

The Public View on Electronic Health Records

Issue Date: 7 October 2003

INTRODUCTION

The National Programme for Information Technology (NPfIT) will spend £2.3 billion over the next three years to improve health care for patients and to secure the future of the National Health Service. Its overall objective is to ensure that the right information is in the right place whenever health decisions are made and acted on. The main vehicle for doing this is the Integrated Care Record Service or ICRS. The ICRS will enable information to be shared among all those providing care, including patients themselves.

ICRS will create a basic health record, called the 'Spine record', for every patient. The Spine record will contain the essential information anyone making health decisions about that patient needs to know. ICRS will enable appointments to be booked instantly by computer and will enable prescriptions and test results, including scans and x-rays, to be shared electronically and therefore instantly. It will allow patients to know what information is being shared about them and who is seeing it. It will give patients unprecedented control over what is shared. Over time more services will be added such as automatic safety checks on prescribing. Eventually, patients will be able to view their records in their own homes via a well-protected internet link.

It is essential that those developing the ICRS understand what patients and the public want and expect from it and what their priorities are. Between April and July 2003, the NHS Information Authority and the National Programme commissioned the Consumers' Association to carry out qualitative and quantitative research with patients and the public to gauge their views, expectations and concerns about an Integrated Care Record Service (ICRS). Qualitative research refers to structured discussions with small groups (called focus groups) and one-to-one or interviews (called depth interviews) or interviews with two people at a time (called paired interviews). Qualitative methods are often used to identify major concerns and issues which can then be further explored with a larger number of people via quantitative research. Quantitative research tests the views of large numbers of people, often via questions on an omnibus survey. Omnibus surveys that we commission are normally conducted face-to-face with people in their homes as part of a larger set of questions on a variety of topics.

The research reported here follows qualitative and quantitative research undertaken by the NHS Information Authority a year ago, also with the Consumers' Association¹. It explored in some detail people's views and concerns on patient confidentiality in a world of shared electronic records. That work gave rise to a set of proposals for a new way of managing

¹ Published as *Share with Care!* by the NHS Information Authority in October 2002 and available at www.nhsia.nhs.uk/confidentiality.

patient confidentiality². Following wide consultation, the amended proposals were incorporated into the technical specifications for the ICRS³ and a new Confidentiality Code of Practice for the NHS⁴. They continue to inform the development of public information materials.

In the qualitative phase of the current research, people in focus groups were shown a brief video of the NHS as it is today with both computerised and paper records, neither of which is easily shared among health care providers. The current situation was also explained to respondents taking part in the face-to-face interviews but they were not shown a video. Participants were then told of plans to create an integrated system of electronic records, on-line appointment booking and electronic prescriptions. The concept of a basic Spine health record was explained to them. They were told how the Spine record would be created and asked for views on its contents. They were asked their views on a range of issues to do with the ICRS and the Spine record, including potential benefits.

The qualitative phase was followed by a quantitative one – a survey of nearly 2000 adult members of the public. They were given basic descriptions before being asked a series of questions about electronic records, booking and prescribing.

The analysis presented here has been conducted and analysed by the Consumers' Association and the researchers they commissioned: Research Works Limited (qualitative) and BMRB International Limited (quantitative). The summary points, observations and conclusions are entirely theirs and not those of the National Programme or the NHS Information Authority.

The results of this research are being used to inform the development of the ICRS. They have already had an influence on the phasing of the ICRS, which will be built up in stages. There will be more input from patients and the public – and other interested parties - as the ICRS is developed, tested, implemented and evaluated.

In this report, headings in **red** refer to the qualitative research and headings in **blue** to the quantitative.

² Published as *Caring for Information* by the NHS Information Authority in October 2002 and available at www.nhsia.nhs.uk/confidentiality. It was one of four documents subject to wide consultation between October 2002 and January 2003. The others were a Confidentiality Code of Practice for the NHS, a national information sharing charter between the NHS and the public, and the script of a public information video proposed as part of a wider public information campaign.

³ Available in summary form and in full at <http://www.doh.gov.uk/ipu/programme/>

⁴ Available at <http://www.doh.gov.uk/ipu/confiden/protect/index.htm>.

SUMMARY OF RESULTS

QUALITATIVE RESEARCH KEY FINDINGS AND CONCLUSIONS

- Overall, patient reaction to the ICRS was **extremely positive** - the only barrier was a perception that **security** was an issue with electronic systems.
- In reality, patients need to be **informed and reassured** about security protocols (fingerprint access was preferred) and sharing routines that **excluded non clinical NHS staff** and non NHS staff.
- Patients' perception of who would share their information in the NHS was restricted to **professionals treating them** within hospitals and GP surgeries.
- Those who perceived themselves to be 'ill' and those with longer records were more interested in the concept of the **sealed envelope** (as a means of patients restricting sharing of certain personal information) and taking a more **active role** in their healthcare.
- Patients pointed out the tension between providing **patient confidentiality** via the sealed envelope and providing NHS care providers with **accurate and relevant information**.
- Patients prioritised the benefits of the service to NHS **clinical personnel** and patients i.e. that information will be **immediately available** about any patient at the point of treatment.
- Additionally, patients looked forward to **improved communication** via ICRS within the NHS, particularly between **referrers and referral services**.
- More personally, patients appreciated the opportunity to **record their wishes** on their medical record and to have access to **test results** and **prescription** information.
- It is likely that the full benefits of patient access will **emerge over time**. At present, simply being party to information about oneself was considered a development.
- Overall, patients felt most comfortable with the idea of accessing their record at the **GP surgery**.

- For the future, the idea of having full access to one's notes (e.g. referral and discharge letter) as well as being able to order **repeat prescriptions** and **make bookings on-line** was appealing. However, patients wanted to see a **consolidation** of current services (so that the system could 'prove' itself) before new developments were introduced.
- At present patients simply doubted whether it was possible for the NHS and **technology to cope** with patients ordering prescriptions, e-mailing GPs and booking appointments on-line.
- The success of ICRS will be judged on **patient experience of current services**. Patients hoped that ICRS would make the NHS **visibly more efficient**.

QUANTITATIVE RESEARCH KEY FINDINGS AND CONCLUSIONS

General Health and Experience of the NHS

- It is estimated that around a third of respondents have been interacting regularly with the NHS over the last 12 months. Those aged 65 and over are more likely to be in this group than other ages. However, around three-quarters (76%) have visited their GP in the last 12 months so it is important not to underestimate the relevance of ICRS to the public in general.
- Four in ten have experienced an event which, it is envisaged, would be addressed by ICRS. Such events include having to change an appointment, having to repeat information already given and missing an appointment.

Access to Medical Records

- In terms of who should have access to at least some part of patients' medical record, paramedics and ambulance crew received the highest response. Overseas hospitals providing them with care were selected by around half of respondents, which bears out the response from the qualitative research.
- There is little appeal for those outside the 'caring loop' to have access to medical records and there is also an indication that older people are less likely to think that access should be given.

Perceived benefits of ICRS

- Just being able to see one's record (including test results and medical history) was important to the majority (six in ten) of respondents. The ability of the GP to make instant referral appointments was regarded highly by six in ten respondents.
- Older people appear less engaged by ICRS – perhaps due to a greater nervousness about new technology. It is important that provision is made for this group so that they don't miss out.
- It is not just benefits to the individual that are seen as important. Half of respondents considered the concept of ICRS assisting the better management of surgeries and hospitals to be important.

Preferred Access Location

- Being able to look at your record on computer in your home was appealing to two thirds of people and was the most appealing benefit presented. However, appeal is lower among the over 65s. Again, it is important to ensure that provision is made for this group.

Electronic Booking of Appointments

- Despite the interest in computerised records, over half of respondents said that they would choose a dedicated call centre to book their appointment. Around a third would choose e-mail and about three in ten would opt for a secure internet site.

Electronically Managing Prescription Information

- There were no clear priorities for the implementation of electronic prescription processing. Each benefit was felt to be important by at least four in ten.

What questions would the public like answered?

- Key questions that the public would most want answered revolve strongly around how secure the site would be and who would have access. Reassurances in these areas would be important when implementing the ICRS.

QUALITATIVE RESEARCH

QUALITATIVE RESEARCH OBJECTIVES

- to understand how patients view the prospect of an **Integrated Care Record Service (ICRS)** including the basic **Spine record**
- to assess the **appeal of the service** and explore options for patient access
- to examine **patient priorities for the service** – early essentials vs. on-going desirables
- to assess the **relative importance of different features**
- to identify '**success factors**' – by what criteria will patients judge the success of the ICRS?
- to explore patient **expectations of accessibility** i.e. who should/should not have access to records
- to discuss **preferences for patient identification** (e.g. NHS number)
- to find out **how patients would like to be informed** and **what they would like to know**.

Summary point: The overall objective was to provide a patient perspective on the ICRS in order to inform future development.

QUALITATIVE RESEARCH METHODOLOGY

Six focus group discussions with the general public (up to 8 respondents, 1.5 hours duration)

Group 1 – Female, Younger family, 'chronic/acute', SEG BC1

Group 2 – Male, Younger family, 'chronic/acute', SEG C2D

Group 3 – Male, Older family/Empty nester, 'chronic/acute' SEG BC1

Group 4 – Female, Older family/Empty nester, 'chronic/acute', SEG C2D

Group 5 – Female, Retired, 'chronic/acute', SEG BC1

Group 6 – Male, Retired, 'chronic/acute', SEG C2D

- all had received NHS treatment within the last six months
- at least two respondents in each group had experienced private health services within the last 12 months (whether within NHS or private setting)
- at least two respondents in each group had caring responsibilities.

18 depth interviews with the general public (45 minutes – 1 hour duration)

- six pair depth interviews with young people aged 12-16 years old
- four depth interviews with people frequently moving between NHS services
- four non-English speakers (Iraqi Kurdish, Arabic, Somalian, Kosovan)
- a mix of 'chronic/acute' conditions was achieved across the depth interviews.

Copies of the topic guide for the focus groups and the interview schedule for the interviews can be found at **Appendix One** on page 41.

Below are the findings in detail.

PERCEPTIONS OF CURRENT NHS RECORD-KEEPING

- Patients tended to **overestimate** the extent to which the NHS already works with electronic records. In particular, patients showed a tendency to assume that their **GP record** would be recorded **on paper as well as electronically**. Patients tended to believe that it was more likely that their **hospital record was paper-based**.
- It was the very youngest respondents who had the **highest expectations** of NHS record-keeping. They were the most likely to assume that there was a central and integrated system: *“There must be a database or something because say you were rushed into hospital they would need to know right away if you had problems with your blood or something.” (Female, Teenager, Acute).*
- Those **newest** to the NHS (arriving in the UK within the last 1-2 years) had found that their GP record had been recorded on computer and considered the NHS system both **efficient and secure**.
- There were plenty of examples when basic information about patients had not been available. The most common problem was **lost notes**:

“Here there are two hospitals and one sent me to the other. When I went there they didn’t have the notes that had been collected over the last ten or so years.” (Male, BC1, Older Family)

My husband went to the hospital they and gave him his notes to take with him to the department. I know our name is Smith but it was the wrong Smith. We could have read everything about him.” (Female, C2D, Older Family)

- In some instances, missing notes had obviously caused patients **considerable distress** for example causing one delayed procedure and a disagreement over correct medication.

Summary point: It seems that patients do not have particularly high expectations of NHS services (and certainly did not appear to have a concept of NHS ‘customer service’).

- The occasions when patient information being accessible had aided care **tended to be far less** visible. Patients struggled to recall times when information sharing had helped them: *“You expect your records to be there for your treatment.” (Male, C2D, Younger Family).*

Summary point: Perceptions of current record keeping and information sharing practices are simply driven by what patients see when accessing NHS services.

PERCEPTIONS OF CURRENT LEVELS OF ACCESS TO PATIENT RECORDS

- At present, access to paper records was perceived to be **open to anyone working in the NHS.**
- It was clear that patients’ biggest concern was that **parties outside of the NHS might have access to their health record** e.g. insurance companies, employers, schools: *“I’m sure insurance companies with all their money have ways of getting to your records if they want them.” (Male, BC1, Older Family).*

Summary point: In reality, patients’ biggest concern is that their records are protected from access from non-NHS parties. Confidentiality within the NHS was a more theoretical concern.

- Around half of each group claimed they knew that they could **see their medical records** (although none had actively tried to do so). Patients assumed that **all** information recorded about them would be **accessible to themselves.** **Teenagers** were particularly vociferous about this right: *“They’re my records, about me, so I would expect to be able to have a look at them if I wanted to.” (Male, Teenager, Chronic.)*

Summary point: Overall, patients struggled to understand why they might want to access their health record. For the future they could envisage wanting to look out of interest or to check that information was correct.

