Centre of
Excellence for
**Information
Sharing**

Sharing health data to improve outcomes for families and children:

Summary report

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Introduction

The Troubled Families Programme was set up in 2012 to support families with multiple and complex problems. In the past, these families have often been failed by services which have tried to respond to the one problem that presented itself to that service at that particular time – whether it was truancy, domestic violence, anti-social behaviour or unemployment – but failed because they have been incapable of dealing with the many interrelated problems the family is facing.

Information sharing has been at the heart of the Troubled Families Programme since it first began. Not only does information sharing allow the most complex and costly families to be identified (by using data to cross reference the demand they are placing on different services), information sharing also means problems can be tackled more effectively. For example, persistent truancy is easier to address when the keyworker knows that a parent has very poor mental health and is struggling to get out of the house themselves.

As the current programme's evaluation is already showing, many areas have made great progress with data sharing, but others still have a way to go and sharing health information has been a problem for some. For this reason, the Department for Communities and Local Government (DCLG) has worked with the Department of Health (DH), the Centre of Excellence for Information Sharing (the Centre), local authorities and health bodies in Staffordshire and Oldham to test new approaches to sharing health information.

Patient confidentiality and patient consent are, rightly, crucial factors for health organisations when considering whether and what information should be shared. However, cultural barriers which have no legal basis can also prevent information being shared. This report identifies some of those cultural barriers and suggests some ways to overcome them.

This report is based on work the Centre did in Staffordshire and Oldham. You can find more detail on how these barriers have been tackled locally by reading their individual case studies. These are available at: www.informationsharing.org.uk/policy-areas/families

Key learning

- **Start small and be targeted** - focus, to start with, on a small set of health data (linked to local health priorities), sourced from a local health organisation, as sharing this data is likely to be easier for partners to sign-up to/support.

- **Collaborate and listen** - work collaboratively with local partners from the start of the process to develop shared agreements on why the data will be shared (the purpose and benefit of sharing), how the data will be shared (data flows, data security and so on) and how local people will be engaged (for example, letters to patients regarding consent/opting out).

- **Understand what motivates your partners** - talk to your partners to find out what their key drivers are and how information sharing might help. For example, GPs may be interested in better understanding the root cause of people's poor health, whilst Clinical Commissioning Groups (CCGs) want to explore the potential to reduce service demand and costs for NHS.

- **Just because it can be done, doesn't mean it will be** - don't assume that once you have developed, agreed and signed off, an Information Sharing Agreement (ISA) with a partner that information will automatically flow. Make sure you discuss who will carry out the data sharing and how they will be informed of the agreement.

- **Find out where your partner is on their 'information sharing journey' and start there** - take time at the start of your discussions with partners to assess what skills and capacity they have for information sharing, and what the organisation's perceptions of information sharing are. Then develop your proposals to start from where your partners are at with information sharing.

- **Take your time** - developing information sharing takes months and years, not days and weeks, as it requires good relationships between partners and the confidence and trust to share information with each other, before effective and sustainable sharing can take place.

Common barriers and how to tackle them

1) Varying levels of information sharing maturity

- **Challenge** - partners will be at different starting points regarding their understanding of information sharing (the reasons for doing it, and the potential benefits), and their information sharing skills and systems.

- **Successful approaches** - take time at the start of your work to understand where your partners are on their information sharing 'journey'. Don't assume that an Information Sharing Agreement will result in the automatic flow of information. Time and effort needs to be invested to develop the relationships that ensure guidance and processes are embedded with partners. Use this insight to select partners who are most ready to work with you or at a similar place to you and be prepared to work in a phased way to support their emerging development of information sharing maturity at a pace that works for them. Then work with these partners (and the evidence from your joint working) to help engage other partners to expand your work.

2) Concerns about security, confidentiality and interpretation of data

- **Challenge** - partners need to meet their responsibilities as data controllers and practitioners by keeping patient data secure, confidential and only shared with those people necessary to help address the individual's and family's complex needs. There may also be concerns about the potential for misinterpretation of health data by non-clinician's and non-health practitioners.

- **Successful approaches** - be clear on the data that is needed and why, as well as who holds it, making sure you have considered if you could use non-confidential, non-clinical or de-identified data, such as a 'flag' which indicates a health need without providing full details of what the health condition is. Involve your partners in the development of, and conversations about:

  - the processes to be used to share data to help address security concerns; and

  - consider involving health practitioners in the analysis of the health data collected, to provide reassurance and share learning around data interpretation.

3) Concerns about legal gateways for sharing health data to support troubled families

- **Challenge** - partners may only have experience of information sharing internally and be less knowledgeable about the legality of sharing information with other organisations.

