

Data sharing case studies

Health and social care integration

Situation

As part of a health and social care integration project, local GPs and social services were asked to combine patient records so that they could access a shared record and see all the necessary information.

In order to do this the local council and the Clinical Commissioning Group (CCG) needed to enter into a data sharing agreement. This was a complicated arrangement as it involved a large number of GP practices.

There was a possibility of problems arising because of the opt-in and opt-out choices offered to patients. For example, if social care clients consented to their social care records being shared but then their GPs did not opt in this would be different to their expectations.

Solution

For this processing of personal information to meet the fairness requirements of the Data Protection Act, the council and CCG worked together to make sure that all affected individuals and organisations were aware of the planned data sharing and knew how they could opt in or opt out. They did this in a number of ways:

- They held public events and delivered presentations to specific user groups to raise awareness of the planned data sharing and to explain how individuals could choose whether to be included in the project.
- They worked with the local press, and their own communications channels (newsletters, emails, websites, social media etc), to raise awareness of the data sharing plans with the general public.
- They engaged local GPs to explain the data sharing plans, how they could opt in to the scheme (on behalf of their patients), and what they needed to tell their patients.
- They worked with Social Care staff to raise awareness of the data sharing plans, and to amend the information sharing consent form / script they used, when asking clients for their consent to their information to be shared, so it would reflect the new arrangements.

This meant that individuals had the opportunity to provide their consent directly to either their GP or Social Care staff for their records to be shared.

Some patients would continue to be unaware that their GPs had not opted-in to the data sharing agreement and so would continue to assume that their data would be shared and their care co-ordinated. So, the CCG and the Council still had to work together with those GPs to let them know that they needed to make sure that their registered patients were aware that their data was not being shared with Social Services. The CCG and the Council would also continue to work with the Social Care team to ensure that their service users were made aware that even though they may have consented to their health and social care records being shared, this would only take place if their GP opted them in to the data sharing arrangement.

Key points

During the planning stage of a significant data sharing arrangement it is important for all the organisations involved to decide whether or not the sharing will take place on the basis of individuals' consent. If so, a decision should be made as to whether to provide an opt-in or opt-out. Both can be valid, but an opt-in generally provides a clearer indication of individuals' wishes. Remember that the Data Protection Act often provides an alternative to consent, which may be preferable, depending on the circumstances.

Public events and meetings can be useful to gauge public sensitivity and to make sure any data sharing arrangement is designed in a way that is acceptable to individuals. Public feedback can also be useful for making changes to an existing or proposed data sharing arrangement.

Where personal information is to be shared for a new purpose, it is vital that this is communicated to people clearly. In cases such as this it is not only communication to the data subjects that is important, it is equally important to communicate with other parties involved in the sharing arrangement (in this case GPs and social workers).

There is a particular need to actively communicate a privacy notice where sharing the data, or not sharing it (both are relevant in this study for example), will have a significant effect on the individual. If people are being given a choice, the options and consequences should be clear and their wishes should be respected.

More information

See the Data Sharing Code of Practice, section 6 'Fairness and transparency'.

Multi-agency team supporting residents with multiple social and healthcare issues

Situation

A multi-agency team wanted to carry out a series of home visits to speak to local residents to find out what problems, if any, they were facing and to identify the support they needed.

The team consisted of representatives from the local housing and social services departments, the police, community nurses and mental health services. It focused on neighbourhoods where there might be complex or multiple social and healthcare issues.

In order for the team to offer appropriate support, it might have to make referrals to another member of the team, a large number of other agencies and potentially new agencies in the future.

The team therefore needed to ensure that residents all understood and consented to their personal information being shared in this way.

Solution

Beforehand, information leaflets were delivered to every address to let people know about the planned visits.

During the visits a standard form of words was used by all team members when asking for consent. This was to help ensure that everyone was given a common understanding of why they were being asked for their consent to share information and the consequences of this.

This was backed up by a consent form which the person interviewed was asked to read and sign.

The consent form could not provide a comprehensive list of every agency that information might be shared with. Instead, the different types of agencies were listed, such as drug and alcohol support services, health services, welfare advice, housing services and children's centres. This satisfied the fair processing requirements of the Data Protection Act as it provided a reasonable level of detail to the people being visited, in terms of the types of organisations involved and the purposes for the sharing. It told them what their information would be used for and who it might be shared with, without requiring the multi-agency team to change its consent form every time there were changes to the support services it worked with.

