

MDFT Study Privacy Notice

We are carrying out a study of young people who come into contact with some of the children's services provided by Barnardo's in the Bristol area. The study is to try to find out whether a new approach might help young people reduce their alcohol and/or substance use in the future. The study is being funded by the Youth Endowment Fund (YEF). At the end of the study, data collected relating to parents or carers of young people taking part in the study will have any directly identifiable information removed and stored in a secure environment at the University of Kent, 5 years for written data and 10 years for electronic data. Data relating to young people who take part in the study will be transferred to the funder who will ask the Department for Education to add a unique identifier, only the Department of Education will be able to link the data to a specific young person. This data might be analysed in the future along with data from other sources within the Secure Research Service managed by the Office of National Statistics. This may include, for example, assessing whether children and young people who took part in YEF-funded projects were less likely to be excluded from school or get involved in crime in the future.

This privacy notice provides should be read alongside the University of Kent research privacy notice

(<https://media.www.kent.ac.uk/se/40432/ResearchParticipantUniversityLevelPrivacyNotice.pdf>)

It contains information about who we are, what we are doing, and why we are doing it. It also explains how we will use personal information we collect as part of the study.

Who are we?

This study is being organised by the Centre for Health Service Studies at the University of Kent (www.kent.ac.uk/chss). When we collect and use participants' personal information as part of the study, the University of Kent is the data controller of the personal information, which means we decide what personal information to collect and how it is used.

What are we doing?

We are evaluating a new approach to working with young people who use alcohol and/ or illicit substances in Bristol. The new approach involves staff who have been specifically trained to provide intensive therapy and support for parents and young people. Our study explores whether this new approach is better than the approach usually employed. Our research will inform us about what works best for young people.

Contact details:

Project Lead – Professor Simon Coulton, s.coulton@kent.ac.uk, 01227 824535
Data Protection Office – dataprotection@kent.ac.uk

1. Who has reviewed this study?

This study has been reviewed and approved by the University of Kent Research Ethics Committee ref SSSREC1200 and Barnardo's Research Ethics Committee ref BREC21.

2. What information will we collect?

We will collect information about [your child/the child in your care] such as their name, address, contact details, date of birth, sex, and ethnicity. This information will be provided by the Barnardo's team working in the Bristol area, we will only be provided with this information if you consent for it to be provided to the research team. We will also collect information using a set of questionnaires that have been specifically designed and tested with young people. We will collect information about [your child/the child in your care] alcohol and/ or substance use, offending behaviour, emotional behaviour, mental health, wellbeing and family. We will also collect information about whether [your child/the child in your care] has been involved with the police or courts and whether they have been suspended or excluded from school. We will collect this information directly from your child or the child in your care.

3. How will we use the personal information that we collect?

Data protection laws require us to have valid reason to use [your child's/the child in your care] personal information. This is referred to as our 'lawful basis for processing'. We rely on the public interest basis to use their personal information (Article 6(1)(e) of the UK GDPR). We will be using special category information (information about health, race or ethnic origin) and criminal offence information) as this is necessary for our research purposes relating to this study or statistical purposes which are in the public interest (Article 9(2)(j) and Article 10 of UK GDPR).

We will use the information you give us to evaluate how well the new approach has worked and to write a report about our findings based on all the questionnaires and interviews we have carried out.

The final report and any other publications produced by the University of Kent will not contain any personal information about the people who took part in the study, and it will not be possible to identify individuals from the report. The report will be published on the YEF's website.

Any personal information that [you/your child/the child in your care] gives us will be stored securely and kept confidential.

- We may share this personal information with another person or organisation if [you/your child/the child in your care] tells us something during the study that makes us concerned about them or about someone else. Our Safeguarding Policy has more information about steps that we might take if we have concerns about [your/your child/ the child in your care] wellbeing, or the wellbeing of another person (<https://media.www.kent.ac.uk/se/46156/SafeguardingPolicyandProcedureSeptember2024.pdf>). We rely on legal obligation (Article 6(1)(c) of the UK GDPR) for this processing. We also rely on Article 9(2)(g) substantial public interest (safeguarding) for any health information we have to report.
- Once we have finished our study, we will share all the information we have gathered about the young people who have taken part with the YEF funder who will ask the Department of Education to allocate a unique identifier, this data is stored in the Office for National Statistics' Secure Research Service. The YEF is the

‘controller’ of the information in the YEF archive and their privacy policy can be viewed here (<https://youthendowmentfund.org.uk/wp-content/uploads/2021/07/YEF-Data-Guidance-Participants-LGR.pdf>)

By maintaining the archive and allowing approved researchers to access the information in the archive, the YEF is performing a public task, and this gives the YEF a lawful basis to use this information.

