

# RECORDS ACCESS

*Enabling Patients to Access their Electronic Health Records*

## Welcome to Records Access

Welcome to the first edition of *Records Access*. This is all about helping you to see your medical records. It is easy when you know how. And you do not even need a computer or the internet at home. All you need is the desire to want to know what is in your medical records.

We want you to learn what *Records Access* is all about. We want to show you how easy it is to see your own health records. We will show you what help there is available and who to turn to if there is something you do not understand. We will show you what other services are available out-of-hours if you fall ill and how you



Graeme Roper, patient, accessing his electronic health record from home

can use access to your records to help you get better care. We will show you how you can keep on top of your health by knowing what is happening. We will help you to understand what the advantages are as well as some of the disadvantages too.

We hope it will help you

to decide whether you want to find out what has been recorded about you and how it might help if you suddenly fell ill and had to go to the Out-of-Hours service or casualty here in the UK or even abroad.

## Why should you access your medical records?

The care you or your loved one receives is becoming more and more complicated. Often, you may need to wait for further blood tests or results of scans that help the doctor decide what to do next. Also more and more, we

work as a team with others who may be in the practice or perhaps work in a community clinic or at the hospital. We are all here to help you but often the information about your health is not available for others to see. You there-

fore are very important in enabling the clinician to know what else is happening by letting them see your records. Also by seeing your own record, you can see what the clinician has said and wants you to do or get!

June 2007

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### Special points of interest:

- Access to your medical records is a RIGHT that you have but with that come certain RESPONSIBILITIES
- Records Access is supported by Tameside & Glossop PCT, the British Medical Association, the General Medical Council, the Medical Defence Union and the Medical Protection Society as well as the Patient Information Forum etc
- It gives you the opportunity to ensure information recorded about you is correct and is available FREE of charge.

# What is Records Access?

**Record Access** is the ability for an individual to see their medical record in an electronic format away from the computer system where it is stored. The individual may be a clinician looking after a patient or it may be the patient.

## Access to your information

Records Access can give you access to just your medications and perhaps any allergies that you may have. Or it may give you access to all your consultations, present medications as well as some of the medications you have had in the past, letters from the hospital or other places that we receive, all test results

## Rights to your information

There is much debate on how much patients can see of their records. The Data Protection Act does give patients rights to see the contents of any medical record although there are some exceptions particularly the contents of any "third party data". This is information that someone else has given to the clinician without your prior knowledge.

## "Grey Areas"

There are also some other "grey areas" where it is unclear what should happen. This includes patients with severe mental illness and those with learning

difficulties or memory problems such as dementia where they may not be able to give consent. Similarly when is a child old enough to be able to access their medical records separately to their parents. What about patients who do not speak English? And what about carers who may well be looking after their loved one and are expected to take them to appointments but find it very hard to know what is happening? These are all situations where we feel that you should come and discuss it with your doctor to identify what is in the best interests of the patient.

Having Records Access may well just help them as well as you!

## Live Record on Our Test Patient

The easiest way to see what a record looks like is to see a "real" record of our test patient. This gives you an idea of the sorts of things you could access.

First log on to:

[www.patient.co.uk/surgery.asp](http://www.patient.co.uk/surgery.asp)

As this is only a test patient, you do not need to register.

Under Appointments / Prescriptions click where indicated and then you will be asked to fill in the boxes.

Fill in the information as below:

Practice ID: 7399  
Access ID: 2558  
Password: HAUGTON1

(case sensitive)

then click "Sign In" button

You can then look at the medication.

## Repeat Prescriptions

[Request a Repeat Prescription](#)

[See more details of your requests](#)

[List of your repeat medication](#)

Clicking on the underlined parts gives you a different window.

You can have this facility to order repeat prescriptions on-line whether you choose to have your medical records or not. At this point neither you nor anyone else could access your medical notes.

## To access your Medical Records Your Medical Record

You can view a summary of your medical record here.

Click on the underlined part. You will then be asked to supply 2 randomly picked digits from an 8 digit password.

In the Test Patient record this will be:

1=H; 2=A; 3=U; 4=G; 5=H; 6=T;  
7=O; 8=N and then click "Submit"

Make sure you use the letter "O" and not the number "0" for digit 7 and they are case sensitive

You can now access the medical record. You will be asked to confirm that you are the named person on the screen. Click on confirm.

