

Ref: care.data/Programme Board/Paper 11

Title: care.data – Draft and generic boiler plate example [NB very much work in progress and will be rewritten and contextualised once the creative approach had been agreed]

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Purpose: To provide the Programme Board with an example of a developing care.data boiler plate [a boiler plate is effectively a core narrative which forms the basis of all other supporting communications]

Background: Tim Kelsey has requested a care.data boiler plate. The attached draft is supplied. In parallel, the appointed care.data creative agency are analysing the insight generated by Ipsos Mori's research and the feedback supplied so far through the listening exercise. As such, their analysis will inform their proposed creative approach and this will be the basis from which products such as the attached boiler plate will be properly developed.

Key Points: The attached draft is not a completed product. It will be developed based upon recommendations from insight-generated creative agency work (see background above) to ensure resonance with key audiences. Once this creative approach is fully developed and agreed (in consultation with the programme board), the attached draft example will be rewritten and other communications collateral, segmented by audience groups, will be produced for the Board to consider.

Desired outcome(s): For the programme board to note that insight-generated communications and creative development work is underway

Circulation: Programme Board attendees

Core narrative – DRAFT 3 version B

Every patient should expect the highest quality care. One of the most powerful ways in which the NHS can be sure it is providing patients with the best possible care is by analysing detailed, high quality information about illnesses, treatments, and health outcomes.

This means we can see where things are working well but also see where there may be problems that need to be addressed. Using patient information to identify gaps in this way – whilst protecting everyone’s personal confidential data – is the purpose of care.data.

The NHS already has some of the best information systems in the world. Since the 1980s, we have been collecting information about every hospital admission, nationwide. This information is brought together at the Health and Social Care Information Centre, the body set up by Government to look after our health and care information, where it is anonymised.

However, there are significant gaps in the information on care provided outside hospitals, meaning that it is not possible to see a complete picture of the care that individuals receive across the health and care landscape. The care.data programme will mean that for the first time, the NHS will find out about the quality of care being provided in all GP practices, and how well GP practices and hospitals are working together to provide joined-up care for patients.

By studying this information in formats that identify conditions but not people, analysts can see what is happening in terms of diagnosis, treatment and quality of care across England.

For patients the real benefits of linking the data from GPs with that collected from hospitals will be to help the health service to

- diagnose some illnesses sooner, giving patients the best possible chance of recovery;
- ensure that patients receive the best treatment possible regardless of age, gender or where they live;
- support research into new treatments, drugs and medicines;
- ensure the highest standards of care and clinical safety are consistently met throughout the NHS and alert us where the standards of care being to drop;
- and help the NHS to spend more wisely, targeting money to plan and deliver the most needed services.

Everyone has a choice about taking part in the care.data programme. If anyone would prefer not to take part, they just need to contact their GP practice and say so. Their decision will be recorded on their records and their wishes will be respected.

Some examples [potentially to be woven into narrative – still work in progress as part of development of creative approach]

Helping the health service to diagnose illnesses earlier

Not all cancers are picked up early by a GP and one in four bowel cancer patients still present as emergencies. For almost all cancer types, you are less likely to survive if you present as an emergency.

Currently, through the Cancer Registry we are fortunate to have access to some data on cancer, which allows research^{1 2} to be carried out. care.data would enable access to information about the whole healthcare system which would provide a better understanding of

¹ <http://www.nature.com/bjc/journal/v110/n3/full/bjc2013734a.html>

² <http://www.hscic.gov.uk/catalogue/PUB12719>

all cancers, other illnesses and long term conditions. This would tell us what treatment works well, what doesn't and ultimately improve the healthcare that patients receive.

Using more comprehensive linked information through care.data we will be able to improve treatments, plan services more effectively, and help **ensure that critical conditions such as cancers are diagnosed as early as possible helping to save lives.**

Improving the quality of service and treatments

More than a million people with asthma across the UK are missing out on essential annual reviews to check whether they are on the right medicine and can use their inhalers properly. In addition the recent National Review of Asthma Deaths (NRAD)³ identified that prescribing errors were involved in nearly half (47%) of asthma deaths and that there was room for improvement in the care received by a shocking 83% of those who died.

Following some analysis into variations in healthcare⁴ an article by the BBC⁵ reported that analysis into hospital data showed that some areas had much higher levels of asthma related hospital admissions than others. Asthma UK wanted to investigate this further but because asthma is primarily treated in GP practices where there is no comprehensive dataset they were unable to do this with the data that was available.

In response, Asthma UK launched a campaign, asking asthma patients to fill in a short survey so that they could understand the problem better. This meant that even without access to GP data they could gather information on the treatment patients were receiving.

Care.data would mean charities such as Asthma UK have access to this linked hospital and GP practice data. This would mean they could fully understand and prove the variation in asthma treatment and ensure that services are improved so that unnecessary deaths are minimised.

³ <https://www.rcplondon.ac.uk/projects/national-review-asthma-deaths>

⁴ <http://www.rightcare.nhs.uk/index.php/atlas/respiratorydisease>

⁵ <http://www.bbc.co.uk/news/health-22383686>