the films.

"It's really a good idea [educational videos]. People do watch these kinds of videos on social media or even the advertisements that are made about diabetes etc. It would help people because some people have not got it, who could possibly get it, they could know what diabetes is about. And also people who have got it, they could show some positivity in there which they can take positives from. "

- Male participant in Pakistani Muslim workshop

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- Male participant in Pakistani Muslim workshop

"[Patients' experiences] should be included....We don't get advisements and stuff like that, so people go through word of mouth. If you wanted to buy a certain thing, we'd definitely ask somebody else and did you use this thing. And people do listen to other people. So I think it is quite informative and there should be certain things for Asian communities because we don't really ask for help."

- Female participant in Punjabi Sikh workshop

"I think the video was quite good, it was informative. And I think by having the real life stories of people, then it's just relatable. People can think okay, it's not like some celebrity mentioning it. It's actually like an everyday sort of person mentioning their stories. And you kind of get the message across really well. "

- Female participant in Punjabi Sikh workshop

"Some people don't want to be seen in the video so it's their, just voice recordings, and there was just like plants or flowers in the background. But I think people will lose a bit of interest. You need to see faces or you need to see people, even if they're covered up. You kind of need to have that to be engaged. But I understand the cultural sensitivities."

- Participant in Bangladeshi Muslim men's workshop

"I think it's really important to see somebody of my parent's generation speaking in their language and speaking from experience. I think there's been a bit of a saturation of health professionals saying, "Oh this is what you should do, this is how you should live your life." But when it's somebody like them saying to them, this is what happened to me and this is how I felt, that's different. And I think that's what we need more of....It's about getting someone like them speaking of their experience that I think for me and when I think of my parents, that would really hit home. "

- Participant in Bangladeshi Muslim women's workshop

"The lady who was telling about, that in our community people don't share their things [health issues], which was a really great one because sometimes people talk about it but they don't actually say it on a video or anything, and I think that was good. But I would have liked to have had people actually saying it rather than pictures of just flowers and things because it just makes it feel that it's a real person.....And the other lady who was, the older lady, she said her daughter helped her come out of it [depression] after five years, and she's a super role model that she's actually worked hard and listened to her daughter and went with the advice and she's done well. So role models who have actually progressed and who had struggled initially. That was really good as well. But having a picture of the person saying 'I've done it' rather than having any, um I don't know, film stars or anybody, I think real people make a lot of difference. "

- Female participant in Punjabi Sikh workshop

Dissemination

1. Dissemination of educational videos for South Asian communities was seen as crucial, and participants stressed the importance of using a diverse range of avenues to reach as wide an audience as possible:

- Whatsapp – links to educational videos can be shared with community centres
- social media (Facebook, Instagram, Twitter)
- relevant patient and professional websites
- YouTube, for people who are unlikely to use patient or professional websites
- community organisations
- faith centres
- local councillors and local leaders
- schools – through messages from head teachers to South Asian parents
- information sessions for parents after school drop-off
- receivers in Muslim households used for Mosque transmissions, to share information about the educational videos and how to access them
- adverts on South Asian TV channels
- local and national radio stations (with talks in different languages)
- GP surgery waiting rooms – videos could be shown in surgery waiting rooms while patients are waiting to be seen.
- health professionals – referring patients to resources aimed at South Asian communities. Some people suggested that text messages about the resources, sent from GP surgeries to South Asian patients, would also be helpful.
- leaflets or posters advertising the educational resources in GP surgeries and community pharmacies

"Most Muslim households, they have a receiver which transmits, you know the Masjid transmits and the households receive the sermon, the daily calls, five time prayer calls from their homes. And they hear the sermons and, you know, all the important death announcements. So that's a really good way to share information. "

- Participant in Bangladeshi Muslim men's workshop

"I think having information that's accessible to the people that we want to get it to is really, really important. And if that means working with, you know, like specific Asian media channels, or whatever, or specific community organisations. ."

- Participant in Bangladeshi Muslim women's workshop

"I was talking about my Mum. I would say she does watch like Bengali channels and things, she watches the news. So just have something, a quick short cut clip, something in between adverts or in between programmes, would get the message out there."