- Information in the YEF archive can only be used by approved researchers to explore whether this, and other programmes funded by YEF, had an impact over a longer period. This will help approved researchers to find out the long- term impact of the projects funded by YEF because they'll be able to see, for example, whether being part of a project reduces the likelihood of being excluded from school or becoming involved in criminal activity.

How is information in the YEF archive protected?

The YEF have put in place strong measures to protect the information in their archive. As well as removing identifiable information described in section 4, the YEF archive is protected by the Office for National Statistics' 'Five Safes' framework. The information can only be accessed by approved researchers in secure settings and there are strict restrictions about how the information can be used. All proposals must be approved by an ethics panel. Information in the YEF archive cannot be used by law enforcement bodies or by the Home Office for immigration enforcement purposes.

You can find more information about the YEF archive and the Five Safes on the YEF's website <https://youthendowmentfund.org.uk/evaluation-data-archive/>. We encourage all participants, parents, and guardians to read the YEF's guidance for participants before deciding to take part in this study.

Once information goes into the YEF archive it can no longer be deleted as that would affect the quality of the archived data for use in future research.

Retention and deletion

The University of Kent will keep an anonymised copy of [your child's/the child in your care's] written data for a maximum period of five years and a maximum period of 10 years for electronic data, after the end of the study. Once the collection and quality assurance of data for the final participant has been collected and, after, the data transferred to the YEF data archive all personal identifiable information will be removed from the dataset held by the University of Kent. At this point no individual will be identifiable using the data held by the University of Kent.

YEF will keep information in the YEF archive for as long as it is needed for research purposes. Data protection laws permit personal information to be kept for longer periods of time where it is necessary for research and archiving in the public interest, and for statistical purposes. YEF we will carry out a review every five years to assess whether there is a continued benefit to storing the information in the archive, based on its potential use in future research.

Data protection rights

[Your child/You and the child in your care] have the right to:

- ask for access to the personal information that we hold about them.
- ask us to correct any personal information that we hold about them which is incorrect, incomplete, or inaccurate.
- Complain to the Information Commissioner's Office.

In certain circumstances, you also have the right to:

- ask us to erase the personal information where there is no good reason for us continuing to hold it, if we have not already erased the identifiable information.

- object to us using the personal information for public task purposes.
- ask us to restrict or suspend the use of the personal information, for example, if you want us to establish its accuracy or our reasons for using it.

If you want to exercise any of these rights during the study period, please contact our Data Protection Officer (dataprotection@kent.ac.uk). We will usually respond within 1 month of receiving your request.

When exercising any of these data rights, we may need to ask for more information from [your child/ the child in your care] to help us confirm [your/their] identity. This is a security measure to ensure that personal information is not shared with a person who has no right to receive it. We may also contact you to ask you for further information in relation to your request to speed up our response.

Other privacy information

Categories of personal information

If you decide that [you/your child/the child in your care] can take part in this study, we will ask for the following personal information on them:

- First name
- Surname
- Date of Birth
- Home address
- Alternative address (if appropriate)
- Telephone number
- Email address
- Social media contact details (if willing to provide)
- Sex
- Ethnicity
- Alcohol and/ or substance use
- Offending
- Mental health
- Physical Health
- Contact with the Criminal Justice System

Sharing [your/your child's/the child in your care] personal information

We only ever use [your child/the child in your care] personal information if we are satisfied that it is lawful and fair to do so.

Data security

We will put technical and organisational measures in place to protect [your/your child/the child in your care] personal information, including:

- Limiting access to specific named researchers who require access to conduct the study, such as contacting young people for follow-up.

- Keeping personal details such as name and address separate from all other data and linking these using a unique identifier.
- Keeping data on a secure encrypted server and ensuring data is regularly backed up for security purposes.

International transfers

The University of Kent uses Microsoft 365 as its main IT system and therefore Microsoft is a data processor. Personal data in our Microsoft 365 tenancy is hosted within the UK. For more information please see <https://www.microsoft.com/licensing/docs/view/Microsoft-Products-and-Services-Data-Protection-Addendum-DPA>.

Feedback, queries, or complaints

If you have any feedback or questions about how we use personal information, or if you want to make a complaint, you can contact the lead researcher or Data Protection Officer using the details provided earlier.

We always encourage you to speak to us first, but if you remain unsatisfied you also have the right to make a complaint at any time to the Information Commissioner's Office (ICO), the UK supervisory authority for data protection issues: <https://ico.org.uk/make-a-complaint/>.