

Utilising data to improve children's outcomes

*Annex to A positive approach to a
parenting: Part 2 of the Independent Family*

December 2022

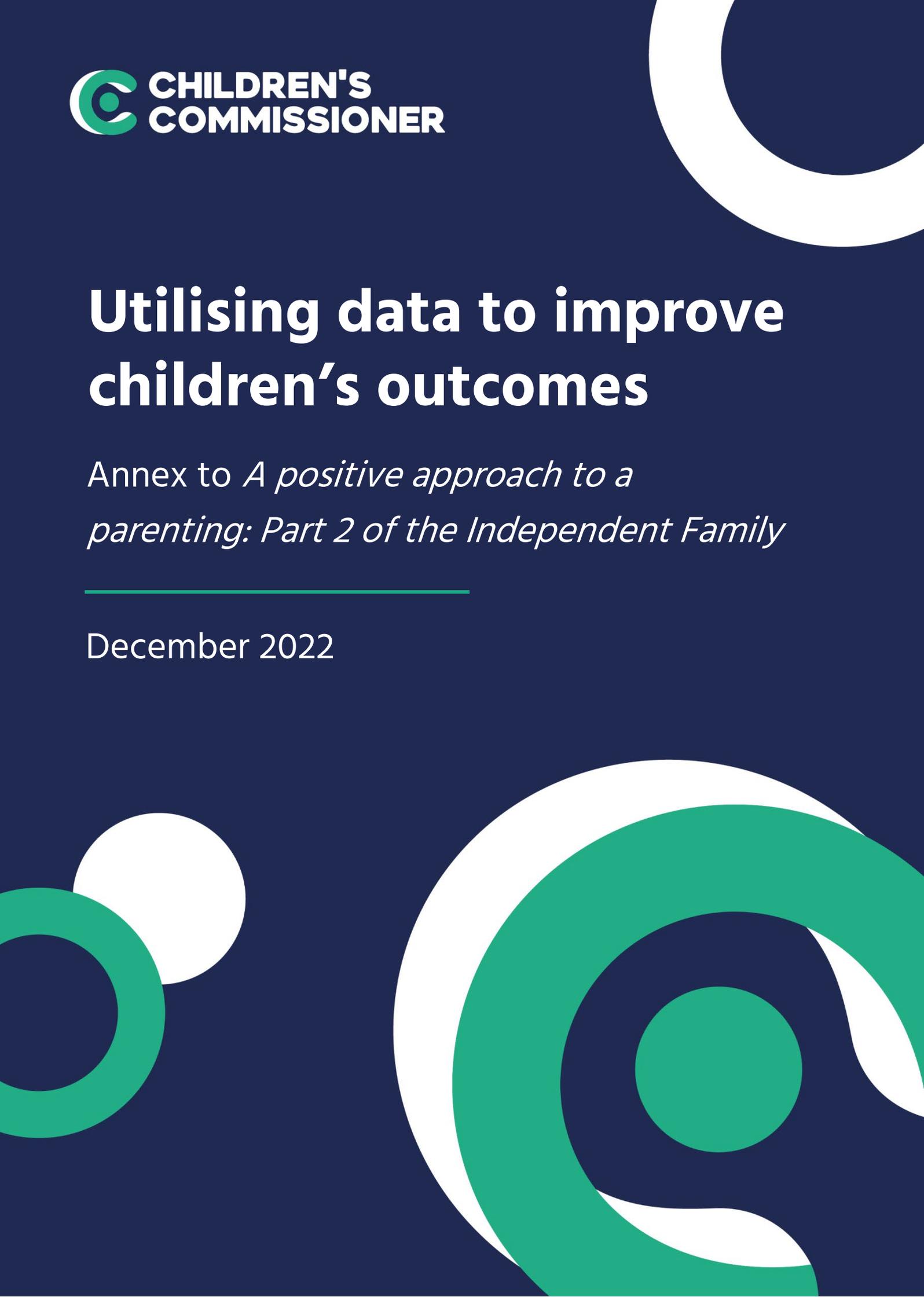


Table of Contents

Executive Summary	3
1. Introduction – A new approach understanding data in public services.....	5
2. The Case for Change: 21st Century Public Services	8
2.1 The current data sharing landscape	11
2.2 There is an overreliance on dedicated individuals and case-by-case data sharing	11
2.3 Understanding of data-sharing legislation is widespread, but identifying the right legal basis is fraught and not supported by good guidance	13
2.4 Data is held by only a few people and organisations within the system. These people often cannot utilise or share it.	15
2.5 Establishing data sharing agreements is complex for many organisations.....	16
3. The way forward	17
3.1 Priorities.....	18
3.1.1 Improve data-collection.....	18
3.1.2 Focus on what is required by frontline professionals to support children and families.....	20
3.1.3 Focus on local systems, not individual cases.	22
3.1.4 Look at the interaction of data-sharing and safeguarding guidance.	23
3.1.5 Invest in creating over-arching data-sharing infrastructure at a local level.....	24
3.1.6 A consistent unique identifier	26
Appendix.....	30
Workshop Attendees.....	30
References	33

Executive Summary

This work is informed by the experiences of more than 120 different practitioners working with data in more than 50 organisations across the public and voluntary sector. The Children's Commissioner's Office (CCo) engaged them through six real-life data-sharing scenarios. The work identified four core findings.

There is an overreliance on dedicated individuals and case-by-case data sharing

Overall, knowledge about effective data sharing is patchy, and training on how to use systems varies greatly. The current data sharing system is often reliant on practitioners talking directly to one another, without a seamless flow of data providing information on who to assist or what services to provide to families and communities. Across our work schools were most readily mentioned as the organisation who would most benefit from acquiring additional data from partners. We heard how schools receive limited information from other schools, the Department for Education and other safeguarding partners, particularly local authorities. At the same time, schools were often the institution which other professionals, including those in the health service, felt would be best place to act on the data they could be provided with.

Lots of data is held at key points within the system

Overall, a strong theme to emerge from the research was that there is less a lack of data across the system, but that much of this data cannot be shared or utilised. The CCo heard that local authority designated officers, and health safeguarding leads, often held lots of data that they were unable to share downwards within the system to those working directly with children and families (for example schools, health visitors and even the voluntary sector).

