

Conversations, communication and co-design

Engaging local people in
information sharing to support
health and social care integration



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Introduction

Health and social care is primarily about people; those who deliver the services, from GPs and district nurses, to pharmacists, hospital specialists and social workers; to those requiring care, including their family and carers, whose health and wellbeing the services are designed to support.

Health and social care integration aims to coordinate the services that people in need receive, giving them the right care, in the right place, at the right time. It also aims to make the best use of the time, knowledge and resources available from the people who deliver the services.

To make this ambition possible, all the people involved need to be able to share information. This includes information such as test results, medication, special equipment requirements, care plans, details of care providers, crisis contacts and the outcomes expected by a patient.

However, the issue of sharing sensitive information, such as healthcare records, can prompt concerns about the control a person has over the sharing of their own information; this might include how securely the information will be treated, who will have access to it and how it might be interpreted or used.

Sharing personal information also comes with a responsibility to ensure that people are aware of the data that is going to be shared about them, as well as the organisations and staff that will have access to it. It is also important that they know the purpose behind sharing their data.

In order to address these concerns and empower people to make informed decisions about consent, local places across the country have been engaging local residents in discussions about information sharing.

Case study scope

This case study looks at the different engagement approaches employed in four areas – Leeds, North West London, Southend and Warrington.¹ It draws on a mixture of interviews and document reviews to compare the different methods they have used, explore their purpose and scope of engagement, identify common themes, and based on lessons learnt make recommendations for future activity.

The case study is specifically focused on engagement in relation to information sharing, rather than health and social care integration in general. However there is an element of overlap, where engagement of local people to help shape health and social care integration locally has acted as a forerunner to engagement specifically on information sharing (in a health and social care integration context).

Reasons for engagement

In the four different areas we have looked at, there were a number of reasons driving the desire to engage people on the subject of information sharing. Aims for engaging people varied depending on the point that local organisations were at in their information sharing journeys and included:

- **Gathering evidence** about what drives people to share information (in Leeds), and on the potential impacts of not sharing on the care provided (in Warrington).
- Engaging local people in a **co-design process** (in North West London).
- **Raising awareness and gaining 'buy-in'** of people to a specific, local, data sharing arrangement (in Southend and Leeds).

¹ A case study document has also been produced for each individual local area and can be found on the Centre of Excellence for Information Sharing's website www.informationsharing.org.uk

Reasons for sharing information

The types of information sharing, at the heart of the engagement activities, also varied across the places covered by this case study. Namely:

- Sharing personal data for the purpose of direct care in Warrington, North West London and Leeds.
- Sharing data in identifiable and anonymised formats, for direct care and secondary uses, in Southend and North West London.
- Initial conversations about information sharing in order to understand people's attitudes towards information sharing for direct care (in Warrington and Leeds) and towards sharing information to help understand the need for services and open data (in Leeds).

What different approaches were taken?

Warrington – Select Committee Inquiry

Due to an inconsistent approach by agencies to sharing personal data and a lack of holistic, cross-community analysis of the overall information sharing problem, Warrington Health and Wellbeing Board and Warrington Partnership Board carried out a rapid and thorough assessment of the situation in autumn 2014.

The board recognised that sharing personal data was a highly sensitive issue that affected many people, and wanted to make the work high profile, inclusive and transparent so they chose a select committee inquiry (SCI) style approach.²

The committee was made up of fourteen representatives who received, carried out or supported the delivery of patient care, including influential senior managers, clinicians and patients. This group then questioned twenty witnesses, including care professionals, patients and carers, at three public hearings in spring 2015. Opportunities were also created for the submission of written evidence and a public survey was undertaken.

The council, with Warrington Clinical Commissioning Group (CCG) and Warrington Hospital, procured an independent party to manage the inquiry process – a factor that they believe may have encouraged participation from people who wouldn't have otherwise engaged directly with a public body.

From the outset, Warrington carried out considerable

communication about the process, promoting it through partner websites, health professional magazines, local press and social media. A dedicated website was also set up to host all of the related documentation, including agendas, minutes, terms of reference and survey results. These channels were used to raise awareness of the inquiry, and to report on its progress.

Southend – Sharing care records

In Southend, the approach taken to engage with local people about the planned data sharing agreement was developed jointly by Southend CCG and Southend Council as part of the Section 251 risk stratification approval process. Feedback was provided by the confidentiality advisory group (CAG) which considered Southend's s251 approval and played a role in shaping the approach.

A key area of concern was ensuring that there was sufficient awareness about the plan to share data between GPs and social care for both primary and secondary uses of data. It was also important that people were aware of the options and processes available to opt in or out of the scheme.

Following a period of engagement with GP practices and social care staff, a joint communications plan was drawn up and included the use of public meetings, patient and voluntary group forums, local media and council publications. To help gain public support, Southend worked closely with the clinical lead for the

² A government select committee is a small group of members of parliament who have been given a remit to investigate and report back. Information is gathered by members through the questioning of witnesses.

project, lending all communications the 'public face' of a trusted doctor.

