# **COVID and Me Vaccine Dramas**

A resource to support community conversations about COVID-19 and vaccines research

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# Introduction

### **COVID-19 and research**

**COVID-19** or **Co**rona **Vi**rus **D**isease 20**19** is the illness caused by a new virus that can affect the lungs and airways. Following several mysterious pneumonia cases in the Chinese city of Wuhan in December 2019, this new virus was reported in January 2020. Despite attempts to contain the virus, it spread across the world and reached the UK in late January 2020. On the 11th March 2020, the World Health Organisation declared a pandemic of a novel disease it named COVID-19.

Little was known about COVID-19 in the beginning. In response, researchers worldwide, including the UK, mobilised to find answers to how we prevent the spread of COVID-19, treat and vaccinate against it. <u>Taking part in COVID-19 research</u> is vital to enable effective treatments to be identified, evidenced and made available to NHS patients as quickly as possible. Over three-quarters of a million people have taken part in COVID-19 research supported by the National Institute for Health Research (NIHR) <sup>1</sup> - at NHS hospitals and care settings across the United Kingdom.

### The COVID and Me project

COVID and Me are a series of short dramas (monologues) - produced to support all communities in understanding the importance of taking part in COVID-19 research.

There are two series of COVID and Me dramas:

- <u>Covid and Me</u> 7 dramas illustrating how people from different communities have been affected by the pandemic and underlining the importance of COVID-19 research. (Two of the dramas are also available in Punjabi)
- 2. <u>Covid and Me Vaccine Dramas</u> 6 dramas exploring people's journeys from vaccine hesitancy to community vaccine champions. The dramas touch on their concerns about vaccine research, health literacy and misinformation, and the different challenges individuals face when deciding whether to participate in research. (Three of the dramas are also available in Urdu, Punjabi and Bengla (also referred to as Bengali)

COVID and Me were informed by a series of workshops that explored the barriers and enablers to involvement in research studies from the perspective of professionals, public and patients. While fictional, the dramas have been co-created and are based on

<sup>&</sup>lt;sup>1</sup> <u>National Institute for Health Research (NIHR)</u>, established by the Department of Health and Social Care, is the nation's largest funder of health and care research.

people's lived experiences, using storytelling as a fresh way to reinforce key messages and disprove false information in circulation.

The production of these dramas was a partnership with communities who in particular, are often hesitant about vaccines and disproportionately impacted by the pandemic - including Black, Asian and minority ethnic groups, older people, and those with existing health conditions and those from communities where there is higher social deprivation.<sup>2</sup> The project was led by Professor Sue Pavitt, University of Leeds and <u>Theatre of Debate</u>, working with the wider community and funded by NIHR.

### Vaccines

Vaccines save thousands of lives every year in the UK. They are the most effective way to prevent infectious diseases. Vaccines have the potential to help us beat COVID-19 and, from December 2020, the first COVID-19 vaccines that have been tested and approved are being rolled out across the UK.

Clinical trials into other COVID-19 vaccines must continue. **Volunteers are still needed to join new and existing COVID-19 studies.** We need people from every part of the UK population to consider taking part in vaccine research. Different vaccines work in different ways. We still need to collect important information about which vaccines work best and are best for different groups of people, and exactly how effective they are. We also need information on matters such as the best way to use vaccines, where to use a single vaccine or use multiple vaccines in combination, the number and timing between doses, and to check long term that there are no safety concerns.

The <u>NHS vaccine research registry</u> was set up to make it easier to take part. Researchers can contact people directly about participating in vaccine research. **Hundreds of thousands of people have already signed up,** but it is important to encourage more people to do the same.

<sup>&</sup>lt;sup>2</sup> Joint Committee on Vaccination and Immunisation. "Independent report: Advice on priority groups for COVID-19 vaccination." *Department of Health and Social Care*, Gov.UK, 6 January 2021, <u>https://www.gov.uk/government/publications/priority-groups-for-coronavirus-covid-19-vaccination-advice-from-the-jcvi-30-december-2020/joint-committee-on-vaccination-and-immunisation-advice-on-priority-groups-for-covid-19-vaccination-30-december-2020. Accessed 26 January 2021.</u>

### **Development of this resource**

This resource has been developed to support people to deliver dialogue-based sessions around the <u>Covid and Me Vaccine Dramas</u>, to help you facilitate conversations about COVID-19; to explore some of the common barriers, enablers and misinformation about vaccine research and encourage people towards reliable sources of information to help decide whether taking part in research is right for them. This resource can work with and alongside the existing plans and the tools you are using to engage priority audiences in your local settings. We have developed it to be non-prescriptive in order to work for a wide range of different audiences and settings, and divided up so you can pick and choose which parts of this resource are of most use to you and adapt them for your purposes.

