



Care.data Survey Report

Prepared by Healthwatch Devon: March 2014

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Acknowledgments

This report has been produced by Healthwatch Devon - The independent consumer champion for health and social care in Devon. Healthwatch Devon would like to thank everyone who took the time to respond to this survey, as well as the organisations and individuals who helped to promote the survey through their own networks.

Registered Charity Number: 1155202 Healthwatch Devon CIO

Introduction

On 6th January 2014, NHS England announced that it would be distributing leaflets to all households in England, which would explain the benefits of sharing the information that is collected about them in relation to the care they receive.¹

The '*Better Information Means Better Care*' leaflet² was designed to inform patients and the public that sharing the information that is held about their care could help the NHS to ensure that the quality and safety of services was consistent across the country. It could also highlight areas where further research or investment might be required, for certain conditions or diseases.

The leaflet explained that people could opt-out of the scheme if they did not want their medical information shared, by contacting their GP. It also provided details of the information line that had been set up for people to use if they had any questions or concerns about the new scheme.

After the scheme was announced, concerns were raised almost immediately from members of the public as well as GPs³, who were worried about where this information would be shared and with which organisations. Many local Healthwatch organisations escalated the concerns that they were hearing to Healthwatch England.

In February, Healthwatch England wrote to NHS England Chief Executive Sir David Nicholson to urge him not to rush this initiative through, with a request to delay the scheme until NHS England was able to explain in plain English exactly how it would work and why it would be of benefit to patients.

Healthwatch England and local Healthwatches have welcomed NHS England's subsequent decision to defer the roll out of the scheme, known as *care.data*. The scheme has now been postponed until Autumn 2014.

Healthwatch Devon initiated a rapid response survey through February 2014, as public and professional concerns about the scheme were growing. The speed at which the issue developed meant that our survey generated a relatively small sample of evidence to review. However our findings echo the message that has been raised at the national level, particularly around the effectiveness of the public awareness campaign and the lack of information provided by NHS England to enable patients to make an informed choice about the scheme.

¹ <http://www.england.nhs.uk/2014/01/06/better-info-better-care/>

² <http://www.england.nhs.uk/wp-content/uploads/2014/01/cd-leaflet-01-14.pdf>

³ http://www.pulsetoday.co.uk/your-practice/practice-topics/it/over-40-of-gps-intend-to-opt-themselves-out-of-caredata-scheme/20005648.article#.UyPyRPI_sWI

Key findings from our survey

- 42% of respondents told us that they had not received an explanatory leaflet that the NHS had sent to every household. A third of people who *had* seen the leaflet were not sure that they understood it
- 69% of respondents said they would not give permission for their GP to share their medical information as part of the care.data scheme. 15% were not sure if they would be opting out of the scheme
- Considerable concern was expressed by respondents about the lack of sufficient, clear information to enable them to make a choice about remaining with the scheme or opting out
- Many gave preference to the approach of opting into the scheme rather than opting out
- One fifth of respondents expressed concern in relation to the way the NHS national public awareness campaign was conducted
- 19% of those who commented on the scheme, acknowledged both the benefits and principles of sharing information, in particular for the purposes of improving the quality of care given to patients. However, the majority of these were still not convinced by the scheme and did not feel confident enough to remain with it and stated that they would be opting out
- The main areas of concern raised by respondents include; a lack of trust around data being identifiable and not knowing exactly who will have access to their information
- Some people expressed concern that big government IT programmes have a bad track record with data security. Others were worried that their personal medical records will be sold to private companies

What we did

At the beginning of February 2014, Healthwatch Devon started to hear from people who had not received their leaflet on the care.data scheme. Devon Senior Voice, a key service delivery partner to Healthwatch Devon, set up public meetings for people to share their views and concerns. At the same time, Healthwatch Devon wanted to ask people:

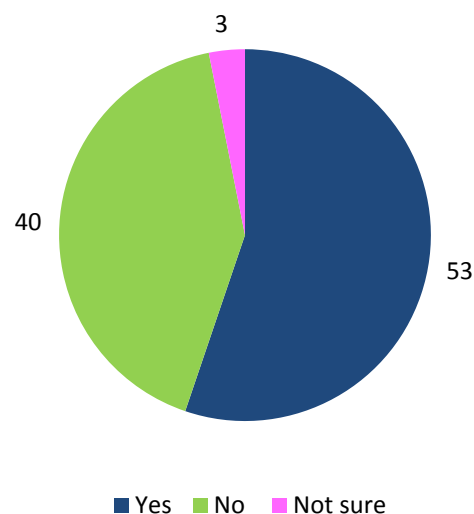
- whether they had received the leaflet
- if so, whether they understood it
- if they are would consent to their medical data being shared as part of the care.data scheme.

