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Good Practice Guide: An introduction to sharing service user data

Project: Fulfilling Lives: Supporting people with multiple needs
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Author: Naomi Gibbs

This guide has been prepared by the University of Sheffield and CFE Research for the local partnerships delivering projects as part of the Big Lottery Fund's Fulfilling Lives: Supporting people with multiple needs initiative. It introduces good practice in sharing service user data, drawing upon the examples explored in a recent webinar.

Introduction

Good practice in data sharing is a vast topic with much guidance already provided. This paper is focused on the issues relevant to projects funded by the Fulfilling Lives: Supporting people with multiple needs initiative and the learning which is emerging.

The initiative seeks to improve the lives of those individuals engaged with the programme whilst also creating lasting and meaningful change to the systems of support which surround them. This is ambitious and requires depth of understanding of the current system coupled with recommendations for change in the light of the evidence gathered. The sharing of service user data is one element that is critical to the success of this programme. Funded projects are seeking to share a wide range of data that is held across different voluntary and statutory bodies.

For the Fulfilling Lives projects there are two main reasons for data sharing:



1. *To provide a more joined up service for people with multiple needs. People with lived experience of multiple needs have made it clear they find it frustrating and off-putting to be continually asked by different organisations for the same information. This can create a barrier to accessing services and hence reduce the breadth of support available to an individual.*
2. *For the purposes of the evaluation. The strength of the evaluation and therefore the efficacy of it as a tool for change relies on good quality data. Data gathered from administrative sources is likely to be more accurate than relying on beneficiaries to recall what services they used and when.*

Funded projects have identified two key challenges in gathering this vital data. The first is sharing service user data between organisations. The second is achieving informed consent from the individual concerned to access and share their data. Learning about gaining informed consent is presented at the end of this guide.

Benefits and challenges to sharing service user data

Benefits

Once data sharing is established it can have many positive outcomes above and beyond what was originally expected. These will vary between projects but may include:

- *Deeper understanding of the key challenges people with multiple needs face, the services they use and the cost of these*
- *Having an evidence base from which to effectively influence*
- *Increased understanding of what different organisations do through continued relationship building and exchange of information*
- *Improved experience for service users as they do not need to give the same information multiple times*
- *Improved outcomes for the service user as a more complete and reliable picture becomes available to those who provide support*

Challenges

Initiating a new data sharing agreement between organisations is rarely simple. Projects have already identified the following challenges:

- *Knowing which organisations hold the data you need and who can help you to unlock it*
- *Winning the trust of the organisation that holds the data*
- *Getting access to organisations who are time and resource poor*
- *Understanding the many and varied internal policies and procedures*
- *Setting up information sharing agreements*
- *Complying with data protection regulation*

