



# Supporting children and young people's interests within Data Trusts:

*Lessons from relevant frameworks and roles*

Kirsty Blenkins  
Association for Young People's Health

April 2025

# Contents

Executive summary .....	<b>3</b>
Introduction .....	<b>4</b>
Methodology .....	<b>4</b>
Supporting young people’s right to be involved .....	<b>5</b>
Understanding data trustees responsibilities .....	<b>7</b>
Learning from other similar roles .....	<b>8</b>
Developing standards for data trustees for children and young people .....	<b>14</b>
Conclusion .....	<b>15</b>
References .....	<b>16</b>

# Executive summary

The concept of data trusts to protect people's data and information in longitudinal and other research studies has been emerging for some time. The Association for Young People's Health has been involved in work led by the University of Warwick and involving the Born in Scotland in the 2020s pilot birth cohort study (hereafter, 'BIS') looking at how data trusts could work to manage the collection and use of data in health research with children and young people. Findings from pilot work to date highlight the need for data trusts to be set up by and involve a diverse group of people representing the views of clinicians, researchers and people with lived experience (Bell et al., 2023). The work has also highlighted the importance of the role of data trustees, as those responsible for the best interests of beneficiaries of the trust, in this instance, parents and young people involved in the BIS study.

Many organisations and institutions have considered issues associated with data trusts, but outstanding questions remain about how best to involve young people in data governance for health research, and how to represent their best interests in the running of a data trust. To help avoid reinventing the wheel this review set out to look at other applicable roles that could inform the development of a data trustee for children and young people. Roles such as Caldicott Guardians and frameworks for Child Advocacy Services provide structures and frameworks that can help in the development of data trustee roles and also have useful replication in other research and engagement contexts to ensure that the best interests of children and young people are always at the heart of work conducted with them.

A number of themes have arisen from this work that are key to the next steps of data trust development in relation to children and young people. First and foremost are the issues of age-appropriate engagement and evolving

capacity. Data trusts need to develop age-appropriate methods to engage with children and young people, ensuring they understand the implications of data sharing and use, and to help support a robust understanding of the data rights framework. Alongside this, trustees must recognise and adapt to the evolving capacity of children to understand and make decisions about their data. It is also key that trustees consider the long-term impact of data use on the lives of children and young people, ensuring that their future opportunities are not compromised.

The need to balance the interests of children and young people with the needs of researchers and other stakeholders whilst always prioritising the child's well-being is clear and goes alongside the necessity for robust safeguarding measures to protect children from any potential harm or exploitation related to their data. Last but not least, ensuring transparency and accountability to the children and young people whose data they manage is crucial. This is not without complexity. One of the key challenges for the inclusion of children and young people, as our pilot work demonstrated, is how complex it is to communicate the concept of a data trust. Finding ways to communicate concepts clearly is key for meaningful engagement and involvement alongside skilled staff and robust governance frameworks.

There is a clear need for co-development with young people in developing a data trust framework. Actively involving young people in explaining and constructing a data trust can foster a stronger sense of representation and potentially enhance their agency in the process.

# Introduction

Data trusts are emerging as a new model for information governance and a participatory approach to data stewardship. (Bell et al., 2023) The Association for Young People's Health (AYPH) is part of a project led by the University of Warwick investigating how data trusts could work to manage the collection and use of data in health research with children and young people. Findings from our pilot include the fact that *'A data trust should be made up by a diverse group of people representing views of clinicians, researchers, and individuals with lived experience'* (Bell et al., 2023).

This scoping review focuses on better understanding of the roles within a data trust that could represent children and young people's

health data interests. It includes a comprehensive examination of several critical areas including: the involvement and representation of children and young people in data trusts, the fiduciary role of data trustees and their legal responsibilities and providing insights from existing roles that represent the interests and rights of young people. It aims overall to inform the development of standards and duties for data trust trustees specifically in relation to children and young people, to inform the BIS data trust and to further develop the debate regarding the role of data trustees more broadly.

