

COVID-19 vaccination program: Guidance and practical tools for supporting disabled people with decision-making and consent



Includes:

Guidance about supported decision-making

Information about accessible formats

Supported decision-making tools

Contents page

PART A: Guidance

Introduction.....	2
Code of Health and Disability Services Consumers' Rights.....	4
Supported decision-making.....	5
Understanding will and preference.....	8
Responsibilities of a supporter.....	10
Upholding the rights of disabled people who do not consent to the COVID-19 vaccine.....	11

Part B: Vaccine Information in Accessible Formats

Accessible information and communication about COVID-19 and COVID-19 vaccine.....	12
--	----

Part C: Supported decision-making tools

Three guidance tools – providing communication supports to a person being offered the COVID-19 vaccine.....	18
Case studies.....	58

PART A:

Introduction

The COVID-19 vaccination program has highlighted the importance of having clear **supported decision-making** and **consent processes** for disabled people. This resource has been developed for family / whanau, close supporters and those working in the disability sector, in preparation of the roll out for the national COVID-19 vaccination programme.

The resource has three parts: guidance, vaccine information in accessible formats, and some tools for supported decision-making.

The guidance and practical support tools have been developed on the basis that family / whanau, close supporters and those working in the disability sector accept that every person has the right to make their own informed decision, to the greatest extent possible, about whether or not they wish to consent to the COVID-19 vaccination. Part of this process is ensuring that disabled people have access to information and supported decision-making tools in order to provide informed consent to the COVID-19 vaccination.

While the NZ Government strongly recommends the COVID-19 vaccination, it is not mandatory and consent must be obtained¹. If a disabled person is having difficulty making a decision this should signal a requirement for supported decision-making and the provision of supports. Every attempt should be made to interpret the will and preference of individuals through the use of a supported decision-making process. This is to ensure that the decision-making capacity of the individual is enhanced to the greatest degree possible. Utilising such supports may enable the individual to communicate their choice or provide persons who know the individual best, with sufficient knowledge to identify their **will and preference**.

¹ This guidance is not intended for use where it is not possible to obtain a person's informed consent i.e. where even using all available support options available, due to the limited ability to communicate, a person's decision remains unknown. In this instances, defer to Right 7(4) and associated sub-clauses.

We hope that family / whanau, close supporters and those working in the disability sector will use this guidance to inform how they can apply and adapt the practical resources with the view to enabling disabled people to communicate their informed choice regarding the COVID-19 vaccination.

In addition to this guidance document, there is also another guidance tool called **“Supporting people through the vaccination process”**. This document provides information about supporting individuals who may need additional reassurance, positive behaviour strategies, social stories, role plays or supports in the form of desensitisation plans as part of their preparation for receiving the COVID-19. You can find this document on the Ministry of Health website:

Code of Health and Disability Services Consumers' Rights

Right 7: Right to make an informed choice and give informed consent²

- (1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- (2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- (3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- (4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where—
 - (a) it is in the best interests of the consumer; and
 - (b) reasonable steps have been taken to ascertain the views of the consumer; and
 - (c) either,—
 - (i) if the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
 - (ii) if the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.

² <https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/>

Supported decision-making

Everyone should have the opportunity to take an active role in making decisions about their:

- their emotional wellbeing
- their physical health and wellbeing
- things important to them.

The **United Nations Convention on the Rights of Persons with Disabilities** says all disabled people have the right to:

- make decisions about their own lives
- have support to assist them with making a decision if they choose it.

Supported decision-making is an important process for disabled people who might need support to make decisions. This support may be needed because of a person's communication needs, learning disability, acquired brain injury, neurodiverse needs, mental health issues or due to other cognitive or physical conditions.

Supported decision-making is a way for people to make their own decisions based on their **will and preferences**, so they have control of their life. It ensures the person who needs support is at the centre of all decisions that concern them.

The UNCRPD. Article 12 promotes supported decision-making as a process which ensures the centrality of a person's **will and preference** within decision making.³

The person who needs to make a decision should get the support they need, which can be one or more **supporters**. This is sometimes also called a circle of support. The supporters make sure the person gets the right information, at the right time, in the right way, with the time they need to consider their decision.

³ <https://www.odi.govt.nz/assets/Whats-happening-files/exploring-article-12-literature-review-october-2016.pdf>

In summary supported decision-making:

- is a right in the UNCRPD
- means that people assist a person to make their own decision
- the disabled person's will and preference is at the centre of the decision-making process
- is a way to make sure disabled people have equal rights with other people.

For more information about supported decision-making:

- La Trobe University have a range of educational tools available at this website:
<https://www.supportfordecisionmakingresource.com.au/>
- IHC has a guide called Supporting Decision-Making: A Guide for Supporters of People with an Intellectual Disability.
https://ihc.org.nz/sites/default/files/documents/10007_1511_SupportedDecisionMaking_Resource_V4.3_WEB_0.pdf
- There is also an Easy Read booklet about Supported Decision Making on the People First website:
<https://www.peoplefirst.org.nz/download/2036/>

Where a disabled person has a **Welfare Guardian** or an **Enduring Power of Attorney** appointed for personal care and welfare⁴, the Welfare Guardian / Enacted Welfare Enduring Power of Attorney must:

- consult with the disabled person
- encourage the disabled person to develop their own skills to act on their own behalf to the greatest extent possible
- encourage the disabled person to exercise the capacity they do have to make and communicate decisions
- consult with other people who are involved in the disabled person's welfare such as the person's doctor, health professional or support services
- promote, protect and act in the disabled person's welfare and best interest.

A Welfare Guardian/Enacted Welfare Enduring Power of Attorney cannot refuse consent to standard medical treatment that could save the person's life or prevent serious damage to them.

You can find more information about Welfare Guardianship or Enduring Power of Attorney:

Ministry of Justice: <https://www.justice.govt.nz>

Community Law: <https://communitylaw.org.nz>

⁴ That has been activated by a way of medical certification of incompetence.