Understanding of data-sharing legislation is widespread, but identifying the right legal basis is fraught and not supported by good guidance

Data collection, sharing and linkage are all types of data processing. The Data Protection Act (DPA) as amended by the UK GDPR provides six valid lawful bases for processing personal data¹⁵. Any organisation processing data must have established one of these lawful bases before any processing begins. This is where the complexity is introduced, for data to be processed under the basis of public task, there must be another piece of legislation or statutory guidance in place which provides the basis for sharing the data. During the research for this work, 10 separate pieces of enabling legislation were

identified. However, in some cases, organisations find themselves identifying legislation to share data with one organisation but then needing to identify different legislation to share the same data with someone else. The quality of guidance accompanying these different statutes is inconsistent and there is a lack of over-arching guidance on choosing the best statute.

Establishing data sharing agreements is complex for many organisations

To establish data sharing pathways and routes, organisations often have to agree to Data Sharing Agreements (DSAs), Data Protection Impact Assessments (DPIAs), ensure they have an appropriate policy document in place and update their privacy notices. These documents record how information is being shared legally, that the risks involved in sharing the data have been identified and mitigated and ensure that the public can understand how their data is being used. While practitioners we spoke to rarely felt they could not provide the justification for such documents, the requirements to complete these for each data-sharing agreement was arduous and was regularly cited as a barrier to better data-utilisation.

1. Introduction – A new approach understanding data in public services

The CCo has sought to understand how data can be better utilised to improve the experiences and outcomes of children and families in accessing public services. This forms a crucial part of the *Children's Commissioner's Independent Family Review, Part II*. The specific research for this report is influenced by the wider work for *the Review* to understand the needs and experiences of children and families when interacting. There are key insights, drawn from 'the Big Ask' (the largest ever survey of children) and the *Family Review Part 1*, which have formed the starting point for this work¹²:

- Children repeatedly emphasised the importance of professionals understanding them, and their needs. Children do not like to have repeat personal or sensitive information to multiple professionals, but nor do they like having professionals make judgements about them without having all the current information.
- Children do not like to have to ask repeatedly for special treatment or dispensation. When children do have an entitlement because of a characteristic or circumstance (such as being a young carer or qualifying for free school meals) they do not want to repeatedly disclose this to the adults around them to receive support.
- Children and parents see themselves as part of cohesive family units, whose experiences and outcomes are inter-dependent. They want to support one another, and their priorities are often centred around each other.
- Children and parents want an integrated and holistic offer from services. Both children and parents express repeated frustration when they are trying to navigate different services which do not connect to one another.
- Children and parents regularly consider their family unit to comprise of people outside their immediate household, such that conflating household and family units limits our ability to understand or engage families.

These issues all relate to the collection, sharing and utilisation of data. Having gained these insights from children and families, the CCo set out to understand the experiences of professionals trying to utilise data within public services. The last decade has seen multiple new statutes governing both data-sharing and safeguarding. This Report has not sought to undertake a detailed study of the legislation, or duplicate existing research. Instead, it has aimed to understand the perspective and experiences of those working in the system.

The Current Data Sharing Landscape



Key stakeholders, their duties and responsibilities.

We have engaged with over 120 stakeholders and practitioners from across over 50 organisations via a workshop, one-to-one engagement with experts, and meetings with children, parents, carers and families.

Departments and stakeholders	Their relationship with child safeguarding data (and examples)	Duties and responsibilities
 Department for Education (DfE)	Data collector and owner. Local Authorities regularly submit data to DfE, such as on attendance and Children in Need (CIN). DfE is developing a Unique Child Identifier.	Responsible for Government policy and legislation on child safeguarding and protection.
 NHS, NHS Digital & healthcare professionals	Data collector and owner. Examples include: Integrated Care Records, GP records, health visitor records.	All NHS staff have a role safeguarding children. For example, GP practices should have a Safeguarding Lead.
 Local Authorities	Data collectors and owners. Examples include: CIN data, Education Health and Care Plan (EHCP) data, attendance data, section 47 data.	Local Authority social services have a statutory duty to safeguard and promote the welfare of children at risk.
 Police	Data collectors and owners. Examples include: Police Protection data, domestic violence data.	The Police investigate allegations of criminal abuse against children and make enquiries to safeguarding the welfare of children.
 Schools and educational institutions	Data collectors and owners. Special Education Needs Co-ordinator (SENCo) assessments at schools, recording low-level and escalating significant concerns.	Schools have a statutory responsibility for safeguarding and promoting the welfare of children and young people.
 Charities and voluntary groups	Data collectors. Use data provided by Local Authorities to deliver services, collect some data from families.	Charities delivering services have a statutory responsibility for safeguarding and promoting the welfare of children and young people.
 Industry experts and other Government departments	Policy makers. Examples include: Setting Government policy on data sharing, programmes to improve data sharing.	Other Government departments set data sharing and child safeguarding policy, and monitor provision.
 Children and families	Sources of data. In most safeguarding cases, children and families may not be explicitly asked for their consent in order for their data to be shared.	

2. The Case for Change: 21st Century Public Services

The National Data Strategy sets out to improve data utilisation to *'revolutionise the public sector, creating better, cheaper and more responsive service.'*³ The Children's Commissioner shares this ambition. Part 1 of the *Independent Family Review* explored the services that provide support to families, and what families wanted regarding improvements. CCo's research has shown that strong families are those which have strong relationships, which in turn provide both love and practical support. Families want public services to work with them in a consistent and cohesive way. Services need to use data to do this.

To achieve positive outcomes, provide opportunities for early intervention for families and end the system wide issues which have led to children coming to harm there needs to be wholesale improvement in how data is collected, shared, and brought together, i.e., 'linked'.

In the UK's current data system, data and information tends to be collected and stored within individual public services, owned by separate departments responsible for different public services. Data systems have been developed which meet the unique needs of that organisation and have not been built to consider how the needs captured by the organisation might inform the service delivered by another.

Statutory guidance on child safeguarding is clear about the roles and responsibilities of child safeguarding agencies and partners in protecting the welfare of children and young people. For example, *Working Together to Safeguard Children*⁴ outlines that practitioners should be proactive in sharing information as early as possible when concerns arise to help identify, assess, and respond to risk. Whilst this guidance is valuable in highlighting the role that everyone must play in child safeguarding, it is on many levels too broad and high level.