Consistent contact details were used for people to provide feedback and air their concerns about the scheme, which made it easier to monitor issues and respond to them in an appropriate and timely manner. The prompt management of responses resulted in a number of local people publically changing their view on the data sharing arrangement from opposition to support.

Southend's communication with local people has continued beyond the 'go live' date of the scheme, and it remains a standing agenda item for patient participation group meetings. It is also featured in the council newsletter, with updates on progress and real life examples of how the data sharing is already helping to improve care. It is hoped that the continued communication will reassure those who chose to opt in and encourage those who opted out to reconsider.

The results of a snap survey carried out by the local newspaper just one day after the data sharing went live, indicated that very few patients chose to opt out of the data sharing process, and only two had been recorded by a local GP practice that has over 3,300 registered patients.³

Leeds – Conversations and care records

In Leeds, this case study looks at two programmes of activity, namely a series of conversations about information sharing with local people known as 'Joined Up Leeds', and the engagement related to the development and delivery of the Leeds Care Record.

Joined Up Leeds - This project had three stages of engagement. The first was developing communications materials following interviews with seventeen key thinkers on data sharing in the city. The second was holding a variety of conversations with people in Leeds and the third was analysing the data collected and using this to develop recommendations. To ensure there was no organisational bias, a procurement exercise was used to employ an independent team who would facilitate and analyse the conversations with

local people.

The overall project was a joint endeavour between the local NHS organisations and the council, led by the informatics team – a centralised resource for the three CCGs operating across Leeds. Communications were handled by the informatics team and the council, with consistent messages from each organisation circulated.

Activities associated with the two-week period of engagement enabled a focussed period of publicity across the city. People could take part by either attending one of seventeen organised 'city conversations', participating in a 'network conversation' which they organised themselves, joining in media conversations using #JoinedUpLeeds or completing a survey.

As a result of this multifaceted approach to engagement, a total of 1,474 people participated in the process, ensuring the desire sought by the local health and wellbeing board for wide representation was met, whilst in-depth insights into why people behaved in the way they do were gathered.⁴

The Leeds Care Record project is a web based solution which enables clinicians to view real time data across care providers and between different systems. A key part of the integrated health and social care programme in Leeds, the project involves collaboration across primary and secondary care, community care, adult and children's social care and mental health services.

All 107 GP Practices in Leeds (approx. 817,000 patients) are currently live with Leeds Care Record. It has also been rolled out across the Trust, Leeds York Partnership NHS Foundation Trust and all thirteen health and social care neighbourhood teams.

Engagement with patients, stakeholders and service users, has taken place from the outset to ensure they are at the heart of the project. Regular meetings with a dedicated patient group have helped provide guidance on a wider reaching patient engagement and to develop the communications material and plan.

³ Echo online, 29 July 15 http://www.echo-news.co.uk/news/13504305.Is_sharing_patient_data_a_big_deal/

⁴ See the Joined Up Leeds full report <http://files.datapress.io/leeds/dataset/joined-up-leeds-results/Joined-Up-Leeds-Final-Report-March-31%20.pdf>

There are also regular updates to Leeds North Clinical Commissioning Group Patient Assurance Group, the project lead for the city. In addition, the team has also met many of the GP practices patient representative groups to inform them of the project.

For specific areas of development, the team have commissioned Leeds Involving People to engage with patients and service users to help inform the project. A number of methods have been used such as surveys, face to face interviews, focus groups and piggybacking network events.⁵

To comply with the 'fair processing' element of the Data Protection Act, a programme of multi-platform communications and extensive engagement has been used to inform individuals about Leeds Care Record.⁶ Ensuring appropriate visibility and communication is provided to allow patients to make an informed decision if they wish to opt out of the initiative.

An example of this focus on 'fair processing' can be seen in the revision of the Fair Processing notice used by Adult Social Services to cover the integration of Social Care data into the Leeds Care Record.

The notice was revised to incorporate all the new features (of the Leeds Care Record) and supported by complimentary changes to the Leeds City Council leaflet 'How we look after your information'.

In addition to changes in written materials, changes were also made to the accompanying processes. For example, changes were made to ensure that the 'How we look after your information' leaflet is given to all new services users on their first visit by a social worker. Social workers also have to sign to confirm that they have given the service user the leaflet and explained the contents to them.

New processes have also been put in place at the Social Care Contact Centre to respond to individuals who want to opt out of information sharing or have refused to give consent. This has included the development of new scripts for Contact Centre staff specifically regarding consent and opting out of information sharing arrangements. Anyone telephoning the Contact Centre will also hear a recorded message regarding information sharing before being put through to a Customer Services Advisor.