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# Making use of the COVID and Me Vaccine Dramas

#### Promoting the dramas across local communities

When co-creating the <u>COVID and Me Vaccines Dramas</u>, we listened to people's concerns and beliefs. These dramas embrace people's hesitation around vaccine research, health literacy in general, and the different challenges individuals face when deciding whether to participate in research. We recognise that people may be scared, concerned or doubtful about taking part in research. These can be challenging conversations to have, in order to support people to have informed conversations and to make informed decisions.

To this end, the dramas follow people's journeys from vaccine hesitancy to community vaccine champions. We have developed this resource to further support people in exploring these personal journeys to help inform and break down local barriers. The dramas can be accessed by the public and patients independently through the NIHR's <u>Be Part of Research website</u>. We encourage people to watch them and share them with friends, family, colleagues and communities so we can make a difference together. They have also been designed for use as a community engagement tool within the context of dialogue-based activities.

A review of vaccine hesitancy interventions found that dialogue-based interventions are the most effective form of intervention<sup>3</sup>. Considering the overlap in barriers between vaccine take up and research engagement (which both include personal and social barriers), we suggest that dialogue-based interventions could be similarly effective in supporting community engagement with vaccine research.

The same review proposed that all interventions work best when part of a multicomponent engagement strategy. Therefore, the COVID and Me Vaccine Dramas are intended to be used alongside other strategies to promote awareness of and engagement with COVID-19 research studies amongst target communities, such as promoting campaigns in local communities and social media campaigns.

<sup>&</sup>lt;sup>3</sup> Jarrett, Caitlin, et al. "Strategies for addressing vaccine hesitancy – A systematic review." Vaccine, vol. 33, no. 34, 2015, pp. 4180-4190. *ScienceDirect*,

https://www.sciencedirect.com/science/article/pii/S0264410X15005046?via%3Dihub. Accessed 19 January 2021.

### How to use the dramas

The COVID and Me Vaccine Dramas should be incorporated within your existing community engagement plan for COVID-19 research and used alongside other tools to engage those communities you have identified as a priority in your area.

In this resource, we set out plans for delivering dialogue-based sessions using the vaccine dramas. These sessions could be delivered:

- On an in-reach basis: joining an established group to deliver a one-off session
- On an open basis: where individuals and groups can sign up to join an open session with others

Research indicates that engagement programmes are most effective when as targeted as possible to the intended group<sup>4</sup>. Therefore even 'open' sessions should be targeted, such as an event for over 65s or the Bangladeshi community - if these were target groups within your area. The dramas and activities you show should be as relevant as possible to the group you are meeting, selecting the characters and themes most likely to resonate with them.

The dialogue sessions using the COVID and Me Vaccine Dramas can also incorporate other interventions that are known to be effective around engagement, these include:

- Access to experts
- The chance to ask questions about specific concerns
- Use of case studies
- Community Leaders

These could be incorporated into either an in-reach or an open session. For example, by having a researcher or GP (expert) introduce the session and be available to answer questions at the end; or by having a trusted member of a community such as faith leader or local organiser (Community Leader) attend an in-reach session with you. You could also ask a member of the public to join and speak about their experience of participating in a vaccine study- as a live case study. Combining these interventions is likely to make your engagement activities far more effective.

Your dialogue sessions should be approached as part of a journey to engagement. The focus should be on the next step you are going to encourage people to take. Ideally one of these steps should be further active engagement, such as an invitation to another session, such as an Expert Panel. For this reason, you may want to plan your sessions using the COVID and Me Vaccine Dramas to be clustered before another event so you can keep building people's knowledge and engagement - for example, you may

<sup>&</sup>lt;sup>4</sup> Bourne, Lynda. "Targeted communication: the key to effective stakeholder engagement." *Procedia* - *Social and Behavioral Sciences*, vol. 226, no. 1, 2016, pp. 431-438. *ScienceDirect*, <u>https://www.sciencedirect.com/science/article/pii/S1877042816308941</u>. Accessed 27 January 2021.

undertake a series of in-reach sessions with community leaders and public representatives in the lead up to a public Q and A with a vaccine researcher or doctor.