Don't forget to sign out when you finish seeing the record particularly if someone else uses the same computer!

# What help is available to understand your health better ?

## The practice.

It might sound like the obvious but we are here to help you understand your health better. We have the added advantage of knowing your personal circumstances better and helping to understand what these mean for you. You can contact the practice any time day or night. However please note that the practice is under incredible pressure to meet the day-to-day needs of patients. We will contact you if there is something urgent. We have a good track record for providing an excellent service. It would help us a great deal if you can try some of the other forms of help described on this page or leave a message for someone in the practice to contact you or to make a routine appointment with the doctor or nurse rather than insisting on seeing someone immediately unless it is something that is very urgent. Your co-operation in this matter would be greatly appreciated. We do not wish to raise expectations beyond what we can deliver.

If we are shut, you will get an answering machine with the telephone number for the *Out-of-Hours* service. There is always a doctor or nurse available. But remember the out of hours service do NOT have access to your medical records. You may have to read out or show them what you can see on your computer screen!

**NHS Direct.** 0845-4647 or

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

The portal to good quality general advice about your health. It is available 24 hours a day 7 days a week and is a good alternative place to contact if you are unable to contact the practice. We recommend this be the first place you look for information about your health if there is something you do not understand and cannot wait for the practice.

[www.patient.co.uk](http://www.patient.co.uk)

This is a web-portal which gives you access to other web-sites on almost any

health related problem. This is usually a good place to start if you want to know more about a condition that you suffer from. The advice is usually from relevant web-sites in the UK and there are opportunities to share your own experiences with others too.

[www.nice.org.uk](http://www.nice.org.uk)

The website for the National Institute for Health and Clinical Excellence. All NHS organisations subscribe to these guidelines and should be offering these treatments to all patients. Click on "Our Guidance". You can click on "Information for the Public" next to any of the specific guidance to see relevant articles.

[www.besttreatments.co.uk](http://www.besttreatments.co.uk)

This is a web-site that has been designed for members of the public to know the best treatments for common conditions.

[www.labtestsonline.org.uk](http://www.labtestsonline.org.uk)

This is an excellent web-site which describes different blood tests that you may have and what they mean.

[www.foldercare.co.uk](http://www.foldercare.co.uk)

This is a web-site that has been designed by patients for patients. It has a number of interesting papers on patients accessing their medical records over the internet and some of the latest thinking on the subject. Well worth a read if you would like to delve deeper and learn a little more.

[www.usercare.info](http://www.usercare.info)

This has also been set up by patients for patients and tries to make sense of where "records access" fits in with life and what people are trying to do. This is a web-site that is still being developed and has not been officially "launched" for the public. But you are welcome to see what is available.

[www.icmcc.org](http://www.icmcc.org)

The web-site of the "international council on medical & care compunetics". This is the international body that is taking a lead on Records Access and describing what is happening throughout the world. If you click on

"Record Access", it will direct you to a number of resources. A large number of people throughout the world are now looking at this as a way of keeping up to date on what is happening. There is also the world's first "Blog" where patients, clinicians, people in the system and system suppliers can all post ideas to inform others about what they think. We want as many different people to post ideas here and what their thoughts and experiences are. Please pass this on to friends and family members all over the world so that they can also see what is happening too.

There may be other sources as well that we have not included. This is by no means an exhaustive list but it may help you to understand your health conditions better. Of course if there is something you do not understand then it is important that you contact the practice to help you further.

It is said that the average GP would need to read 5000 papers per day just to keep on top of all the developments that are going on! Clearly this is an impossible task for anybody. These web-sites give you access to up-to-date information in a concise, easily readable manner for those of you that wish to know a little more and share that knowledge with your clinician. The clinician may not have seen the specific information but should be able to evaluate it or perhaps go away and find out more about it and what it means for you.

We are beginning to learn what it means to build a "Partnership of Trust" where we support each other to deliver better health-care. Patients have a better understanding of how their illness is affecting them. Clinicians have a better understanding of what health-care is available locally and how it can be accessed and to help guide patients through the "system.". **Access to your health record enables you to get better care!**

# The Patient's Perspective of Records Access

Having access to your medical records via the internet has proved to be very popular with many patients. Before signing for access to your records it is important that you look at both the advantages and disadvantages. You will need to use 2 passwords. The 1<sup>st</sup> is for ordering repeat prescription, checking and cancelling appointments only. The 2<sup>nd</sup> is to access your medical records and needs to be 8 digits which can be a mixture of letters and numbers. They are case sensitive so remember whether you used upper or lowercase. Remember the computer treats the letter O and number 0 as different characters.

