



GUIDANCE AND PRACTICAL RESOURCE PACK IN PREPARATION FOR COVID-19 VACCINATION PROGRAMME IN DISABILITY SERVICES



HSE National Disability Services

Guidance & Practical Resource Pack to prepare for the COVID-19 vaccination programme in Disability Services

Jan 21 2021 Version 2

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1. Introduction

This guidance and practical support pack has been developed for Disability Services in preparation for the imminent roll out of the national COVID-19 vaccination programme. In developing this guidance, we have endeavoured to respond to issues raised by people with disabilities, their families and direct support staff working in disability service. The guidance has been developed in accordance with national guidelines and legislation, and on the basis that those who provide health and social care services must work on the presumption that every person who uses our services has the capacity to make decisions about whether or not they wish to consent to the COVID-19 vaccination. A person who lacks capacity continues to enjoy individual rights such as access to information in order to provide informed consent to the COVID-19 vaccination.

While the HSE strongly recommends the COVID-19 vaccination, consent must be sought. No-one has the legal authority to force or coerce any citizen to accept the COVID-19 vaccination. The fact that a person with disability may not have sufficient understanding regarding a decision, should signal a requirement for the provision of supports, in order 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.

We hope that all professionals working across the domain in health and social services will use this guidance to inform how they can apply and adapt the practical resource pack we have included with the view to enabling people with disabilities to communicate their informed choice regarding the COVID-19 vaccination.

2. The National COVID-19 Vaccination Programme

What is COVID-19?

- COVID-19 is an illness that can affect your lungs and airways, and sometimes other parts of your body. It's caused by a virus called coronavirus. COVID-19 is highly infectious.

Who is most at risk from COVID-19?

- People over the age of 65 and people with certain health conditions have a higher risk of getting seriously ill if they get COVID-19.
- Older people living with others in long-term care facilities have a greater risk of getting seriously ill if they get COVID-19, as this virus spreads quickly among people living together.
- Healthcare workers have a higher risk of being exposed to COVID-19 than others.

What is a COVID-19 Vaccine?

- A COVID-19 vaccine is a substance that should offer protection from COVID-19. If people are vaccinated they are much less likely to become seriously ill or even die from COVID-19.
- Vaccines teach your immune system to protect you from diseases. It is much safer for your immune system to learn how to protect you through vaccination than by getting COVID-19.

Who are the HSE offering the vaccine to first?

We are offering the vaccine to the people who are most at risk of COVID-19 and in the following order:

- People over the age of 65 living with others in long-term care facilities, including people with disabilities
- Healthcare workers* in frontline direct support roles
- People aged 70 and older who are living at home
- Healthcare workers* who are not in frontline direct support roles
- People aged 65-69 who having underlying medical conditions**
- Essential key workers required for the vaccination programme roll out
- People aged 18-64 with underlying medical conditions**

- People aged between 18-64 living with others in long-term care facilities, including people with disabilities and their staff
- People aged 18-64 who are living in crowded accommodation
- Essential key workers
- People working in the education system
- People aged between 55-64
- People aged 18-54
- We do not yet have evidence that the vaccine can be safely rolled out to children and adolescents.

*Healthcare workers include people working in and out of all healthcare settings including disability services

**Underlying medical conditions include chronic heart disease, including hypertension with cardiac involvement; chronic respiratory disease, including asthma requiring continuous or repeated use of systemic steroids or with previous exacerbations requiring hospitalisation; Type 1 and 2 diabetes; chronic neurological disease; chronic kidney disease; body mass index >40; immunosuppression due to disease or treatment; chronic liver disease.

3. Information on getting the COVID-19 Vaccine

Benefits of getting the vaccine:

- The COVID-19 vaccine will offer protection from COVID-19. If you catch COVID-19 after vaccination you should be protected from the serious illness the virus can sometimes cause
- The vaccine is free
- If you have already had COVID-19 you still need to get the vaccine because you could become infected with the virus again
- The HSE strongly recommends that you get the vaccine

How will I get the vaccine?

- The HSE will let you know when it is your turn.
- You will get the vaccine as an injection in your upper arm. It will only take a few minutes.
- You will need two doses, at least 4 weeks apart.
- The person who will give you the vaccine will be a nurse, doctor or someone who is specially trained.
- Your vaccinator will answer any questions that you may have and will provide you with an aftercare advice leaflet and vaccine record card.

Possible side effects:

- Like all vaccines, the COVID-19 vaccine can cause side effects in some people.
- More than one in ten people are sore in their arm where the injection is given, or get muscle pain and fever. These symptoms are mild and do not last long.
- A few people feel unwell after getting the vaccine
- Rarely people can get a temporary one sided facial drooping (Bell's palsy). This has happened in less than one in 1000 cases.
- Very rarely there is a serious allergic reaction to the vaccine. This has happened in less than one in 100,000 cases and the vaccinator is trained to treat such a reaction.

Do Not Get the Vaccine if:

- you currently have COVID-19. You will need to wait until it has been 4 weeks since you noticed first symptoms or tested positive.
- have a fever (temperature of 38 degrees or higher), wait until you feel better.
- have a serious allergic reaction to any of the ingredients in the vaccine or have had a serious allergic reaction to a previous dose of the vaccine.

This will help prepare you and individuals you support for the Coronavirus Vaccine



- People are still talking about the Coronavirus. It is called **Covid-19**.
- There are yellow posters in my house.
- Lots of places are closed



- To stop people getting Covid-19, Ireland is getting **a vaccine**.



- A vaccine helps your body to make antibodies.
- After getting a vaccine, your body will have antibodies and be a better fighter against Covid-19.



- Vaccines can stop diseases without you getting sick.
- The vaccine does not give you Coronavirus.

IT TEACHES YOUR BODY TO FIGHT THE VIRUS

-

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- A top-down view of various medical supplies arranged on a solid teal surface. The items include several white, oval-shaped pills scattered across the scene; a red and white striped cap; a green pen; a white surgical mask; a red first aid kit with a white cross; a white cloth; a small dark jar; a syringe with an orange plunger; a roll of white gauze; a red circular object; and two white cotton swabs. The lighting is even, highlighting the textures and colors of the objects.

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- On the day of the vaccination, you will be offered an injection.
- It will be just as you practiced.



- A specially trained health professional (doctor, nurse) will offer you the injection.



- The vaccination will need 2 injections.
- You will have another injection 28 days or 4 weeks after you get the first dose.



- After the injection some people may feel a little sore. This is because the vaccine is new to your body.
- If you don't feel well, your doctor can check that you are OK



- It is important that you and people around you still wear a face covering and use social distancing after having the vaccine.



IT IS GREAT NEWS THAT THE VACCINE IS READY.