Signing up to the <u>NHS Vaccine Research Registry</u> is another key step that people should be made aware of as an option at the end of the dialogue session. Signing up to the registry does not require that individuals commit to taking part in any specific vaccine study- it is important to emphasise this. However, once they sign up they will be kept up to date with news about vaccine studies and if they could be a potential candidate for a study will receive information about that at the time: it will be their choice whether or not to take part, and they will be under no pressure.

### Where to use the dramas

It is likely that most dialogue sessions will need to be facilitated on a remote platform due to the national COVID-19 restrictions. This will present barriers to access for some target communities due to digital exclusion. This is another reason why dialogue sessions should form one element of a comprehensive engagement strategy which uses a range of targeted approaches to reach varied communities.

Examples of organisations that could be approached about undertaking an in-reach COVID and Me Vaccine Dramas session include:

- Adult learning clubs or centres
- Community centres and hubs that are running online services and groups
- Community voluntary services
- Faith or cultural groups that meet remotely
- Local Healthwatch
- Patient groups within health Trusts
- Schools and colleges
- Some libraries are hosting remote activity sessions

### Using this resource

In this resource, we have identified four key themes to explore as part of your local engagement activities around COVID-19 and vaccine hesitancy:

- Taking Part in Vaccines Research
- Speed of Development of COVID-19 Vaccines
- Older People and Comorbidities (one or more additional conditions)
- Misinformation.

For each theme, we have outlined a possible dialogue-based workshop and have:

• Highlighted some of the underlying barriers that might prevent people from engaging with COVID-19 vaccines research to help you think about your approach

- Identified relevant COVID and Me Vaccine Dramas to watch, to stimulate self-reflection and discussion about how people might tackle similar barriers in their own lives
- Suggested an accompanying activity to facilitate experience sharing and collaboration to help people address barriers for themselves and others
- Provided take-home messages about COVID-19 vaccines research to share with participants.

These workshops can be delivered within 1-2 hours. We recommend an experienced facilitator leads them to help deliver on the learning outcomes and ensure everyone has a positive and enriching experience (see the <u>Support</u> section with where to seek advice on finding a good facilitator). The workshops have been designed in order to work for both learners in school and college settings, but also with mature and older adult learners in mind<sup>5</sup>, namely that this group of learners:

- Are self-directed and motivated to learn
- Draw on their own life experience when learning
- Are Goal orientated
- Need to know how the information is relevant and of immediate use
- Are practical, and need problem-centred learning.

At the end of this resource, we have also provided a list of links to accurate and reliable sources of information about COVID-19 research to support you in leading local discussion. These can also be shared with participants to help tackle misinformation and facilitate further self-directed learning.

### Managing misinformation during a public dialogue

The following guidance from the World Health Organisation (WHO) has been developed for spokespersons from health authorities to talk about vaccines. However there are some valuable takeaways for anyone who may find themselves in a situation where a participant is a vocal vaccine denier; someone who is distrusting of vaccines and may want to spread misinformation<sup>6</sup>:

- There is almost no chance of you being able to change the mindset of a vaccine denier
- A vaccine denier will likely ignore and reject evidence that doesn't confirm their beliefs; keep switching topics to avoid losing the discussion; shut down or attack opposing opinions

<sup>&</sup>lt;sup>5</sup> "The Adult Learning Theory - Andragogy - of Malcolm Knowles ...." 9 May. 2013,

<sup>&</sup>lt;u>https://elearningindustry.com/the-adult-learning-theory-andragogy-of-malcolm-knowles</u>. Accessed 17 January 2021.

<sup>&</sup>lt;sup>6</sup> "How to respond to vocal vaccine deniers in public - WHO ...." <u>https://www.who.int/immunization/sage/meetings/2016/october/8 Best-practice-guidance-respond-v</u> <u>ocal-vaccine-deniers-public.pdf</u>. Accessed 27 January 2021.

- Don't work alone. Seek out a well-informed expert who is an engaging speaker to support you in your local discussions
- During a public conversation it is important to keep your efforts and focus on the wider audience and not on the vaccine denier
- There is a vast body of evidence in support of vaccine efficacy and safety, as are the majority of scientists and clinicians
- Having a few clear, simple key messages you can keep coming back to (backed up by credible scientific evidence) is the most effective way to influence people's attitudes
- Don't repeat back misinformation or challenge a vaccine denier directly but do listen to what they are saying so you can include corrective information in your discussions
- Stay calm. Be truthful, treating the topic seriously and keeping focused on the positives and benefits of vaccines and vaccines research

### **Feeding back**

We are keen to understand how people are using the COVID and Me Vaccine Dramas and to get feedback on this resource. Perhaps you have developed your own related tools and resources you would be willing for us to share with others? You can get in touch with us at <u>crncc.ppie@leeds.ac.uk</u>.

