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DISABILITY SUPPORT WORKERS AND THE COVID-19 VACCINE

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About this report

Between March and April 2021, researchers from the University of Melbourne and UNSW Canberra conducted an online survey of over 350 disability support workers (DSWs) about their opinions and needs surrounding the COVID-19 vaccine.

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EXECUTIVE SUMMARY

Background

Disability support workers (DSWs) are at greater risk of being infected with COVID-19 because they work with people with disability who may also be supported by numerous other support workers. DSWs are also at risk of transmitting the virus to the people with disability they support, many of whom have underlying conditions that place them at risk of serious complications from COVID-19 if they become infected.

It was for these reasons that people with disability living in disability residential settings (group homes) and the disability support workers (DSWs) working in the homes were prioritised in Phase 1a of the vaccine rollout. DSWs not working in group homes are in Phase 1b.

The survey

368 DSWs across Australia participated in a survey about their experiences during the COVID-19 pandemic. They were asked about perceptions of their risk of infection, where they obtained information about the COVID-19 vaccine and what sources of pandemic information they trusted, their intentions for vaccine uptake (vaccine hesitancy) and, for those who were hesitant, the reasons why.

Key findings

Offered vaccination

- Overall 21% of DSWs had been offered vaccination
- 29% of DSWs in group homes had been vaccinated compared with 14% of DSWs who did not work in group homes

Information

- The main sources of information were government websites (72%), employers (62%) and official news media (62%)
- DSWs' own doctors and Chief Medical Officers were the **most** trusted sources of information about the COVID-19 vaccine

Vaccination intentions

- 50% would get the vaccine as soon as possible
- 9% would wait until available for a while
- 11% would only get vaccine if required
- 13% hadn't decided either way
- 17% will not get vaccine

Vaccine hesitancy

The main reasons for delaying the vaccine or refusing it were:

- Inadequate safety data
- Concern about the side effects
- Lack of trust in government to ensure vaccines are safe and effective

Very few were against vaccines in general so the concerns related to COVID-19 vaccine only

Views on vaccine

Many DSWs did not display confidence in the vaccine which is a cause for concern.

- 58% agreed the vaccine is the best way to stop the COVID-19 pandemic
- 63% agreed that the vaccine will only stop COVID-19 if most of the community is vaccinated
- 54% agreed that their chances of getting COVID-19 will decrease after they had the vaccine
- 54% agreed that their clients were less likely to get COVID-19 if they had the vaccine

Interpretation of findings

The high levels of vaccine hesitancy, concerns about safety, and the lack of trust in the government to ensure safety needs significant work to be done to build trust in the vaccine among DSWs. In our previous surveys DSWs described feeling forgotten in the pandemic so their low levels of trust in government is understandable in this context. DSWs seemed

to lack confidence in the vaccine protecting them, the community and the people with disability they support. Less than 1% of the overall sample were against all vaccines. Thus, vaccine hesitancy appears to be related to COVID-19 vaccines in particular.

Ways forward

Given that very few DSWs are opposed to all vaccines, it is possible that higher levels of vaccination could be achieved.

We recommend that a strategy to improve uptake of vaccination among DSWs is developed urgently. However rather than a strategy that just covers DSWs, **we recommend that a COVID-19 disability vaccination strategy that is co-designed with the whole sector including people with disability, DSWs and service providers.** First trust needs to be built by listening and responding to the concerns of these groups. Only then can confidence about the efficacy and safety of the vaccine be improved. It is important that communication is transparent. Key influencers in the community must be engaged as they can facilitate effective communication. Government and others should consider engaging independent medical professionals to assist rather than rely on messages from government.

DISABILITY SUPPORT WORKERS: COVID-19 VACCINE HESITANCY AND COMMUNICATION NEEDS

Disability support workers (DSWs) are at greater risk of being infected with COVID-19 due to the nature of their work, which often involves close physical contact, sometimes with numerous people who are themselves at high risk. DSWs are also at risk of transmitting the virus to the people they support, many of whom have underlying conditions that place them at risk of serious complications from COVID-19 if they become infected. [Findings](#) from our first two surveys of DSWs conducted last year showed that they were supporting an average of 5 to 6 clients per week⁽¹⁾.

