

Closing the Gap through Changing Relationships

Final Report for Closing the Gap through Changing Relationships (award holders)

Project Title:	myRecord
Lead Organisation:	NHS Alliance
Partner Organisations:	
Project Lead:	Dr Brian Fisher

Abstract

The myRecord project aimed to change the nature of the relationship between patient and clinicians in primary care by giving patients access to their GP medical record online. We aimed to encourage practices in Lewisham and Berkshire East to offer this service to their patients, and to encourage patients to utilise it. We did this by meeting with practices and ‘selling’ them the benefits of using record access (RA) and then by marketing the innovation to patients. The goal of this intervention was to make the relationship of clinicians and patients more equitable through the sharing of information.

Unfortunately we discovered problems with the IT system we were trying to implement which resulted in frustration for patients and practices. We therefore moved our focus from mass uptake of RA by practices and patients towards trying to understand how to engage and influence practices in order to cultivate a culture of openness in which RA could flourish. We worked with a small practice in Lewisham and delivered workshops and training in which they shared with us their fears about record sharing. Instead of ‘selling’ RA to them we explored these fears together in order to recognise them, work together to alleviate them and to ultimately change attitudes towards the sharing of information through online RA.

In the process, we have learned a lot about what support patients and practices need to be able to deliver and harness RA. We have produced some research tools and materials that are likely to make this easier for others.

We have been able to demonstrate that access to records, even with a clumsy system that doesn’t always work:

- does improve the service for some users
- ultimately leads to a change in relationship with regard to how they feel about their own health management.

The legacy of the project will be building a knowledge base for others to use in order to inform the future national roll-out of RA.

Effective Environment

On the condition that a RA system was released that was patient friendly and operational we believe the ideal environment to deliver this intervention is one in which:

- Clinicians believe in the patients right to have access to their medical record
- Clinicians believe in shared decision making and actively work to include this in consultations
- Practices are financially incentivised to encourage their patients to utilise having access
- A critical mass of people is sufficiently dissatisfied with the status quo to push through real change

The first piece of advice for any undertaking an IT project would be to make sure that they have a working system that can fulfil its remit.

Steps for a CCG

- **Start in one small practice**

We found that working in small practices (1 to 3 GPs) is much easier than working in larger ones. With fewer staff members in an organisation, gathering them all for meetings and workshop is much simpler.

- **Engage clinicians from the outset**

Clinicians don't need to be convinced on the benefits of RA but they do need to be willing to at least be open to the idea of trying something different, and commit to giving it a try.

- **Clinicians referring patients to RA**

Nurse referral may become the norm – they work most closely with patients with long-term conditions (LTCs) who benefit most from RA.

- **Identify clear measures from the beginning**

Know what you want to measure and how you'll do it before starting any of the work

- **Pay real attention to the fears and concerns of those who will be offering the access**

Our initial reaction to fears and concerns was a ‘don’t worry about it’ approach and with time and experience we’ve discovered this is wholly the wrong attitude in this environment. If someone has a concern then try to understand why they are voicing it and what motivates that feeling. Validate it, listen and work collaboratively to find a resolution that everyone feels comfortable with and in control of.

- **Support the CCG in developing a RA strategy.**
See the suggestion on the myRecord website as an example:
www.myrecord.org.uk
- **Use the tools and marketing ideas on the myRecord website**
They have been drawn from the experience of practices around the country.
- **Develop a network of practices to support each other**
These would be primarily managers and staff, but should also include clinicians.
- **Draw in your Local Area Teams and CSU.**

1. Introduction

1.1 Background Knowledge

In 2010 approximately 50 practices in the UK were offering patients online access to their medical records. Of these 50, 20 were situated in Lewisham, and had been recruited to offer access through a previous project¹ run in conjunction with Dr Brian Fisher and funded by Lewisham Primary Care Trust (PCT).

