

Meeting between NHS Connecting for Health and the Office of the Information Commissioner

February 3, 2010 11 am to 1pm

Tavistock House, London

Agenda

ICO

Jonathan Bamford
Ian Miller

NHS CFH

Marlene Winfield
Gillian Braunold
Richard Clay
Tim Davis
Mary Barber's team dialing in?

1. Welcome and introductions
2. Review note and actions from last meeting and arrangements for note of this meeting
3. [REDACTED]
• [REDACTED]
4. SCR update, including Release 2 issues - Gillian Braunold/ Richard Clay
5. [REDACTED]
6. [REDACTED]
7. [REDACTED]
8. [REDACTED]
9. Enquiry re policing content of Clinician sealed envelope
10. Enquiry from NE Strategic HA re mailings for SCR roll-out.
11. Validating and auditing NHS personnel against DVLA records.
12. Review actions from this meeting
13. AOB

Meeting between NHS Connecting for Health and the Information Commissioner's Office

February 3, 2010
Tavistock House, London

ICO

Ian Miller
Jonathan Bamford

NHS CFH

Marlene Winfield
Phil Walker
Gillian Braunold
Richard Clay
David Gray

Actions from previous meeting (June 4th)

Carried forward:

1. NHS CFH to brief ICO on criteria for deciding if a record should have been used in care.
2. Gillian Braunold to send case studies of impact of SCR as they become available.
3. ICO to involve regulation manager to explore possibility of an adequacy audit of some of NHS CFH's activities – will await appointment of new head of audit


Closed or removed:

1. Richard Clay to brief SCR team about need for distance between supervisor and administrator in SCR back office. Completed.
2. Review plans for flag migration. NHS CFH will update ICO when relevant.
3. Clinical back office to be put on future agendas. Closed. NHS CFH will update ICO when relevant.

[REDACTED]

[REDACTED]

[REDACTED]



Summary Care Record update – Richard Clay/ Gillian Braunold

2m people have been written to and 1m SCR's have been created. There will be an acceleration in the first quarter of this calendar year with the intention of mailing out 20m letters. This scale enables a more ambitious campaign around the mailing. While there may be a time lag between getting the letter and having an SCR, people will be able to opt out as soon as they have the letter.

New patients will be able to opt out at the time of registration and, if unsure, can request a recall. Or the practice can identify new patients and send them the SCR letter initially and then make it part of registration later on.

The SCR Programme is in the process of requesting that Sheila Shribman, the National Clinical Director for Children, Young People and Maternity, advises GPs of their responsibility to act in the best interests of the child when parents/guardians want to opt a child out of the SCR. GPs must satisfy themselves by checking the records that there are no risk factors for the child. The ICO advised that these decisions must be made on a case by case basis.

There have been two requests for physical deletion so far, involving five patient records. Guidance has been prepared for staff. Audit logs have been adapted to help in making decisions about whether the record has been used in care.

Some GPs are opting all of their patients out en masse and this raises issues of fairness, inadequate notification and rendering data inadequate for its purpose.

ACTION: NHS CFH WILL SEEK A VIEW FROM THE ICO ABOUT GPS WHO OPT ALL OF THEIR PATIENTS OUT WITHOUT CONSULTING THEM

ACTION: THE ICO WILL GIVE NHS CFH A VIEW ON THE LAWFULNESS OF GPS OPTING THEIR PATIENTS OUT EN MASSE WITHOUT CONSULTING THEM FIRST.

Summary Care Record – Addition of Release 2 content to the SCR – Richard Clay/Gillian Braunold

Richard Clay presented a paper on arrangements for informing patients when discharge summaries and other documents are added to SCR's from care given in places other than the GP surgery. In some cases, this will be the point when the SCR is created, eg. for people not registered with a GP.

Staff will be advised of the importance of explaining to all patients at the point of care that information will be sent to the SCR relating to that care episode, and that an SCR could be created (if the patient does not currently have an SCR).

All patients will be given the opportunity not to add information relating to that care event to their SCR. In the case where the patient did not have an SCR already, and they chose not to add the information relating to that care episode to their SCR, an SCR would not be created at that point. If they already had an SCR but didn't realise it and didn't want one, they would be given information about how to opt out..

- The ICO advised that at the point of creation of an SCR, the patient must be informed and have the ability to opt out, whether at the GP surgery or elsewhere in the NHS.
- THE ICO said that ideally staff in secondary care should be able to tell if someone already had an SCR so that they could concentrate explanations on those who have not been informed previously.

ACTION: THE ICO WILL CONSIDER THE PAPER FURTHER.