In Victoria's second wave, we saw COVID-19 outbreaks in over 50 group homes in Victoria. In recognition of their increased risk they were prioritised for access to personal protective equipment, and in Victoria, there were initiatives to reduce worker mobility, introduction of paid pandemic leave, and a COVID-19 Disability Rapid Response Group (DRRG) was established.

Given their increased risk of becoming infected and transmitting COVID-19, [DSWs have been prioritised for the vaccine rollout](#)⁽²⁾. DSWs working in group homes are in Phase 1a, the highest priority group for vaccination; other DSWs are in 1b⁽²⁾. On 8 April the [Prime Minister recommended](#) that AstraZeneca was reserved for people over 50 with Australians under 50 prioritised for Pfizer⁽³⁾. This occurred because there was consensus internationally that the AstraZeneca vaccine was a likely cause of a condition associated with a [serious clotting disorder](#) associated with low platelets, which are more common among younger people and women⁽⁴⁾. Concerns about AstraZeneca had been reported across the world for some weeks before the Prime Minister's announcement.

The inclusion of DSWs as a high priority group is an important first step; however, unless high-levels of vaccination occurs among workers, people with disability and workers are at risk of contracting COVID-19. We currently lack knowledge about the intentions of DSWs' regarding COVID-19 vaccination, who they trust to provide information, their knowledge around efficacy, and any concerns that they may have. However, we know from other vaccines, and

emerging evidence on COVID-19 vaccination, that a significant proportion of the population are either concerned about the vaccine, plan to delay vaccination or will refuse vaccination for [COVID-19](#)⁽⁵⁾. [Vaccine hesitancy](#) may be delayed acceptance or refusal of administration of a vaccine. Acceptance or refusal of vaccine specific (e.g., only related to COVID-19)⁽⁶⁾.

The survey

The Centre of Research Excellence in Disability and Health ([CRE-DH](#)) conducted a survey of DSWs between 5 March 2021 and 8 April 2021 to gather information about vaccination in this workforce.

Therefore, the survey started 2 weeks after the rollout of Phase 1a (commencement 22 February 2021), where DSWs working in disability residential settings (group homes) were included and 3 weeks before the rollout of Phase 1b (commencement 22 March 2021). We recruited DSWs through social media, disability services and unions. Respondents from our previous [DSW surveys](#) were also asked to participate. The survey was conducted online.

Questions were asked about DSWs experiences during the COVID-19 pandemic and perceptions of their risk of infection, where they obtained information about the COVID-19 vaccine, what sources of information they trusted the most, their intentions to be vaccinated or not and, for those who were vaccine hesitant, the reasons why.

“I trust independent medical professionals that are not connected to government, media, or pharmaceutical companies.”

Survey participant

RESULTS AND RECOMMENDATIONS

Who participated?

368 DSWs from around Australia participated in the survey. Only 15 participants (4% of the overall sample) responded after the Prime Minister's announcement of prioritising the Pfizer vaccine for those younger than 50 years of age.

75% of participants were female; 51% of participants were 50 years or younger. 47% worked in a group home in February 2021.

COVID-19 risks and experiences

- Only 2% reported being in contact with a COVID-positive client.
- 52% said they were very worried or somewhat worried that someone they know would fall sick with COVID-19.
- 75% DSWs reported feeling their State or Territory had put in 'About the right amount' of restrictions in an effort to slow the spread of COVID-19.
- 20% DSWs felt that the seriousness of COVID-19 was seriously exaggerated in the news and on social media; 67% felt the communications around seriousness were generally correct.

Information on the COVID-19 vaccine

As shown in Figure 1, DSWs reported getting information about the COVID-19 vaccine predominately from government websites (72%), their employer (62%) and official news media (62%). Participants were asked how much they agreed or disagreed with statements about whether they trusted information from government (Federal, State and Territory), Chief Medical Officers, their own doctor, pharmaceutical companies, family and friends and social media and employers, with results shown in Figure 2. The highest level of trust was for their own doctor and Chief Medical Officers. In the text responses to the question, many described their distrust of government emphasising the importance of advice from medical professionals not working for government.

"The rollout is politically and economically motivated."

