



**15<sup>th</sup> May 2020**

## **Formal Advice**

### **Antibody Testing Considerations for Children and Young People**

I welcome the opportunity to provide further information on children's rights in the context of antibody testing for those aged under 18 years old. I would however highlight that I was consulted with short timescales, which makes scrutiny and advice very challenging. I appreciate that the current public health situation has been fast-moving, however the plan to purchase and administer antibody testing must have been considered and decided upon quite some time in advance of seeking advice on the implications for children's rights. Considerations as to the impact of decisions on the rights of children and young people and indeed adults should be embedded at the beginning of the decision-making process to allow for a human rights-based approach to decision making.

It is important that children and young people's right to be involved in decisions which affect them are respected. The United Nations Committee on the Rights of the Child have highlighted that the state is required to ' [P]rovide opportunities for children's views to be heard and taken into account in decision-making processes on the pandemic. Children should understand what is happening and feel that they are taking part in the decisions that are being made in response to the pandemic.'<sup>1</sup> This makes it clear that the onus is on the Government to ensure meaningful engagement with children on this issue.

All children and young people have rights protections under the United Nations Convention on the Rights of the Child (UNCRC), as extended to Jersey in 2014. This includes the right to life<sup>2</sup>, the right to the highest attainable standard of health<sup>3</sup>, as well as the right to privacy<sup>4</sup>.

It is vital that robust consideration is given to children and young people's rights under international as well as domestic law prior to any decisions being made. In order to support these considerations, I have grouped my key questions and concerns into a number of areas, as set out below.

#### **General points**

- Is the testing lawful?
- Have any children and young people been asked about this programme? If not, why not?
- Why hasn't there been information and consultation on this sooner?
- The UK jurisdictions have now diverged on testing, as on other matters; which approach is Jersey planning to take?

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<sup>1</sup> See paragraph 11, available at <https://www.childcomjersey.org.je/publications/international/un-committee-on-the-rights-of-the-child-covid-19-statement/>

<sup>2</sup> Article 6, United Nations Convention on the Rights of the Child

<sup>3</sup> Article 24, United Nations Convention on the Rights of the Child

<sup>4</sup> Article 16, United Nations Convention on the Rights of the Child

- How are children in the care system or living other than with birth families to be safeguarded, both them and their data?

### **Consent and Capacity**

In order to be able to consent, children and young people must be fully informed and so there is a need for child-appropriate resources and information to support decision making. This principle is reflected in the Data Protection (Jersey) Law 2018, which places an emphasis on informed consent as being true consent.

Under the Consent to Medical Treatment (Jersey) Law 1973, those aged 16 years and over can consent to medical treatment, however the age limit does not fully take into account the evolving capacities of children and young people.

In England, a child or young person can be identified as having capacity to give consent to medical treatment below the age of 16 through the 'Gillick Competency' test, which provides that "whether or not a child is capable of giving the necessary consent will depend on the child's maturity and understanding and the nature of the consent required. The child must be capable of making a reasonable assessment of the advantages and disadvantages of the treatment proposed, so the consent, if given, can be properly and fairly described as true consent".<sup>5</sup>

- Can children and young people aged under 18 consent to this?
- How is this to be interpreted for children who do not have English as a first language, children with communication issues or other special educational needs? What happens in situations where children are not able to give informed, swift or absolutely certain consent?
- Does a parent have to also give consent if the child is aged under 13? Under the Data Protection (Jersey) Law 2018, "a child under the age of 13 may not give valid consent to the processing of his or her personal data by a controller for the purposes of an information society service but valid consent on behalf of that child may be given by a person with parental responsibility for him or her."<sup>6</sup>
- What if a parent consents but child does not?
- If a child were to refuse a test, would this have any adverse consequences in terms of how they will be allowed to enjoy their education, recreational activities or health care, for example? This would then raise privacy concerns around data sharing on who has or has not had a test.
- It is our understanding that the approach adopted in England provides that children aged 12 and over are treated as having capacity to consent to the swab diagnostic tests and are assisted by medical staff to administer the test. Those aged between 5 -12 has been offered testing on a voluntary basis which is carried out by a parent or guardian. However, the swab tests are distinct from antibody tests which are blood tests and therefore more invasive.

### **Ethics and Data**

There are a host of ethical considerations which must be addressed. Universities often have good practice in this area and can be learned from. There are also data protection issues, medical research issues, and liability issues which need to be considered. Ethics panels need medical and legal members, and to be sensitive to local issues, such as the

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<sup>5</sup> Gillick v West Norfolk & Wisbeck Area Health Authority [1986] AC 112

<sup>6</sup> 11 (4) Data Protection (Jersey) Law 2018

anonymisation of data in a voluntary programme on a small island and the implications for privacy.

- Is it ethical?
- Is this for the benefit of the child's health or research? The World Health Organisation "recommends the use of these new point-of-care immunodiagnostic tests only in research settings. They should not be used in any other setting, including for clinical decision-making, until evidence supporting use for specific indications is available."<sup>7</sup>
- Has ethics approval been granted for this research?
- How will the personal data be used?
- How will the personal data be stored?
- How will the personal data be shared?
- If Jersey is to follow the approach of 'test & trace', who is responsible for the data and who owns the information, both in the immediate term and long term?

I would be pleased to provide further advice on any guidance or planning that may be in the pipeline.

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<sup>7</sup> <https://www.who.int/news-room/commentaries/detail/advice-on-the-use-of-point-of-care-immunodiagnostic-tests-for-covid-19>