

‘Never heard of it’ – Understanding the public’s lack of awareness of a new electronic patient record

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Abstract

Background The introduction of electronic patient records that are accessible by multiple providers raises security issues and requires informed consent – or at the very least, an opportunity to opt out. Introduction of the Summary Care Record (SCR) (a centrally stored electronic summary of a patient’s medical record) in pilot sites in the UK was associated with low awareness, despite an intensive public information programme that included letters, posters, leaflets, and road shows.

Aim To understand why the public information programme had limited impact and to learn lessons for future programmes.

Methods Linguistic and communications analysis of components of the programme, contextualized within a wider mixed-method case study of the introduction of the SCR in pilot sites. Theoretical insights from linguistics and communication studies were applied.

Results The context of the SCR pilots and the linked information programme created inherent challenges which were partially but not fully overcome by the efforts of campaigners. Much effort was put into designing the content of a mail merge letter, but less attention was given to its novelty, linguistic style, and rhetorical appeal. Many recipients viewed this letter as junk mail or propaganda and discarded it unread. Other components of the information programme were characterized by low visibility, partly because only restricted areas were participating in the pilot. Relatively little use was made of interpersonal communication channels.

Conclusion Despite ethical and legal imperatives, informed consent for the introduction of shared electronic records may be difficult to achieve through public information campaigns. Success may be more likely if established principles of effective mass and interpersonal communication are applied.

Introduction

Electronic health records and informed consent

Policymakers have high hopes that shared electronic patient records, accessible by health professionals and managers outside the organization where they are created or stored, will make healthcare more effective, efficient, safe, and patient-centered as well as supporting secondary uses such as audit and research.^{1,2} Electronic patient records may bring both benefits and risks.³ In relation to the storage and sharing of sensitive personal health data, for example, there is a trade-off between making data accessible and protecting privacy^{4,5}; public trust in Internet-based information is low⁶; and there are ethical and legal implications of potential security breaches in Internet-accessible record systems.⁷⁻⁹

Whilst the sparse research literature summarized in the previous paragraph emphasizes the need to obtain the data subject's consent before personal health data are shared, the focus to date has been on the nature of consent – especially whether an 'opt in' (informed consent) or 'opt out' (assumed consent) model is preferable.¹⁰⁻¹⁴ Apart from two pilot studies in the UK,^{11,15} we could find no previous research on efforts to inform the public of proposed changes in how their personal health data are stored. Policy documents refer somewhat vaguely to the need to inform the public but lack explicit guidance on how these should be conducted.¹⁶

Against this background, and as part of a wider study into the introduction of a new Internet-accessible electronic record in pilot sites in the UK,^{5,17,18} we followed the fortunes of the information programme designed to inform people in pilot sites of the initiative and seek their consent for their own record to be uploaded. Our research questions were (i) How was the public information programme conducted?; (ii) What was its impact on public awareness and behaviour – and why?; and (iii) What are the main lessons learnt for future programmes? We sought to address these questions via a detailed qualitative analysis of the

various components of the information programme, nested within a wider ethnographic case study of the introduction of the SCR and HealthSpace.

Public information campaigns: the evidence base

Back in 1947, Hyman and Sheatsley¹⁹ summarized the evidence base for effective communication. In addition to the audience not being adequately exposed to the message or not paying attention to it, they suggested, communication barriers include fear of potential negative outcomes, alternative readings of the message, rejection of applicability to self, dismissal of unappealing recommendations, and apathy. Two years later Shannon and Weaver published their classic mathematical model of communication (Fig. 1), in which communication was seen to involve a sender, a target recipient, a message which has to be 'coded' and 'decoded', a medium (channel) through which the message was sent, and a greater or lesser amount of 'noise'.²⁰ Messages must be carefully targeted to the intended audience, meaningfully coded (e.g. using engaging language), and sent via appropriate channels (i.e. in a suitable format and medium) with minimum noise (i.e. things that distract the audience from the message).²¹