## Advantages

### **GP/Healthcare**

The patient has an active role in their own healthcare and develops a good relationship with their GP and Practice. This is being backed up with the 'Choose-and-book' option where the patient can choose which hospital they would like to be referred to.

### **Repeat Prescriptions**

These can be ordered via the internet whether you take advantage of the access to records or not. You must register for this service.

### **Results**

With access to your medical records you can check any results or letters

### **Holidays**

You may be in another country and taken ill. You may decide to allow the doctor access to your records (a personal decision). It might be that you forgot to order your repeat prescription and need it to be ready on your return. You can do this by using an internet café. You usually find such facilities in most holiday complexes. This has been tried very successfully from abroad.

### **Appointments**

Appointments at the Practice can be seen on screen and cancelled if you wish. If you are going to see a health-care professional outside your area

you can allow them to see your records online (if facilities exist) or print out the relevant information and take it with you. (The date will be on the bottom of the printout)

### **Community**

It might be that you are receiving care at home and it is necessary for latest results of tests to be known before treatment is given. You can check the results yourself or allow anyone else you see fit to do so.

### **Nursing Homes**

If a relative is in a nursing home, and you have been given access to their records, by monitoring the 'consultation' section you can monitor their care. Records of visits by doctors along with comments by the doctor will be recorded here. This could be done from anywhere in the world.

### **Relatives**

*Only if you wish* you could share all your records with relatives or just part by printing the part you wish to share.

### **Time**

For most people there is never enough time – doctors included. Much time can be saved by ordering repeats via the net. You can track the details and progress of your request before instructing the chemist to collect. Blood results, x-rays or letters can be checked. If they are normal it saves you time not having to travel to the surgery (can be lengthy & expensive if you don't have your own transport). It also leaves a free appointment allowing the doctor to see someone who is in need of an appointment.

### **Information**

You can easily check information about any medication prescribed by clicking on the blue 'i' button listed next to your medication in the list. This also includes information on how to take the medication such as 'on an empty stomach' or 'with food' etc which is not always available when you receive tablets in bottles. You can check what results mean or check a condition and some help guidelines.

There are links to support groups e.g. Diabetes UK.

### **Security**

It's as safe as internet banking ***IF*** you keep your passwords secure. You wouldn't leave your bankers card and pin numbers lying around (particularly at work) and then wonder how someone managed to withdraw money from your account. Don't leave your passwords where they can be found. This may also include at home if you don't want family members to view your records. Don't use obvious ones such as names, birthdays or anniversaries etc.

### Disadvantages

#### **Forgotten History**

There may be something in your history you don't want any family members to see. It might be information you had put to the back of your mind and are now confronted with it!

#### **Bad News**

You may read some bad news before the doctor has seen it.

#### **Abnormal Results**

Results may be abnormal and cause you to worry

#### **X-rays**

A chest x-ray may show a shadow and hence the possibility of cancer

The alternatives are the same for all three.

**What to do if you get Bad News, an Abnormal Results or an X-ray or other letter suggesting a possibility of cancer!**

Ring the surgery and ask for telephone consultation

If out of hours:

- Don't look at the results if you are prone to worry
- Wait until the surgery opens before checking
- Speak with NHS direct
- Ring surgery for out of hours number



• Ring A&E only if you are really bad  
Remember had you not had access you would not have known the results until either the doctor/practice/contacted you or you rang for the results.

### 3<sup>rd</sup> Party Info

You might want to tell the doctor something about your spouse/partner/child etc in confidence.

If the doctor records the information and the patient then sees this it could cause problems. If the doctor doesn't, vital information may get lost or forgotten. The information may be malicious and again cause problems

### Children

When is a child not a child? Some may be 12 year old going on 20 while others could be 18 year old going on 10 year. At what age do they have their own passwords? What about a teenage girl who wants contraception but doesn't want the parents to know?

### Unknown Issues

There are many unknown areas that may arise at any time.