# Methodology

This preliminary review establishes the scope of our inquiry and identifies current knowledge gaps. While not a systematic review, it highlights key themes emerging from existing research and evidence we have to date.

We conducted a cross-sector review of roles relevant to the development of data trust trustees. This involved identifying sectors with established roles in data management, privacy, or advocacy for children and young people, including health, social care, and education. Within each sector, we identified roles with responsibilities similar to those envisioned for data trust trustees. We then analysed the

key functions and responsibilities of each role, focusing on data management, privacy protection, and representation of children and young people's interests. This approach enabled us to develop a comprehensive understanding of common themes to inform the development of a role definition for data trust trustees. Building on this understanding, this paper sets out a detailed definition of the roles and responsibilities of data trust trustees, specifically focusing on their function in representing children and young people's interests.

# Supporting young people's right to be involved

Based on AYPH's experience working with young people and our involvement in the data trust project, we recognise that young people's rights and the power dynamics in participatory work are crucial considerations. Drawing from our previous work and leading approaches in youth participation, we have identified several key considerations regarding young people's rights in the context of data trusts:

## 1. **The best interests principle:**

This fundamental principle, derived from the UN Convention on the Rights of the Child, must be at the forefront of all decisions involving young people's data (Children's Rights Alliance for England 2022). Our work has shown that prioritising young people's best interests leads to more effective and ethical data management practices.

**2. A holistic approach:** In our experience, considering the overall well-being of young people, including physical, emotional, and social aspects, is crucial in health data management. This aligns with AYPH's commitment to comprehensive youth health advocacy (PHE & AYPH, 2014).

**3. Privacy and security:** Implementing robust privacy and security measures is paramount (Bell, 2020). Our interactions with young people have highlighted their concerns about data protection, emphasising the need for stringent safeguards against unauthorised access and misuse.

## 4. **Stakeholder engagement:**

AYPH strongly advocates for involving multiple stakeholders, including young people, parents, carers, and advocates, in the decision-making process. This multi-faceted approach ensures a more comprehensive and representative perspective.

## 5. **Age and development considerations:**

Our work has underscored the importance of recognising that children and young people's capacity to consent evolves as they develop. Early conversations with young people in this project revealed their desire for the ability to opt out of studies once they reach an appropriate age, though consensus on the specific age was not reached (Open Data Institute, 2020).

These considerations, rooted in AYPH's extensive work with young people and our involvement in the data trust project, form a crucial foundation for developing ethical and effective data trust frameworks that genuinely respect and uphold young people's rights.

The examples of youth participation models and engagement strategies mentioned are informed by AYPH's experience in youth engagement and advocacy. While not directly quoted from a single published document, these approaches reflect AYPH's accumulated knowledge and best practices developed over years of working with young people (AYPH, 2022) (AYPH, 2021).

Below we have set out some examples of youth participation models that could be considered within a data trusts context:

- **Direct representation:** Including young people as members of the trust to ensure their perspectives and concerns are directly incorporated into decision-making processes. This can be achieved through the formation of a youth advisory board or direct inclusion of young people as trustees similar to young people who have formal roles as board members.

- **Proxy representation:** As part of a proxy representation model for data trusts involving children and young people. For children and younger adolescents who may not have the capacity or those unable to participate directly, appoint adult representatives (e.g. youth advocates or guardians) who can effectively communicate the interests and concerns of young people.
- **Mechanisms for ongoing engagement:** Establish permanent structures for ongoing engagement to sit alongside the data trust, such as youth councils or advisory panels, which regularly consult with and gather feedback from young people.

Ensuring participatory approaches are inclusive and accessible is really important so that a wide range of experiences and needs are captured. Representation from diverse groups is important including for example a range of ages, ethnic backgrounds, socio-economic status as well as specific groups such as looked after children, children and young people with mental health needs and disabilities etc. Communication materials, incentives and dissemination of opportunities are also a key part of enabling inclusive participatory approaches (AYPH, 2024).