Understanding will and preference ⁵

Will refers to the longer term and more enduring sense of what the person wants to achieve in life.

For example John wants to have more independence and live in his own home.

Understanding a person's will helps to understand why they have particular preferences.

Preference refers to what the person wants now, at this point in time.

For example John wants to move out of his parent's home and move into a flat with others in the inner city.

Preferences stem from a person's own values and cultural beliefs and are also influenced by past experiences and the consequences of previous decisions.

Preferences are communicated by people in many ways, including through:

- words
- signs
- gestures
- expressions, including facial expressions like staring at an item of interest
- behaviour
- actions or lack of actions.

For some people, preferences have to be interpreted by supporters based on their knowledge of the person, or acquired from the perspectives of others who know the person well or in different contexts.

For more information and practical resources on will and preference:

<https://www.supportfordecisionmakingresource.com.au/step-3-understanding-the-persons-will--preferences-for-the-decision.html>

⁵ <https://www.supportfordecisionmakingresource.com.au/step-3-understanding-the-persons-will--preferences-for-the-decision.html>

In order to determine a person's will and preference about the COVID-19 vaccination, the best place to start is by having a conversation with the person about their current understanding of the vaccine.

Accessible information about the COVID-19 vaccination should be provided and explained to the person, in a form and manner that enables the person to understand the information. (See Part B of this guidance document for more details about accessible information). Once their supporters are confident that the person seems to understand and agree to proceed, they can then operate on the basis that the person has the capacity to consent.

When supporting a person with understanding information it is important to be aware of the concept of **positive presumption**. Positive presumption is what happens when “people pleasers” say yes and are agreeable without necessarily having full understanding or genuinely consenting. Here it is important use pronouns and engage with the person using first person language such as “you” and their first name.

It is useful and important for supporting persons, whether whanau, family or an independent support person⁶, to document and record conversations and discussions that take place about the vaccine. Disability service providers **must** record the ongoing discussions in the person's clinical file or progress notes. These notes will form the record of a process of seeking consent - rather than a ‘one-off’ signature on a form. On the day of the vaccination, the vaccination team may enquire of the person's support person if there is evidence on file that the person is giving consent. The vaccination team may document this evidence by making a note in their records, or ask to make a copy of the evidence.

It is important to point out that no other person such as a family member, next of kin, friend or carer and no organisation can give or refuse consent on behalf of an adult with a disability unless they have specific legal authority to do so. Include those who have a close, ongoing, personal relationship in discussions, not to make the decision, but to provide greater insight into the views and preferences of the person.

⁶ I.e where the support person is not employed through a disability or health provider.

Responsibilities of a supporter

It is the responsibility of a supporter to assist the person to make decisions for themselves. There may be one or more supporters who work together as part of a team in supporting the disabled person with their decision-making.

The key to being a good supporter is knowing how the person's prefers to communicate. A good supporter also needs to have knowledge of the person's will and preference. They need to know and understand what is important for the person—from their relationships, what they like doing, their culture, rituals and routines.

If you're asked to be a supporter, consider whether you're the right person for the decision being made and whether you know the persons will and preferences. Are there any potential or actual conflict of interests where you have a personal interest in the outcome?

It's also important to be aware of any health and safety concerns, including physical and emotional health and safety.

You can get additional information from a personal plan (if they have one) and by talking with family, friends, support worker and other people who care about and know the person.

Upholding the rights of disabled people who refuse the COVID-19 vaccine

While the NZ Government strongly recommends the COVID-19 vaccine; it is not mandatory.

In situations where, after being provided with:

- information that meets the person's needs
- discussion
- visual supports
- and time to make a decision

an individual who has understood the information and made an informed decision communicates that they do not want to be vaccinated, this decision must be respected.

It is important however to explore the reasons why the individual does not wish to be vaccinated, if the person agrees to do so. A person is not required to justify a refusal to consent. Some individuals may require additional explanations, reassurances, role plays or supports in the form of a desensitisation programme or anxiolytic medication to reduce anxiety related to needle phobia.

Again it is important to record any ongoing discussions that take place in the person's personal plan (if they have one) and notes. The vaccination team may request to review and document this information during the vaccination event.

PART B:

Accessible information and communication about COVID-19 and the COVID-19 vaccine

It is important that disabled people:

- are supported to access information about the COVID-19 vaccine by people who they know and trust. This may include their family / whanau, close supporters, doctor, support workers, friend or advocate
- are provided with information about the COVID-19 vaccine in a format that is accessible to their needs. Some accessible formats and resources include:
 - Easy Read
 - New Zealand Sign Language (NZSL)
 - Braille
 - Large Print
 - Audio
 - videos with captions
 - picture on picture (videos with a NZSL interpreter in the corner of the screen)
 - videos with audio-description
 - photos or images of the vaccination process that include an explanation or narrative
- are provided with this information before they make a decision to accept or refuse the COVID-19 vaccine
- are given time to consider the information provided about the vaccine and have the opportunity to ask questions and have them answered. Making a decision like this may be easy and quick for some, while for others they need a period of time in which to come to their own decision; they may need to have several discussions at different times before making a decision.

It is also important that:

- disabled people are able to use any communication tools needed to ask questions and communicate their decisions. These may be augmentative or alternative communicators, devices or assistive technologies such as electronic speech devices, electronic speech apps, talking mats or other visual / non visual aids
- hearing impaired, or Deaf people, who use NZSL as their first language, have access to an NZSL interpreter at their vaccine appointments if they want
- disabled people bring a support person/s to their vaccine appointments if they would like to
- everyone has their decisions respected – if they make an informed choice that they do not want the vaccine, this is their decision.

