

## WHAT IS ALREADY KNOWN ON THIS TOPIC

Global assessments by patients and doctors are commonly used to assess the effectiveness of treatments for various diseases

Some evidence suggests that assessments by patients may differ from those by doctors

## WHAT THIS STUDY ADDS

Doctors' and patients' global assessments agreed on average on the derived estimates of treatment effects

Modest differences in either direction for specific conditions and treatments cannot be excluded

empirical evaluation should not necessarily be interpreted as evidence that one of the two is redundant.

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## Patients' attitudes to the summary care record and HealthSpace: qualitative study

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### ABSTRACT

**Objective** To document the views of patients and the public towards the summary care record (SCR, a centrally stored medical record drawn from the general practice record) and HealthSpace (a personal health organiser accessible through the internet from which people can view their SCR), with a particular focus on those with low health literacy, potentially stigmatising conditions, or difficulties accessing health care.

**Design** 103 semistructured individual interviews and seven focus groups.

**Setting** Three early adopter primary care trusts in England where the SCR and HealthSpace are being piloted. All were in areas of relative socioeconomic deprivation.

**Participants** Individual participants were recruited from general practice surgeries, walk-in centres, out of hours centres, and accident and emergency departments. Participants in focus groups were recruited through voluntary sector organisations; they comprised advocates

of vulnerable groups and advocates of people who speak limited English; people with HIV; users of mental health services; young adults; elderly people; and participants in a drug rehabilitation programme.

**Methods** Participants were asked if they had received information about the SCR and HealthSpace and about their views on shared electronic records in different circumstances.

**Results** Most people were not aware of the SCR or HealthSpace and did not recall receiving information about it. They saw both benefits and drawbacks to having an SCR and described a process of weighing the former against the latter when making their personal choice. Key factors influencing this choice included the nature of any illness (especially whether it was likely to lead to emergency care needs); past and present experience of healthcare and government surveillance; the person's level of engagement and health literacy; and their trust and confidence in the primary healthcare team and the

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**Box 1 Key characteristics of the summary care record****The technology**

The summary care record (SCR) is a centrally stored summary of key medical details that is created from a person's existing NHS record (currently, the detailed record held by their general practitioner) and made available to NHS staff in emergency and unscheduled care situations (accident and emergency departments, general practice out of hours clinics, and walk-in centres).

**What information does the SCR contain?**

Information held on the SCR is currently limited to current medication, allergies, and adverse reactions (the "phase 1 upload"), but a minimum clinical dataset (such as whether someone has diabetes—the "phase 2 upload") is being developed and added in selected sites.

**Security safeguards**

Extensive technical safeguards have been built into the SCR to prevent unauthorised access. Role based access controls restrict access to NHS staff with a legitimate relationship to the patient. Access by staff without such relationships are logged and audited; penalties for unauthorised access are severe and might include dismissal.

**The consent model**

The current consent model for the SCR is one of implied consent or "opt out" (that is, unless a person explicitly withdraws consent, an SCR will be created). Patients can choose one of three options: "don't store" (a blank SCR will be created; nothing will be uploaded beyond the demographic details that are already on the spine); "store and share" (a full SCR will be created); or "store but don't share" (a full SCR will be created but explicit consent must be obtained from the patient every time a health professional wants to access it). There will also be an option for a "virtual sealed envelope"—a "store but don't share" option applied to selective sensitive information.

wider NHS. Overall, people with stigmatising illness were more positive about the SCR than people who claimed to speak for "vulnerable groups." Misconceptions about the SCR were common, especially confusion about what data it contained and who would have access to it. Most people were not interested in recording their medical data or accessing their SCR via HealthSpace, but some saw the potential for this new technology to support self management and lay care for those with chronic illness.

**Conclusion** Despite an extensive information programme in early adopter sites, the public remains unclear about current policy on shared electronic records, though most people view these as a positive development. The "implied consent" model for creating and accessing a person's SCR should be revisited, perhaps in favour of "consent to view" at the point of access.

**INTRODUCTION**

A large scale IT project is under way in England to place a summary version of the electronic patient record (the summary care record or SCR) on a central store, accessible on a secured extranet by a wide range of National Health Service (NHS) staff and made accessible to patients via the "HealthSpace" website.<sup>1-3</sup>

Box 1 summarises details of the SCR. HealthSpace is a personal health organiser accessible through the internet on which people can store their medical details (such as blood pressure readings) and which also serves as an interface for NHS patients to view their SCR. For storing their own medical details, individuals must create a basic HealthSpace account; to view their SCR, they must create an advanced account.