WE WILL BE READY FOR THE VACCINE WHEN IT IS OUR TURN

4. Preparing People with Disabilities to Provide Informed Consent to the Vaccine

It is important that people with disabilities are supported to access information about the COVID-19 vaccination by people who they know and trust. This may include their key-worker, family, direct support staff, friend, advocate and/or member/s of the clinical team (for example nurse, social worker, speech and language therapist, psychologist etc.) before they make a decision to accept or refuse the vaccine.

Each individual's circle of support must begin to provide them with information and to adapt this information to match the person's communication profile. There is a suite of resources and adapted materials available to assist support staff to have these conversations:

- The HSE has developed an 'Easy Read' guide to the COVID-19 vaccination <https://hse.drsteevenslibrary.ie/Covid19V2/immunisation>
- We have developed four levels of communication aids to empower each individual's circle of support to identify how best to support their decision making in advance of the vaccination process.
- In all conversations that healthcare workers have with the people they support it will be important to explain that there is overwhelming evidence that there is a much greater risk to their health and well-being from contracting COVID-19 than there is from accepting the vaccination.

5. Supporting People with Disabilities to communicate their will and preference

In line with the HSE National Consent Policy, all citizens should be presumed to have capacity to make decisions about their care and support. A diagnosis of intellectual disability, or the need for additional support, does not mean that a person cannot make a decision about their healthcare.

The vast majority of the people with disabilities who we support will have had previous experience of vaccinations (e.g. the annual flu vaccination) and will be familiar with the process of providing informed consent or have communicated 'assent' through written or verbal or non-verbal means. Similar processes will apply for the COVID-19 vaccination.

In order to determine an individual's will and preference about the COVID-19 vaccination it is best to ask the person. If they are in agreement, proceed with vaccination.

When you provide information and explain to each person with a disability about the COVID-19 vaccination and the person seems to understand and agrees to proceed, you can then operate on the basis that the person has the capacity to consent. It will be helpful to record any such ongoing discussions that take place in the person's clinical file or progress notes. These notes will form the record of a process of seeking consent- rather than a 'once off' signature on a form. On the day of the vaccination, the vaccination team will enquire of the person's support staff if there is evidence on file that the person is giving consent.

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 person who lacks capacity to consent unless they have specific legal authority to do so. Include those who have a close, ongoing, personal relationship in discussions, not to make the final decision, but to provide greater insight into the views and preferences of the person.

6. Upholding the Rights of People with Disabilities to Refuse the Vaccine

While the HSE strongly recommends the COVID-19 vaccination; it is not mandatory. No citizen should be coerced and it is not permissible to force someone to accept the vaccination against their expressed consent or dissent.

In situations where, after being provided with the appropriate information, discussions and visual supports, an individual communicates that they do not want to be vaccinated this decision must be respected.

However:

- It is the responsibility of the healthcare support staff to explore the reasons why the individual does not wish to be vaccinated
- 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 (see sections 7, 8 and 9)
- The HSE is of the view that COVID-19 vaccination is for the benefit of the person; therefore, every effort should be made to support, reassure and persuade the individual to accept same
- Staff familiar with the individual and the clinical team may be in a position to support this process in advance of the vaccination date.

Supporting Decision Making:

Person has capacity and consents- vaccinate

Person does not have capacity and agrees/ does not refuse- vaccinate

Person has capacity and does not consent- do not vaccinate

Person does not have capacity and refuses- do not vaccinate

7. Additional supports to be considered to optimise the coping abilities of people with disabilities during the vaccination process

In order to prepare people with disabilities for a COVID-19 vaccination, a programme of supports has been prepared by the Muiriosa Foundation for staff and carers who are supporting people with disabilities. This programme of supports is intended to guide staff and carers to prepare, encourage and support people with disabilities to receive the vaccination.

Managing Anxiety

All of the steps outlined in this document are designed to

- ❖ Alleviate anxieties
- ❖ Give predictability as best as is possible
- ❖ Enhance emotional and physical wellbeing and activities
- ❖ Nurture social connectedness with loved ones
- ❖ Managing future anxiety (COVID-19 inoculation) & desensitisation.

Some of the individuals we support may/will experience anxiety around having a vaccine injection and because of very real reasons; for example:

- Past Experiences
- Pain Sensitivity
- Sensory Impairments e.g. – Blindness, Deafness, tactile defensiveness
- Lack of understanding about 'What is happening'

There are steps that key supporters and family can take to help prepare a person with intellectual disability for an injection. Given the limited time that may be available to administer the vaccine to each individual; it is a good idea to start the preparation process as soon as possible.

Below is a checklist consideration / suggestions to support anxiety and make adjusting to having the vaccine easier for the people we support. From previous experience staff teams may know that the individual would benefit from not having too much advance notice as this may increase anticipatory anxiety. The decision of when to notify the person in advance of the vaccination should be made by the circle of support/people that know the person best, similar as you might do for routine blood tests or the flu vaccination. It is important to be aware of the fact that for some of the individuals we support, not knowing when the vaccination is going to happen could increase anxiety.

A. Environment:

- **CONSIDER WHERE THE VACCINE WILL TAKE PLACE:**
 - The person may be more comfortable, prefer to have the vaccine in a familiar environment, with familiar things close by.
 - The person may be more comfortable, prefer to attend a centre or a clinic to have the vaccine.
 - Speak with the individual and key stakeholders about options on where the vaccine can take place.

B. Familiar Person:

- The presence of a person with whom the individual has a trusted relationship can help reassure and support anxiety around the administration of the vaccine.

C. The Person administering the vaccine

- **EXPLORE:**
 - Requesting that Doctor or Nurse that the person is already familiar with administer the vaccine.
 - Key support staff who are trained in the administration of the vaccine

D. Time of Administration of Vaccine

- Can time be planned, adjusted to meet the needs of the person e.g. first or last appointment of the day to reduce anxiety caused by waiting; afternoon versus morning if morning is a more stressful time for the person?

E. The use of Numbing Cream or pain relief for the area of injection

- May help to stop pain on the skin
- Speak to GP about prescription and options before and after having the vaccine.

F. Preparation

- Talking about the vaccine in a natural way.
- Social Stories (outlining what the vaccine involves)

- De Sensitisation (can help relax and build up the person's confidence of the vaccination process)
- Role Play one or two scheduled times every day. Light hearted approach using a and b above.

G. Distraction

- Identify things that help distract:
 - favourite movie iPad;
 - Music (iPad, Wireless Headphones);
 - Hold a favourite object;
 - Hold and squeeze a stress ball;
 - Chat about favourite things; simple visualization.

H. Motivation

- Something really nice to support the person get through the process:
 - favourite coffee;
 - Beverage;
 - Dessert;
 - Magazine;
 - Something that the individual really likes

8. Preparing people with disabilities for the vaccination process through practice and role play

It may be helpful for some people to practice what it will be like to receive a Covid-19 vaccine. Staff can do this in the home by role-playing this with other staff before asking the residents to get involved and practicing this in a fun way regularly until the vaccine arrives. Remember to keep it casual and fun and to encourage conversations and questions around receiving the vaccine and the benefits of same versus the risks of getting very sick with coronavirus. Staff can begin by reading the '**Social Story for Practicing how to receive a Covid-19 Vaccine**' and then begin the modelling or role play scenario.

