



## Prompts to support flu vaccination decision making for people with a learning disability.

NHS England, Safeguarding Team, London Region  
Learning Disability, Autism & SEND team, London Region  
NHS England, Vaccination Directorate, London Region

1 September 2024 Version 3

### Background

The Confidential Inquiry into the Deaths of People with Learning Disability<sup>1</sup> (CIPOLD) in 2013 found that respiratory problems were a major cause of death and recommendations from the report led to people with a learning disability being identified as a high-risk group and included in seasonal influenza vaccination programmes. Learning from lives and deaths programme (LeDeR)<sup>2</sup> have shown that respiratory problems remain a major cause of death of people with learning disabilities<sup>3</sup>.

### Aim of the Document

- Provide a brief prompt list on approach to be taken to support flu vaccination decision making for people with a learning disability.
- Useful resources to support the process of providing information and communicating to the individual and their families regarding the vaccination

### Please note

There cannot be a blanket decision-making approach to any vaccinations being in the best interests for individuals as this would be contrary to the requirement of the Mental Capacity Act 2005 that it is the best interests of that person at that particular time which are determinative.

<sup>1</sup> <http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf>

<sup>2</sup> <https://leder.nhs.uk/>

<sup>3</sup> <https://www.gov.uk/government/publications/flu-vaccinations-for-people-with-learning-disabilities/flu-vaccinations-supporting-people-with-learning-disabilities>

## Prompts to support approach and decision making when an individual lacks capacity<sup>4</sup>.

### Knowing the facts about influenza and the vaccination.

Individuals or their families need to understand what flu is and how it can affect people.

There is lots of information about flu and individuals need to be provided with the opportunity:

- To look at the information provided and have any questions answered.
- To find out what the vaccine is, how it works and how it can prevent people becoming seriously ill from the influenza virus.

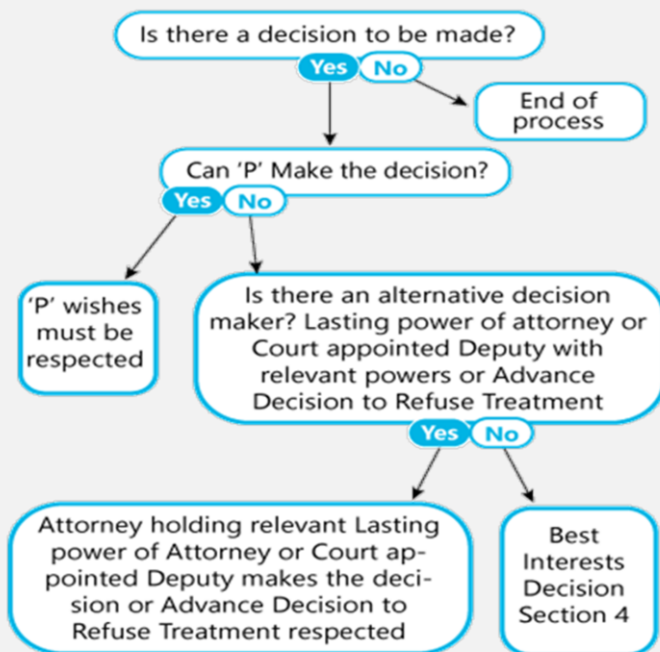
Healthcare professionals offering the vaccine to someone who may lack the mental capacity to consent should take all practicable steps to support the person to make the decision for themselves. This means the individual with a learning disability will need:

1. Comprehensive information about the vaccine and the benefits it can provide.
2. What the side effects of the vaccine might be.
3. To understand what could happen if they choose not to have the vaccine.
4. The process involved in having the vaccine.

When helping a person to decide, it is important to think about what helps them make decisions and the type of information that works for them.

Healthcare professionals should record steps taken and response from the individual.

### Decision making under the Mental Capacity Act 2005



Section 3(1) Mental Capacity Act states that a person is unable to make a decision for themselves if they are unable:

- to understand the information relevant to the decision; or
- to retain that information; or
- to use or weigh that information as part of the process of making the decision; or to communicate his decision (whether by talking, using sign language or any other means).