ACTION: RICHARD CLAY WILL FOLLOW UP WITH THE ICO.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

- [REDACTED]



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DVLA verification as part of HealthSpace Registration – Ian Miller

Ian Miller clarified that the question related to patients rather than NHS staff. It is proposed that one form of identification patients could provide for online registration for an advanced HealthSpace account is a driving license that could be verified by the DVLA. It was not clear whether the terms of the data collection by the DVLA would allow it to process data for this purpose. If not, processing would be unlawful even if it was fair because the patient had consented.

- ICO advised that if processing is lawful, the applicant has choice of a range of options, and the applicant consents, the level of risk is acceptable.
- ICO advised that the DVLA verification itself is not a strong identifier. NHS CFH made clear that more than one identifier would be required.

ACTION: PHIL WALKER WILL PURSUE WITH THE DVLA WHETHER PROCESSING THEIR DATA TO IDENTIFY HEALTHSPACE APPLICANTS WOULD BE LAWFUL.

Local NHS approaches to the ICO when something has been decided nationally – ICO

The ICO would like steps to be taken to minimise the number of organisations asking them the same question when they have given a clear decision to NHS CFH, for example the requirement to mail named individuals in a public information campaign for the SCR rather than use a household mail drop. NHS CFH emphasised that while they can advise the local NHS of decisions, some will still want to seek further advice from the ICO. However, steps might be taken to minimise those who felt the need to consult the ICO.

ACTION: THE ICO WILL CONSIDER PUTTING KEY DECISIONS ON THEIR WEBSITE

ACTION: NHS CFH WILL CONSIDER OTHER ACTIONS SUCH AS COMMUNICATING DECISIONS BETTER TO SHA CIOS.

ACTION: MARLENE WINFIELD TO ADD AGENDA ITEM TO MEETINGS: COMMUNICATION ISSUES ARISING

There was no other business.

Summary Care Record: Addition of Release 2 Content to the SCR

ICO Briefing Paper, January 2010

Purpose

1. To outline the approach for adding Release 2 (non-GP information) to the Summary Care Record.

Background

1. Since 2006, patients have a choice on whether to have a Summary Care Record (SCR) or not. Prior to SCR being introduced at a practice, all adult patients registered at a GP practice are written to. Patients who do not wish to have a SCR can express this preference, and no SCR will be created for them.
2. This paper outlines the approach for adding Release 2 information to the SCR. Any information added to a patient's SCR is still subject to all the controls listed in the Care Record Guarantee (Smartcard access, establishing Legitimate Relationships etc) plus Permission to View the patient's SCR.
3. Currently the only content within the SCR is a GP Summary, sourced from the records held by the patient's registered GP. Initially this comprises a core data set of allergies, adverse reactions and patient medications which can be enriched later on with other information held in the GP record. This GP summary is updated as new information is added to the patient record.
4. In addition to the GP Summary, a patient's SCR can include information generated from other care settings. This is termed "SCR Release 2 information". Release 2 information will be generated from non-GP care settings, including secondary or unscheduled care settings.
5. Release 2 information is episode based meaning a separate summary document will be generated for each episode of care and added to the patient's SCR. In the future as more systems supply information to the SCR, the SCR of a patient may comprise a single, current GP Summary, any preferences expressed by the patient through HealthSpace and a collection of other summaries/discharge letters relating to individual episodes of care that have taken place in "Release 2" care settings.

6. The clinical content of SCR Release 2 that has been endorsed by the SCR Programme Board and the National Clinical Reference Panel (which is responsible for the clinical content of the SCR) includes: Accident and Emergency (A&E) discharge summaries, Out of Hours encounters, Out Patient Discharge Letters and Inpatient Appointment letters.
7. Patients do not need to have a GP Summary before other Release 2 information can be added to their SCR. This is because not all patients have a registered GP and this would exclude those patients from the benefits that SCR will bring.
8. The SCR Programme is currently working with a supplier of information systems to Accident and Emergency Departments to develop their system to generate electronic discharge summaries to the SCR for episodes of care which have taken place in A&E. It is currently planned that this capability will go live in two pilot trusts from May 2010.

