Guidance Note:

Supporting the consent process in those who lack capacity and are anxious / or refusing vaccination v1.1 5 Feb 2021

National Consent for COVID 19 Vaccination Working Group

The following guidance may be helpful to when vaccination is refused by someone who, despite all support, lacks capacity to decide regarding vaccination. Some tips below may also be helpful when a person is anxious about the vaccine injection process.

When vaccination is for the benefit of the person, every practicable effort should be made to persuade (not force) them to accept it. "For the benefit of" includes not only the potential for preventing serious Covid illness (the risk of which will vary depending on factors like where the person lives and their age and underlying health conditions) but also the potential for vaccination against their wishes to cause distress and to damage trust and relationships. Benefit also includes benefit to society in general, for example, in increasing herd immunity to the virus.

Those who refuse vaccination are not a homogenous group. The reasons for refusal should be explored. For some, additional time, support and explanation will allow the person, even if unable to consent, to agree with vaccination. For others, often those with the most severe cognitive impairment, this may not be achievable, and the person may, even with support, be entirely unable to understand what is proposed. Refusal of vaccination in such cases may be part of a general resistiveness to care.

Those close to the person will be best at determining how someone can best be persuaded to accept vaccination. Measures that may be helpful include:

Preparation during the period before vaccination:

- Talking about the vaccine in a natural way.
- Use of social stories outlining what the vaccine involves
- Desensitisation measures to help relax and build up confidence in vaccination process
- Light hearted role-play at scheduled times every day.

Providing appropriate support and environment:

- Having a familiar, trusted person present to reassure and support
- Providing a quiet space with as little stimulation as possible and plenty of time so the person doesn't feel pressured or rushed
- Distracting the person: identifying things that help distract such as music on headphones, a favourite object, squeezing a stress ball or a chat about favourite things
- Motivating the person: providing something the person really likes, such as a favourite drink, dessert, magazine, to look forward to after vaccination

Supporting those with anxiety and fear of needles

The use of numbing cream or pain relief for the area of injection may be helpful for some people.

Although it is not appropriate to use physical force to vaccinate, some physical support may be appropriate and sometimes needed to ensure the safety of the person and vaccinator. Those close to the person will be best at determining what will be acceptable for that person. Such measures include

therapeutic touch and clinical holding, for example, to reassure the person or to stabilise the arm of someone who may have tremors or unexpected movements.

In all situations the level of intervention used to support the administration of the vaccine needs to be proportionate to the situation and level of potential risk posed to the person in not receiving the vaccine at that time. While the logistics of vaccine timing and administration may pose particular challenges these should not be the overriding determinants in administering the vaccine in a person who is refusing it and who lacks the understanding or capacity to engage with the process.