The Shannon–Weaver model, developed by engineers at a time when communications research was heavily influenced by studies of the telephone and telegraph, was later refined to include a recognition that good communication involves two-way exchange of information (e.g. the sender knows how the receiver is reacting)²² and greater emphasis on the human elements.²³ Berlo, for example, emphasized that the goal of

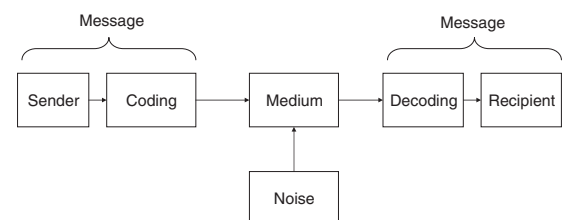


Figure 1 Transmission model of communication [adapted from Shannon and Weaver²⁰].

most communication is the transfer of *meaning*, which is dependent upon shared concepts, attitudes, and values as well as on the communication skills of the sender.²³ A more recent review added that mass media communication will be particularly ineffective if the message is regarded as 'offensive, disturbing, boring, stale, preachy, confusing, irritating, misleading, irrelevant, uninformative, useless, unbelievable, or unmotivating' (p. 51) – all key dimensions of meaning.²⁴ A heterogeneous audience will need to be *segmented* so that the message can be properly targeted to different subgroups.

In 1969, Bass analysed a large sample of marketing campaigns and concluded that whilst mass media campaigns may be effective at creating awareness, they are, overall, less effective (by around 15-fold) at changing behaviour than interpersonal channels.²⁵ At the same time, sociologist Everett Rogers was building a new research tradition on interpersonal communication, introducing and systematically exploring concepts such as opinion leaders, champions, change agents, and other embodiments of social influence.²⁶

Early research into mass communication had shown that people already interested in a topic were more likely to pay attention to new messages about it.^{19,27,28} In the 1980s and 1990s, Rogers' theory of interpersonal influence was extended using theories of engagement and mindfulness.^{24,29–33} According to such theories, an audience lies somewhere on a continuum from 'mindlessness' (passive unawareness) to 'mindfulness' (active engagement with the issue, seeking further information). Strategies to increase mindfulness include presenting the message in an unusual or novel way; creating a discrepancy between expectation and reality (e.g. displaying the message in unusual locations); highlighting a controversy; and including a request for personal involvement or specific action. Such approaches may be even more important in contemporary society, given the numerous and sophisticated messages to which individuals are exposed.

Also in the 1990s, researchers in linguistics began to explore 'plain English'.³⁴ This body of

work underpins contemporary policies on communicating with individuals with low health literacy or limited English proficiency.³⁵ In short, a message will be understood more readily if it uses immediate rather than non-immediate language (see examples in Table 1, message content). Drawing on this evidence base, the Plain English Campaign advises that communications should be short, clear, and presented in simple, active everyday language (http://www.plainenglish.co.uk/free_guides.html).

Overall, then, modern communication research has gradually evolved from a pre-occupation with mathematical and technical models to a focus on meaning, engagement, and understanding. This shift resonates with the teachings of Aristotle, who argued that messages are rhetorical – that is, they appeal to an audience and seek to persuade.³⁶ He believed that an effective message has three components: *logos* (the 'evidence' in the message), *ethos* (the credibility of the speaker) and *pathos* (the appeal to emotions), and suggested various strategies to increase each of these dimensions. Aristotle's classic work underpins modern-day marketing principles – for example, that balanced appeals (which set out both pros and cons) tend to have greater credibility and impact than unbalanced ones, especially with sophisticated or knowledgeable audiences.²⁴ In 'The New Rhetoric', Perelman and Olbrechts-Tyteca³⁷ have built on Aristotle's speaker-focused model to include a systematic analysis of the audience. The appeal of a message to a particular audience, they argue, depends (among other things) on that audience's points of departure (i.e. their values, beliefs and taken-for-granted assumptions). Persuasion is more likely if the speaker has determined these points of departure and tailored the message accordingly.