Healthwatch Devon carried out a short, online survey to ask the public the three questions listed above. The survey ran for 5 weeks. In total, 97 surveys were completed and 83 people provided further feedback by sharing their thoughts in the comment box. Analysis of the feedback received is included throughout this report.

Survey Results

Question 1: Have you received the leaflet: *Better Information Means Better Care?*

- 96 people responded to this question
- Over half (55%) of those who responded said yes, they had received the leaflet
- Just under half (42%) had not received the leaflet
- A small amount, (3%) were not sure whether they had received the leaflet.



The NHS public awareness campaign

20 people commented about the way in which NHS England had communicated the information about care.data to the public. All comments were negative. Some people were aware that a leaflet was due to arrive and therefore were looking out for it. Of those that had received the leaflet, comments included; *“leaflet arrives with a lot of junk mail and is very poorly explained”* and *“Royal mail delivered the leaflet wrapped up in a larger leaflet about Hillary's Blinds and covered up by several other leaflets, so lots of people may have never seen the NHS leaflet.....The leaflet should have been individually posted to each home.”*

7 people commented in relation to not having received the leaflet.

One person said they had *“checked the post since January every day including junk mail - no leaflet”* another *“Definitely haven't received the leaflet”* and asked *“Why is this not publicised more widely?”* Another mentioned the *“lack of media coverage to highlight this taking place”* One person said that *“If it wasn't for Healthwatch newsletter we wouldn't know that we should have had a letter and so wouldn't have been able to tell our GP not to pass on our data.”*

Several people expressed concern that many people may not even be aware of the care.data scheme and therefore would unintentionally remain opted into the scheme. One person wrote:

“I am most concerned that the greater population is unaware that this is taking place. I went into my Surgery today and had to wait while opting out forms were printed, this leads me to believe that they really do not expect many people to take this up.”

Another said: *“This seems to be misinformation on a massive scale, with an opt-out option which most people will probably not even see let alone act on.”*

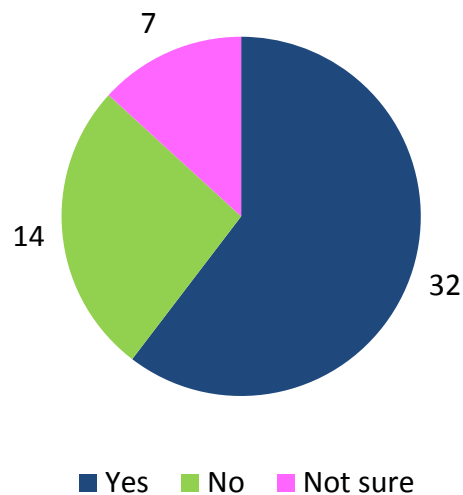
One person highlighted that *“there has been very little publicity nationally about this until last week-only 2 months before the deadline. Yet they have been discussing how*

to convince us not to opt-out for well over a year. Most people will choose to do nothing or will not be aware of it at all despite the leaflet.”

One person had written to their GP practice asking for their stance on it and stating that if they had not heard from them soon they would opt-out of the scheme. However, they had not received a reply.

Question 2: If yes, did it make sense to you?

- 53 people responded to this question
- 60% respondents said the leaflet made sense
- Just over a quarter (26%) of respondents said the leaflet did not make sense
- 13% of respondents were not sure either way.



The information leaflet: Better information means better care

With more than a quarter of people stating the leaflet did not make sense to them, most of the comments referred to a lack of clarity as to what data would be shared and with whom. The majority of those who commented about the leaflet itself, referred to a lack of clear information, suggesting that people did not feel able to make an informed choice about whether to remain with the scheme or to opt-out.

Insufficient information to enable people to make an informed choice

One person called for an “immediate delay” to the uploading of patient records “to allow sufficient time for appropriate consultation and to ensure that ALL patients are able to make a decision re their personal information based upon the full facts.”

Another said “Having read the leaflet here, it is quite vague and not enough to make an informed decision.”

Many people indicated a lack of clarity as to how and with whom their information would be shared. Many called for more detailed information so that they could make a measured decision and more detail as to “exactly who will be given access to the data.”

One person stated that the leaflet is “talking about my records being shared with “other organisations” which are unspecified, for the purposes of research. Again what is meant by research is unspecified. This is thus a blanket permission to share my personal health records with private companies.” Another referred to the leaflet as being “deliberately vague. Patients have a right to know exactly which categories of users will be able to access the data and know that this cannot change without their explicit permission.”