### Getting the most from the COVID and Me project

You don't need to limit yourself to the themes and activities we have suggested. The more you make your COVID and Me conversations relevant and engaging for local communities, the more everyone will get out of them. You could also try:

- **Mixing them up** try adapting some of the suggested activities in this resource to work with different themes.
- **Coming up with alternative activities** you may have tried and tested methods for engaging with local groups already. Why not choose a theme from this resource and try those.
- Identifying other themes we have identified four important themes, but there are others. Why not, review the COVID and Me Vaccine Dramas and see if there are different themes, perhaps more relevant to explore with your local groups and communities.
- Starting with COVID and Me this resource focuses on the vaccines series. The first <u>COVID and Me</u> series is still very relevant, particularly for groups and communities who are still new to the idea of research.
- Following a developing story some of our characters feature in the first COVID and Me series. Why not pick someone and follow the developing story across the two series (e.g. Asif, Varsha, Ife).

### Support

Before beginning any COVID and Me conversations, consider what additional support you might need:

- Experienced facilitator
- Local researcher or clinician
- Trusted Community Leader (e.g. a religious leader)
- Member of your community group who has taken part in and/or is an advocate for research.

People will often look to trusted figures for reassurance like a trained professional such as a doctor, a local leader or their peers. Questions may arise during conversations which require an answer from an expert or someone with relevant experience. The <u>Find out more</u> section of this resource includes links to information and frequently asked questions which provide up to date information about COVID-19 and vaccines research and address common misinformation.

The NIHR Clinical Research Network (CRN) coordinates and supports high-quality research in the NHS and wider health and social care environments. This includes delivering research into COVID-19, including vaccine research, and the continuation of research into other health conditions during the pandemic. This is made possible through our 15 local CRNs (LCRNs), all of which have extensive researcher networks. Each LCRN supports a regional network of <u>public Research Champions</u> - volunteers who help spread the word about health and care research to patients and the public, especially to those less likely to participate. Our experienced LCRN Patient and Public Involvement Leads will be able to advise you on finding support with facilitation, or co-facilitate with you themselves.

Your <u>local CRN</u> may be able to offer further help and support. You can also contact us at <u>crncc.ppie@leeds.ac.uk</u>; we may also be able to provide support through our national network.

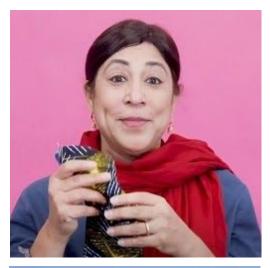
For questions about this pack contact the CRN Coordinating Centre at <u>crncc.ppie@leeds.ac.uk</u>.

For questions about the COVID and Me project or taking part in research, please contact <u>bepartofresearch@nihr.ac.uk</u>.

# The COVID and Me Vaccine Dramas

# **COVID and Me Vaccines** - short dramas sharing reflections about vaccine research

**Remember:** each drama is standalone and viewers do not have to have seen the previous set of drama to engage fully with those in this set.







### Varsha - Why Not Me

Varsha featured in our first series, <u>COVID and Me</u>. Varsha is coming to terms with her only son deciding to sign up to participate in a vaccine trial. Will she stop him or support him?

Urdu and Bengali versions are now available.

Written by Sudha Bhuchar Performed in English by <u>Shaheen Khan</u>

### Asif - Tie Your Camel Up

Asif lost his father from COVID-19 in the first series of COVID and Me. This monologue focuses on the influence that family members have on people's views of taking part in vaccine trials.

Urdu, Bangla and Punjabi versions are now available.

Written by Sudha Bhuchar Performed in English and Punjabi by <u>Peter Singh</u>

### Mandy - Hugs

Mandy has diabetes. She is <u>Ollie's</u> neighbour; he's encouraging her to face her fears about catching COVID-19. Mandy wants to be able to hug her children without fear of catching COVID. She needs to be brave and consider taking part in a vaccine trial.

Written by Judith Johnson Performed by <u>Bella Hamblin</u>



### Sheila - 27 Across

Sheila was diagnosed with cancer a few years ago but now in remission. Her keep-fit class instructor has asked the class to consider taking part in a vaccine trial which is being run from the gym hall they usually go to for their keep-fit class. Sheila has to decide if she has enough information to 'let go and leap'.