North West London (NWL) – Co-production and co-design

In North West London (NWL) Pioneer partnership's overarching commitment to co-production has meant that that patients, service users and local residents (known as lay partners) have been proactively engaged and involved across all activity – not just information sharing.

Emerging from a previous integrated care pilot for the eight boroughs in NWL⁷, the Whole Systems Integrated Care (WSIC) pioneer programme in NWL is a partnership of CCGs, hospital trusts, councils, GP networks, mental health and community organisations, and patients and service users as representatives ensuring that the patient's voice is at the heart of all plans and discussions.

Embedding Partnerships originally sat within Whole Systems Integrated Care (WSIC) as the co-production work stream, supporting lay partners to come together with professionals as equal partners, and co-produce integrated care, ensuring that the individual remains at the heart of any plans throughout. Within the WSIC Programme, as part of the cross-cutting 'Embedding Partnerships' workstream, a Lay Partner Advisory Group and the wider Lay Partners Forum form an unique and integral part of the governance structure.

⁵ Reports available to view on www.LeedsCareRecord.org/news

⁶ Reports available to view on www.LeedsCareRecord.org

⁷ Brent, Ealing, Hammersmith and Fulham, Harrow, Hillingdon, Hounslow, Kensington & Chelsea, Westminster

The success of this programme and the need for patient involvement has been recognised across the whole of the NWL Collaboration of CCGs' Strategy & Transformation activity⁸, and, therefore, Embedding Partnerships is being extended so that patient engagement and co-production sits at the heart of all key programmes and workstreams.

From the outset of the development of the integrated care pilot, partners across NWL felt it was important to engage with all local communities, and particularly to include patients and carers in the development of plans for integrating care services.

Lay Partners (a term used to describe patients, carers and service users) are primarily engaged in two ways:

- The Lay Partners Advisory Group (LPAG) – a strategic group established in October 2013 made up of around 20 individuals. Meeting every three weeks, lay partner representatives on the Advisory Group helped to define the overall NWL framework for integrating care. They participate in strategic discussions and act as the voice of the Lay Partner Forum at higher board-level meetings.
- The wider Lay Partners Forum (LPF) - created in March 2014 to widen the demographic, and broaden the range of patients and service users engaged across NWL, the Lay Partners Forum has over 150 people. Meeting three times a year, the Forum is intended to be broadly representative of local communities and to capture a range of views on local care provision.

Over time, the Lay Partners Forum (LPF) and Lay Partners Advisory Group (LPAG) have influenced the work of the WSIC pioneer programme by voicing the opinions of patients and carers, to draw attention to what is working and what is not working. This influence can be seen clearly in the vision and structure for Embedding Partnerships, which were co-developed with a group of service user leaders from across NWL.

The importance placed by Lay Partners on information sharing can also be seen in the Embedding Partnerships vision. Set out as a series of 'I' statements (designed to enable person-centred,

accessible and proactive high-quality care) the vision makes explicit the role of information sharing in realising integrated care. The vision also helped to articulate the agreed purposes of information sharing and expected benefits, providing a basis for further engagement with both local people and practitioners.

Embedding Partnerships vision

- I can access my own health and social care data and correct any errors.
- I can discuss and plan my care with a professional, focusing on my goals and concerns.
- I know what I can do to keep myself as well and active as possible.
- I know whom to contact and where to go when I need extra support.
- I can make sure that the professionals who support me have access to my up to date health records and care plan.
- I am regularly asked what I think about the care I am getting, I know that my feedback is listened to.
- I know that when changes are being planned to my services, my interests and those of people like me will be taken into account because we have been part of the planning process from the start.

Embedding Partnerships vision, NWL Whole Systems Integrated Care (WSIC) programme.

In addition to their role in placing information sharing at the heart of the WSIC programme, lay partners and have been involved in helping shape and address key questions such as what is being shared, how, and with whom.

⁸ The Strategy & Transformation (S&T) team is part of the collaboration of North West London Clinical Commissioning Groups (CCGs) and works across all eight CCGs to support them in bringing about changes to health and social care services in their area, with the aim of improving patient health and wellbeing.

How did local people become engaged?

In Leeds and Warrington, local people were involved in conversations about information sharing more generally, in order to generate a local evidence base of their experiences and attitudes towards information sharing.

A select committee inquiry (SCI) style approach was employed in Warrington where evidence was gathered from patients and professionals to test the hypothesis that; 'benefits of sharing relevant information among those responsible for an individual's care will outweigh the risks associated with sharing'.

In Leeds, a series of conversations were held to explore local people's experiences of data sharing across the NHS and council. To fully understand the drivers behind the sharing of information, references were made to people's application of information sharing in other areas, e.g. online shopping.

In North West London, engagement with the local community was part of an ongoing programme in which patients, service users and carers were involved in shaping and influencing the development of the Whole Systems Integrated Care programme. Topics such as information sharing, as well as personalised budgets and the use of accessible language, were shaped by discussions and input from the NW London Lay Partners Advisory Group (LPAG) and LPAG Forum.

