The Better Care Fund

Delivering integrated care webinars

Data sharing

3.30 - 4.45pm, Wednesday 10 May 2017

Department of Health

Local Government Association

Department for Communities and Local Government

NHS England

Masterclass organisers

scie social care institute for excellence

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Introductions

Iris Steen, Head of Marketing and Communications, SCIE

1. Information Sharing: Things to Consider

- Rebecca Nutting – Data Sharing and Privacy Team, NHS England

2. Approaches to Information Sharing

- Mark Golledge, Programme Manager – Digital Health and Care, Local Government Association

3. Case Study: Connecting Care – An Information Governance Perspective

- Helena Ashton – Information Governance, Manager Connecting Care, South Central and West CSU

4. Case Study: LPRES and the Information Sharing Gateway

- Helen Speed, IG lead for LPRES

5. Questions and Discussion

Before we start….

- Information sharing is a large area so we won't be able to cover everything in the webinar today!

- Because of purdah (General Election) we can't talk about future policy or areas which may influence future policy.

- The focus therefore of this webinar will be more on practical, operational support to provide assistance to your local work.

- From our short survey with you we found that you wanted to hear about:

  - *Things to consider when sharing information*
  - *Examples of how information sharing is being used to support direct care and commissioning*

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Information Sharing: Things to Consider

Rebecca Nutting, Data and Privacy Team – NHS England

An Introduction to Data Sharing

- Experience-its an approach

- The building blocks

- People, Process/law, technology

- The reams of guidance – but where do you start in practice?

- Understanding the organisational changes

Where to start: The first steps

- Data Sharing the premise of transformation in the NHS, Sustainability and Transformation Plans (STPs), Vanguards, Pioneers

- Traditional organisational boundaries coming down

- The law is a barrier to Data Sharing! True/False

- Privacy by Design & Privacy Impact Assessments (PIAs)

- Asking questions, who, what, where, how-WHY

Privacy by Design-What is it?

- Information Commissioners Office, best practice to become mandatory under General Data Protection Regulations (GDPR)

- Senior Level Buy in

- Contract management & Project Management initiation

- Understanding the fundamental principles

What to consider

- Privacy Impact Assessment –useful start-asking questions

- Know the landscape-information governance

- Purpose – Why are we doing this, key

- Legal boundaries - article 8, Confidentiality, Data Protection

- NHS Policy –what are our internal processes that we must adhere to

Legal basis –Confidentiality & Data Protection

- Duty of confidentiality – offer

- Purpose, legal vires: function, activity

- Schedule conditions in Data Protection Act (DPA)

- Article 8- the impact on the private life of the individual

- Finding the basis: legal duties, incidental powers, justification

- Duty to Share, Direct care

- Health & Well Being of the Population
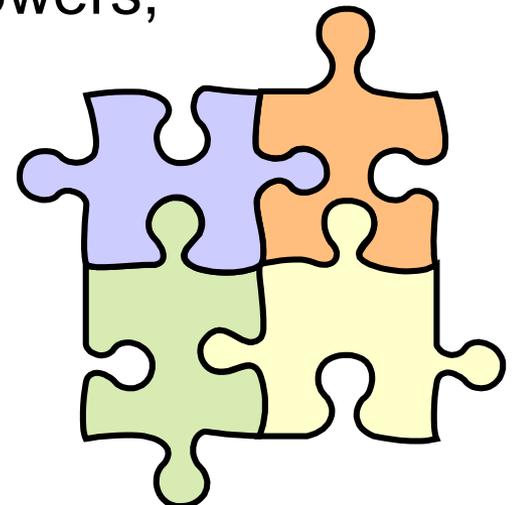
Practicalities
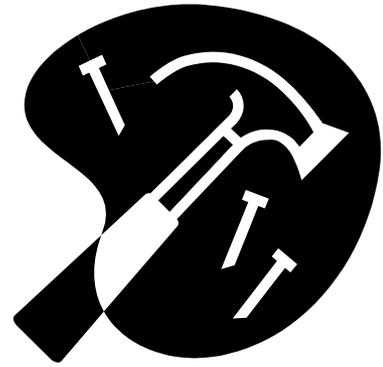
- Data Sharing Operating Models –agreements & platforms

- What data, how will it be share, securely & appropriately with safeguards in place

- Identifying the stakeholders and stakeholder engagement

- Identifying the Data Controller –the organisation in possession of the data?