Protagonists of shared electronic patient records anticipate several benefits. Clinical care, especially in the emergency setting, will (they believe) be better informed; fewer medical errors will occur; handovers between clinical teams will be smoother; people with limited English and those with low health literacy will receive as high a standard of care as everyone else; patients will be empowered; and as the efficiency of care rises, its costs will fall.<sup>4,5</sup> Opponents have argued that the

**Box 2 Benefits of the SCR perceived by service users****Individual interviews (n=103)****Commonly mentioned (by more than 10% of the sample)**

- SCR is a "good thing" (unspecified or "the more information the better")
- Having medical details safely and consistently in one place, especially in emergency situations or chronic/complex illness
- Makes care easier/more efficient/saves time/helps you fill out other forms
- Not having to answer questions, fill out forms, or remember what medication you are on

**Less commonly mentioned (by less than 10% of the sample)**

- Stops people giving you the wrong medication or medication that you are allergic to
- Medical record available when not near own general practitioner/can move house without changing general practitioner\*
- Could prevent a recurrence of a previous bad experience (lost medical record, duplicate blood test, bad allergic reaction, collapse)
- Can print off for own records or to take to another healthcare professional
- Provides evidence about a problem that patient knows they have but which health professionals might doubt
- Stops people lying (because it provides an "objective" version of reality)
- Useful for deaf people

**Additional themes raised in focus groups (seven groups, 67 participants in total)**

- The SCR could be printed out and taken to another clinician for a second opinion
- New immigrants might change general practitioner often and often have particular problems articulating key aspects of their medical record (some of which might be traumatic). The SCR will help continuity of care in this group
- Potential research uses of aggregated data from SCR
- If someone has an SCR a general practitioner would not be able to refuse treatment pending arrival of records
- Useful for elderly people who might be forgetful but who are on lots of different tablets
- "To put my side of the story"

\*Two people independently described the SCR as a "fantastic" idea because (in their view) it allowed them to remain registered with a GP in a different part of the country after moving house.

**Box 3 Drawbacks of the SCR perceived by service users****Individual interviews (n=103)**

- Malicious or inappropriate access
  - Hackers/fraudsters
  - Benefits agency
  - Employers/insurance companies/credit control agencies
  - Local NHS colleagues (unauthorised access to records of NHS staff)
  - Parents (in relation to pregnancy test or termination of pregnancy)
  - “The general public”
  - Receptionists
  - “Foreigners”
- Security breaches
  - Technical error (includes power cuts, system breakdown)
  - Human error or not enough people to run the system
- SCR a “bad thing” (unspecified or all computers are bad)
- Stigma/labelling (such as, depression, counselling, sexual infections, child with ADHD (attention-deficit/hyperactivity disorder))
- Waste of money
- People won't understand their choices/too complicated
- NHS would need to provide more computers—for example, in operating theatres
- Mistaken identity (for example, similar name)
- If inaccurate, could cause more harm than good

**Additional themes raised in focus groups (seven groups, 67 participants in total)**

- Allows general practitioners to turn away patients who seek to register with them but might be expensive to treat
- Government would sell data to private companies
- Staff “incompetence” is likely to exacerbate problems if the SCR is introduced as more can go wrong
- An accurate and complete SCR depends on data quality standards and practices
- People with sexually transmitted infections might be open to blackmail as information indicating an affair could be passed to a spouse
- Discriminates against those who have chosen not to register with a general practitioner
- Family members could learn of a drug addiction

risks in terms of practicality, technical complexity, cost, and threats to confidentiality outweigh any potential clinical benefits.<sup>6,7</sup> Some take a middle ground, arguing that projects like the SCR will depend crucially on effective business management, engagement of clinicians, and active participation of patients.<sup>8-11</sup>

As part of a wider evaluation of the SCR and HealthSpace in early adopter primary care trusts, we sought to explore the attitudes of patients and the public to these new technologies, which had recently been introduced in their area.

**METHOD****Setting**

We carried out the study in three primary care trusts that were participating in the early adopter programme for the SCR. All had higher than average levels of socioeconomic deprivation and lower than average levels of limiting long term illness; ethnic mix was similar to the UK average.