To prepare for Covid-19 Vaccination role play staff can make a kit to include:

- Standardised PPE (gloves, mask, visor and apron (where appropriate))
- A box to hold items
- A small container to simulate a vaccine vial
- A needle-less syringe (a retractable pen is also a good alternative)
- Cotton ball
- Band-Aid

Visual supports:

- **Social Story for Practicing how to receive a Covid-19 Vaccine**

Covid-19 Vaccination Role Play Practice Steps:

1. The individual sits on a chair and staff explain they are going to practice what will happen when they get a Covid-19 vaccine.
2. Staff sit beside / stand to the side of individual while wearing mask, gloves, plastic apron (and protective glasses/visor if possible).
3. Staff will ask the individual to roll up their sleeve, initially this may need to be modelled by staff. It would be best for the individual to wear a short sleeve, if possible.
4. Staff will let the individual know that they are going to administer the vaccine now while simulating drawing some vaccine out of the vial using the needless syringe/pen.
5. Staff will suggest that the individual looks away now if they prefer and to count to three.

6. Staff will press the needless syringe against the skin of the individual on their upper arm holding for 3-5 seconds.
7. Staff will remove the syringe and place a cotton ball on the area for three seconds.
8. Staff will remove the cotton ball and place a small Band-Aid on the area.
9. Staff will provide verbal praise to the individual and thank them for practicing. If it is appropriate staff will have set it up that the individual has something nice on offer following each practice session.

*Staff will stop the practice session as soon as the individual indicates that they have had enough. Staff will provide reassurance, praise and the opportunity to practice again when they are ready.

Social Story for Practicing how to receive a Covid-19 Vaccine



- Today we are going to practice what it will be like to receive a Covid-19 vaccine.
- It looks and feels like the flu vaccine expect this will help us to fight against Coronavirus.



- On the day we might have to go to your G.P. to get the vaccine, you might get it here at home or, they could set up a centre and we will all go together to get the vaccine.
- We will have to wait and see.



- Today when we practice you can roll up your sleeve or wear a t-shirt and show staff your upper arm.



- Staff will use the syringe to take the vaccine out of the vial.



- Staff will practice giving you the vaccine on your upper arm. If you like you can look away now and count to three.
- 'One... two... three'.



- Staff will use a cotton ball and put a plaster on your arm just like the day you get the vaccine.

YOU'RE ALL DONE. THE MORE YOU PRACTICE IT WITH STAFF THE EASIER IT WILL BE ON THE DAY.



9. Desensitisation protocol for supporting people with disabilities who may have a needle phobia

There are many good reasons why some people with disabilities are afraid of needles, including past experiences of being forced to have blood tests or injections. Some research has shown that almost one sixth of people with intellectual disabilities have a significant fear of healthcare interventions including needles.

It is important to use desensitisation procedures to address and reduce people's fears and anxieties around needles. Many of the people we support need additional accommodations when they are having routine blood tests or their annual flu vaccines. It will be important to look at their person centred support plan to find out what accommodations have worked in the past. If somebody has required and benefitted from the topical application of a numbing cream (e.g. Lidocaine, Prilocaine or Ethyl chloride) or an anxiolytic medication (e.g. a short-acting benzodiazepine) in the past it will be important to have discussed this with the person's G.P. and clinical team as these will need to be prescribed and added to the individual's medication Kardex as a short-term pro re nata, or 'as required' medication. As the COVID-19 vaccine will be available in the coming weeks support staff can begin these processes now.

The following protocol is designed to help staff teams, and the people they support, become familiar with receiving a Covid-19 vaccination. **This section is especially aimed at those who may have a fear or phobia of needles.** Some individuals may consent to the vaccine, or communicate their will and preference to receive the vaccine; however, they may have a difficulty tolerating the experience because of a needle phobia. This protocol is designed to reduce these anxieties over the coming days and weeks.

Remember, the COVID-19 vaccine is not mandatory, nor is it an emergency intervention. No-one should be coerced to accept the vaccine.

In preparation for the de-sensitisation programme staff can make a kit to include:

- Standardised PPE (gloves, mask, visor and apron (where appropriate))
- A box to hold items
- A small container to simulate a vaccine vial

- A needleless syringe (if you do not have one a retractable pen can be used as an alternative)
- Numbing cream (if appropriate, and will be used on the day)
- Cotton ball
- Band-Aid

Visual supports

- Social Story for Practicing how to receive a Covid-19 Vaccine (above)
- A visual of steps
- 'First' and 'then' visual support
- A preferred activity/ item visual that will be delivered immediately following a success step

Covid-19 Vaccination De-sensitisation guide for staff:

1. Staff will review the recording sheet to see what step is being completed
2. Staff will place the 'first and then' visual on the table with the visual appropriate visual in the 'first' and 'then' section.
3. Each step must be completed for 3 consecutive days before moving on to the next step – For example, John must tolerate step 2 for 3 days before moving on to step 3.
4. If John is not tolerating a step continue with that step for a further two days and consider changing up the motivating item to something even better!
5. The preferred item is delivered once John tolerates the step
6. The preferred item is only to be used for the de-sensitisation programme. (i.e. it is not available at any other time)

Step by step for de-sensitisation protocol

Step 1: The individual sits in the chair wearing a short sleeve

Step 2: Staff will apply lotion to the area to simulate numbing cream

Step 3: Staff will simulate drawing the vaccine from the vial

Step 4: Staff will use a free hand to feel around the area and move the arm slightly encouraging the person to relax their arm

Step 5: Staff suggest the person looks away and counts to three

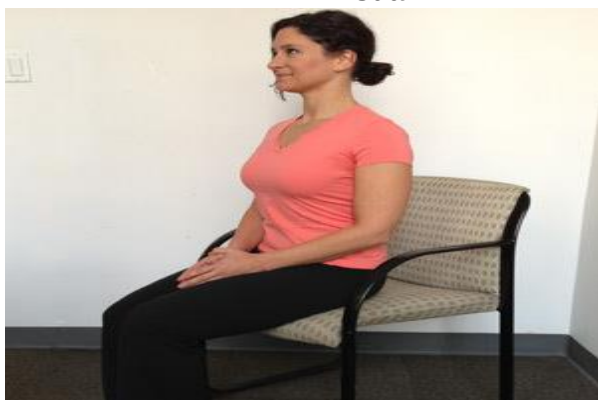
Step 6: Staff will press the needless syringe against the persons skin and count loudly '1, 2, 3'.