How young people are involved is also key. Face-to-face engagement, preferred by many young people, can allow for a fuller discussion of complex concepts and greater relationship building. However digital engagement platforms can play an important part in effective engagement if used well. They can allow for geographically dispersed groups of young people to be involved in processes and have useful functionality in terms of anonymity – allowing young people to share their views in a confidential way. Appropriate safeguards need to be in place when using such platforms to ensure young people are supported.

# Understanding data trustees responsibilities

In a data trust, trustees would be appointed to look after the data and/or data rights of groups of individuals including children and young people. This could involve individuals handing over responsibility for their data, to an entity they trust to look after their interests. This leads to what is known as a 'fiduciary duty' on the part of the trustees.

Fiduciary roles are ones where individuals are entrusted to carry out a particular act for another person. While there are many existing examples of this in the management of money for children, the concept of data trusts for children's interests is an emerging area with potential for meaningful trustee roles. (Open Data Trust Institute, 2020). Trustees in a data trust would be responsible for safeguarding children and young people's health data and ensuring its ethical use. This is also described in the literature as data stewardship: collecting, maintaining, sharing and in particular, deciding who has access to data, under what conditions and to whose benefit. (UK Government)

The responsibilities outlined for data trustees in this section are informed by a combination of factors, drawing from established practices in data governance, child safeguarding, and risk management across various sectors. While there isn't one single source that encapsulates all of these responsibilities, they represent a synthesis of best practices and legal obligations.

The range of responsibilities for trustees could include:

## **Ensuring robust data protection measures**

are in place to safeguard young people's health information. This would include:

- Implementing strong access controls to limit data sharing only to authorised individuals

- Regularly auditing data security practices to identify and address vulnerabilities
- Complying with data protection and GDPR laws (UK Government)
- Establishing clear governance frameworks for data management (Assured Private Wealth, 2024)

**Safeguarding responsibilities** (NHS Safeguarding) involving taking proactive steps to protect young people from harm including:

- Creating a safe environment for all who come into contact with the organisation, including beneficiaries, staff, and volunteers
- Protecting young people from abuse, neglect, emotional harm, exploitation, and radicalisation
- Ensuring appropriate safeguarding training for all staff and volunteers
- Responding swiftly and appropriately to any safeguarding concerns or incidents (Information Commissioner's Office)

**Effective risk management** to fulfil the trustee's duty of care, including:

- Implementing procedures to assess and mitigate potential risks associated with data processing
- Conducting regular risk assessments and audits to maintain high standards of data security
- Developing strategies to protect data assets from breaches or misuse

By fulfilling these responsibilities, trustees can ensure they are prioritising the health, privacy, and well-being of young people. (NHS England, 2024)

# Learning from other similar roles

There are a number of roles that we can learn from in other contexts to help shape new duties of data trust trustees. We have looked at examples from local authorities, public sector bodies, health, social care, education and youth provision. In this section, we highlight the key aspects of these roles in three different categories – data governance roles, statutory roles in social care & mental health and parent, trusted adult/independent advocate roles.

## A. Data governance roles

### **Data Protection Officers**

A Data Protection Officer (DPO) is an important role required by the General Data Protection Regulation (GDPR) for certain organisations, especially public authorities and those processing sensitive data<sup>1</sup>. The DPO's main responsibilities include ensuring compliance with data protection laws, advising the organisation on its obligations, and monitoring internal policies. They act as a liaison with data protection authorities, handle complaints, and provide training to staff on data protection issues.

To be effective, a DPO must have expert knowledge of GDPR and relevant laws, operate independently without conflicts of interest, and report directly to senior management. Overall, the DPO plays a crucial role in helping organisations manage personal data responsibly and securely while adhering to legal requirements (European Data Protection Supervisor, 2024).