**Sampling and recruitment**

Individual participants were recruited from general practices, out of hours centres, accident and emergency departments, and walk-in centres. Potential participants were generally approached by someone who was not a member of the research team (such as a booking-in clerk) and, if they were interested, were given a “plain English” invitation to participate, followed by a more detailed information sheet. “Special” (that is, shorter and simpler) invitation letters and information sheets had been prepared to be offered to those with cognitive difficulties or low health literacy, or both.

There were seven focus groups with participants recruited from voluntary sector organisations and NHS interpreting and advocacy services. The group participants were: advocates of vulnerable groups; advocates of people with limited spoken English; people with HIV; users of mental health services; older people; young people; and people on a drug recovery programme (see [bmj.com](http://bmj.com) for further details).

**Individual interviews**

Individual interviews were brief (around five minutes) and were not recorded, so as not to put people off participating. We asked the following questions, adapted flexibly to fit with the person's responses:

- Do you know anything about electronic [computer] health records?
- Did you get a letter/have you heard about the SCR [explain if necessary]?
- Would you want an SCR? Why/why not?
- What would you see as the benefits of the SCR?
- What would you see as the disadvantages of the SCR?
- Any other concerns?
- Have you heard of HealthSpace? [explain if necessary]
- Would you want an advanced HealthSpace account to see a summary of your medical record? Why/why not?

We made contemporaneous notes on paper, writing down responses verbatim as much as was practical. Recruitment continued until saturation of themes was achieved.

**Focus groups**

Focus groups were held at community venues with which participants were already familiar. After explaining the study, the researcher asked if anyone had heard of the SCR and HealthSpace, explained these if necessary, and invited comments (see [bmj.com](http://bmj.com)). Focus group discussions were transcribed and independently checked; contemporaneous notes were also made during the groups.

**Data analysis**

We conducted an initial content analysis of free text responses in the individual interviews (by counting the number of people who mentioned a particular topic such as security). In a more detailed qualitative analysis, three

researchers independently coded the write-ups of individual interviews and focus group transcripts. We held a series of discussion meetings to refine these coding categories and developed a shared analytical framework. Disagreements were resolved by discussion.

## RESULTS

### Demographic characteristics

Overall, 41% of our sample were men; 83% were white, 8% Asian, 6% African, and 3% mixed race. Of those who chose to give their occupation, most described white collar, manual, or homemaker jobs, and 6% were unemployed; we estimated 20% of the sample to have high health literacy, 45% medium, and 38% low. People attending the walk-in centres seemed to represent a particularly deprived group (typically, young mothers seeking advice on a minor health problem in a toddler) and accounted for a high

proportion of the participants with low health literacy. About a third of individuals approached, and a similar proportion of people invited to join focus groups, chose not to participate in the study. See [bmj.com](http://bmj.com) for characteristics of the sample.

### Awareness of the SCR and HealthSpace

Official statistics suggest that by the date of the interview, around 95% of the population in our sample area had been sent a letter informing them that the SCR was being introduced in their area. Only about one in seven recalled receiving this letter. Overall, 29% were aware of the SCR (some via the media or their general practitioner) and 8% were aware of HealthSpace. Awareness of the SCR was higher in those we had classified as having high health literacy (one in two aware) than those with medium or low health literacy (one in four aware). Many believed (wrongly) that electronic records were already shared between health professionals either locally or nationally.

#### Box 4 Attitudes of service users to HealthSpace

##### Individual interviews (n=103)

##### *Would not want any kind of HealthSpace account (total n= 62)*

- Not interested, wouldn't want to see own record (n=44)
- Worried about security (n=9)
- Prefer to discuss my health with my general practitioner or other practice staff (n=8)
- Don't use the internet for anything/haven't got a computer/"I'm old fashioned" (n=7)
- Pointless, wouldn't tell me anything I don't already know (n=6)
- Registration process too much hassle (n=4)
- Worried about a family member or partner seeing (n=3)
- A printout of my general practice record would give all the information needed (n=3)
- "No time to mess around" (n=1)

##### *Yes, would like some sort of HealthSpace account (total n=23)*

- Sounds like a good idea/sign of progress in the NHS (n=5)
- Would like HealthSpace to keep track of child or elderly parent's illnesses (n=5)
- Would like to see HealthSpace once, just to have a look at what is there (n=4)
- Have a lot of health problems myself, would like to keep track of them (n=4)
- Enjoy using computers/interested in playing with the technology (n=2)
- See my [child's] x ray pictures (n=1)