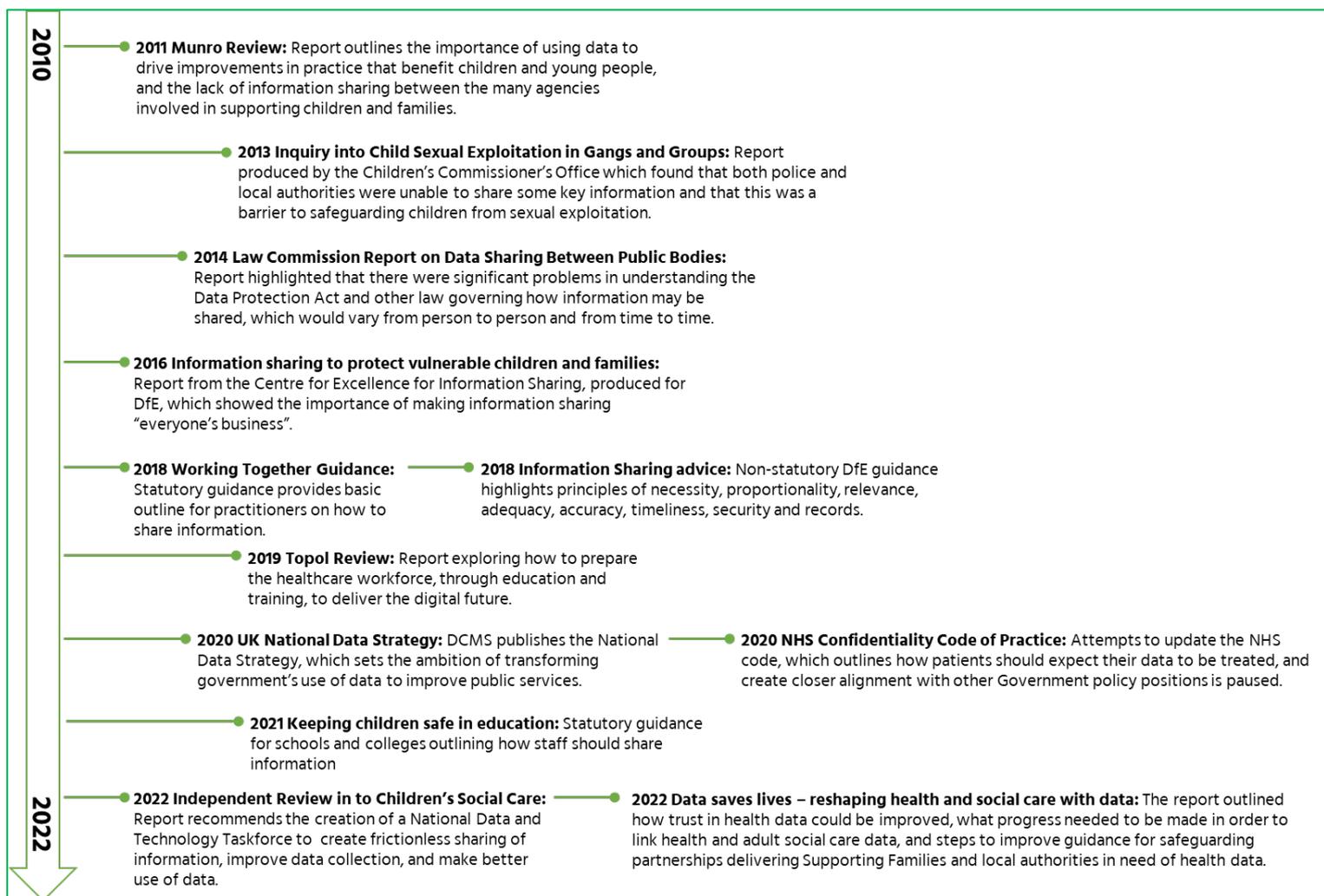
Several nationwide reports have been published which amplify the importance of data sharing. The *Independent Review into Children's Social Care*⁵ recommended the creation of a National Data and Technology Taskforce. Building on the publication of the 2020 UK National Data Strategy⁶ and commitment to transforming government's use of data to drive efficiency and improve public services, the *Independent Review* lays the foundation for a service which will have the remit and finance to fundamentally transform digital services and in turn data sharing.

There is a clear need to be able to better connect services around families and see families as units not a collection of individuals and to accurately reflect the dynamics of the modern-day family. Better connecting services also requires improved data collection and sharing between agencies working with families. This is a sensitive and complex area, but it can be improved. The solution is the answer to the question: how can the system make it as simple and easy as possible for practitioners to do the right thing?

This report provides a series of proactive measures to answer this question, building on those in the Independent Review, which can be introduced in the short and long term to deliver immediate support and change for practitioners. The Children's Commissioner's role, overlooking the whole safeguarding system across education, health, and social care, has a unique perspective on improvements that can be made across sectors and government. Working together to make a more collaborative system will only undo the entrenched siloed working in organisations.

The CCo's proposed way forward, seeks to make safeguarding interventions as timely and effective as possible, with the voice of the child at the centre.

Figure 1. A timeline of attempts to improve data-sharing around children and families



2.1 The current data sharing landscape

There are examples of good work taking place across the country, where data from multiple sources is being pulled together and made accessible to practitioners. However, this was not the common experience of the professionals – or families – engaged throughout the course of this research. Approaches to data sharing are highly inconsistent, with several structural, technological, resource and cultural factors preventing more effective sharing of information.

Some individual services, and local areas are using data well, and are utilising it to improve services, family experience and to connect services to families receive a more cohesive offer. The Government has consistently aimed to improve data sharing across agencies, especially for the benefit of supporting outcomes for children, young people, and their families. Programmes, like Supporting Families have supported the utilisation of data across multiple public sector bodies, underpinned by a shared and linked data to enable targeting of services and tracking of outcomes. This has required local areas to develop systems to support this.

Unfortunately, the research for this report found that good practice is not consistent, and data sharing across organisations (even within safeguarding partnerships and across statutory bodies) is in some cases very poor. The CCo's research has shown that the current system has weak data foundations which are still reliant on close working between individuals who lack clear and consistent guidance and use technology which is outdated.