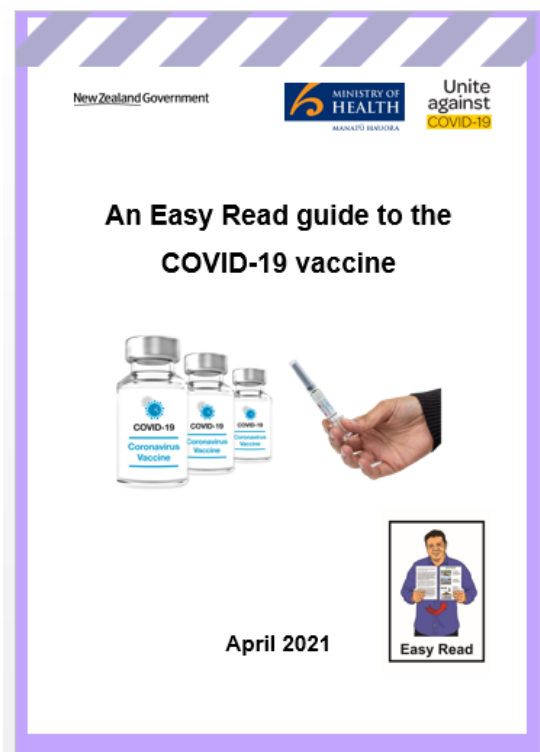
There are a range of resources and adapted materials about the COVID-19 vaccine available to assist family / whānau, supporters, circle of support members and disability support workers to have these conversations. Many of these resources are available in Easy Read, NZSL, Braille, Large Print and Audio. You can find these accessible formats and resources on the Unite against COVID-19 website:

<https://covid19.govt.nz/updates-and-resources/alternate-formats/>

It is important to understand that even with information in accessible formats some people may still need support to fully understand the information. Offering a supportive environment and plenty of time (sometimes on more than one occasion) to read / watch videos / listen to audio and ask questions is really important.

Some of the resources developed and available from the Ministry of Health website are:

- **An Easy Read guide to the COVID-19 vaccine – Ministry of Health and Unite Against COVID-19. .**



This guide provides an overview of:

- what COVID-19 is
- the COVID-19 vaccine and how it works
- who can get the vaccine
- reasons to get the vaccine
- the risks and potential side effects of the vaccine
- what happens before, during and after the vaccine is given.

This simplified guide is also available in NZSL, Braille, Large Print and Audio. You can find these resources on both the:

Ministry of Health website:

www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-information-specific-audiences/covid-19-information-disabled-people-and-their-family-and-whanau (OR WHATEVER website it ends up on)

Unite against COVID-19 website:

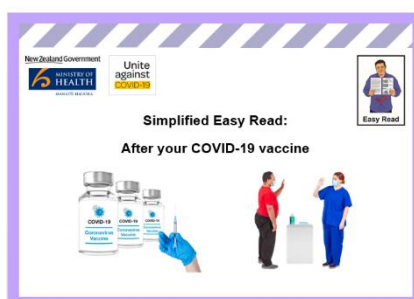
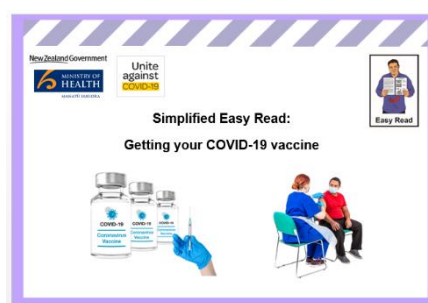
<https://covid19.govt.nz/updates-and-resources/alternate-formats/>

- **Simplified Easy Read booklets about the COVID-19 vaccine**

These booklets use only few large images per page and less words than a standard Easy Read. These booklets are aimed mostly for people with higher support needs and low literacy however can also be a great tool for anyone seeking to understand more about the vaccine.

There are 3 Simplified Easy Read booklets:

- Before getting your COVID-19 vaccination
- Getting your COVID-19 vaccination
- After your COVID-19 vaccination.



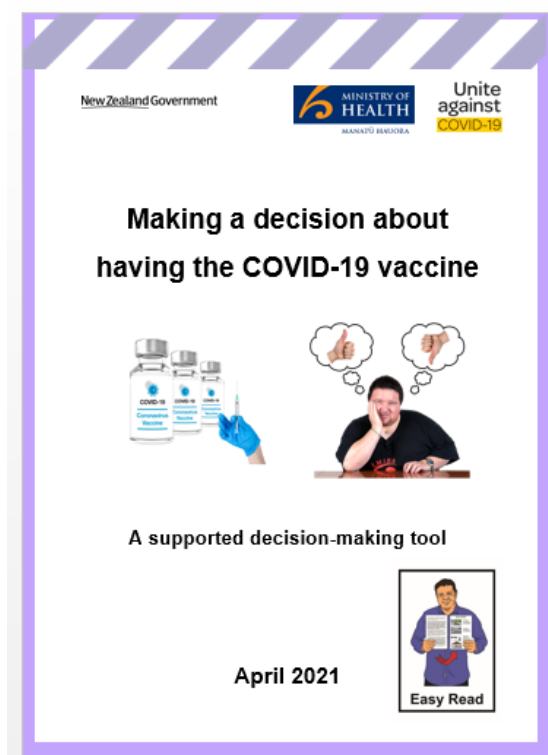
You also find these booklets on the:

Ministry of Health website:

www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-information-specific-audiences/covid-19-information-disabled-people-and-their-family-and-whanau (OR WHATEVER website it ends up on)

Unite against COVID-19 website: <https://covid19.govt.nz/updates-and-resources/alternate-formats/easy-read/>

- **Making a decision about having the vaccine for COVID-19**



This booklet provides:

- an overview of disabled people's rights to make their own decisions
- an overview of supported decision-making
- information about people's rights in regards to making a decision about the COVID-19
- a Supported Decision-making tool that can be completed by the disabled person, their supporter/s or circle of support.