In Southend and Leeds, local people were engaged in order to raise awareness of a specific data sharing arrangement, namely the Leeds Care Record and the 'Your Health Care Record' in Southend. Communication about the scheme was designed to help local people understand the reason behind sharing their data, the implications this might have for them, and the options available to them. Giving them the information needed to make an informed choice about whether to opt in (for social care users in Southend) or opt out (via their GP) of the local data sharing arrangement.

Was everyone engaged in the discussions, or only specific groups of people?

In the four local places covered by this comparative case study, engagement activity was aimed at all local people, rather than specific groups of people. However, in order to engage a representative group of local people, some approaches to targeting were used.

In Leeds, the health and wellbeing board was keen to gather a wide range of views through the Joined Up Leeds conversations, in particular from:

- Those living in the more deprived areas of the city.
- Males aged between 18-35 who hadn't been engaged in previous research.
- People who weren't receiving any healthcare services at that time.

This meant the engagement events were held in places where people gather for social reasons, such as bars, cafes and gyms, as well as in community centres and work places.

Targeted engagement also took place as part of the roll out of the Leeds Care Record, for example, with local people involved with the mental health service. Led by the Chief Clinical Information Officer, open discussions about the Leeds Care Record took place with patient representatives from mental health services. These were used to explain what the Leeds Care Record currently did, why information was being shared in this way (to support direct care only), and that mental health information was looking to be

included. A list of the data proposed to be shared through the Leeds Care Record was given to patient representatives, who were then asked if they would be comfortable to share this type of information. Discussions also took place around the benefits to patients of sharing information in this way.

In North West London, the pioneer programme also took steps to engage a wide representative group of local people as members of their Lay Partners Forum, which has a membership of over 150 people from across North West London. This is underpinned by a targeted, ongoing recruitment strategy and support from an Engagement Team (who form part of the NW London Collaboration of CCGs). Forum members were chosen by the reach and depth of their networks – ensuring that membership was representative and could reach deep into the local community.

In addition, the Lay Partners Forum also looks to have equalities-based representation. Focused on the ‘protected groups’ set out in the Equality Act⁹, emphasis is also placed on engaging subsets of these groups sometimes known as ‘seldom heard voices’ such as, but not limited to:

- Care home residents.
- Elderly people living at home alone.
- Users of day centres.
- Non-registered health and social-care staff.

It is worth noting that whilst engagement activity in each area looked to reach the whole population, the issue of information sharing didn’t necessarily apply to everyone in the local population. For example, in Southend the data sharing arrangement did not include health care records for children, people with a mental illness or people with learning difficulties.

What methods were used to engage local people?

In each of the four local places, different methods were used to engage local people. These included communications to inform people what was happening and what it meant for them; meetings and events at which people could ask questions and receive further information; and opportunities to be directly involved in shaping, supporting and contributing to the communications and event activities.

Common methods used to communicate information and engage local people across the four places included press releases and articles in the local media, creating specific websites or webpages about information sharing, holding or attending public meetings, presenting information to existing patient forums and community groups, placing information leaflets and posters in public places, and using social media to share messages and engage in conversations with people.

Leeds used a multi-channel approach for both the Joined Up Leeds conversations and the Leeds Care Record, ensuring that people were able to receive information and respond to it using the channel most suited to them. When looking to roll-out the use of the Leeds Care Record across the City, use was made of the website and local media, such as the Yorkshire Evening Post newspaper and Look North regional news programme, rather than sending out a letter to every resident (which was not regarded as an efficient method of communication).



⁹ The Equality Act 2010 sets out the following protected characteristics (or groups) - age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation. <http://www.legislation.gov.uk/ukpga/2010/15/section/4>

In Southend, the distribution of letters to households was also considered but discounted as a high-cost option which wouldn't realise the required level of awareness or engagement. Their resulting decision to focus on awareness-raising through local media and public meetings (rather than issuing letters to every household) formed part of their approved s251 agreement.¹⁰

In both Warrington and Leeds a survey was used as one method of engagement (within a wider package of engagement activity) to help reach a broad range of people. For the Joined Up Leeds project, local people were recruited to complete the survey through community organisations, workplaces, and the council run Leeds Citizens Panel. Most of the survey responses (85%) were received from members of the Leeds Citizens Panel, which meant that the responses came from people living in a representative range of locations in Leeds and from a good balance of genders (53% female). However, younger adults were less well represented and the majority of people responding were white/white British (93%). Efforts were made

to include more young people by contacting the Universities and liaising with Youth Watch to circulate a link to the online survey.

In addition to engagement activity directly linked with information sharing, this case study also touches on engagement of local people with health and social care transformation more generally, where it has taken place in advance of, but has a direct impact on, their involvement with information sharing activity.