Step 7: Staff will remove the syringe and hold a cotton ball in place for 5-seconds

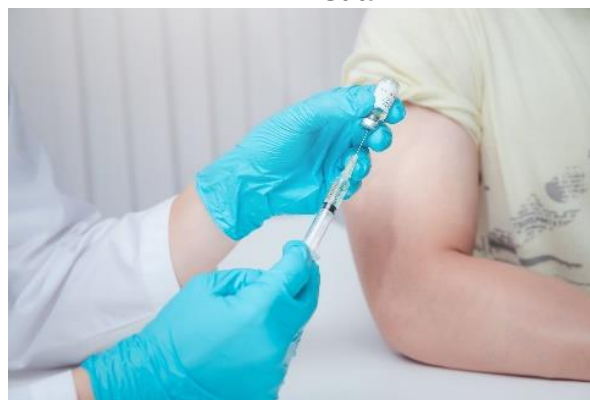
Step 8: Staff will remove the cotton ball and apply a Band-Aid to the area.

The following visuals can be printed and displayed in front of the individual on the 'first' section of the 'first and then' board during practice sessions and brought with them on the day of vaccination for familiarity, if appropriate.

Visual 1



Visual 2



Visual 3



Visual 4



first 	then 
---	---

Covid-19 Vaccination Desensitisation Prog. Recording Sheet

Name: _____

Date	Step being completed	Tolerates	Pulls away/engages in behaviour of concern	Preferred item delivered	Preferred item accepted	Comments
Sample 01/10/17	1	✓		✓	✓	

Introduction to the four *Providing Communication Supports to a person being offered the COVID-10 Vaccine* tools – (Appendices 1- 4)

There are **four** different guidance tools included in this pack to help staff to support a person with a disability who is being offered the vaccine.

Guidance #1 – pages 26 – 31

This document may be used with people whose understanding of language is limited to routines and simple language and whose needs are interpreted by watching their facial expression body movement etc. and culminates on page 31 with a **Record of Consent Process** which must be made available to the vaccinator.

Guidance #2 – pages 32 – 43

This document may be used with people whose understanding of language is limited to routines and they are aware when their routine changes. Their use of language is purposeful and they can communicate using body language or facial expression. They may communicate distress when change is not communicated appropriately with them. This document culminates on page 43 with a **Record of Consent Process** which must be made available to the vaccinator.

Guidance #3 – pages 44 – 54

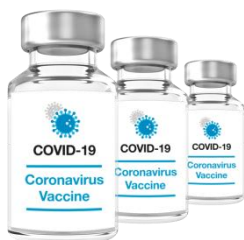
This document may be used with people who are aware of time so will understand their schedule and changes made to it. They may be able to communicate their concern/frustration/distress to staff. This document culminates on pages **53 AND 54** with a **Record of Consent Process** which must be made available to the vaccinator.

Guidance #4 – pages 55 – 62

This document may be used with people who may require support to manage the volume of information they are being exposed to. They may also need support to understand medical jargon and unfamiliar vocabulary and may require support to put information in context to reduce anxiety. This document culminates on pages **61 AND 62** with a **Record of Consent Process** which must be made available to the vaccinator.

IMPORTANT - *It is the decision of the support staff who knows the person best, based on their knowledge of the person, as to which support guidance should be used, or maybe a combination may work best.*

Appendix 1



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

Guidance # 1.

Person's
photo
here

Hi, my name 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 movement etc.

My understanding of something is supported in the moment

Steps to explain the vaccination process:

1. Please ensure I am in a quiet space
2. Please ensure familiar staff are supporting me
3. Staff say: “(person’s name) the doctor/nurse/etc is going to come and give you medicine”.
4. Please show me the syringe if possible.
5. Staff say: “The medicine will make sure you are well”.
6. Staff say: “The medicine goes in your arm”
7. Staff say: “Now you are finished. Well done (person’s name)”.



Preventing my distress

- Know the strategies/phrases/language to use to reduce my anxiety.
- Know the meaningful ways to engage me positively in the testing 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 well-being.
- 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 calm.



If you don't know the above, please find out - read my Personal Care Support Plan and talk to a familiar staff member who knows me well.

A Framework for Staff for Decision Making during the COVID-19 Pandemic.

(Adapted from St. Michael's House Ethical Framework for Decision Making for all Staff during the COVID 19 Pandemic, 2020)



All individuals are supported to take an active role in their emotional wellbeing, their physical health and in making choices about things important to them and for them. **It is presumed that all adults have the capacity to make their own decisions unless the contrary is shown.**

The COVID-19 pandemic has rapidly brought us to a place where difficult decisions need to be made and significant changes are happening within service users' everyday lives. The current public health crisis requires a new way of thinking, so that we act in ways that are **both** person-centred **and** will benefit the health and welfare of the individual, society and the population as a whole.

It is important we think about how these decisions are experienced by adults in the service. It is important that as staff we have a process that informs the decisions that are taken, within which a service users' will and preferences can be considered in line with Public Health policy and relevant legislation.

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 options?



Involvement of the Person in the Decision Making Process

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 etc? 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 appropriate information about the situation, in a way they can understand?
4. Nominate a support person for the service user, agreed in advance, with an alternative.
5. Support person explains decision(s) and options to the service user.
6. Presume person has capacity to make their own decisions unless/until the contrary is shown.



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, staff 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?





Record of the Consent Process

Name: _____ Support staff name: _____
 Date: _____

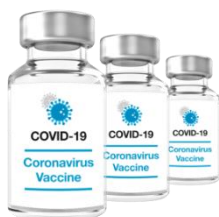
Each person has the right to refuse a treatment proposed (Supporting People's autonomy, HIQA 2016). Persons with disabilities must be involved in decision making about their own healthcare (Inclusion Ireland 14/04/2020).

- This document is designed to help you know how to support someone with the above communication profile to consent to the COVID 19 vaccination.
- The person you are supporting may find making decisions easier 'in the moment' and may find consenting to an unfamiliar procedure before it has happened difficult.
- It is important that the decision maker is informed and the person is with a familiar staff member before the procedure happens.
- Please check the person's Personal Care Support Plan / Communication Guidelines to identify comforts that the person might have whilst waiting for the vaccination.
- During the 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 staff member, you are familiar with the person, have read their Personal Care Support Plan / Communication Guidelines and recognise what a person is communicating. They may need additional supports like a reassuring positive voice, a comfort or music. Or they may need a break or for the procedure to stop.

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 the vaccination
- ☐ Did not more subtly express they did not want the vaccination

Appendix 2



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

Guidance # 2.

Person's
photo
here

Hi, my name 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 or facial expression
- I may communicate distress when change is not communicated appropriately with me.

Steps to explain the vaccination to me:

1. Please bring me to a quiet space to inform me about the vaccination.
2. Please have a familiar staff with me when explaining the vaccination.
3. Please read through the attached script.
4. Please allow me some time to process what was said.
5. Staff to read through the script again, take one page at a time and point to the picture when speaking.
6. Staff to also point to their own arm when it is mentioned in the script
7. Staff can also use the script to talk through the vaccination with me in the moment. Please use the consistent language in the script.