---

1 UK GDPR is principal legal framework for regulation of data in UK: Regulation (EU) 2016/679 of the European Parliament and of the Council of 27th April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation) as it forms part of the law of England and Wales, Scotland and Northern Ireland by virtue of section 3 of the European Union (Withdrawal) Act 2018.



### **Caldicott Guardian**

A Caldicott Guardian is a senior role within organisations that process health and social care personal data in the UK. This role is crucial for ensuring that personal information about service users is used legally, ethically, and appropriately, while maintaining confidentiality of health and care data. (The MDU, 2025)

### **Key Responsibilities**

Caldicott Guardians have several primary responsibilities:

1. **Leadership and Guidance:** Providing leadership and informed advice on complex matters involving confidentiality and information sharing.
2. **Ethical Decision-Making:** Applying the eight Caldicott Principles wisely to guide decisions about sharing patient information (Virtual College, 2024).
3. **Confidentiality Maintenance:** Ensuring that their organisation satisfies the highest practical standards for handling person-identifiable information.
4. **Organisational Conscience:** Acting as the “conscience of the organisation” in matters of data privacy and security.
5. **Strategic Role:** Representing and championing information governance requirements at senior management and board levels.

### **Organisational Requirement**

It is a requirement for every NHS organisation to have a Caldicott Guardian. The role has been expanded to include a wider range of bodies that handle health and social care data.

### **Challenges and Future Outlook**

As data use in healthcare evolves, AYPH observes that the role of Caldicott Guardian is likely to expand, potentially incorporating new technologies and addressing emerging ethical concerns in data governance. Key challenges include balancing data sharing for improved care with privacy protection and adapting to technological advancements.

## b. Statutory roles in child social care, mental health:

### **Child Advocate**

A child advocate is a role specifically designed to support looked after children and young people. The main purpose of a child advocate is to represent the wishes and feelings of looked after children and young people. The aim of child advocacy is to encourage empowerment of children and uphold their human rights.

Article 12 of the UN Convention on the Rights of the Child states that “Every child has the right to say what they think in all matters affecting them and to have their views taken seriously, taking into account their age and maturity” (Children and Young People’s Commissioner Scotland).

The Care Act 2014 in the UK requires local authorities to provide independent advocates to support people and carers who need assistance in the Care and Support process. The duty to provide an advocate applies to people with Care and Support needs, regardless of where they live or the nature of their support.

### **What does an Advocate do?**

- Make sure a child or young person’s wishes and feelings are known
- Attend decision making meetings with the local authority or school on behalf of a child or young person
- Uphold a child or young person’s legal rights and ensure they are fairly treated
- Provide impartial information to the child or young person
- Prepare meetings with social workers for the child or young person
- Assist the child or young person in making a complaint in a constructive and effective manner
- Negotiate with social workers and other relevant people
- Ask questions to relevant people and speak on the child or young person’s behalf (Coram Children’s Legal Centre)

To control the quality of children’s advocacy services in England and Wales, the Department of Health released ‘National Standards for the Provision of Children’s Advocacy Services’ in 2002. These advocacy standards were created to help agencies and councils across the country to support looked after children and young people in need. (DH, 2012)

Several of these standards are particularly relevant to data trusts:

**Standard 1: Purpose and function:** Advocacy services should have a clearly defined purpose and function, and the service must make sure they work in a way which is consistent with this.

**Standard 2: Accessibility and entitlement:** This standard ensures that advocacy services are accessible to all eligible children and young people, who are fully aware of their right to an advocate. This translates to data trusts ensuring children are aware of their data rights.

**Standard 3: Young person-centred approach:** Children and young people’s wishes and feelings will be central to the advocacy provided.

**Standard 7: Independence and impartiality:** Advocacy services should operate independently and impartially, free from conflicts of interest.

In conclusion, child advocates play a crucial role in ensuring that the voices of vulnerable children and young people are heard and considered in decisions affecting their lives. By adhering to national standards and focusing on the child's wishes and feelings, advocates help to uphold children's rights and promote their best interests within the care system.