The above theoretical approaches and models have contributed to the emerging science of 'evidence based health promotion' which underpins health-related public information campaigns.^{38–41} However, almost all such campaigns to date have been oriented to changing individuals' health-related behaviour and health outcomes [see, for example, examples in heart

Table 1 Summary of questions used to guide data analysis

Aspect of programme	Questions asked in analysis	Method of analysis
Message content	<ol style="list-style-type: none"> 1. To what extent does the text of the message conform to Plan English campaign guidelines? (http://www.plainenglish.co.uk/free_guides.html) 2. To what extent is 'immediate' language used?^{30,31} In particular, to what extent does the message show: <ul style="list-style-type: none"> • Denotative specificity (does it state the agent, object and action clearly, simply and directly?); • Spatial immediacy (does it use close demonstratives such as 'this', 'these', 'here', rather than distant ones such as 'that', 'those', 'there'?); • Temporal immediacy (does it use the present tense, rather than conditional or future?); and • Few or no qualifiers (e.g. does it avoid words like 'may', 'might', 'could', 'possibly'?). 	Detailed linguistic analysis of text of letters, posters and leaflets
Message transmission	<ol style="list-style-type: none"> 3. Who is the sender of the message?²⁰ 4. Who is the intended recipient – and to what extent might the audience need to be segmented and different messages sent to different subgroups?²⁰ 5. To what extent is the transmission channel clear? (e.g. how much 'noise' is there)²⁰ 	Analysis of sender and target audience for letters/posters/leaflets. Interpretive analysis of wider case study data for 'noise'.
Message meaning/significance	<ol style="list-style-type: none"> 6. What meaning is the message likely to hold for different intended recipient groups?²³ 	Contextualization of linguistic analysis in relation to particular audiences.
Efforts to engage audience	<ol style="list-style-type: none"> 7. How and where is the message transmitted? To what extent is there novelty, surprise and a cue to action?^{24,29–33} 	
Efforts to persuade audience (rhetoric)	<ol style="list-style-type: none"> 8. To what extent is the message balanced? (presenting both pros and cons)³⁶ 9. What level of credibility does the sender of the message hold with the intended audience(s)?³⁶ 10. What are the points of departure of different intended audiences (i.e. their values, beliefs and taken-for-granted assumptions) and to what extent have these been taken into account?³⁷ 	<p>Linguistic analysis of message, with a focus on use of rhetoric and argumentation (associations, dissociations, metaphors etc).</p> <p>Interpretive analysis of wider case study data for audience characteristics.</p>

health,⁴² alcohol,⁴³ breast-feeding,⁴⁴ low back pain,⁴⁵ HIV,³² smoking,⁴⁶ and unnecessary consultations for minor illness.⁴⁷ As previous pilot studies in Hampshire and Staffordshire showed, information campaigns oriented to informing people about how their personal health data are stored differ from these in a number of key aspects^{15,48}:

1. The purpose of the campaign is not merely to inform but to satisfy the legal requirement to do so;

2. The message may have less intrinsic interest value than a topic that directly pertains to health and which seeks active behaviour change;
3. The message tends to be generic (i.e. it is relevant to everyone in the target population rather than to a particular subgroup such as smokers), so individuals may feel less personally engaged;
4. Such campaigns may be carried out in a politically sensitive climate.

The Summary Care Record and HealthSpace

The Summary Care Record (SCR) is part of the National Programme for Information Technology (NPfIT) in the English National Health Service (NHS). It is a centrally stored summary of key medical details for use in unscheduled care settings, created by uploading selected data from the person's general practitioner (GP) record onto a central 'Spine'. It is hoped that NHS patients will eventually be able to access their own SCR via a separate technology (HealthSpace). Our team conducted an independent evaluation of the introduction of the SCR and HealthSpace in four pilot sites,^{5,18} and are continuing to follow the fortunes of the programme as efforts are made to roll it out nationally. We were contracted to provide regular formative feedback to Connecting for Health, the central body charged with implementing the NPfIT on behalf of the Department of Health, to inform the national rollout of the programme.

