

Ref: care.data/Programme Board/Paper 04

Title: care.data Core Public Facing Communication Materials

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Purpose: To provide the Programme Board with the final versions of the core public facing communication materials for approval, including a summary of the development process with the Pathfinders and the approval process to date.

Background: The implementation of the care.data Programme requires data extractions of people's health information, including identifiable data, from the GP practices that are participating in the Pathfinder stage. The fair processing obligations in the Data Protection Act 1998 requires the public to be informed that their data is to be shared, and that they have a choice to opt-out if they do not want their identifiable data to be shared. The core public facing communication materials have been developed to explain the way that the NHS shares data and the changes that are being introduced.

Key Points: The core public facing communication materials have been completed through the co-production process with the Advisory Group and the four Pathfinder areas and are ready for review and approval by the Programme Board.

Desired outcome(s): For the programme board to approve the core public facing communication materials at their meeting on 24 March 2015.

Circulation: Programme Board attendees

Date Presented to Programme Board: 24/03/2015

PURPOSE

1. To provide the Programme Board with a summary of the development process of the public facing communication materials. This includes the co-production stages with the Pathfinders and the approval process to date.
2. To seek the Programme Board's approval of the core public facing communication materials.

BACKGROUND

3. The implementation of the care.data Programme requires data extractions of people's health information, including identifiable data, from the GP practices that are participating in the Pathfinder stage. The fair processing obligations in the Data Protection Act 1998 requires the public to be informed that their data is to be shared, and that they have a choice to opt-out if they do not want their identifiable data to be shared.
4. The core public facing communication materials have been developed to explain the way that the NHS shares data and the changes that are being introduced. A creative agency was appointed to work on these materials and three creative concepts for the materials were tested with the public through qualitative research. The findings of this research were used to inform the further development of the final creative approach for the materials. This final creative approach was approved by the Programme Board in November 2014.
5. The core public facing communication materials that are being produced will be made available to the public within the four Pathfinder areas by:
 - **Direct mail:** a mailing will be sent to all patients over the age of 15 $\frac{3}{4}$ years registered with the participating GP practices in the Pathfinder areas. The mailing will include the envelope, patient letter, introduction booklet, opt-out form and a pre-paid return envelope.
 - **GP practices (and other NHS and stakeholder services):** communications materials will be made available to the public from GP practices and other public places within the pathfinder areas. These materials include: Posters, strut card, Introduction booklet and booklet dispensers.
 - **Patient Information Line:** Accessible versions of the materials will be produced for audiences with specific communication needs and will be available to order from the patient information line. These will be based on the core materials and include: large print version of the introduction booklet; British Sign Language video of the introduction content; audio version of the introduction content; and an Easy Read version of the introduction booklet.
 - **Online (NHS Choices):** Detailed information about data sharing within the NHS will be provided through the NHS Choices website, including the patient FAQs and electronic versions of the public facing materials are also being produced. These will be produced as navigable PDFs and will include: the introduction booklet; translated versions and the accessible versions of the booklet.
 - **Social media:** approved posts, emails and SMS texts will be provided to the Pathfinder teams to deploy through their owned social media accounts.

CO-PRODUCTION

6. The first drafts of each of the different core public facing communication materials were produced by the creative agency and were presented to the Pathfinder teams and the Advisory Group for feedback as part of the co-production process.
7. The Pathfinder Teams arranged local patient engagement activities, including setting up local Reference Groups, to provide public and patients' feedback on the materials. The feedback from the Pathfinder teams included the views of these local groups (see the Somerset Pathfinder Alternative Versions).
8. The core public facing communication materials have been through three stages of co-production where they have been shared with the Pathfinders and key national stakeholders for feedback. At each stage this feedback was captured through forms and a formal response was provided for each comment received.
9. The information below provides a summary of the three main stages of the co-production process and the final approvals stage. Please note that more versions of the materials were circulated as we received feedback.

Stage 1 (October 2014 – January 2015)

- First draft of core public facing communication materials discussed and reviewed by the Advisory Group.
- First draft of core public facing communication materials shared with the Pathfinder Teams for feedback.
- Feedback comments on the materials received from Department of Health, HSCIC, IIGOP, MedConfidential, BMA – GPC, and the four Pathfinder teams.
- Response to feedback comments provided to the Pathfinder teams.

