

Gillick Competence in the age of Covid-19

Empowering Children to Make Informed Medical Decisions

A MANUAL FOR PARENTS





Introduction

It is an established legal principle in the UK that children can make their own healthcare decisions (within certain limitations) if they are considered competent, that is, mentally and emotionally mature enough. Such a child is called Gillick competent, after the court case that established this law.

Following media reports that children of secondary school age may be offered the Covid-19 vaccination in school from September 2021, this subject has found renewed interest. As with HPV and teenage booster vaccinations, schools should notify parents of scheduled vaccination dates and send consent forms. However, a competent child can override parents' decision to consent or to refuse consent.

This document aims to give parents and others with parental responsibility practical guidance on empowering children to make informed decisions around consent and to help prepare them for the consequences of this decision.

As a charity we work for respect for parental healthcare decisions. We do not tell parents what to do and we rarely take a position for or against any particular healthcare measure. However, we do consider it reasonable for parents to decline vaccinations. Declining a prophylactic medication when a child isn't ill would not normally sound controversial, was it not for the polarised and emotive debate surrounding vaccinations.

At the time of writing (May 2021) there is considerable opposition to vaccinating children against SARS-CoV-2 among scientists. See for example the BMJ here and here and the Lancet here and here.

What follows in this document should be read in this context.

Consent and Gillick competence in the context of school vaccinations

The law courts in the UK accept that children become more mature and autonomous as they get older and that this gives them the right to make their own medical decisions in certain circumstances. Young persons aged 16 or 17 are assumed to have that maturity and they can decide for themselves, except in some extreme cases. Below that age, each case is judged on its merits. How mature is the child? How serious is the decision they are making and what are the consequences? Vaccinations are not considered a serious intervention and it has to be expected that the courts will see Covid-19 vaccines in the same light.



This sets the level of competence needed to make that decision relatively low.

When Gillick competence was established as a legal test, its application was fairly narrow. Over the years, however, the child's competence to decide for themselves has become a factor in all sorts of areas, including school vaccinations, disagreement between parents themselves, disagreement between parents and doctors and disagreement between parents and state authorities.

It is right that children's views are taken into account. A school environment poses problems, however. Our charity has written to NHS trusts and Public Health England to highlight these issues and we believe that obtaining valid consent from a child in such a setting is unrealistic. However this hasn't been tested in court and parents are therefore best advised to assume that their consent or refusal of consent is not going to be the final word.

Gillick Competence and Valid Consent

In most situations no medical intervention may be administered without valid consent. In order for it to be valid, i.e. lawful, consent must be:

- given voluntarily and freely, without pressure or undue influence being exerted on the person either to accept or refuse treatment.
- informed, which means your child needs to be given age-appropriate information to understand the nature and purpose of the vaccination as well as any relevant information pertaining to risk.
- given by a child who has the ability and sufficient maturity to understand what is involved and weigh up the options.

See also Understanding Valid Consent in Medicine and Consent Process Check List

Although the Care Quality Commission expects Health Care Professionals to be trained in Gillick competence assessments, we have not found any evidence of any consistently applied training or even an assessment framework. We have asked NHS trusts, Public Health England and care commissioning groups about any training given to school immunisation teams but have not had a response at the time of writing.

The Process of Empowering our Children

A multi focus approach is needed to empower children to make an informed decision which will stand up to possible scrutiny and judgement by peers and teachers. Putting our emotions aside, we can equip our children to anticipate and manage the consequences of standing by the decisions they may have to make in our absence.

Listening and being child-led are key to this process. It is vital to keep communication open and non-judgemental, regardless of the direction the child is taking. It is hard to support your child in their choice if communication breaks down and you subsequently don't know the entire picture.