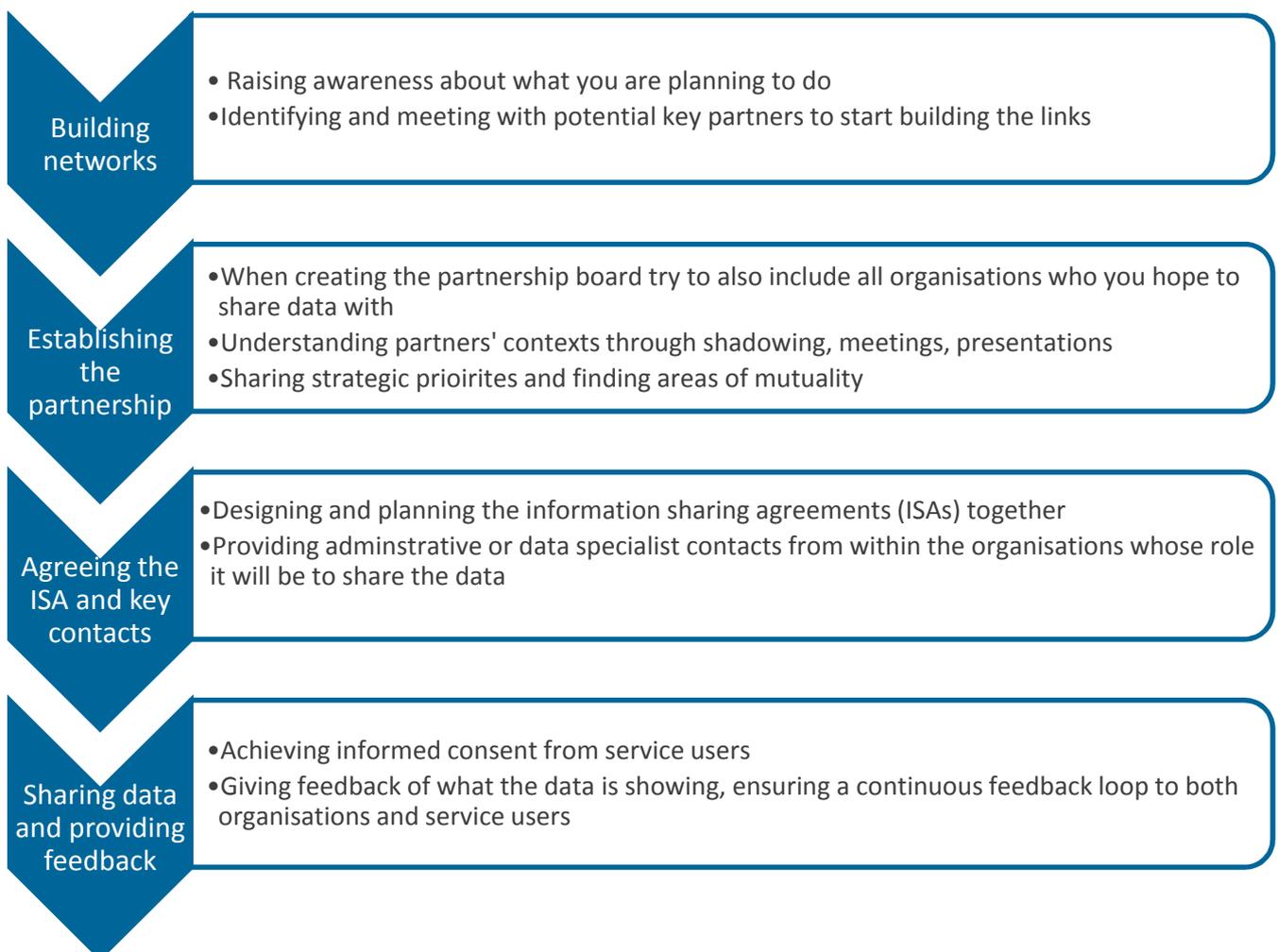


- *Turnover of staff resulting in losing a relationship you have cultivated*
- *Obtaining informed consent from service users*

Successful data sharing

Successful data sharing includes both a structural and a personal element. Creating the right culture is as important as having the right procedures. Both aspects need to be in place for data sharing to become embedded within a partnership. Culture does not shift easily or quickly and it may take many small steps and a great deal of time to reach a place of mutual understanding and data sharing.

A simplified and linear path for data sharing within the context of Fulfilling Lives (multiple needs) might look like this:



The above process may be successful with some partners but it can often be less straight forward in reality. Many projects have found it challenging to engage with statutory services, such as the NHS, due to their size, complexity and lack of joined-up working. Where this is the case, relationships have been built at different access points such as alcohol liaison services or hospital discharge. Although this may not immediately provide a complete data set it can start to build the links and take the small steps needed to move towards a cultural shift.

A great resource to find out more about this topic is the [Centre of Excellence for Information Sharing](#), which was established in 2014. The Centre's role is:

... to challenge, inspire and support change in order to transform services through improved information sharing across the public sector.

We work with a variety of local places, across a range of policy areas to help uncover and understand what is limiting good information sharing between them and their partners.

Challenging culture is at the heart of our work. We recognise that you can have the best policies and databases in place, but without the right culture and mind set, these will only take you so far.¹

Centre of Excellence for Information Sharing

They provide various case studies and an [information sharing journey toolkit](#) with which to get started.

Case studies

Here follows two case studies drawn from the Fulfilling Lives (multiple needs) webinar on sharing service user data, which took place in May 2015.

Case Study One: Leicester troubled families

Troubled Families is a government initiative to provide more effective support for families who are experiencing issues including youth crime, unemployment and non-attendance at school. The approach is to build upon good practice and connect services that already exist as opposed to creating a brand new service.

In Leicester the initiative is called Think Family and includes a strategic board and an operational board. The operational board is attended by organisations engaged with families, including Voluntary Action Leicestershire, Adult Social Care, the Department for Work and Pensions (DWP), youth offending services and the police.

¹ <http://informationsharing.co.uk/about/what-we-do/>



Cases are discussed at allocations review panels with a resulting recommendation for a Think Family worker who assesses the families' involvement with various services and plans the way ahead.

In order to share service user data an information sharing agreement was formed which partners signed up to. This conformed to Leicestershire County Council's Data Sharing Protocol.² The project also uses the Safe Network Standards³ to further ensure best practice in relation to safeguarding and data sharing.