Survey participant

Figure 1. Where DSWs get COVID-19 vaccine information

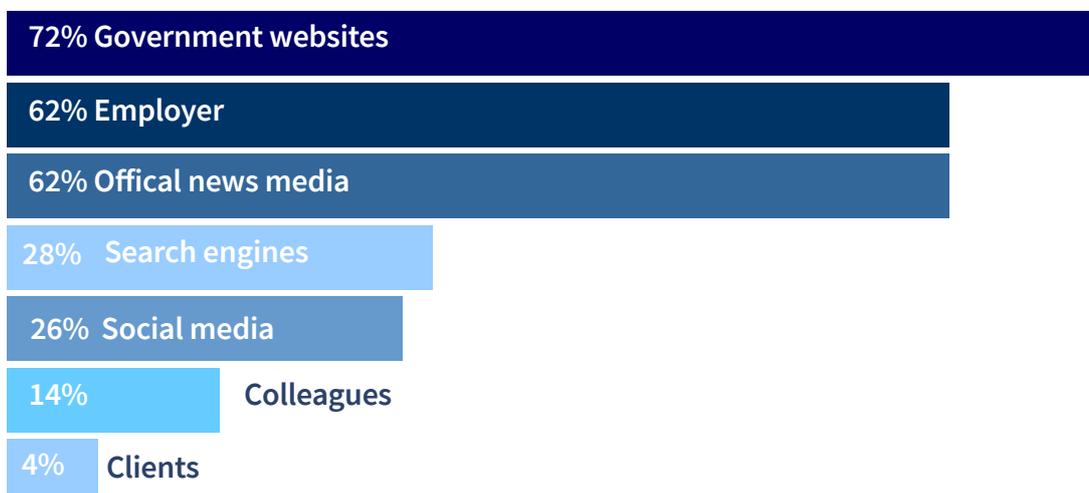
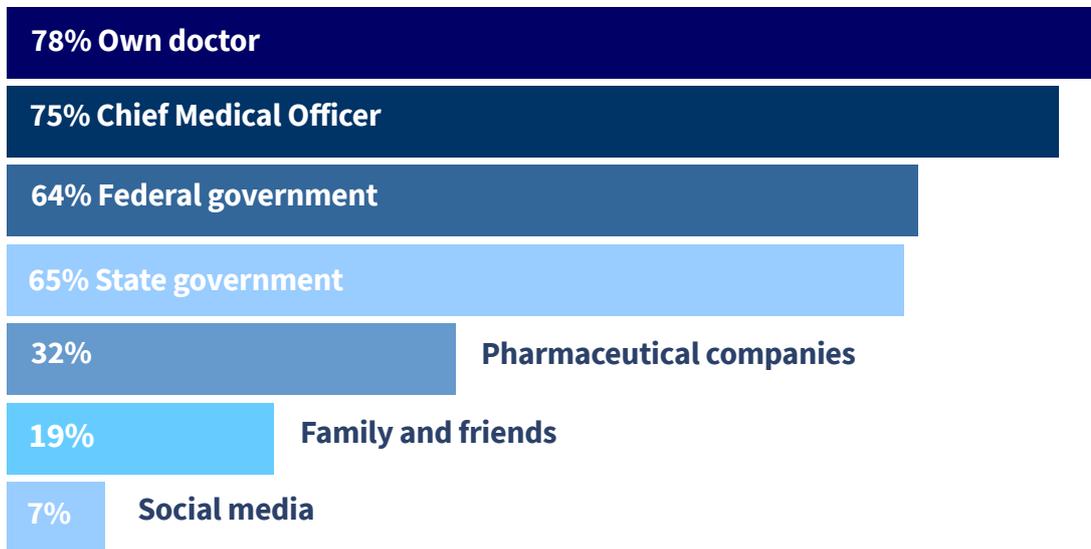