One person had spoken to 16 other people about the information leaflet *“only three said that they had received the leaflet and the remainder had no/minimal idea of the data harvesting process and/or how the information will be used”*

Comparisons to the sharing of Summary Care Records - Your emergency care summary

Some people acknowledged the fact that the NHS already shares patient medical information with other services within the NHS and therefore expressed concern that this is not explained in the leaflet.

There were a number of comments that referred to the medical information that is shared with other medical professionals, known as your *summary care record*⁴. There seemed to be some confusion as to whether by opting out of care.data, you would also be opting out of this system too. One person said it was *“not clear whether if you say no, the data is available to emergency services”* another said that it was *“not clear what would happen if had an accident or were ill and unconscious in a place other than your GP surgery, whether a hospital or ambulance crew would be able to access data - allergies to drugs etc.”*

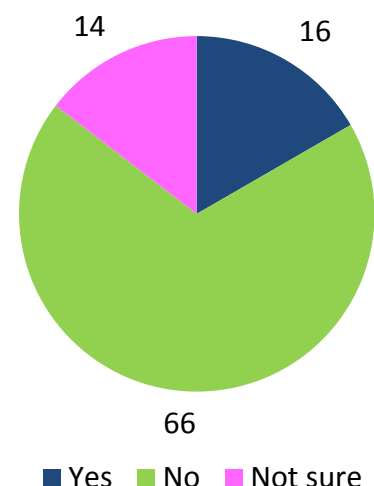
One respondent described the confusion that the publicity had caused: *“people are writing to their GPs saying they don't want their information shared and GPs are then having to go back to them asking if they want to opt out of SCR (summary care record)... as well as care.data.”*

Some people acknowledged that care.data is a separate scheme to the summary care record scheme. One said;

“Having telephoned our GP surgery I established that we could advise them that we were happy for our medical data to be shared with other health care professionals - e.g. hospitals for emergency care etc. but we did not want our personal data entered into the national database”

Question 3: Will you be letting your GP pass your personal medical records to care.data?

- 96 people responded to this question
- 69%, nearly three quarters of respondents, said they would not be letting their GP pass their medical information on
- 17% of respondents said they would consent to their data being shared
- 15% were not sure whether to allow their GP to pass on their medical data



⁴ <http://www.nhscarerecords.nhs.uk/>

A high number of respondents ticked 'no' to letting their GP pass on their medical data. Even some who made positive comments about the benefits of sharing data for research purposes, still said they would be opting out of the scheme, with the main reasons being:

- A lack of trust around the misuse of data
- Concerns about data being identifiable
- A lack of adequate information to enable people to make an informed choice.

A lack of trust around misuse of data

Nearly one third of people who completed the survey expressed their concerns over what might happen to their information and many suggest that much more clarification and reassurance from NHS England is needed, so that people have confidence in the scheme and feel that their information is being used in the right way, by the right people.

A number of comments are focussed around mistrust. Examples include;

"I wish I had more information.....but I don't trust the government so probably I will say no",

"I don't trust that the information will not be used to exploit people with illness and ailments from commercial companies out for profit."

"I have little faith in the government's ability to keep this data safe and not identifiable. I think this information will eventually become available to insurance companies and also to private providers amongst others as over time the general public forgets that access has been granted"

Some people highlighted the human error factor in data management, referring to data not being encrypted, medical record errors, or data going missing as key risks for concern.

"The recent history of the use of personal information is that whatever safeguards are set in place someone, somewhere will eventually find a way around the protection scheme and/or someone will lose, or have stolen, their laptop on which the information is stored."

Others fear that the technology will not be robust enough to manage the huge amount of data that is entered into it, so that it remains safe and secure from the misuse of data for commercial gain or from external hacking into the system.

Several people expressed concern that the data would be made available to private sector companies, such as pharmaceutical or insurance companies and many people seem unconvinced that the data will remain secure in the future, and fear that there may not be substantial mechanisms in place to safeguard the data from being released to other 'interested' companies.

"If the data was to only be used by the NHS I wouldn't have a problem, but to give it away to private firms is going down a dangerous path."

“What if we suddenly find that we cannot get travel insurance, for instance, or are refused help in the future?”

With regards to being accountable to the public, there was a suggestion made for a *“highly visible and effective 'office of public scrutiny”* that individual members of the public could interact with, that would *“go a long way to 'policing' care.data properly.”*

Concerns about data being identifiable

A fifth of respondents expressed their concern that the data could be identifiable and that if this was the case, they did not want their data shared. People feared that it could be easy to *“cross reference data from other sources”* to obtain your profile. Those who feared that anonymity would be compromised, were seeking clarity as to how confidentiality will be protected and retained.

“Patient confidentiality should be paramount. Unidentifiable statistics would serve the medical purposes for which this scheme is supposed to be being set up.”