Other supports that assist with making information and communication accessible:

- NZSL interpreters can be booked by contacting iSign:

Phone: 0800 934 683

Free Text: 3359

Email: bookings@isign.co.nz

- The NZ Relay Service also provides access to the phone for deaf, hard-of-hearing and speech impaired people. NZ Relay also provides a Video Interpreting Service that Deaf people can use to access a NZSL interpreter on video calls.

NZ Relay service: <https://www.nzrelay.co.nz/index>

Video Interpreting Service: <https://www.nzrelay.co.nz/VideoInterpretingService>

PART C:

Guidance tool – Process to support a person to make an informed decision when offered the COVID-19 vaccine

We have looked to overseas examples of the COVID-19 vaccination roll out processes for disabled people. The Health Service Executive (HSE) National Disability Services in Ireland wrote a comprehensive document called Guidance and Practical Resource Pack in Preparation for COVID-19 vaccination programme in Disability Services ⁷

We have adapted HSE's communication guidance tools into a **process to support a person to make an informed decision when offered the COVID-19 vaccine**.

This process has three versions or levels which correlate to three different communication profiles. This tool is designed to empower the people in each person's life to identify how best to support the disabled person in their vaccination decision-making processes.

At the end of each version of the guidance tool is a **Record of the Decision-making and consent process** which should be made available to the vaccinator.

You can find this **process to support a person to make an informed decision when offered the COVID-19 vaccine** included as part of this guide.

Important: it is the decision of the family / whanau, close supporter / circle of support / support worker who knows the person best, based on their knowledge of the person, as to which version of guidance tool should be used, or whether a combination of tools may work best.

⁷ <https://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/guidance-and-practical-resource-pack-in-preparation-for-covid-19-vaccination-programme-disability-services.pdf>

Process to support a person to make an informed decision when offered the COVID-19 vaccine.

Guidance tool #1	<p>This guidance tool may be used with people whose:</p> <ul style="list-style-type: none">• understanding of language is limited to daily/weekly routines/activities and plain language• wants and needs are interpreted by watching their facial expressions and body movement etc.
Guidance tool #2	<p>This guidance tool may be used with people whose:</p> <ul style="list-style-type: none">• understanding is limited to routines and they are aware of routine changes• use of language is purposeful and they can communicate using body language or facial expression• may communicate distress when change is not communicated appropriately to them.
Guidance tool #3	<p>This guidance tool may be used with people who:</p> <ul style="list-style-type: none">• are aware of time so will understand their schedule and changes made to it• may be able to communicate their concern, frustration and/or distress to family/whanau and support workers• may need support manage the volume of information they are being exposed to• may need support to understand medical jargon and unfamiliar vocabulary• support to understand the context of the information to reduce anxiety

Dependant on which guidance best describes the communication style of the person being supported to consent, please go to the appropriate tool below

Guidance tool # 1

For people whose:

- understanding of language is limited to daily/weekly routines/activities and plain language
- wants and needs are interpreted by watching their facial expressions and body movement etc.

Instructions for Supporters:

- This document has been designed to help you know how to support someone with the above communication profile to consent to the COVID-10 vaccination.
- The person you are supporting may find making decisions easier “in the moment” and may find consenting to unfamiliar procedure before it has happened difficult.
- It is important that the person receiving the vaccine and their Supporter/s are informed and the person is with a familiar person such as family / whānau or a close supporter or support worker before the vaccines happens.
- Please check the person’s Personal Support Plan / Communication guidelines to identify comforts that the person might have whilst waiting for the vaccination.
- During the vaccine procedure you may record a person’s implicit consent. This means a person may not be able to tell you clearly if they do or do not want the vaccination until they are in the situation and they may give (or not give) consent through body language, facial expressions, vocalisations, walking away or gestures. Sometimes these signs are obvious to an unfamiliar person but at other times distress can be communicated more subtly. It is important, that as their familiar supporting person, you are familiar with the person, have read their Personal Support Plan / Communication guidelines and recognise what a person is communicating. They may need additional supports like reassuring positive voice, a comfort or music, or they may need a break or for the procedure to stop.

Guidance tool # 1 continued

The Decision

1. What decision (s) need (s) to be made?
2. Why do we need to make this decision?
3. Who needs to be involved in making this decision?
4. What options are there (including not acting?)
5. Have you considered the risks and benefits of all your options?



Question for Supporters to Review

1. Have you established what the person's will and preferences are in this situation? How will the decision impact on their physical health, emotional wellbeing, community access, education/employment opportunities and maintenance of important relationships? What was their previous experience of a similar situation?
2. What steps need to be taken to support the person to engage in the decision-making process?
3. Has the person been provided with information in a way they can understand?
4. Nominate a support person for the person, agreed in advance, with an alternative if that person is not available at the time.
5. Support person (s) explains decision (s) and option to the person.
6. Presume the person can make their own decisions unless/until the contrary is shown?



Guidance tool # 1 continued

Making the Decision

1. Does the proposed measure *minimise harm* (to the person and/or others)?
2. Is the proposed measure *proportionate* (to the benefits of doing it and the risks of not doing it)?
3. Is it *fair and reasonable*? (Does it treat the person as equal to all others and is it based on best available evidence and sound clinical judgement?).
4. Are we fulfilling our *duty to provide care* (to the person, family, support workers and others)?
5. Is the decision making process *open and transparent*?
6. Have all key stakeholders been included in the decision making process?



Making a Plan to Review/Revise the Decision

1. Is the decision-making responsive? How will it be revisited as the situation changes? How will complaints/appeals be managed?
2. What are the systems of accountability? Who is responsible for the decision? Who has oversight?
3. How has all of this been recorded in the person's file? How is the rationale for the decision **and** the decision making process documented? The vaccination team may ask to review the documentation.



Guidance tool # 1 continued

Preventing my distress:

- Know the strategies/phrases/language to use to reduce my anxiety.
- Know the meaningful ways to engage with me positively in the vaccine process.
- Know my unique communication profile.
- Know the things that are likely to cause me distress and take steps to avoid them / minimise their impact.
- Know the things that impact on my ability to cope and remain calm.
- Know how to support my wellbeing.
- Know what visuals support my communication and have them prepared in advance.