An extensive public information programme in the first two SCR pilot sites included a letter sent to every person aged 16 and over for whom an SCR was to be created, as well as posters, leaflets, 'road shows', talks to community groups, local radio and newspaper coverage and a helpline run by NHS Direct. A confidentiality pack including the NHS Care Records Guarantee (a nationally produced leaflet assuring people of both technical security and controls over who would access their record) was sent out on request. Consent was assumed for all individuals who had not opted out within 16 weeks of the letter drop. People were also informed (either as part of the initial SCR campaign or separately) that they could view their SCR via the secure HealthSpace website. In contrast to the SCR, HealthSpace operates on an opt-in model – that is, people need to actively sign up for an account. Both Connecting for Health, and participating Primary Care Trusts (PCTs), the NHS bodies responsible for commissioning and overseeing healthcare on behalf of a population of 100–250 000 put considerable energy and resources into the information programme.

Previous work by our team showed that at the time of these early pilots (2007 to mid-2008), there was very low public awareness and little interest in either the SCR or HealthSpace.^{5,18} By the date of our individual interviews (early- to mid-2008), at least 95% of the population in our sample area should have received a letter informing them that the SCR was being introduced in their area. However, fewer than 30% of NHS service users whom we surveyed were aware of the SCR, and only around one person in seven claimed to have received the letter about it. Indeed, one of the most common responses to our question whether the patient knew anything about the SCR was '[I've] never heard of it'. Only one in 12 said they had heard of HealthSpace, although the latter was not publicized as widely as the SCR. Of those who were aware of the SCR or HealthSpace, one in five had heard about it through press articles rather than via the official information programme. A before-and-after survey of 250 people by a market research company broadly confirmed these findings (unpublished data available from Connecting for Health). Interview studies by ourselves and others showed that most people in the UK appear happy to allow their personal health data to be shared amongst health professionals (indeed, many assumed this was already happening); they expressed relatively high trust in the NHS but little if any desire to view their own SCR using HealthSpace.^{15,18}

Methods

The study was carried out as part of the wider SCR and HealthSpace evaluation, a large, mostly qualitative study which explored the challenges associated with the introduction of these technologies in four pilot sites.^{5,18} Ethical approval for the study was obtained from Thames Valley Research Ethics Committee (06/MRE12/81 and subsequent amendments). As explained in detail in our previous publications,^{5,18} our overall data set included ethnographic observation in participating healthcare settings (including how and where information was available), semi-structured interviews with

staff and patients, focus groups with selected service users (e.g. mental health patients) or their representatives, and documents (letters, emails, strategy documents, business plans, minutes of meetings, and so on). This wider study highlighted the low levels of awareness described earlier and provided important context for our more detailed analysis reported below of how the public were informed about the programme.

In relation to the public information programme, we considered the following specific data sources as well as relevant material from the wider study:

1. The letter sent by the two pilot PCTs to target populations (one chose to target their entire patient list whereas the other targeted only the patients of participating GP practices). The two PCTs sent out a slightly different letter (although both were modelled on a similar template) and there were also slight variations between the versions sent to different 'waves' of recipients as GP practices came on board.
2. The NHS Care Records Service leaflet, a folded A5 brochure which was sent as an enclosure with the above.
3. Official posters produced by the communications leads in the participating PCTs as well as a more informal, handwritten notice displayed in one GP surgery.
4. Mass media initiatives including road shows and local radio programmes.
5. Visits from PCT staff to minority ethnic organizations and patient self-help groups.
6. Local newspaper articles and PCT press releases.

For each genre of communication (letter, leaflet, poster, and so on), and in relation to the audience and context, we applied a number of complementary approaches which are summarized in Table 1. The analysis of these documents was guided by the issues identified in section 'Main findings'. In particular, we undertook detailed linguistic analysis of the text and images used in the different communications, and asked questions about the significance and meaning which these held for different sectors of the target audience. We found that there

was strong alignment between the findings of these different approaches so it did not prove necessary to resolve differences between them.