Preventing my distress

- Know the strategies/phrases/language to use to reduce my anxiety.
- Know the meaningful ways to engage me positively in the testing 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 well-being.
- Know what visuals support my communication and have them prepared in advance.



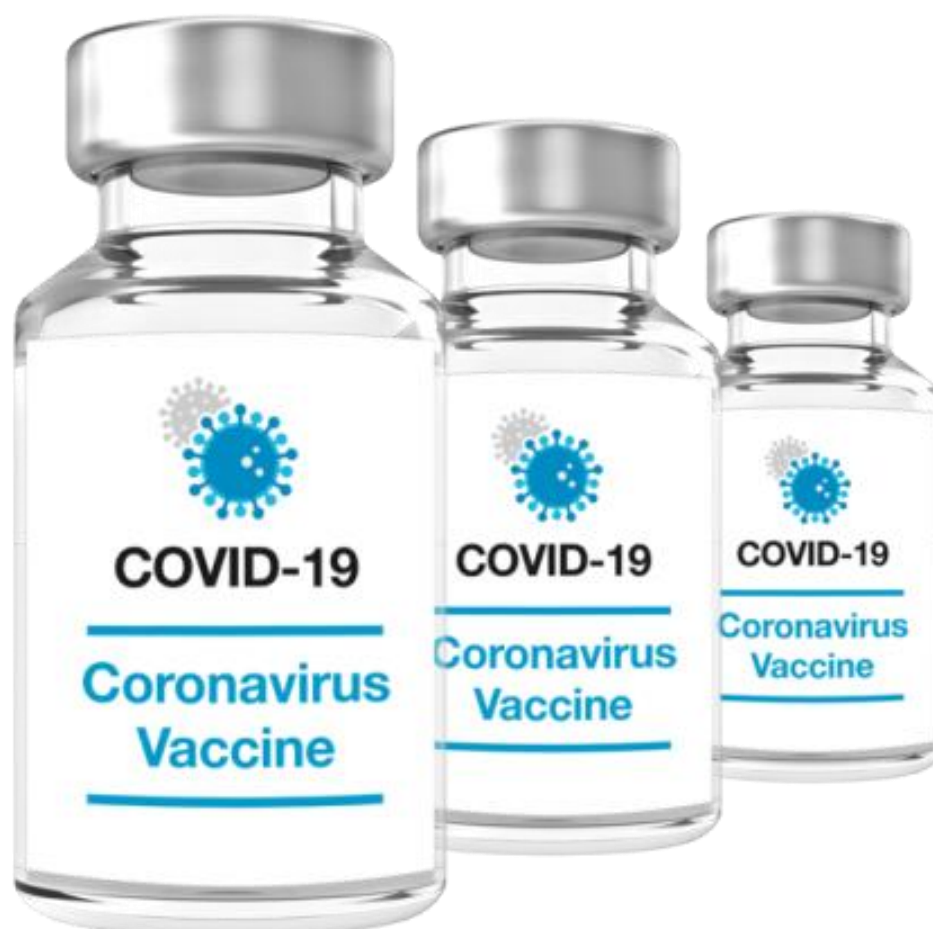
Addressing my distress

- 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 calm.



If you don't know the above, please find out - read my Personal Care Support Plan and talk to a familiar staff member who knows me well.

Vaccination



The government are giving everyone the COVID 19 vaccine.

If the person has autism, use their own name instead of “you” or “your” etc.



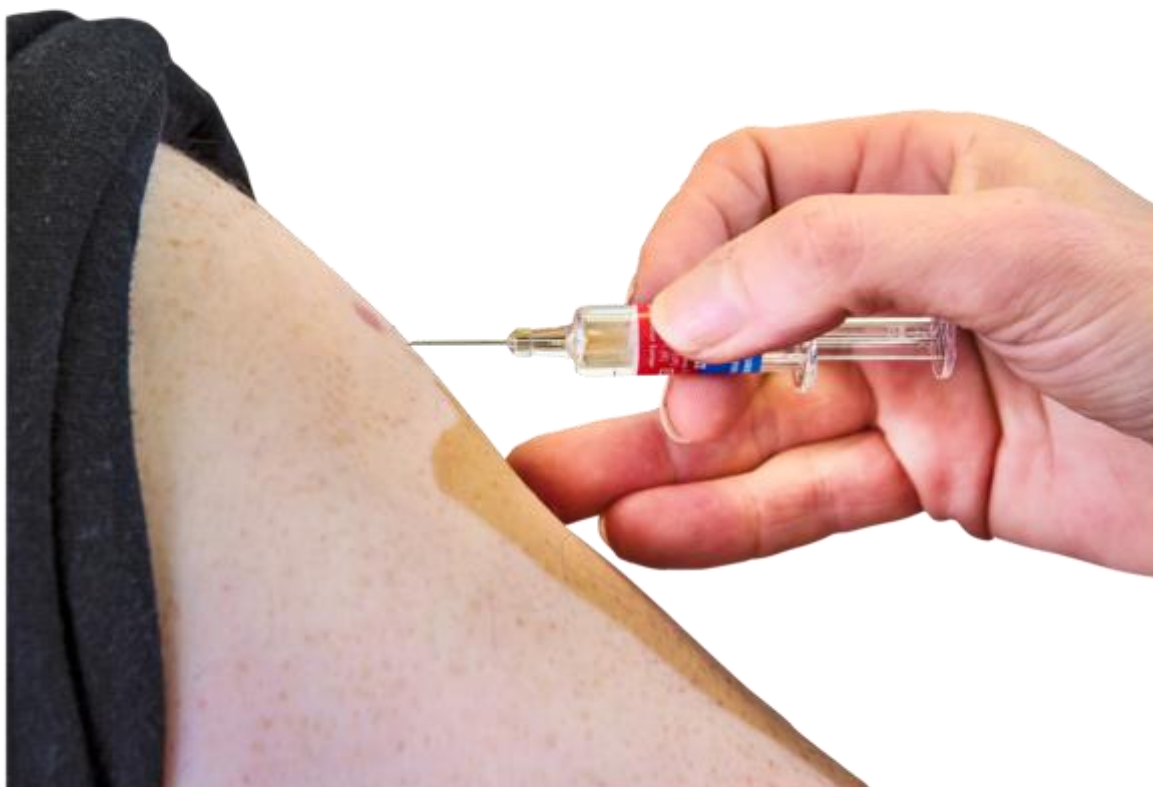
The vaccine is medicine to help you
stay well.

**If the person has autism, use their own name instead of “you” or
“your” etc.**



The vaccine is an injection.

If the person has autism, use their own name instead of “you” or “your” etc.



The injection goes in your arm.

If the person has autism, use their own name instead of “you” or “your” etc.



Staff will go with you when you get the vaccine.

If the person has autism, use their own name instead of “you” or “your” etc.



Thank you for listening.