Figure 2. Trusted sources of information on the COVID-19 vaccine



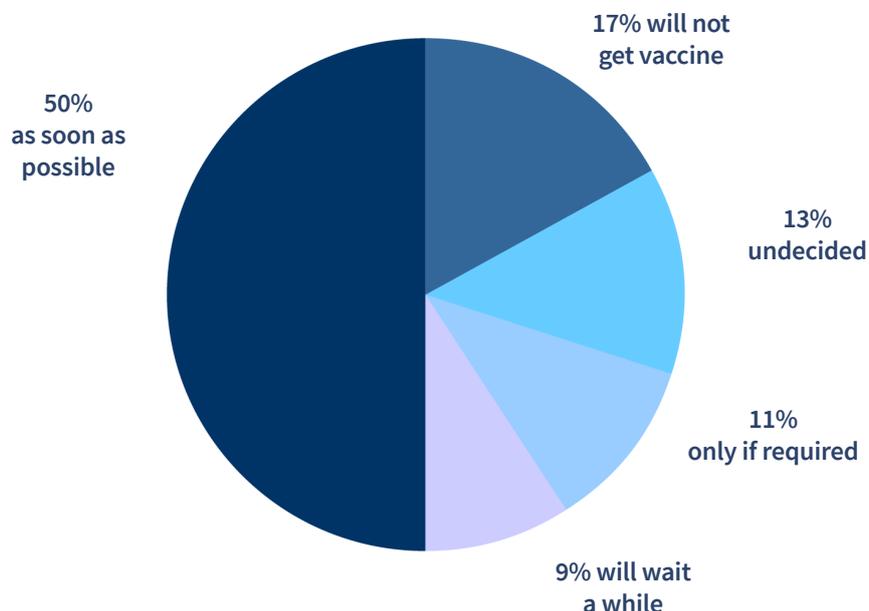
Participants were also asked to select the top two sources of information they trusted the most. The most frequent responses were medical professionals (62%) and the government (50%). The least common were the media (4%) and family and friends (1%).

COVID-19 vaccine administration

Less than 2% of respondents had been vaccinated, all with AstraZeneca. Only 21% had been offered vaccination. 29% of DSWs who work in group homes had been offered vaccinations compared with 14% of those who did not work in group homes. The following findings were similar for DSWs working in group homes and those not working in group homes, so all statistics have been reported for the entire sample.

As shown in Figure 3, half of all respondents said they would get the vaccine as soon as possible and 17% said they will not get the COVID-19 vaccine at all.

Figure 3. Percentage of participants that will get the COVID-19 vaccine when it becomes available



VACCINE HESITANCY

We then asked the 50% of respondents who would not get the vaccine as soon as possible the reasons why. We divided this group into ‘refusers’ and ‘delayed vaccinators’ (those who will wait and hadn’t decided and only if required). The results from these questions are shown in Figure 4.

Refusers

81% of refusers indicated that the inadequate data about safety contributed to their decision not to have the vaccine and 60% worry about the side effects of the vaccine. 54% didn’t trust the government to make sure the vaccine was safe and effective. Notably only 6% (3 participants) were against vaccines in general, indicating that vaccine refusal was specific to COVID-19 vaccines.