##### *Undecided (total) 10*

- Haven't thought about it, but haven't ruled it out (n=6)
- Might want it but it's not a priority (n=4)
- Ambivalent (because of security worries) (n=2)
- Unable to understand explanation of what HealthSpace is (n=2)

##### *Additional themes raised in focus groups (seven groups, 67 participants)*

- Creates a route for hackers to access the SCR
- Not fit for purpose—could just as easily write personal health data down in a book or keep a file on a personal computer
- A person's medical record could be accessed by a partner without their full consent if they were in a coercive domestic relationship
- Registration process is complex and requires high IT literacy; this will discriminate against people with low literacy and those who are dyslexic
- Registration process requires a consistent date of birth, consistently spelt surname, and three pieces of identification—for example, utility bill, driving licence; refugees and asylum seekers might not have these documents and might use different spellings of their surname.

### "Benefits" v "drawbacks"—a personal equation

Most people were positive about the SCR and happy that if they did nothing, one would be created for them. Few were unequivocally in favour of the idea. Rather, people described a process of weighing perceived benefits (box 2) against drawbacks (box 3) for them personally and, when relevant, their dependent relatives. The balance between benefits and drawbacks was different in different situations (as the parent of a child with a behaviour disorder put it, "records are very delicate things"). See [bmj.com](http://bmj.com) for full details of the benefit-drawback equation.

The most commonly cited factor influencing the decision to have an SCR was personal experience. People who had had an adverse drug reaction, an episode of loss of consciousness, lost medical records, or a "near miss" medical error, and those with serious or complex health problems (especially those with multiple comorbidities) tended to view the SCR positively. Those who had been the victim of mistaken identity (in the NHS or outside it), an incorrect medical diagnosis, or identity fraud (such as stolen credit card) tended to be opposed to it. Those who lacked relevant personal experience were often undecided about, or disinterested in, the SCR.

For most people, the personal risk-benefit equation came out in favour of having an SCR but against having a HealthSpace account (box 4). Many were unsure of the purpose of HealthSpace, describing it as "pointless," "irrelevant," and not fit for purpose. They also saw HealthSpace as a potential weakness in the system in terms of security. A small but important minority, however, saw potential benefit of HealthSpace for keeping track of their own or a relative's chronic illness.

## DISCUSSION

Our study, published just as the Department of Health plans to extend the SCR programme from a few early adopter sites to much of the country, has shown that a person's decision to have (or not to have) a summary

**WHAT IS ALREADY KNOWN ON THIS TOPIC**

The English Department of Health is about to extend a programme to create an electronic summary of medical details, accessible to NHS staff via the internet, for every NHS patient who does not opt out

Previous research in relatively affluent areas suggested that patients are willing and able to engage with decisions about their electronic medical record

**WHAT THIS STUDY ADDS**

Levels of awareness of, and knowledge about, the summary care record (SCR) and HealthSpace (to enable records to be viewed over the internet), especially among those with low health literacy, are currently low in early adopter sites, despite an extensive public information programme

People's attitudes to these new technologies vary but most are positive towards the SCR and negative towards HealthSpace

The decision whether to have an SCR involved balancing perceived benefits with perceived risks and was heavily influenced by previous personal experience (of illness, the healthcare system, government surveillance, or data loss)

care record (SCR) is both individual and complex. The benefits of the SCR (especially the availability of medical information in an emergency situation) must be weighed against its drawbacks (such as the risk of security breaches, human error, the potential stigma of disclosure, or a label that becomes a self fulfilling prophecy) in a way that addresses personal priorities and context. Key mediating factors include the nature of the illness (especially whether it is likely to lead to emergency care needs when the individual is unable to communicate); the person's past and present experience of both healthcare and government surveillance; their level of engagement and health literacy; and their level of trust and confidence in the primary healthcare team, the NHS, and the government.

**The importance of sampling frame**

While there is a substantial body of literature on what patients think about access to electronic records held by their general practitioner, and while doctors have published their own views on the ethics and practicality of the SCR, previous studies on patients' attitudes to internet based records have been limited. The population in one study in north Oxford had levels of health literacy and engagement that make it unlikely to be representative of the wider UK population.<sup>12</sup> Another study, a pilot project on internet based medical records in Hampshire, had a poor response rate.<sup>13</sup>

Our own sample broadly reflected the ethnic mix of the general population and was purposively skewed towards lower sociodemographic groups, those with lower health literacy, and those with high health and social care needs. While the articulate "empowered" middle classes are under-represented in our sample, they are also under-represented in the section of the population that seeks health care in emergency and unscheduled care situations (the main group for whom the SCR was designed<sup>11</sup>).

