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Accessing records and files for care experienced children and young people in health

Learning outcomes

- The workshop will explore the legal, ethical and practical considerations involved in supporting access to health files.
- It will discuss common challenges and how professionals can navigate this complex area while keeping the child’s best interests at the centre.

What motivates people to access adoption and care records?

"There was just a lot of things that I didn't know and I was like really shocked, and then there was really hurtful things about the pregnancy and stuff, that was all in there. ***And it wasn't just a one off incident there was several different health visitors and doctors all saying the same thing, so because I was able to read that I was then able to say to myself 'yeah I really wasn't to blame'.*** *But what I also realised going through that was that no one else was to blame either."*

Purpose of health records

- Provide crucial medical and developmental history
- Inform prospective adopters or carers
- Support the child's long-term wellbeing and identity needs
- Ensure continuity of healthcare
- Health report is (completed by a MA or AMA) collates information from GPs, hospital records, health visitor, birth family history etc
- Loss or delay, disrupted medical histories, inadequate recordkeeping vs parents intimate knowledge

Contents of health records

- A personal child health record
- Immunisation data
- School health records
- Community-run clinic records such as vision or audiology
- Child guidance or mental health records
- Records from speech and language therapist, physiotherapy, etc
- Hospital records
- GP’s records

NB records will contain information about child, parents and siblings

Incomplete records or poor sharing

- A 12-year-old transferred without any medical records to an out-of-area placement. The night after, admitted to hospital, seriously ill with acute asthma, spent 3 days in intensive care. The foster carer was not aware of the asthma and medication had been inadvertently stopped in his previous placement.

- A 29-year-old adopted woman not wanting to have children of her own because they had no knowledge of thier own health history.

Health assessments

Confidentiality

- Reporting to social worker, can deter young people from accessing health care
- Act in the best interest, offer confidential healthcare where possible
- Offer a copy of written reports and where they will be sent, seek consent for the release of information, keep medical information confidential if asked by a ‘Gillick competent’ patient (unless risk of harm or abuse)

Sharing info held by agencies

- Disclosure of information restricted to those who need to know
- Consider partial disclosure where sufficient for the purpose
- Comprehensive policies regarding confidentiality, sharing, retention and access, with input from agency medical adviser and specialist nurse

Competing duties

- Duty of confidence is not absolute and may overridden, for example, to comply with statutory duties. Explain reasons and obtain consent, where possible.

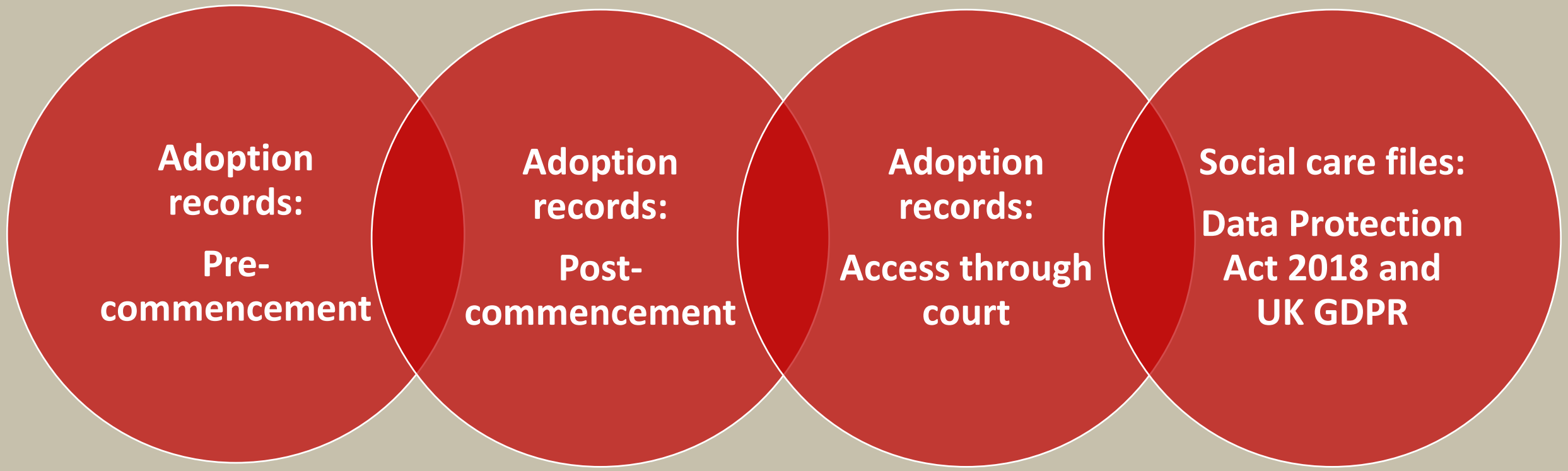
Dealing with medical records for adopted patients