### FAQ (Frequently asked questions)

#### Passwords?

Case sensitive and remember difference between O or 0. If you leave pass-

words lying around then no it's not secure



Dr Hannan with Yvonne Bennett

#### Identity Theft?

No address or NHS or National Insurance number given on screen. Only obtainable by reading letters

#### What if I mess it up?

No matter what you click you can't alter it. You can cancel appointments. You can order repeat prescriptions and your are given a chance to check it before submitting and can leave a message with your request

#### What if I am seeing a doctor and there is no computer in the room?

It can easily happen. If you know you are going to see a doctor then take a print out with you. This could include any of their letters to your GP and any recent test results

#### What if the doctor I am seeing objects?

Then be polite, and apologise. You brought them to assist the doctor not antagonise them

#### What to Do Next

Carefully weigh up the advantages against the disadvantages. Consider are there other issues that have not been answered for you?

It's up to the individual to decide if they want access and not other members of the family.

If you are seeing a solicitor regarding Power of Attorney for a relative it might be a good idea to ask the solicitor to include access to medical records.

If any of the disadvantages are a problem for you then record access may not be for you. The treatment you receive or the relationship with your doctor will not be affected in any way. You could still use the online ordering of repeat prescriptions and cancelling appointment facilities.

Being able to choose to have access to records is for the benefit of the patient and it is necessary to apply for such. You may wish to discuss this further with your doctor.

*Yvonne Bennett, age 59*

## Creating your own Passwords

### Create a good (strong) password:

Include both uppercase and lowercase letters (case-sensitive) if you have a good memory or just 1 case if not.

Include both letters and numbers (alpha-numeric but not birthdays).

Do not include your login name, a.k.a. username, in any form (as-is, reversed, capitalized, doubled) or any other name.

Avoid words that can be found in a dictionary (including foreign and technical dictionaries) these includes names.

Do not use a password that has been given as an example of a good password.

### Create an easy to remember password:

One possible way to pick a good password is to make up your own acronym. Create a phrase that has meaning to you and pick the first letter of each word. Make sure your phrase has

One possible way to pick a good password is to make up your own acronym.

numbers in the middle. A combination of numbers and letters is harder to guess or crack with a computer program.

For example:

"I love to shop for sandals in the Spring." (I~~l~~s4sitS)

12 x 12 are 144 (12x12r144)

"I'm going to work out 3 times a week." (Ig2wo3taw)

"Last summer I caught a 30 inch striped bass." (LsIca30isb)

I married a lazy slob which seems like 90 years ago (imalswsl90ya)

My password needs to be 8 letters long (mpntb8ll)

A similar method is to take out all the vowels from a short phrase.

For example:

"I work 8 hours a day." (wrk8hrsdy)

# Marple Cottage Surgery

## Secure on line remote consultations

### Winners of The NHS Leadership in Health Informatics Accolade Scheme 2007

Marple Cottage Surgery team's aim was to provide a mechanism for remote asthma reviews and to build upon services already offered to patients via EMIS Access. This new secure online service includes patient's ability to 'push' information to the GP/nurse, which was simultaneously documented in their medical records and for GP/nurse single entry consultation in the patient's medical record, including a personalised self-management plan. Several years ago we developed a website for patients ([www.marplecottage.co.uk](http://www.marplecottage.co.uk)) and since then we have been keen to use

the website for patients to communicate electronically. Patients have also enjoyed the use of the on-line EMIS Access facilities including appointment booking and prescription ordering. We persuaded EMIS to extend EMIS Access to include asthma "remote consultation".

The general feedback from our patients so far has been extremely positive. This is particularly beneficial for those patients who struggle to attend the surgery for their asthma reviews due to work commitments. This new system enables them to submit various changes that they experience with their asthma, online 24 hours a day 7

days a week to our practice nurse, who will then respond to the patient with advice on the next steps to take and in some cases will enable the patient to manage their asthma care without having to make an appointment.

Once tested with patients, EMIS will be able to offer it to other practices as a ready product. In addition, it is simple to apply to other long-term conditions i.e. Diabetes, COPD etc as well as health screening data to help maintain an 'up-to-date' patient medical record.

