

# HEALTHY INFORMATION SHARING

Imogen Fuller, Engagement Manager, Centre of Excellence for Information Sharing, describes how local communities around England are changing the way they share health and social care information, and how this approach is helping to improve services to patients.

Across the country, health and social care providers are facing pressure to deliver improved, integrated services to more people, with fewer resources. The challenge for these organisations is to make the most of what they have and focus their efforts where they can deliver the maximum positive impact for the people they care for.

This is where the Centre of Excellence for Information Sharing (the Centre) comes in: working with providers in England to unlock one of their biggest assets – information.

Sharing information has the potential to make a real difference to services and the people who access them, but it is paramount to ensure it is used appropriately and that any confidential information is properly safeguarded. Sue Bateman, Deputy Director of Better Use of Data in GDS, and chair of the Steering Group for the Centre, said: “Effective information sharing can lead to improving services at lower cost, but some of the perceived barriers mean

that this can still be challenging. The work of the Centre is crucial in helping overcome some of those barriers, leading to a greater understanding of the potential of information sharing and an increase in collaborative working.”

A key challenge for local initiatives is to ensure that patients are supportive of the necessary changes in the information sharing that supports joined-up work. Their permission to use patient data is critical, but there is a balance to be struck with the potential to create society-wide benefits from this data. As well as being informed enough to feel comfortable in consenting to share their information, patients should be able to see the tangible benefits it delivers.

## THE VALUE OF GOOD INFORMATION

Why is information such an asset? The more effectively that providers can share information with partners, the more detailed the picture they can build of patients and the local population, allowing them to tailor their support and target their services at those who need them most.

One approach to maximise this untapped data is to introduce a ‘common electronic record’, in the form of an Integrated Digital Care Record (IDCR). In simple terms, this is a single point of reference for some or all of a patient’s data. This can then be accessed and, in some cases, added to by the different health professionals involved in that person’s care.

This move from a siloed approach to a single shared record was initially seen by local areas as a way to improve services and save money. However, additional benefits have been noticed, such

as allowing partnerships to reflect on and evaluate the culture in which they work, inform the way they can deal with future service demands and fully realise the opportunities that IDCRs offer.

Early adopters of IDCRs have already tackled the main cultural barriers to information sharing – such as leadership, communication, relationships and trust – helping them to work even more closely with partners.

As with all activity that involves sharing personal information, the feelings of the individuals whose data is being shared has to be central. The challenge is to implement the necessary changes to provide an improved service and better outcomes while reassuring the public.

## CONVERSATIONS ARE KEY

Leeds is one area to have put information sharing at the heart of integrating healthcare services, highlighting early and ongoing citizen engagement as critical to its success.

The commitment to citizen input led to the formation of ‘Joined Up Leeds’. This enabled conversations between local people and health and social care providers, giving an insight into people’s motives when deciding whether or not to share information. This helped to understand local viewpoints on information sharing both in health and social care and the wider context.

The conversations began with influential local thinkers to provide a baseline of current experience of information sharing. They were then widened to a larger audience of local people, through carefully chosen channels, to improve accessibility.



This engagement identified public opinions that needed to be addressed. These included the perception that information might be sold to private companies (raised by 71% of participants); or that it might not be stored securely (a concern for 61% of participants). Busting these myths helped to create a groundswell of positivity for information sharing.

Leeds has now created a solid evidence-base of public opinion – the Leeds Care record – to call on when designing their IDCR, and set some important early communication messages for local people to help alleviate public scepticism.

### PUTTING PUBLIC OPINION AT THE HEART OF SERVICE REFORM

Health and social care for the 2.1 million residents of North West London is provided by a Whole Systems Integration Care (WSIC) programme made up of 30 health and social care organisations.

From the outset, WSIC put patients and local community engagement at its heart. In particular, they wanted to ensure that service integration met people's needs through lay partners (the term used locally for patient, carer and community representatives), who are engaged in two ways.

They did this, firstly, through discussions at higher board level to define the overall framework for integrating care; and then through a wider forum.

This gave a voice to patients and carers, drawing particular attention to what is working and what could be improved, ensuring decisions about the services offered and the way information is shared are influenced directly by the end-users.

### CONVERTING PUBLIC NEGATIVITY

Southend is another area where information sharing is a key component in creating integrated health and social care with a single, comprehensive care package for a patient's needs.

When a vocal opponent of the local data-sharing scheme used Twitter to vent their opinions, instead of ignoring this or fighting

## LESSONS LEARNED

What do these examples show us about the change in attitudes and culture needed to encourage greater information sharing that supports the needs and wants of service users?

- **Leadership:** Leadership is one of the biggest enablers of information sharing, especially in bringing together different organisations to operate, share information and respond as one. All the stories show the crucial contribution of strategic and clinical leaders to driving projects forward. Although representing different organisations, what these leaders had in common was an appetite for proactively engaging with local people; the willingness to answer questions directly; and the focus and commitment to deliver.
- **Building relationships and trust:** The creation and maintenance of strong, reciprocal relationships based on common values and outcomes was critical. It helped the different partners discuss issues constructively, secure 'buy-in' from patients and carers, and develop the knowledge and trust to articulate and agree a shared vision.
- **Communication:** Ensuring clear, simple, well-managed channels for two-way communications is key to allowing patients and other end-users to give their views.

back, Southend chose to engage directly to address them. The result was that the campaigner posted a positive video about the work and later asked how to promote it to other people with the same condition.

Tackling negative comments head on helped Southend turn a campaigning opponent of the scheme into an independent advocate – one of the most powerful aids to communication in public engagement.

### SHOWCASE THE BENEFITS

The development of an IDCR in Bradford and Airedale is supporting health and social care integration and delivering improvements to a range of services. These include its end-of-life care, which reduces the number of unplanned hospital admissions that service users neither need nor want. Called 'Gold Line', the service provides a 24-hour telephone line for end-of-life patients, their carers and families. It allows patients' information to be shared and accessed so the best care can be given first time, in line with their wishes.

Angela, who is her husband's carer, sums up the positive impact of Gold Line:

"Since being part of Gold Line our lives are much calmer, and

it's been a real help knowing that there's always someone available to reassure or support me. I just wish we had had this service earlier, because it has taken the frustration and the fear out of what we have to do. One number, one call and everything is sorted - no chasing for appointments. I cannot praise the staff enough."

### IF YOU ONLY REMEMBER ONE THING

Experience at national and local level tells us that information sharing can stand or fall on the effectiveness of public engagement. Information sharing and the development of the nuts and bolts for how it will work needs to be supported by effective and strong engagement and communication with the public. The prize is public trust, support and even championing of information sharing, because people understand, see and feel the benefits it delivers.

For more details about the IDCRs and the examples covered in this article visit [www.informationsharing.org.uk/hsc](http://www.informationsharing.org.uk/hsc).

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