Lessons learned:

- *To ensure success it was essential to have a named person at each partner organisation.*
- *Equality of partners on the board and respect for their opinions led to a sense of shared ownership.*
- *Data sharing can result in systems change as organisations begin to understand one another better and how an individual might journey through the system.*
- *It is time intensive to build relationships and get organisations on board; taking decisions and actions in the meetings are critical to moving things forward.*
- *It is important to have the operational infrastructure in place to receive the data, such as a workable database.*

Case Study Two: Reciprocity in data sharing, Stoke-on-Trent

Where there is successful data sharing there is often a high level of reciprocity. If both parties can directly see the benefit in data sharing then the relationship is far more likely to be sustained. This combined with both structural and personal commitment to data sharing has led to a positive outcome between VOICES, one of the Fulfilling Lives (multiple needs) projects, and Staffordshire Police.

VOICES worked hard in advance of any data requests to raise awareness of the project and build the partnership approach. They set about delivering a city wide pre-launch road-show which included lots of networking, presentations at team meetings and one-to-one conversations.

To build their relationship specifically with the police there were a number of key steps that they took to ensure success.

² www.leics.gov.uk/information_sharing_protocol.pdf

³ http://www.safenetwork.org.uk/resources/safe_network_standards/Pages/safe_network_standards.aspx



- *A member of the police was invited to sit on the Service Liaison Group.*
- *A local police contact was nominated who arranged for VOICES service coordinators to shadow police officers. Mutual respect and understanding between police officers and service coordinators was fostered.*
- *The VOICES evaluation lead then met with the nominated police contact to explain in more detail the purpose of the project and what data they needed.*
- *The police officer was happy that the way VOICES were going to share and use the data would comply with Staffordshire Police regulations on data protection.*
- *Ultimately, the police could see that the evaluation purposes were in line with theirs.*

I was happy that the data sharing was being done for a policing purpose and it was going to ultimately benefit with the reduction of crime and antisocial behaviour in Stoke-on-Trent.

Sergeant David Fenton, Staffordshire Police

VOICES have had to take a different approach to collecting and sharing service user data relating to benefits. They are not currently able to access data directly from the DWP; however, this information still needs to be collected in order to provide a complete picture of an individual's situation. The approach VOICES took was to commission a part-time specialist from the Citizens Advice Bureau. This specialist was able to upskill the service coordinators about the benefits available to their service users, as well as to provide broader training about the welfare system and DWP. Every organisation has its own language and there was a realisation at the VOICES project that they needed to learn the language of the DWP. The integration of this specialist knowledge has enabled VOICES to increase positive outcomes for their clients whilst also being able to record the service user's benefits. Relationships are continuously being built and VOICES are actively working towards accessing administrative data directly from the DWP; this would be the ideal. Until this is achieved they have an excellent work-around.

Top Tips from both case studies

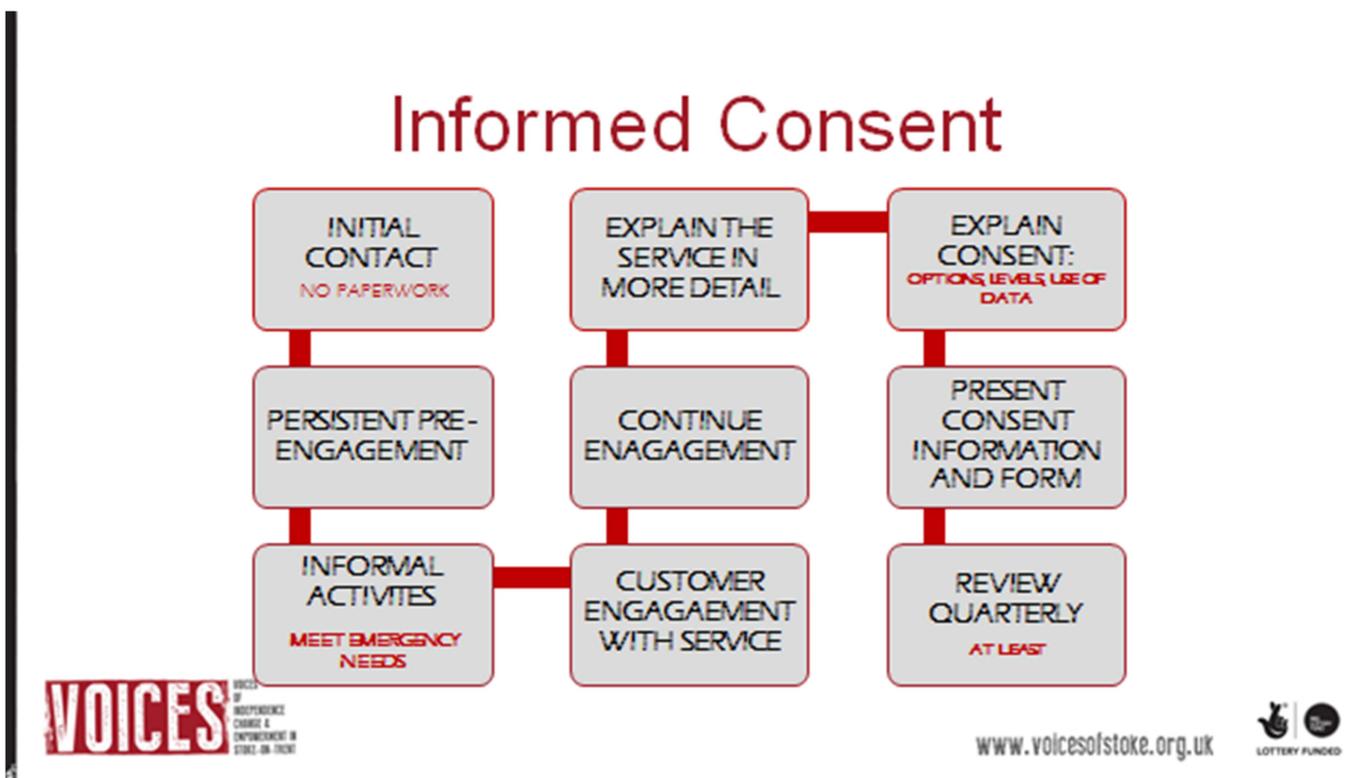
- *Don't underestimate how long data sharing will take*
- *Involve the Information Commissioner's Office to reassure agencies and inspire confidence*
- *Ensure representation of data-sharing partners at the project board level*
- *Ensure you have a named individual at operational level*
- *Give feedback on the data at every opportunity*