- **Successful approaches** - partners found it helpful to share the existing national government guidance[1] with one another. This helps to reassure the partnership that there is support from goverment departments for this activity and to support their learning in this area. Also consider the use of de-identified, aggregated health data, as this may be more acceptable to health partners from an information governance perspective. Lastly, when developing information governance documents, such as privacy notices, make sure you include the names of the local and national health partners you plan to share data with, and consider if local people might need additional information on these health partners to fully understand how, and for what purpose, any data shared would be used. Opportunities to engage health partners and local people in the development and testing of privacy notices should also be considered.

Some key things to include in a privacy notice/letter to local people about data sharing between troubled families and their GP practice:

- a description of the purpose for sharing data (for example, to help support people with complex needs);
- details of what data will be shared, between whom, and how this will be managed securely;
- a clear description of the information rights and responsibilities of the individual, especially if consent is being requested. This should include specific instructions on how to indicate their consent preference, any deadline by which they need to respond initially, and what to do if they change their mind afterwards; and
- be as clear as possible in the terms and language used, for example changing 'co-work' to 'working in partnership with...'

The latest advice and guidance on privacy notices can be found on the Information Commissioner's Office (ICO) website.[2]

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[1] Interim guidance for troubled families programme early starter areas: sharing health information about patients and service users with troubled families: www.gov.uk/government/publications/troubled-families-supporting-health-needs

[2] See: www.ico.org.uk/for-organisations/guide-to-data-protection/privacy-notices-transparency-and-control/

4) Different approaches to consent

- **Challenge** - as sharing data for identification and validation of troubled families occurs before a consent conversation takes place, health partners can voice concerns about including health data in this process.

- **Successful approaches** - a recommended approach for sharing health data to identify troubled families is set out in the interim guidance on sharing health information. Sharing this approach with partners can provide a framework for partners to agree key points, such as which health needs should be targeted, how many non-health criteria should an individual have before their health data is looked at, and which partners need to be involved. Starting with this agreed national approach can provide a starting point for engagement between partners and a route to building trust and confidence before exploring other approaches to sharing (which may go beyond the national guidance). Local troubled families teams should also develop relationships with local partners to encourage and support direct referrals of people felt to be in need of support from the Troubled Families Programme, rather than relying entirely on identification of eligible families through data matching.

Extract from 'Interim guidance on sharing health information' (November 2014)

Our recommended approach

1. Local troubled families teams (TFT) and local health services agree a set of health issues that they intend to target as part of their identification and prioritisation of families for support.

2. TFT create a list of families that have already been identified as meeting one or more of the programme's other indicators. Local TFT share a filtered list of families with appropriate local health services e.g. GPs, community health teams, child and adolescent mental health services/adult mental health services etc. The size of the list and with whom it is shared should be agreed between the TFT and local health services so that the data shared is proportionate and in line with the requirements under the Data Protection Act.

3. Local health services mark those families on the list that meet one of the programme's agreed health indicators. They do not need to disclose which family member it is, or what the problem is.

4. Local TFT can approach those families who have health concerns and meet the programme's other criteria and seek their consent for support.

5. It is very likely that further information on the relevant family member and the problem will become apparent once work has begun, but being able to identify families on the basis of a health problem ensures that the right families are targeted for support at an earlier stage.

6. Once a family begins to receive support from the programme, the TFT may seek consent from the family to access information about their health needs.

5) Addressing a lack of trust and shared vision

- **Challenge** - a lack of trust between partners is likely to undermine attempts to share data. Building trust between these partners can be made more difficult by the lack of:
    - a common (non-clinical) language;
    - shared objectives; and
    - aligned national indicators.
- **Successful approaches** - building trust between troubled families teams and health partners can be supported by working alongside individuals able to bridge the gap between the two sectors, such as public health practitioners or school nurses. An alternative approach is to co-locate troubled families' workers alongside other frontline health workers, such as the substance misuse or mental health team. These approaches of working alongside health practitioners lends a sense of professional credibility to the messages being given by the troubled families team, as well as helping to ensure both parties speak the same language. Health practitioners working with troubled families teams can also help to identify and understand what might motivate health partners to support data sharing, for example by adding value to their work or addressing gaps in health demand mapping.

6) Poor engagement due to lack of explicit joint benefits

- **Challenge** - a lack of understanding of the value of working with the partnership by senior leaders, can result in poor engagement at a strategic level, which then creates further difficulties when trying to communicate the benefits of the Troubled Families Programme and influence the wider sector. There can also be uncertainty about the benefit of looking at health data at such a low (geographic) level.