SCR Release 2 Approach

9. Prior to an organisation commencing to add Release 2 information to the SCR a Public Information Programme will not be undertaken for Release 2 content, as is currently done for GP contribution to the SCR, involving a personalised letter to all registered patients where the local GP practices have not have gone live with GP contribution (SCR Release 1). This is because:
 - Acute and unscheduled care settings do not have “registered patients”;
 - Not all patients who may use the acute and unscheduled care setting are registered with a GP; and,
 - The patients using the acute and unscheduled care setting could come from any geographical location.
10. The design for Release 2 assumes that any system sending Release 2 content to the SCR must check the patient’s SCR consent preference on the National Spine, to check that the patient has not dissented to having a SCR. This ensures that no patient has information added to their SCR that they do not wish to be added.
11. There will be some patients who attend Release 2 care settings who have not been subject to the SCR Public Information Programme (e.g. patients not registered with a GP or in those areas where the SCR public information programme has not been completed). As an additional safeguard, before Release 2 content can be added to a patient’s SCR, the patient will be made aware that the information relating to this care episode will be sent the SCR. The responsibility to ensure the patient is made aware of this will rest with the sending

organisation. If the patient has concerns over this, information relating to that episode of care will not be sent to the SCR.

12. Discharging this responsibility requires a discussion to have taken place with the patient during the episode of care, informing the patient that information relating to this encounter will be passed to the SCR. This will need to be explained plainly and clearly to patients so that they understand the choice they are presented with. This will be supported by appropriate information and communication materials, which are being developed with the pilot trusts.
13. The SCR Programme is proposing to go live with adding Release 2 information in the Emergency Departments of two trusts. This will be subject to an evaluation. Evaluation of the pilot will include the practical lessons learnt, the quality and effectiveness of information provided to patients and the business processes involved.
14. The SCR Permission to View model will act as an additional safeguard should any Release 2 information be uploaded without consent. In addition, to support the pilots, the SCR Programme will update the processes to resolve any instances where information has been added to the SCR when the patient did not wish this to happen. This will include making the information unavailable for staff to view this information or to completely remove the information from the patient's SCR.
15. Existing guidance will be updated to support patients who do not have a registered GP but wish to change their SCR consent preference. This will be in place to support the Release 2 pilots.

Respond / *Speak to Phil to ?* / *Marlene* / *envelope* / *sealed*

Ian Miller

From: Winfield Marlene (NHS Connecting for Health) [marlene.winfield@nhs.net]
Sent: 22 October 2009 16:45
To: Ian Miller; Cayton Harry (NHS Connecting for Health); [REDACTED]
Subject: Policing content of Clinician Sealed Envelope

envelope
sealed
to

Hi Ian, [REDACTED] and Harry,

We had the query below from one of our patient reps and it is really a policy issue rather than a technology one. I read it as requiring a decision that it is necessary to police clinician sealed envelope content which IT could then enable. I know that without a policy direction from the DH, a change to IT specification along the lines he is recommending will not be funded.

Do you feel that there is sufficient risk of clinicians abusing the sealed envelope to press for such a safeguard?

Regards, Marlene

"What safeguards are there in place to ensure that the Sealed envelope, for 3rd party information, which (I am led to believe) a Patient will never be able to access, is not misused by anyone for notes on the Patient which are inappropriate?

I talked, informally to Harry Cayton some time back, about the possibility of a red flag system. A system where, whenever anything is added to a Patient's 'Clinician Sealed Envelope', perhaps a Caldicott Guardian, could just check that the information entered is appropriate and in the correct place. It would, otherwise, be all too easy for Clinicians to put information for other Clinicians in this part of the record, which in fact is not 3rd party information but is in fact anecdotal about the Patient without any scrutiny."

I work from Tuesday to Friday

Marlene Winfield OBE
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PA Deborah Perry
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Ian Miller

From: Winfield Marlene (NHS Connecting for Health) [marlene.winfield@nhs.net]
Sent: 11 December 2009 16:14
To: Ian Miller
Cc: Singh Inderjit (NHS Connecting for Health)
Subject: Clinician sealed envelopes

Hi Ian,

You may remember you asked for some background briefing on the above in response to the question from [REDACTED] about policing what is put into them.

Attached are some fairly straightforward (I hope) slides.

Marlene

I work from Tuesday to Friday
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Clinician Sealing Overview

Version 0.1
11-Nov-2009



Clinician Seals

- Clinician Seals:
 - Are associated with one or more reasons
 - May have an Expiry date
- Those who can access the Clinician Sealed information are:
 - Any Clinician or other Health Care user
- But NOT through HealthSpace by:
 - The Patient
 - A Patient's Legal Representative

11-Nov-2009

2

Clinician Sealing - Aspects

1. Clinician Seal Reasons
2. Clinician Sealing Actions
3. Viewing Clinician Sealed Information
4. Communicating Clinician Sealed Information