### **Independent Reviewing Officers (IROs)**

IROs are qualified social workers tasked with enhancing outcomes for looked after children. They play a vital role in quality assuring the care planning process, ensuring that the child's current wishes and feelings are fully considered. IROs chair review meetings for looked after children, which are held at least every six months, and monitor the progress of care plans between reviews to prevent delays. Appointed by local authorities under the Adoption and Children Act 2002, IROs operate independently from a child's immediate line management to maintain objectivity. They have the authority to challenge poor practices and can escalate serious concerns to the Children and Family Court Advisory and Support Service (CAFCASS). Beyond their primary responsibilities, IROs may also chair child protection conferences, foster carer reviews, private fostering reviews, and secure reviews, with a consistent focus on promoting the welfare of children and ensuring their safety from harm.

### **Independent Mental Health Advocates (IMHAs)**

IMHAs are specialist advocates who provide crucial support to individuals subject to the Mental Health Act 1983 and are available to individuals aged 16 and over. They play a role in ensuring that patients understand and can exercise their rights under this legislation. IMHAs assist people who are detained under the Mental Health Act, those subject to Community Treatment Orders and individuals under guardianship.

Their key responsibilities include providing information about patients' rights and entitlements, facilitating communication between patients and healthcare professionals, and representing patients' views during meetings and treatment discussions. Operating independently of mental health services, IMHAs ensure unbiased support by accessing patients' medical and social records, meeting with healthcare professionals, and attending relevant meetings or hearings. Ultimately, their primary focus is to empower patients, ensure their voices are heard, and safeguard their rights during what can be a confusing and distressing time.

## C. Parents, trusted adult or independent advocate roles:

### **Parental responsibility**

#### **Parents, legal guardians or carers with parental responsibility**

Parents or guardians with parental responsibility can decide whether to place a child's data in a trust and set parameters for its use.

Parental responsibility is defined in s 3(1) Children Act 1989 as being:

"All the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property."

The term 'parental responsibility' attempts to focus on the parent's duties towards their child rather than the parent's rights over their child. When important decisions about a child must be made, all those with parental responsibility for the child should be allowed to participate. Day-to-day decisions should be made by the resident parent or the person with whom the child lives, without interference from other parental responsibility holders.

In practical terms, parental responsibility means the power to make important decisions in relation to a child. Such as: consenting to a child's operation, medical treatment or accessing a child's medical records.

A person with parental responsibility cannot transfer their responsibility to another person. Although it is possible to delegate responsibility for childcare to a partner, childminder, teacher, friend, or relative, the person with parental responsibility remains liable and responsible for ensuring that proper arrangements are made for the child.

Parental responsibility is the legal concept defining the rights and responsibilities of parents or guardians in relation to a child. As defined in the Children Act 1989, it encompasses all the rights, duties, powers, responsibilities, and authority that a parent has in relation to a child and their property. In the context of data trusts:

- **Authorising data sharing:** Parents or guardians with parental responsibility typically make the initial decision about placing a child's data in a trust and setting parameters for its use
- **Representing the child's interests:** Those with parental responsibility initially act as representatives of the child, ensuring the child's best interests are central to the data trust structure
- **Decision-making:** Parental responsibility holders make key decisions about data collection, access, and usage on behalf of the child within the trust framework

It is important to recognise that as children grow older, their own views and capacity to make decisions about their data should be increasingly considered, balancing parental responsibility with the child's evolving autonomy and right to participate in decisions that affect them. As the child gains capacity, the level of influence from parental responsibility lessens.

Parental responsibility is a legal concept that grants certain rights and duties to individuals in relation to a child. In the context of data trusts and data protection, parental responsibility is crucial for determining who can make decisions about a child's personal data.

**A trusted adult or independent advocate for children and young people** is a person chosen by the young person as a safe figure who listens without judgment and supports them. This individual is independently selected by the young person.