**Health literacy**

Our approach to classifying people according to their health literacy found that in participants with low

health literacy, lack of interest in one's own health seemed to be the key moderating factor that explained the mismatch between the decision to have an SCR (almost all "yes" or "don't care") and the decision to have a HealthSpace account (almost all "no"). This supports a recent finding that the "empowerment" agenda requires cognitive skills that not all citizens possess.<sup>14</sup> This finding is preliminary, however, and should be explored further.

**Implications for the consent model**

Two key findings from this study—that many people fail to engage with the SCR until they have a relevant personal experience, and that trust is a feature of the interpersonal relationship rather than being associated with particular healthcare roles—suggest that seeking a patient's consent to view their record should occur as far as possible at the point of access in an unscheduled care setting. A "consent to view" model might be both more pragmatic and more ethically justifiable than the current model of implied consent to upload, after which the record can be accessed by anyone who can claim a "legitimate relationship" with the patient.

We found several misconceptions about the SCR and HealthSpace (see [bmj.com](http://bmj.com) for further details). Importantly, many people do not understand the difference between the PDS (personal demographics service—a demographic database on which all NHS patients are listed), the electronic record held by the general practitioner, and the SCR. They have limited understanding of what data are currently shared or what technical and access control measures are in place to protect their data. These findings align with those of other surveys<sup>15</sup> and are unsurprising given the inherent complexity and rapid development of electronic records in the NHS. In a world in which health care is supported by technologies that are beyond the awareness of most and the comprehension of some, "informed consent" might have unstable foundations—a finding that questions the adequacy of existing legislation about consent for the creation of, and access to, electronic patient records more generally.<sup>16</sup>

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## Befriending carers of people with dementia: randomised controlled trial

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### ABSTRACT

**Objective** To evaluate the effectiveness of a voluntary sector based befriending scheme in improving psychological wellbeing and quality of life for family carers of people with dementia.

**Design** Single blind randomised controlled trial.

**Setting** Community settings in East Anglia and London.

**Participants** 236 family carers of people with primary progressive dementia.

**Intervention** Contact with a befriender facilitator and offer of match with a trained lay volunteer befriender compared with no befriender facilitator contact; all participants continued to receive "usual care."

**Main outcome measures** Carers' mood (hospital anxiety and depression scale—depression) and health related quality of life (EuroQoL) at 15 months post-randomisation.

**Results** The intention to treat analysis showed no benefit for the intervention "access to a befriender facilitator" on the primary outcome measure or on any of the secondary outcome measures.

**Conclusions** In common with many carers' services, befriending schemes are not taken up by all carers, and providing access to a befriending scheme is not effective in improving wellbeing.

**Trial registration** Current Controlled Trials ISRCTN08130075.

### INTRODUCTION

Providing care for a person with dementia is stressful and demanding, and carers of people with dementia have poorer physical and mental health than carers of people with other conditions.<sup>1</sup> A short term (eight week) trial of the provision of a befriending, peer support intervention for family carers of people with dementia found that it had no significant impact.<sup>2</sup> As

friendships take time to evolve, and therefore befriending should be evaluated over the long term, we carried out the befriending and costs of caring (BECCA) randomised controlled trial of a long term voluntary sector based befriending intervention.<sup>3</sup>

### METHODS

#### Design

We used a randomised controlled trial to compare usual care plus a social support intervention (access to a befriender facilitator) with control (usual care) for carers of people with dementia. We collected data at baseline and at 6, 15, and 24 months after randomisation. We identified the 15 month data as the main outcome data at the start of the trial.

#### Participants

Participants were family carers of a community dwelling recipient of care with a primary progressive dementia. We recruited carers between April 2002 and July 2004 in community settings in the counties of Norfolk and Suffolk and in the London Borough of Havering. Carers were eligible to participate if they were spending 20 hours or more a week on care tasks.

#### Baseline assessments and randomisation procedures

Researchers did baseline assessments before randomisation. Interviews generally took place in carers' own homes. Baseline measures included demographics; service use; carers' wellbeing and health related quality of life; and carers' burden, relational deprivation, loneliness, and perceived social support. We block randomised participants and stratified them by kinship of the carer to the person with dementia and by density of population. Trial participants were not blinded to group

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