11-Nov-2009

3

Clinician Sealing Reasons

- a) Information has been withheld that is likely to cause serious harm to the physical or mental health of the data subject or any other person;
- b) Confidential third party information has been withheld;
- c) A child has asked that the information should not be disclosed to a responsible person who would otherwise be entitled to see it (e.g. parent);
- d) A person incapable of managing their own affairs has asked that the information should not be disclosed to people who would otherwise be entitled to see it (e.g. a legal guardian);
- e) The information has been withheld because a patient explicitly asked not to know about it;
- f) Information which might otherwise alarm the patient has been withheld temporarily by a clinician to give time for the clinician to speak to the patient;
- g) A test result has been automatically withheld for a standard period to allow a clinician time to review the results and take action accordingly

Clinician Sealing Reason Display Names

- Withheld from patient/patient-representative – likely to cause serious harm to patient or others;
- Withheld from patient/patient-representative - third party information;
- Withheld pending consultation (clinician's decision);
- Withheld temporarily – test result (automatic).
- Withheld from patient/patient-representative (patient's request not to discuss);
- Withheld from patient-representative (child's request);
- Withheld from patient-representative (incapable person's request).

Clinician Sealing Actions

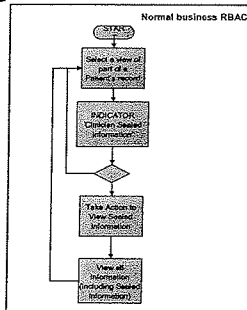
- Seal
- Unseal
- Change/Remove Expiry Date
- Append Text

Clinician Sealing Action

Record Details

- Reason(s)
- Expiry Date
- Who
- When
- Where
- Additional notes

Viewing Clinician Sealed Info.



Communicating Clinician Sealed Info.

- Can send Clinician Sealed Information in messages
- Currently – Must NOT send to PSIS
 - Clinician Sealed Information
 - Information that should be Clinician Sealed
- Clinical sealing is to be handled through local system functionality or business process

Ian Miller

From: Evans Graham (Q30) North East SHA [graham.evans@northeast.nhs.uk]
Sent: 26 January 2010 06:44
To: Ian Miller
Cc: marlene.winfield@nhs.net; rob.longstaff@nhs.net
Subject: Re: Summary care Record communications approach in NE England



Dear Ian

Thank you for your reply.

As stated in my previous email, it is the SHAs responsibility as a public sector organisation to both meet the obligations of the Data Protection Act and to investigate options fully before committing public finances, particularly in this difficult financial climate.

The NE SHA was aware that the issue had been debated between the CfH and the ICO before sending the letter, but the original proposal from CfH was not explicit in terms of the wider communications activities that SHAs would be undertaking.

Prior to submitting our proposals to the ICO for clarification and guidance, we undertook an internal and external legal review of our explicitly defined proposed communications approach. The outcome being that, we came to the conclusion that our explicit proposal did meet the need to process data fairly, but required clarification and guidance on our specific proposal from the ICO before proceeding, so as not to undertake an approach which was inconsistent with the ICOs view.

As the ICOs clear guidance is that an individual mailing is required for this specific initiative in order to provide the data subjects with fair processing information, we will therefore now undertake a communications campaign using an individual mailing approach as advised.

Thank you for your feedback once again.

Regards

Graham

Dr Graham Evans
Chief Information Officer
Director of Informatics

North East Strategic Health Authority
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----- Original Message -----

From: Ian Miller <Ian.Miller@ico.gsi.gov.uk>
To: Evans Graham (Q30) North East SHA
Cc: marlene.winfield@nhs.net <marlene.winfield@nhs.net>
Sent: Tue Jan 19 10:33:26 2010
Subject: RE: Summary care Record communications approach in NE England

Dear Dr Evans

02/02/2010

I am sorry that I have not replied to this email sooner but I have been off work sick since before Christmas and I have only just returned to work today.

As I explained in my email of 17 Dec to Marlene Winfield and you, I did try to call you to discuss the matter but you were in a meeting. I thought I had made it clear in that email that the Data Protection Act requires "the individual who is the data subject of the personal data" to be provide with fair processing information; I don't really see how this could be any clearer. When Marlene replied on 18 Dec said that she would explain the matter in more detail to you and in your email of 18 Dec to Marlene (copied to me) you said, "I fully understand the ICO position".