Addressing my distress:

- Know the signs of my distress, particularly the early signs.
- Know the strategies/phrases/language to use to address my distress in the moment.
- Provide reassurance (know the phrases that are helpful).
- Acknowledge my upset.
- Know what object/person/activity will support me to be calm.



If you do not know the above – please find out.

- **Read my Personal Support Plan**

Talk to familiar person such as family / whānau or a close supporter or support worker who know me well.

GUIDANCE TOOL # 1:

The following document is intended for use in discussions prior to the vaccination and taken to the vaccination event. If applicable, documentation or record of discussions should also be made available for the vaccination team, as well as information about the persons health and medication.

Process to support a person to make an informed decision when offered the COVID-19 vaccine

Person's
photo
here

Hi, my name is: _____

My NHI number is: _____

The following best describes my communication profile:

- My understanding of language is limited to routines and simple language.
- You interpret my needs by watching my facial expression, body movements.

Guidance tool # 1 continued

Steps to explain the vaccination process:

1. Please ensure I am in a quiet space.
2. Please ensure there is a familiar person such as family / whānau or a close supporter or support worker are supporting me.
3. Supporting person says: “(Person’s name) the doctor/nurse/vaccinator is going to come and give you medicine.
4. Please show me the syringe if possible.
5. Supporting person says: “The medicine will make sure you are well”
6. Supporting person says: “The medicine goes in your arm”
7. Supporting person says: “Now you are finished. “Well done (Person’s name)”.



Please document any of the ways that the person may have given consent during the test:

- ☐ During the vaccination appeared calm and relaxed
- ☐ Accepted the vaccination in the arm and did not push away or change facial expression
- ☐ Did not appear upset
- ☐ Did not obviously express they did not want to receive the vaccination
- ☐ Did not more subtly express they did not want the vaccination
- ☐ Other: _____

Record of the Decision-making and consent process



1. Hi - my name is:



2. I make decisions about my health and wellbeing:

☐

by myself

☐

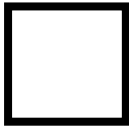
with support from:



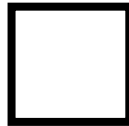
3. To make my decisions I need:



information in ways I
can understand



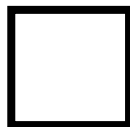
time



information about what
will happen if I decide
yes



information about what
will happen if I decide
no



to see what having a
vaccine would look
like.



4. This is a space to write down any other things you need to make decisions:

5. Making a decision about the COVID-19 vaccine:

	Comments	<input checked="" type="checkbox"/>
What is the decision I need to make?		
What information do I need to help me understand?		
What support do I need to make this decision? Who supported me with this decision?		
What are the good things about having the vaccine for COVID-19?		

	Comments	<input checked="" type="checkbox"/>
What are the risks of having the vaccine for COVID-19?		
<p>What is the summary of the conversation?</p> <p>Must include my:</p> <ul style="list-style-type: none"> • preferences and wishes • any support I might need if I decide I want the vaccine. 		
My decision is:	<input type="checkbox"/> Yes - I want to have the vaccine for COVID-19 <input type="checkbox"/> No - I do not want to have the vaccine for COVID-19	



You can show your decision at any time to your:

- doctor
- anyone else who may ask you if you want to have the vaccine.



Take this decision-making tool with you to your vaccine appointment.

GUIDANCE TOOL # 2:

This guidance tool may be used with people whose:

- understanding is limited to routines and they are aware of routine changes
- use of language is purposeful and they can communicate using body language or facial expression
- may communicate distress when change is not communicated appropriately to them.

Information for Supporters

- This document has been designed to help you know how to support someone with the above communication profile to consent to the COVID-10 vaccination.
- It is important that the person receiving the vaccine and their Supporter /s are informed and the person is with a familiar staff member before the vaccines happens.
- Use the Easy Read booklets and visuals to explain the vaccination process.
- A person can say ‘No” or stop the vaccine procedure at any point after they have signed the Decision-making and consent form.
- Please check the person’s Personal Support Plan / Communication guidelines to identify comforts that the person might have whilst getting the vaccination.

Preventing my distress:

- Know the strategies/phrases/language to use to reduce my anxiety.
- Know the meaningful ways to engage with me positively in the vaccine process.
- Know my unique communication profile.
- Know the things that are likely to cause me distress and take steps to avoid them / minimise their impact.



- Know the things that impact on my ability to cope and remain calm.
- Know how to support my wellbeing.
- Know what visuals support my communication and have them prepared in advance.

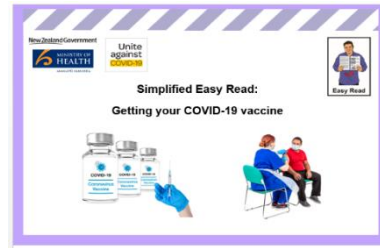
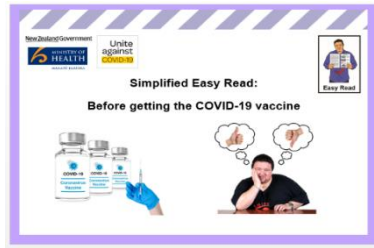
Addressing my distress:

- Know the signs of my distress, particularly the early signs.
- Know the strategies/phrases/language to use to address my distress in the moment.
- Provide reassurance (know the phrases that are helpful).
- Acknowledge my upset.
- Know what object/person/activity will support me to be calm.



If you do not know the above – please find out.

- **Read my Personal Support Plan**
- **Talk to a familiar person such as family / whānau or a close supporter or support worker who know me well.**
-
- Read through with me **Simplified Easy Read – Before, During and After COVID-19 vaccine**, You can find these booklets on the Ministry of Health [website](#).