Whilst practitioners are working hard, often with limited resources and in a system taking on additional caseloads, there is a sense that many are inhibited by the systems in which they are operating. As one individual in the workshop said when describing the challenges:

'It's not insurmountable. It's just a complex piece of work'

2.2 There is an overreliance on dedicated individuals and case-by-case data sharing

Overall, the message from professionals working across the system was that knowledge about effective data sharing is patchy, and training on how to use systems varies greatly. The current data sharing

system is often reliant on practitioners talking directly to one another, without a seamless flow of data providing information on who to assist or what services to provide to families and communities. Across all safeguarding partners, there is a reliance on institutional knowledge and practitioners with the historical experience of working with specific young people. Whilst this allows for some collaboration, it can also lead to working in silo's where (according to one individual in our workshop) *'it's difficult when one practitioner moves on. I think that's difficult because you build those relationships [and] that trust [sic]'*.

Over-relying on individuals poses challenges for two reasons:

1. When dealing with individual safeguarding concerns or vulnerable children, it can become unclear who is dealing with the safety of a child or what the status of that child is.
2. Relying on individuals for insights makes it difficult to use data to create an overview of the households and families who may be eligible for help or who services may want to engage with. It's clear that we need to move past a point where data is held in the hands of a few individuals and towards a system where there are more flows of quality information across agencies.

One specific area which suffers from an overreliance on individuals is data sharing between schools, especially those not sitting in a family of schools or part of Multi-Academy Trusts (MATs). Attendees at the workshop recognised that schools do not always share safeguarding data with each other in a timely manner, for example when a young person transfers between settings or a sibling at a feeder or local school may be impacted by events taking place involving a family member at another school. Whilst guidance exists on what information should be shared, many schools are reliant on a single individual to act on this. As one practitioner in our workshop identified:

'We're relying on hundreds of thousands of individual practitioners in that moment to remember to do that thing.'

2.3 Understanding of data-sharing legislation is widespread, but identifying the right legal basis is fraught and not supported by good guidance

Data collection, sharing and linkage are all types of data processing. The DPA as amended by the UK GDPR provides six valid lawful bases for processing personal data⁷. Any organisation processing data must have established one of these lawful bases before any processing begins.

The legal bases are set out in Article 6 of the UK GDPR and include consent, legal obligation, vital interests and public task.

Most processing undertaken by public bodies will rely on public task as the legal basis, i.e., the processing is necessary for them to perform a task in the public interest or for their official functions, and the task or function has a clear basis in law or is included in common law tasks, functions or powers, or statutory guidance⁸.

This is where the complexity is introduced, for data to be processed under the basis of public task, there must be another piece of legislation or statutory guidance in place which specifies the tasks that the organisation is able to carry out, and the organisation must be able to demonstrate how the processing meets this task.

During the workshops, 10 separate pieces of enabling legislation were identified. However, in some cases, organisations find themselves identifying legislation to share data with one organisation but then needing to identify different legislation to share the same data with someone else.

For example, regarding sharing data for safeguarding children, the Children Act 1989, the Children Act 2004 and the DPA 2018 make provisions for the sharing of data without an individual's consent for the purposes of safeguarding. However, the Children Act limits information sharing for this purpose to sharing only with the Local Authority Designated Officer, who is then unable to share that information with any other organisation. The DPA sets out a broad definition of safeguarding in Schedule 8 ('safeguarding of children and individuals at risk') but only applies this definition when sharing without

consent for law enforcement purposes (specified in Part 3, Chapter 2, Section 35 and Section 42)⁹¹⁰¹¹. Law enforcement purposes are then defined in Part 3, Chapter 1, Section 31.

The web of legislation is convoluted and complex. In practice what this means is that two areas undertaking the same task, and sharing and processing data in the same way, may use completely different pieces of statute to underpin this, and often one data-system will require multiple different statutory justifications. Some local areas reported that had to employ two members of staff just to trawl through and identify the most relevant statute for each data-sharing agreement.

In the case of child safeguarding this complexity, coupled with the lack of clear guidance, is extremely concerning, given the findings from serious case reviews that poor information sharing has been a factor in all the investigations to date. The 2018 guidance *'Information sharing, advice for practitioners providing safeguarding services to children, young people, parents and carers'*, does not provide guidance sufficient to support an organisation with responsibilities for safeguarding¹². For instance, it specifies that practitioners must consider whether the common law duty of confidence can be overcome when sharing data for safeguarding without consent on a case-by-case basis. It does not however define what the common law duty of confidence actually is. Additionally, as this paper has set out, relying on case-by-case decision making contributes to a system where decisions take too long to be made and frontline practitioners are expected to become data protection experts alongside their existing professional role. This guidance contributes to unrealistic expectations being made of frontline practitioners without providing a clear framework which links statute to outcome.

Furthering the complexity in this space is the over-emphasis on consent as a model for data processing. Under UK GDPR consent is only one of the six valid legal bases for data processing and the ICO sets out that no one basis is 'better' than another. However, the 'information sharing' guidance and the DPA make multiple references to consent and only identify alternative routes 'when consent cannot be obtained'. This creates an environment where practitioners are unsure whether they should be trying to seek consent, or if they can proceed without it, even when there is a clear route under public task.

2.4 Data is held by only a few people and organisations within the system. These people often cannot utilise or share it.

A key concern to emerge from the professionals with whom we worked for this research was that data is concentrated at a few points, and with a few individuals, within a safeguarding system. This is a problem if these individuals cannot either utilise or share the data. For example:

- All organisations working with children are required to refer safeguarding concerns with the local authority, and specifically the Local Authority Designated Officer (LADO). The local authority can assess the information, store the information and action the information by commencing child protection or family help processes. But under the Children Act 1989, the local authority has very limited ability to share the information with partners. So, for example, they cannot tell schools or Family Hubs key information about the child or family.
- The same issue was raised in regard to safeguarding leads within the health service. They may hold or be able to access a lot of data, but they can only share it or action it in very limited circumstances.

