

# APiC Research with Children and Young People: Ethics and Data Protection Policy

There are high ethical and data protection standards that must be followed when involving children and young people in research, to ensure they are protected and their rights are respected. APiC is fully committed to conducting work with the highest of ethical integrity and ensuring compliance with all regulations set out in the Data Protection Act 2018 which incorporate the General Data Protection Regulation (GDPR) 2018 (Europe-Wide). This document sets out the ethical and data protection principles that APiC abides by to ensure compliance with law, regulations, guidelines, and other considerations pertinent to research with children and young people.

In developing these principles, we have been guided by up-to-date codes of practice set out by prominent research funding bodies, high-quality academic publications and leading research institutions. Within these is a clear development of thought around how to work with children and young people in a rights-respecting way. This ethical statement has therefore incorporated codes and practices we know can be relied on to ensure children's human rights are respected. It is not a fixed document and will be regularly updated whenever law, guidance, or methodological thought requires.

Though academic-level ethical procedures should be in place in all instances where academic-level research is being conducted, we must also be cognisant that not all projects commissioned as 'research' by public and third sector partners fall into this category. Market research and development of products and tools do not require the same level of adherence to those where personal data is being collected and analysed. Therefore, codes and practices adopted by other charities, Community Interest Companies, partners and clients are also kept in mind in this statement.

APiC will adhere to this policy when carrying out any project work that involves a clear research element, whereby personal or sensitive data is being collected for analysis. For project work that does not collect such data the below principles will still be borne in mind, and APiC will work closely with its partners and clients to determine the relevance of these policies to the project in hand. In all cases, APiC's Working with Children and Safeguarding Policies are relevant. As with all of APiC's work, research should conform to our Principles of Communication.

### The UN Convention on the Rights of the Child (UNCRC)

Fundamental to upholding APiC's mission is adherence to and promotion of the UNCRC. This is integrated across all of our work and breaching it would undermine the charitable purposes and core values of the charity. All board trustees and employees are expected to familiarise themselves with the UNCRC before working with children and young people. In particular, we must be driven by its key tenets: best interests of the child; non-discrimination; and respect for the views of the child. Individual projects will also have other articles that are especially relevant due to the topic of conversation. In nearly all situations, the three below will be relevant, and should be built into all procedures and research instruments:

 Article 12 – the right to have opinions and for these opinions to be expressed freely, heard and taken seriously



- Article 13 the right to freedom of expression, and to find and share information
- Article 15 the right to gather and organise in public space, as long as no laws are broken:
- Article 31 the right to play, rest, leisure and access cultural life
- **Article 29** the right to an education that helps their mind, body and talents be the best they can. This includes attention to the rights of others and the environment.

Choice is fundamental to respecting children's human rights and aligning with APiC's values. Children and young people participating in our research should therefore have the right to choose whether and how to participate in our projects wherever this is feasible, taking a codesign or co-production approach. Power differentials are also important to be mindful of, and this requires a reflective approach from the team in order to be aware of how children and young people see us, as well as how we see them. The team must also acknowledge the impact of individuals from partner agencies on CYP and their participation. APiC upholds the rights of the child over and above the interests of partner agencies. This is in all of our ethical policies when we work with parents/schools/health etc.

# **Competence of the Researcher**

APiC's core activities involve working directly with children and young people, which is classed as regulated work under the Protection of Vulnerable Groups (PVG) (Scotland) Act 2007 and Rehabilitation of Offenders Act 1974. Employees and board members of APiC must therefore have obtained Enhanced Disclosure through a criminal records' check that covers the relevant jurisdiction for where the project is taking place, prior to their involvement in any research activity. In Scotland, this involves registering with the Protecting Vulnerable Groups (PVG) scheme, while England and Wales have their own schemes. This is stipulated in all employee contracts, and integral to seeking ethical approval from 'gatekeepers' such as individual schools or local authorities.

Research carried out by APiC will always be designed to be inclusive for the age groups taking part, with appropriate methods used to enable children and young people to engage fully with the research. Employees and board members are also expected to keep abreast of ethics and skills developments in working with children and young people. An understanding of appropriate methods is a pre-requisite for undertaking research. APiC follows a mentorship model, whereby less experienced members of the team can assist more experienced members to increase their understanding and competence before leading any project themselves. They can also seek support from the varied experiences of the wider board to ensure they feel able and confident to conduct research with integrity and full ethical underpinnings.

In research with children and young people, it is more likely than with adults that sensitive issues are raised incidentally by participants. APiC has a Safeguarding Policy that should be followed in any such incidents. If any child or young person appears in any distress during our research, we must discontinue research activity, comfort the participant, and direct them towards appropriate support. For any research conducted remotely – for example, online – we must be aware of the ability of the child or young person to seek appropriate physical reassurance from a parent or caregiver. We cannot ethically conduct such work without these assurances.