GUIDANCE TOOL # 2:

The following document is intended for use in discussions prior to the vaccination and taken to the vaccination event. If applicable, documentation or record of discussions should also be made available for the vaccination team, as well as information about the persons health and medications.

Process to support a person to make an informed decision when offered the COVID-19 vaccine

Person's
photo
here

Hi, my name is: _____

My NHI number is: _____

The following best describes my communication profile:

- My understanding of language is limited to routines and simple language and I am aware when my routine changes
- My use of language is purposeful and I can communicate using my body language and / or facial expression
- I may communicate distress when change is not communicated appropriately with me.

Guidance tool # 2 continued

Steps to explain the vaccination process:

1. Please bring me to a quiet space to inform me about the vaccination.
2. Please have a familiar person with me when explaining the vaccination
3. Please read through **the Simplified Easy Read Before, Getting and After the COVID-19 vaccine booklets** with me).
4. Please allow me time to process what was said.
5. Supporting person to read through the booklets again, take one page at a time and point to the picture when speaking
6. Supporting person to also point to their own arm when it mentioned in the booklets.
7. The supporting person can also use the booklets to talk through the vaccination with me in the moment. Please use the consistent language in the script.



Please document any of the ways that the person may have given consent during the test:

- ☐ During the vaccination appeared calm and relaxed
- ☐ Accepted the vaccination in the arm and did not push away or change facial expression
- ☐ Did not appear upset
- ☐ Did not obviously express they did not want to receive the vaccination
- ☐ Did not more subtly express they did not want the vaccination
- ☐ Other: _____

Record of the Decision-making and consent process



1. Hi - my name is:



2. I make decisions about my health and wellbeing:

☐

by myself

☐

with support from:



3. To make my decisions I need:

☐

information in ways I
can understand

☐

time

☐

information about what
will happen if I decide
yes

☐

information about what
will happen if I decide
no

☐

to see what having a
vaccine would look
like.



4. This is a space to write down any other things you need to make decisions:

5. Making a decision about the COVID-19 vaccine:

	Comments	<input checked="" type="checkbox"/>
What is the decision I need to make?		
What information do I need to help me understand?		
What support do I need to make this decision? Who supported me with this decision?		
What are the good things about having the vaccine for COVID-19?		

	Comments	<input checked="" type="checkbox"/>
What are the risks of having the vaccine for COVID-19?		
<p>What is the summary of the conversation?</p> <p>Must include my:</p> <ul style="list-style-type: none"> • preferences and wishes • any support I might need if I decide I want the vaccine. 		
My decision is:	<input type="checkbox"/> Yes - I want to have the vaccine for COVID-19 <input type="checkbox"/> No - I do not want to have the vaccine for COVID-19	



You can show your decision at any time to your:

- your doctor
- anyone else who may ask you if you want to have the vaccine.



Take this decision-making tool with you to your vaccine appointment.

GUIDANCE TOOL # 3:

Guidance tool #3

This guidance tool may be used with people who:

- are aware of time so will understand their schedule and changes made to it
- may be able to communicate their concern, frustration and/or distress to family/whanau and support workers
- may need support manage the volume of information they are being exposed to
- may need support to understand medical jargon and unfamiliar vocabulary
- support to understand the context of the information to reduce anxiety

Information for Supporters

- This document has been designed to help you know how to support someone with the above communication profile to consent to the COVID-10 vaccination.
- It is important that the person receiving the vaccine and their Supporter /s are informed and the person is with a familiar staff member before the vaccines happens.
- Use the Easy Read booklets and visuals to explain the vaccination process.
- A person can say 'No' or stop the vaccine procedure at any point after they have signed the Decision-making and consent form.
- Please check the person's Personal Support Plan / Communication guidelines to identify comforts that the person might have whilst getting the vaccination.

Preventing my distress:

- Know the strategies/phrases/language to use to reduce my anxiety.
- Know the meaningful ways to engage with me positively in the vaccine process.
- Know my unique communication profile.
- Know the things that are likely to cause me distress and take steps to avoid them / minimise their impact.
- Know the things that impact on my ability to cope and remain calm.
- Know how to support my wellbeing.
- Know what visuals support my communication and have them prepared in advance.



Addressing my distress:

- Know the signs of my distress, particularly the early signs.
- Know the strategies/phrases/language to use to address my distress in the moment.
- Provide reassurance (know the phrases that are helpful).
- Acknowledge my upset.
- Know what object/person/activity will support me to be calm.

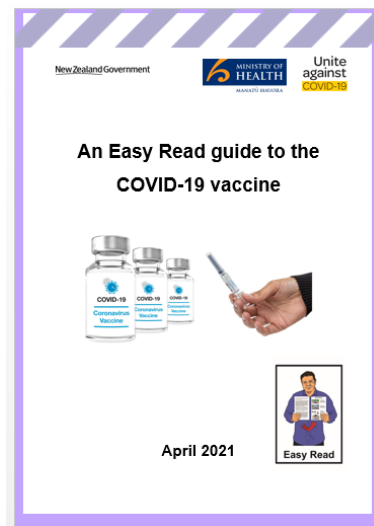


If you do not know the above – please find out.

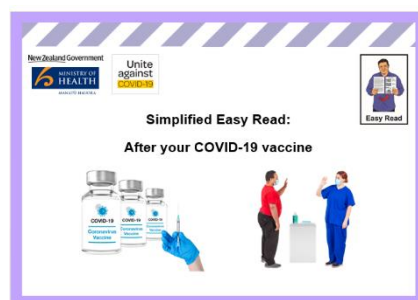
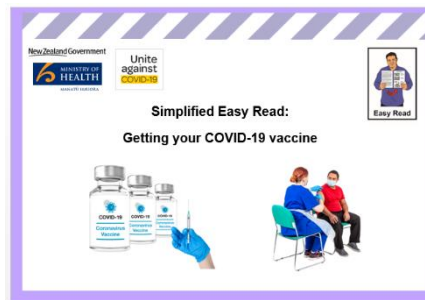
- **Read my Personal Support Plan**
- **Talk to a familiar person such as family / whānau or a close supporter or support worker who know me well.**

Read through with me:

1, An Easy Read guide to the COVID-19 vaccine. You can find this booklet on the Ministry of Health [website](#).