In both cases the data held by professionals with tightly proscribed roles within the system. Their ability to share or utilise this data is normally limited unless there is evidence a child is at risk of serious harm. But at the same time there may be several professionals in other parts of the public service, such as schools or health visitors, who could utilise the information to support the child or their family. Often these professionals will have their own sources of information, and if they also had access to the information held centrally, the two pieces of information would show the child to be at risk. For example, the LADO will know that the police were called out for a domestic violence call out at a child's home last week. The school will know that the child did not attend for 3 days following this. Neither professional knows both pieces of information unless a specific data-sharing template has been agreed¹³.

2.5 Establishing data sharing agreements is complex for many organisations

To establish data sharing pathways and routes, organisations often must agree to Data Sharing Agreements (DSAs), Data Protection Impact Assessments (DPIAs), ensure they have an appropriate policy document in place and update their privacy notices. These documents record how information is being shared legally, that the risks involved in sharing the data have been identified and mitigated and ensure that the public can understand how their data is being used.

In practice, it can be challenging to have different partners sign DSAs. Many practitioners and service leads described how services can take many months, and in some case years, to agree the wording of DSAs, delaying the implementation of technological solutions.

Solutions are possible, for example the Wales Accord on the Sharing of Personal Information (WASPI) aims to address these issues. The WASPI is directly concerned with health, education, safety, and crime prevention, and has created tools and templates to help share personal information¹⁴. Such templates standardise processes across the country, which is especially beneficial to those safeguarding partners who have jurisdiction or work across several localities. The Children and Social Work Act 2017 amended the Children Act 2004 to give local safeguarding partnerships the power to collect and distribute key data within the partnership.

Many practitioners expressed a keen interest in being able to develop technological solutions which would link data from multiple safeguarding partners, and which could both more easily allow practitioners to record concerns or engagement with a child or family, as well as assist in designing and targeted delivery of services. However, many are constrained by resources and the need to prioritise urgent safeguarding issues.

Clearly, more efficient ways of creating and agreeing data sharing agreements need to be devised so that services can better share greater quantities of data.

3. The way forward

Below are a set of priorities for improving the use of data across public services. There are two things to note about the recommendations.

1. They generally apply equally to all services and different levels of Government. There are a few specific recommendations to Central Government in terms of how they support frontline services, but generally the recommendations speak to common aims which can be shared across different services and levels of Government.
2. The recommendations are inter-dependent. This is deliberate and reflects the reality that there is no silver bullet for improving data use. We need to support better knowledge of the legislation, better utilisation of existing technology and change cultures.

For example, a particular issue that has been highlighted in research for this report, and previous work on this topic, has highlighted the particular challenges of utilising health data across wider safeguarding systems¹⁵. There is no singular response to this, but all the recommendations below would help improve the situation. This will be illustrated by one example which was raised by a professional at one of our workshops:

'A single mother of a young child attends an appointment at her GP to discuss her mental health struggles. The mother is, understandably, reticent about speaking up on this and there is no evidence that she has been neglectful or abusive to her child. Yet it is clear to the GP that she goes through periods where her mental health is utterly debilitating, and she cannot identify any close family or friends who she can go to for help. The GP makes a referral to specialist mental health services, outlining his understanding of the likely medical diagnosis. The GP is very concerned about this information being shared more widely for fears it will be misinterpreted by non-healthcare professionals and deter mother from coming back to the GP. Yet the GP is aware that there is an obvious need for mother to get some parenting help at key moments of crisis, and that there is a risk to the child if this is not provided.'

Through the recommendations below, we explain how improved data-sharing and utilisation can respond to this dilemma, without compromising the GP's professional ethics or sharing unnecessary personal information about the mother.

3.1 Priorities

3.1.1 Improve data-collection.

Data and information are routinely collected by public bodies during the delivery of services. Data collected for this purpose is known as 'administrative' data and it is usually structured to facilitate the delivery of a service, such as allocation of a benefit payment, or registration for a school place, to an individual. The case has long been made for repurposing administrative data for more than simply delivering a service, but instead to use it for service evaluation, delivery planning and forecasting, safeguarding and statistical research. The alternative to repurposing administrative data is to create and collect additional datasets, for example through surveys, which reach only a small percentage of the population and represent additional costs to taxpayers.

The limitation of administrative data lies in its origin, in that it is designed for service delivery aimed more often than not at an individual. In practice this means that whilst a service may have access to a child's patient record through their GP, there is no system for relating that child's data to their parent or guardians' data. The implication of this for families is that there is no way to look at a family's health in a holistic way and use the data proactively to identify people potentially in need of greater support. To use the example of the single mother accessing her GP given above, the data-held on the mother is only useful for supporting the child if the data records can be linked.

The research for this report identified numerous individual examples of good data-sharing and linkage for individual level data. However, there were fewer examples of family-level data linkage.

Such a system has the potential to deliver significant cost savings and efficiencies for families. To reach the point where services are delivered in a family-centric manner, as this Review has found to be crucial, the data systems which services rely on will require revolutionising. Rather than seeing this done in a piece-meal fashion, relying only on pockets of local innovation, there needs to be a cross-government programme to identify the solutions and work with local areas to develop the appropriate methods and guidance. This way every service can see the benefits, rather than further entrenching the current post-code lottery of whether service delivery is data led.

Alongside improving the ability to bring records together the system needs to agree what information is shared. As this paper has set out, decisions regarding data sharing should be governed by the principles of proportionality and necessity. Often in complete service records, there is far more information recorded than would be needed to be shared for safeguarding or service delivery purposes.

Returning to the example of the single mother at the GP again, the local authority young carers service does not need to know the mother's complete medical history, nor the details of the GP assessment or any onward referrals at this point. The only thing that they need to know, is that there is a child who is potentially a young carer and thus entitled to a young carers assessment. This single piece of key information is often lost amidst complex records collected by services.

The solution is to improve data recording systems with the facility to record these key pieces of information in specific fields, creating a 'flag' that the individual has met a certain criterion or would be eligible for support from another service. This would mean that rather than sharing detailed medical notes, a much simpler set of information can be shared.

An example of how this can be done, and the benefits of doing it, is the Family Context tool developed by Social Finance, which brings together high-level, key information regarding a child or a linked adult¹⁶. The Family Context tool is a data access solution for social workers, who were spending time chasing information and often had access only to incomplete records which impacted decisions and outcomes. The Family Context tool has been deployed in Stockport, bringing together data from Adult Social care, Education, Housing and Children's Social Care. An evaluation of the pilot found that social workers were spending less time searching for the right information, able to identify relevant information quickly before meeting with families and conducting new assessments with access to the right information from the start, supporting their ability to make decisions quickly. However, successful deployment of the tool requires a local area to have the data and technological maturity to bring records together, identify adults linked to children as well as the information governance maturity to establish the legal bases for linking data together. It also requires significant buy-in from leadership across services who recognise the need to try something new to drive service improvement and who embrace data sharing and linkage as a technological solution.