INITIAL REACTIONS TO THE ELECTRIC RECORDS CONCEPT

- Initial reactions to the ICRS concept were **extremely positive**: *“It needs sorting out. Computer records are the way forward, in principle.” (Male, BC1, Older Family).*
- The biggest advantage was felt to be that information about a patient would be **readily available** in any treatment situation. Patients’ primary concern was that all personnel involved in treatment should have **access to all the medical information they might need when treating a patient**: *“That’s good. It would be there whenever you needed treatment. They would know what problems you have had in the past.” (Female, C2D, Older Family).*
- The exceptions to this sharing arrangement were **receptionists** (i.e. non-treatment staff): *“Why does a receptionist need to know? The one from my GPs surgery lives on the same street as me. I’m not sure I want her to know everything about me.” (Male, BC1, Older Family).*
- Additionally, patients could see that ICRS could potentially **reduce the numbers of lost records**.
- Despite an extremely positive reaction to the concept, the idea of one’s details being so readily accessible also made patients feel a little **vulnerable**: *“It’s not far from the tagging system they use with pets now.” (Female, Frequent mover, Chronic).*
- The biggest concern (across the sample, regardless of age) was **security**. This view was persistent, despite respondents readily acknowledging that the security around records (and particularly paper records) is **extremely poor at present**: *“How easy is it at the moment to see records? I suppose anyone in the hospital could go in the records room if they wanted.” (Male, BC1, Older Family).*
- The concept of a wholly electronic information system **consistently provoked anxiety**, most commonly about **‘hacking’** and therefore **unauthorised access by non-NHS personnel**: *“People would be able to hack into the system. No system is totally secure.” (Male, BC1, Older Family).*

- In reality, their fears were less to do with rogue individuals, but that their information should be **protected from routine sharing with insurance companies and employers.**
- Other **potential drawbacks** mentioned included: system failure, cost and logistical problems: *“What happens if it crashes? They would have to have paper copies as well.” (Female, BC1, Retired).*

Summary point: Security concerns tended to be raised as a response to a new and, at the moment, untested system

- Whilst respondents **sought reassurance** about security, an over-emphasis on **security and confidentiality** protocols *within the NHS* had the potential to cause concern in itself. There were concerns voiced about the Spine system either **not providing enough information** or security around the Spine **delaying access for key personnel**: *“What happens if you are unconscious and you need treatment, but the person there doesn’t have access to all the relevant information? They would have to get someone with the next stage access, then someone else.” (Male, C2D, Younger Family).*
- Patients need to be reassured that the Spine will contain **all the necessary and relevant information** for their treatment, and that **all front line staff** will have access to this information.

Communication about security and confidentiality should make clear that the security access protocols for NHS staff are designed to keep the (non NHS) outsiders out.

SPINE CONTENT

- The majority appeared to be comfortable with the suggested inclusions. In reality, patients appeared very **accepting** of what was being presented to them as ‘need-to-know’ information: *“They’re the professional, you can’t tell them what they need to know. They should be able to scan through and think yes, it is relevant that I know about a termination 20 years ago.” (Female, Frequent mover, Chronic).*
- There were some objections to some of the **social information** included, for example, ethnic group: *“I always cross that out when I fill in forms. It is nothing to do with them.” (Female, BC1, Retired).*
- Some felt that it would be impossible to keep **non-prescribed supplement** information up-to-date: *“You change vitamins all the time. What do you do? Ring up your doctor and get him to change it?” (Female, C2D, Older Family).*

- Only the most recent **referral letters** were considered relevant.

THE SEALED ENVELOPE

- The concept of patients being able to hide information in a kind of 'virtual sealed envelope' elicited variable levels of **understanding and appeal**. Some patients (notably younger male C2DE respondents and teenagers) considered the concept solely in relation to themselves and simply could not envisage information they might want to hide. Younger male respondents also argued that information which a patient has concealed (e.g. HIV status) might be **relevant to patient care**, and disputed the patient's right to decide what to conceal: *"How do you decide what is relevant or not? It might not be relevant now but at some point it might be."* (Male, C2D, Younger Family).
- Those new to the NHS from overseas expressed a **very high level of trust** in NHS doctors and did not see why people might want to use the patient's sealed envelope: *"They may need to know things like whether you are divorced or tried to commit suicide. There are emotional things doctors should know so they can know you better and help you."* (Male, Iraqi Kurd).
- Many in **favour** of the patient's sealed envelope were also able to imagine that information about sexually transmitted diseases, abortions and mental health details might well be relevant: *"I suppose you can see it if it something like that [abortion]. But that might be relevant in terms of mental health or if you are pregnant now."* (Male, BC1, Older Family).
- In the qualitative depth interviews respondents raised the issue of clinicians being able to hide information from patients in a kind of **clinician's sealed envelope**. Respondents were able to see both the pros and cons of this option, particularly in sensitive cases involving adoption and abuse.

Summary point: Patients pointed out the difficulty of achieving a balance between patient confidentiality and health professional access and between health professional confidentiality and patient access.

PATIENTS HAVING ACCESS TO THEIR RECORDS

- All felt that patients *should* be able to access their record, although in reality **few felt they were likely to do so**. Patients did not automatically perceive the **potential benefits** of having on-going access to their health record e.g. **increased involvement** in their health care: *“I suppose you could check up on things and see if they had done something wrong.” (Female, BC1, Retired).*
- It is likely that individuals with **chronic illnesses**, who are therefore more involved in services, will be interested in learning more about their healthcare situation: *“It would be good to look up not only what medication you’re on but the positives and negatives about it. When you’re put on these medications you’re never told the side effects and if I’d known what steroids can do to you when I’d first been prescribed them, I’d never have taken them.” (Female, Frequent mover, Acute).*
- Some patients did realise (albeit rather theoretically) that **patient access may change** the way that health professionals write records, which could therefore **improve GP-patient relationships** and increase the level of patient involvement in their health care: *“It would mean that your GP would be more likely to tell you what they are writing, because you can see it anyway.” (Female, C2D, Older Family).*
- Most felt that the **GP surgery** was the most preferable environment in which to access their record. Although many felt they would like access at home, there were too many concerns about **Internet safety** for patients to perceive this as a viable option.
- Patients suggested some kind of **‘smart card’** that would enable access from home, feeling that this would provide a more secure arrangement than directly accessing details via the Internet. Patients regularly suggested that a ‘smart card’ could be **carried around at all times** and used to access patient information whenever the patient accessed NHS services: *“You could carry it with you at all times. Then wherever you are they would be able to see what to do with you.” (Male, BC1, Older Family/Empty Nester).*
- The idea of carrying around identifiable patient information raised the issue of **civil liberties**. Some respondents said that they would not want to carry **identifying information** with them: *“It would be worrying. People can steal your identity.” (Male, BC1, Older Family/Empty Nester).*

- **Computer literacy** clearly varied across the sample. Some (and particularly older) respondents felt that they would need support from surgery staff in order to access their records: *“I don’t think booking appointments would apply to me as I can’t use computers and would never work out how to do it.”* (Female, Frequent mover, Acute).
- Respondents least familiar with computers tended to prefer the idea of a **touch screen format**.
- Respondents with **sight loss** pointed out that they would need to be able to **hear** their way through the system.

THE ACCESS LOOP

- Patients were happy to include **private and overseas hospitals** in the sharing loop, if these services were providing the patient with treatment.
- **Nursing homes** was a slightly more controversial inclusion. Most felt that staff should be able to see information relevant to the resident’s care, but were wary about sharing whole records.
- **Pharmacists** and **opticians** were not regarded as automatic inclusions by some patients who felt that consent should be sought if the NHS wanted to share information with these parties. However some (those who generally advocated NHS wide sharing and also did not perceive why anyone would need a ‘sealed envelope’) felt that they should be included in **routine information sharing**.

“It could be important with some opticians. They spot cholesterol and all that.” (Female, C2D, Older Family)

“You would be able to decide whether you wanted them to [see it] or not.” (Female, C2D, Older Family)
- **Voluntary services** were also excluded from the sharing loop, but this was largely due to a lack of knowledge of the role voluntary services can play in patient care.
- Some respondents **intrinsically distrusted social workers** and therefore did not feel they should have access to NHS patient information; others felt that the NHS should provide information about anyone being **‘investigated’** by social services.
- Patients did not perceive **alternative therapies** to be integrated within mainstream NHS services and therefore did not feel that they should be party to information sharing.

- Those who were not in **caring situations** found it difficult to see why a carer should have access. Those with experience of caring situations felt that access could be important.
- Some patients also wanted their relatives to be able to see their health record. These included: people from cultures where **information was typically shared within families** and those who needed **translators** from the family: *“We have a culture where our responsibilities stretch further than ourselves and therefore I am responsible not just for myself but my brother, sister, cousin and nephew too. I would not want to think they could not see what I can see.” (Male, Arabic speaker)*
- Other patients did not want their **health details** to be shared with family, suggesting that that patient consent would be **needed for access** by a family member.
- **Chaplains** were also excluded – patients could not understand why some one looking after spiritual well-being would need access to one’s medical file.
- Patients failed to see why **other government departments** would need access to identifiable patient information. They tended to assume that information would be anonymised: *“I wouldn’t mind if they use me for research reasons because it wouldn’t say your name, just your symptoms.” (Male, Teenager, Chronic).*

Summary point: Whilst patients generally purport that they are comfortable to have their basic Spine record shared ‘within the NHS’ for treatment purposes, their understanding of the full range of NHS services is limited and therefore their definition of ‘the NHS’ is both traditional and narrow.

BUILDING AN INTEGRATED CARE RECORD SERVICE (ICRS)

- Patients **prioritised the benefits** of ICRS for the NHS above the improvements which were suggested as of **direct benefit** to the patient. First and foremost, they wanted **24 hour access to records** for those treating patients. Then they wanted the ICRS to make NHS systems more **efficient** (again ultimately promoting patient care).
- They wanted **quick referral procedures** – the ability for NHS services to talk to each other directly (i.e. GP to hospital), to **book appointments** immediately and **correct mistakes**.

- As a direct benefit to patients, the opportunity **to record one's wishes** on one's electronic record was extremely well-received: *"I think this idea of what they call a Living Will would be great."* (Female, Frequent mover, Acute)
- Patients also wanted access to information without needing to contact NHS services, particularly **recent test results** as well as **prescriptions and dosages**.
- Elements for patients which were considered **desirable**, but not necessarily essential at this stage:
 - access to letters about you (e.g. referrals and discharge letters)
 - (in theory) repeat prescription ordering
 - (in theory) booking appointments on-line.
- There were certain elements which many **doubted technology** could currently support:
 - ability to book appointments on-line *"You can just imagine it, you fill in your name in a time space and someone else is doing it at the same time and the system puts you both in or something."*
 - ability to e-mail GPs *"GPs don't have time to be answering e-mails as well."*
 - repeat prescription ordering *"...you sometimes need to go in for a check up anyway..."*
- The benefits for 'the greater good' were less tangible, although theoretically welcomed. **Anonymised data** being made available for **research/management** was accepted as a step forward.

Summary point: Patients prioritised improvements to the current service, rather than new innovations.

PATIENT IDENTIFICATION

- The **fingerprint** was the preferred method of identification, understood to be:
 - unique (and therefore secure)
 - simple (and therefore easy for all to use)
 - instantly accessible (and therefore beneficial in an emergency)
- In comparison, **postal addresses** and **dates of birth** were perceived to be too common to identify an individual accurately. Patients did not remember their **NHS number** and therefore this does not seem like a particularly accessible option. A **new pin number** was simply felt to be adding to the host of pin numbers we already need to remember.

Summary point: Overall, the fingerprint provided an added reassurance about the security of the system as well as being accessible for all.

INFORMING THE PUBLIC

- The **NHS** was felt to be the logical source of information about ICRS. Patients expected to see more information about ICRS in a **variety of places open to the general public**: GP surgeries, hospitals, libraries, post offices.
- The **timing** of this information was felt to be dependent on when the system is actually likely to be put in place (at present some found it difficult to believe that this system is a real possibility).
- Questions regarding the **development of the new system** included:
 - how will ICRS **improve** the NHS?
 - what are the **benefits for me?** (and in particular the benefits of patient access)
 - how is it going to be done?

Patients are also likely to need reassurance about **security and access issues** i.e. that the security and access protocols are designed to keep **insurance companies and employers** out of the system and to provide NHS treatment staff with all relevant medical details whenever needed.

SUCCESS FACTORS

- A number of potential 'success factors' were put to respondents. Some of the suggested 'success factors' were not necessarily **discernable** (or meaningful) to the individual patient. **Fewer lost records** was therefore understood to be of common benefit to all NHS patients (but not a particularly motivating benefit for oneself per se).
- **Increased confidentiality** was perceived as a beneficial by-product of the new system. Patients cannot afford to scrutinise current levels of confidentiality too carefully since they have no choice in the way their information is currently managed.
- Similarly, the NHS '**knowing who they are**' is not a particularly motivating benefit because it forces patients to realise the failings of the current system.

Summary point: The success factors identified were those that were perceived to enhance current NHS services (rather than dwell on resolving current inadequacies)

- Patients judged success factors as those of benefit to themselves **personally as patients**:
 - seeing health professionals accessing patient information **on-the-spot**
 - sending referrals on-the-spot and **booking appointments immediately**.
- Patients demonstrated that they wanted ICRS to **consolidate** current NHS services first, before moving on to **newer** ideas (e.g. ordering repeat prescriptions and booking appointments on-line).
- **Patient access to their records** is a benefit which patients are likely to discover over time, as they begin to understand what the system can do for them: *“I wouldn’t want to look. I just presume that when I’m in their hands they’ll look after me. I can only see it if there’s grounds for complaint I suppose. I think it’s important that there’s a central system that they can all access in the NHS though.”* (Female, Frequent mover, Chronic)

Summary point: Over time, all these elements have the potential to build and create a sense of customer service which patients do not at present associate with the NHS.