- Be mindful of how difficult it is for a child to juggle the expectations of other people in positions of authority, peer pressure, and the wishes and beliefs of parents. Your child will respond to what you do, not what you say. They will either follow what you do or do the opposite, depending on how they feel about you and their own sense of what is right.
- Regardless of how difficult this process is for you, come alongside your child
 to build a foundation of knowledge as a solid basis for future critical thinking,
 rather than avoiding the issue in the hope that it does not exist or doesn't
 affect you, and them.
- Every child is different and will have different motivators. You know your child better than anybody. A child driven by performance, or by being "good", will respond differently to a child motivated by acceptance, for example. Use your unique knowledge of your child and what drives them to enlighten, prepare and empower them.

Take your time. Plan for several sessions and discussions. Prepare beforehand.

Why the Parent's Respect for the Child's Choice is Important

Parenting the decision-making process built on free will is far more powerful than imposing your point of view on your child. The reality is that your children will have to make decisions increasingly by themselves as they get older and they may have to communicate their choice independently and robustly in a situation where their right to privacy may not be honoured.

Understanding the Decision-Making Process using Identity Aspects

Guiding your child through a sound decision-making process, by allowing them to deconstruct and analyse the issue against key aspects of their own identity provides them with a vital life skill. It will also add to their development and understanding of who they are in this world. Consider gradually introducing concepts you wish them to consider, pacing the effort so as not to overwhelm. You may start by selecting topics of interest to them as research subjects first.

- Mind: Prepare the process by discussing your child's own perceived strengths. Keep age and level of independence as your guides and be childled in terms of pace and scope. Find examples where they were able to firmly stand their ground on issues important to them.
- Free Will: A child communicating a decision made of their own free will is more robust and confident when faced with scrutiny from peers and authority figures. A child acting from a place of obedience or compliance is more easily influenced by others and can become distressed. It is important that you and your child understand, without judgement, where they are on this spectrum of independence and work out how best to support them.
- **Knowledge**: Discuss with your child the importance of having a broadspectrum knowledge base from which to begin the process of making an informed choice. Explore their current level of knowledge, have them ask questions and plan how to acquire the information lacking.

Constructing the Decision-Making Process

Don't be afraid to discuss the science behind the illness and the vaccine. We make science-based decisions about all sorts of things on a daily basis: foods we eat, medical interventions we choose, etc. Use a variety of reputable resources. If you find inconsistencies over time or across agencies, compose questions about these together.

- **Before broaching the issue**: Decide on a topic they are interested in and compare the results of a Google search against a different search engine or the coverage of one media outlet against another. Using this skill, look at research on a topic of their choosing and examine who commissioned/funded each item and why. Explain what conflicts of interest are. Examine information sources, their 'community standards' and how they influence our perceptions. Highlight vague or propaganda language and the fact that sometimes it's not what is said but what is left out that causes distortion of facts. Give examples of media stories with a slant. Before examining the facts that are presented, unpack information sources and question with your child how reliable they are and whom they represent.
- Vaccination Risk/Benefit Analysis: Look up and discuss what the media and school say are the benefits and risks of choosing to have this vaccination. Regardless of your parental viewpoint, don't gloss over the benefits. Transparency and authenticity are pivotal to your child trusting you on the issue. Your child will be deluged with the benefits of vaccinations at school, so the importance of unpacking the risk/benefit ratio is essential for them to be able to develop a sound decision-making process. The next step is to explore official documentation on risk. Once you have the data, you can prepare a risk/benefit analysis. This can be a table or a pair of lists of pros and cons. Be sure to weight the items according to how important they are to your child by prioritising them. Depending on your child, it may be appropriate to have factual references next to each of those points so they can then count or discount certain points depending on the evidence they have researched.

Social, Emotional and Societal Pressure

- Consequences of making the decision: Be mindful of your child's personality and their confidence in standing up in situations where they are in a minority. Be sensitive to how difficult this prospect may be for them and how that could influence their decision. It is important they realise that agreeing to have the vaccine because they don't want people to be mean to them is not consent. Discuss the concept of being a leader and a follower and the consequence of being either. It is important that they know they have the right to say if they are being made to feel uncomfortable.
- People in Position of Authority: Help your child to identify when people in a position of authority are voicing opinion rather than fact and to recognise this in other life situations.