Recommendations:

- The Department for Education should lead a cross-Government review of how the following groups of children are identified:
 - Children affected by parental imprisonment
 - Children of a parent in inpatient mental health provision
 - Children in families with no recourse to public fund
- The Children's Commissioner recommends that the national safeguarding leads across Government convene a working group to identify the key pieces of information and the existing data systems into which they could be integrated.
- The Children's Commissioner recommends that the Cabinet Office should convene a cross-government working group, led by the Office for National Statistics (ONS) to establish the best practice for designing administrative systems to facilitate bringing together family records as well as individual records. The group should work to produce practical guidance for local authorities and system designers to improve the data recorded and the methodologies needed for bringing data together.

3.1.2 Focus on what is required by frontline professionals to support children and families.

It is important that data-sharing is not seen as an end in itself. Instead, the motivation should be to ensure professionals working with children and families have the information they need – and that children and parents expect them to have – while minimising the amount of personal information shared. Focusing on the end product of better utilisation of data by professionals, should be the starting point for all data-sharing discussions.

Put more focus on making data accessible to professionals working directly with children and families.

As highlighted above, a key issue to emerge through this report is the way data is concentrated in certain points within children's safeguarding systems, most notably Local Authority Designated Officers

(LADOs) and health safeguarding leads¹⁷. These individual positions within the system have limited ability to act on this data, or to disseminate it downwards. When case studies were tested with key professionals, the key message was that data was most useful when it could inform everyday decisions or interactions with families.

To return to the example of a single mother speaking to their GP about mental health issues detailed above; the information disclosed here would be unlikely to reach the threshold where either the LADO or the health safeguarding lead would intervene, but the fact that the child was a young carer could be utilised by their school. The school could make small adjustments to the pastoral offer to the child and, crucially, would respond differently if another issue arose, such as poor school attendance.

The best examples of data utilisation encountered through the research for this report were where high-level data was available to a range of frontline professionals interacting directly with families, including schools, social workers, housing officers and police officers. Critically important was making this data available in real time, so it could inform early encounters with professionals.

Ensure all professionals understand how data will be used

A frequent concern raised throughout the research was that professionals are wary of giving away data when they are unsure how it will be used, or to whom it will go. Conversely, they may end up sharing unnecessary amounts of data if they are not clear about what is needed. In the example of the GP above, there are clear referral pathways, within health to specialist services and within children's services for a safeguarding referral. In both cases it is clear what data is needed, and for what purpose. But systems that seek to collate data more broadly on children or families need to ensure all professionals understand how it will be used.

The best examples of this are systems which both seek information from professionals and make data available to them. Thus professionals can see what is required, and how it will be used. In these instances, minimal amounts of data need to be shared, but these nuggets of data can be utilised quite widely. Often this might just be a flag to say 'child/family is/has been open to x service, this is the lead professional to contact if you need more information'. In the GP example above, the key information to share is that the child may be considered a young carer. If the GP could share this information, through a portal which they could also access this information, they can see how small amounts of key

information that will inform how professionals treat a child can be shared, *amongst those working with or known to the family.*

Share awareness of best practice

There is huge variation at present as to how data is utilised within and across different agencies. The research for this report encountered outstanding examples of data-utilisation within individual public sector bodies (including schools and local authorities) and of the sharing data between different public bodies within one area. There is a lot to learn from their innovative work, and more focus should be placed on sharing this learning, within and between sectors.

Recommendation:

The Children's Commissioner recommends the Department for Education should provide practical materials (such as guidance on the 2017 Act, draft memoranda of understanding and data protection impact assessments) to support local safeguarding partnerships utilise the partnership for the purposes of data-sharing.

3.1.3 Focus on local systems, not individual cases.

At present, existing guidance on data-sharing with safeguarding systems focuses on individual cases, and how to assess the proportionality of data-sharing. Yet if we want to use data systematically to inform and improve public services, we need to move from sharing data on a case basis, to a system-wide approach to sharing, linking and utilising data. This is to enable small, and proportionate amounts of data to be routinely utilised by professionals to improve service delivery for children and families. It also reduced the risk that arises ad-hoc data-sharing on individual cases. All the recommendations in this report are aimed at making this easier to achieve.

Recommendation:

The Children's Commissioner recommends the Department for Education update the guidance on data-sharing for safeguarding purposes to:

- reflect the updates to *Working Together to Safeguard Children* and the broader definition of safeguarding it contains

- focus as much on data-sharing across systems as in the cases of individual children
- set out the relevant legal gateways contained in safeguarding statutes which may enable system-level sharing of data under the Data Protection Act (DPA)

3.1.4 Look at the interaction of data-sharing and safeguarding guidance.

As set out in the challenges above, during the course of the research for this project, the CCo encountered high levels of understanding and appreciation of the requirements of the Data Protection Act, but much lower levels of understanding as to how various other statutes could be utilised to provide the legal justification for this. What is required is over-arching guidance for practitioners on how to combine different pieces of legislation to create a data-sharing system which enables frontline professionals to access the data they need.

Similarly, there is high quality guidance available as to when those working with children should share data they hold on individual cases, but much less guidance available for system wide-guidance. Overall, there are big gaps in the guidance available to professionals that means available guidance does not cover all available legislation.

Recommendations:

The Children's Commissioner recommends that the Information Commissioner's Office (ICO) continue their work to meet the Public Service Committee recommendation to create a clear and practical resource that helps practitioners navigate data protection law in the context of child safeguarding.¹⁸

This should:

- Help practitioners understand the interplay between data-sharing and safeguarding legislation, in particular the distinction between times when data must be shared and when it may be shared.
 - Set-out the process organisations need to go through when deciding to share data for safeguarding purposes on a systematic basis, including how to assess the legal gateway.
 - Provide clear and practical guidance to professionals as to when they may rely on the safeguarding exemptions included with the Data Protection Act.
-

- Help practitioners navigate separate terminology between systems. For example, the new guidance should explain whether the ability to share data in an emergency situation applies in all situations when the threshold of serious harm has been met.