<sup>4</sup> <https://mentalcapacitytoolkit.co.uk/>

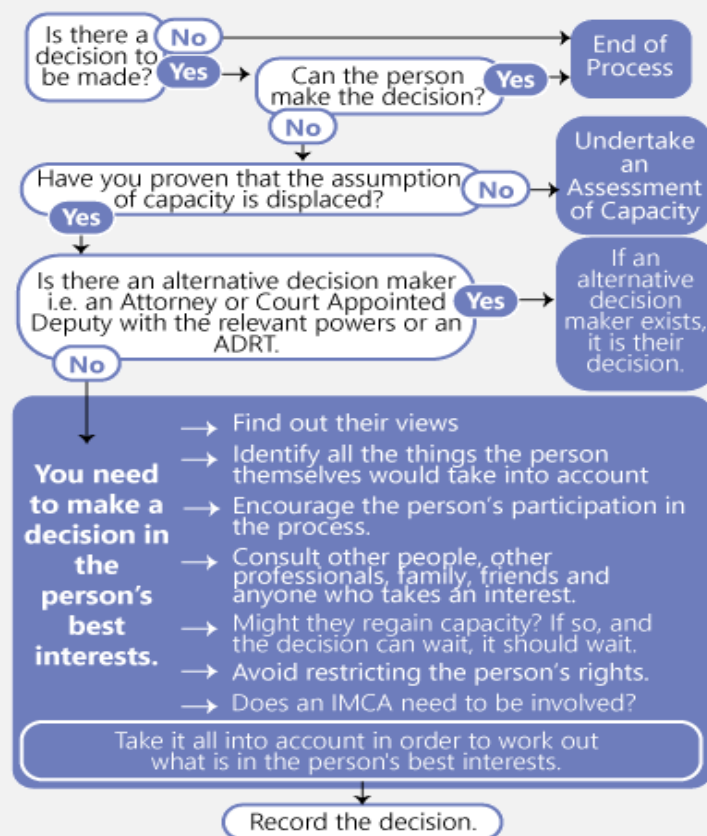
**Assessment of capacity:** In order to assess an individual's capacity a three-part test is required. Professionals must ask themselves:

- Is the person unable to make the decision in question? If so:
- Is there an impairment or disturbance in the functioning of the person's mind or brain? If so:
- Is the person's inability to make the decision because of the identified impairment or disturbance?

**When an individual is not able to decide regarding the flu vaccine:**

If the above has been tried and the person is not able to understand and make a decision, then a 'best interests' decision must be made by relevant professionals in accordance with the Mental Capacity Act 2005.

**Best interest decisions**



**Who is the decision-maker if the person does not have capacity to consent?**

- If there is no attorney or deputy with powers, the healthcare professional administering the vaccine will be the person to make the final decision whether to administer it.
- It is very likely that their decision as to whether or not to administer will be based upon information collected by others, including from family members and others interested in the person's welfare, in particular as to whether or not the person would want the vaccine. It is for this reason that it is so important that steps are taken well in advance of the day when the vaccination is to be delivered.

## Support with best interest decision making

Care workers and family members should be able to supply the medical professional, who will be the decision maker, with supporting information. For example:

- Why would it be in a person's best interests to have the vaccine?
- What are the risks to that person if they don't have it and the risk to other residents and staff?

The medical professional can consider the benefits and risks of the vaccine utilising the following guidance to help inform the best interests decision:

Flu vaccination programme 2024 to 2025<sup>5</sup>  
JCVI Guidance, Influenza: The green book, chapter 19<sup>6</sup>

The medical professional could consider an alternative such as the nasal spray<sup>7</sup> instead of an injectable vaccination where indicated.

The flu vaccination does not amount to serious medical treatment. It is analogous to other routine vaccinations and the considerations for best interest will be similar.

## When there are differing views regarding the flu vaccination

- Consider if all parties have been provided with adequate information and had any questions regarding the information answered.
- Does the family require more time to process the information and decide?
- Review the individual's history in having vaccinations. Have they had vaccines in the past?
- If it is felt the individual's deputy or attorney is not making the decision based on the individual's best interest seek legal advice from your organisation.
- Consider a referral to the local Community Learning Disability Service<sup>8</sup> for support and advice.

