



# CONNECTING INFORMATION FOR THE HEALTH OF THE NATION

IF WE CAN SEE WHAT'S HAPPENING, WE CAN MAKE THINGS BETTER

# Introducing Care.data

- Our roles in the context of the Care.data programme
- Care.data & Pathfinders
- Patient communications & Information sharing
- Information collected, opting out and protecting patient information

# What is Care.data – your perception

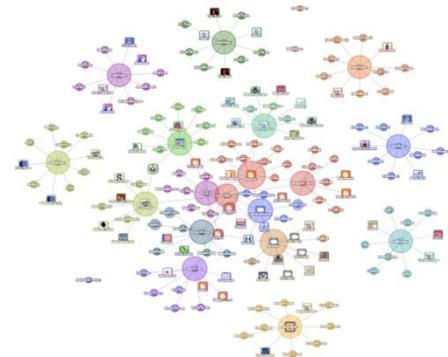


# What is Care.data?

- Care.data is a programme of work which will **bring together** health and social care information from a variety of healthcare settings such as GP practices, hospitals and care homes
- As a result, the NHS in England will be able to start joining the dots to see what is happening to patients as they travel through the healthcare system
- This information can only be used for the **purpose of supporting health and care**

# What is Care.data?

- The first phase of Care.data is for the Health & Social Care Information Centre to **collect information about the care provided by GP practices** across England and connect this with information already collected from hospitals



## Last 12 months in Care.Data

- Extensive listening exercise & 180 events across the country
- Agreed to approach Care.data in a phased manner
- In October 2014, 4 CCG areas agreed to take part in the Pathfinder stage of the Care.data programme
- To date, 122 Pathfinder GP practices have agreed to work with us
- Pathfinders cover a wide range of demographics to test the programme with different social groups

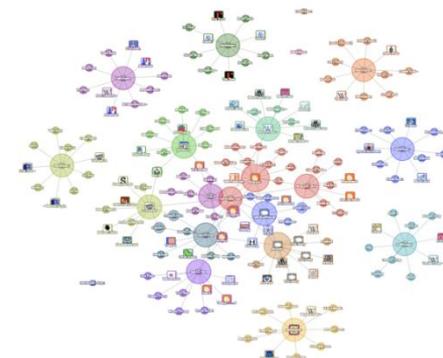
# About the pathfinder stage

- **Four CCG areas – Blackburn with Darwen, Somerset, West Hampshire, Leeds CCGs announced October 2014**
  - **November 2014 to date:** co-production of communications materials, GP practices signed up as pathfinders, developed local plans to support the pathfinder programme and (with Healthwatch) engaged with local special interest groups, patient groups and wider public to prepare for pathfinder programme to ‘go live’
  - **September / October 2015** start testing patient communications, registered patients in participating GP practices will receive a letter, Introductory booklet, opt-out form and pre-paid envelope in the post

# Why Blackburn with Darwen CCG?

- Sharing information for the health of the nation – agree that this is the way forward
- Caldicott Report review of 2012 and the 7th principle
- NHSE offered support and guidance – Governing Body
- The CCG and GPs are dedicated to improving services
- Patients care is our number one priority
- Social makeup of BwD of interest to the project
- GPs – proved that they want to be involved
- No data extraction unless National Data Guardian assurances met

# Questions so far?



# Patient Communications

- In September, each patient will receive a letter and Introductory booklet explaining about **information sharing in the NHS**:
  - What information the NHS collects and why
  - What's changing and why
  - The benefits of collecting information about the care provided in GP practices
  - Their choices and how patients can opt out
  - How patients can find out more
- Each letter will be accompanied by an opt out form and pre-paid envelope

# What is information sharing in the NHS?

- The NHS in England uses information for different purposes. The two main purposes are:
  - For direct care
  - For purposes beyond direct care

**Care.data is an example of a programme using information for purposes beyond direct care**

# Why does the NHS share information for purposes beyond direct care?

- Collecting information leads to improvements in the treatment and care of patients
- Gathering information about care provided across the nation, is expected to help:
  - diagnose serious conditions sooner
  - give everyone access to high quality care, whoever they are, wherever they live
  - understand which groups are most at risk of developing certain diseases and conditions

It will help the NHS in England provide better services and find more effective ways to prevent, treat and manage illness.

# Benefits to sharing information for purposes beyond direct care?

**Diagnosis of illnesses sooner, e.g. identifying trends/patterns in disease.**

An NHS Study of information, collected from hospitals showed that 1 in 4 diagnoses of bowel cancer are made following an emergency attendance at a hospital, which is associated with lower survival rates.