The Children's Commissioner recommends a central depository is created where professionals using data in public services can access all relevant information and guidance on different pieces of legislation enabling data sharing (e.g. The Digital Economy Act, the Children Act 2004 etc)

3.1.5 Invest in creating over-arching data-sharing infrastructure at a local level

Through the course of the research, two approaches to improving data-sharing and utilisation at a local level were identified:

1. Incremental improvements achieved through bilateral data-sharing agreements between organisations.
2. Wholesale change achieved through the creation of a single over-arching system which brought together multiple datasets into a single product

Both approaches are labour intensive, and all the recommendations in this report are aimed to reduce the burden on public services in doing this. Creating a single system requires large amounts of senior-buy-in and requires significant investment in crating the legal and technical infrastructure. In turn this requires the recruitment of staff with these skills, which is a particular challenge. However, the alternative is slow and cumbersome. For example, one local authority had to review 8 separate data-sharing agreements in response to the re-location of a small number of families under the Ukrainian Resettlement Scheme.

The Children's Commissioner believes there needs to be a single-overarching infrastructure within each area, such that it can:

- Enable the linking of multiple datasets
- Link practitioners across multiple agencies through a single system

Many of the recommendations made previously would reduce the burden of establishing these systems, but investment will still be required.

3.1.6 A consistent unique identifier

This paper has thus far set out the case for redeveloping data systems, how the system can collect data which better reflects individuals lives and share that information between organisations.

However, simply bringing data into a single organisation but not joining it together around an individual or family unit limits its usefulness¹⁹. The final piece of the data puzzle is to be able to bring datasets from these different sources together to create holistic views of a child or their families experience.

Bringing data together from multiple sources and in doing so, joining records together that relate to the same person is known as 'data linkage'. There are many methods of data linkage currently employed by public bodies. The current suite of methods employed are driven by data availability, data quality and the purpose of the linkage²⁰. The simplest form of data linkage relies on matching on a unique identifier, for example, if NHS number is present on both datasets, then this can be used to link the individual records together.

However, this is complicated by the lack of consistency in unique identifiers used by different government departments and public bodies. For example, most children in England have the following unique identifiers:

- NHS number, assigned to all children registered with an NHS health service
- Unique Pupil Number (UPN), assigned by local authorities to children enrolled in school and used by the Department for Education (DfE) to bring education records together for a child.
- LA-ID, a unique identifier assigned by their local authority, used only by the local authority to bring together internal records
- Passport number, for children with a passport

These unique identifiers are used by government departments to manage their internal records and provide services, as well as to carry out analysis and produce official statistics. There is no system that relates one identifier to another routinely. Instead, to identify that a record with the NHS number 485 777 3456 belongs to the same person as a record with the UPN H801200001001, one would also need to have access to additional identifiers on both datasets, such as full name, date of birth, address and sex. There are then linkage methods which process these additional identifiers to ascertain the likelihood

that a record from one dataset belongs to the same person as a record in another. Methods which rely on these additional identifiers are subject to some degree of error and linkage methodology has had to become increasingly complex to overcome some of the most common errors²¹. It also requires large amounts of personal data to be shared purely for the purpose of linkage simply because as many data-fields as possible have to be shared to reduce error.

In the case of data linkage, error can occur either where a link is made between two records which do not in fact belong to the same individual, or where two records which do belong to the same individual are not linked²². Often, linkage error is a result of poor data quality and changes in individual identifiers. For example, name and address are highly changeable and therefore limit the ability to link two datasets which were recorded at different points in time. Further, these additional identifiers are more likely to change for certain groups compared to others. For example, children's names are the most likely to change following changes to their family structure. Linkage which relies on name could then bias against children whose parents are divorced, as their name is the most likely to have changed between data sets. Unique identifiers such as NHS number are not subject to change and therefore can act as a 'golden thread' across a diverse range of datasets over time.

Were the use of a single consistent unique identifier ubiquitous across those services which interact with children then there would be a 'golden thread' not just between records held by one agency, but between records held by multiple agencies. In Sweden for example, a unique identifier common across all systems, known as the personal identify number (PIN) was introduced in 1947 and is used in healthcare, migration, taxation, education, and social security etc. The PIN is the basis for data linkage and enables straightforward evaluations of public services across Sweden²³.

However, the presence of a consistent unique identifier across data sources is not a panacea to solve all the challenges set out in the earlier sections of this paper. Data governance arrangements will still need to be in place to protect individuals' data and organisations will still need to set out clear justifications for the linkage. Additionally, there will still be data quality considerations to be considered, such as whether every individual in the data has the identifier recorded or the reliability of the method used to input the identifier. For example, some systems ask an individual to input their unique identifier alongside additional personal information such as name and address, and the identifier is then validated using that information. In other data systems individuals are asked to provide the identifier but the

validation does not occur in real time, leading to incorrect identifiers remaining recorded in the data system.

Research has also shown that certain people are more likely to approve of data linkage by services than others which could lead to bias in linkage that relies on consent. For example, in one study, parents in higher occupation, qualification, and income groups were more likely to approve of data linkage, than Black parents, lone parents, younger parents, and parents in larger households. Those least likely to approve were in marginalised groups who would most benefit from programmes which focus on early intervention and service improvement²⁴. Alongside any efforts to introduce a consistent unique identifier there needs to be a corresponding public information campaign to explain the merits of data linkage.

The vision for a consistent unique identifier

Recommendation: The Children's Commissioner wants to see the NHS number adopted as the consistent unique identifier and that this be rolled out across education and child protection services. The NHS number is the most appropriate identifier as it is assigned upon registration with the NHS, which is usually at birth and remains with an individual throughout their life. Other identifiers, such as the UPN, only cover an individual whilst they are of a limited age range and do not cover the early years, which is a crucial data gap.

In 2016 the Department for Health gave an undertaking to the Information Commissioner that the NHS number will be used for health and social care only. However, the NHS number is not widely used in children's social care and given social care data is often linked with education data, the distinction would be hard to maintain. The alternative to using the NHS number would be to create a new unique identifier for the population, which would incur huge costs to the taxpayer through design, validation and implementation.