Written by Jonathan Hall Performed by <u>Amanda Orton</u>

### <u>Ife - Vacca</u>



If e is trying to find love during lockdown and social distancing. Having nearly lost her father to COVID in the last <u>COVID and Me series</u>, If e is trying to convince her date not to believe all of the conspiracy theories.

Written by Farah Najib Performed by <u>Adaya Henry</u>



### Jide - I Can Hear You Now

Jide is a male nurse married to Fola in his mid-fifties who is a devout church-goer. This monologue focuses on the lasting friendship between Jide and Pa Olu who is a respected elder in the Nigerian community and the reluctance of the church community to listen to him as a healthcare professional.

Written By Oladipo Agboluaje Performed By Tunde Euba

# **Themes and workshop ideas**

### 1. Taking Part in Vaccines Research

#### Why talk about taking part in vaccines research?

From December 2020, the first COVID-19 vaccines to have been tested and approved are being rolled out across the UK. Clinical trials into other COVID-19 vaccines must continue. Volunteers are still needed to join new and existing COVID-19 studies. Different vaccines work in different ways. We still need to collect important information about which vaccines work best and are best for different groups of people, and exactly how effective they are. We also need information on matters such as the best way to use vaccines, the number of doses, and to check long term that there are no safety concerns.

#### **Barriers:**

There are many reasons people might be hesitant to take part in vaccines research; these include:

- A lack of awareness that vaccines research needs to continue even with approved vaccines becoming available
- Misinformation about COVID-19 and what taking part in vaccines research means
- Concerns over safety when taking part, including from family and friends
- Perceived conflicts between health matters (including research and vaccination) and people's cultural and religious practices.

#### Workshop activity

#### Dramas to watch:

The following Covid and Me vaccine dramas deal with some of these barriers:

- <u>Varsha</u>
- <u>Asif</u>

Both dramas deal with the questions or concerns that a family member or a friend might have about a loved one taking part in COVID-19 vaccines research. Varsha talks from the perspective of a parent whose only child wants to enrol into a vaccine study, and Asif speaks as someone who wants to enrol in research and talks about how his family reacted.

#### Coffee Chat:

As an icebreaker, you could begin by asking a question at the start of discussions (and then again at the end) to gauge whether people's thoughts and opinions about taking

part in vaccine research have been influenced. For example: **Would you be willing to** take part in vaccines research?

Use the following open questions to help explore this topic either in a one-to-one or small group conversation?

- Have you had conversations with your friends and family about taking part in vaccines research? What was discussed?
- What points raised in the dramas most resonated with you and why?
- Did you learn anything about taking part in vaccines research from the dramas that you didn't know before?
- Have the dramas changed the way you think or feel about taking part in a vaccines study?
- Is there more information you might need/want about taking part in a vaccines study?

**Remember:** some people may be happy to talk about their personal experiences whereas others might be more comfortable reflecting on the themes as they relate to the dramas.

#### Take homes:

As part of your discussions, you might want to try to include the following key messages about vaccines research:

- COVID vaccines must work for everyone in our community
- We need more than one vaccine and to include people from all ages and backgrounds in research so we know vaccines will be effective for everyone
- Vaccines protect people from contracting illness this is why we need volunteers who are not currently ill with COVID
- While every drug or treatment has some risks, all research in the UK, including vaccines research, is carried out to strict safety and ethical standards, assessed and approved by independent experts before beginning
- <u>Registering your interest to take part in vaccines research</u> is quick and easy to do.

**Remember:** it's important to help people learn where to go for accurate and reliable information about vaccine research for themselves and share with others to make an informed decision about taking part. While some people are open to learning more about vaccines research, you won't be able to change everyone's opinion.

### 2. Speed of Development of COVID-19 Vaccines

#### Why talk about the speed of development of COVID-19 vaccines?

Experts worldwide believe that vaccines are our best option to control the infection and spread of COVID-19. It usually takes between 10-15 years to produce a safe and successful vaccine from start to finish. However, researchers have been able to develop, test and deploy a number of COVID-19 vaccines within the space of a year. This has understandably raised questions, among the public as to how this has been possible and whether new vaccines are safe. It has also helped to fuel <u>misinformation</u>.