If the person has autism, use their own name instead of “you” or “your” etc.

A Framework for Staff for Decision Making during the COVID-19 Pandemic.

(Adapted from St. Michael's House Ethical Framework for Decision Making for all Staff during the COVID 19 Pandemic, 2020)



All individuals are supported to take an active role in their emotional wellbeing, their physical health and in making choices about things important to them and for them. **It is presumed that all adults have the capacity to make their own decisions unless the contrary is shown.**

The COVID-19 pandemic has rapidly brought us to a place where difficult decisions need to be made and significant changes are happening within service users' everyday lives. The current public health crisis requires a new way of thinking, so that we act in ways that are **both** person-centred **and** will benefit the health and welfare of the individual, society and the population as a whole.

It is important we think about how these decisions are experienced by adults in the service. It is important that as staff we have a process that informs the decisions that are taken, within which a service user's will and preferences can be considered in line with Public Health policy and relevant legislation.

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 options?



Involvement of the Person in the Decision Making Process

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 etc? 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 appropriate information about the situation, in a way they can understand?
4. Nominate a support person for the service user, agreed in advance with an alternative.
5. Support person explains decision(s) and options to the service user.
6. Presume person has capacity to make their own decisions unless/until the contrary is shown.



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, staff 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?





Record of Consent Process

Name: _____
Date: _____

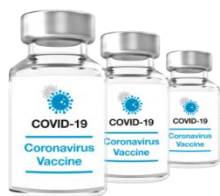
Support staff name: _____

Each person has the right to refuse a treatment proposed (Supporting People's autonomy, HIQA 2016). Persons with disabilities must be involved in decision making about their own healthcare (Inclusion Ireland 14/04/2020).

- This document is designed to help you know how to support someone with the above communication profile to consent to the COVID 19 vaccination.
- The person you are supporting may find making decisions easier 'in the moment' and may find consenting to an unfamiliar procedure before it has happened difficult.
- It is important that the decision maker is informed and the person is with a familiar staff member before the procedure happens.
- There are information packs and visuals to explain the vaccination process within this package.
- During the 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 staff member, you are familiar with the person, have read their Personal Care Support Plan / Communication Guidelines and recognise what a person is communicating. They may need additional supports like a reassuring positive voice, a comfort, a film, a preferred thing (e.g. favourite drink) or a preferred activity (e.g. drive). Or they may need a break or for the test to stop.

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 the vaccination
- ☐ Did not more subtly express they did not want the vaccination
- ☐ Other _____



Appendix 3

Process to support a person to make an informed decision when offered a COVID-19 vaccine. Guidance #3

Photo
here

Hi, my name is _____

The following best describes my communication profile:

- I am aware of time (e.g. days / months /etc) so will understand my schedule and any changes made to it.
- 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:

1. Please ensure I am in a quiet space
2. Please give me lots of time before the 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. picture sequence of the task, easy read information).
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.

Preventing my distress

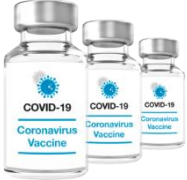
- Know the strategies/phrases/language to use to reduce my anxiety.
- Know the meaningful ways to engage me positively in the testing process.
- Know my unique communication profile.
- Know the things that are likely to cause me distress and take steps to avoid them / minimise their impact.
- Know the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

If you don't know the above, please find out, read my Personal Care Support Plan and talk to a familiar staff member who knows me well.

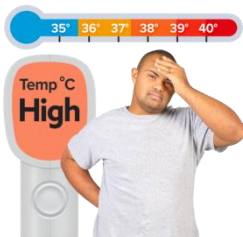
The COVID 19 vaccination

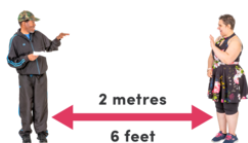
	COVID 19 / Coronavirus is a virus that can make some people sick.
	The government wants to keep everyone safe and well.
	The government is giving everyone the COVID 19 vaccine.
	The vaccine is medicine to help keep you well.
	The vaccine is given in an injection. The injection is in your arm.

HSE National Disability Services

Guidance & Practical Resource Pack to prepare for the COVID-19 vaccination programme in Disability Services

Jan 21 2021 Version 2

	A doctor or nurse will give you the injection.
	After the injection, you will need to wait for 15 minutes before you go home.
	You will need to get one more injection in a few weeks time.
	Your arm might be a little sore afterwards. You might have a temperature. This is ok.
	If you feel ill you can ring your doctor.



After you have the vaccine, you must still wear a mask.

You must still stay far away from other people.



If you want to know more about the vaccine, you can ask your doctor or nurse.

How you will be supported to have the COVID vaccination.



You will be given information about the COVID 19 vaccine in a way that helps you understand.



Staff can give you information like this easy read document.



Staff can use pictures to show you each step of the COVID 19 vaccination.



Staff can show you the special clothes that the person doing the vaccination will wear.



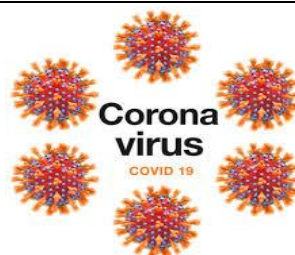
Staff or family can be with you when you get the vaccination.



If you have any questions about the vaccine, you can ask your doctor or nurse

What is COVID 19?

COVID 19 / Coronavirus is a virus that can make some people sick.



- I might have a cough.
- I might feel hot.
- It might be hard for me to breathe.



Most people get better very quickly.



I will cough and sneeze into my elbow or into a tissue.
Staff will show me how to do this.



It is important that I wash my hands.



I will wash my hands:

- When I come home.
- When I touch other people.
- When I touch pets.
- If my hands are dirty
- After I use the toilet.
- Before I eat or drink.



If I am worried about COVID 19 / Corona virus, I can talk to family, staff or friends.



Record of the Consent Process

Name: _____ **Support staff name:** _____

Date: _____

Each person has the right to refuse a treatment proposed (Supporting People's autonomy, HIQA 2016). Persons with disabilities must be involved in decision making about their own healthcare (Inclusion Ireland 14/04/2020).

- This is a form is designed to help you know how to support someone with the above communication profile to consent to the COVID 19 vaccination.
- On the next page is a record of the consent process form. It must be signed by the person before the procedure. If requested you, the staff member, may support a signature with (e.g. hand over hand support) but the person themselves must make their own choice and mark the page.
- A person can say 'no' or stop the procedure at any point even after they have signed this document.
- Please ensure you have read the person's Personal Care Support Plan / Communication Guidelines and offer additional supports during the procedure when needed (for example, letting the person know something nice is going to happen after – favourite drink, watch a film, go for a drive etc).