QUANTITATIVE RESEARCH

QUANTITATIVE RESEARCH OBJECTIVES

The key objectives of this stage of research were to:

- understand what patients and the public see as the main benefits of the Integrated Care Record Service (ICRS) are:
 - for themselves
 - for the NHS when it treats them.
- understand how important the proposed features of the ICRS are and patient priorities i.e.:
 - access to test results
 - electronic booking of appointments
 - electronic prescription ordering
 - electronic access to GPs.
- identify how patients would like to be able to access their record
- understand how far reaching this service could be
- assess who people think should be in the ICRS sharing loop
- establish what questions about ICRS the public would want answered.

QUANTITATIVE RESEARCH METHODOLOGY

It was vital to ensure that the views of a representative sample of the general public were obtained. An effective way to do this is via an omnibus survey. Such studies provide a large, nationally representative and demographically weighted sample enabling comparisons within sub-groups of the population such as demographic factors and experience of the NHS. The Access Face-to-Face survey run by BMRB International Limited was used. Interviews were conducted face-to-face, in home using a random location sampling technique and Computer Assisted Personal Interviewing (CAPI). The actual sample achieved was 1997 adults aged 15 and over in Great Britain.

A full copy of the questionnaire is provided in the [Appendix Two](#) on page 50.

The results in detail are given below.

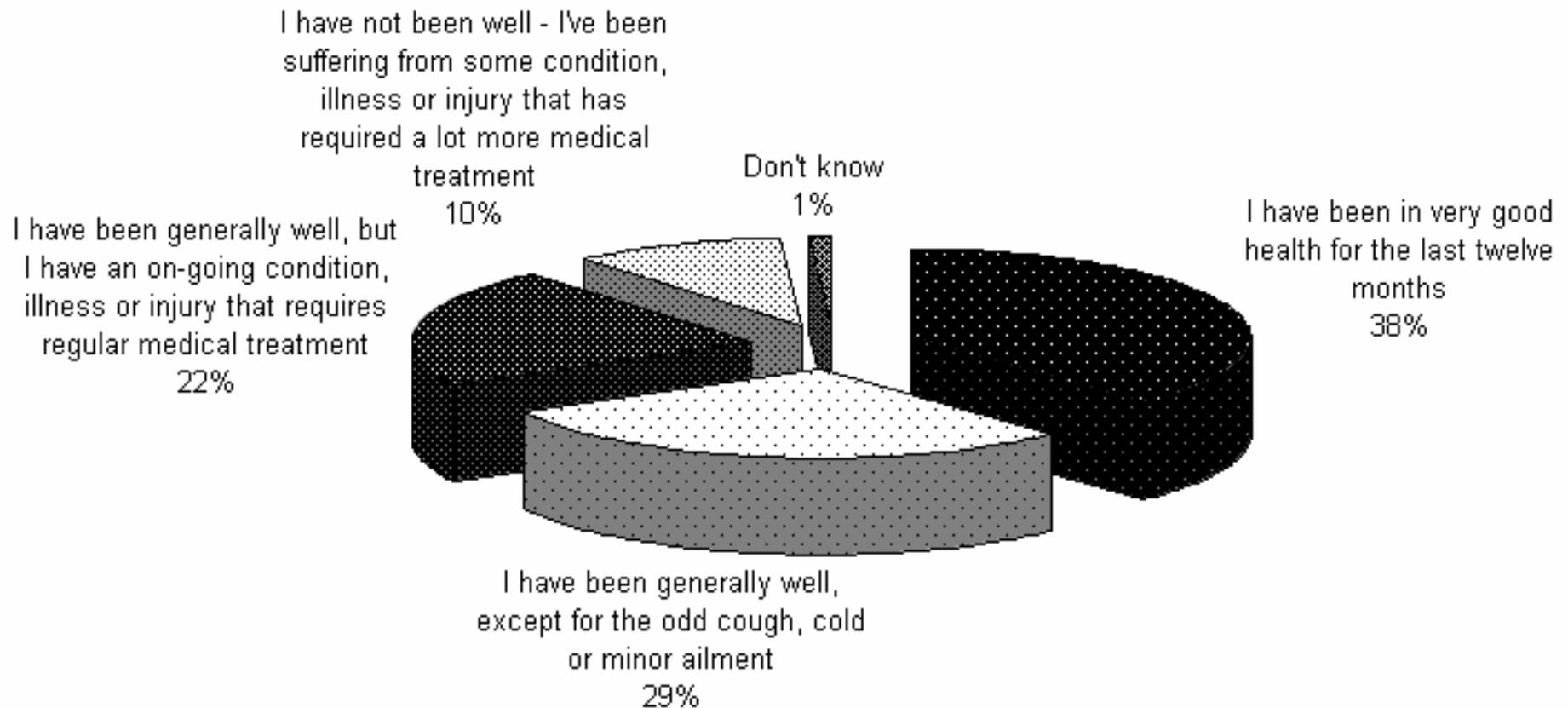
GENERAL HEALTH AND EXPERIENCE OF THE NHS

In order to ensure that attitudes to the ICRS can be placed within the context of respondents' experience of the NHS, it is important to establish a 'health profile' for respondents. Respondents were asked to describe their health over the last 12 months, to select which parts of the NHS/other care services they have come in contact with and to indicate which, from a list of NHS-related experiences, had happened to them.

Around two thirds probably had fairly limited personal exposure to the NHS in the last 12 months: four in ten (38%) claimed to have been in very good health and three in ten (29%) had been generally well apart from the odd cough, cold or minor ailment. A fifth (22%) said that, while they are generally well, they had an on-going condition requiring regular medical treatment and one in ten (10%) had been unwell with a condition requiring a lot of medical treatment. It would probably be safe to infer then, that this third of respondents had more contact with the NHS over the last year.

As would be expected, age plays a part in people's state of health. Around half (48%) of 15-24 year olds, 45% of 25-34 year olds and half (49%) of 35-44 year olds said they had been in very good health for the last 12 months compared to 26% of 55-64s and a quarter (25%) of those aged 65 and over. Two fifths (42%) of those 65 and over had been generally well but had an on-going condition requiring medical treatment compared to just 11% of under 45s. Almost a fifth (18%) of people 55 and over said that they have not been well, compared to only 6% of under 55s. Generally then, this older group is likely to have had more interaction with the NHS.

Which of these statements most closely describes your general health status over the last twelve months? (Base: All Adults 15+ n=1997)

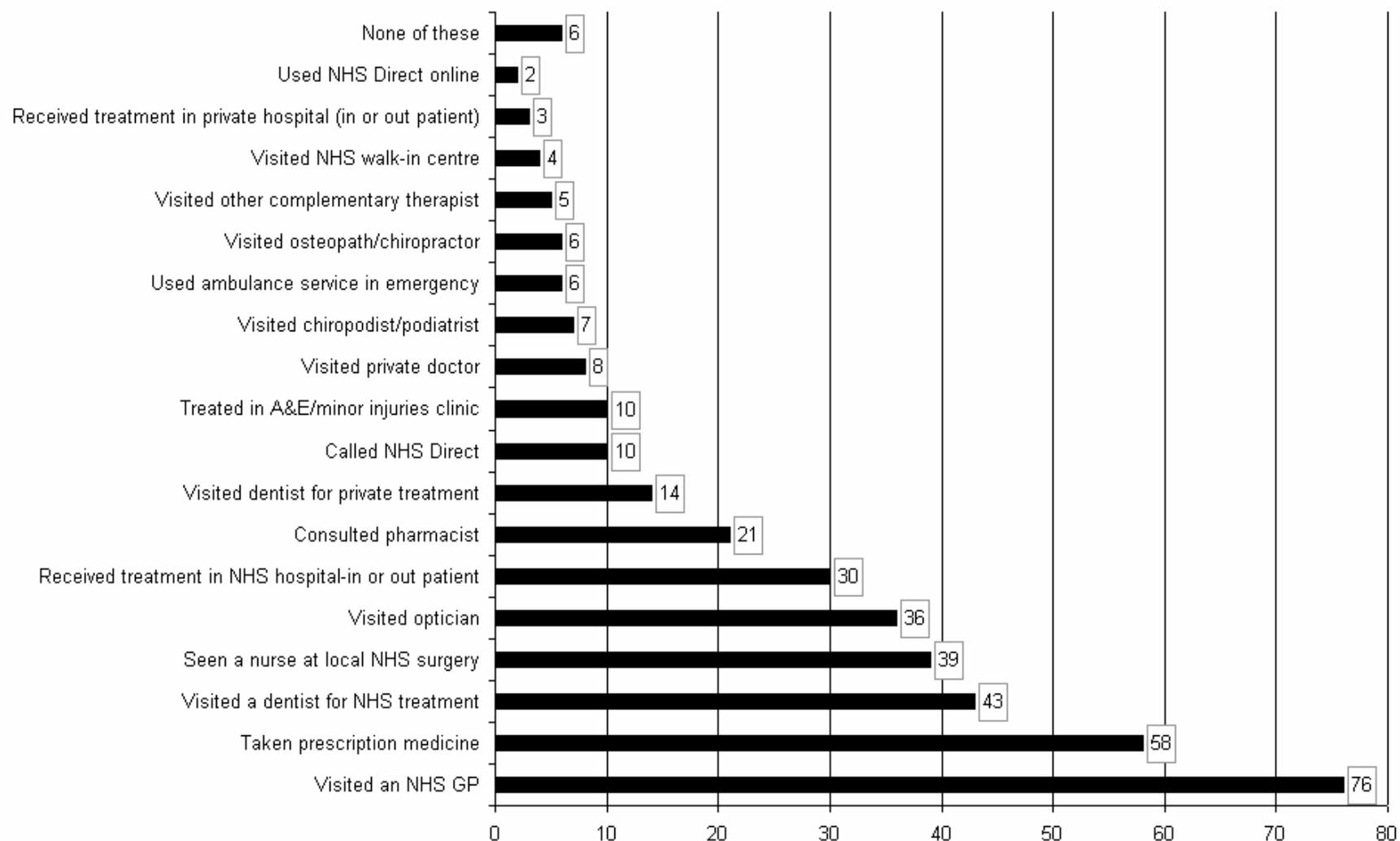


Visits to health professionals within the last 12 months

The likelihood of greater exposure to the NHS among older people is borne out by the public's experience of visits to health professionals in the last 12 months. Around three-quarters (76%) of respondents had visited an NHS GP in the last 12 months. Unsurprisingly, those aged 55 and over were more likely to have done so than under 55s (83% vs. 72%). Almost six in ten (58%) had taken prescription medicine and, again, age is a factor in the likelihood to have done so. Three quarters (76%) of people aged 65 and over had taken prescription medicine compared with 45% of under 25 year olds. As would be expected, those who were not well or with an on-going condition were more likely to have:

- visited an NHS GP
- seen a nurse at their surgery
- taken prescription medicine
- visited an optician
- received treatment at an NHS hospital
- been treated in accident and emergency/minor injuries clinic
- used an ambulance in an emergency
- visited a chiropodist.