#### **Consent of the Individual**

At all stages of our work, we will ensure compliance with the General Data Protection Regulation (GDPR) by following the latest guidance issued by the Information Commissioners Office (ICO). GDPR adds additional measures to earlier Data Protection legislation and emphasises that children have the same data protection rights as adults, as 'data subjects'.

Informed consent must be sought from all participants in research carried out by APiC. Only if there is evidence to suggest a child is *not* competent to exercise their own data protection rights or consent to processing themselves should a parent/carer act on their behalf. This can be determined by consulting 'gatekeepers' beforehand on their knowledge of any reason why a child or young person should not be considered competent to exercise this right. In Scotland, a person aged 12 or over is presumed to be of sufficient age and maturity to be able to exercise their data protection rights. If a child is competent and the nature of the work has a very low chance of raising sensitive issues, then in most cases it should be appropriate to let the child act for themselves.

As the overriding consideration should always be the best interests of the child, where sensitive topics or personal information will be integral to the research, or the child is below the age of 12, then more stringent measures to ensure consent should be used. Primarily this will be a parent/carer giving informed consent on their behalf (up to age 16). Yet, all efforts should be made to ensure that the child is involved in that decision. This ensures that the child retains a sense of control and autonomy over their own privacy and individuality and ensures compliance with APiC's core values.

When conducting research online, parents or carers must be involved in the consent procedure for anyone below the age of 16, and fully briefed about any possible impacts on the child's emotional state. It is our ethical duty to ensure physical and emotional comfort can be provided if needed, and the Safeguarding Policy must be enacted if previous assurances that a parent/carer can provide comfort turn out not to be the case.

In all cases, children and young people should be provided appropriate information for their age and stage of development, using APiC's templates for pictorial information and consent forms, or producing videos if necessary or more appropriate. They should also be given time to consult with a trusted adult before confirming consent if they so wish. For this reason, it is prudent and effective to arrange introductory sessions with participants whereby information is given and questions are answered. Wherever possible, confirmation of initial consent should be left to a subsequent session.

It is vital that consent is viewed as an ongoing process, and participants are informed of their ability to withdraw consent at any point, including after all data has been collected (but before it has been analysed). Employees and board members working with children and young people on research should make prior arrangements for alternative activities for participants to do in the event that they withdraw their consent but still want to take part in the session. This could be allowing a child to continue to take part in group activities without taking part in research, or providing an individual activity that would not make a child feel stigmatised or as if they had done something wrong.



## **Confidentiality and Anonymity**

Wherever possible, all data collected should be kept confidential and anonymous. Where there are reasons not to do so, these should be carefully thought out and communicated clearly to all involved. The main situation in which confidentiality could not be upheld is if a participant reveals something that puts themselves or others at risk. In such cases, the Safeguarding Policy should be enacted. It is vital that participants are fully informed around the meaning and practicalities of confidentiality and anonymity and any limits to these.

Pseudonyms are a good way to allow individual data to come through in outputs without compromising a participant's anonymity. It may be a fun and empowering activity to ask children to choose their own pseudonyms for any outputs. Distinctions may also need to be made where participants would like others to know about their participation, for instance through producing a video to share online. This should be negotiated sensitively and on a case by case basis, as the spirit of the UNCRC is to allow children to be recognised for their participation if they so wish.

# **Data Processing and Storage**

Where a project does not require the gathering or storing of personal or sensitive data (for which GDPR gives a strict definition) then measures on how data is processed and stored are no more stringent than with other types of information. However, any research data or consent forms containing personal information about participants, such as their name, address or name of school, must be transported to the relevant staff or board members' home or office with great care and not be accessed in any public places. Signed consent forms should then be stored in a locked box or drawer and destroyed 12 months after completion of the research. If they are uploaded electronically, they should be stored securely (e.g. password protected or on secure APiC servers).

Projects where sensitive or personal data will be collected should stipulate exactly who will see said data, and the number of people with access should be limited to only those necessary. Password-protected recording devices should be used for interviews and focus groups and transcribed only by trusted partners where we can be sure strict alliance with GDPR. Once transcribed, audio recordings should be permanently deleted, and transcripts appropriately anonymised. All research data will be maintained securely and destroyed or deleted upon completion of the project and related reporting.

Using the principle of data minimisation, audio should only be recorded and transcribed where note-taking will not suffice for the purposes of the project. Similarly, video data collection should only be employed where integral to the aims of the project. This differs from using videos or audio files as an engagement method whereby the precise content is not interrogated for the purposes of producing outputs. This is a fun and engaging way to involve children and young people that should be encouraged.

The use of online applications to record interviews or focus groups should only be used if and when the providers' privacy policy and ethical practices comply with the requirements of this document. Sensitive or personal data can only be analysed on encrypted laptops or desktops, and should never be accessed in a public place. Online audio and video should always be recorded directly to an encrypted laptop or desktop via an encrypted connection.