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

- ☐ Read information with familiar staff and verbally agreed
- ☐ Read information with familiar staff and pointed to the picture denoting 'Ok'
- ☐ Listened to information and used Lamh, gesture, body language or Sign Language to agree
- ☐ Listened to the information and used a communication board or communication device to agree
- ☐ During the procedure appeared calm and relaxed
- ☐ During the procedure followed instructions to open / close mouth
- ☐ Did not appear upset
- ☐ Did not obviously express they did not want the vaccination
- ☐ Did not more subtly express they did not want the vaccination
- ☐ Other: _____



The government are giving everyone the COVID 19 vaccination.



- On (*day*), the GP/Nurse/etc will come to (*location*).
- They will give you an injection in your arm.
- Then the treatment is finished.
- You can say 'stop' at any time.

Do you want the vaccination?

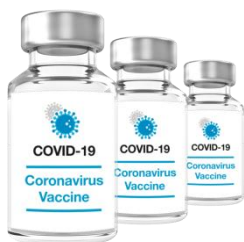


Ok



Not ok

Appendix 4



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

Guidance # 4.

Person's photo here

Hi, my name is _____

The following best describes my communication profile:

- I may require support to manage the volume of information I am being exposed to.
- I may require support to understand medical jargon and unfamiliar vocabulary.
- I may require support to put the information in context (to reduce anxiety).

Although I may understand the information given to me verbally, it helps my processing and recall if I also have it in written / visual form:

Steps to explain the vaccination:

1. Please ensure I am in a quiet space
2. Please give me lots of time before the procedure to get myself ready
3. Explain the process is clear, logical, factual steps.
4. Use an easy read to support processing and retention of the information.
5. Answer any questions that I have honestly and factually.
6. Take time to explain any medical jargon / unfamiliar vocabulary.



Preventing my distress

- Know the strategies/phrases/language to use to reduce my anxiety.
- Know the meaningful ways to engage me positively in the testing 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 well-being.
- Know what visuals support my communication and have them prepared in advance.



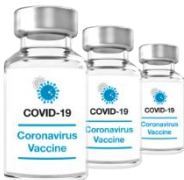
Addressing my distress

- 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 calm.



If you don't know the above, please find out - read my Personal Care Support Plan and talk to a familiar staff member who knows me well.

The COVID 19 vaccination

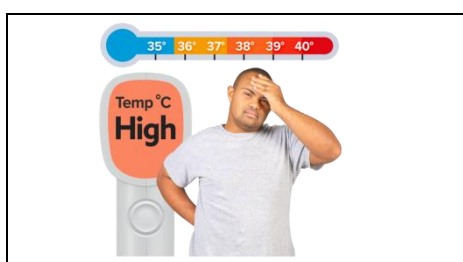
	COVID 19 / Coronavirus is a virus that can make some people sick.
	The government wants to keep everyone safe and well.
	The government is giving everyone the COVID 19 vaccine.
	The vaccine is medicine to help keep you well.
	The vaccine is given in an injection. The injection is in your arm.
	A doctor or nurse will give you the injection.



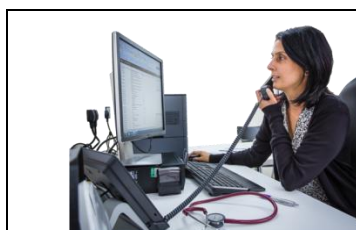
After the injection, you will need to wait for 15 minutes before you go home.



You will need to get one more injection in a few weeks time.



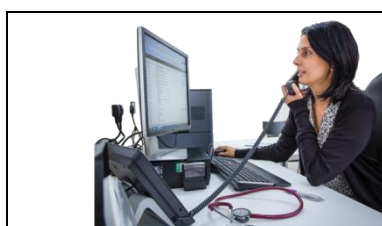
Your arm might be a little sore afterwards. You might have a temperature. This is ok.



If you feel ill you can ring your doctor.



After you have the vaccine, you must still wear a mask. You must still stay far away from other people.



If you want to know more about the vaccine, you can ask your doctor or nurse.

How you will be supported to have the COVID vaccination.



You will be given information about the COVID 19 vaccine in a way that helps you understand.



Staff can give you information like this easy read document.



Staff can use pictures to show you each step of the COVID 19 vaccination.



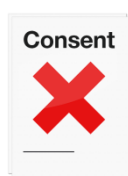
Staff can show you the special clothes that the person doing the vaccination will wear.



Staff or family can be with you when you get the vaccination.



If you have any questions about the vaccine, you can ask your doctor or nurse



Record of the Consent Process

Name: _____

Support staff name: _____

Date: _____

Each person has the right to refuse a treatment proposed (Supporting People's autonomy, HIQA 2016). Persons with disabilities must be involved in decision making about their own healthcare (Inclusion Ireland 14/04/2020).

- This document is designed to help you know how to support someone with the above communication profile to consent to the COVID 19 vaccination.
- On the next page is a record of the consent process form. It must be signed by the person before the procedure. If requested you, the staff member, may support a signature with (e.g. hand over hand support) but the person themselves must make their own choice and mark the page.
- A person can say 'no' or stop the procedure at any point even after they have signed this document.
- Please ensure you have read the person's Personal Care Support Plan / Communication Guidelines and offer additional supports during the procedure when needed (for example, letting the person know something nice is going to happen after – favourite drink, watch a film, go for a drive etc).

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

- ☐ Read information with familiar staff and verbally agreed
- ☐ Read information with familiar staff and pointed to the picture denoting 'Ok'
- ☐ Listened to information and used Lamh, gesture, body language or Sign Language to agree
- ☐ Listened to the information and used a communication board or communication device to agree
- ☐ During the procedure appeared calm and relaxed
- ☐ During the procedure followed instructions to roll up their sleeve, put their arm out, etc
- ☐ Did not appear upset
- ☐ Did not obviously express they did not want the vaccination
- ☐ Did not more subtly express they did not want the vaccination
- ☐ Other: _____



The government are giving everyone the COVID 19 vaccination.



- On (*day*), the GP/Nurse/etc will come to (*location*).
- They will give you an injection in your arm.
- Then the treatment is finished.
- You can say 'stop' at any time.

Do you want to have the vaccination?



Ok



Not ok

Appendix 5 – Case Studies

Case Example 1

Eileen is 70 years of age, has a moderate intellectual disability and lives in a group home with two other women. Eileen has lived in residential care since her teenage years. Her parents are deceased and Eileen has siblings living in different parts of the country who visit frequently and who like to be informed about Eileen's health and well-being. Eileen has an underactive thyroid and has annual bloods tests to check her thyroid function. Eileen does not like blood tests but tolerates same with the support of her key-worker and staff team.

In preparation for the HSE COVID-19 vaccination, Eileen's support staff have started discussing the roll-out of the vaccination programme with all of the women in the house. They have explained that the HSE is offering the vaccination to older people living in residential care facilities and that Eileen and her house-mate will be offered the vaccine. The staff have used the communication supports contained in this resource pack to assist Eileen's understanding of the reason for the vaccine. With repeated and informal discussions over a week it is clear that Eileen understands that the COVID-19 vaccine can prevent people getting very sick if they contract the Coronavirus. Eileen understands that the vaccination will involve two injections at 3 week intervals. Eileen understands that she may have a sore arm and feel tired after the vaccine. Eileen's support team have documented these discussions with Eileen in her progress notes and clinical file.