#### **Barriers**:

There are many reasons people might be concerned at the apparent speed of COVID-19 vaccine development; these may include:

- Uncertainty over how it is possible to produce a vaccine in a fraction of the time it normally takes
- Concern that researchers have cut corners and compromised on safety in order to have COVID-19 vaccines ready this quickly.
- COVID-19 are being rushed out without having been properly tested

#### Workshop activity

#### Drama to watch:

The following COVID and Me vaccine dramas deal with some of these barriers:

- <u>Mandy</u>
- <u>lfe</u>

Both dramas deal with the questions or concerns about the speed of COVID-19 vaccines research. Mandy talks from the perspective of someone who is concerned, and Ife talks about how she corrected someone's misinformation on this topic.

**Remember:** the dramas raise some of the issues, but also address them as well. You might wish to show these after the Recipe for success activity below.

#### **Recipe for success:**

Begin discussions by asking people what they have heard about the development of the vaccines: What are your concerns (e.g. they have been developed too quickly, not been tested properly, corners have been cut etc.)?

Provide participants with a recipe to bake and decorate a cake, preferably one with a number of steps and ingredients and one that would take several hours to make. Set them the following task: **Tomorrow is a friend's birthday and you want to make them their favourite cake. You don't have as much time as you need. In what ways could** 

you speed up making the cake without compromising the quality? You want the cake to still look and taste as it should.

Suggestions may include:

- Buying a packet mix
- Using an electric mixer rather than mixing by hand etc.
- Using shop bought icing to decorate it
- Using a microwave cup cake recipe

**Remember:** the recipe is an analogy for research. You are looking for a recipe that lends itself to suggestions that are about labour-saving and that would make baking more efficient.

Following a discussion of this exercise, you can explain further that a similar principle can be applied to research. We are able to speed up research without compromising safety because:

- We have experienced experts (the baker) who already know how to make vaccines (the recipe)
- We are undertaking several stages of the research process at the same time rather than one after the other (shop bought cake mix with pre-weighed ingredients) and streamlining steps (ready made icing on the cake)
- We are implementing the latest technologies and advancements (the electric mixer)

After the recipe activity, along with the COVID and Me vaccine dramas, it would be useful to show participants the following films about vaccines research:

- Be Part of COVID-19 Vaccines Research
- How are COVID-19 vaccines being developed so quickly?

Finish the activity by reflecting on the recipe task and the films:

- What have people taken away from this session?
- Have people's concerns about vaccines development changed?
- Would people now be more willing to consider taking part in a vaccines study?

#### Take homes:

As part of your discussions, you might want to try to include the following key messages about the speed of vaccines research<sup>7</sup>:

• Researchers haven't started from scratch -they are adapting existing vaccines for new disease

<sup>&</sup>lt;sup>7</sup> Provided by the NIHR Clinical Research Network North West London, 2020-21.

- Technology means what used to take ten years can take a fraction of the time now
- Streamlined processes- more staff for research and administration, more funding available
- Lots of volunteers the <u>NHS Vaccines Research Registry</u> has helped speed up recruitment for trials
- Regulation The Medicines and Healthcare products Regulatory Agency (MHRA) has been involved in reviewing the vaccines throughout the process not just at the end<sup>8</sup>
- Safety is never compromised in UK research.

<sup>&</sup>lt;sup>8</sup> <u>The Medicines and Healthcare products Regulatory Agency (MHRA)</u>, established by the Department of Health and Social Care, is the executive agency that reviews and approves medicines and medical devices for their effectiveness and safety for use in the UK.

### 3. Older People and Comorbidities

#### Why talk about older people and comorbidities?

Older people and people with comorbidities (i.e. having one or more other underlying health conditions) are high-risk groups for having poorer outcomes if they get COVID-19. Many older people may also have one or more underlying health condition. We need to ensure new vaccines will work and are useful and safe for a range of older people, and people with complex health needs. We also need vaccines that can be delivered easily in community settings to reach people who might be shielding or who might find travelling to receive a vaccine challenging.

#### **Barriers**:

There are many reasons older people and people with comorbidities might be hesitant to take part in vaccines research; these include:

- Concerns over safety when taking part and whether the vaccine may make them ill
- Unsure if they could take part in COVID-19 vaccines research because they have an underlying condition already
- Concerns over whether the vaccine will affect their underlying conditions or interfere with their medicines.

#### Workshop activity

#### Dramas to watch:

The following Covid and Me vaccine dramas deals with some of these barriers:

- <u>Sheila</u>
- <u>Mandy</u>

Sheila discusses the concerns that she and her friends had about taking part in vaccines research - they are all older and have other health concerns. Mandy has diabetes and is a smoker and is concerned about taking part in vaccination research.