As I made clear in my email to Marlene on 17 Dec, I can't see anything in your proposals that provide any new information to cause the ICO to change its view on this "key and fundamental requirement of the Data Protection Act 1998". However, I am more that happy to discuss the matter with you if you fee that would help to clarify things. If so please give me a ring on the number shown below; please note I don't work on Mondays or Fridays

Ian Miller

Senior Data Protection Development Manager

Information Commissioner's Office

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Website Address: <http://www.ico.gov.uk> <<http://www.ico.gov.uk/>>

Email; ian.miller@ico.gsi.gov.uk <<mailto:ian.miller@ico.gsi.gov.uk>>

From: Evans Graham (Q30) North East SHA [<mailto:graham.evans@northeast.nhs.uk>]
Sent: 06 January 2010 12:09
To: Ian Miller
Cc: rob.longstaff@nhs.net; McElroy Helen (Q30) North East SHA
Subject: Summary care Record communications approach in NE England

Dear Mr Miller

Thank you for copying me into your email to Marlene Winfield of 17 December 2009 (timed at 16:21) and also for speaking to my PA, I am sorry that I was not available to take your call.

Please be assured that NHS North East appreciates the importance of national consistency in the approach to the roll out of the Summary Care Record. My letter to you was not intended to undermine the discussions which have been held between CfH and the ICO to date.

NHS North East finds itself in a position where it has received notification of the ICOs stance on the individual versus the household approach but does not have the detail of the reasoning behind it nor its application to the specific circumstances of NHS North East.

As you will note from my letter to you, I have suggested that the requirement to process data fairly would be met by the proposed approach to the roll out of the Summary Care Record in the North East. Given the financial implications of an adopting an individual approach, NHS North East is under an obligation to seek clarification of the ICO's views on its specific proposals before committing public funds to either option.

02/02/2010

I would be very grateful if you could provide me with a response to my letter so that I may progress this matter on behalf of NHS North East. If you could respond by 15th January 2010 it would be appreciated.

I look forward to working together in relation to this matter.

Kind regards

Dr Graham Evans

Chief Information Officer

Director of Informatics

North East Strategic Health Authority

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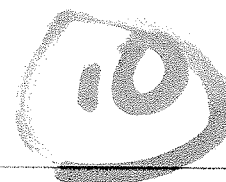
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Ian Miller

From: Ian Miller
Sent: 17 December 2009 16:21
To: 'marlene.winfield@nhs.net'
Cc: 'Graham.evans@northeast.nhs.uk'
Subject: Enquiry re SCR Roll out in N E England

Dear Marlene

Thank you for returning my call so promptly. As I explained when we spoke on the phone, we have received a letter dated 11 December 2009 from a Dr Graham Evans, Chief Information Officer and Director of Informatics at the North East Strategic Health Authority. He is seeking advice on the proposed approach to the roll-out of the SCR in the North East. These proposals include making information mailings to households rather than to individuals. As you will recall we discussed the idea of mailing households rather than individuals when we last met and we made our position entirely clear i.e. that the Act requires the data subject i.e. "the individual who is the subject of the personal data" to be provided with fair processing information in order to ensure compliance with the fairness requirement of the First Principle. This is a key and fundamental requirement of the Data Protection Act 1998.

Whilst we appreciate that Connecting for Health cannot override local autonomy in relation to national issues such as the SCR roll out we have always worked on the basis that the discussions we have with Connecting for Health on this matter, and others, are national level discussions and the outcome of these will be cascaded down to local level to inform the arrangements made there. This should, amongst other things, ensure some consistency of approach across the country and also reduce the number of local separate enquiries to the ICO about the same issue from regional and local health bodies such as Health Authorities. We have already seen this year what can happen as a result of inconsistencies of approach to the SCR roll out at local level with the issue of the deletion of SCRs

I did try to discuss the matter with Dr Evans on the phone today but he was in a meeting so I explained our position on the matter to his PA. Dr Evans has asked us to respond by 8 January 2009; I am afraid I cannot guarantee to meet this deadline given my current workload and the imminent Christmas holidays. However, I have made time to have an initial look at his proposals and they do not appear to provide any new information that would cause us to change our view over this matter.

I gave Dr Evans PA your contact details so that he can speak to you directly about this matter. Would you please explain to him in more detail the discussions we had and the background to this matter, thank you.