The primary roles of an advocate include:

- Listening to the young person
- Providing information about rights and options
- Supporting the young person in expressing their thoughts and desires to others

Independent advocates, often known as children’s rights officers, empower young people by helping them voice their opinions and desires. They facilitate informed decision-making through clear explanations, active listening, and representing the young person’s perspective, ultimately challenging decisions that do not align with their best interests (Coram Children’s Legal Centre).

Trusted adults and advocates can be found in various settings, including youth clubs, pastoral teams in schools and extended family. They play a crucial role in supporting young people’s mental health and wellbeing, often serving as the first point of contact when a young person is struggling.

**‘A trusted adult is chosen by the young person as a safe figure that listens without judgment, agenda or expectation, but with the sole purpose of supporting and encouraging positivity within a young person’s life’** (Young Minds, 2023)

There are a number of clear parallels between these different roles including: an emphasis on the importance of data protection, ethical data use, and compliance with relevant laws and regulations; how independence and objectivity are crucial to advocate for the best interests of the individual (child, young person, patient, etc.); the importance of meaningful representation to ensure the voice and wishes of the individual are heard and respected in decision-making processes; and the need for competence and training with all roles requiring skilled and experienced individuals who are well-trained in their respective areas. These are instrumental for the development of standards for data trustees.

The review also highlights an existing workforce that is potentially well-placed to ‘upskill’ and perform the role of a data trustee, based on their expertise working with young people and/or navigating key issues that could be encountered in the life course of a data trust.

# Developing standards for data trustees for children and young people

Based on the themes from the review of other roles, together with considerations of children and young people's rights, and the responsibilities of data trust trustees we have set out below some areas for future standards or principles to focus on. These are designed as a foundation to be built upon with feedback from young people and other stakeholders<sup>2</sup>.

- 1. Child-Centred Approach:** Prioritise the rights, well-being, and best interests of children and young people in all data-related decisions.
- 2. Ethical Data Use:** Ensure data is used ethically and responsibly, adhering to the highest standards of data protection and privacy.
- 3. Informed Consent and Participation:** Obtain informed consent from children (where appropriate, considering their age and development) and their parents, carers or guardians.
- 4. Transparency and Communication:** Provide clear, accessible, and age-appropriate information about how data is collected, used, and shared.
- 5. Independence and Objectivity:** Act independently and objectively, without conflicts of interest.
- 6. Data Minimisation:** Collect and store only the data that is necessary for the specified purposes.
- 7. Data Security and Safeguarding:** Implement robust data security measures to protect children and young people's data from unauthorised access, misuse, or disclosure.
- 8. Accountability and Oversight:** Establish clear lines of accountability and oversight to ensure that data is managed responsibly.
- 9. Promote Data Literacy:** promote understanding of data and data rights.
- 10. Continuous Improvement:** Regularly review and improve data trust governance practices based on feedback from children, young people, and other stakeholders.

How this is achieved depends on the specific representation model, be it direct, or ongoing engagement, as outlined earlier. Ultimately, it requires a commitment to active listening, accessible information, and challenging decisions that do not align with the young person's best interests. Furthermore, ongoing work aims to formulate the specific duties and responsibilities of data trust trustees, providing a clearer roadmap for how these professionals can effectively uphold the rights and well-being of the young people they represent.

---

<sup>2</sup> This review will inform a subsequent stakeholder workshop to further refine data trust governance practices for children and young people.

# Conclusion

This review has looked at relevant frameworks and roles for representing children and young people's interests within a data trust.

To get data trusts right for children and young people there is much to learn from effective youth participation models in terms of supporting meaningful and ongoing engagement. This includes lessons about the importance of inclusive approaches that enable a diverse representation of young people to be involved. Not all young people will view data sharing in the same way and capturing a wide range of experiences and needs is therefore vital.