- **Standing Strong**: If your child's opinion is different from the one being presented by the school, empower them to challenge this in a way that shows they are critically thinking rather than being rebellious. They may want to ask about the danger Covid-19 poses to their age group or seek their teacher's opinion on any of the reserch they have done with you.
- A Right to Privacy: Ensure your child understands that they have the right to make their decision without having to justify it. Their medical choices shouldn't have to be discussed with teachers, strangers or in front of their school friends. If your child has made their decision with you and is being challenged at school to justify their choice, they can simply refuse to engage in debate. It is when going against a parent's decision that a child should be assessed for competence and prove they have the required knowledge, not otherwise.
- Logistics: Prepare your child for the logistics of how vaccines are likely to be administered in a school environment and discuss coping strategies based on their decision. Having prior notice of vaccine administration day is important and there may be a build-up in conversations at the school. They may feel singled out on the day if they have chosen not to have the vaccine. You could discuss scenario-based coping strategies to help them through. Consideration may be given to missing school on the day of the vaccine administration. If your child is anxious about the whole situation, then this tactic could be used as an avoidance strategy. Be aware that catch-up days are often not announced in advance, so it is possible that the school vaccination clinic may be set up again, without notice, to 'mop up' those who have not yet received the vaccine. In the long term the decision will still have to be made.
- **Coping Strategies**: Discuss how to conduct or avoid the discussion by using avoidance, abstinence or measured responses. If the children are asked to put their hand up in class to identify their vaccination choice, they may choose not to participate. In a conversation, they can bring up a new topic. If they wish to discuss the issue, they can carry an item that exemplifies their decision, e.g. their risk/benefit analysis. This will help reinforce that theirs was a thoughtful decision-making process, although it is important they know that they are under no obligation to do this. They could simply smile and walk away. Let your child know that you are a team and that you will support them in their choices.

Acknowledging your child's feelings about what is going on with class mates on a daily basis is important to avoid your child becoming anxious or even depressed about it. Encourage your child to maintain friendships with those who have made different decisions from theirs. They are not enemies all of a

sudden just because they have different views. Also, that when they are ready and, on their terms, then a discussion between them is healthy and can even strengthen their friendship through mutual respect.

Body Autonomy and changing one's mind

If a child consents to receiving a vaccine, this is not irrevocable. They can change their mind at any time, up to the moment the vaccine is about to be administered. All they need to say is "I have changed my mind, I don't want it". Talk to your child about what words they would use should they ever find themselves in that situation. They may feel confident and say they are withdrawing their consent, or they may want to express that they are really not sure about it and would prefer to delay. The wording is secondary. What matters is that they decline having the vaccine at that time.

In the unlikely event that they are being ignored, they have every right to get up and leave or to physically resist. We do not expect this to ever become necessary but even without going to extremes, it can be helpful to get up or to leave the room as a gesture of finality and to show that no discussion is wanted.

Advocating for your Child

If you feel that your child is at risk of making a medical decision without fully understanding the consequences or due to pressure from others, consider writing a calm, measured letter to the school.

You could state that you do not believe your child understands the consequences of accepting or declining the vaccine and therefore lacks Gillick competence. Warn them that you will ask to see verbatim records of how such competence was assessed. You could also say that you do not believe their consent would be lawful due to pressure from others.

Appendix 1 - Ways to identify undue influence

The following points are adapted from Biderman's Chart of Coercion (various versions are available online), originally published by Amnesty International in a report on torture. It has since been used for domestic abuse cases and can also help parents identify undue influence exerted on their child. Remember to check your own influence on your child as well.

- Induced fear of losing social support or of being discredited or ridiculed
- Rejection of alternate information and separate opinions. Rules exist about permissible topics to discuss. Communication is highly controlled.
- Negative consequences for any actions that show resistance or independence
- Wearing someone out emotionally so that resistance becomes too costly;
 compliance in order to be left alone
- Being singled out or publicly shamed
- Prolonged pressure to change one's mind
- Told or implied that bad things will happen if they don't comply; implied blame for the suffering of others; non-compliance labelled "selfish"
- Not respecting body autonomy
- Rules that are illogical or contradictory but have to be followed because they are rules

Appendix 2 - Quality of Information

When performing research, it is important to assess the quality of information that is most readily accessible. These days, the first few pages of results from any online search are from sources that agree with government policy and may not reflect best science. Below are some examples allowing you to compare and assess data sources for independence and balance.