#### COVID-19 checklist:

Here are some questions to help you kick-off thinking and discussions:

- Reflecting on Sheila's story, are there any points she raised that resonated with you?
- Thinking about your health, what might prevent you from volunteering to take part in research?
- If you would like to take part in research, is there anything about your health that you think might make you ineligible to take part in research?

**Remember:** some people may be unfamiliar with what is involved in taking part in research. The film <u>Taking Part in a COVID-19 Vaccine Trial</u> may be helpful in explaining what to expect.

Being approached to take part in research can sometimes feel daunting. It may be easier for some people to say no right away if they don't feel they have the time to think through all of their questions and concerns properly. Having a checklist of things to talk through with the researcher may help people feel they are having a more informed conversation. In groups or individually ask people to write a checklist: **What I need to say to a researcher**.

A checklist might include:

- What underlying conditions I have
- What medications I am currently taking
- Any significant signs or symptoms I experience

Encourage people to also think about related accessibility needs they might have, for example:

- I don't have my own transport
- I experience stiffness and poor mobility in the mornings
- I find it difficult to travel in the dark

Finally, what questions would they like to ask of the researcher, for example:

- How often will I need to come back to the hospital?
- What time would my appointment be?
- What are the common side effects I might experience?

**Remember:** people often only have their own experiences to draw on. Why not encourage people to share their checklists, as they may have thought of something someone else hasn't.

#### Take homes:

As part of your discussions, you might want to try to include the following key messages about vaccines research:

- Researchers will be looking for lots of different people to participate in their studies to make sure it works for everyone
- <u>Registering your interest to take part in vaccines research</u> is quick and easy to do
- Some studies may be looking specifically for people of different ages with an existing condition or a suppressed immune system
- You should be told how many people have already been tested with the vaccine before you decide to take part in a study
- You will be told about common side effects and what to do about them. These are usually mild and clear up in a few days.

• While every drug or treatment has some risks, all research in the UK, including vaccines research, is carried out to strict safety and ethical standards, assessed and approved by independent experts before beginning.

### 4. Misinformation

#### Why talk about misinformation?

As the world responds to the COVID-19 pandemic, we face the challenge of an overabundance of information related to the virus. Some of this information may be false and potentially harmful. Inaccurate information spreads widely and at speed, making it more difficult for the public to identify verified facts and advice from trusted sources - from the World Health Organisation (WHO)<sup>9</sup>.

#### **Barriers:**

There are many reasons why people might be inclined to believe misinformation; these include:

- People having low levels of trust in information coming from the 'establishment'
- The story agreeing with how they are already thinking and feeling, making them more likely to think it is true and share it
- When the misinformation is coming from someone, including friends or family, that they might consider to provide reliable information in other aspects of their life
- They may not be aware of more reliable and accurate sources of information of these may not be accessible to them

#### Workshop activity

#### Dramas to watch:

The following COVID and Me vaccine dramas deal with some of these barriers:

- <u>Jide</u>
- <u>Asif</u>
- <u>lfe</u>

Each of these dramas discusses misinformation that has been circulating about COVID-19 and vaccine research through their family, friend and community networks. Jide in particular focuses on misinformation about the impact of COVID on African communities.

#### **Digging deeper**

In this workshop participants should consider:

- How misinformation could spread through their local networks (e.g. WhatsApp groups and other social media platforms)
- How to recognise misinformation

<sup>&</sup>lt;sup>9</sup> "How to report misinformation online - World Health Organization."

https://www.who.int/campaigns/connecting-the-world-to-combat-coronavirus/how-to-report-misinfor mation-online. Accessed 17 January 2021.

• Where to seek out reliable and accurate sources of information such as the NIHR and Be Part of Research.

You could start this workshop by watching the dramas. Focus on the different ways in which misinformation has spread in these communities (e.g. person-to-person, WhatsApp etc). Ask people to think about their own family, friends and community networks:

- What are the different ways you share information?
- Do you think there is a risk of misinformation spreading over these channels?

**Remember:** don't spend time going through what the misinformation and fake stories are, this may only help reinforce them.

Next begin a discussion with participants around two of the common drivers of misinformation identified by the WHO - fear mongering and fake experts.

**Fear mongering:** use of emotionally charged language, often negative language, which inflames people and encourages them to share misinformation which helps it go viral.

• Create a word bank - a list of words and phrases that you think are emotionally charged (i.e. words that stir up your emotions); words that you feel people should be cautious about when reading stories related to COVID-19 (e.g. guinea-pig, conspiracy, secret, lie etc.)