Key points

It won't always be possible to list each particular organisation information might be shared with. It can be sufficient to explain the types of organisation that might be involved. However, it is good practice to provide a simple way for people to access more detailed information if they want this.

It is good practice to make sure people understand whether their information will be shared in a 'one off' way or as part of an ongoing process.

If an organisation is relying on consent as its basis for sharing information, in normal circumstances it must be prepared to stop sharing if consent is withdrawn. It should be as easy to withdraw consent as to provide it. The implications of providing or withholding consent should be made clear to people.

Sharing with partners in the voluntary sector

Situation

A local area initiative was set up to improve the co-ordination of health and social care in the community. As part of this, a group of voluntary sector organisations worked with health and social care partners on a project to deliver improved outcomes for older people in the community and in hospital.

The project team recognised that it needed to establish a culture of shared information, along with a phased, proactive approach to seeking individuals' consent. It also recognised that the involvement of volunteers could have implications for the sharing of data within the project team, as they have a different legal status to the agencies' employees and perhaps a different culture, in terms of information security and so forth.

Solution

The project was set up as follows:

- The volunteers signed honorary contracts setting out their roles, responsibilities and standards equivalent to those of the agencies' employees. The contracts were intended to formalise and support the volunteers' information-gathering and sharing responsibilities.
- Elderly patients were asked by their GP whether they would like to take part in the project. They were asked specifically whether they agreed to relevant information from their health record being shared with a multi-disciplinary project team consisting of health, social care and voluntary sector practitioners.
- At the initial home visit, carried out by a volunteer, the information-sharing aspects of the service were explained and written consent was asked for.
- All of the organisations and GP practices involved in the project entered into a single data sharing agreement. This built accountability and trust between the agencies involved. It also helped to ensure that the people whose information was being shared understood and had confidence in the process.

Key points

Volunteers and agency employees may come from very different

backgrounds, in terms of information security or confidentiality rules, for example. Although it is not necessary to make them sign a particular contract, it is essential to ensure that the use of volunteers does not lead to a lowering of data protection standards. Suitable training and ongoing support can ensure that this is not the case.

It is important to consider whether the necessary legal power or ability to share personal data is in place. This will depend on whether an organisation is a public sector body or one in the private or third sector. Private and third sector organisations should be aware of the legal issues that can arise when sharing personal data with the public sector. This is an increasingly common issue as private and third sector bodies take on a wider range of traditionally public sector functions.

More information

See the Data Sharing Code of Practice, section 4 'Data sharing and the law'.

Multi-agency safeguarding hub

Situation

Various public service professionals wanted to ensure that they made timely and appropriate decisions about the support they provided to vulnerable children and young adults.

Agencies representing Children's Social Care, Policing, Health, Education, Probation, Housing and Youth Offending operated under different legislative, governance and confidentiality arrangements. Most had an over-arching statutory duty to share information to promote the safety and welfare of children and young adults at risk of abuse or neglect.

Solution

The agencies worked together within a Multi-agency Safeguarding Hub (MASH) to gather intelligence and share information when referrals concerning vulnerable children and young people were received.

Each member of the MASH signed up to an information sharing agreement which, amongst other things, set out the types of information they would share between members.

The information sharing agreement also set out the conditions that were available under Schedules 2 and 3 of the Data Protection Act in order to ensure that the data sharing had the necessary legal basis.

Consent

- In many cases, the data sharing could take place on the basis of consent.
- However, it can be possible – and indeed necessary – to share without consent, for example where there is a legal requirement to do so or where it is necessary to protect the vital interests of a child.
- When a referral that contained a clear child protection concern was received, the MASH had a duty to share information with Children's Social Care, the police and other agencies with safeguarding remits, and so there was no requirement to obtain consent.
- In other cases, for example those involving the sharing of information about wider families, the MASH would not accept a referral until parents had given their informed consent for partner agencies to share information about them and their children. (The sharing of necessary information could still

take place without consent where an individual's safety was at risk.)

- o If a referral was received without the informed consent of a parent or guardian, the referring agency would be asked to seek the necessary consent before the case was investigated or acted on by the MASH.

Key points

It is necessary to identify whether there is legislation that permits, or requires, the data sharing. The relevant legislation may not mention data sharing specifically, for example where the sharing is incidental to a wider duty to protect children.