Main findings

Our analysis identified eight possible explanations, considered in turn below, for the limited impact of the programme: its politically sensitive context, the challenge of audience heterogeneity, lack of clarity about sender and receiver, poor signal to noise ratio, low 'plain English' score, ambiguity in key aspects of meaning, poor rhetorical appeal, and low levels of audience engagement. Most of these explanations included some issues that were avoidable and some that were unavoidable.

The politically sensitive context of the programme

This programme occurred in the context of a number of other government-driven, large-scale IT initiatives in the UK, which were perceived by critics as grandiose, politically driven, poor value for money, and ethically contentious.^{49,50} There was a vocal civil liberties movement (see <http://www.thebigoptout.com>) and threats of legal challenges, and some GPs in participating PCTs were strongly opposed to the introduction of the SCR as they perceived it as conflicting with their duty of confidentiality to patients.^{5,18} Pressure to provide complete and accurate information to the public about their right to opt out, along with political pressure on Connecting for Health to create as many shared records as possible in as short a time frame as possible, created a sensitive and legalistic atmosphere (for example, the first letter sent to the public about the SCR went through more than 50 iterations and was checked and re-checked by various official bodies and committees).

The challenge of audience heterogeneity

The target audience for the information programme was geographically restricted but demographically very diverse. The same message

was not appropriate for everyone. Both PCT and general practice staff worked hard to give customized talks to various voluntary sector, ethnic minority, and special interest groups, but reaching the entire target audience in this way would have been impossible. For practical reasons, drop-in sessions were mostly (although not exclusively) held during the day, which made them inaccessible to most of the working population. Furthermore, as receiving a message about the SCR would be highly confusing to an individual whose GP was not participating in the project, mass media messages were strictly contained within particular geographical areas. So, for example, radio advertisements were only played on small, local radio stations rather than on the more popular stations that covered metropolitan areas.

Lack of clarity about sender and receiver

Many people were unsure who the various messages were from and whether *they* were really the intended recipient. The sender of the mail merge letter, for example, was unclear to most people we interviewed. Some of these letters were officially sent from the Primary Care Trust (although the text had been largely drafted by Connecting for Health staff) and signed by the Trust's Chief Executive (a person most people had never heard of). One early example begins with the personal pronoun 'I' but later on in the same letter this becomes 'we' – a term which, in different paragraphs, variously embraces 'the NHS', 'NHS Advisors', 'staff', 'GPs', and 'GP practices'. A few general practices decided to depict a much clearer and personal sender by addressing the letter from the practice rather than the PCT. Even in these letters, however, the PCT, the NHS and government remained implicit co-senders.

There was also a certain amount of ambiguity in defining the receiver. Whilst the envelope was addressed to a named individual, the letter itself began 'Dear Patient...'. Some of the people we interviewed indicated that because of this, they did not feel the message was directly relevant to them.

Poor signal to noise ratio

Shannon and Weaver's concept of 'noise' (Fig. 1) is highly relevant here. The information programme for the SCR ran concurrently with numerous other local and national campaigns, and posters were typically crowded out on notice boards (we found them difficult to spot even when looking for them). Some NHS patients had received the letter about the SCR at around the same time as another letter asking them to participate in the 'Biobank' project (see <http://www.ukbiobank.ac.uk/>), which seeks to assess both genetic risk and health outcomes in a large sample of the population, and which also seeks to store people's health data on a central database. Some interviewees had assumed these projects were one and the same. The NHS Care Records Service (CRS) leaflet may have added to the confusion because it tried to contextualize the SCR within a wider IT programme which included local detailed (GP-held) records.

Low 'plain English' score

Press articles and materials produced at local level (e.g. by front line NHS staff) often scored well against the Plain English Campaign guidelines (see section 'Introduction'), although these ad hoc materials were not designed to convey full details of the overall campaign message. In contrast, the mail merge letter sent out by PCTs contained much important information, some of which was either legally necessary or considered prudent to avoid generating anxiety or inflaming the civil liberties movement. It also listed further sources of information including a more detailed information pack which people could send for in different languages, as well as an NHS Direct helpline.