Once we gather information from GP Practices and link it with information from hospitals, we expect this will enable us to identify the reasons for the delays in the diagnoses of bowel cancer. Hopefully, this will save lives; as the earlier bowel cancer is detected and treated, the better someone's chance of survival.

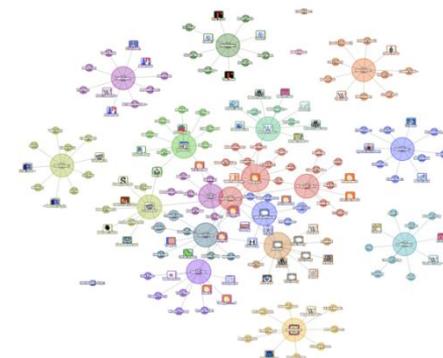
## Collecting information leads to improvements in the treatment and care of patients.

Chantal (14) has asthma. She has to see her doctor regularly for check-ups. She also has to go to A & E sometimes, when her asthma gets really bad.

Chantal's happy for information about her healthcare at the doctor and the hospital to be connected. Once it's connected, it's put together with information about thousands of other people with asthma. Scientists use information from doctors and hospitals together to spot when things are working well and when they are not.

Chantal's care doesn't change straight away because she's agreed that her information can be connected. But in the future, things might get better for her and lots of other people with asthma, when the information has been used to improve treatments and care.

# Questions so far?



# What information will be collected for the Care.data programme

## Information collected for the Care.data programme:

- ✓ NHS number, date of birth, gender, postcode and ethnicity.
- ✓ Information recorded by the GP in the previous four months about prescriptions, referrals and diagnoses - such as diabetes, heart disease, cancers, asthma
- ✓ Information is collected as codes only (e.g. code C10EL for diabetes)

## Information NOT collected for the Care.data programme:

- × Notes such as conversations between the GP and the patient
- × Name, full address or telephone number
- × Sexual orientation, marital status, employment, use of illegal substances, sexually transmitted infections, domestic violence, convictions, or terminations

# Protecting Patient Information

- The NHS is absolutely committed to keeping patient information safe and secure and is legally bound to protect it
- Confidentiality is an essential part of the relationship of trust between patients and doctors and the NHS takes every appropriate step to protect your privacy
- For example, the information that's collected can only be seen by people working under very strict legal and contractual controls

# Opting out

## It is every patients right to opt out

- If a patient does not want their GP information **to be used for purposes beyond direct care**, they can opt out
- Patients will receive an opt out form and a pre-paid envelope with the covering letter and introductory leaflet
- To opt out, patients can fill in the form and return it to their GP practice
- If a patient opts out, they are opting out of all data sharing for purposes beyond direct care, not just Care.data

# Who can use information collected for Care.data?

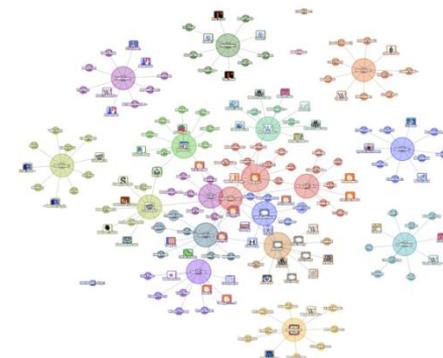
- During Pathfinders, the only organisations that can **apply** to access the information collected are:-
  - HSCIC
  - NHS England
  - Care Quality Commission
  - Public Health England
- Data will **never be shared** with organisations that wish to use it for purely commercial purposes e.g. insurance or direct marketing

# Who can use information collected for Care.data?

The HSCIC will only allow organisations outside of the NHS to use patient information **if it will benefit patient care**. These include:-

- **Universities**, for example researchers investigating new treatments
- **Companies**, such as commercial organisations using the information to help hospitals understand how well they're performing and pharmaceutical companies researching new drugs
- **Charities**, for instance those involved in medical research or providing care or support, such as Macmillan Cancer Support and Asthma UK

# Any Questions?



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# The BWD Pathfinder Approach

- Event held in November 2014, good support with twenty practices attending
- Twenty three out of twenty seven GP practices signed up to the Pathfinder, this is great, BwD leading the way
- Practices offered the opportunity to influence the GP Toolkit, patient facing materials
- Communications and Engagement Strategy – working document to support the Communications and engagement process in Blackburn

