

Care.data benefits: Improving patient outcomes through greater understanding

Purpose of this document

The care.data programme has developed the following scenarios to illustrate some of the ways that information sharing can benefit health and care. These examples have been reviewed and endorsed by some of the programme's key stakeholders. They will help GPs and practice staff to explain in real terms the benefits that information sharing can bring.

1. Preventing disease

Scenario

Hazel had become confused over a period of a couple of days. She was seen by her GP who arranged an urgent investigation. Hazel was found to have damage to her kidneys which had developed rapidly and had caused them to stop working properly. She was admitted to hospital and the underlying cause was identified and treated. Hazel was discharged and returned home. Hazel's GP will now continue to monitor her kidney function to see whether she becomes one of the majority of people who recover with the same level of kidney function as they had before they became ill, or whether she develops long-term kidney failure.

Currently we do not know who is at risk of long-term kidney failure after an episode of kidney damage. Collecting and linking general practice data following discharge and hospital admission data will provide valuable insight into this complex condition, thereby helping us to improve care and outcomes.

Endorsed by:

Kidney Research

Scenario

Janice accepts the offer for shingles vaccination. She's keen to do all she can to avoid getting shingles because she remembers the long-term pain the condition had caused her mother.

Linking GP data and hospital data will allow us to understand more about the long-term effectiveness of vaccination programmes in preventing illness in different patient groups.

Endorsed by:

Public Health England

Scenario

A GP chats to her colleague about her morning surgery. They discover that they had both seen patients with severe flu-like illnesses. A similar conversation is taking place in a neighbouring surgery.

Collecting GP data will allow greater disease surveillance and any preventative measures to be taken at an earlier stage.

Endorsed by:

Public Health England

Scenario

Mrs Jones has moderate arthritis of her hip. It causes pain at times but she is able to cope and doesn't wish to have any further intervention at present. However, she knows that her hip may get worse as she gets older and would like to consider a hip replacement once she decides that it is significantly hindering her quality of life.

Mrs Jones needs a hip replacement service to be available to her at her time of need. Coded GP data will support greater understanding of the prevalence of conditions being managed in general practice, and allow more informed planning of future services.

Endorsed by:

NHS England

Scenario

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Endorsed by:

Public Health England

2. A reduction in health inequalities

Scenario

Amelia has learning disabilities but no physical condition. Her sister, Jo, doesn't have learning disabilities. Studies show that statistically Jo will live 15 years longer than Amelia. We don't understand why.

Collecting general practice data and linking it with hospital data will help us to understand more about why someone with learning disabilities has a higher chance of early death; and consequently how we can improve the care and outlook of those with learning disabilities. It will also allow us to better monitor inequalities in vulnerable groups.

Endorsed by:

NHS England
Public Health England

3. Earlier diagnosis

Scenario

Jim listens to his radio and learns that coughing for more than 3 weeks could be sign of cancer. He becomes concerned about his cough and he decides to see his GP. He is investigated and reassured that he doesn't have cancer.

Sally also hears the campaign and recognises that she has been coughing for months. However, she doesn't feel that the campaign applies to her. She decides not to waste her GP's time with what she believes to be a 'normal smoker's cough'. One year later she develops increasing shortness of breath and starts coughing up blood. She sees her GP; sadly her lung cancer has become incurable.

Collecting coded GP data and linking it with hospital data will help us to understand more about the effectiveness of cancer awareness campaigns and understand if there are groups of people who are at risk but the campaign doesn't target them sufficiently, or where key information is not fully understood.

Endorsed by:

Public Health England

4. A greater understanding of: how to use NHS funding most effectively; the changes needed in the NHS

Scenario

Collecting general practice data will allow better prevalence estimates of numbers who smoke, who are overweight and obese, have high alcohol consumption and low levels of physical activity. General practice data will also allow better prevalence estimates of risk

factors for serious disease, such as blood pressure and cholesterol. This will enable more informed public health intervention and service planning.

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Public Health England

5. More effective integrated pathways

Scenario

Mr Jones has diabetes, asthma, leg ulcers and heart disease. He was admitted with a minor infection that caused him to temporarily become confused and unsteady on his feet. On discharge, services rallied around him to manage all of his medical conditions and provide additional care. He was visited by his GP, carer, ulcer nurse, physiotherapist, occupational therapist, asthma nurse and someone to monitor his blood sugars. Mr Jones and his wife became quickly confused and distressed at the number of different people in and out of their house throughout the day. They closed the door to everyone apart from their GP whom they knew well.

Many people have more than one medical condition. At present our services tend to be focused on each condition rather than the whole person. However, more person-centred services are being planned and delivered. Having data relating to all episodes of care will allow us to understand more about the needs of people, rather than just the condition, and will help inform the re-design of how care is delivered.

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NHS England

6. Safer and more effective treatment

Scenario

Josh has a heart condition that gives him palpitations with shortness of breath and dizziness. He knows that his condition could cause sudden death. He is offered a new heart intervention which is thought to improve his condition. He understands that this is a new procedure and decides to proceed with it.

Linking general practice coded data and hospital data will undoubtedly help to understand more about the potential effects and benefits of new procedures like this. This will enable doctors to offer the best treatments to their patients and for patients in the future to have more information to help them make their decisions.

Endorsed by:

NICE

Scenario

Dave has diabetes, high blood pressure and had a heart attack 5 years ago. He takes 6 different medications to help keep him well. His recent blood test shows that his diabetes is not under control and so his GP prescribes additional diabetes medication. Dave hates taking tablets and declines this new medication, despite his GP explaining why it is important to his wellbeing to follow diabetes treatment guidelines. Dave feels that he can improve his diabetes control through diet and exercise. His GP reminds him that's exactly what he told him at his last review...

There are many guidelines to help ensure that patients are optimally treated and consequently have the best outcomes. We do not know how closely some of these guidelines are followed. Collecting GP data and linking it with hospital data will help us understand more about the factors that contribute to sub-optimal care, which in turn can help to identify interventions to address areas of weakness.

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