Which of the following have you done in the last 12 months? (Base: All Adults 15+ n=1997)

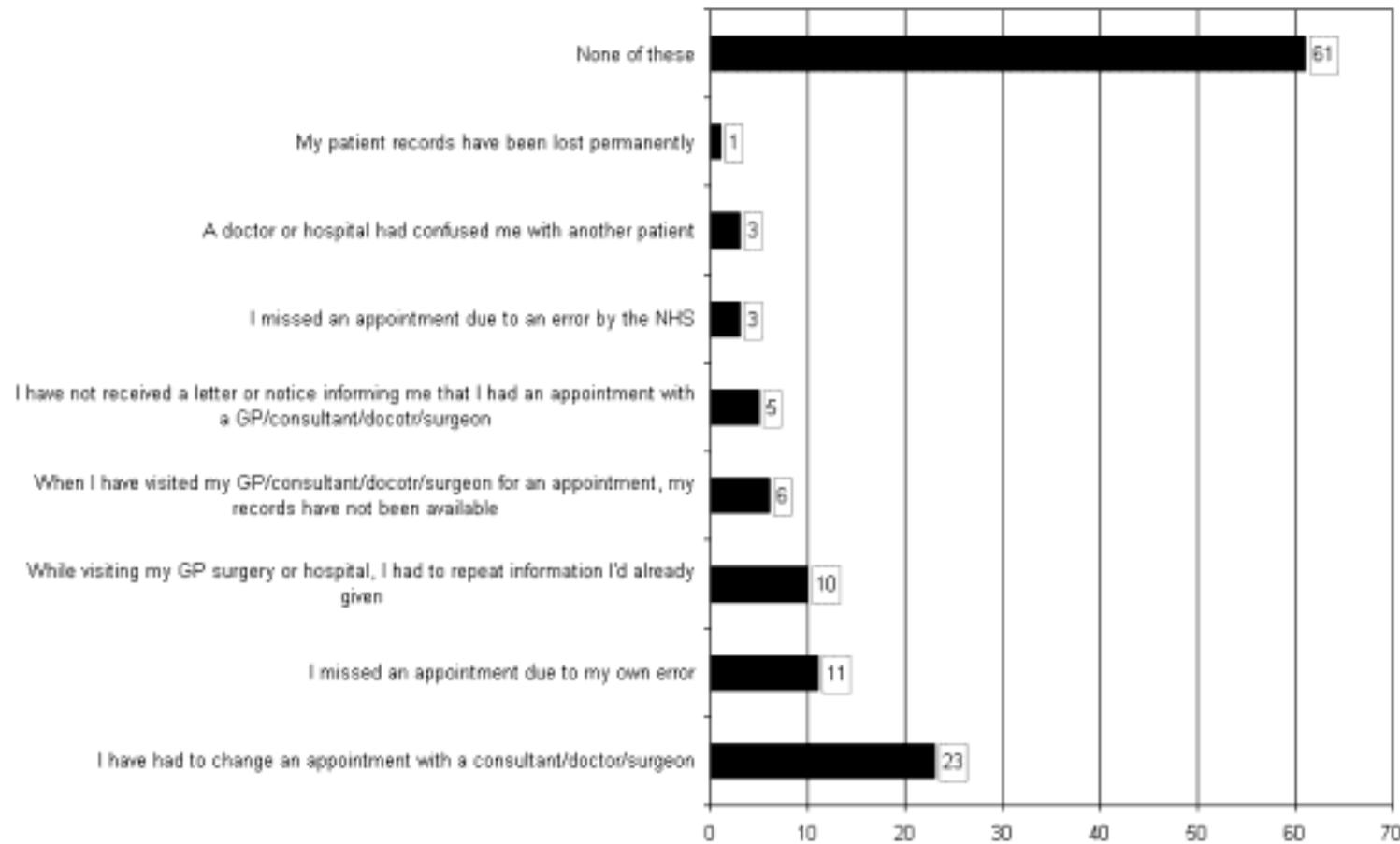


Experiences with the NHS

Four in ten (39%) respondents had experienced an event which – it is envisaged – would be addressed to some extent by the introduction of the Integrated Care Record Service. A quarter (23%) had had to change an appointment with a consultant/doctor or surgeon. Those with children in the household were more likely to have done so than those without (31% vs. 19%). Under 55s were more likely to have done so than those aged 65 or over (26% vs. 14%). One in ten (10%) found that they had to repeat information they had already given when they visited their GP surgery or local hospital. 11% had missed an appointment due to their own error. Not surprisingly, those likely to have had more contact with the NHS were more likely to have experienced these events. A third (33%) of those who had not been well, for example, had had to change an appointment compared with 17% of those in very good health.

Have any of the following events happened to you or someone you've been looking after?

(Base: All Adults 15+ n=1997)



WHO SHOULD BE IN THE ACCESS LOOP?

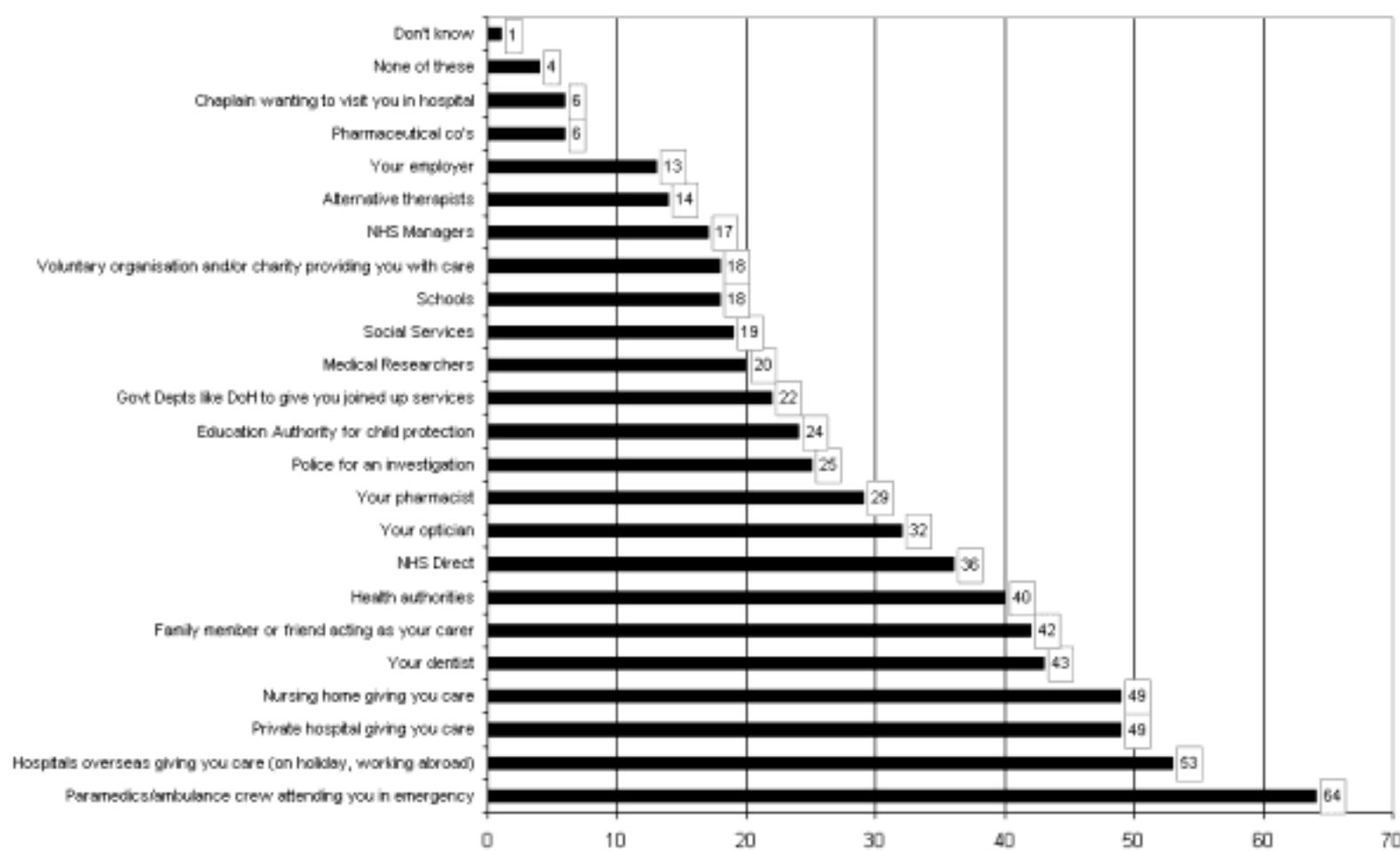
Respondents were given an explanation of ICRS and were asked who they thought should have access to at least some part of their medical record. During the qualitative research, the feeling was very much that the record should stay within hospitals and GP surgeries. Within the quantitative stage, access (of some description) by other caring professions was explored. Paramedics and ambulance crew being able to access part of patients' medical records received the most positive response (64%). Over half (53%) felt that hospitals overseas providing them with care should be able to access part of their record (and this was borne out in the qualitative focus groups and interviews).

Opinions on whether access should be given depended to some extent on the respondent's contact with that caring profession. Consequently, while half (49%) thought that private hospitals giving care should have access, this rose to 63% among people who had had private care in the last 12 months. While just 14% thought that alternative/complementary therapists such as acupuncturists should be given access, this figure rose to a quarter (24%) among people who had had alternative treatment.

Half (49%) of respondents thought that nursing homes should have access (in the qualitative research, most respondents said they were happy for nursing homes to have limited access.) Four in ten thought that part of the record should be available to dentists (43%), with a similar proportion thinking that family members/those acting as your carer should have access (42%). 40% thought that health authorities should have access to at least part of the record. Only a small minority of respondents thought that access should be given to pharmaceutical companies (6%) or chaplains wanting to visit patients in hospital (6%). Just 13% believed that access should be given to their employers.

There is some difference in attitude to who should have access by age, however. For example, while two thirds (67%) of under 55s thought ambulance crews should have access, only 56% of people aged 65 and over thought this. While 57% of under 65s thought that access should be allowed to hospitals overseas, just 39% of the over 65s thought this. Similarly, while half (52%) of under 65s said that private hospitals should have access to some part of the record, this dropped to 38% among the over 65s.

Which of the following do you think should have some access to at least some part of your medical record? (Base: All Adults 15+ n=1997)



PERCEIVED BENEFITS TO PATIENTS OF ICRS

Respondents were shown a list of the proposed benefits of ICRS and asked which would be important to them. Each of the proposed benefits was considered important by around a quarter of respondents or more. However, the ability to see recent test results, being able to look at your medical history at any time and the facility for a GP to book appointments at hospitals and clinics during the appointment were felt to be important by the greatest proportion of respondents (63%, 60% and 60% respectively).

Half (52%) of respondents felt that having access to their records wherever they were in the NHS was important (58% of those with an on-going illness vs. 48% of people in very good health). Half (51%) thought it was important to be able to record their wishes, such as organ donation or life support.

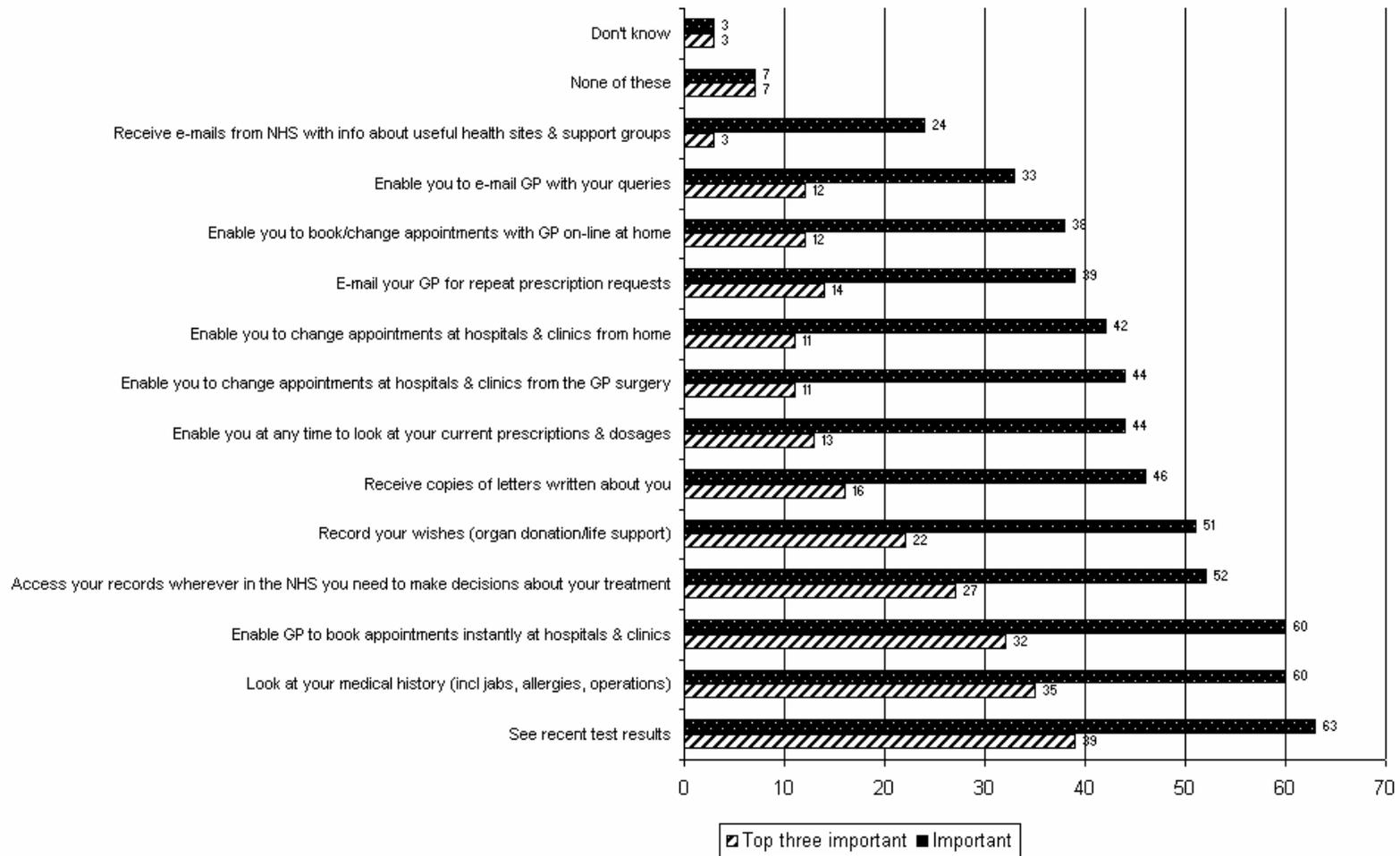
Respondents were also asked which the three most important benefits to them were. Interestingly, there was no clear front runner. However, 39% considered seeing test results to be one of the three most important benefits while a third (35%) selected the facility to look at their medical history at any time and a third (32%) chose the facility for a GP to book appointments at hospitals and clinics during the appointment.

