Comments on 'Fundamentals for a child-orientated approach to data processing'

We welcome the recent publication of the draft version of 'Fundamentals for a child-orientated approach to data processing' by the Data Protection Commission (DPC). This arose from a public consultation process to address the issue of the General Data Protection Regulation (GDPR) with regard to children and young people. The DPC recognised that one quarter of the population of Ireland are children and young people and that their personal data was being processed both on and offline on a daily basis. GDPR emphasises the need for clear communication with children and young people with regard to the use of their data, and their rights to protection. The 'Fundamentals for a child-orientated approach to data processing' draft document is based on pilot workshops with school-aged children and their teachers, in addition to consultation with DPC counterparts in other jurisdictions. This draft document outlines fourteen 'fundamentals' that should be followed to enhance the protection of children and young people with regard to processing of their data, particularly with respect to the use of online data, and the interactions of children and young people with online agencies.

We represent a group of paediatric doctors and researchers from the Royal College of Surgeons in Ireland. We are involved in a number of paediatric research studies and it is from this perspective that we offer comments on this draft document. We think that this is an excellent document which aims to protect children with regard to use of their data predominantly online, as well as empower children and young people to be advocates for controlling their own data.

We think that a further section should be added to this draft document specifically looking at data processing in paediatric clinical and academic research. We also feel that it would be worthwhile engaging with children and young people who have been involved in research studies to understand what they would like to know about the processing of their data with regard to research studies, and how they would like this information to be conveyed in the literature that they are provided with during the research recruitment process.

We thank you for the opportunity to comment on this process. Kind regards