**Remember:** language can be used in many different ways. The point here is not to discount all articles that contain these words but to be cautious of articles that use a lot of these emotionally charged words, particularly when the overall tone of the article is particularly negative.

**Fake experts:** misinformation can appear more reliable when you can cite a source, but often that source doesn't exist, isn't credible, or was misquoted

• What makes a reliable expert for COVID-19 - think about what makes someone an expert. What are the defining characteristics you are looking for (e.g. qualifications, a balanced point of view, first-hand experience in the topic they are discussing, other experts refer to them, they publish on the topic in reputable peer-review publications etc.)?

**Remember:** experts come from many different walks of life. The main point here is to explore people's credibility. Can you find out anything about them that suggests they are indeed an expert? For example, if they have no background in medicine, viruses or vaccines they are probably not a reliable expert on COVID-19. If someone is reported as an expert saying something quite emotionally charged, check if they have said similar things elsewhere and see if similar experts generally agree with them or not.

The WHO have developed an <u>online game called Go Viral!</u> to show how quickly these drivers of misinformation can cause false facts to spread on social media and how easy it is to increase the amount of misinformation and false claims you see by liking and sharing misinformation. It may be helpful before the workshop to ask people to give the game a go or perhaps even complete it together during the workshop, it only takes around 5-minutes.

You could end this workshop by taking people through Be Part of Research and some of the other resources in the **Find out more** section. The WHO also provides information on <u>reporting misinformation</u> and provides <u>mythbusting facts</u> for some common false claims around COVID-19.

#### Take homes:

As part of your discussions, you might want to try to include the following key messages about misinformation:

- People have the right to access accurate and reliable information from trustworthy sources
- Misinformation is dangerous and can lead people to make poor choices that could negatively impact their health and the health of others
- Misinformation often plays on people's fear and anxiety and is often written to be convincing and/or emotionally charged to encourage people to share it further
- Investigates the claims made, always check whether experts and cited sources seem credible
- People have their own bias. If someone is a trusted source of information in one area it doesn't necessarily mean they are in another
- Experts and mainstream sources are where you are most likely to find accurate and reliable information about COVID-19 and research.

# **Find out more**

### **Be Part of Research**

<u>Be Part of Research</u> is an online service that provides an opportunity to help members of the public understand what research is, what it might mean to take part and show what research is currently happening across the UK.

Be Part of Research is an up to date, accurate and reliable source of information about COVID-19 research for the public. Be Part of Research is run by the <u>National Institute</u> <u>for Health Research (NIHR)</u>. The information provided on Be Part of Research comes directly from the NIHR and its partners:

- National Health Service (NHS)
- UK Government and the devolved administrations of Northern Ireland, Scotland and Wales
- UK Research and Innovation (UKRI)
- Researchers and research organisations conducting research in the UK

Be Part of Research contains frequently asked questions, films and links to further information. You might find this a helpful first point of call when planning your engagement activity to inform discussions; to prepare to respond to questions from community members; to share with others so they know where to get further information:

- Information for patients and the public about COVID-19 research
- How to get involved in COVID-19 research
- <u>COVID-19 research frequently asked questions</u>
- <u>Taking part in vaccine studies</u>
- Sign up to the NHS Vaccine Research Registry
- Latest vaccine news
- <u>COVID-19 vaccine studies frequently asked questions</u>
- List of COVID-19 studies being supported by the NIHR
- Information for Black, Asian and minority ethnic communities

#### Other vaccine resources

- COVID-19: search for a vaccine podcast UK Vaccines Taskforce
- Let's Talk About Vaccination European Patients Forum
- <u>COVID-19 vaccines: development, evaluation, approval and monitoring -</u> <u>European Medicines Agency</u>

### **Other COVID-19 resources**

- <u>NIHR's COVID-19 response NIHR</u>
- Coronavirus: the science explained UKRI
- <u>Tackling the impact of COVID-19 UKRI</u>
- <u>Coronavirus disease (COVID-19) pandemic WHO</u>
- Coronavirus disease (COVID-19): vaccine research and development WHO
- Coronavirus information Service on WhatsApp Gov.UK
- NHS Test and Trace and the NHS COVID-19 App Gov.UK
- <u>Get the latest NHS information and advice about coronavirus (COVID-19) -</u>
  <u>NHS</u>

### Introduction to health research

- What is health and care research? Be Part of Research
- What is Health Research? free online course from NIHR
- Improving Health Through Clinical Research free online course from NIHR

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