Trustees in data trusts have a fiduciary duty to safeguard children's data, ensure its ethical use, and prioritise the privacy and well-being of young people. They must fulfil a set of key responsibilities in relation to data protection, safeguarding, and risk management in order to do this. This includes strict adherence to GDPR requirements, such as conducting thorough Data Protection Impact Assessments (DPIAs) for any data processing activities that pose a high risk to the rights and freedoms of children, as detailed in Chapter 16 of the Child House Toolkit (Mayor's Office for Policing and Crime).

Existing roles such as Caldicott Guardians and Child Advocates provide valuable insights for shaping trustee responsibilities in data trusts, but it is vital that trustees have a comprehensive understanding of data protection law. This includes the need to implement appropriate

technical and organisational measures to ensure the security and confidentiality of children's and young people's data.

Moving forward it is clear that there is a need for improved communication of complex concepts about these issues with young people as well as multi stakeholder consideration of appropriate safeguards, checks and balances necessary for data trusts to work for children and young people.

By drawing on these lessons and incorporating elements from existing roles, data trusts and indeed other research frameworks and protocols can develop robust frameworks for representing and protecting the interests of children and young people in the management and use of their data.

# References

- Association for Young People's Health (2021) *How to manage research and participation projects: Ethical considerations according to young people*. Available at: <https://ayph.org.uk/wp-content/uploads/2021/11/Ethical-considerations-according-to-young-people-Common-Room-Report.pdf> (Accessed: 25 April 2025).
- Association for Young People's Health (2022) *Engaging young people in health services research and service design: a new look at ethical issues*. Available at: [https://ayph.org.uk/wp-content/uploads/2022/03/AYPH\\_EthicsBriefingPaper\\_March22.pdf](https://ayph.org.uk/wp-content/uploads/2022/03/AYPH_EthicsBriefingPaper_March22.pdf) (Accessed: 25 April 2025).
- Association for Young People's Health (2024) *Engaging young people in NHS service delivery and development: A scoping review of the evidence*. Available at: <https://ayph.org.uk/wp-content/uploads/2024/05/AYPH-Engaging-young-people-in-NHS-service-delivery-scoping-review.pdf> (Accessed: 25 April 2025).
- Assured Private Wealth (2024) *The Role of Trusts in Protecting Your Privacy: Essential Strategies for Safeguarding Personal Information*. Available at: <https://www.apw-ifa.co.uk/the-role-of-trusts-in-protecting-your-privacy/> (Accessed: 15 April 2025).
- Bell, J. (2020) 'Data Access Committees', *BMC Medical Ethics*, 21(1). Available at: <https://bmcmethics.biomedcentral.com/articles/10.1186/s12910-020-0453-z> (Accessed: 13 April 2025).
- Bell, J., Reynolds, R. and Hagell, A. (2023) *Born in Scotland Data Trust: What is a data trust and what are the opportunities and challenges for health research?* University of Warwick. Available at: <https://warwick.ac.uk/fac/soc/law/research/projects/scotland-data-trust/research-outputs> (Accessed: 14 April 2025).
- Bell, J., Reynolds, R. and Hagell, A. (2023) *Data Trust Initiative: End of Pilot Report: Born in Scotland Data Trust*. University of Warwick. (Unpublished)
- Children and Young People's Commissioner Scotland (n.d.) *The United Nations Convention on the Rights of the Child*. Available at: <https://www.cypcs.org.uk/rights/uncrc/full-uncrc/#12> (Accessed: 15 April 2025).
- Children's Rights Alliance for England (2022) *UK implementation of the UN Convention on the Rights of the Child – Civil UN Committee*. Available at: [https://crae.org.uk/sites/default/files/fields/download/CRAE\\_UN-CIVIL-SOCIETY-SUMMARY-%28DIGITAL%29.pdf](https://crae.org.uk/sites/default/files/fields/download/CRAE_UN-CIVIL-SOCIETY-SUMMARY-%28DIGITAL%29.pdf) (Accessed: 14 April 2025).
- Coram Children's Legal Centre (n.d.) *Advocacy*. Available at: <https://childlawadvice.org.uk/information-pages/advocacy/> (Accessed: 15 April 2025).
- Coram Children's Legal Centre (n.d.) *Parental Responsibility*. Available at: <https://childlawadvice.org.uk/information-pages/parental-responsibility/> (Accessed: 15 April 2025).
- Department of Health (2012) *National Standards for the Provision of Children's Advocacy Services*. Available at: [https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4018893.pdf](https://webarchive.nationalarchives.gov.uk/ukgwa/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4018893.pdf) (Accessed: 13 April 2025).
- European Data Protection Supervisor (2024) *Data Protection Officer (DPO)*. Available at: [https://www.edps.europa.eu/data-protection/data-protection/reference-library/data-protection-officer-dpo\\_en](https://www.edps.europa.eu/data-protection/data-protection/reference-library/data-protection-officer-dpo_en) (Accessed: 25 April 2025).