- NHS Digital –major stakeholder

Its easy!

- Culture, policy & processes

- Ideas are often well developed or breaking new ground

- Playing catch up

- Clarity is required in some areas e.g. Risk stratification, linking data

- Stakeholder engagement , operating models differ

- Information Governance Alliance & IG Network, Lessons Learned & authoritive sources
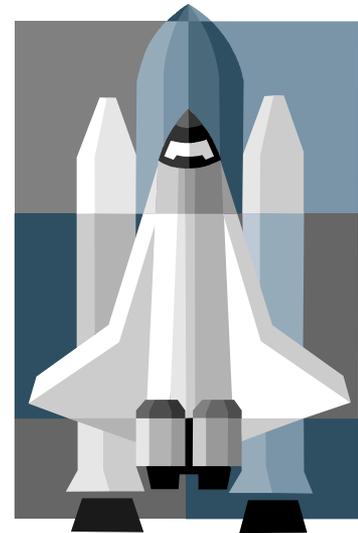
Some of the challenges….

There are various challenges raised by local organisations when it comes to information sharing:

Information Governance (Policy / Process / Legal)	Technology (Systems)	Culture (People / Behaviour)
• Need for clarity about confidentiality • Confusion about the process for data sharing • Understanding the role of, and applying to the Data Access Request Service (DARS) • Pseudonymisation (how to apply policy / law) .	• Identifying cohorts e.g. those in care homes and impact of interventions • Using a common identifier to link data between providers • Risk stratification of linked groups • Improving data quality • The need for real-time (or near-real time) data	• No common language • A lack of understanding about the benefits • A fear of sharing, getting it wrong and the consequences • Different interpretations of the rules/changing perceptions about the purpose

3 Building Blocks for Information Sharing

1. **Design, Communication and Engagement with Users:** It is important that approaches engage meaningfully with end-users. This might be citizens, carers or professionals (care professionals or commissioners).

2. **Having a Shared Vision and Commitment:** Integrated care programmes need a common and shared vision across organisations and individuals involved. This requires local leadership and understanding different values and culture.

3. **Transformation First not Technology First:** It's important that the focus is on system or service transformation – rather than bolting technology on top of existing service delivery.

Dimensions of Information Sharing to Support Integrated Care

1. Sharing information to support the delivery of integrated and coordinated care

- Developing a shared care record (single view), enabling the effective transfer of information across care settings or giving citizens access to information.

2. Sharing information to support preventative models of care

- Risk stratification for case finding (identifying people at risk of an adverse event) to support early intervention.

3. Sharing information to support population based analytics and segmentation

- Tracking outcomes across a pathway or care setting
- Identifying activity and spend at a system wide level.

1. Sharing Information to support the delivery of integrated and coordinated care

Questions you might be considering:

- How can we ensure that professionals working with an individual (i.e. MDT) have (near) real-time access to the relevant information needed?

- How do we make integrated working across organisations more efficient and effective by improving the flow of information?

- How can we put citizens in control through access to their information?

- What if we need to share information with care providers or the third sector?

Things to consider for sharing:

- Be clear on what information health and care professionals need to see (see Merseyside iLinks Information Sharing Framework).

- Consider the technology & what arrangements are needed to support sharing (interoperability).

Examples from local areas:

- **Connecting Care** work in Bristol and the South West including sharing of children's information.

- **NHS Digital** work on supporting admission and discharge information (e.g. hospital to social) and also with care homes.

2. Sharing information to support preventative models of care

Questions you might be considering:

- How do we move towards a proactive and preventative model of care – and have a different conversation with the public?

- Who are individuals or families most at risk of an event (not just hospital)?

- Who will benefit the most?

- What interventions will have the most impact (based on interventions of people with similar experiences)?

Things to consider for sharing:

- There is an agreed approach for risk stratification adopted by NHS England which supports local areas for sharing.

- Look at the ICO guidance in relation to the General Data Protection Regulation (GDPR) on Profiling.

Examples from local areas:

- **Sunderland** approach to Risk Stratification which forms part of their new care model.

- **Wigan** working with Integrated Neighbourhood Teams and utilising for "Start well, Live well and Age well" approach.

3. Sharing information to support population based analysis and segmentation

Questions you might be considering:

- What is our pattern of spend & activity across the health and care system and how might this enable us to change our local funding model?