Specifically, in North West London, local people (known as lay partners) were proactively recruited to play an active part in the co-production of all aspects of the local integrated care programme. Initially drawn from people who had been working with other local health initiatives (such as 'Shaping a Healthier Future' or Integrated Care Pilots), local people invited to join the Lay Partners Advisory Group (LPAG) were also recruited through nominations from the local CCGs, Healthwatch, Adult Social Services, patient participation groups and various health and social-care related charities.

How were partners and local people involved in the design of communications?

In Leeds and Southend, communications to local people about data sharing schemes have been developed jointly by the local health organisations and council, in order to ensure consistency.

In Leeds, this meant that a co-branded communication pack was produced and all information about the care record was hosted on a dedicated website and a single social media channel.

In Southend, the approach was set out in a joint communications plan developed by both parties. Associated publications were co-branded and content about data sharing on both the council and CCG websites was consistent.

In addition to organisations working together on communications, local people were also involved in designing information leaflets about information sharing, alongside practitioners and communications experts. This approach helped to ensure the message was understandable and encouraged practitioners to display the documents.

In Warrington, the inclusion of patients on the select committee panel ensured that local people not only played a role in shaping the inquiry process, but also influenced how people were made aware of, and engaged in, the hearings and associated public survey.

Involving local people in shaping communications plans and content was also a strong element in the

¹⁰ Section 251 was established in 2006 to enable the common law of duty of confidentiality to be overridden to enable the disclosure of confidential patient information for medical purposes – where it is not possible to seek consent or used anonymised data. Further information can be found at: <http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/what-is-section-251/>

work of the lay partners who supported the North West London pioneer programme. Stemming from their overarching commitment to co-production, the 'Lay Partners Advisory Group' took on a role of challenging the approach to, and being local champions of, information sharing (in addition to their involvement in all five of the integrated care work streams - population and outcomes, GP networks, provider networks, commissioning governance and finance, and informatics).

A key element of the Lay Partners work on engagement was the development of a set of shared principles for co-production across the Whole Systems Integrated Care (WSIC) programme. These principles were seen as key to ensuring moving beyond the traditional boundaries of 'consultation' or 'service user engagement', to create something that would be meaningful for those giving up their time and energy to be involved.

We are committed to our shared principles for co-production in the programme

1. Co-production for the Whole Systems programme starts with co-design, through which we can then embed co-delivery. This is the core of our programme and is embedded throughout the whole process.
2. We are dealing with new relationships for which we need a new language of inclusion: we will avoid "consultation" and aim at all times to have "conversations" for a genuine partnership.
3. We are people driven: we will actively reach out to those whose voice is rarely heard.
4. We are all responsible for driving progress and educating each other along the way.
5. We recognise the political and social context in which the programme sits.

Co-production principles for North West London's Whole Systems Integrated Care programme.

As highlighted in the principles for co-design (above), the language used by the WSIC programme has been a particular focus for Lay Partners, and has influenced their input into communications on information sharing (and other topics).

In addition to flagging up the need for simple, concise and jargon-free language, Lay Partners also emphasised the need to:

- Avoid using language which might imply any kind of power difference (between people commissioning or providing a service and the people using a service).
- Use language which takes the point of view of the individual rather than the system.

In relation to information sharing, the Lay Partners acknowledged that there was a risk-averse approach towards sharing information and concluded that positive and consistent messages in plain English around the issue would be critical in changing this stance. They also raised concerns about the danger in confusing messages about sharing personal information and those about sharing non-personal information.

To address these issues, the partners lead by example, working on the design of posters and leaflets that showed how sharing information could be of benefit to patients. In addition, members of the group from each borough in the area played a role in communicating key messages and updates on progress around information sharing back to the wider community.

"Professionals prefer to prepare something for consultation with patients, but the full benefits of co-production come when you have their views from the start. It also saves time in the long run."

Lis Paice, Joint Chair, NWL Integrated Care Management Board

How do you raise awareness and manage expectations?

What messages can be used to raise attention?

From the outset, local places should consider the messages that will gain the attention of citizens. These should give them a complete picture of what data will be shared, who is involved, the impact it will have on them and an overview of their options. They will also need to pre-empt local people's concerns and develop consistent responses to these with partners.

Drawing on the experiences and learning of the four places covered in this case study, the following concerns and benefits could form the basis for key messages to local people:

Benefits of information sharing

- Saving lives – for example, by preventing people from being prescribed medicines in hospital which they are allergic to or knowing who to contact in an emergency or crisis situation.
- Improving care – for example, a patient not having to explain the reason for their referral to a clinician and health and social care professionals coordinating care between one other.
- Reducing bureaucracy – for example, people not needing to answer the same questions repeatedly, or having to duplicate the same information on multiple forms.
- Providing control – for example, opening up the potential for individuals to access their own medical records and take more responsibility for managing their own health.
- Saving money – for example, by addressing the above four points, the efficiency of public services will be improved (although this message should be addressed with sensitivity).