As a result of all this 'required' information, and perhaps also of 'redrafting by committee', the mail merge letter was lengthy (15 paragraphs), and much of its content was inherently dull (although ironically the initiative was described as 'exciting'). The NHS CRS leaflet was similarly detailed and bland. In the original mail merge letter, the average sentence length

was 23 words (range 6–40), compared with a maximum recommended by the Plain English Campaign of 20 words, and no bullet points were used to break up text. The leaflet used shorter sentences and some headings and bullet points, but remained very ‘text heavy’. Much jargon and confusing acronyms had been successfully removed in the various iterations of the letter, although some obscure terminology remained (e.g. ‘the process of creating a summary record for you will begin’). Similarly, iterations to simplify language and grammar had some success (e.g. ‘adverse reactions’ became ‘bad reactions’) but the final version still contained 15 passive verbs (e.g. ‘your consent will be assumed’). Some of the language was non-immediate (‘...see a demonstration of what a typical Summary Care Record *would* look like’; emphasis added), vague (‘our intention is...’), and written in an impersonal style despite the repeated use of the personal pronoun ‘you’. The letter talked of a ‘first step’ (uploading details of medication and allergies onto the SCR) but not of any subsequent steps.

Ambiguity in key aspects of meaning

There seemed to be a distinct mismatch between the understandings of the information programme organizers and those of some sectors of the audience. For example, it unfortunately omitted a crucial item of information – that the SCR was an *electronic* record. Some people who had read the letter had not grasped this fundamental fact. Many people had a hazy notion of what medical records currently existed (e.g. some interviewees in the pilot sites believed that their records were already widely shared electronically and one or two were unaware that clinicians made any records at all). Local press articles sometimes did a good job of clarifying these issues.

Poor rhetorical appeal

In sharp contrast to the highly controversial context of the SCR pilot programme (described above), communications sent to the public

appeared to duck the key questions on which a person’s decision to opt in or opt out depended. The knotty issue of security failures (e.g. the risk of human malice or error), for example, was not addressed directly in the mail merge letter, and the CRS leaflet presented the topic in confident, absolute terms (‘...will use the strongest national and international security measures available [which will] make sure that your information is stored safely’) rather than facing the controversies square-on (e.g. the information could have been presented as ‘the risk of your record being accessed by a hacker or member of staff without proper permission is extremely small but not zero’). The absolute tone of the assurances served to lower their credibility, especially at a time when various data loss scandals by government departments were being reported in the media. As one participant in focus group of HIV positive service users put it, ‘My main concern is anybody hacking into the system. If it’s a computer, it can be hacked into’.

The Communications Department of Connecting for Health worked hard to try to reduce public anxiety about data sharing. For example, they introduced official terminology that a person’s SCR would be ‘created’ rather than data being ‘uploaded’. But this enforced language seemed deliberately to obscure the fact that data previously accessible only by a few known and trusted health professionals would now be potentially accessible by thousands of NHS staff. People were not told precisely who would have access to their records or the circumstances of such accesses. Vague expressions (e.g. ‘people involved in your treatment’ and ‘in a range of locations’) suggested obfuscation. The statement ‘GPs [in this town] have considered this carefully and believe that it’s in the best interest of patients’ rang hollow when contrasted with contemporaneous press articles (e.g. ‘Half of all GPs refuse to put patients’ records online’ – local newspaper headline, 21st November 2007).

The lack of clarity was partly because the SCR was an evolving technology for which the precise contexts of use were still being developed, and also perhaps an attempt to reflect the

fact that *technical* aspects of security were known to be extremely robust. However, the principles of rhetoric and argumentation suggest that an honest statement about the uncertainty of the programme, the possibility of human error and the extent of local professional dissent would have been more credible than bland assurance or systematic vagueness.