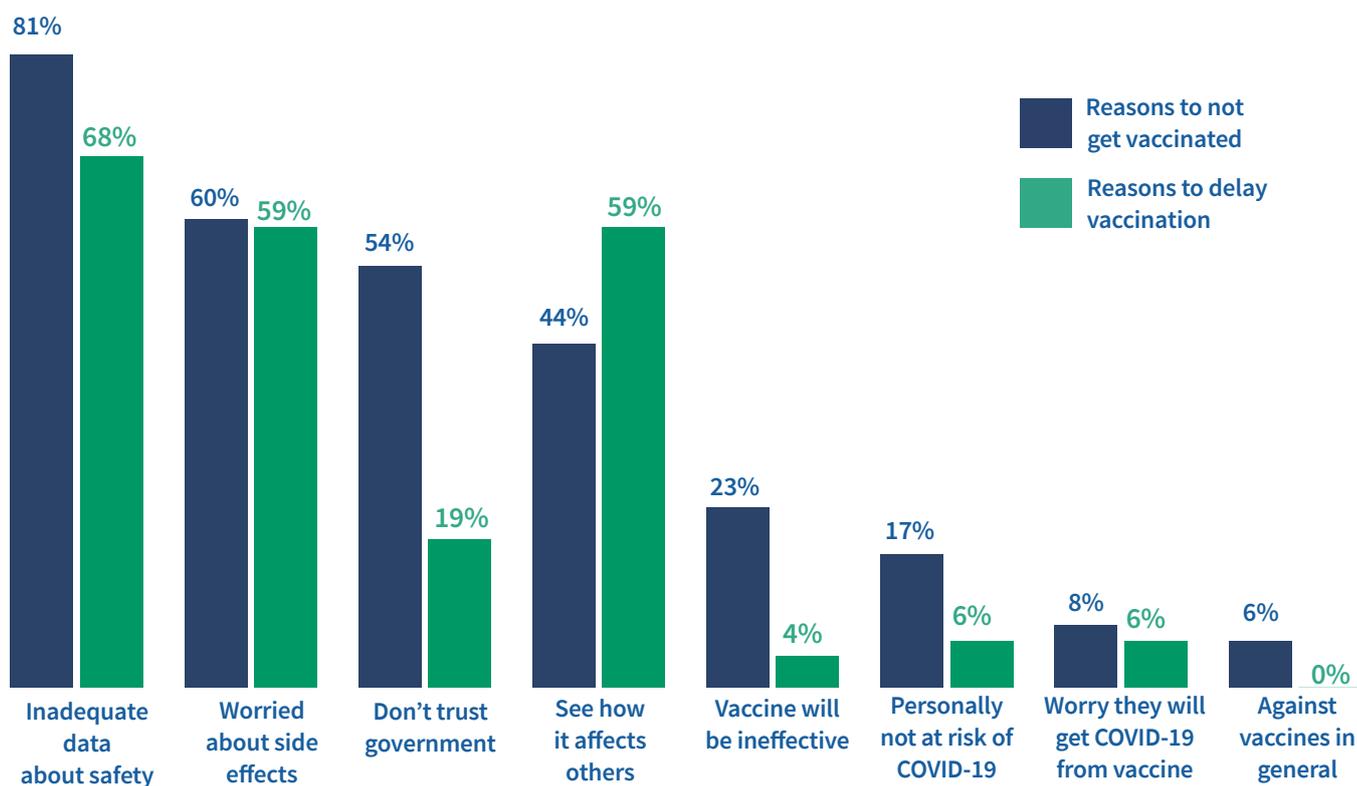
“I will not get the vaccine, because COVID is only a serious risk to people of expiring age anyway.”

Survey participant

Delayed vaccinators

Like vaccine refusers, delayed vaccinators said concerns about safety (68%), side effects (59%) and their lack of trust in government (19%) were the main reasons they would not get the vaccine straight away.

Figure 4. Reasons for participants deciding they will not get the vaccine or delaying the vaccine



VIEWS ON THE COVID-19 VACCINE

We asked participants about whether they agreed or disagreed (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree) with a range of statements about the vaccine. We report the percentage of respondents who strongly agreed or agreed with these statements in Table 1 below.

About half the respondents thought that once the vaccine was available and approved that it was safe. Only 58% saw the vaccine as the best way to stop the COVID-19 pandemic. 54% agreed with statements that they were less likely to get COVID-19 if they were vaccinated. The same proportion reported that they were less likely to give COVID-19 to their clients if vaccinated.

Finally, we asked whether participants would support the vaccine being made compulsory for workers in the disability sector. 43% DSWs supported this; 35%

did not and 22% participants were undecided. 20% of workers said they would not continue to work as a DSW if it the vaccine was made mandatory and 16% said they were undecided as to whether they would continue.

“I trust independent medical professionals not connected to government, media or pharmaceutical companies.”

Survey participant

Table 1. Percentage of DSWs who agreed or strongly agreed with the following:

The vaccine will only stop COVID-19 if most of the community is vaccinated	63%
I am concerned about the safety of the COVID-19 vaccine	61%
I am concerned about how well the COVID-19 vaccine will work	60%
The vaccine is the best way to stop the COVID-19 pandemic	58%
The best way to avoid complications of COVID-19 is by being vaccinated	56%
I will be less worried about catching COVID-19 if I have the vaccine	56%
My chances of getting COVID-19 will decrease after I have the vaccine	54%
The vaccine will only stop COVID-19 if most of the community is vaccinated	63%
The clients are less likely to get COVID-19 if I have had the vaccine	54%

DISCUSSION

This survey shows the very low levels of vaccination of DSWs even though they were prioritised for vaccine rollout. Most had not yet been offered the vaccine. This demonstrates what has been reported in the media about the lack of prioritisation of this group despite them being in the highest priority groups for vaccination⁽⁷⁾.