Historical practice	• NHS central registry attempted to ensure there was no link between the old and new names, and that the fact if adoption was concealed.
Change of surname	• Children may not be known by a new surname unless everyone with PR gives written consent or court permission. In practice, children may have extensive medical file when change occurs.
Merging records	• When a child is adopted and given a new NHS number, their medical records should be merged with the new post-adoptive details where possible across all health records.
NHS England guidance *Last updated 12 March, 2025	• NHS England » Key principles for ensuring continuous health records of adopted children • AD Medical Records Practice Guide v1.0 March 2025.pdf

7 principles for ensuring continuous health records of adopted children

1. **The child's clinical health records remain intact and continuous after the adoption order has been granted.**
2. Only accurate current demographics can be viewed or used by administration personnel, medical professionals or patients/carers.
3. Information governance and data principles must be enhanced to prevent any accidental disclosure of addresses or third-party information contained in the record.
4. Reminders should be used on the record to highlight the sensitivity of the record.
5. The GP remains the Data Controller with regards to the child's medical record and as such the process of merging records relies on good communication between primary care, the local Looked After Health/Adoption team and other stakeholders, including your local Child Health Information Service team.
6. The use of standard SNOMED CT codes should be universal, in this case:
   1.Record contains third-party information (finding), SCTID
   2.888931000000108; Adopted child (person), SCTID: 393547004.
7. Subject access requests must be handled by NHS provider medico-legal teams with advice from the designated looked after child (LAC) professionals and/or adoption medical.

Disclosure of (health) records



Pre-commencement

- Adoptions before the Adoption and Children Act (ACA) 2002 came into force on 30.12.2005
- Adoption agency has discretion to disclose info held on adopted person's file to that person, including in childhood, for example, if necessary to provide support.
- **May include health info, agency may seek medical adviser's help in deciding what should or should not be disclosed, or in interpreting medical info or outdated medical terms.**

Post-commencement

- Adoptions after the ACA 2002 came into force on 30.12.2005
- An adopted person has a right, at 18, to receive a copy of the info disclose to their prospective adopter/s at the time of placement.
- Will include Child's Permanence Report (CPR), containing the medical adviser's summary of the child's health assessment.
- The adopted adult may request access to further info held on the adoption file, including the full medical report, which the agency will have discretion to disclose.
- **The agency may seek advice from the medical advisor before disclosing.**