- What is the existing (and future) capacity and demand across the system?

- What impact is an intervention having for a specified cohort?

- What are the patterns of engagement and service use by different residents, families and households – and how can we shift towards prevention?

Things to consider for sharing:

- What information is *really* needed – and who needs to see it (*does it really need information which identifies an individual?*)

- Consider what approach you are going to take to linking information in your local area.

Examples from local areas:

- **Kent and Leicestershire** have undertaken work using data across health and social care to inform STP and BCF (see LGA publication).

- **Health Foundation** have recently published an evaluation into care home interventions for residents.

And Finally…

Some key sources of information that you may find helpful….

- **Information Governance Alliance:** Authoritative source of advice and guidance about the rules on using and sharing information in health and care - https://digital.nhs.uk/information-governance-alliance

- **Information Sharing Centre of Excellence:** Focused on challenging the cultural barriers to information sharing - http://informationsharing.org.uk/

Connecting Care - An Information Governance perspective.

Helena Ashton – Information Governance Manager Connecting Care, South Central and West CSU.

Connecting Care partnership

Connecting Care is the Bristol, North Somerset and South Gloucestershire (BNSSG) programme that is delivering a shared local record to support local care pathways and improved patient care.
We are a diverse group of organisations united by a common purpose and a common vision.

Our common purpose is to serve the million people in Bristol, North Somerset and South Gloucestershire by meeting their need for health care and social care.

Our common vision is that, by sharing information securely and effectively, we will make a lasting contribution to the health, well-being and opportunity of our population.

Connecting Care has been identified as the mechanism to deliver the Local Digital Roadmap, supporting the STP (Sustainable Transformation Plan) across BNSSSG.

3 Acute Trusts

3 Community Providers

3 Local Authorites

1 Mental Health Trust

Out of Hours Provider

100 + GP Practices

Ambulance Service

3 Clinical Commissioning Groups

AHSN, NHS England, Central and South West CSU

Background / the start of Connecting Care

Connecting Care started off as a pilot in 2013

Before we started the pilot, we carried out a Privacy Impact Assessment (**PIA**) – using an external consultancy. The results of the PIA told us what work we needed to undertake before and during the pilot

As a result of the PIA, we set up a multi-organisational **IG Group** to manage the 'work plan' for information governance for the pilot. All Connecting Care partners were invited to be members

The IG group agreed an initial **work-plan** based on the recommendations in the PIA, and collectively monitored progress and ensured that we delivered

Background / the start of Connecting Care

- Some of the main elements in the initial **work-plan** based on the recommendations in the PIA were:
  - Creation of a **Data Sharing Agreement**
  - Creation of an **opt out** mechanism and supporting processes for patients (e.g. phone line for dealing with queries – PALS)
  - Legal **Partnership Agreement** signed by partners who started the pilot
  - Active input into designing aspects of the **system security**
  - Setting up appropriate **role based access**
  - Creating a suite of **audit reports**
  - Creating a set of IG **Training** materials
  - Setting up agreed processes for **user management**
- All of the above were worked on during the pilot and delivered. They continue to be part of the programme today
- You can see some of this work on our project website http://nww.connectingcare.swcsu.nhs.uk/ (if you have an N3 link)

The ICO have published helpful information on "Privacy by design"

Informing & consent – context within the programme

In line with the requirements of the Data Protection Act Connecting Care includes **informing** as a key part of our IG work.

We have a **legal duty to inform** our patients and citizens what we do with their information **Consent** is only one factor that governs whether we share information

Often our professionals do not need consent to share information, and another schedule condition can be relied on. **Consent is not necessarily required to deliver direct care where other applicable legal powers exist** including legal powers to support those that are vulnerable

Our informing has been wide-ranging –
- Some of the informing that we have done has been programme wide
- Some of the informing that we have done has been targeted to specific groups (e.g. students)
- Some of the informing that we have done has been in relation to a specific project
- **Informing is an on-going activity and not a one off**
- The next slides show the some of the informing activities we have undertaken in the Programmes and further informing required for one of the Connecting Care projects…

We do have some 'consent functions' built in within the system

Informing & consent – context within the programme

DPA Schedule 2/3 conditions that can be relied upon where applicable other than consent:
Schedule 2 (2,3,4,5,6) Schedule 3 (3,7,8)
Equivalent GDPR Articles: Article 6 and Article 9

ICO has advised:
"You should always be honest with the public and not lead them to believe that they can exercise choice over the collection and use of their personal information when in reality they cannot."
"Public authorities, employers and other organisations in a position of power over individuals should avoid relying on consent."