2. Simplified Easy Read – Before, During and After COVID-19 vaccine, You can find these booklets on the Ministry of Health [website](#).



GUIDANCE TOOL # 3:

The following document is intended for use in discussions prior to the vaccination and taken to the vaccination event. If applicable, documentation or record of discussions should also be made available for the vaccination team, as well as information about the persons health and medication.

Process to support a person to make an informed decision when offered the COVID-19 vaccine

Person's
photo
here

Hi, my name is:

My NHI number is: _____

The following best describes my communication profile:

- I am aware of time (e.g. days / months / years) so will understand my schedule and any changes made to it.
- I may need support to manage the volume of information I get given about the vaccine
- I may need support to put the information in context (to reduce anxiety)
- I am able to communicate my concern / frustration / distress to you.

Support my understanding in advance and then again in the moment (as a reminder)

Steps to explain the vaccination process:

1. Please ensure I am in a quiet space.
2. Please give me lots of time before the vaccine procedure to get myself ready
3. Explain the process in clear, logical, factual steps
4. Use visuals to support my understanding of the information (e.g. **Simplified Easy Read – Before, Getting and After the COVID-19 vaccine** and / or **An Easy Read guide to getting the COVID-19 vaccine**)
5. Let me know how long it will take
6. Reassure me that my usual routine will continue
7. Have something I like to do afterwards.



Guidance tool #3 continued

Please document how the person gave their consent (you can tick more than one)

- ☐ Read information with familiar person and verbally agreed
- ☐ Read information with familiar person and pointed to the picture saying “Yes” to the vaccine
- ☐ Listened to the information and used words, gesture, body language or Sign Language to agree
- ☐ Listened to the information and use a communication board or communication device to agree
- ☐ During the procedure appeared calm and relaxed
- ☐ During the procedure followed instructions to roll up sleeve and remain still
- ☐ Did not appear upset
- ☐ Accepted the vaccination in the arm and did not push away or change facial expression
- ☐ Did not appear upset
- ☐ Did not obviously express they did not want to receive the vaccination
- ☐ Did not more subtly express they did not want the vaccination
- ☐ Other: _____

Record of the Decision-making and consent process



1. Hi - my name is:



2. I make decisions about my health and wellbeing:

☐

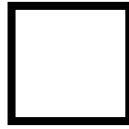
by myself

☐

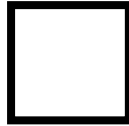
with support from:



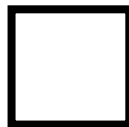
3. To make my decisions I need:



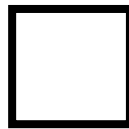
information in ways I
can understand



time



information about what
will happen if I decide
yes



information about what
will happen if I decide
no



to see what having a
vaccine would look
like.

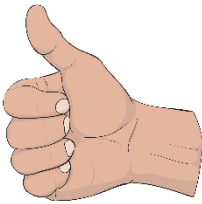
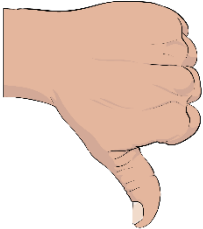


4. This is a space to write down any other things you need to make decisions:

5. Making a decision about the COVID-19 vaccine:

	Comments	<input checked="" type="checkbox"/>
What is the decision I need to make?		
What information do I need to help me understand?		
What support do I need to make this decision? Who supported me with this decision?		
What are the good things about having the vaccine for COVID-19?		

	Comments	<input checked="" type="checkbox"/>
What are the risks of having the vaccine for COVID-19?		
<p>What is the summary of the conversation?</p> <p>Must include my:</p> <ul style="list-style-type: none"> • preferences and wishes • any support I might need if I decide I want the vaccine. 		

<p>My decision is:</p>	<div data-bbox="703 241 906 443">  </div> <div data-bbox="962 230 1286 495"> <input type="checkbox"/> Yes - I want to have the COVID-19 vaccine </div> <div data-bbox="724 685 927 913">  </div> <div data-bbox="962 674 1286 938"> <input type="checkbox"/> No - I do not want to have the vaccine for COVID-19 </div>	
<p>Signed by:</p>		
<p>Date:</p>		



You can show your decision at any time to your:

- doctor
- anyone else who may ask you if you want to have the vaccine.



Take this decision-making tool with you to your vaccine appointment.

Case studies

Case example 1: Stacey

Stacey was unsure about the COVID 19 vaccine. Like many of us, she had heard some negative/bad things about the vaccine, mostly on social media. This meant she was cautious about receiving the vaccine. Stacey heard differing opinions about the side effects and how fast the vaccine was developed, which was not surprising given that it was so new. But mostly she was afraid of needles.

Stacey stopped reading social media and went to the COVID-19 website, which she had heard could be trusted. After looking at the website, Stacey could see that having the vaccine could help stop her from getting sick with the virus and help us all return to spending time with family and loved ones. However, even knowing this, Stacey knew that, at the end of the day, she had a choice to decide if she wanted to get the vaccine or not.

The COVID-19 website said if you have any questions or concerns or a specific health condition, it was important to talk with your doctor. So Stacey did. Her doctor said she would be ok to get the vaccine, although she might have a sore arm or feel a bit tired after the injection. Stacey left the doctor's office feeling happier because she trusts her doctor.

Deciding to get the vaccine didn't make getting the vaccine any easier because of her needle fear. But Stacey had been in touch with family who were a great support and said it was going to be okay.

When she arrived at the place where she was to get her vaccine, Stacey was greeted by a healthcare worker with a big smile who asked her some questions. They explained why they were asking the questions which made her feel at ease. Before Stacey knew it, she had been given the injection.