Regards

Ian

Ian Miller
Senior Data Protection Development Manager
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Email; ian.miller@ico.gsi.gov.uk

17/12/2009

SCANNING

11th December 2009

16 DEC 2009

North East

The Information Commissioner
The Information Commissioner's Office
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Direct dial: 0191 210 64465
Graham.evans@northeast.nhs.uk

Roll out of NHS Summary Care Record in the North East of England Compliance with the Data Protection Act 1998

Dear Sir

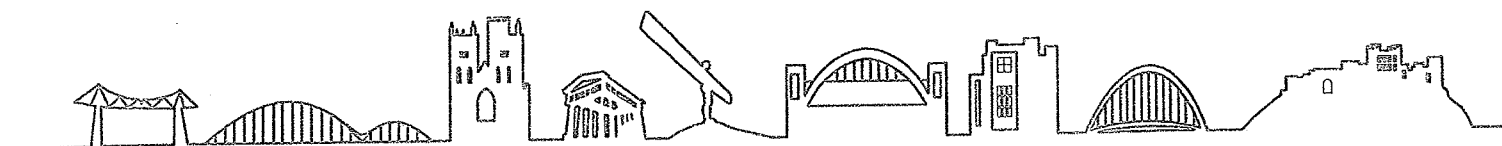
We enclose a copy of the draft working paper submitted to you in August 2009 by NHS Connecting for Health (NHS CFH) "Summary Care Record – approach to Public Information Programme".

The purpose of the draft working paper was to update the Information Commissioner's Office (ICO) on the progress and suggested approach for the national roll out of the NHS Summary Care Record (SCR). One of the key issues raised in the draft working paper was whether it would be acceptable, from a Data Protection Act perspective, to issue letters informing the public about the SCR using a household letter rather than a personalised letter to individuals.

NHS North East, which is responsible for the roll out of the SCR in the North East region (consisting of approximately 2.14 million people aged of 15 years and 9 months and over), understands that the ICO's response to the suggestion of household letter, rather than personalised letters, was:

"After full consideration and exploration of all the points raised, the meeting concluded that the most appropriate way for data controllers to discharge their responsibilities under the Data Protection Act is to write to each patient individually."

We wish to understand the reasoning behind this guidance. In particular, before NHS North East places reliance on the ICO's advice, it wishes to ensure that the ICO has had access to sufficiently detailed information in relation to the proposed roll out of the SCR in the North East of England. We would ask therefore that you consider this letter and provide a response so that we can consider the position further.



Sir Peter Carr
Chairman

Ian Dalton
Chief Executive

The NHS in the North East is to embark on a full implementation of the SCR from March 2010. Therefore, we intend to commence a SCR public information campaign across the North East from mid-January 2010. Further details of the proposed approach are set out below.

In view of our intended timescales, it would be helpful if you could provide a response to this letter by **Friday 8th January 2010**.

We are mindful that it is not the role of the ICO to provide legal advice and we do not seek such advice from you. The roll out of the SCR is a high profile national project and the importance of communicating good quality information to the public is paramount. NHS North East hopes that the suggested roll-out programme for the North East region meets this aim and ensures compliance with the Data Protection Act 1998. NHS North East is looking to the ICO for specific guidance in relation to the North East roll out programme.

The proposed approach to be adopted in the North East of England

NHS North East is proposing a revised approach from that undertaken as part of the national pilots. As you may be aware the national pilots were conducted on a GP practice population basis for those participating GP practices. Therefore, the starting point for the public information campaign for the pilots was the patient lists for the GP practices concerned. The starting point for a national and regional roll out is the relevant population.

NHS North East is proposing the following public information campaign for the roll out of the SCR to the population of its region:

1. Household mailing to all residential properties within the SHA catchment area. A sample patient pack including draft letter is enclosed. The mailing to include:
 - Envelope with NHS logo and labelled 'To the Household' with wording '*This envelope contains important information about changes to your health records – please read carefully – do not throw away*'
 - A letter addressed to 'the members of the household':
 - Explaining what a Summary Care Record is;
 - Explaining details on where to access further information;
 - Explaining timescales from when summary care records will be created;
 - Explaining what to do if any individuals within the household wish to opt out;
 - Directing the person opening the letter to share its contents with all other members of the household who would be able to understand;
 - Guidance on how parents and carers should communicate the letters contents with children or adults in the household at that time lack the capacity to make the necessary decisions in relation to the SCR; and
 - Details on any locally organised information sessions and directions on other ways to find out about the Summary Care Record
 - A standard Summary Care Record leaflet explaining the changes and how to get more information.
 - An order form to enable recipients to request information in a different format and language.
 - A business reply paid envelope in which to return the order form for different formats and languages.

Compliance with the Data Protection Act 1998 in the North East of England as a result of the SCR public information campaign

NHS North East is aware that the creation of a SCR for a patient will involve the processing of sensitive personal data. Furthermore, each time the record is accessed after that will also involve the processing of sensitive personal data. The latter aspect of the processing is to be authorised by seeking express patient consent via the "Permission to View" mechanism and is not therefore discussed further in this letter.