Only half of the sample had full acceptance of COVID-19 vaccination, with a large proportion planning to delay vaccination or unsure about whether to get vaccinated and 17% being outright refusers. The 50% who were vaccine hesitant (would not get the vaccine straight away) reported that concerns about safety, side effects and their lack of trust in government to assure the safety of the vaccine were driving their concerns. Despite the fact that 17% of DSWs planned to refuse to have COVID-19 vaccination, the vast majority did not say they were against vaccination in general. This demonstrates that the vaccine hesitancy is specific to COVID-19.

Recently there has been debate about whether COVID-19 vaccination [should be mandatory among DSW](#)⁽⁸⁾ however only 43% of DSWs were supportive of this. 11% would only get vaccinated if it were compulsory however 18% of workers said they would not continue to work in the sector if it were made compulsory.

In our previous surveys, DSWs reported high levels of frustration about not being recognised as essential workers and largely forgotten by governments in COVID-19⁽¹⁾. This may explain their low level of trust in government. There seemed to be low levels of confidence about COVID-19 vaccination with only 58% agreeing that the vaccine was the best way to stop the pandemic and 54% that it was the best way for them to protect themselves and the people with disability they support.

While DSWs were predominantly getting their information from government websites, their employer and news media, these were not the most trusted sources of information. The highest levels of trust were reported for medical professionals.

Interpretation of findings

It is very concerning that vaccine hesitancy is so high among this group and that more than half do not believe that approval of the COVID-19 vaccine use meant it was safe. This is understandable given the likely link between AstraZeneca and clotting disorders. However, the large majority of respondents (96%) completed the survey before the Federal Government's announcement of prioritising Pfizer for adults aged under 50 years.

Concerns about safety because the vaccine was new and potential side effects were major reasons why DSWs were vaccine hesitant. Of those that planned to refuse COVID-19 vaccination, 80% did not trust government to ensure its safety. In our previous surveys DSWs reported feeling like they had been overlooked during the pandemic, that they had not been considered essential workers, that information was inadequate, and they did not get access to Personal Protective Equipment (PPE) until late into the COVID-19 crisis in Australia. This experience is likely to have contributed to their low levels of confidence in government found in this survey. DSWs had relatively low levels of confidence in the efficacy of the vaccine for themselves, the people with disability they support, and the community in general. This is also concerning because without vaccination among DSWs people with disability are at high risk of infection if there is community transmission of COVID-19.

A challenge for Australia is that with little or no community transmission people are genuinely at very low risk of COVID-19. Australia has also not seen the devastation of COVID-19 that other countries have witnessed. This is likely to contribute to DSWs concerns about safety of the vaccine being so prominent. This is challenging for public health messaging for COVID-19 vaccination where individual risk is low or non-existent in the current context. Most DSWs have not supported someone with COVID-19 or know anyone who has been positive. They have not been exposed to the harsh realities of COVID-19 spreading in the community, including among people with disability.

WAYS FORWARD

However, without high levels of vaccination in Australia we will not achieve herd immunity and the community, including people with disability, are at risk when Australia opens its borders and/or residents' return.

While we find concerning levels of COVID-19 vaccine hesitancy, very few DSWs are opposed to all vaccines. This means that it is possible to achieve a high-levels of vaccination among DSWs, but this requires greater engagement with a sector that already feel 'left behind' by government in the COVID-19 response. Confidence about the efficacy and relative safety of the vaccine needs to be built.

The WHO emphasise the importance of [community engagement](#) in building vaccine strategies⁽⁹⁾. They recommend that it is important to collect information around perceptions and beliefs about the vaccines and emphasise the importance of acting on that feedback. This survey represents the first step in that process. It is now important that the government respond to the concerns of this group and build tailored communication strategies with them.

We recommend that a strategy to improve uptake of vaccination among DSWs is developed urgently. However rather than a strategy that just covers DSWs, we recommend that a COVID-19 disability vaccination strategy that is co-designed with the whole sector including people with disability, DSWs and service providers.

First trust needs to be built by listening and responding to concerns of these groups. Only then can confidence about the efficacy and safety of the vaccine be improved. It is important that communication is transparent, that the potential severe adverse effects and that the possibility that the vaccine does not provide them with protection, are acknowledged. As the World Health Organization notes, it is important that key influencers in the community are engaged as they can facilitate communication. Government and others should consider engaging independent medical professionals

to assist or suggest that DSWs discuss their concerns with their own doctors, rather than rely on messages from government.

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