Low levels of engagement

Local implementation teams had an uphill struggle achieving active engagement from the public because, as described in section 'Introduction', most people were unengaged and passive in relation to this issue. We found some isolated examples of imaginative efforts to engage the target audience using novel formats and an explicit request. For example, one general practice produced a handwritten poster which explained the SCR to patients, told them why the topic was important, and how and by when to opt out if they wished to do so. This poster attracted much attention and generated discussion. It was innovative, colourful, personalized to the practice's own patients, displayed prominently in a place where posters were not usually seen (on a flip chart in the reception area), and had an air of spontaneity and brainstorming. It also directly asked patients to decide whether or not to opt out.

Another source of information that tended to engage the audience was press coverage. Some of this was prompted by the PCTs via press releases and arranged interviews, although most was produced spontaneously by local and national newspapers. Local journalists in particular were skilled in producing simple, short, novel messages, often personalized using individual stories. These grabbed the attention; prompted people to seek more information; and encouraged them to debate and form an opinion. Some press coverage, especially in national newspapers, was sensationalist and occasionally overtly misleading but local coverage was generally accurate, enhanced the official information programme and may have reached

audiences that would otherwise have been hard to reach.

The less successful components of the public information programme did not fully apply the principles of audience engagement. Posters were professionally produced but had a very 'standard' format and were displayed in conventional healthcare settings. For the minority who were already engaged with issues such as confidentiality or government surveillance, these posters sometimes triggered action, but for most, they had little or no impact. The mail merge letter looked like numerous other public-sector mail shots; it included a request ('Important: Please Read'), but this was not a clear cue to do something active (i.e. decide whether to opt out or not).

Indeed, whilst the letter was strong on the rhetoric of empowerment ('As a patient you have choices....'), the accompanying leaflet assured people that they should 'do nothing' as records would be created 'automatically'. They were not told what they might like to weigh up in making their choice. The over-emphasis on the benefits of the SCR (such as 'better' and 'safer' care) without consideration of any potential disbenefits (e.g. data loss or intrusion) made the notion of choice seem absurd (who in their right mind would choose the possibility of 'worse' or 'less safe' care?). It may have helped to engage the audience by asking the reader to balance benefits and risks from their own perspective and arrive at a decision.

Discussion

This study of the limited success of the public information programme in SCR pilot sites identified a number of contributing factors which the communications team could not influence – including the sensitivity of the SCR as a 'government driven' IT programme; the programme's complex geography (the technology was implemented in some GP practices but not other adjacent ones); the demographic and social diversity of the target population; and the very low initial level of public awareness and interest in shared electronic records. Some

contributing factors, however, were potentially remediable – including clarity and simplicity of the message; attending to the meaning which the message held for the target audience; ensuring that arguments were balanced; maximizing audience engagement, and including a specific and immediate appeal to the reader to make a personal decision about whether to opt out or not. Perhaps this explains why the levels of public interest and engagement were even lower than in previous pilot studies of regional shared record projects in the UK.^{11,15,48}

Whilst the main data set for this study was collected in the first two PCTs to go live with the SCR, it is encouraging that versions of the mail merge letter produced by most PCTs who have joined the SCR programme more recently are considerably more appealing and readable than the ones we studied in depth. In particular, the message in these later materials more often has a clear sender and is personalized to the recipient; it is shorter, clearer and uses more immediate language; and the text is broken by the use of bulleted lists. However, even later versions of the letter and leaflet continue to present the introduction of the SCR as uncontroversial and offer assurances that security is absolute.

The overwhelming majority of individuals who are asked to consider the personal risks and benefits of the SCR spontaneously construct an equation that comes out in favour of having one.¹⁸ Aside from the ethical aspects (if the benefits of a new technology are unknown, and/or if it has real or potential drawbacks, these should be acknowledged), an invitation which asks people to weigh the benefits of the SCR against the disbenefits and ‘make their mind up’ (perhaps by including an opt-out form in the same envelope, as piloted elsewhere⁵¹) would probably increase engagement and prompt action. Whilst a more transparent message style might prompt an increase in the proportion of people actively opting out, the absolute numbers are likely to remain small (current opt-out rates are less than 1%), and the proportion of the population whose consent is *informed* is likely to increase substantially.