Therefore, concentrating on the creation of the SCR, NHS North East is mindful of the need to comply with the First Data Protection Act Principle and in particular must be able to show that the processing necessary to create the SCR is done:

- Fairly
- Lawfully
- In accordance with at least one of the conditions in Schedule 2 of the DPA
- In accordance with at least one of the conditions in Schedule 3 of the DPA

Taking each of these requirements in turn and making express reference to the North East SCR roll out campaign:

Fairly

NHS North East believes that compliance with this requirement may be the issue with which the ICO was most concerned in relation to the position as described in the Draft Working Paper.

NHS North East acknowledges that regard must be had to principle that there should be no surprises when it comes to the use and disclosure of health data. Patients need to be aware of the purposes for which their health data will be processed. At present, patients are aware that their health data will be stored by their GP or hospital and may be shared between health professionals for the purposes of their care and treatment. The storing of health data in the SCR format represents a change from these accepted uses and as such, demands further work in respect of the requirement to process health data fairly.

NHS North East submits that the requirement to process data fairly is met by the use of household mailings when this method of communication is seen as part of the wider package of the public information campaign. As referenced in the Draft Working Paper, the household approach has advantages over the personalised approach in terms of the penetration of the target audience (page 5 of the Draft Working Paper). It is also worthy of note that the household approach was adopted in Scotland, Northern Ireland and Wales and therefore, presumably, thought to comply with the Data Protection Act 1998.

Should NHS North East choose the personalised approach to mailing then it will be necessary to process sensitive personal data as part of the process of sending out the personalised letters. This is most likely to happen as a result of retrieving the data from patient lists held by GP practices in the region. Therefore, inherent in the personalised approach is a preliminary processing of sensitive personal data. Despite robust validation

2. Care and nursing homes will also receive written SCR briefings to ensure that staff are adequately equipped to inform residents and their families about the SCR. In addition, SCR posters and leaflets will be used to raise awareness amongst residents and visitors.
3. SCR posters and explanatory patient leaflets will be supplied to all Patient Advice and Liaison Services (PALS) and GP practices for display and to take away. GP practices and PALS services will be briefed both verbally and in writing, to ensure that they are equipped to be able to answer any public enquiries on the Summary Care Record.
4. NHS North East will provide a series of proactive media messages to enable mainstream and specialist local and regional media outlets to run ready prepared features and articles and a full page feature in the health supplement of the key regional newspaper. The series would include:
 - a. **Summary Care Record is coming** - generic press release which raises awareness of the Summary Care Record and advises residents of the planned mailing and who to write to if they have not received a letter
 - b. **Your Rights** - a generic press release reminding patients of their right to access the SCR via the website HealthSpace and when the SCR will be created, and how to opt out
 - c. **Drop in engagement sessions** – tailored releases

These SCR features will also be made available for use in local authority publications, voluntary group publications and for internal NHS communication mechanisms.

5. Extensive use will be made of SCR posters and flyers, which will be made available in health care settings such as GP practices, Walk-In Centres, Hospital A&E and Hospices and public facilities such as libraries, student unions and halls of residence.
6. Information on the Summary Care Record, the benefits, where to access information and how to opt out will be available on Strategic Health Authority, NHS Commissioner and Provider websites.
7. Stakeholder e-briefings will be sent to MPs and councillors, plus regionally based voluntary groups.
8. GP Practice/Health Centre drop in sessions will be organised and advertised through media and patient representative groups to allow patients to find out more about the Summary Care Record.
9. Advertisements will be developed and run routinely on the Life Channel, which is broadcast in the waiting rooms of 53% of GP practices in the North East region, with this number increasing over time.
10. Ongoing face to face involvement by NHS staff with difficult to reach groups regarding the communications preferences on how to access to services and giving information about the SCR.

procedures and secure transfer mechanisms, there are significant risks attendant with the extraction and transfer of registered lists to the mailing house. It is significant to note that a major benefit that the household approach has over the personalised approach is that it will not be necessary for NHS North East to process sensitive personal data in order to effect the household mailing, as it will be sourced direct from Royal Mail's residential address listing.

NHS North East also notes the ICO's guidance (*Use and Disclosure of Health Data – May 2002*) which states, at page 8;

"The provision of fair processing information by means of a poster in the surgery or waiting room or by a notice in the local paper etc is unlikely to be sufficient to meet the requirements of the Act since not all patients will see or be able to understand such information. Such methods may, however, be used to supplement other forms of communication. Methods by which the fair processing information may be provided include a standard information leaflet, information provided face to face in the course of a consultation, information included with an appointment letter from a hospital or clinic, or a letter sent to a patient's home".