Stage 2 (January – March 2015)

- Second draft of core public facing communication materials discussed and reviewed by the Advisory Group.
- Second draft of core public facing communication materials shared with the Pathfinder Teams for feedback.
- Feedback comments on the materials received from Department of Health, IIGOP, MedConfidential, BMA – GPC, and the four Pathfinder teams.
- Response to feedback comments provided to the Pathfinder teams.

Stage 3 (March 2015)

- Third draft of core public facing communication materials discussed and reviewed by the Advisory Group.
- Third draft of core public facing communication materials shared with the Pathfinder Teams for feedback.
- Feedback comments on the materials received from Department of Health, and IIGOP.
- Response to feedback comments provided to the Pathfinder teams.

Approval Process (March 2015)

- Materials approved by the four Pathfinder teams, subject to minor amendments.
- HSCIC approved the materials as Joint Data Controllers.
- NHS England as Joint Data Controllers.
- *SRO to approve.*
- *NHS England CEO to approve.*
- *HSCIC CEO to approve.*
- *Programme Board to approve.*

MATERIALS

10. The following public facing communication materials have been produced for use within the Pathfinder areas:

Patient Letter

11. The patient letter is intended to engage the recipient and encourage them to read the accompanying Introduction booklet. The letter provides the basic details of data sharing and the changes that the NHS is introducing for those that do not choose to read the booklet.
12. The letter is to be sent from NHS England, but will include localised copy specific to each Pathfinder area. This will be a short description of local data sharing initiatives to help explain the difference between data sharing for direct care and purposes beyond direct care.

Introduction Booklet

13. The introduction booklet is intended to provide people with an explanation as to the way that the NHS shares data for purposes beyond direct care and the changes that are to be introduced. It sets out the reasons why the change is needed, the main benefits, the measures being taken to ensure the security of the data and to protect people's privacy and details of how people can opt-out. It also directs people to sources of more detailed information.

Opt-out Form

14. The opt-out form will be sent within the patient mailing. It will enable patients to opt-out of having their identifiable data shared outside of their GP practice by filling in their details and posting it back (in the supplied freepost envelope) to their GP practice. The form also enables patients to request confirmation that their opt-out has been actioned by their GP Practice.
15. The opt-out form will be available on request from GP practices and will also be available to download from the NHS Choices website.

Envelope

16. The envelope will contain the patient letter / opt-out form and a copy of the Introduction booklet.

Posters

17. The posters have been designed to gain the attention of audiences and raise awareness of NHS data sharing and encourage people to seek further information. These are to be displayed on noticed boards in NHS services, primarily GP practices, where the public have access to further information, such as the introduction booklet.

Strut Card

18. The strut card has the same purpose as the posters, but is designed to be displayed on reception desks, where the public have access to further information, such as the introduction booklet.

Booklet Dispenser

19. The booklet dispenser has been created to contain copies of the Introduction booklet for people to pick up and read. The dispenser is intended to be displayed in a prominent position in the reception area of NHS services, primarily GP practices.

SOMERSET PATHFINDER ALTERNATIVE VERSIONS

20. During the co-production process the Reference Group set up by the Somerset Pathfinder expressed concerns with the creative approach for the core public facing communications materials. The group proposed testing an alternate creative approach within their area.

21. It was agreed that we would commission the creative agency to produce alternate designs to test within the Somerset Pathfinder area. The agency created a new design for the Introduction Booklet cover, the Posters, and the Strut Card. These alternate designs were provided to the Somerset Pathfinder on 5th March 2015 and were approved by the Reference Group at their meeting on 17th March.

NEXT STEPS

22. The Programme Board are asked to note the development stages that the core public facing communication materials have completed.

23. The Programme Board are asked to approve the core public facing communication materials for use within the Pathfinder areas.

24. The creative agency will complete the approval of the materials by the Plain English Campaign and ensure they achieve the crystal mark.

25. The accessible versions of the core materials will be produced by specialist agencies contracted by the creative agency and supplied to the Pathfinder areas and the patient information line.

26. The materials will be printed and supplied to the Pathfinder areas for distribution and to the appointed mailing agency to arrange the patient mailing as per the agreed programme schedule.