Products & materials

Here is a list of some of the products, materials (and processes) we have in place. Many of these date back to our pilot, but have been improved and continue today:

- Programme PIA
- PIA process for each new project
- An IG Group which meets monthly
- A Data Sharing Agreement (DSA) and processes for reviewing and changing the DSA when required
- A list of the legal powers to share information
- Patient 'Opt Out' process
- User Management process
- Role based access & security definitions
- System recording of reason for access / legitimate access

- Automated audit reports and processes
- IG Training materials
- IG Informing materials (which are continuing to evolve)
- IG Communications included in the weekly CC email / newsletter which goes out to all users of the system
- An annual rolling IG Work plan – agreed with the IG Group
- Links with PALS and HealthWatch for patient queries

We have worked with the ICO - they have assured and worked with us on some specific project work

Project example: Children's Social Care Project

- Our main **Leaflet** was updated, re-printed and redistributed and the **3 CCG websites were updated with new opt-out forms**
- The **Child Health Card** was re-written, re-printed and redistributed
- All three BNSSG **Local Authority websites** were updated and Local Authority **Information Sharing Leaflets** were updated
- We updated the **Connecting Care Data Sharing Agreement** (and this was re-signed by all of our Caldicott Guardians)
- We created recommendations and **approved content for use by others** (e.g. text for all Local Authorities to add to the privacy notice to be included with their Council Tax Notice Letter)
- 2 of the Local Authorities included an **article in their residents newsletter** advising residents of Connecting Care
- **Letters to maintained and academy schools** were sent out (school informing letters are given by schools to all new starters). We also provided a **template letter** to the Local Authorities, for them to provide to their **local Independent Schools**
- **Children's Centres Registration Forms** were updated

Future informing?

Next / now …

- The IG work-plan for 2017/18 includes a **review of the informing methods** used by Connecting Care partners. We plan to review what is being done and the programme will produce a set of recommendations for partners
- The IG work-plan for 2017/18 includes close monitoring of the upcoming legislative changes. We know that changes coming in the **General Data Protection Regulation** (GDPR) will necessitate changes to how we inform
- We plan / expect to carry out more informing either
  - in relation to specific projects *and*
  - in relation to specific rollout (e.g. so that service users from that organisation are informed)
- Informing is an **on-going activity** and not a one off. It is the responsibility of Connecting Care and all the partners

Future informing?

GDPR:

Article 14 – states what information the data controller shall provide to the data subject

The ICO has produced a Code of Practice on privacy notices https://ico.org.uk/for-organisations/guide-to-data-protection/privacy-notices-transparency-and-control/

NHS Digital publishes IGA guidance on information sharing

The IGA – in particular The GDPR Working Group aims to support NHS, social care and partner organisations in preparing for the requirements of the EU General Data Protection regulation when it comes in to force in May 2018. This will be provided by NHS England Data Sharing and Privacy, they will produce the resources and author many of the documents. NHS Digital GDPR link

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LPRES and the Information Sharing Gateway

Helen Speed, IG lead for LPRES

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Information Sharing Gateway & LPRES

The Information Sharing Gateway

The Information Sharing Gateway (ISG) has been developed by a sub-group of organisations in the Lancashire & Cumbria IG Group in order to improve and modernise the administration and risk assessment of information sharing in the public sector. It has been designed by IG specialists, for IG specialists, to support their IG reporting on data flows and information sharing (principally to IG Toolkit).

The development was funded by the LPRES programme in Lancashire, to support the use of the LPRES healthcare information exchange platform. It is a generic tool and is not 'tied' to use with LPRES, although it is developed with the needs of sharing via interoperable systems in mind. It is a 'next generation' Sharing Framework that will adequately support electronic information sharing across care boundaries in a way that current, paper-based systems cannot. The purpose of this system is to provide assurance that the information being shared, managed and processed will be done so in such a way that is Data Protection Act compliant. It centralises and shares key resources in a way that is accessible and transparent.