The findings of this study resonate with the empirical evidence from the wider communications literature (see section ‘Introduction’) that mass media campaigns alone, even if they include personalized letters to individuals, have limited impact. It follows that such approaches provide a limited basis for assuming ‘implied consent’. Whilst there is much work to be carried out to optimize the message and the medium for mass communications about the SCR, the potentially powerful impact of interpersonal communication also needs to be recognized and exploited. Unpublished data from Connecting for Health show significant differences in opt-out rates for the SCR between general practice populations depending on whether the practice actively supported the SCR, took a neutral stance, or expressed internal dissent (e.g. with one GP resisting a practice decision to be part of the scheme). Whilst enquiries from patients may place additional strain on busy GPs (and GPs in turn may try to negotiate a fee for responding to these), such input could have a positive impact on engagement.

This study raises important issues for the ‘digital inclusion’ agenda.⁵² Official health policy in the UK gives great weight to patient empowerment and seeks to support patients and citizens in taking more control of their health.^{53,54} However, people with low health literacy may not be able to comprehend health information, leading to confusion and feelings of powerlessness,⁵⁵ and this could increase existing health inequalities as well as creating new ones based on access to, or ability to process, electronic information.^{52,56} The ‘don’t know, don’t care’ stance taken by much of the lay public towards shared electronic records in this and other studies is a contemporary example of the low engagement scenario of which Lord Wanless⁵⁷ warned 5 years ago. Our findings contrast starkly with the original policy vision of empowered, information-literate patients accessing their SCR via HealthSpace, correcting inaccuracies and driving up the quality of data (and indirectly, the quality of care).⁵⁸

An NHS that is increasingly organized around the assumption that people are partners in their

Box 1 Recommendations for future information campaigns in relation to electronic patient records

1. In letters, address the recipient personally (not 'Dear Patient'). Use a sender who is known to, and trusted by, the recipient, and make it clear who has sent the message.
2. Make the message clear and simple, for example by consistently following the guidelines of the Plain English Campaign (short sentences, active verbs, personal language, subheadings, bullet points, avoidance of jargon, and acronyms and imaginative use of colour and illustrations).
3. Avoid 'drafting by committee' and minimize the amount of information provided for political or legal reasons.
4. Present a balanced argument and encourage debate about pros and cons to increase engagement.
5. Include a specific, immediate, and personal appeal to make a decision, and provide all relevant information needed for the person to make it.
6. Encourage local initiatives to personalize and make sense of a wider campaign. 'Grass roots' efforts do not have to be polished or standardized to be effective. On the contrary, there is much to be gained from spontaneous, creative formats and unusual settings.
7. Build relationships with the media and invite local stories.
8. Consider tailored campaigns for particular target audiences, and work with local groups to develop these.

own care and active choosers of particular service developments and models is, arguably, increasingly out of touch with a significant proportion of the population. Ensuring that people are aware of their rights and choices in relation to the sharing of their personal health data is a challenging task. Ensuring that they take full personal responsibility for 'opting in' or 'opting out' is probably impossible. Not all people have the motivation or the capacity to engage with complex messages about sharing electronic data. If we are to make any inroads into the predominantly 'don't know, don't care' attitude towards shared electronic records, policymakers need to take careful note of the lessons learned from this study (Box 1). These recommendations (which are not in order of importance) are not a guarantee for success, but may increase the chance of informing and engaging potential participants in the programme rather than merely fulfilling legal requirements.

The lessons learnt in this study may have wider implications for non-UK and non-healthcare settings where citizens are asked to make important decisions about participation in a programme. However, whilst this study has drawn eclectically on a number of different theories of communication to produce a preliminary unifying framework for the study of contemporary information campaigns, there is much scope for further theoretical and empirical work in this area.

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