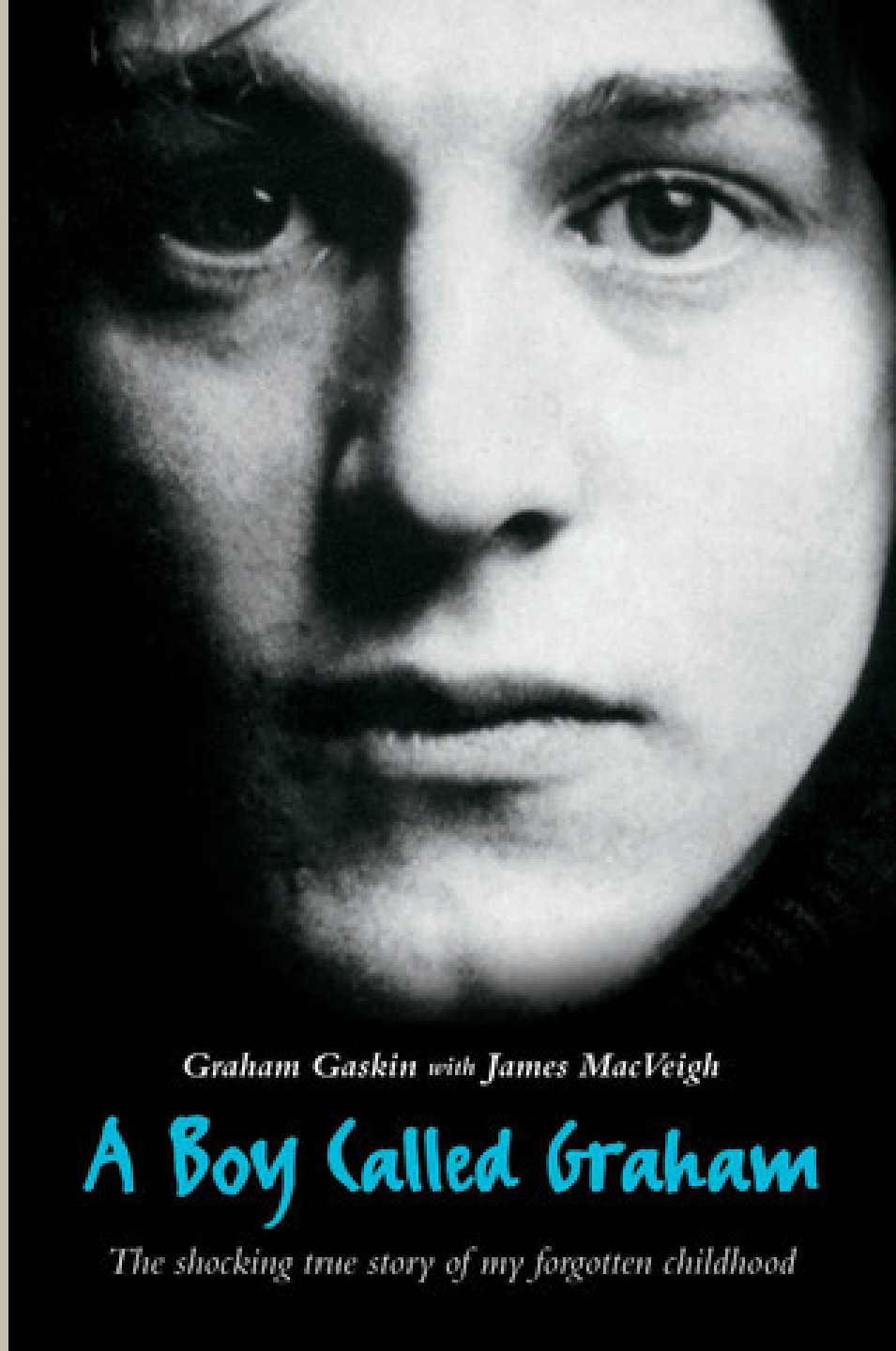
Data protection principles

- Lawfulness, fairness and transparency; purpose limitation; data minimization; accuracy; storage limitation; security; accountability

Social care files

Gaskin v UK (1989) 12 EHRR 36: the ECtHR ruled that failure to disclose the files was a breach of Article 8 ECHR (respect for private and family life)