Many of the proposed benefits of ICRS are slightly less likely to be considered important by the older audience. For example:

- enable you to see recent test results (66% under 65 vs. 51% 65 and over)
- enable you to look at your medical history (64% under 65 vs. 45% aged 65 and over)
- enable you to record your wishes (53% aged under 65 vs. 40% aged 65 and over)
- enable you to change appointments with hospitals and clinics from home (45% under 65 vs. 32% aged 65 and over).

This difference could perhaps be due to the older audience being more technology averse. 10% of those aged 65 and over have access to the Internet, compared to 52% of those aged under 65. It is important to bear in mind then, that provision needs to be made for the less technologically-minded so that they are not disadvantaged by the new system in favour of those who find it easier to master (this is particularly important as older people have been shown to have a more contact with the NHS). Nervousness about new technology among older people was also highlighted in the qualitative research, where some respondents felt they would need help with using the computer from surgery staff.

Which of these proposed benefits would be important/most important to you? (Base: All Adults 15+ n=1997)



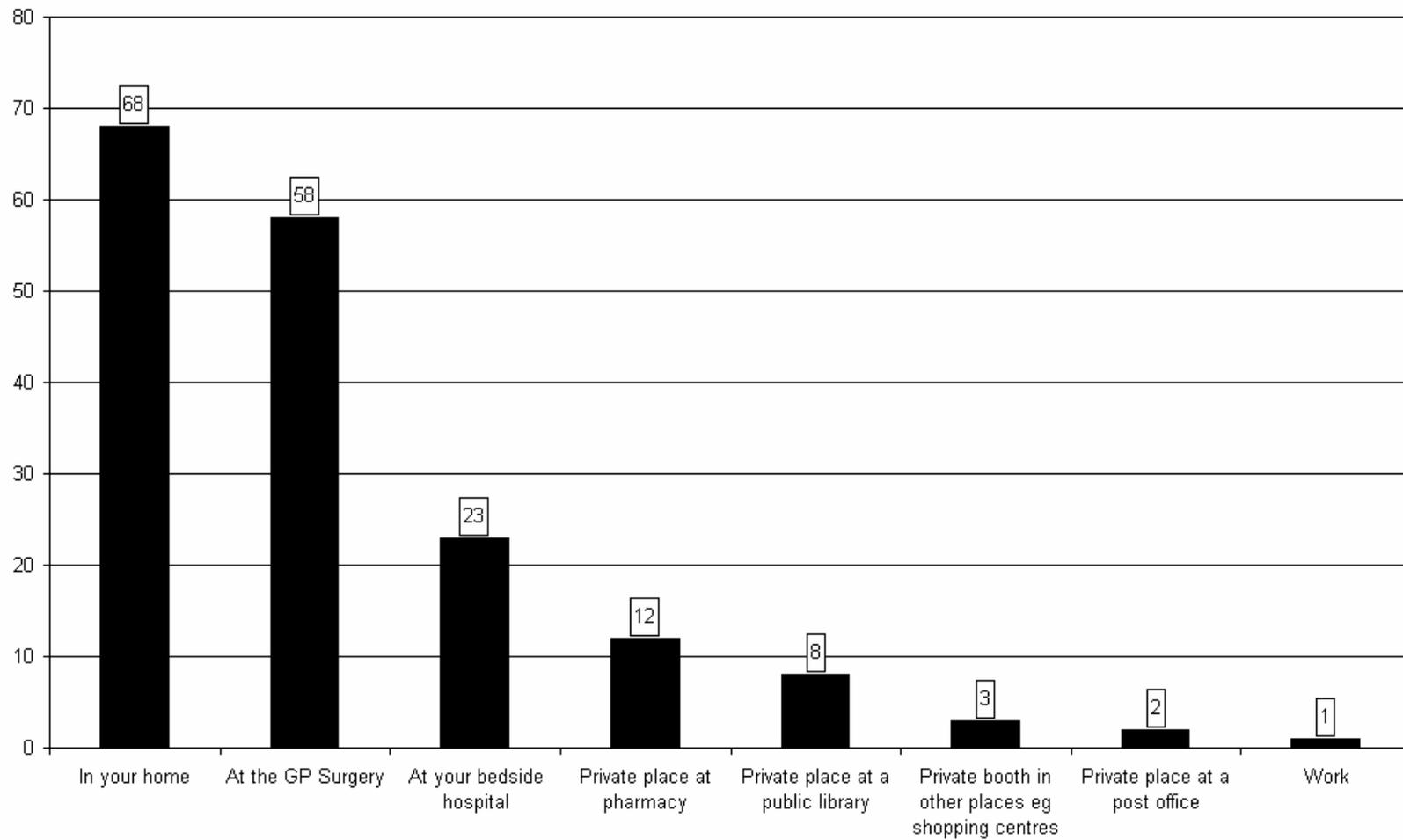
PREFERRED LOCATION FOR PATIENTS ACCESSING THEIR OWN MEDICAL RECORDS ON COMPUTER

Respondents were asked where they would like to be able to access their medical record on computer.

The concept of being able to look at your record on computer in your own home appealed to two thirds (68%) of people and was the most appealing concept of those presented. Consistent with other results, this idea had greater appeal for the under 65s than the over 65s. Access in home had greater appeal among the higher social grades in terms of job, income and education (79% of ABs, 72% of C1s and 68% of C2s, compared to 58% of Ds and 57% Es.) Again this may be linked to how many of this group are on-line.

Six in ten (58%) would like to be able to look at their record on computer at their GP's surgery (an option which also came out strongly in the qualitative stage) and there was no variation in this across age bands. The appeal of accessing medical records in places such as libraries, post offices, pharmacies and shopping centres was limited across the board. Pharmacies had greatest appeal (12%), perhaps because they are more health related than the others.

From which of the following places would you like to be able to look at your record on computer? (Base: All Adults 15+ n=1997)

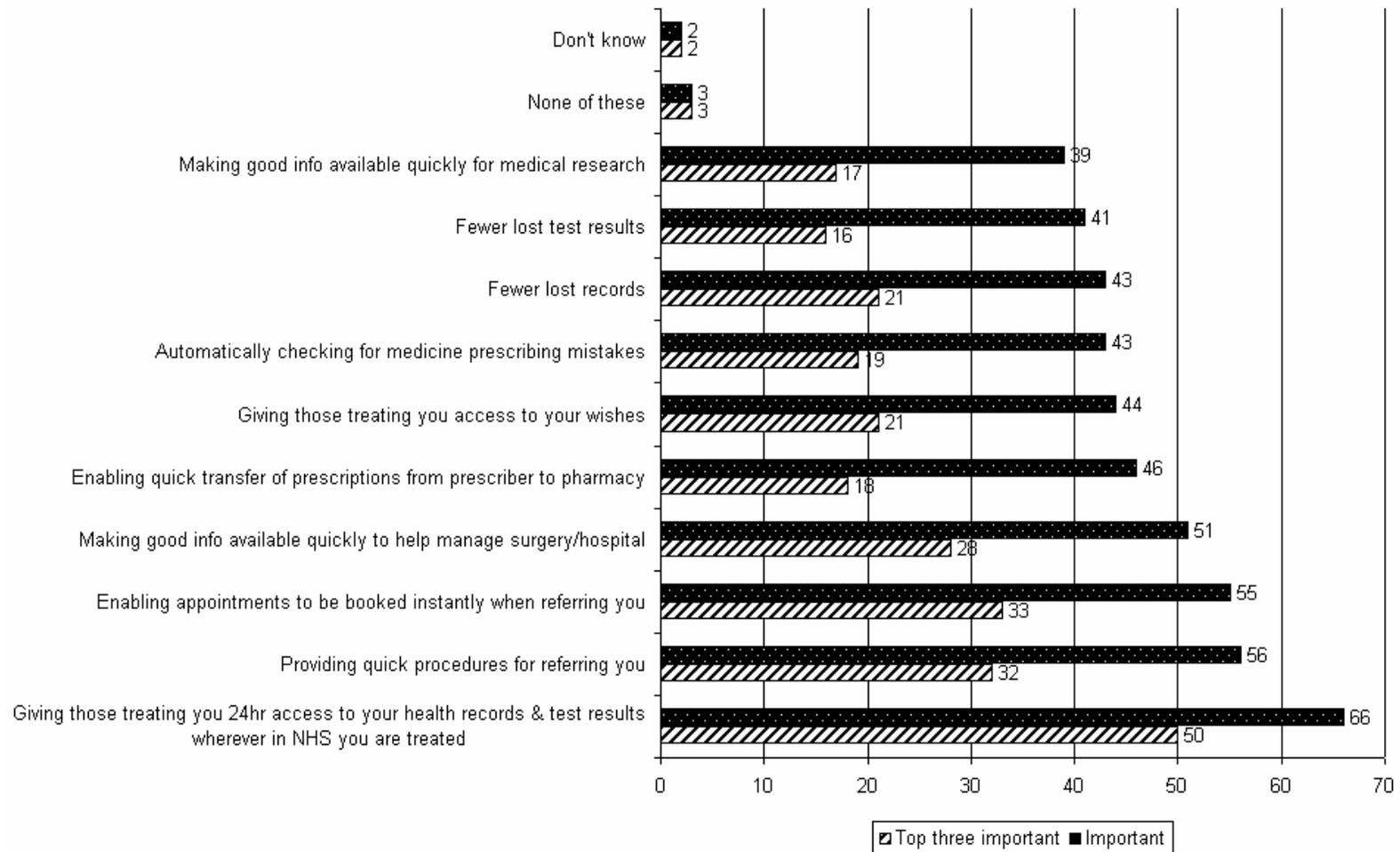


PERCEIVED BENEFITS OF ICRS FOR THOSE PROVIDING CARE

Having been shown a list of the ways in which the ICRS could potentially be of benefit those providing care in surgeries and hospitals, respondents were asked which they thought were important and which three were most important for care providers. Each potential benefit was considered important by at least two-fifths of respondents. Two thirds (66%) felt that the facility to have access to medical records across the NHS was important (this perceived benefit also featured strongly in the qualitative research). Half (50%) considered this to be one of the three most important benefits. 56% felt that the provision of quick referral procedures was important. 55% selected as being important the facility to book appointments instantly when being referred. Interestingly, half selected 'making available good information to help manage the surgery/hospital' and this was felt to be one of the most important aspects by 28% of respondents, illustrating that it is not just the benefits to the individual which are considered important.

There were no real differences in what was considered important by state of health of the respondent.

Important/most important benefits of ICRS for those treating you (Base: All Adults 15+ n=1997)



ELECTRONIC BOOKING

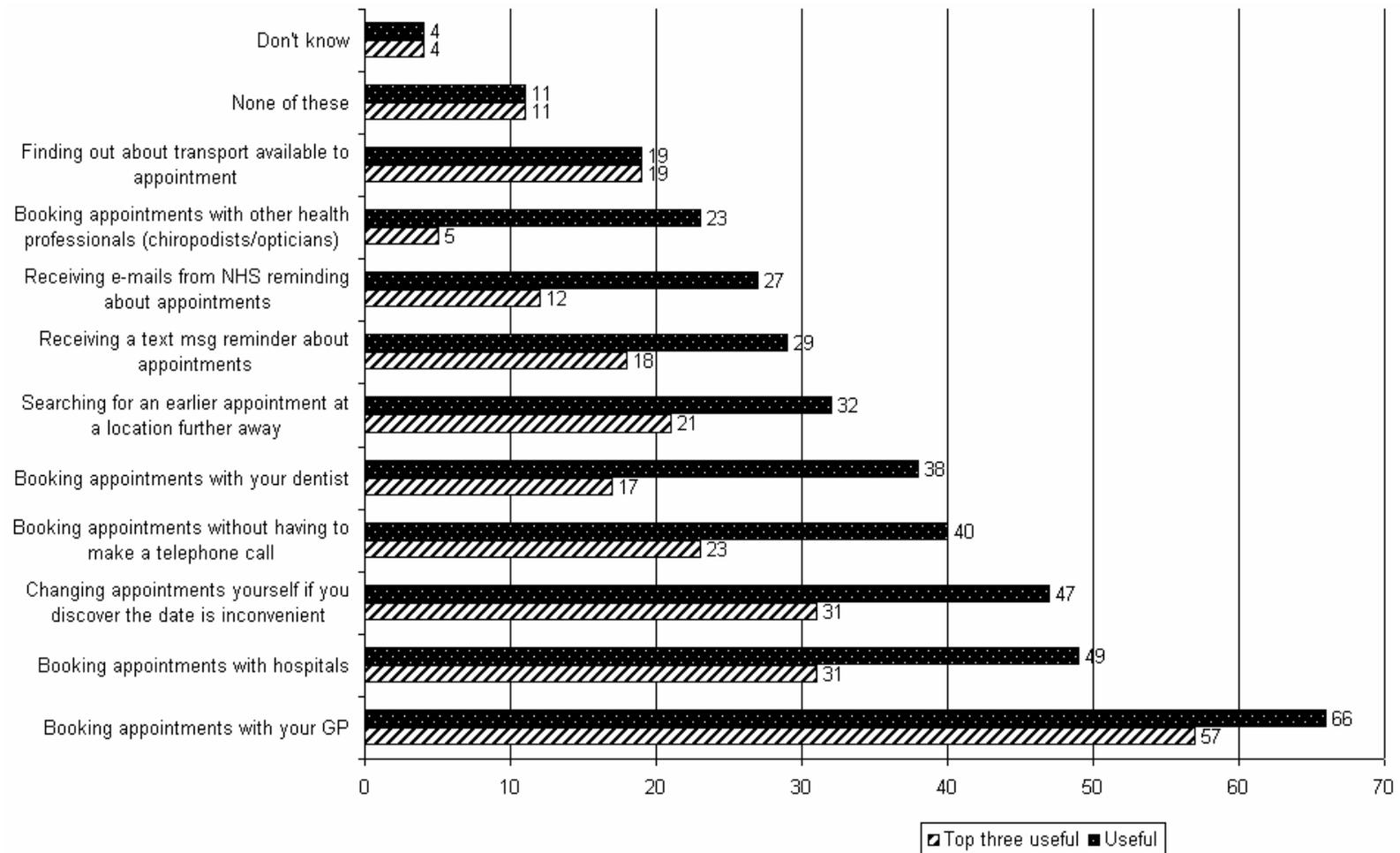
Respondents were told that the development of new computer systems would enable appointments to be booked electronically. A list of the proposed benefits of electronic booking was given and respondents were asked which they would find useful and which three would be most useful. Two thirds of respondents felt that the facility to book appointments with their GP would be useful and this was felt to be the most useful of the possible developments (57% put it in the top three). The over 65s were least likely to find this useful. For example, while 71% of 15-24 year olds and 73% of 25-34 year olds would find this useful, only 49% of those aged 65 and over would.