## How Records Access is helping Patients and their Relatives

***Do you have any stories that you would like to share for the next edition of Records Access ?***

*There is a social change happening right before our eyes. I am finding grandparents who perhaps suffer with multiple chronic diseases are the ones who are mainly interested in accessing their medical records. This may be perhaps because they have so much contact with the medical profession.*

*But they may not necessarily have the IT skills. So they are getting their grandchildren (with the IT skills) to help them. Ironically this is bringing whole families together again so that they support each other in different ways!*

**Dr Hannan Blog, [www.icmcc.org](http://www.icmcc.org)**

### ***My 'Records Access' Experience***

My 90 year-old Aunt recently died in the care home where she had been living for the past five years. I was her next of kin and held Power of Attorney for her, a responsibility complicated by the fact that my Aunt lived in England and I live in Australia.

Most of her affairs could be managed with the use of modern technology and annual visits to the UK. But it was between these visits that I felt frustrated when trying to gauge how my Aunt was actually feeling, whether she had any medical problems and how they were being handled. Speaking with her on the phone was sometimes difficult because she could not always hear me clearly and when she wasn't well she could be a bit confused.

When I spoke to staff members at the care home, they could mostly only give me a general picture of my Aunt's state of health. When I was particularly concerned I phoned my Aunt's surgery. This was helpful but I couldn't always contact a doctor who had seen my Aunt recently. It was during one such call when Dr. Hannan spoke to me about the 'records access'. My Aunt was enthusiastic for me to have the access and it was quickly set up.

What a boon this turned out to be. Now I could get complete and current medical information. I could see what problems or symptoms had prompted the doctor being called, what the results of the examination were and what had been prescribed or recommended.

The back history, referrals, results of hospi-

tal visits and tests was also valuable information and enabled me to ask more relevant questions, by phone or by email. I also believe that as a result of my overt interest in my Aunt's health, through 'records access,' my Aunt got more regular and thorough attention. The staff at the care home were also more forthcoming in accurately describing what was happening. All this information meant that as my Aunt was declining in her final weeks I was kept in the picture, almost day-by-day as the end approached.

It's unfortunate that we, my Aunt and I, only had the benefit of 'records access' for such a short time, but I am very grateful for having had the opportunity to participate in it.

**Niece of Deceased patient from Australia**

## Benefit of Ordering Repeat Prescriptions on line

*"As the first patient to get my prescription on line this means a lot to me. I am now finding it difficult walking up to the surgery. Now I send for my repeat prescription on-line. Then I ring the chemist to pick it up for me. All I need to do then is collect it when I go to town for shopping. I can also check any appointments and my records at home which is most helpful"*

*Margaret Rickson, age 78*

**"Free up your time and take control. Access your records anytime or anywhere"**

*Sandra Boyce, age 65*

## Benefit of Booking Appointments On-Line

*It was about 10.30pm when I said to my partner, "Don't let me forget to ring the doctors in the morning for an appointment to see Dr Hannan – I need a prescription and what I want isn't on a repeat". She was on the computer at the time so she said, "I'll try and book one on-line". So she logged onto the EMIS Access web-site and within minutes I was picking a date and time from those available and without holding on or the constant re-dialing in the morning to get through.*

*Graeme Roper, age 34*

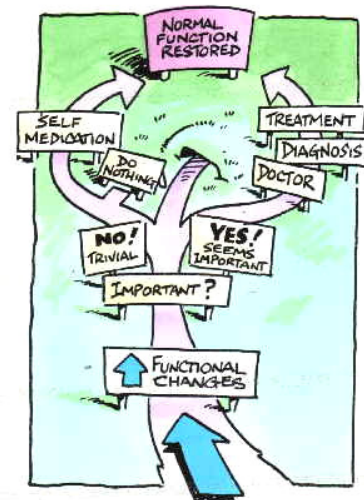
**"Help your Doctor to help you. Access to your medical records on line: it's fast, it's free and it's easy"**