Potential concerns about information sharing that will need to be addressed:

- Who can see information about me? Do I have any control over this?
- What type of people (medical staff, volunteers etc) or organisations will see my information?
- Is my information safe, securely stored and protected from misuse? Will all of the agencies involved in sharing my data have the same ethical, professional and security standards?
- Is the information being shared about me up to date and accurate?
- If I opt out of information sharing, will it affect my care?
- Will information be shared to address an issue with high-cost patients or to prioritise specific groups of people, to reach financial or other targets?
- Will my information be sold on to third parties?
- Will the information shared about me actually be used for a purpose, or is it just creating jobs for the sake of it?

During the Joined Up Leeds conversations the most common concerns raised by people about information sharing were:

- It might be sold to private companies (71%)
- It might not be stored securely (61%)

What challenges have been encountered?

The concerns listed above were generated in response to personal worries and experiences as well as statements made by friends, family and acquaintances of patients, and stories covered by the media.

Confusion between different local and national information sharing schemes were the most common concerns raised in the places covered by this case study. In particular, uncertainty centred around the purpose of sharing, clarity about the different types of data shared and who data is shared between.

Confusion about the NHS England initiative, Care.data has created a particular challenge for local places. This is due in part to the high level of negative media coverage it has received which in some cases, has led to misunderstandings about the scope of the data to be shared by local schemes, and suspicions about data being sold to third parties.

In Leeds, they have produced a leaflet that hopes to tackle this confusion by setting out the differences between local data sharing schemes and national schemes, such as the Summary Care Record and Care.data.

Misinterpretation or misunderstanding of the language used to describe the reasons for sharing information was cited as another challenge encountered by local places.

In Southend, clear and accessible explanations were used to explain its local data sharing scheme directly to local people, but it was described with more formality in council and CCG minutes as well as in the s251 submission, which included a reference to identifying and reviewing the care of 'high-cost patients'.

This term was misinterpreted or misunderstood by the media and local people, and conclusions were drawn that the scheme was financially driven and purely focused on saving money, rather than improving quality of care. This inevitably led to concerns from some local people about the potential impact of their data being shared, as they might become the target of cost-cutting activity.

As a result, it became clear that communications about the scheme not only needed to clarify what the data sharing would involve, but also what the scheme was not about i.e. financial targets.

Where citizens were directly involved in conversations about consent, concerns were raised in some of the four places as to **whether people would fully understand the implications of their choice to opt in or out of sharing.**

In Warrington, concerns centred on people being properly informed and whether the consent they may give is truly informed consent. Similarly, concerns were also raised as to how care providers could address the additional challenges of talking to those who do not have the capacity to give consent, or who have trouble doing so.

Taking steps to address potential concerns about consent in Leeds, the Adult Social Care Service have amended the consent / opt out statements in a number of their forms, including the:

- Initial Contact Form
- Supported Self-Assessment Form
- Care and Support Plan
- Carers Assessment Form

These standards are now being rolled out across the rest of Adult Social Care to include Mental Health and Learning Disabilities, addressing this challenging area of talking about consent with people who may have trouble fully understanding and giving consent, or may not have the capacity to give consent.

A further challenge identified by the four places was the **management of local people's expectations regarding what happens with their data.** This is particularly relevant if communications include statements that information will be shared, unless a person actively opts out of the arrangement.

People may then reasonably assume that their information is being shared if they chose not to opt out, however, as this arrangement also requires the GP practice to participate in the local data sharing scheme, their expectations may not always be met.

In Leeds, they have taken steps towards addressing this by publishing an online list of local GP practices which participate in the local data sharing scheme.

Local places need to consider how to manage this potential challenge in their communications activity and make it clear to local people that the sharing of their information will depend on their own, individual choices, as well as by those made by their GP practice.

“There is something about communicating; if you tell people what you are doing and don’t hear back from them you assume they agree with you and your actions.”

Trevor Begg, NWL LPAG Member

Communicating with the communicators

Who can help communicate with local people?

In addition to focusing on how to engage local people, it is also important to consider who will be communicating and engaging with them, and what support those communicators might need.

Key communicators will vary from place to place, but are likely to include GPs and practice staff, members of multi-disciplinary teams (MDTs) linked to GP practices, social workers, local voluntary and community groups, carers and relative of patients, and of course local media.

In Southend, communications with local GP practices were deliberately carried out in advance of engagement with local people. This was in acknowledgement of the role that GPs and other practice staff would play in responding to queries from local people. The timing of this was designed to give enough time for practices to request further details of the local information sharing scheme, and to cascade this to all staff.

In some cases, there may be a need for other support to be given to healthcare practitioners. At the early stages of the Leeds Care Record programme a communications toolkit was developed to support GPs in communicating with patients – enabling a consistent message to be delivered. This was also published widely across the city to ensure transparency.