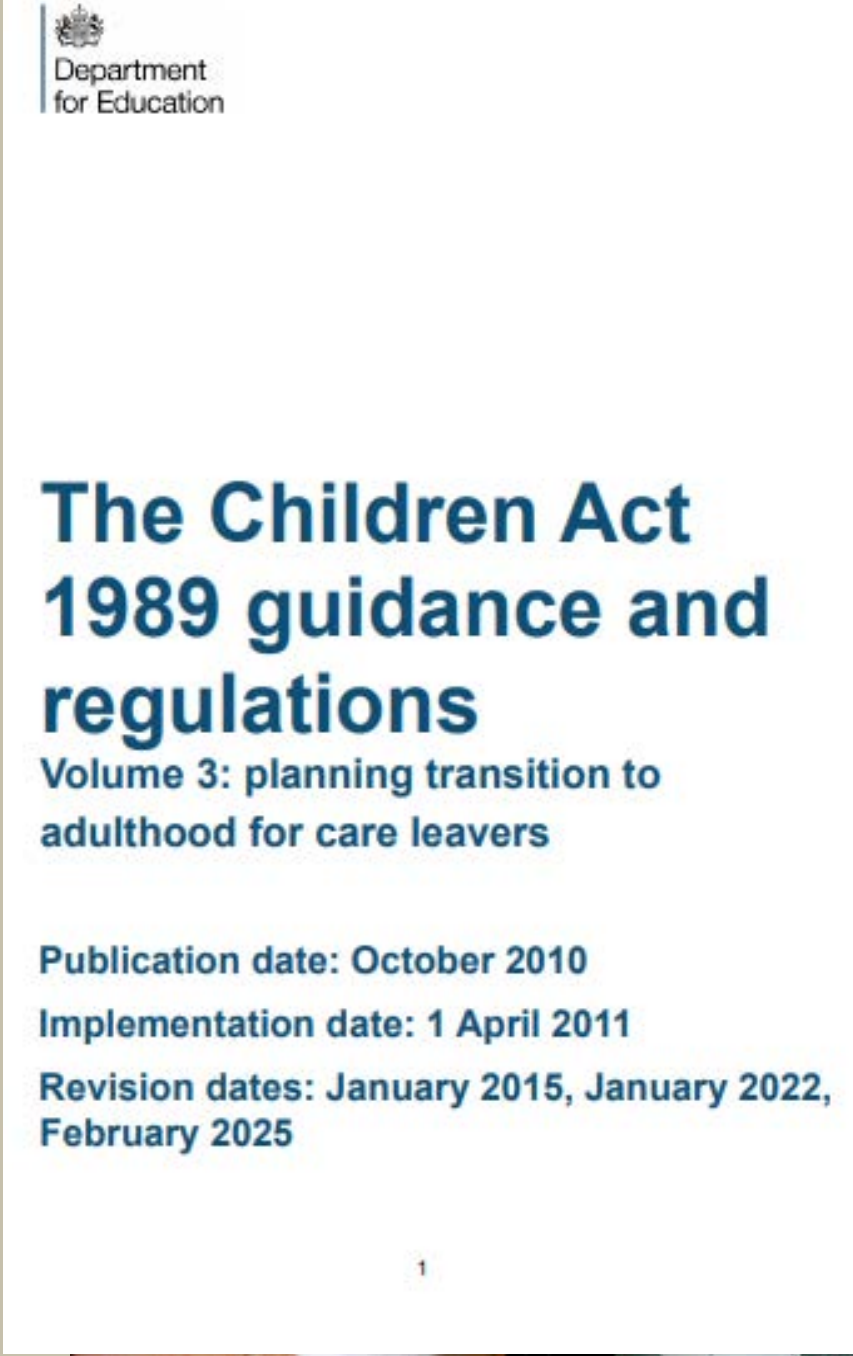
- [47] ...the "absence of any procedure to balance the applicant's interest in access to the file against the claim to confidentiality by certain contributors, and the consequential automatic preference given to the contributors' interests over those of the applicant," was disproportionate to the aim pursued and could not be said to be necessary in a democratic society.



Social care files

- “Care leavers have a fundamental right to access information that affects their lives, and the services that are available to enable them to make informed decisions”

- “The DPA is an **enabling framework** allowing people to have access to personal information held about them and should not be misunderstood and applied as a legal barrier preventing an individual from having this information.”