Information Commissioner's Office (n.d.) *Information Commissioner's Office*. Available at: <https://ico.org.uk> (Accessed: 15 April 2025).

Mayor's Office for Policing and Crime (n.d.) *Child House in a Box Toolkit*. Available at: [https://www.london.gov.uk/sites/default/files/child-house-in-a-box-toolkit-final\\_v1.pdf](https://www.london.gov.uk/sites/default/files/child-house-in-a-box-toolkit-final_v1.pdf) (Accessed: 15 April 2025).

NHS England (2024) *Transform: Personal data breaches and related incidents*. Available at: <https://transform.england.nhs.uk> (Accessed: 15 April 2025).

NHS Safeguarding (n.d.) *Information sharing: NHS*. Available at: <https://safeguarding-guide.nhs.uk/raising-concerns/s1-05/> (Accessed: 13 April 2025).

Open Data Institute (2020) *Data trusts in 2020*. Available at: <https://theodi.org/news-and-events/blog/data-trusts-in-2020/> (Accessed: 15 April 2025).

Public Health England and Association for Young People's Health (2014) *Improving young people's health and wellbeing: A framework for public health*. Available at: [https://assets.publishing.service.gov.uk/media/5c49cc6ce5274a6e40f39023/20150128\\_YP\\_HW\\_Framework\\_FINAL\\_WP\\_\\_3\\_.pdf](https://assets.publishing.service.gov.uk/media/5c49cc6ce5274a6e40f39023/20150128_YP_HW_Framework_FINAL_WP__3_.pdf) (Accessed: 24 April 2025).

Smith, L. (2020) 'Parenthood Is a Fiduciary Relationship', *University of Toronto Law Journal*, 70(3), pp. 395–452. Available at: [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3691803](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3691803) (Accessed: 13 April 2025).

The MDU (2025) *The Caldicott principles and guardian roles explained*. Available at: <https://www.themdu.com/guidance-and-advice/guides/the-caldicott-principles-and-guardian-roles-explained> (Accessed: 15 April 2025).

UK Government (n.d.) *Data protection*. Available at: <https://www.gov.uk/data-protection> (Accessed: 25 April 2025).

Virtual College (2024) *The 8 Caldicott Principles Explained*. Available at: <https://www.virtual-college.co.uk/resources/2022/03/caldicott-principles-explained> (Accessed: 13 April 2025).

Young Minds and UK Youth (2023) *Someone to turn to: Being a trusted adult for young people*. Available at: <https://www.youngminds.org.uk/media/by3o0aru/someone-to-turn-to-report.pdf> (Accessed: 13 April 2025).

## Acknowledgment

This work is part of the [BIS Data Trust](#) project led by Dr Jessica Bell and funded by the Open Collective Foundation.

## For more information

For more information about this project,  
email [info@ayph.org.uk](mailto:info@ayph.org.uk)

[ayph.org.uk](http://ayph.org.uk) [@AYPHcharity](#)