Even if an organisation has a legal basis for sharing data on a basis other than consent, it should still be transparent about its general data sharing practices. In some cases, telling a person, for example an abusive parent, that their information is being shared could prejudice a particular investigation or undermine the effectiveness of social work – ultimately resulting in harm to children. In these circumstances the Data Protection Act normally allows the sharing to take place without the individual's knowledge or consent.

Using consent as a legal basis for data sharing can bring about transparency and give individuals control over their information. However, in contexts such as child protection it may be more appropriate to legitimise the sharing because it is necessary to protect a child's vital interests or because there is a legal duty to share information. Remember that consent has to be freely given, specific and informed. It will not be possible to reach this standard in many contexts. If this is the case, an alternative legal basis to consent must be used.

Care home data sharing

Situation

Staff in a care home did not have access to the recent medical history of residents – something that could be relevant to their well-being. This was a risk - for example, the home's staff might need to check which medicines residents were taking and what dosages, in order to ensure they could treat them safely. To resolve this, the home used to need to call out a GP, sometimes on an emergency call-out, to get the information they needed to ensure residents' well-being. This was inefficient for both the home and the GP.

Solution

In order for the care home to access their residents' medical history, they were given access to the residents' electronic medical records, held by their GP.

This sharing of residents' data was made possible because the local GP practice and the care home signed up to a formal agreement to share patient records when necessary. The GP practice and local Clinical Commissioning Group made potential residents aware that if they were admitted to the care home there was a possibility that their medical record would be accessed. In addition, when patients were admitted to the care home, their explicit consent - or that of their representatives – was sought before their electronic medical record was accessed. Where consent was not provided, the former system of contacting a GP would continue to be used.

Other key features of the data sharing agreement were:

- Access to residents' records could only take place while they were under the care of the home.
- Access was restricted to the clinical and professional nursing staff at the care home.
- Access was only allowed where this was necessary to provide treatment and for residents' safety.
- Access was restricted to information relevant to the provision of care to residents.

Key points

A formal data sharing agreement can put effective safeguards for residents in place and can ensure the various parties involved in data sharing are playing to a common set of rules. An agreement can also help to deal with the ethical and confidentiality issues that can arise in health

and social care.

Data sharing agreements can be very useful where the same type of personal data is shared repeatedly, because they can set out the compliance issues and solutions that need to be addressed on an ongoing basis. For example, they can ensure that only the relevant parts of a health record are accessed.

Even if there is a data sharing agreement in place, the other aspects of data protection compliance still have to be addressed. Both the care home and the GP practice need to make sure that individuals whose data may be shared are aware of what is taking place. This can be done through a privacy notice, but depending on the circumstances, it can be far more effective to talk to patients to explain the situation and to find out whether they agree to their information being shared. Their decision should be documented.

More information

See the Data Sharing Code of Practice, section 14 'Data sharing agreements'.

Landlord and tenant data sharing

Situation

A Housing Association occasionally received requests from bodies such as utility companies, debt collectors and councils for information about current and former tenants. However, it was considered not to be appropriate to enter into a data sharing agreement as the sharing was not systematic or ongoing.

On one occasion, a utility company contacted the Housing Association and asked for the forwarding address of a former tenant who was apparently in arrears on his gas and electricity account. The Housing Association was able to disclose this information because they had advised tenants at the start of their tenancy that they would make such disclosures because of the contractual relationship between tenants and the utility company. All tenants had agreed to this.

On another occasion, a debt collection company acting for a third party contacted the Housing Association for the forwarding address of a former tenant. The Housing Association decided that it could not disclose the information because there was no relevant exemption from the Data Protection Act's non-disclosure of information provisions. For example, there was no legal obligation (such as statutory duty or a court order) to make the disclosure. As the Housing Association had no legal basis for making the disclosure, it withheld the tenant's new address from the debt collection company.

Solution

The Housing Association dealt with requests for information effectively because it had put a system in place which required a senior person or group of people to decide whether or not to release personal information on a case-by-case basis.

This involved verifying the identity of the requester, insisting that all requests were in writing and ensuring that enough information was provided to make a proper decision. If the Housing Association decided to disclose, they only provided relevant, necessary information and in every case they made a record of the disclosure decision.

Key points

Even when a formal data sharing agreement is not appropriate, organisations should still have systems in place to help them decide whether data can be shared in 'one off' situations.

Although policies and procedures can be very helpful, disclosure decisions often depend on the exercise of careful judgement in a particular case.

Documentation is very important, particularly if someone complains about a disclosure of their information. It is important to be able to explain your decision making process to the individual concerned – and if necessary to the ICO.