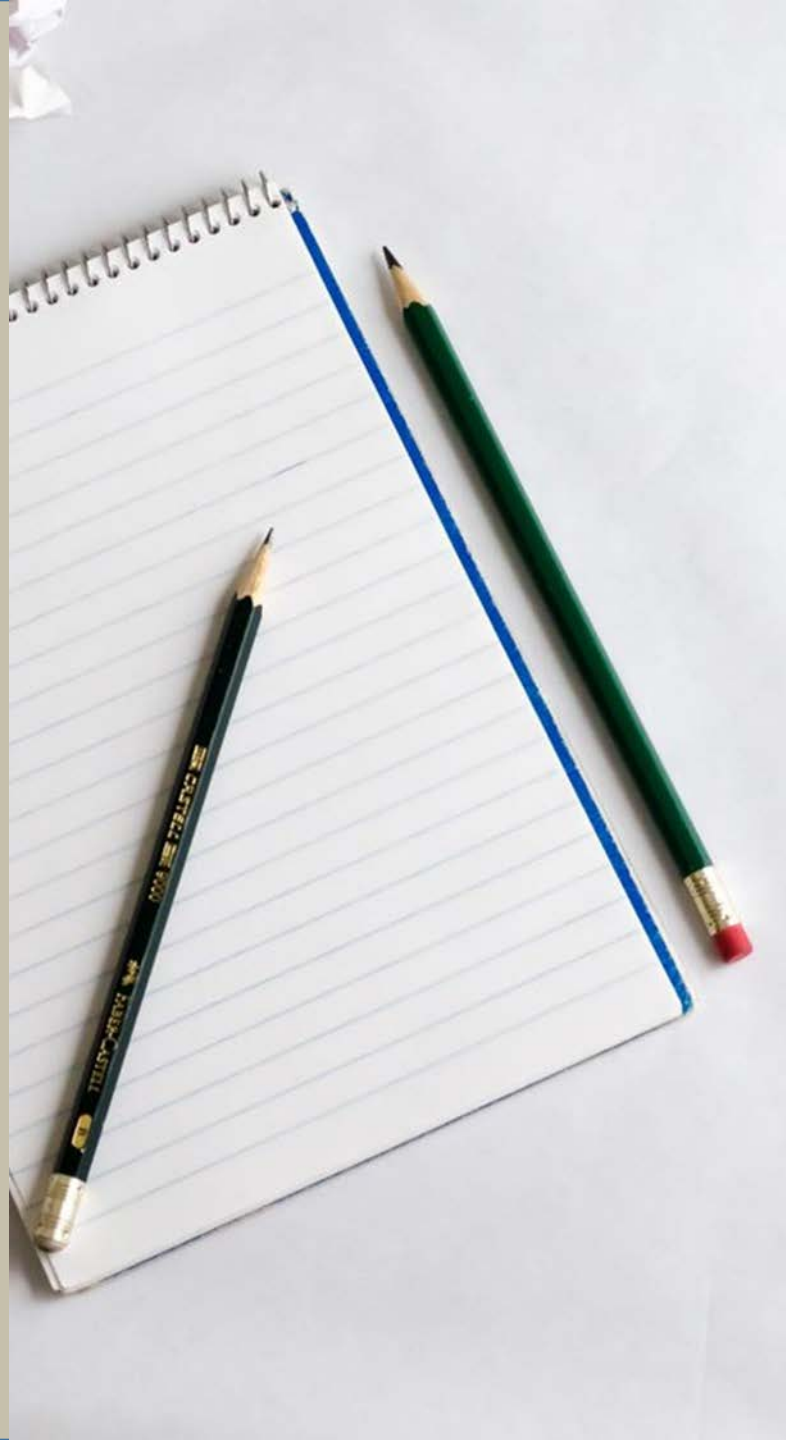
Exercise

What information should be included in the child's health report, and what should be redacted? Consider the following scenarios.

1: [Name of sibling] alleged sexual abuse by [full name of uncle]

2: Birth/first mother had 2 terminations before becoming pregnant with [name of child]

3: Medical or educational information about a sibling.



Reflections

- **What information would a child living with their birth family typically have access to, either directly or through everyday experience?** How does this compare to the information available to a child in care? Are you helping to bridge that gap?

- **What assumptions, values, or biases might you be bringing into your assessment and analysis?** How might your cultural background, professional training, or personal experience shape what you record, and what you omit?

- **Are you acting defensively (consciously or unconsciously)?** Are you reports truly centred on the child's best interest and identity needs, or might they (perhaps unintentionally) best serve the interests of your organisation or professional role?

- **Have you become desensitised to what you are recording?** What may feel like just another difficult detail to note could, for the child, be a defining truth. An answer to a question they may carry with them for life.

- **When recording, do you visualise the child "on your shoulder"?** What may feel like a case note to you could become a defining piece of their life story. Are you writing with that future reader in mind?

Bias: unconscious & conscious

- Bias exists in all of us!
- Unconscious/implicit: informs decisions without awareness, may contradict beliefs or values
- Conscious/explicit: intentional, can be overt
- Impact: influences decisions, behaviors
- Awareness helps dismantle stereotypes
- Undoing bias takes time, just as it took time to develop

advice@corambaaf.org.uk