# GP Engagement

- GP training and education – visits to all practices (including branch surgeries) to ensure practice staff have the knowledge for the Pathfinder roll out
- GP Readiness Checklists sign off to ensure practices are fully informed and ready for the letters going out to patients
- On-going support for GP practices from BwD CCG, HSCIC and NHS England
- GP toolkit available to all practices for support and advice including FAQ's
- On-going Comms with practices including a Care.data regular update bulletins
- Attended local LMC, with an LMC Officer attending two GP engagement sessions

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# Patient Engagement

- Face to face engagement with patients and members of the public in various venues and settings including GP surgeries, hospitals patient groups, colleges, libraries, town centres & other public areas to commence in September
- Aim to engage with as many diverse communities within the area including GRT, BME, Carers, looked after children, people in nursing homes
- Care.data Information on CCG website and GP websites, twitter and Facebook
- NHS Choices, an online resource will host patient information in alternate languages and formats.
- Help available: GP Practice, Patient Information Helpline, text phone

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# Stakeholder Engagement

- Attending GP practice Patient Participation Group meetings
- Stakeholder letters sent out this week
- Attendance at stakeholder events
- Press releases, social media

In 2014 a quarter of the local Healthwatch network raised concerns over NHS England's attempts to explain the Care.data programme.

Residents throughout the country reported to Healthwatch that they felt unable to make an informed decision about whether to opt out of the programme.

Healthwatch England research indicates that many adults would be happy to donate their personal health data to help research if it was anonymous.

Healthwatch is currently neutral on the project, and our involvement at this stage is to enable local residents to make an informed decision.

Following the pathfinders Healthwatch England will review the reports from the 4 local Healthwatch involved, and continue to evaluate the program using their 10 principles of information sharing.



# 10 principles of information sharing

1. People can **access their own health and social Care data** and records to see what the system has collected and who they are sharing it with
2. Data is collected and shared in a manner that **does not unjustifiably compromise people's anonymity, safety or treatment.**
3. Collecting and sharing data **cannot be used to justify treating people on an unequal basis** with others.
4. Data collection and sharing will **not have impact on a person's wellbeing** by, for example, causing them additional anxiety or distress.
5. **People are provided with all the information they require** about Care.data or any other data sharing initiative, to make an informed choice about whether they want to opt in or out.
6. Frontline **professionals are upfront and honest about the benefits and dis-benefits** of opting in or out of Care.data or any other similar programme.
7. **If an opt out is offered, it must be a genuine option** (i.e. not overly burdensome) and people must be informed about the restrictions and limitations of this option.
8. **If someone raises a concern** or makes a complaint about the collection or sharing of their records, **this must be taken seriously** and staff must take immediate action to address the concern and, if it relates to a breach of confidentiality, put safeguards in place to restore the person's anonymity.
9. People should be **able to opt out of Care.data later if they change their mind** about the programme in future.
10. People should be **offered an opportunity to get involved in local decisions** at their GP surgeries about whether or not records are shared with the Care.data programme.

Healthwatch BwD has been commissioned to provide additional engagement in Blackburn with Darwen.

**Aim:** increase the awareness within the local population to ensure they're able to make an informed decision regarding sharing their data.

**Method:** Engage with members of the public who may not engage with local community groups or other services.

The engagement completed by Healthwatch BwD will be additional to the engagement from provider organisations, and will aim to reach additional communities and residents within the Borough.

### Community Access Points

- Asda
- Blackburn Job Centre
- Blackburn Market
- Darwen Leisure Centre
- Darwen Health Centre
- Barbara Castle Health Centre

### Targeted Engagement

- Asylum Seekers and Refugees
- Blackburn College



# How you can be involved?

- Check that your members and networks receive a letter through the post about information sharing
- Ensure that the people you work with have access to information about the changes, e.g. display posters, website
- Proactively share accessible materials, e.g. easy read, different languages

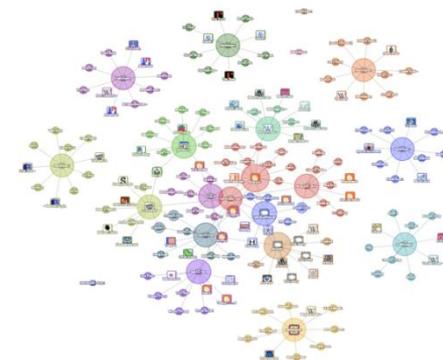
**Help local people to make an informed choice.**

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# Community Engagement Toolkit

- Information resource for Voluntary Community Sector organisations
- Developed based on feedback with stakeholders during the 'listening exercise'
- Contains information about specific groups, e.g. carers and how they are affected/supported
- Tells you what materials are available in what formats, languages and how you can access them
- Signposts you to more information, e.g. Carers Trust

# Any Questions?



# Facilitated discussion