Acknowledging the benefits of the care.data scheme

19% of those who commented on the scheme, acknowledged both the benefits and principles of sharing information, in particular for the purposes of improving the quality of care given to patients.

Some people expressed surprise that this had not happened sooner, stating that without having that bigger dataset *“little informed evidence of what-works, what-doesn't, through to what-causes will ever be formulated”*

Those who were happy to allow their GP to share their data provided reasons such as: *“It may mean that there is an end to the never-ending retelling of my story to one professional after another. It may lead to a situation where it doesn't matter where in the country I am the health professional caring for me will have my record to work with and that can only help keep me safer”*

And *“I want the whole world to benefit from my medical journey. I don't care who sees what and if it helps future sufferers no one will be more pleased than I am”*

One person raised the point that if the information is available to other organisations, then *“the patient should also have online access to their own health data.”*

Several people acknowledge the positive value that large data sets provide to research and the development of future healthcare. One pointed out that the *“media spin has not made this any easier.”* One person discussed the benefits of one overall computer system that other organisations could access parts of *“Think of the advantage of the DWP, NHS, Social Services and Police knowing that the person they are dealing with has dementia etc.”*

As one person pointed out, the sharing of information between health and social care staff has been part of a very active agenda in Devon. The Single Assessment Process is based on the fact that many people already assume that information about them is

shared between professions. Other people said: *"Don't you people talk to one another?"* This is an extension to that *"sharing on a personal level"* to one where data can be used for planning as well as looking at trends in how interventions have worked.

Consent to Opt In

More than 10% of those who commented suggested that there should be an 'opt in' process for patients, rather than the option to opt-out. One said, *"Patients should be asked to opt in to the system, not have to opt-out, together with the assumption that if no response is received it equates to consent. Hardly complies with Freedom of information/Data Protection principles."* Another said *"Patients should not be on this database, unless they ask to be put on it!"*

"This should definitely be an opt-in rather than an opt-out decision. What happened about the Government promise "No decision about me without me"?"

Opt-out process

Several people raised the question as to what the time limit was for opting out of the scheme. The information leaflet states that "you can change your mind at any time" but some readers have either not understood this, or do not trust that the process is truly open-ended, without time limit.

Some people commented on the variations in what they needed to do to opt-out of the scheme. Some GP's are requesting written confirmation from patients, while others take the opt-out request by telephone. One person shared their experience of their attempt to opt-out of the scheme: *"It tells you to contact your GP surgery. I did so and was told (by a very helpful receptionist) that you need to visit a website, download a form, fill it in and drop it off at the surgery. Not such an easy task for many people, who probably won't bother as it's too much hassle."*

Others remain unconvinced about the opt-out process and the lack of clear information that the NHS has provided to patients as to what they are opting out of. *"NHS info has deliberately withheld details of opt-out codes and not supplied public with an easy form to fill in"* and *"I think that even if you tick both opt-out options you WILL still have your data uploaded and cannot refuse- think you are opting out of 'red' data but 'amber' and 'green' data will still go to HSCIC. It is scandalous that information that patients thought was private can be made public."*

GP Responsibility

Several people expressed unease at having to contact their GP to opt-out of the care.data scheme. One referred to it as a *"liability dumped on GPs"*, another felt it should not be their responsibility with *"many of them not being in favour of the scheme themselves"*. Several people were concerned that it was creating more work for GPs.

Use of public money

Some people felt that the money being spent on the care.data scheme could be better spent on local *"poorly funded"* services, e.g. mental health services or on *"more doctors and nurses."*

Next steps

The care.data scheme has its supporters and its detractors. But for matters such as this, Healthwatch does not take sides. For us, the key issue at stake is "informed choice".

Healthwatch England's vision for rights in health and social care includes the belief that service users have a right to information. Our position is that if the NHS collects any confidential information about you, it should be kept safe and secure. You should be told how information about you might be used, and you should be able to request that your confidential information is not used beyond your own care and treatment.

So our immediate next step is to continue informing people about care.data - raising awareness of the scheme, and of patients' views, by sharing this report with Healthwatch England and Health Service Commissioners in Devon. The report will also be made available to the public on our website www.healthwatchdevon.co.uk

Following that, it is important, for a national initiative like the care.data scheme, that Healthwatch Devon co-ordinates its activity with other local Healthwatches and with our umbrella body, Healthwatch England. So in this instance, we will take a lead from Healthwatch England, which will be actively seeking to influence NHS England's attempts to produce better and more effective information for the relaunch of care.data in the autumn.

In the meantime, Healthwatch Devon will continue to listen and capture any further comments it receives about the care.data scheme and these will be shared with Healthwatch England and local commissioners on an ongoing basis.