## Resources to support approach and decision making

- Flu vaccination easy read invitation letter<sup>9</sup>
- Influenza easy read leaflet<sup>10</sup>
- Flu Communications Toolkit<sup>11</sup>
- Flu jab for people with a learning disability video<sup>12</sup>

---

<sup>5</sup>[National flu immunisation programme plan 2024 to 2025 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/publications/national-flu-immunisation-programme-plan-2024-to-2025)

<sup>6</sup><https://www.gov.uk/government/publications/influenza-the-green-book-chapter-19>

<sup>7</sup>[Flu vaccination programme 2024 to 2025: healthcare practitioners - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/publications/flu-vaccination-programme-2024-to-2025-healthcare-practitioners)

<sup>8</sup><https://www.england.nhs.uk/london/london-clinical-networks/our-networks/learning-disabilities/publications/>

<sup>9</sup><https://www.gov.uk/government/publications/flu-vaccination-easy-read-invitation-letter-template>

<sup>10</sup>[Flu vaccination: easy-read flu vaccination resources - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/publications/flu-vaccination-easy-read-flu-vaccination-resources)

<sup>11</sup><https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2020/09/Flu-Comms-Toolkit-learning-disability-focus-2020-21.pdf>

<sup>12</sup><https://www.youtube.com/watch?app=desktop&v=TYgH181Xijs>

## Mental Capacity Act Specific Guidance and Tools

- The Mental Capacity Act toolkit<sup>13</sup> aims to support health and social care professionals working with individuals whose decision- making capacity is limited, fluctuating, absent or compromised.
- The BMA Ethics Toolkit Mental Capacity Act - England and Wales<sup>14</sup>.

### Best practice checklist to ensure consideration of all possible solutions to assist people with a learning disability to have vaccinations.

1. Ensure all people who have a learning disability are on the GP Learning Disability register.
2. Help identify individuals who may have a learning disability. See General Practice guidance: Improving identification of people with a learning disability for guidance<sup>15</sup>.
3. Invite /sign post all people with a learning disability on the GP Learning Disability register for their Learning Disability Annual Health Check<sup>16</sup> and make every contact count<sup>17</sup> by using the health check to talk about and offer vaccinations.
4. Ensure communication preferences are recorded on your systems in line with the Accessible Information Standard<sup>18</sup> and use the preferred communication method.
5. Ensure any reasonable adjustments required are recorded and implemented in accordance with the Equality Act 2010<sup>19</sup>. Give particular attention to environmental and sensory needs when considering reasonable adjustments. Some examples of reasonable adjustments such as perhaps offering a vaccination in a car can be found [here](#)<sup>20</sup>.
6. Use current resources specifically aimed at supporting people with learning disabilities for example: Top tips for primary care teams<sup>21</sup>.
7. Ensure you understand your responsibilities under the Mental Capacity Act 2005<sup>22</sup>.
8. Consider who else within the individuals' network might be able to offer support.

---

<sup>13</sup> [Mental Capacity Toolkit](#)

<sup>14</sup> <https://www.bma.org.uk/media/4z1l3khg/mental-capacity-act-england-and-wales.pdf>

<sup>15</sup> <https://www.england.nhs.uk/wp-content/uploads/2019/10/improving-identification-of-people-with-a-learning-disability-guidance-for-general-practice.pdf>

<sup>16</sup> <https://www.mencap.org.uk/easyread/annual-health-checks>

<sup>17</sup> <https://www.mecclink.co.uk/london/>

<sup>18</sup> <https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/>

<sup>19</sup> [Reasonable adjustments: a legal duty - GOV.UK \(www.gov.uk\)](#)

<sup>20</sup> <https://www.england.nhs.uk/wp-content/uploads/2021/02/COVID-19-vaccination-training-for-clinicians-feb-2021.pdf>

<sup>21</sup> <https://www.england.nhs.uk/wp-content/uploads/2021/02/COVID-19-vaccination-training-for-clinicians-feb-2021.pdf>

<sup>22</sup> <https://mentalcapacitytoolkit.co.uk/>

9. Check if the individual is known to and /or would benefit from a referral to the local Community Learning Disability Service<sup>23</sup> for support and advice.
10. Where the individual might have a fear of needles, consider desensitisation<sup>24</sup> and support people with a learning disability to overcome needle phobias<sup>25</sup>.

---

<sup>23</sup> <https://www.england.nhs.uk/london/london-clinical-networks/our-networks/learning-disabilities/publications/>

<sup>24</sup> <https://www.guysandstthomas.nhs.uk/health-information/needle-phobia-and-overcoming-your-fear>

<sup>25</sup> <https://www.healthylondon.org/wp-content/uploads/2020/10/OVER-COMING-NEEDLE-PHOBIA-presentation-PDF.pdf>