The CCo recommends that the decision not to enable the linkage of health, social care and education data through the NHS number is revisited. There is an overwhelming body of evidence which demonstrates that data sharing and linkage is ethical and beneficial not only to individuals but to wider society through improved service delivery. The idea that the NHS number should only be used for health and social care is a stark example of the silo's which exist within government and a way of thinking

about data which continues to lead to children remaining at risk of harm, unable to receive the support to which they are entitled.

Appendix

Workshop Attendees

We would like to express our thanks to those individuals, schools, agencies, organisations, and safeguarding partners who expressed an interest and supported the workshop and subsequent development of this report.

London Borough of Islington	Brighton & Hove Council
Care Quality Commission	Early Intervention Foundation
What Words for Social Care	Ofsted
Association of Directors of Children's Services	Hull City Council
Social Finance	Norfolk Constabulary
National Police Chiefs Council	Department for Health & Social Care
Reach Foundation	Department for Education
Somerset County Council	NHS Digital
Government Data Sharing Working Group (Department for Education)	Nottinghamshire Constabulary

Royal College of Paediatrics and Child Health	NHS Hampshire Trust
NHS North Cumbria CCG	NHS Cambridgeshire Trust
Surrey Constabulary	Metropolitan Police Service
Action for Children	HM Inspectorate of Constabulary and Fire & Rescue Services
Department for Levelling-Up, Housing & Communities	Inspiration Trust
Academies Enterprise Trust	Local Government Association
Essex Constabulary	Stockton-on-Tees Council
Norfolk County Council	West London Zone
Education Scotland	NHS Portsmouth CCG
NHS Hampshire, Southampton and Isle of Wight CCG	West Yorkshire Constabulary
NHS England	NHS Birmingham & Solihull CCG
NHS Sussex CCG	Information Commissioner's Office

Bristol City Council	Home Office
Liverpool City Council	London Office of Technology & Innovation
West Mercia Constabulary	Manchester Youth Zone
West Midlands Constabulary	Hartlepool College of Further Education
Hartlepool Council	Jesmond Primary School
South Yorkshire Constabulary	NHS Solent
Cleveland Constabulary	NHA Lancashire and South Cumbria Trust
Ark Academies	NSPCC
Central Digital & Data Office (Cabinet Office)	National Data Guardian

References

- ¹¹ Children's Commissioner for England, *The Big Answer*, 2021, [Link](#). Accessed on 12/10/2022.
- ² Children's Commissioner for England, *Family and its protective effect: Part 1 of the Independent Family Review*, 2022, [Link](#). Accessed on 12/10/2022.
- ³ DCMS, *National Data Strategy*, 2020, [Link](#). Accessed on 25/07/2022.
- ⁴ DfE, *Working Together to Safeguard Children*, 2018, [Link](#). Accessed on 15/07/2022.
- ⁵ Josh McAlister, *The Independent Review of Children's Social Care*, 2022, [Link](#). Accessed on 18/07/2022.
- ⁶ DCMS, *National Data Strategy*, 2020, [Link](#). Accessed on 25/07/2022.
- ⁷ ICO, *Lawful basis for processing*, [Link](#). Accessed on 12/10/22.
- ⁸ ICO, *Public Task*, [Link](#). Accessed on 19/10/22.
- ⁹ Data Protection Act 2018, Part 3, Chapter 3, Section 35, [Link](#). Accessed on 19/10/22.
- ¹⁰ Data Protection Act 2018, Part 3, Chapter 2, Section 42, [Link](#). Accessed on 19/10/22.
- ¹¹ Data Protection Act 2018, Schedule 8, [Link](#). Accessed on 19/10/22.
- ¹² HM Government, *Information sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers*, 2018, [Link](#). Accessed on 19/10/22.
- ¹³ The school is legally able to inform the LADO of a child's non-attendance through normal safeguarding referrals process, but this would not reach the threshold for a safeguarding referral unless the school had other information which added to the risk level. Under the Children Act 1989, the LADO is not allowed to tell the school unless a child protection inquiry has been established. The threshold for this is risk of serious harm. There are other statutes which would enable a data-sharing agreement to be established to share this information both ways.
- ¹⁴ Website, *Wales accord on the sharing of personal information*, [Link](#). Accessed on 19/10/22.
- ¹⁵ House of Lords Public Service Committee, *Letter from Rt. Hon Baroness Armstrong of Hill to Rt. Hon Oliver Dowden, 'Data-sharing by providers of public services'*, 3rd Feb 2021, [link](#)
- ¹⁶ Social Finance, *Why the Family Context project is so promising for children's services*, 2021, [Link](#). Accessed on 19/10/22.
- ¹⁷ These roles were previously in Clinical Commissioning Groups but will now sit within Integrated Care Systems.
- ¹⁸ House of Lords Public Service Committee, *Letter from Rt. Hon Baroness Armstrong of Hill to Rt. Hon Oliver Dowden, 'Data-sharing by providers of public services'*, 3rd Feb 2021, [link](#)
- ¹⁹ ONS, *Guidance: Joined up data in government: the future of data linking methods*, 2021, [Link](#). Accessed on 10/10/22.
- ²⁰ ONS, *Developing standard tools for data linkage: February 2021*, 2021, [Link](#). Accessed on 10/10/22.
- ²¹ Dusetzina et al, *Linking Data for Health Services Research: A framework and Instructional Guide*, 2014, Agency for Healthcare Research and Quality, [Link](#). Accessed on 10/10/22.
- ²² Bohensky et al, *Data Linkage: A powerful research tool with potential problems*, 2010, BMC Health Services Research, [Link](#). Accessed on 10/10/22.
- ²³ Ludvigsson et al, *The Swedish personal identity number: possibilities and pitfalls in healthcare and medical research*, 2009, European Journal of Epidemiology, [Link](#). Accessed on 10/10/22.

²⁴ Edwards et al, *Data linkage for early intervention in the UK: Parental social license and social divisions*, 2021, Data & Policy Volume 3, [Link](#). Accessed on 11/10/22.



**Sanctuary Buildings, 20 Great Smith
Street London, SW1P 3BT**

020 7783 8330

 @childrenscommissioner

 @ChildrensComm

 @childrenscommissionersoffice