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INFORMATION GOVERNANCE

Acknowledgements

The following organisations helped develop the Information Sharing Gateway:

- Blackpool Council
- Cumbria Clinical Commissioning Group
- Cumbria Partnership NHS Foundation Trust
- Lancashire County Council
- Lancashire Teaching Hospitals
- Lancashire Constabulary
- North West Ambulance Service
- North West SIS
- University Hospitals of Morecambe Bay NHS Foundation Trust
- Wrightington Wigan and Leigh Foundation Trust

INFORMATION GOVERNANCE

Terms of use   Security   Privacy

Trust, based on assurance..

Data sharing agreements at a glance

Dashboard view

Summary

Number of Sponsored Organisations:	4
Number of Data Assets Registered:	6
Number of Organisations Sharing With:	15
Number of Data Sharing Summaries:	17
Number of Data Flows:	2

Data Sharing Matrix

Organisation	Flows	Assurance
University Hospitals of Wherever NHS Foundation Trust	2	Significant
Pink Potts	1	Significant
bluetree	2	Limited
WRIGHTINGTON, WIGAN & LEIGH NHS FOUNDATION TRUST	1	Significant
NORTH WEST AMBULANCE NHS TRUST	1	Significant
BLACKPOOL COUNCIL	1	Significant
New test sponsored centre	1	Significant
DALTON SQUARE PRACTICE	3	Significant
Green Tree	1	Significant
Test3	1	Limited
Anytown Nursing Home (Nelson) Ltd	2	Significant

Data Sharing Map
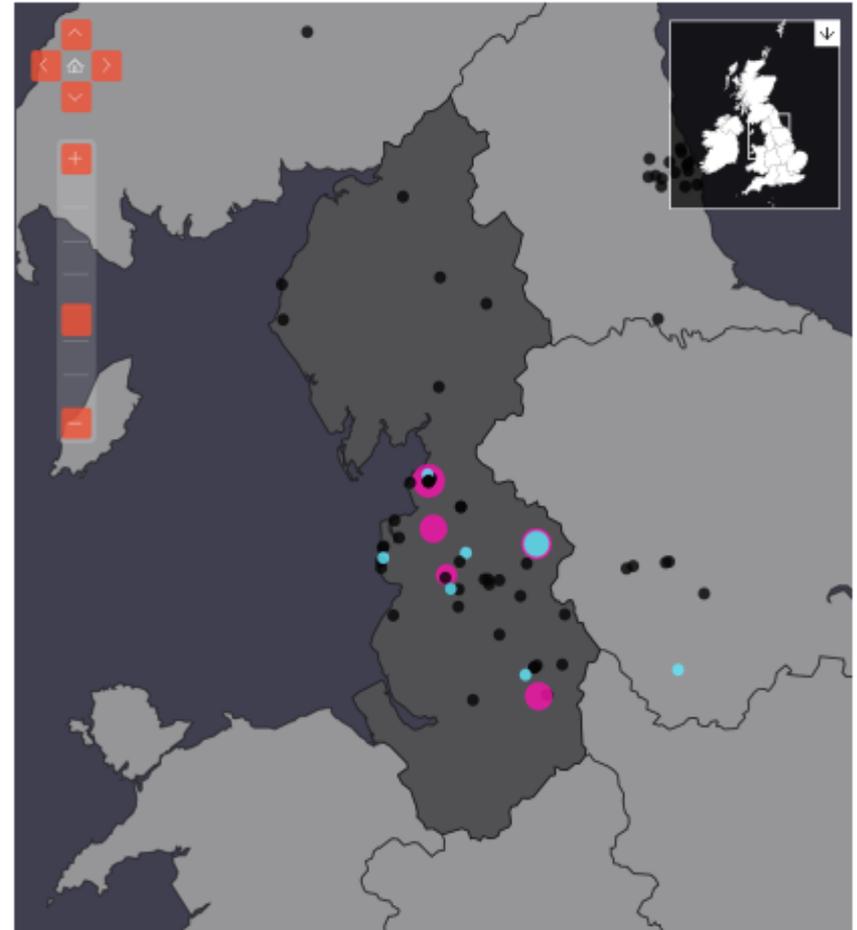
Current status, future plans

- >1000 organisations using ISG across the North, Midlands and South

- Users include Health organisations, LAs, charities, Police

- Financially sustainable despite deliberate low cost

- API under development to link with sharing platforms, due Aug 17

- Integrates additional layer of governance into electronic sharing

- Potential for dynamic sharing agreements based on risk

www.informationsharingsandpit.org.uk

Questions and Discussion