Other key groups of communicators include local voluntary and community groups which can provide a channel to disseminate messages about information sharing to large networks of people, including those who are currently using healthcare services as well as those that are not. For example, the Joined Up Leeds project made use of links to local community groups to engage their members in the local city conversations. In North West London, Lay Partners are seen as a conduit for messages out to the wider community, and have been supported to maximise their impact and reach, for example by the provision of social media training to members of the Lay Partners Forum.

In Southend, steps were taken to engage the community voluntary services (CVS) umbrella organisation early on. Sessions were held to provide information and respond to questions about the local data sharing scheme for community group representatives. The CVS helped disseminate information about the data sharing project to all of its member organisations, and through them, their individual members.

In Southend, this relationship building with community champions / campaigners formed part of a wider programme of engagement by the CCG, which is happening in relation to a range of issues (not just data sharing). This work has involved the chief officer and head of communications going out to meet with local community champions and campaigners to listen to their concerns, build trust and explain who the

CCG are, what they do and how they fit into the new structure of the NHS.

This approach to relationship building, combined with a proactive approach to contacting and engaging vocal opponents (to issues such as data sharing) in debate, is making a difference as campaigners are now engaging more positively with the CCG.

Converting campaigners to champions in Southend

A vocal opponent to the scheme was contacted on Twitter by Southend (CCG) and asked to get in touch with them so they could be given more information. Following the resulting engagement, the campaigner posted a positive video about the scheme and later asked how they could promote this to other people with the same condition.

A learning point from the Joined Up Leeds conversations was to do more to get the local media involved to promote the activity taking place. The important role played by the local media was also highlighted in Southend, where prior to the public launch of the local data sharing work had already been taking place with local press to help improve their understanding of the CCG and its role, and who to contact in the CCG to get comments on a story etc. (as being a relatively new organisation meant that journalists had little previous material about the CCG to draw on).

This ongoing engagement with the local media (alongside continuous communication with patient groups etc.) helped to limit the impact of negative news stories in the national and trade press. As such, local journalists' stories were generally more balanced in their content. Following the 'go live' date for the data sharing scheme, stories changed in focus from raising concerns to reporting on the very low opt out numbers at a local GP practice (two opt outs from over 3,300 registered patients).



Conclusions and recommendations

Using insights drawn from the work carried out by Leeds, North West London, Southend and Warrington, we have drawn the following recommendations to support other places that are working to engage local people with information sharing plans or proposals.

Communications planning

- ▶ Develop a joint communications plan with all relevant agencies, which sets out a coordinated approach to engagement with stakeholders, messaging, internal communications to staff and external communication to service users and the public.
- ▶ Ensure there is clarity within the joint communications plan about which agency will lead on its implementation, who will progress its delivery and how issues encountered will be reported and managed.
- ▶ Consider who, if anyone, will be the public face of the data sharing proposal; some local places felt that public acceptance for data sharing is higher if the spokesperson is a health professional, rather than a politician or council officer.
- ▶ A consistent set of public contact channels, i.e. email, social media, phone, to submit and access queries reduces the possibility of these being responded to by staff without sufficient knowledge, and enables analysis to be carried out that can help shape ongoing communications and engagement activity.
- ▶ Identify key issues and concerns during the planning stage of communications activity. These will vary depending on the purpose of sharing data and the people who will be affected by data being shared.

Engagement and communications with local people

- ▶ In order to comply with the requirements of the Data Protection Act (DPA) around Fair Processing, communications will need to focus on making people aware of the plans to share data, what their information will be used for, by whom and how to opt in or out of their data being shared.
- ▶ Care should be taken to use appropriate language. Making sure communications are concise, clear and easy to understand, avoiding the use of jargon and making them people-focused.
- ▶ Existing groups of patient representatives or lay partners can provide a key route through which awareness about information sharing can be shared and widely disseminated. Regular conversations with these groups can also provide opportunities for co-design of communications materials, as well as a route for responding to local queries and creating advocates.
- ▶ GP practices are a key location for patients to receive information about data sharing. They should already display fair processing notices to cover the existing national data sharing arrangements and most will appreciate further communications that will help them inform their patients.
- ▶ People who go to their GP practice or council centre to meet their social workers will encounter other staff, such as nurses, receptionists, volunteers etc. who they may ask about the data sharing project. Consideration will need to be given as to how to support these staff to deliver the right information.
- ▶ The scale of the communications about data sharing and how to opt in or out should be proportionate to the scale and duration of the project planned. The cost of writing a letter to every

individual adult in the local population may be out of proportion to the data sharing activity planned, especially if the proposed arrangement is for a short period of time only.

- ▶ Awareness-raising methods should be explored for delivering cost-effective communications about planned data sharing schemes, such as advertising in a local free paper, placing articles in council newsletters, delivering presentations at existing public events and holding meetings with patient and voluntary group representatives.
- ▶ The use of existing Citizens or Residents Panels should be explored as a way to gain feedback and views about information sharing from a representative group of the local population.