Stacey did find that her arm was a bit sore but the next morning she felt good. She remembered she was told if she felt unwell to contact her doctor but didn't need to. One word of advice from Stacey is don't be afraid to ask questions and if you don't understand don't be afraid to ask them to repeat the answers in plain language.

Advice to those giving the vaccine – help people understand the process by breaking down the process, and provide a kind smile and support. If the person has a support person, speak to the person and not the support person.

The most appropriate level of guidance tool for Stacey's communication profile would likely be Guidance Tool 3.

Case example 2: Ron

Ron is 70 years of age, has a learning disability and lives in a group home with two other men. Ron communicates using plain verbal language and body language and prefers to have regular routines and daily activities. Ron has lived in residential care since his teenage years. His parents are deceased and Ron has siblings living in different parts of the country who visit frequently and who like to be informed about Ron's health and well-being. Ron has an underactive thyroid and has annual bloods tests to check his thyroid function. Ron does not like blood tests but tolerates same with the support of his key-worker and support team.

In preparation for the COVID-19 vaccine, Ron's support worker team have started discussing the roll-out of the vaccination programme with all of the men in the house. They have explained that the government is offering the vaccination to older people living in residential care facilities and that Ron and his house-mate will be offered the vaccine.

The support team have used the communication supports contained in this resource pack to assist Ron's understanding of the reason for the vaccine. With repeated and informal discussions over a week it is clear that Ron understands that the COVID-19 vaccine can prevent people getting very sick if they contract the COVID-19. Ron understands that the vaccination will involve two injections at 3 week intervals. Ron understands that he may have a sore arm and feel tired after the vaccine. Ron's support team have documented these discussions with Ron in his progress notes and clinical file.

A few days before Ron is scheduled to be offered the vaccine his support team have used the decision making framework contained in this resource pack to document the fact Ron's decision to give informed consent to accepting the COVID-19 vaccination.

On the day the vaccination team arrive at Ron's home, Ron and his key-worker have the record of the consent process ready to show the vaccinator. Ron receives the COVID-19 vaccine.

The most appropriate level of guidance tool for Ron's communication profile would likely be Guidance Tool 2 or 3.

Case example 3: John

John is a 35-year-old man with a learning disability, visual impairment and has high levels of support. John has recently moved to live in a group home with one other man.

John enjoys good health but has a significant phobia of medical interventions, to the extent that he cannot tolerate physical examinations and dental intervention can only take place under general anaesthetic. When John becomes anxious or upset he bites his wrist and hits himself on his temple with a closed fist.

John's elderly parents have instructed the support workers that they want John to be prioritised for the COVID-19 vaccination and that they will sign the consent form. John's support team use the communication supports contained within this resource pack to inform John about the COVID-19 vaccine. It seems apparent to John's team that he does not fully understand and retain information on the benefits of the vaccination or the risks of not having the vaccination. John's support team, in consultation with the occupational therapist and behaviour therapist attempt the desensitisation programme with him contained within the resource pack; however, this process seems to cause John distress and he engages in self-injury.

The support team meet with John's parents and explain that while John cannot give informed consent to the COVID-19 vaccination, it is not sufficient for his parents to provide consent on his behalf if they are not legally appointed to be his welfare guardians or to have enduring powers of attorney. It is agreed to use the guidance tools contained within this resource pack to determine the best estimate of John's will and preference. It seems apparent that John is communicating that he does not wish to receive the COVID-19 vaccination. It is agreed that, given the level of distress, self-injury and active dissent that John demonstrated during the attempts at desensitisation, that the vaccination cannot proceed on this occasion on ethical grounds.

The decision-making framework is completed by John's support team in collaboration with the clinical team and John's parents. John does not receive the COVID-19 vaccination.

The most appropriate level of guidance tool for John's communication profile would likely be Guidance Tool 1.

Case study 4: Margaret

Margaret is 45 years of age and has autism and moderate learning disability. Margaret lives in residential care where she has support all daily living tasks. Margaret has been in residential care since her early childhood years and has limited family contact. Margaret is an anxious woman who experiences episodes of low mood. She attends the mental health service. Margaret lives on her own with one to one support worker. Margaret is fearful of doctors, hospitals and medical interventions. Margaret has some underlying health difficulties including obesity and type two diabetes.

In preparation for the COVID-19 vaccine, Margaret's support team have liaised with her mental health team to discuss how best to empower Margaret to make an informed decision about whether or not to have the COVID-19 vaccine. Margaret's support staff decide to use the communication supports contained in this resource pack as Margaret understands and retains information better when she can read the words and look at photos. Initially Margaret says that she does not want to get the vaccination because she is afraid of injections.

The staff team explain to Margaret that this is her choice but that they would like to ensure that she is making the right decision for her health and well-being. They explain to Margaret that if she was to get COVID-19 that she could become very ill and need to go to hospital and that they would be very worried about her. Margaret's support team ask her if she would like to practice what it might be like to get the vaccination. They use the social stories and desensitisation plan contained in this resource pack and work through the different steps. Margaret's team document all of these discussions in her progress notes.

When they role play the vaccination process it becomes clear that Margaret is agreeable to the vaccination but is terrified of needles, because of situations in her past when she was forced to have blood drawn and was held by staff. In consultation with Margaret's mental health team and GP, Margaret is supported to make a decision in relation to having a short term 'pro re nata' anxiolytic medication prescribed to mitigate her anxiety about the vaccination process. Margaret's support

team remind her that she is a strong woman to overcome her fears and continue to practice the desensitisation protocol. Margaret makes a plan to treat herself to a new mobile phone after the vaccination process is complete.

Margaret's support team use the guidance tools contained in this resource pack and provide this to the vaccination team.

The most appropriate level of guidance tool for Margaret's communication profile would likely be Guidance Tool 2 or 3.