Half (49%) of respondents felt that booking appointments with hospitals would be useful and three in ten (31%) felt that this would be one of the most useful of the proposed developments. Again, the over 65s were least likely to feel they would find it useful: 52% of under 65s felt compared to just 37% of over 65s.

Changing appointments upon discovering that the date is inconvenient was felt to be a useful facility by 47% of respondents and, again, three in ten (31%) felt that this was one of the most useful of the proposed developments. The opportunity to find out what transport would be available for the appointment was felt to be useful by just a fifth (19%) of respondents. However, a fifth (19%) said that it would be one of the most useful developments. It is possible to infer then that it has strong minority appeal.

Interestingly, 27% of people aged 65 and over and 16% of those aged 55-64 said that none of these proposed features would be of benefit to them. Indeed, in all areas except 'finding out what transport would be available' the over 65s were less likely than the other age groups to find the benefits useful. There is also a similar picture across social grades, with people of social grades D and E less likely to find some of the features useful than ABC1s and C2s. To an extent this can probably be explained by the fact that people in social grade E (the lowest in terms of job, income and education) are more likely to be over 65. This does however highlight the need for care to be taken to avoid disadvantaging those who did not feel ICRS has as much to offer as other sections of the population do.

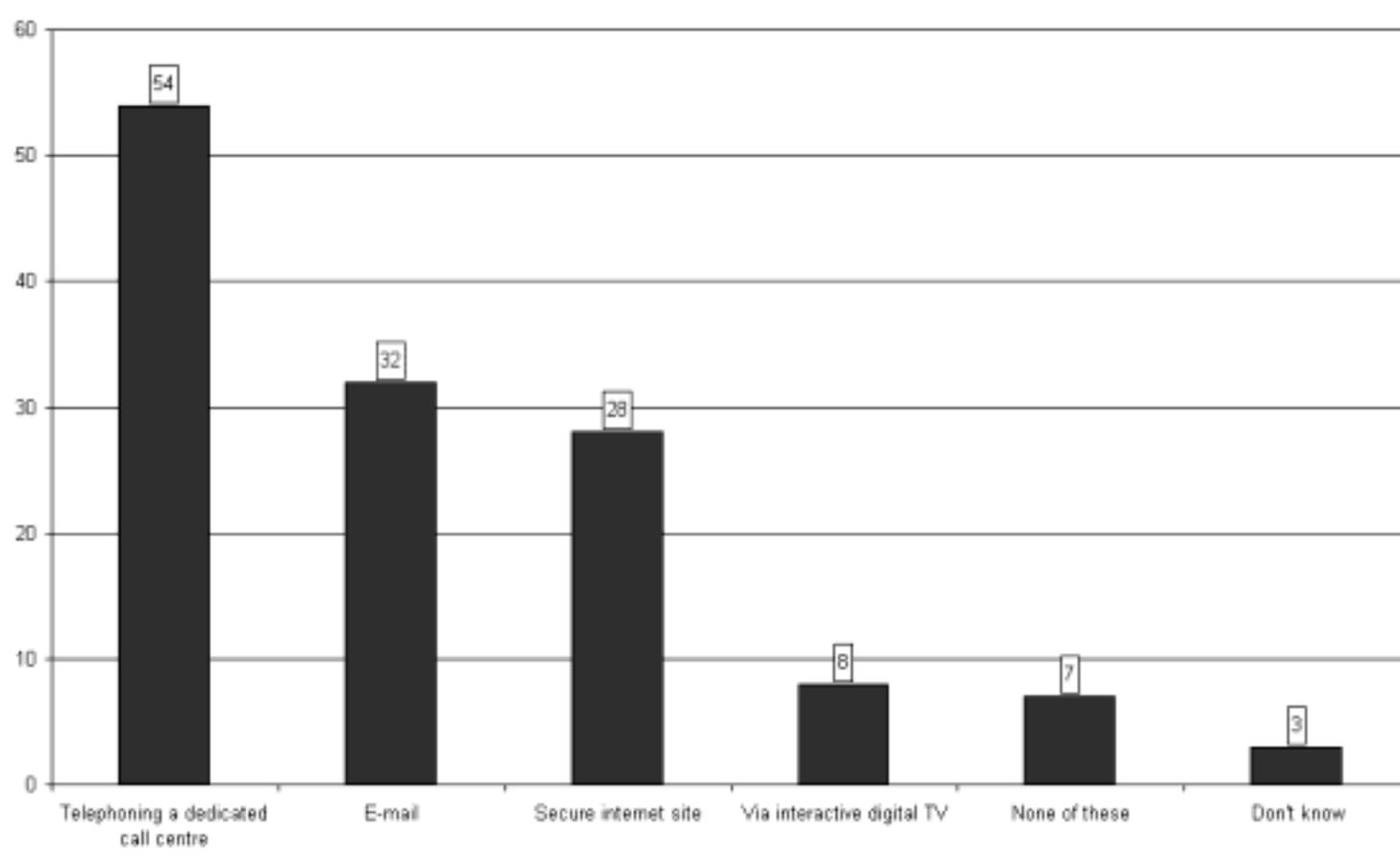
Useful/most useful aspects of electronic appointment booking? (Base: All Adults 15+ n=1997)



Respondents were told that the development of new computer systems could enable appointments to be booked in several different ways such as e-mail, a secure internet site, interactive digital TV or telephoning a dedicated call centre. They were asked which, if any, of these routes they would choose to use to book appointments. Around half (54%) said they would choose to telephone a dedicated call centre. People aged 65 and over were more likely to choose a call centre (64% vs. 51% of under 65s). A third (32%) would choose e-mail and around three in ten (28%) would opt for a secure internet site. (E-mail was particularly popular with ABs, 49% of whom would choose to book appointments in this way).

Interactive digital TV clearly has minority appeal as a booking mechanism (probably particularly because it is a relatively new medium) and just 8% of respondents would opt for this.

Which of these, if any, would you choose to use to book appointments? (Base: All Adults 15+
n=1997)

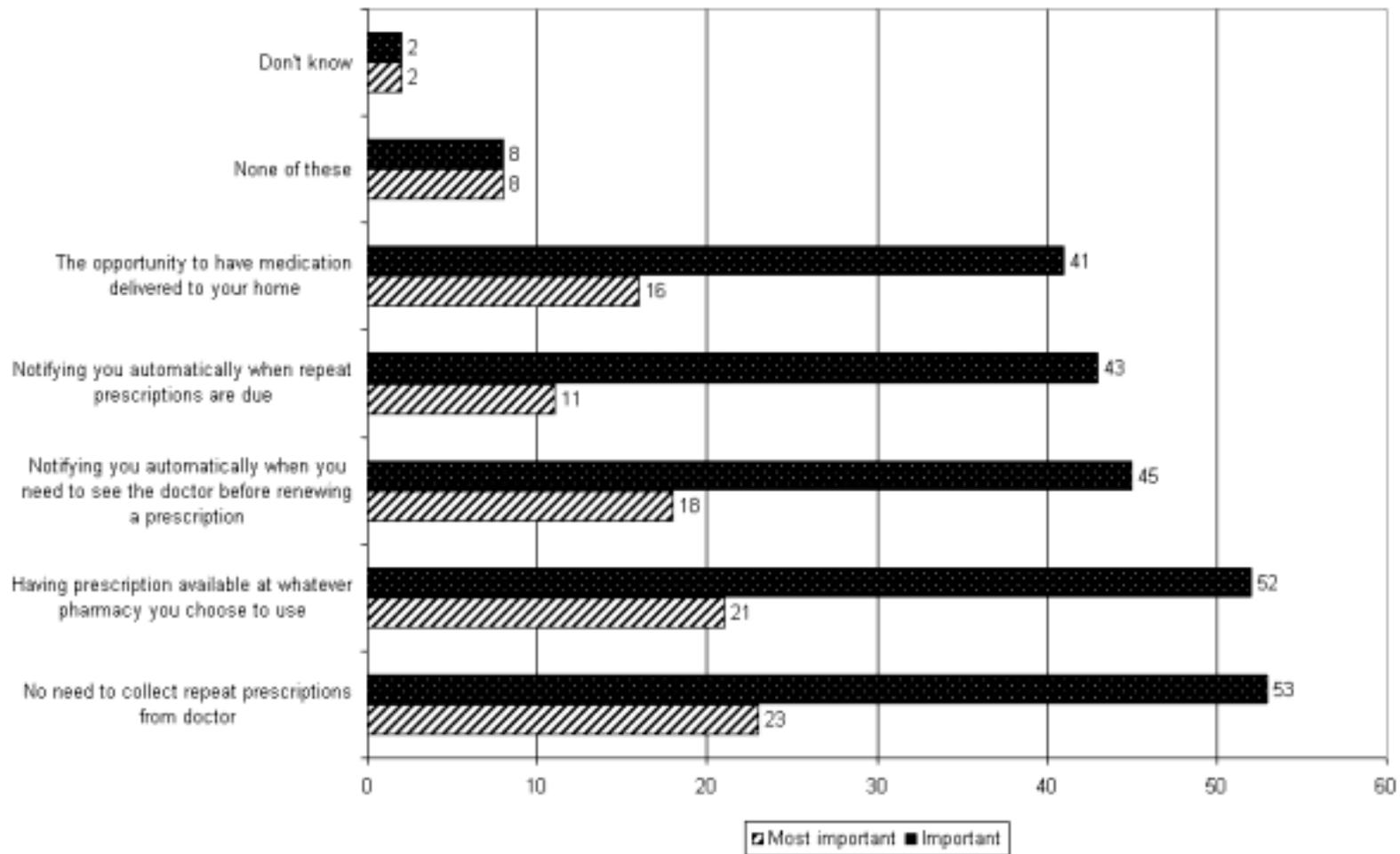


ELECTRONIC PRESCRIPTIONS

It was explained to respondents that new computer systems would enable their doctors to send their prescription information electronically. Respondents were shown a list of the potential effects and asked which of these would be important to them and which one would be the most important. Each of the potential effects was considered important by at least four in ten respondents.

Around a quarter (23%) of respondents felt that not needing to collect repeat prescriptions from their doctor was most important, while the facility to notify you automatically when you need to see the doctor before renewing a prescription was felt to be most important by 18%. A fifth (21%) said that having their prescription available at whatever pharmacy they chose to use would be most important to them, while 16% selected having the opportunity to have medication delivered to their home. 11% felt that being notified automatically when repeat prescriptions are due was most important.