*Sandra Boyce, age 65*

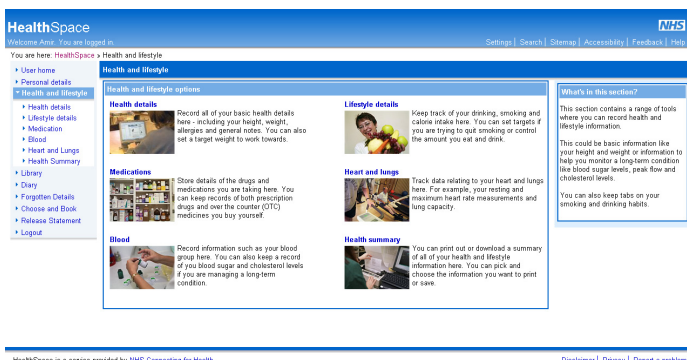
## www.usercare.info

Patients of Dr Richard Fitton at Hadfield Medical Centre, Glossop have helped to develop the first web-site in the world to help patients and the public to understand what it means to access medical records over the internet and how it transforms the relationship patients have with their clinicians. Through a series of steps, patients are first introduced to the idea of information being recorded on a

computer system which can then be shared. They talk about the journey of life from conception through to death and along the way, we learn about disease and illness, symptoms and signs, investigations and ultimately diagnoses, leading to immediate, continuing and preventive health-seeking care to help lead healthier, longer lives and achieve happiness and contentment.



## www.healthspace.nhs.uk



This is a web-site that allows you to access and store your personal information about your health. This is your personal space where only you can see

This is also available now for all citizens in England.

Pilots have recently begun in some parts of the country enabling a sum-

mary of the medical record to be visible from this site. Initially this will include current and repeat medication as well as any drug allergies or other adverse reactions. Subsequently it is hoped summary medical information may also be viewed through this site.

This is a separate venture from that of EMIS Access which allows full access to the whole GP-held record but does allow patients in practices that are not offering Records Access to have somewhere to see their medical information via the internet.

We are very grateful for a number of sponsors including the following who have enabled the production of this magazine and supported further developments in Records Access.

**emis**

EMIS is the UK's leading IT supplier in primary healthcare, hosting over 39 million electronic patient records within its systems. Around 55 per cent of doctors in the UK currently use EMIS software each day.



**Pharmacy**

**Your Community Pharmacy**

Prize money for "Involving Patients and the Public" at Tameside & Glossop Primary Care Trust's **People Pursuing Excellence!** Excellence Awards for work in enabling patients to access medical records over the internet has also been kindly donated by the winners



Produced by Dr Hannan & Patients.

For further information, please e-mail  
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**Record Access Collaborative**  
Patient Access to Medical Records

The record access collaborative is being developed as a service to the public, patients, the NHS and industry. The aim is to bring together those who have an interest in seeing record access more widely available and maximising benefits that flow from it.

The NHS has made a clear statement of principle that patients should be able to access their records, subject to legal safety restrictions. There is good evidence of substantial benefits for patients.

#### THE AIM OF THE COLLABORATIVE

- to raise awareness of record access (RA) nationally and internationally
- to make RA as useful to patients and health care professionals as possible by linking data to facilitate understanding and empower patients to share decisions if they want to.
- to increase the take-up of RA by patients and practices, with possible extension to other healthcare organizations such as outpatient departments and pharmacies
- to support the development of national standards for RA.

Its development has been made possible by bringing together the knowledge and experience of EMIS, the leading supplier of IT systems to General Practices in the UK and PAERS (Patient Access to Electronic Records). PAERS is a small company run by 3 doctors that has developed the software that underpins full record access. It enables the record to be extracted from the GP system, reformatted for ease of use and linked with information and advice to improve the understanding of their data by patients.

For further information about the Records Access Collaborative please contact Dr Brian Fisher on [brian.fisher403@ntlworld.com](mailto:brian.fisher403@ntlworld.com)

## How can you also get Records Access?

There are 3 simple steps for you to also get the benefits of Records Access if your practice is offering it:

1. Ask for your Access ID and Pin number from the receptionist to register on-line for ordering repeat prescriptions and booking appointments too.
2. Ask for an information pack which includes further information about accessing your medical records.
3. Once you have decided you would like access to your full GP-held medical records, you need to:
  - a. fill out a questionnaire (if required by your practice),

- b. sign a consent form and
- c. provide an 8 character pass phrase

Hand this in to the receptionist. Once these have been processed, you will be able to access your medical records. Contact your practice manager if you have any problems.

Over the coming months, we hope to do further editions of Records Access targeting particular groups of patients who could benefit from this and show what specific use Records Access may have for them

We are hoping to recruit over 1000 patients at each practice and start to really demonstrate significant improvements in health-care deliv-



ery. Please share this magazine with other family and friends too so that they may be able to benefit from Records Access also!