ADR England Children & Young People Representative Panel

Terms of Reference (May 2021)

Background

ADR UK (Administrative Data Research UK) is a UK-wide partnership with a mission to facilitate greater access to public sector administrative data for research in the public interest. One of our flagship areas of research is Children & Young People, with a number of projects underway in the scope of ADR England which are linking and curating children and young people’s data and making it securely available to approved researchers.

The Growing Up in England (GUIE) dataset, for example, linked and curated by the Office for National Statistics (ONS), includes 2011 Census and Department for Education (DfE) attainment data from the All Education Dataset for England (AEDE). This newly linked data will enable a more comprehensive understanding of how factors such as family background, school type and geography could shape outcomes.

The ECHILD (Education and Child Health Insights from Linked Data) project involves the creation of a research-ready database linking health, education and social care data for all children in England for the first time. The study involves the linking of around 14 million children’s records, which will be used to better understand how education affects children’s health and how health affects children’s education.

These and other datasets will give policymakers valuable evidence for developing services that work better for children and young people by allowing researchers to shine light upon what does and doesn’t work in supporting them to thrive.

Purpose and scope

The purpose of the ADR England Children & Young People Representative Panel is to provide opportunities for those using children and young people’s data for England – for example, ADR UK Research Fellows – to engage with those who work directly with or for children and young people in England and therefore have the first-hand knowledge and expertise to be able to represent their interests in discussions around the data and its research uses. This will ensure research using the data is as impactful as possible by enabling researchers to frame their work around the most important issues faced by children and young people. It also provides an
opportunity for representatives to highlight any ethical or other concerns with the work, and how these might be mitigated.

More specifically, the purpose of the Panel is to provide input and advice to researchers, data handlers and others using children and young people's data for England on, for example:

- **The current most pressing needs** of children and young people in the UK
- **Research questions** for projects using children and young people’s data
- **Flagging potential unforeseen impacts** of research using children and young people’s data upon the children and young people Panel members work with/for
- **Contextualising research findings** with qualitative understanding and policy relevance
- **Implementing research findings into policy** – acceptability and methods for doing so
- **The facilitation of direct engagement** with children and young people where feasible and appropriate
- **ADR UK Research Fellowships**, including the scope of fellowship calls
- **Extending and enhancing available data for research**
- **Other relevant input and advice** in relation to the research use of children and young people’s data

The Panel is advisory and is not required to take a direct role in facilitating any of the above, though there may be opportunities to do so and this remains at Panel members’ discretion.

Some Panel members may have more expertise in relation to certain topics than others – Panel members are not expected or required to have expertise in relation to all of the above, or existing knowledge of the discipline of administrative data research more broadly.

As the Panel is a new initiative, it will be piloted for an initial period of 12 months, at the end of which an evaluation will be conducted and next steps devised.

**Management of the Panel**

The ADR England Children & Young People Representative Panel will be managed by the ADR UK Strategic Hub in consultation with partners, particularly relevant data owners (such as ONS, DfE and NHS Digital). Data owners will be kept informed about the operation of the Panel where it relates to research uses of their data – planned sessions, outcomes and so on – and invited to offer input and advice where desired.

**Membership**

It is proposed that membership of the Panel will consist of a pool of around 15-20 members – dependent on levels of interest – with varying expertise. For each Panel meeting, expertise relevant to the projects in question will be selected from the pool to ensure researchers and data handlers receive advice tailored to their projects.
It is hoped membership will include:

- Representatives from a mixture of third sector organisations, voluntary and community groups and professional practices (for example teachers, social workers) – all working directly with or on behalf of children and young people
- Representatives from across England, including those working in a variety of regions and geographical contexts
- A mixture of knowledge and expertise, for example relating to: different aspects of children’s lives; a variety of different communities and social groups

Membership of the Panel will involve an initial commitment of **12 months**, to be reviewed at the end of the period. The start date for membership of the panel, which will resume with an induction session for all Panel members, is **June 2021**.

**Working methods and frequency of sessions**

**Panel members are expected to attend both Panel Meetings and Panel Sessions:**

1. **Panel Meetings:** Panel members will be expected to attend **roughly four** Panel Meetings of no longer than two hours each over the 12-month period. These are an opportunity for Panel members to learn more about the work of ADR UK and prepare for Panel Sessions. The first of these will be an induction meeting at the beginning of the 12-month period; the last will be an evaluation meeting.
2. **Panel Sessions:** These will constitute the main task of Panel members. Panel Sessions are an opportunity for researchers, data handlers and others (‘presenters’) making use of children and young people’s data to seek advice and input on their work from Panel members.

The below sets out the working methods and proposed nature of **Panel Sessions**.

- **Nature of Panel Sessions:** Presenters will be asked to conduct a short presentation about their work and the areas where they seek the input and advice of the Panel. This will be followed by feedback from the Panel, and will finish with the opportunity for further Q&A.
- **Panel Sessions will be targeted at relevant points in time on an ad hoc basis** – e.g. towards the beginning and end of ADR UK Research Fellowship funding periods – rather than at regular intervals. This ensures we can make use of the Panel’s expertise at the most relevant points in time and reduce the burden upon Panel members.
- **Members of the Panel’s pool will be invited to Panel sessions based upon the relevance of their expertise to the topics being presented.** In some instances, all Panel members may be invited to provide input – whether at the meeting itself or via other means – whilst in others, only those with the most relevant expertise may be asked.
• **Frequency of Panel Sessions:** We expect the Panel to be called into session roughly three to five times over the 12-month period. Individual members are expected to attend at least one session during the 12-month period, and are likely to be invited to attend anything from one to four sessions over the year, depending on the relevance of their expertise to the topics being discussed (and the number of sessions called in total).

• **Length of Panel Sessions:** This will vary depending on the number of projects being presented to the panel; however, Panel Sessions are expected to last for around two hours, or three at the very most.

• **Those presenting to the Panel will be required to share documentation** about their project/topic prior to the Panel Session, which Panel members will be expected to review in advance of the session.

• **Each project/topic presented at a Panel Session will be allocated an equal portion of time** to present their work, receive feedback from the Panel and for further Q&A.

• **Panel Sessions will take place in person where possible (and virtually when not)** and will be rotated around locations across England where feasible (unless a particular location is more convenient for a majority of Panel members and presenters, therefore reasonably saving costs and travel burden). Where sessions are held in person but some Panel members wish to join remotely, hybrid sessions are also possible.

• **Panel members are not required to offer ad hoc advice on an individual level to researchers/data handlers outside of organised Panel Sessions**, though are welcome to do so if they wish.

**Membership benefits**

**Benefits to Panel members include:**

• The opportunity to represent the research interests of their organisations in research projects using children and young people’s data, and connect with researchers they may wish to collaborate with

• The opportunity to speak on behalf of children and young people and contribute to shaping research which has real potential to positively impact lives

• The opportunity to be part of a valuable network of professionals from organisations and practices with similar goals to their own

• Reasonable travel and accommodation costs for attendance at Panel meetings will be covered by the ADR UK Strategic Hub

• Receive regular news and updates about the projects that have been advised upon, other projects using children and young people’s data, and other relevant ADR UK work

• **Remuneration:** Panel members (including the Chair) will be remunerated at a rate of £80 per half-day (£160 per full day) for Panel meetings and sessions.