Priorities for electronic prescription processing (Base: All Adults 15+ n=1997)

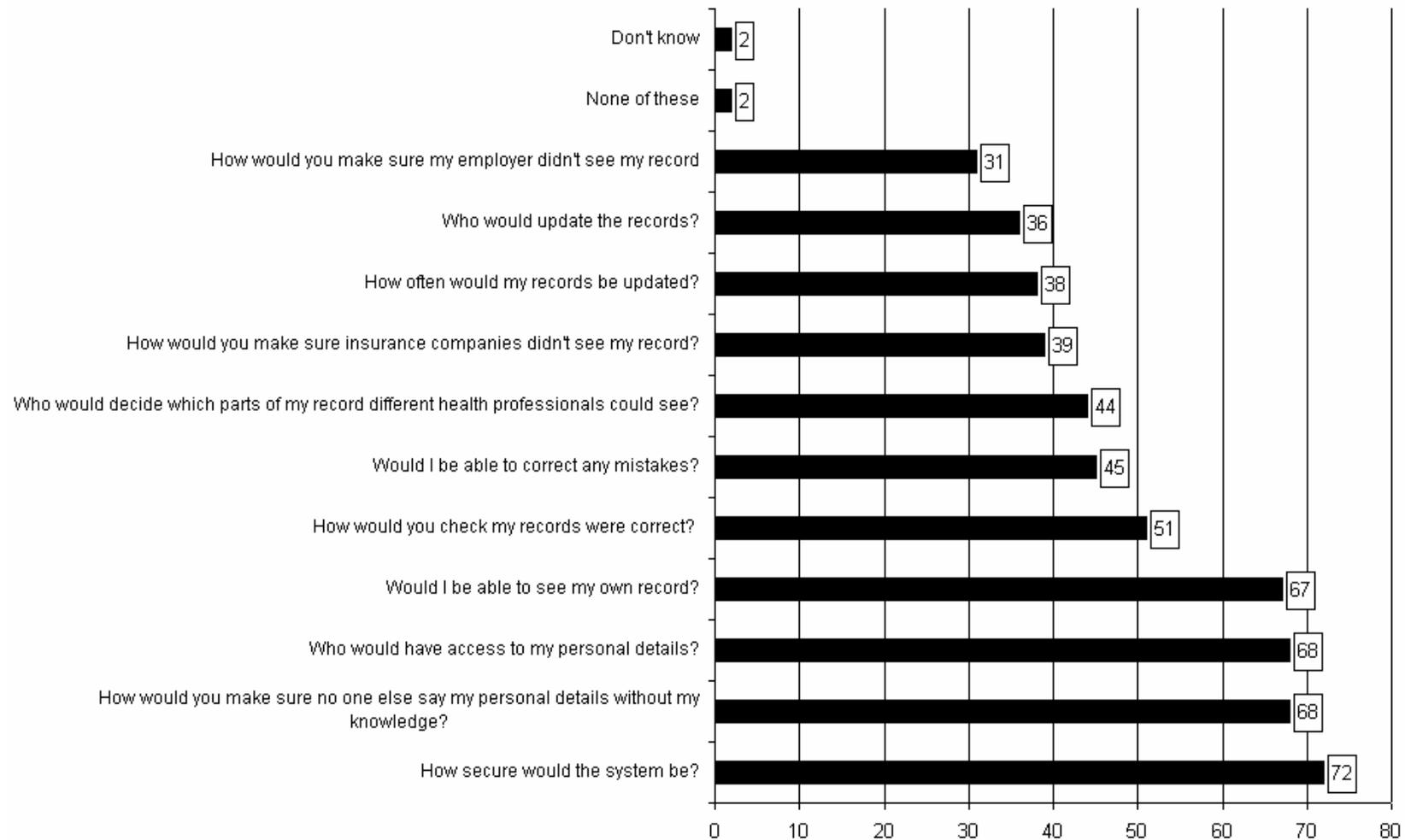


FURTHER QUESTIONS

Respondents were shown a list of questions that people may have about ICRS and asked which would be important to them. Key questions for the public revolve strongly around security and access (both by themselves and others). This was similar to findings in the qualitative stage. Such questions were more likely to be asked by the under 65s and the ABC1C2s, all of whom – this report has shown – are generally more likely to be engaged by ICRS.

Seven in ten (72%) would want to know how secure the system was. Around two thirds (68%) would want to know how the NHS made sure no one else saw their personal details without their knowledge. Two thirds (68%) would like to know who had access to their personal details. A similar number (67%) would like to know whether they could see their own record. Around half (51%) of people would like to know who checked if their records were correct, while 45% would like to know if they could correct any mistakes.

Which questions about ICRS would you like answered? (Base: All Adults 15+ n=1997)



APPENDIX ONE: INTEGRATED CARE RECORD SERVICE TOPIC GUIDE FOR FOCUS GROUPS AND INTERVIEWS (FINAL)

Introduction

- introduce self and Research Works Limited
- explain the purpose of the research: *“to explore patient priorities for the future of NHS record-keeping”*
- explain confidentiality and ask permission to record the session.

Warm Up

- Respondents to introduce themselves, in particular their family and employment situation. Briefly, have they ever considered the issue of patient records prior to this evening?

Discussion of Pre-task

- How do you think your medical records are currently **recorded**?
- Do you think you have an **electronic record** at all? If so, where?
- Have you had experience of basic information **not being available** to you i.e. test results? If yes: why? What happened?
- Have you had any experiences where **sharing of information helped your care**? What were they?
- **Who** do you think can access your records?
- What information about you should be available to health professionals when you are in their care?
- Do you think **you can access your health record**? Why/why not?
- Have you ever tried to access your health record?
- What information should be available to you?
- **Present NHSIA video (first section) explaining the current NHS record-keeping situation.**
- Any surprises?
- Any problems you can envisage with this system?

Presenting the concept

- **Draw the ICRS diagram (Appendix A)**
- **Explain the security procedure (Appendix B)**

- What are your **initial thoughts** about ICRS?
- What **differences** can you see from the current system?
- **Explain sealed envelope (Appendix C)**

- What are your reactions to this concept?
- What kinds of things can you imagine patients wanting to be put in the patient's sealed envelope (and therefore protected from routine sharing within the NHS)?
- What **should not** be put in the patient's sealed envelope?

Pros and cons

- **Syndicate exercise – two groups to discuss and present:**

- Syndicate 1: What do you see as the **benefits** of shared electronic records
 - to you
 - to society?

- Syndicate 2: What are the **drawbacks** (if any) of electronic records?

Demonstration

- Any surprises?
- Any questions?
- Any problems?

Spine content

Show respondents options for Spine content (Appendix D) explaining that this part of the record will follow the patient through the NHS

- Which of these pieces of information **should** be in the Spine (and therefore available for routine sharing)? Why?
- Which of these pieces of information **should not** be in the Spine (and therefore not available for routine sharing)? Why?

Patient benefits

- How **important** would it be for you to be able to access your own record?
- How would you **use** the information within your records?
- How would you like to **access** your record? Probe:

- at home vs. at the surgery
 - touch screen vs. mouse
 - NHS 'smart card' system or the Internet.
- What effect might access have on the **patient role**?
 - What effects might it have on **your role** in your own healthcare?
 - What effect might access have on health care professionals caring for you?
 - How could it **positively** affect those giving you care?

Access issues

Given the security measures that would be in place, show respondents types of personnel who might be in the access loop (Appendix E)

- Of these people, who **should** have access to your record?
 - Who **should not** have access? Why?
- In which particular circumstances do you feel that the public interest out weighs the personal interest? For each, probe why?
 - E.g. information shared between health, social services, the police and education to detect child abuse
 - E.g. information shared with the government [e.g. Secretary of State, Department of Health] for health related purposes like disease registries

Building the service

Show respondents with all the service elements that are being planned. (Appendix F)

- Which are the **priorities**?
 - Which are the **essentials for longer term development**?
 - Which are '**nice-to-have**' elements?
- If we wanted to link records about you in different places without naming you, how would you like your record to be identified (so that information can be linked across the NHS)?
 - NHS number
 - new identification (e.g. pin) number system
 - postal address
 - postcode only
 - date of birth or age only.

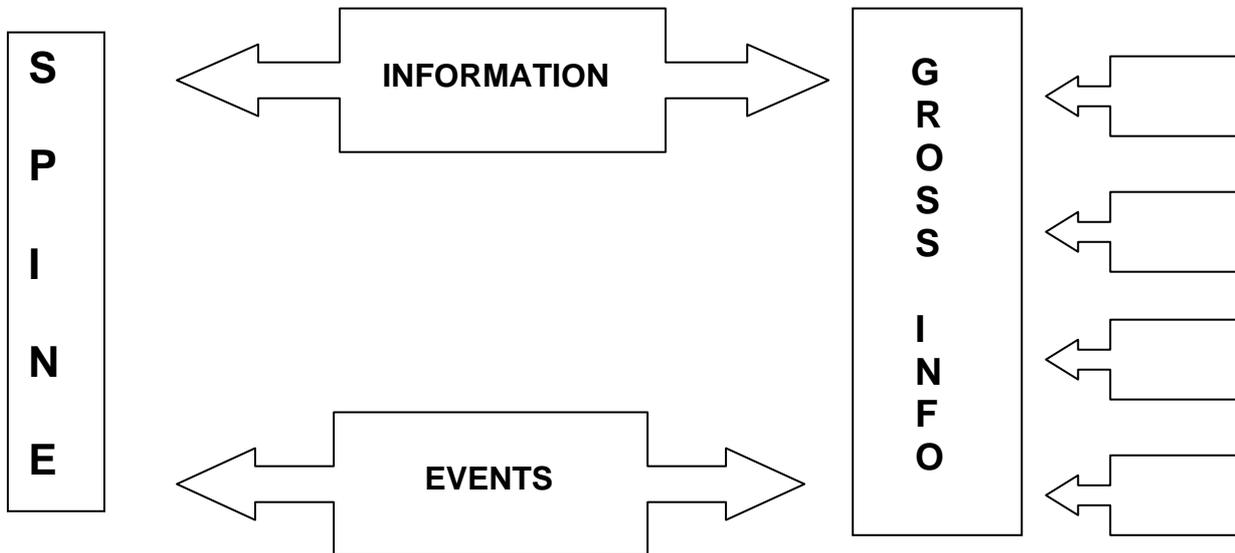
- Do you know your NHS number?
- How would you like to find out about the ICRS?
- When, where and who from?
- What would you like to know?

Conclusions

- What changes would demonstrate that the ICRS was working?
- What are the opportunities of the ICRS?
- What are the drawbacks?

APPENDICES A - F

Appendix A – ICRS Diagram



Appendix B – Security Procedure

- Information sharing will be on a 'need to know' basis.
- NHS personnel will need to prove their identity and that they have a relationship with you, the patient.
- The view they have will depend on their role (i.e. Spine vs. gross information).

Appendix C – Sealed Envelope

- Patients will have their own confidential envelope into which they may place pieces of information.
- Access to this envelope will only be given with patient permission.

Appendix D – Spine Options

1. Patient Demographics

- names, addresses, emergency contact (next of kin)

- NHS number
- caring responsibilities
- ethnic group, country of birth, religion
- language spoken, interpreting needs
- access needs
- specific care wishes (e.g. organ donation).

2. Details of Care Providers and Carers

- contact details of carers
- consent for information sharing with carers.

3. Illnesses, conditions, other important issues

- summary of current health problems
- reactions to therapies
- social issues
- summary of significant past conditions.

4. Procedures, including operations and immunisations

5. Medication profile

- current medicines, vitamins, supplements
- significant medications taken in the past
- alternative and herbal remedies
- dosage, frequency, length of time taken.

6. Relevant family history (where family health issues are of direct relevance to the patient)

7. Allergies and adverse reactions

8. Care Plan

9. Records of Healthcare Events, Reports and Correspondence

- referral letters, discharge letters, transfer of care letters
- reports of encounters (e.g. A&E visit)
- key test results
- prescriptions and dispensing.

Appendix E – Potential staff access to identifiable patient information (With all the security measures already described)

- private hospitals
- hospitals overseas
- social Services

- voluntary organisations and charities providing care
- nursing homes
- people providing alternative therapies like acupuncture
- opticians
- pharmacists
- chaplains
- carers
- government departments (e.g. DoH)
- public services (e.g. police, education).

Appendix F – Prioritisation of ICRS elements

For you:

- access to letters written about you, e.g. when you are referred or discharged
- 24 hour access to your medical history including jabs, allergies and operations
- access to your current prescriptions and dosages
- access to recent test results
- ability to book appointments with your GP on-line
- ability for your GP to book appointments instantly at hospitals and clinics during your appointment
- repeat prescription ordering
- ability to e-mail GPs
- a place to record your wishes, e.g. about donating your organs when you die or whether you want to go on life support if your are very ill.

For those providing you with care:

- 24 hour access to your health record and test results
- ability to book appointments instantly when referring you to someone else
- quick referral procedures
- checks against mistakes, e.g. when prescribing medicines that might not go well with other medicines you are taking or checks on dosage
- access to your wishes, e.g. about organ donation if you die
- good information quickly and easily (that does not identify individuals) to help manage the surgery or hospital better
- ability to get good information quickly and easily (that does not identify individuals) for research, e.g. into which treatments produce the best results.

REVISED SAMPLE

Six focus groups recruited according to the following criteria:

	SEG BC1	SEG C2D
--	----------------	----------------

Younger Family (Children 0-6 years old)	Female, 'chronic/acute'	Male, 'chronic/acute'
Older Family/Empty Nester (Children 7-18 years old)	Male, 'chronic/acute'	Female, 'chronic/acute'
Retired	Female, 'chronic/acute'	Male, 'chronic/acute'

- all to be receiving NHS treatment within the last six months
- at least two respondents in each group to have experience of private health services within the last 12 months
- a mix of private hospital experience to be achieved across the six focus groups: those treated privately in NHS hospitals and those treated privately
- 'chronic' to be defined as respondents (or their children) with an on-going condition which requires regular appointments at the GP/hospital/other NHS services at least once every six months
- 'acute' defined as respondents with a condition which requires appointments at the GP/hospital/other NHS service at least once a month (or to have experienced an 'acute' condition within the last 12 months)
- Eight respondents per focus group, 1.5 hours duration.