- Participant in Bangladeshi Muslim women's workshop

"Would the doctor's surgery for instance have people's telephone numbers and they can send it directly to individuals rather than something which is circulated through social media...If it's targeted to individuals and the phone numbers of the patients, then they're more likely, if it's come from the doctor, then they're more likely to open and listen to it and read it. "

- Participant in Bangladeshi Muslim men's workshop

"Local councillors, like community local councillors, they're very reliable people. People respect them. Local leaders....it could be our local doctor....So these people are very, very influential people within the community. Like I can give you another example, [name of Imam], people respect him so much. So if something comes from [name of Imam], people will listen to them, what the Imam is saying....Those who have high regard in society, if they actually say something, that will have much more impact than any other thing. "

- Participant in Bangladeshi Muslim men's workshop

"The schools are a good source. I have, as I say our kids are at primary school and I often get messages from them. So, you know, the head teacher at the school, if they send a message to parents, that might be a good source as well. "

- Participant in Bangladeshi Muslim men's workshop

"The older generation they don't like to watch YouTube videos or listen or read leaflets or anything like that. So for example on a Friday Mosque, you know when they have the sermon, if a ten minute talk was delivered by like a, you know, health professional alongside the Imam, men at the Mosque I think they would listen to that instead of listening to a YouTube video or having leaflets. And with regards to women, I think when they drop their kids off to school, if the school was to do something like that, for ten or fifteen minutes, where they have tea, coffee, biscuits, you know I think they're more likely to interact and get involved and listen to that information. "

- Participant in Bangladeshi Muslim women's workshop

"I work in a GP surgery and when patients come in and they're waiting in the waiting area to be seen either by the nurse or the doctor, we have these TV screens up where they show things about diabetes, all other illnesses as well. And whilst people are waiting, they all, I've seen many patients that are just watching the screen because that's the time when they can actually just sit and watch, because they're waiting to be seen anyway. And they get a lot of information from there as well. "

- Female participant in Pakistani Muslim workshop



7. Recommendations for co-producing health information resources

1. Health information in a range of formats can be helpful in urgent situations such as the COVID-19 pandemic. For long-term conditions, educational videos were preferred by participants over written information because they can be understood by all community members. Video information was seen as the most engaging and useful format for people who do not speak English. This echoes previous research with diverse communities in Australia that showed that video had advantages over other forms of health education resources, and learning through video was seen by participants as more fun. It also enabled learning to be done more quickly and easily and was, overall, a better experience of learning (14).

2. Educational videos (e.g. about different long-term conditions) aimed at South Asian communities need to be co-designed and co-produced with patients, health professionals and researchers. Conducting workshops with South Asian communities before developing resources is a useful way of exploring views about optimising relevance and acceptability.

3. Health information resources need to include evidence-based information and patients' experiences. Evidence-based medical information communicated by healthcare professionals needs to be simple, clear and consistent. Qualitative interviews focusing on patients' experiences need to include a wide range of perspectives reflecting the diversity within and across communities (e.g. age, language, religion, migration history, country of birth, education, literacy) (15).

4. Evaluating co-produced educational resources with patients and other stakeholders can help ensure that the content included is accurate, sensitive, appropriate, and unlikely to cause fear or anxiety.

5. Resources about physical health also need to include information about the emotional and mental health impacts of the condition.

6. Educational resources (or links to them) need to be disseminated through as wide a range of credible sources as is practical to reach as many people as possible.

7. Adequate time and funding is needed to co-produce high quality educational video resources that are based on rigorous research and conducted in a range of languages.



8. Conclusion

There is an urgent need for culturally appropriate health information for South Asian communities to help reduce inequalities in health outcomes seen prior to the pandemic and exacerbated during it. There is a lack of research into optimal ways of developing culturally relevant health information resources. Building on lessons learnt from COVID-19 health messaging is crucial. Dedicated funding is needed to co-produce educational videos on conditions that disproportionately affect British South Asians. Patients, health professionals and researchers working together can help ensure relevance. Working with local communities and partners can help ensure that resources reach as many people as possible, particularly those who need them most.



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