- 1. Look up the community guidelines if it is a social media site. For example YouTube community guidelines say: "YouTube doesn't allow content that ... contradicts local health authorities' or the World Health Organization's (WHO) medical information about COVID-19."
- 2. Watch reporting from a mainstream news outlet such as the BBC. Do you find balanced information being broadcast?
- 3. Check the funding and collaboration patterns of the information source in questions. For example the UK medicines regulator MHRA has published its board members' conflicts of interest or check the conflict of interest information included in any medical journal publications.
- 4. Pick out a leaflet or learning material from school and talk about whether it gives balanced information or reads like promotional material. For example, here is one that has been critiqued by a UK GP.
- 5. Compare the language of how dissenting voices are portrayed, for example here vs here.
- 6. Review these articles in the New York Times and the BMJ and consider the consequences on available information.
- 7. On 11th September 2019 a doctor from the Wellcome Trust appeared on BBC Radio 4's Today programme blaming anti-vaxxers for the resurgence of Scarlet Fever. However, the UK has never had routine Scarlet Fever vaccinations. What does this mean and how does it affect their trustworthiness?
- 8. Compare internet searches for "children covid vaccination" to "bmj children covid vaccination" or "lancet children covid vaccination". The BMJ and Lancet are world-leading medical journals. How do the results compare?

Appendix 3 – Data sources

Once you are ready to start looking at the actual data, you will need sources that are reliable and well referenced. It would not be right for us to tell you what information to look up or how much weight to give to each. However, if you don't know where to start, some of the following points may be helpful.

Sources:

UK medicines regulator MHRA information on vaccines safety

Office of National Statistics Coronavirus data

BMJ – a leading medical journal

The Lancet Infectious Diseases – a leading medical journal

Pubmed – international database of medical research and scientific literature

The Green Book – UK government immunisation manual

VAERS – US based vaccines adverse events reporting system

Some questions to challenge yourself

How has official advice changed over time? What was official policy a year ago (e.g. on wearing masks, vaccine passports, mandatory vaccinations)? What is the policy now?

How is vaccine efficacy measured? Do all scientists agree that the measure is adequate?

Why is there a campaign asking that all clinical trial data should be made public, not just what pharmaceutical companies choose to publish? Why does it matter?

Is there a scientific consensus that vaccinating children against Covid-19 is a good idea? What does the government's Green Book say?

Does the vaccine stop someone from contracting Covid-19 or from spreading it?

Appendix 4 - Consent process check list relating to children under 16

This list is based on UK regulatory guidelines and best practice (General Medical Council) and is aimed at most common situations. Its aim is to help parents and medical staff ensure that parental consent to any intervention has lawfully been obtained and to encourage best practice.

Children should be included in the process as appropriate to their level of maturity.

Has valid consent been obtained from the patient?

- Has required information been given in ways the parent/child can understand?
- This should include diagnosis & prognosis, any uncertainties, treatment options incl. option not to treat, purpose of each treatment, incl. any risks and likelihood of success, side-effects & complications, in particular serious adverse outcomes.
- Has the information been given in a balanced way, disclosing any conflicts of interest?
- Has the parent / child been encouraged to ask questions?
- Have staff checked if the information is understood and whether more information is wanted?
- Has the parent or child been told they can change their mind at any time?
- Have they been given time to decide?
- No pressure has been put on parents and their decision has been respected?
- Are the medical staff involved suitably trained, have sufficient knowledge of the proposed investigation or treatment, incl. risks involved, and understand the GMC guidelines?
- If consent is given by a competent minor, has all relevant information been provided and discussed before they were assessed as competent to understand such information?