18 depth interviews divided as follows:

- six paired-depth interviews with young people aged 12-16 years old
- four interviews with frequent movers (a mix of those moving between NHS services regularly and those without an NHS number)
- four interviews with respondents with sight or hearing impairments
- four non-English speakers (to include those speaking Arabic and Balkan languages)
- a mix of those with '**chronic**' and '**acute**' conditions would be achieved across the 18 depth interviews.

APPENDIX TWO: Quantitative Questionnaire

ICRS Project - FINAL QUESTIONNAIRE

H142 - JN: 11116-705 (15-21 May 2003) - 14 May 2003

Quanquest v2.1 - QAL v2.2bmr13 - CAPI

H142

**INTERVIEWER PLEASE SHOW SCREEN UNTIL OTHERWISE
INSTRUCTED**

1. Which of the following have you done in the last 12 months?

Visited an NHS GP	1	(108)
Seen a nurse at my local NHS surgery	2	
Visited a private doctor	3	
Taken a prescription medicine	4	
Visited a dentist for NHS treatment	5	
Visited a dentist for private treatment	6	
Visited an optician	7	
Received treatment in a NHS hospital, either as an in-patient or out-patient	8	
Received treatment in a private hospital, either as an in-patient or out-patient	9	
Been treated in accident & emergency or a minor injuries clinic	0	(109)
Called NHS Direct	1	
Used NHS Direct Online	2	
Used the ambulance service in an emergency	3	
Visited an NHS walk-in centre	4	
Consulted a pharmacist	5	
Visited an osteopath/ Visited a chiropractor	6	
Visited a chiropodist/podiatrist	7	
Visited some other complementary therapist	8	
Don't Know	Y	(108)
None of these	X	

2. Have any of the following events happened to you or someone you've been looking after?

INTERVIEWER, PLEASE CLARIFY IF NECESSARY: By 'missed an appointment due to my own error' we mean that you did not cancel an appointment that you did not turn up for. This might have been unavoidable e.g. work commitments/traffic etc, or because you forgot

INTERVIEWER, PLEASE ALSO CLARIFY IF NECESSARY: By 'someone you've been looking after' we mean someone whose care you are responsible for, e.g. your child or an elderly parent:

I have had to change an appointment with a consultant/doctor/surgeon	1	(110)
When I have visited my GP/consultant/doctor/surgeon for an appointment my records have not been available	2	
I have not received a letter or notice informing me that I had an appointment with a GP/consultant/doctor/surgeon	3	
My patient records have been lost permanently	4	
A doctor or hospital had confused me with another patient	5	
While visiting my GP surgery or hospital, I had to repeat information I'd already given	6	
I missed an appointment due to an error by the NHS	7	
I missed an appointment due to my own error	8	
Don't Know	Y	
None of these	X	

I would now like to ask you some questions about patient health records.

Everybody in the UK has NHS patient health records which contain all health related details including immunisations, illnesses, test results, operations and records of your visits to your GP.

Everywhere you get treatment, you will have some kind of a patient record.

Your GP's will be the fullest.

-
- 3. The NHS is developing a system which will enable patient records to be accessed electronically across the NHS and potentially by other caring professions. Levels of access are still to be decided however, it is anticipated that information would be shared on a 'need to know' basis and the amount of information that could be seen would depend on the role and the relevance of those seeking access.**

Which of the following do you think should have access to at least some part of your medical record?

Private hospital giving you care	1	(111)
Hospitals overseas giving you care (e.g. if you were on holiday or working abroad)	2	
Social Services	3	
Voluntary organisation and/or charity providing you with care	4	
Nursing home giving you care	5	
People providing you with alternative therapies like acupuncture	6	
Your Optician	7	
Your Pharmacist	8	
Your dentist	9	
NHS Direct	0	(112)
Chaplain wanting to visit you in hospital	1	

Paramedics/ambulance crew attending you in an emergency	2	
Family member or friend acting as your carer	3	
Government Departments like the Department of Health to give you joined up services	4	
Police for an investigation	5	
Your employer	6	
Education Authority for child protection	7	
Schools	8	
NHS Managers	9	
Health Authorities	0	(113)
Medical Researchers	1	
Pharmaceutical companies	2	
Don't Know	Y	(111)
None of these	X	

4. This is a list of the different ways in which electronic patient records could potentially benefit you as a patient.

Which of these are important to you?

Give you access to your records wherever in the NHS you need to make decisions about your treatment	1	(114)
Enable you to email your GP for repeat prescription requests	2	
Enable you to receive e-mails from the NHS with information about useful health sites and support groups	3	
Give you copies of letters written about you e.g. when you are referred or discharged	4	

Enable you at any time to look at your medical history including jabs, allergies and operations	5	
Enable you at any time to look at your current prescriptions and dosages	6	
Enable you to see recent test results	7	
Enable you to book or make changes to appointments with your GP on-line at home	8	
Enable your GP to book appointments instantly at hospitals & clinics during your appointment	9	
Enable you to change appointments at hospitals & clinics from the GP surgery	0	(115)
Enable you to change appointments at hospitals & clinics from your home	1	
Enable you to e-mail GPs with queries	2	
Enable you to record your wishes so that doctors know them e.g. about donating your organs when you die or whether you want to go on life support if you are very ill	3	
Don't Know	Y	(114)
None of these	X	

**IF TV142A1 > 3
THEN ASK: 5**

5. And could you please tell me which THREE are the most important to you?

Give you access to your records wherever in the NHS you need to make decisions about your treatment	1	(116)
Enable you to e-mail your GP for repeat prescription requests	2	
Enable you to receive e-mails from the NHS with information about useful health sites and support groups	3	
Give you copies of letters written about you e.g. when you are referred or discharged	4	
Enable you at any time to look at your medical history including jabs, allergies and operations	5	
Enable you at any time to look at your current prescriptions and dosages	6	
Enable you to see recent test results	7	
Enable you to book or make changes to appointments with your GP on-line at home	8	
Enable your GP to book appointments instantly at hospitals & clinics during your appointment	9	
Enable you to change appointments at hospitals & clinics from the GP surgery	0	(117)
Enable you to change appointments at hospitals & clinics from your home	1	
Enable you to e-mail GPs with queries	2	
Enable you to record your wishes so that doctors know them e.g. about donating your organs when you die or whether you want to go on life support if you are very ill	3	
Don't Know	Y	(116)

End of Filter I142A

6. From which of the following places would you like to be able to look at your record on computer?

INTERVIEWER: PLEASE PUT " " AROUND OTHER RESPONSES

In your home	1	(118)
At the GP surgery	2	
At your bedside in hospital	3	
In a private place at a public library	4	
In a private place at a post office	5	
In a private place at a pharmacy	6	
In a private booth in other places such as shopping centres	7	
Don't Know	Y	
None of these	X	
Other	0	

Other specify...

(119 - 122)

7. This is a list of the different ways in which electronic patient records could potentially benefit you by being available to those giving you care such as GPs and hospitals.

Which of these do you think are important?

Giving those who treat you 24 hour access to your health records and test results wherever in the NHS you are treated	1	(123)
Enabling appointments to be booked instantly when referring you (e.g. to a consultant)	2	
Providing quick procedures for referring you (e.g. to a consultant)	3	
Enabling quick transfer of prescriptions from prescriber to pharmacy	4	
Automatically checking for medicine prescribing mistakes	5	
Fewer lost records	6	
Giving those treating you access to your wishes e.g. about donating your organs when you die or whether you want to go on life support if you are very ill	7	
Fewer lost test results	8	
Making available good information quickly and easily (that does not identify individuals) to help manage the surgery or hospital better	9	
Making available good information quickly and easily (that does not identify individuals) for research e.g. into which treatments produce the best results	0	(124)
Don't Know	Y	(123)
None of these	X	

**IF Tv142A2 > 3
THEN ASK: 8**

8. And could you please tell me which THREE you think are most important?

Giving those who treat you 24 hour access to your health records and test results wherever in the NHS you are treated	1	(125)
Enabling appointments to be booked instantly when referring you (e.g. to a consultant)	2	
Providing quick procedures for referring you (e.g. to a consultant)	3	
Enabling quick transfer of prescriptions from prescriber to pharmacy	4	
Automatically checking for medicine prescribing mistakes	5	
Fewer lost records	6	
Giving those treating you access to your wishes e.g. about donating your organs when you die or whether you want to go on life support if you are very ill	7	
Fewer lost test results	8	
Making available good information quickly and easily (that does not identify individuals) to help manage the surgery or hospital better	9	
Making available good information quickly and easily (that does not identify individuals) for research e.g. into which treatments produce the best results	0	(126)
Don't Know	Y	(125)

End of Filter i142B

9. The development of new computer systems will enable you to book appointments electronically.

Here is a list of the proposed benefits of electronic booking. Which of these do you think you would find useful?

Finding out what transport is available to get you to your appointment	1	(127)
Booking appointments with your GP	2	
Booking appointments with hospitals	3	
Booking appointments with your dentist	4	
Booking appointments with other health care professionals such as chiropodists/opticians	5	
Searching for an earlier appointment with a consultant or hospital at a location further away from your home	6	
Booking appointments without having to make a telephone call	7	
Changing appointments yourself if you discover that the date is inconvenient	8	
Receiving e-mails from the NHS reminding you about appointments	9	
Receiving a text message to your mobile phone reminding you about appointments	0	(128)
Don't Know	Y	(127)
None of these	X	

**IF TV142A3 > 3
THEN ASK: 10**

10. And could you please tell me which THREE you think would be most useful?

Finding out what transport is available to get you to your appointment	1	(129)
Booking appointments with your GP	2	
Booking appointments with hospitals	3	
Booking appointments with your dentist	4	
Booking appointments with other health care professionals such as chiropodists/opticians	5	
Searching for an earlier appointment with a consultant or hospital at a location further away from your home	6	
Booking appointments without having to make a telephone call	7	
Changing appointments yourself if you discover that the date is inconvenient	8	
Receiving e-mails from the NHS reminding you about appointments	9	
Receiving a text message to your mobile phone reminding you about appointments	0	(130)
Don't Know	Y	(129)

End of Filter I142C

11. With new computer systems, it will be possible to book appointments in several different ways such as by e-mail, via a secure Internet site, via interactive TV or by calling a dedicated call centre.

Which of these, if any, do you think you would choose to use to book appointments?

E-mail	1	(131)
Secure Internet site	2	
Via interactive digital TV	3	
Telephoning a dedicated call centre	4	
Don't Know	Y	
None of these	X	

12. New computer systems will also mean that your doctor will be able to send your prescription information electronically.

Here is a list of the potential effects on you. Which of these would be important to you?

No need to collect repeat prescriptions from your doctor	1	(132)
Notifying you automatically when repeat prescriptions are due	2	
Notifying you automatically when you need to see the doctor before renewing a prescription	3	
The opportunity to have medication delivered to your home	4	
Having the prescription available at whatever pharmacy you decide to use	5	
Don't Know	Y	
None of these	X	

**IF TV142C > 1
THEN ASK: 13**

13. And which one would be most important?

No need to collect repeat prescriptions from your doctor	1	(133)
Notifying you automatically when repeat prescriptions are due	2	
Notifying you automatically when you need to see the doctor before renewing a prescription	3	
The opportunity to have medication delivered to your home	4	
Having the prescription available at whatever pharmacy you decide to use	5	
Don't Know		
	Y	

End of Filter i142D

14. Here is a list of questions that people might ask the NHS about electronic patient records.

Which questions do you think you would be important to you?

How often would my records be updated?	1	(134)
Who would update the records?	2	
How would you check my records were correct?	3	
How secure would the system be?	4	
Would I be able to correct any mistakes?	5	
How would you make sure my employer didn't see my record?	6	

How would you make sure insurance companies didn't see my record?	7	
Who would decide which parts of my record the different health professionals could see?	8	
How would you make sure that no one else saw my personal details without my knowledge?	9	
Would I be able to see my own record?	0	(135)
Who would have access to my personal details?	1	
Don't Know	Y	(134)
None of these	X	

15. And finally, please may I check, which of these statements most closely describes your general health status over the last twelve months?

INTERVIEWER NB: IF THE RESPONDENT HAS HAD A SERIOUS ILLNESS FROM WHICH THEY HAVE FULLY RECOVERED, E.G.: BROKEN LEG, CAR ACCIDENT, PLEASE CHOOSE CODE 4

I have been in very good health for the last twelve months	1	(136)
I have been generally well, except for the odd cough, cold or minor ailment	2	
I have been generally well, but I have an on-going condition, illness or injury that requires regular medical treatment	3	
I have not been well - I've been suffering from some condition, illness or injury that has required a lot more medical treatment	4	
Don't Know	Y	