Taking all of the above points into account, NHS North East is unable to see how it could be said that a household mailing, when taken together with the package of public information measures, can be said not to comply with the requirement to process data fairly, whereas a personalised mailing (along with the same package of public information measures) can be said to comply with this requirement. The narrow distinction between the two global packages of communication methods is not sufficient to make one compliant and the other non-compliant.

The ICO is invited to confirm whether it agrees with this interpretation.

Lawfully

It is well recognised that the ICO supports the opt-out method of securing implied consent to the processing of sensitive personal data for the purposes of the creation and maintenance of the SCR.

Again, when the household approach is seen as part of a package of public information measures, NHS North East is of the view that this complies with the requirement to process information lawfully. If implied consent is obtained via the opt out mechanism then the use of health information to create the SCR will not be in breach of the common law duty of confidence, nor the Human Rights Act 1998.

If the personalised approach (as part of a wider package of public information measures) is deemed to comply with the requirement to process data lawfully then so must the household approach when seen as part of a similar package. The same points which we have made in relation to the 'fairly' requirement apply here. The distinction between the two approaches is minimal in terms of compliance with this aspect of the DPA given their respective merits in reaching target audiences.

Schedule 2 and Schedule 3

NHS North East believes that the conditions used to demonstrate compliance with Schedule 2 and 3 are the same regardless of whether a household approach or a personalised approach is adopted.

For completeness, these conditions would include:

- the data subject has given his consent to the processing (Sch 2 – implied consent via opt out)
- the processing is necessary for the exercise of any other functions of a public nature exercised in the public interest by any person (Sch 2)
- the processing is necessary for the purposes of legitimate interests by the data controller or by the third party to whom the data is disclosed (Sch 2)
- the processing is necessary for the exercise of any functions conferred on any person by or under an enactment (Sch 3)
- The processing is necessary for medical purposes and is undertaken by a health professional or a person who in the circumstances owes a duty of confidentiality which is equivalent to that which would arise if that person were a health professional (Sch 3)

Additional factors supporting a household approach

As presented in the document "Summary Care Record – approach to Public Information Programme", due to a significant percentage of patients not living at their registered address or not currently registered with a GP, a household mailing has a higher chance of reaching the intended recipients.

The use of public funds is a major consideration for any public sector organisation. The forecasted costs based on 30p per letter for an individual mailing based on the 2.14 million over the ages of 15.5 population is £630,000. Using a conservative estimate that 10% of the mailing will be returned undelivered, this will increase the postage element of the cost by £63,000 to a total of £693,000. The forecasted costs of a household mailing based on 1.15 million households (source: office of national statistics) is £334,500, which is a difference of approximately £360,000 of public expenditure.

The cost of the broader public information campaign also has to be borne in mind and if less funds are spent as a result of adopting the household approach then these can be diverted into the other aspects of the public information campaign thus ensuring a more robust system for ensuring compliance with Data Protection Act 1998.

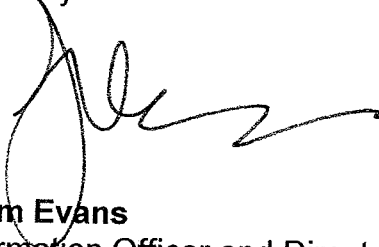
The ICO's view

We are very grateful for the ICO's assistance in addressing the points raised in this letter and hopefully providing some assistance to NHS North East in relation to the plan for the roll out of the SCR in it's region.

We hope that this letter has provided you with sufficient information to allow you to consider the specifics of our roll-out plans. If you require any further information before being in a position to respond, please contact us at the earliest opportunity.

Thank you again for your assistance in this matter.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Graham Evans', written over a faint circular stamp or watermark.

Dr Graham Evans
Chief Information Officer and Director of Informatics
North East Strategic Health Authority

(19)

Use of Driver Entitlement Checking Services for identity checking (Connecting for Health).

- Connecting for Health (CfH) has proposed a system to validate and audit personnel authorised to log-in and access electronic patient records against driving licence numbers recorded on the vehicle keeper database. It is proposed this will form part of an access control validating the legitimacy of an individual's interest in accessing a particular patient's records.
- [REDACTED] and [REDACTED] stated the concern that this may exceed DVLA's statutory function.
- DJE noted that the person within the ICO who works on CfH issues is Ian Miller.
- MH pointed out that the CfH proposal entails a considerable scope for misuse. Numerous agencies and public bodies are granted ready access to the DVLA database.
- [REDACTED] said the DVLA is skeptical about the proposal. It has been refused on the basis that it is an ID check and there are doubts over whether the arrangement is compatible with the purposes for which DVLA data is processed.