Communicating with the communicators

- ▶ Ideally GPs should be engaged as early as possible in the development of a data sharing project. This will give them time to understand and consider the associated benefits of sharing data, to ask questions, and to help shape communications with their patients and the public, before they are asked to sign up to share their patient records.
- ▶ The local community voluntary services (CVS) and similar umbrella groups for community and voluntary section groups, should be engaged to help disseminate messages about information sharing to its member organisations and individuals.
- ▶ Positive staff engagement can help create project champions; doctors and social workers who understand the potential benefits that data sharing can offer to clients and patients could become spokespeople and/or advocates.
- ▶ Relationship building with the local media could be a key aspect towards promoting communications linked to a data sharing project. Briefings that help improve journalists' understanding of who is involved, who key contacts are and specific key information, could support positive coverage to the public about the scheme.
- ▶ Consider providing personal development to community champions/key spokespersons on the

use of social media to help them maximise the impact and reach of their messages

Consent conversations

- ▶ Existing forms and guided conversations should be developed for use with social care clients, in order to ask for consent to share data. When introducing a new data sharing arrangement, care is needed to ensure that communication with clients is clear.
- ▶ Consideration should be given to the materials and support that GPs and other healthcare professionals may need so they can conduct conversations with patients who enquire about the scheme, or request to opt out of it.
- ▶ Supporting materials should help to explain the difference between the local scheme and national schemes, such as Care.data and the Summary Care Record, and could include the provision of a script or checklist to help guide a conversation.

Further information

More information on the four areas covered in this case study, and their approach to engagement and information sharing, can be found in individual 'mini case studies' for each local place on www.informationsharing.org.uk/hsc



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Further information can be found on the following websites or by contacting the relevant local team.

Warrington

Warrington CCG press release on the data sharing survey and select committee inquiry

<http://www.warringtonccg.nhs.uk/News/Can-data-sharing-be-improved-There-is-still-time-to-have-your-say.htm>

Local Media coverage of Warrington's data sharing survey

http://www.warringtonguardian.co.uk/news/11650851.Have_your_say_during_data_sharing_survey/

Warrington Together website content on information sharing

<http://www.warringtontogether.co.uk/key-projects/supporting-integration/sharing-information-for-better-care-better-health/>

Contact selectcommittee@warrington.gov.uk

Southend

Southend Clinical Commissioning Group website materials on information sharing

<http://southendccg.nhs.uk/about-us/data-sharing>

Newspaper 'wraparound' used to raise awareness of the local data sharing arrangement

<http://southendccg.nhs.uk/about-us/key-documents/1070-nhs-health-care-records-ya-wrap/file>

Local media coverage about the local data sharing arrangement

http://www.southendstandard.co.uk/news/13504305.Is_sharing_patient_data_a_big_deal/?ref=mr&lp=3

Contact sccg.communications@nhs.net

Leeds

Joined Up Leeds summary report

<http://www.inspiringchangeleeds.org/wp-content/uploads/2015/04/summary-joined-up-leeds-report.pdf>

Joined Up Leeds full report

<http://files.datapress.io/leeds/dataset/joined-up-leeds-results/Joined-Up-Leeds-Final-Report-March-31%20.pdf>

Brainbox Research website

<http://www.brainboxresearch.com/joined-up-leeds/>

Better Lives Leeds website

<https://betterlivesleeds.wordpress.com/tag/joined-up-leeds/>

Leeds Citizens Panel

<http://www.leeds.gov.uk/council/Pages/Citizens-panel.aspx>

Leeds Care Record website

<http://www.leedscarerecord.org/>

Leeds Care Record communications toolkit for participating organisations

http://www.leedscarerecord.org/wp-content/uploads/2014/03/Leeds-Care-Record_Comms-Toolkit_12pp-A4_UPDATED.pdf

North West London

North West London Whole Systems Integrated Care (WSIC) website

<http://integration.healthiernorthwestlondon.nhs.uk/>

Lay partners role

<http://integration.healthiernorthwestlondon.nhs.uk/our-work-together>

Recruitment of, and support for, lay partners

<http://integration.healthiernorthwestlondon.nhs.uk/section/how-can-we-support-lay-partners->

Recruitment poster for Lay Partners Forum

<http://healthwatchcwl.co.uk/wp-content/uploads/2014/02/Embedding-Partnerships-Lay-Partners-Forum-Poster.pdf>

Introduction to information sharing

<http://integration.healthiernorthwestlondon.nhs.uk/informatics>

Communications materials developed to support information sharing

<http://integration.healthiernorthwestlondon.nhs.uk/informatics/communications-materials>

We have a range of tools and case studies that we update regularly on our website. Sign up for updates on the site or connect with us to keep updated.

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