Home Office Commission: Information Management and Access

1. **Identify key barriers to data sharing** across cultural, legal, capacity and capability constraints

- **Legal**
  - [redacted]
  - [redacted]

- **Technical**
  - Data landscape is fractured, with lots of different systems that have often poor interoperability with each other. Different parts of the country have different data sharing capabilities
  - In many areas people's key health information is not widely shared between services; and some services cannot see any electronic record of a patient's needs or history.
  - Challenges around the context of requests – work ongoing with Counter Terrorism Police on improving a data subject access request template
  - A lack of understanding and knowledge around data protection and data sharing. Whilst individuals across the business are not expected to be experts in DP legislation and regulations, the issue is often that they aren't aware of the existence of their organisation's DPO team, or how to contact them, or the internal processes which need to be followed re: contacting the DPO team and completing necessary assurance processes (e.g. DPIAs, data sharing agreements, etc.). A common complaint across all DPO teams will be that they are brought into the conversation too late to provide quality advice. Many DPO teams will try and increase awareness via engagement sessions and activities, but reaching people is difficult if such events are not well publicised and cascaded by senior leaders, and at times when resources are stretched.

- **Cultural**
  - Risk appetite – more risk-averse organisations or staff will be more reluctant to share information if they are not absolutely clear on legality.
  - Challenges around confidence that staff can share information / Staff unsure if they can/should share in particular circumstances – Royal Colleges and regulators have published professional practice guides for info sharing

- Sharing information outside health family, or receiving information from outside health family, worries people (as well as being difficult technically)
- Ignorance of the law – law allows for sharing for direct care, or with police for prevention/detection of crime/apprehension of offenders
- Fear of regulatory action by ICO if shared inappropriately

Children's Social Care to Adult Social Care Transitions

- **Cultural and Legislative Barriers:**
  - The two systems are underpinned by different legislative frameworks as well as different service delivery structures. Children's social care is heavily focused on safeguarding, child protection and early family intervention operating with team around the family approach. Comparatively adult social care is centred on increasing and enabling the individual's independence and autonomy, whilst this includes involving loved ones and wider community it is not a "whole family" approach. This has implications for how/when and to whom data is shared.

- **Data Capability Barriers:**
  - The transition into adult social care involves different cohorts of young people moving through a range of support settings, resulting in various transition pathways. While data on some of these individual groups is available, we do not have a single complete view of everyone transitioning.
  - Case management systems (CMS) between CSC and ASC vary and there is also inconsistent recording on CMS where there is a joint responsibility between children's and adults' teams.
  - Central government has difficulty tracking individuals across the transition from CSC to ASC because linking individual records from children's services to adult services is difficult in the absence of standardised person identifiers in children's data collections. Local authorities vary in how they capture and record this information.

- **Capacity Barriers:**
  - Local systems require sufficient workforce capacity across children's and adults' services, including social workers, health professionals and SEND teams, alongside clear local transition pathways, shared data systems, and protected time for early, joint planning.
  - Workforce capacity is a significant challenge across health, social care, and education.

- Effective transitions require coordinated input from multiple professionals, and pressures on workforce availability can affect early planning and ongoing support.

2. **Identify examples and case studies of best practice** on information management and sharing. This should cover a variety of locations and HO are specifically keen to understand where anything could be rolled out nationwide.

Best Practice:

- Good examples of data sharing from within the Better Outcomes through Linked Data (BOLD) programme which is jointly led by DHSC & MOJ
- Shared Care Records program (now called Connecting Care Records program) have been a success in enabling clinicians to access integrated patient records. But has significant regional variation (they operate at a regional rather than national level)
- Single Patient Record (SPR) will build on Shared Care Records – all providers will feed into SPR, so all patient information in one place, enabling all parties to see information held about a person in one place. This will be a national solution. But as outlined in our response to the we are still in the design and build phase of SPR. Requirements and functionality will need to be determined in the round as part of broader design considerations for the SPR. There are also complex legal, ethical, practical and financial considerations to be worked through, when determining how best to make risk information from other agencies available to health and care professionals.
- NHS Safeguarding is currently collaborating with CTP to bring a single digital referral form to the system by August 2026
- Statutory safeguarding data set of SnoMed codes due to be published by September 2026

- **Get Adult Social Care Data (GASCD)**
  - Get Adult Social Care Data (GASCD) is a DHSC digital service that is testing new approaches to making public sector data easier to discover, access and use. It addresses a common challenge across government: valuable data is often held in different systems, making it difficult for organisations to access timely insights and make informed decisions. Through GASCD, we are exploring how data from multiple sources can be brought together and presented securely as accessible insights for authorised users, while maintaining appropriate safeguards around privacy and security. This includes developing approaches for making insights from sensitive person-level datasets available in ways that protect

confidentiality. The programme is also generating wider lessons on user needs, data governance, trust and access controls that can inform future data-sharing initiatives across other sectors.

- **Children's Social Care to Adult Social Care Transitions**
  - The DHSC CMS Data Standards programme (which is joint with DfE's programme) aims to promote data standardisation and interoperability across local authority digital systems. It will establish a consistent social care terminology, develop a core data set for care and establish the access and permissions needed to enable data to be shared between local authority systems and partners across the health, care and education sectors.

- Local authorities that have been identified as having good practice in terms of transitions including data sharing are:
  - **Southend on Sea-** people told CQC of effective partnership working during transitions from Children's to Adult services, enabling good communication and sharing of knowledge to enable smooth transitions. All young people who required support were then allocated an adult social care worker when they reached the age of 17 to support timely assessment and transition planning.
  - **Oxfordshire-** many young people and their parents described positive experiences of transitions from children's services to adult services, stating their needs were thoroughly assessed and considered with aspirational, ambitious conversations that led to a flexible approach to their care packages.
  - **Northumberland** - people felt supported and happy in the transition from children's services to adulthood and were pleased with the joint working between statutory partners. Young people's voices were instrumental for developing their future plans and ambitions.