Informed consent

An aspect equally as important as working with organisations to share data is working with the service users to achieve their informed consent. CFE have already produced a good practice guide on informed consent,⁴ which focuses on the wider issue of informed consent to participate in research generally. It is also worth noting that not all data sharing requires consent and there are many legal avenues for sharing data. The Centre of Excellence for Information Sharing provides a document showing the process for deciding the legal basis for sharing information.⁵ However, in the context of Fulfilling Lives (multiple needs) informed consent is needed to share data for the national evaluation. Learning is beginning to emerge as to how best to do this.

It can be a challenge to build up trust with service users and asking permission to share their data can feel obtrusive and counter-productive. This process, however, is critical to the success of the evaluation. In the recent webinar on sharing service user data Sharon Sharman, Learning and Evaluation Manager at VOICES, presented their approach to achieving informed consent.



⁴ <http://mcnevaluation.co.uk/wpfb-file/good-practice-guide-informed-consent-final-sept-14-pdf/>

⁵ <http://informationsharing.co.uk/wp-content/uploads/2012/07/Process-for-deciding-the-legal-basis-for-sharing-information1.pdf>

Crucially, the service users are not asked to provide informed consent until they have progressed through other stages. These include having their emergency needs met and continuing to engage with the project. In fact, in the majority of cases no paperwork is introduced to the service user for some time after their initial engagement with the project. Once a trust relationship is established then a conversation takes place to explain informed consent including options, levels and use of data, again with the absence of any paperwork. The service user can then choose to give informed consent or not at the next time of meeting when paperwork is provided. VOICES check at least quarterly with their service users to ensure they are still happy with their decision and to give them the opportunity to either withdraw consent or provide it for the first time. This process is not rushed but is allowed to move at a speed which the service user is comfortable with. It relies on the ability of those staff in direct contact with service users to build a relationship of trust and sensitivity. This approach has resulted in a very high service user consent rate of between 80 – 85 per cent and consequently a broad evidence base.

Involving service users and expert citizens in both the design and delivery of the Fulfilling Lives (multiple needs) projects has provided another opportunity to increase the number of service users giving informed consent. This is due in part to the insight provided by individuals with lived experience as to what barriers or fears people might be facing. It can also help to build trust with the evaluators who are working alongside peer researchers and expert citizens.

Further reading

As mentioned in the introduction, this guide serves only as an introduction to sharing service user data in the context of Fulfilling Lives (multiple needs) initiative. There is much more breadth and depth of information contained in the following resources:

Information Commissioners Office

<https://ico.org.uk/>

Data sharing code of practice

<https://ico.org.uk/for-organisations/guide-to-data-protection/data-sharing/>

Information Sharing Centre of Excellence

<http://informationsharing.co.uk/>

Leicester City Council

www.leics.gov.uk/information_sharing_protocol.pdf



CFE good practice guide on informed consent

<http://mnevaluation.co.uk/wpfb-file/good-practice-guide-informed-consent-final-sept-14-pdf/>