- **Successful approaches** - taking a targeted approach to engaging key partners (based on troubled families priorities such as mental health) helps to ensure that relationships are built with those partners best placed to support and benefit from the Troubled Families Programme. This makes it easier to demonstrate and communicate messages about the benefits of the Troubled Families Programme to senior leaders. When approaching a local partner, consider approaching the overall board, as well as any operational or information governance working group, to gain a wider range of views. Once you have engaged one local partner, they may be able to help you build links with other relevant organisations. For example, working with the local Clinical Commissioning Group (CCG) can 'open doors' to the provision of health data analysis by the Data Services for Commissioners Regional Office (not available to councils on their own). Opportunities should also be taken to evidence health benefits as part of the normal troubled families reporting process, for example, by highlighting health referrals and measures of success against health criteria. Using health criteria within your family assessment process will enable you to measure and show these positive health impacts effectively through creating a baseline and a measure of progress over time. This information may then help you to engage health partners (and gain buy-in for information sharing) by being able to demonstrate the potential for your Troubled Families Programme to reduce service demand and costs for NHS.

7) Partners can have complex systems

- **Challenge** - navigating and understanding other sectors can be difficult and time consuming as there are overlapping boundaries, lots of different organisations, and often many teams within them. For example, health data isn't all held in one single organisation, but split between them. This makes health data sharing a daunting task for troubled families teams, as it is hard to find the right people to talk to about, and agree decisions on, data sharing.

- **Successful approaches** - don't try to do everything and engage everyone at once. If sharing health data, consider focusing on a small set of health data, sourced locally, to start with as this may be easier for partnership to respond/agree to. Also, identify partners who are most relevant to you (for example, they are focused on your health priorities or are based in a neighbourhood pilot area). Once you've identified the organisations you want to engage, think about which people you need to talk to and consider who might be best placed to engage with them from within your programme/organisation. For example, if you are meeting with a potential partner information governance specialist, consider taking your own information governance lead to the meeting with you. Health partners will have a Caldicott Guardian who the partnership might want to consider approaching as a starting point. You can find their details on the national register of Caldicott Guardians.[3]

8) Not everyone is used to 'thinking family'

- **Challenge** - Troubled Families Programmes have been designed around a holistic 'think family' approach, so information is looked at and assessed in a family context. This way of thinking often contrasts with the culture and approach in other services where the focus is more on the individual, which can limit the amount of information shared by practitioners.

- **Successful approaches** - development of a shared, 'early help' assessment used across a range of frontline services (both health and non-health) can provide a common framework for assessing needs for both individuals and families. When supported by a programme of multi-agency training on the use of the assessment tool, this can provide an opportunity to embed a 'think family' approach in relevant partner organisations, such as Child and Adolescent Mental Health Services and GPs. Involving GPs in the development or use of a shared assessment tool can help respond to their interest in being better able to understand underlying root causes – for example, by cross referencing how patients have been presenting/what they've been prescribed with in the past against insight around non-health factors.

To find out more about the health information sharing project, and read the more in-depth Staffordshire and Oldham case studies, visit: www.informationsharing.org.uk/policy-areas/families

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[3] See: www.digital.nhs.uk/organisation-data-service/our-services

Further guidance

Further support and guidance on information sharing generally, and in the context of supporting troubled families, is listed below:

Government guidance

- Interim guidance on health data sharing (November 2014) - www.gov.uk/government/uploads/system/uploads/attachment_data/file/370960/data_sharing_guidance.pdf

- 'Troubled Families Leadership Statement' (2014), joint statement by Public Health England, Department of Health, Local Government Association, and NHS England - www.gov.uk/government/uploads/system/uploads/attachment_data/file/370957/LeadershipStatement.pdf

- Financial framework for the expanded Troubled Families Programme (January 2018 onwards) - www.gov.uk/government/publications/financial-framework-for-the-troubled-families-programme-january-2018-onwards

Centre of Excellence material

- Sharing information to identify and work with Troubled Families - www.informationsharing.org.uk/policy-areas/families

ICO guidance

- Data sharing code of practice (May 2011) - https://ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf

- Code of practice on privacy notices, transparency and control (Oct 2016) - https://ico.org.uk/for-organisations/guide-to-data-protection/privacy-notices-transparency-and-control/

- Privacy notices under the EU General Data Protection Regulation - https://ico.org.uk/for-organisations/guide-to-data-protection/privacy-notices-transparency-and-control/privacy-notices-under-the-eu-general-data-protection-regulation/

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