A few days before Eileen is scheduled to be offered the vaccine her support team have used the ethical decision making framework contained in this resource pack to document the fact that, in their view, Eileen has the capacity to give informed consent to accepting the COVID-19 vaccination.

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

Case Example 2

Margaret is an autistic woman who is 45 years of age and has a moderate intellectual disability. 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 staff support. 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 HSE COVID-19 vaccination, 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 avail of 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 contract 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 staff 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 complete the ethical decision framework contained in this resource pack and provide this to the vaccination team.

Case Example 3

John is a 35-year-old man with a severe intellectual disability, visual impairment and who is tactile defensive. 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 staff 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 have capacity to understand and retain the benefits of the vaccination or the risks of not availing of the vaccination. John's staff 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.

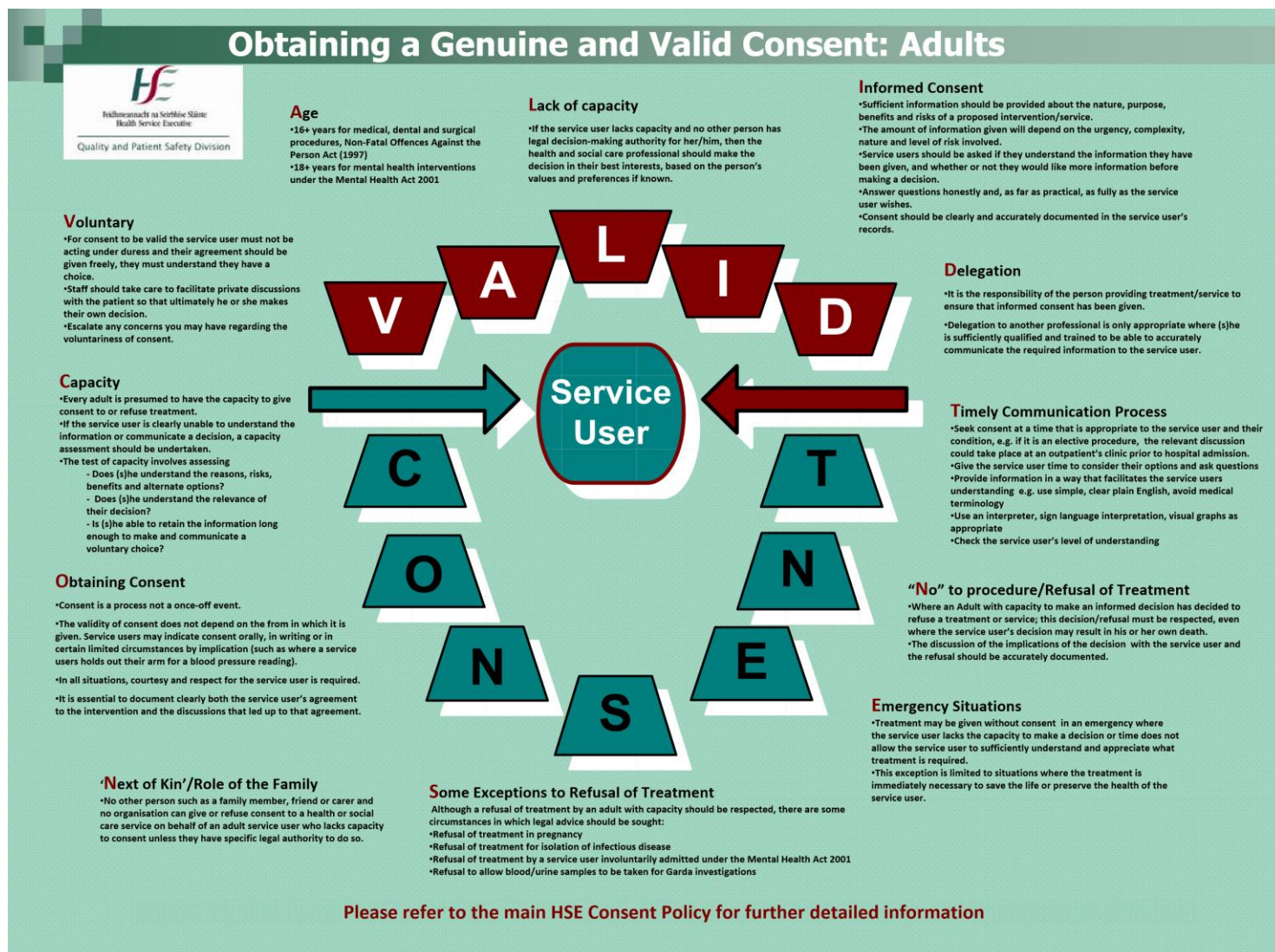
The staff team meet with John's parents and explain that while John does not have capacity to provide informed consent to the COVID-19 vaccination, it is not sufficient for his parents to provide consent on his behalf. It is agreed to use the ethical decision making framework contained within this resource 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 avail of 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 and legal grounds.

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

Appendix 6 – References

1. Assisted Decision Making Act 2015.
2. HSE Policy on Consent <http://bit.ly/ConsentQID>
3. Mental Health Act 2001
4. Advices of the Attorney General to the HSE regarding the Covid Vaccine 2020.
5. STATUTORY INSTRUMENTS. S.I. No. 698 of 2020 MEDICINAL PRODUCTS (PRESCRIPTION AND CONTROL OF SUPPLY) (AMENDMENT) (NO. 7) REGULATIONS 2020

Appendix 7 - Additional Tools:



Link to Mencap easy read: <https://www.mencap.org.uk/sites/default/files/2020-12/Vaccines%20ER%20Final%20Version%208-12-20%20%282%29.pdf>

Link to Mencap questions and answers about the vaccine::
<https://www.mencap.org.uk/sites/default/files/2021-01/Vaccine%20Q%26A.pdf>

Link to EasyHealth easy read:
<https://www.easyhealth.org.uk/wp-content/uploads/2020/03/Coronavirus-Easy-Read.pdf>

NHS video about what vaccines are:

https://www.youtube.com/watch?v=M3Wh23PDnfE&feature=emb_logo&ab_channel=NHSEnglandandNHSImprovement

Injections easy read:
<https://happylearners.info/pdf/injections.pdf>

Injections easy read 2:
<https://happylearners.info/pdf/injections2.pdf>

Coronavirus social story:
https://www.youtube.com/watch?v=Us8nf15r-g&feature=youtu.be&ab_channel=NationalFragileXFoundation

NHS easy read 'Looking after your feelings and your body':
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/876996/Easy_read_looking_after_your_feelings_and_body.pdf

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