A private company, PAERS, had developed a way in which patients could access their medical records online, and this was available to the 52% of practices in the UK which used EMIS GP software. Full RA was available free to all EMIS practices. If ‘turned on’, patients would have secure access to their full electronic GP record from an internet browser anywhere in the world. The record was reformatted to be patient-friendly and easily navigable and could be accessed in its entirety or in part. People were able to see virtually all personal data held at their practice plus many useful features (e.g. links to patient information, secure messaging to and from the practice, access to laboratory results and comments from their doctors).

¹ In the preceding project GP practices had been offered a £500 incentive to make record access available to their patients and trial it with at least one member of their practice population. There was no further obligation from the practices beyond the trial period.

Although the ability to offer patients access to their medical records online had been available for four years, take up nationally had remained low and the handful of practices that were offering it (outside of Lewisham) had evangelical pioneers at the helm. The project aimed to encourage and enable GP practices in Lewisham and East Berkshire to tackle the barriers that hindered further uptake of online RA and offer solutions for successful implementation across the wider NHS.

The Project Team

Project Director – Dr Brian Fisher

Project Manager Year One – David Gilbert

Record Access Facilitator – Richard Ince

Project Manager Year Two – Richard Ince

Research and Project Coordinator – Anna Burns

1.2 Local Problem and Context(s)

Initially we started the work in two very different areas, Lewisham and Berkshire East.

NHS Lewisham was a PCT in South London with significant deprivation and health inequalities. There are many community groups with a good relationship with the borough and the PCT. Financially; the PCT was on a sound footing, with constant vigilance. There were 48 practices in the borough (now 43 due to mergers and closures), all but one using the EMIS system. Lewisham is Dr Brian Fisher's home borough and the relations between the project and the PCT were strong. We were allocated desk space within the office building and were given honorary contracts – we had clearance to work within GP practices, full information governance training and provided with NHS email addresses that helped lend gravitas and authority to the work

NHS Berkshire East had a relatively affluent population with important health indicators that are better than the national average. However, significant pockets of deprivation exist with associated health inequalities and problems that are among the most challenging nationally. We had a key link within the Berkshire East PCT, Andy Ferrari, who was an IT project manager within the PCT. He was to head up the Berkshire East arm of the project with support from the core team.

myRecord Initial Strategic Advisory Group

We were working within the primary care sector and supported by an influential stakeholder group that included links at local and national level.

Helen Bevan		NHS Institute for Innovation and Improvement
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Alan Nobbs (for Helen Bevan)		NHS Institute for Innovation and Improvement
Jeremy Taylor	Strong User Voice	National Voices
Prof Brendan Delaney	Brian Fisher contact with strong research and IT background	King's College
Bruce Elliot		Health Informatics Development Programme Manager
Malcolm Alexander		National Association of LINk members
David Jones		Diabetes UK
Kerri O'Rourke		Diabetes UK
Marlene Winfield		Connecting for Health
Siobhan Roberts		Connecting for Health – SCR Team
Practice Manager (Anon)	Practice Manager, Practice 1	Practice 1 test-bed site
Mary Fitton	RA advocate (GP)	
Andy Ferrari	Berkshire Project IT Manager	Berkshire Shared Services
Miriam Long	LINk Development Manager	Ladywell Leisure Centre
Mark Doughty	Mark works for Inhealth Associates; David Gilbert's colleague	
Elizabeth Hill Smith	Consultant for project sponsor	Berkshire Consultancy
Libby Morris		Royal College of General Practitioners
David Abraham	Lewisham GP	
Elizabeth Murray	Academic interested in e-solutions	

Test-bed sites

While we were working to encourage as many practices as possible to offer records access to their patients, we also planned to work intensively in two practices to find out how best to recruit patients to use the system and how to optimise their usage. In these practices we would be working with staff and patients to gather their experiences and learning. During the course of the project it became apparent that we needed to try something different, so we also started working with a third test-bed site

Practice 1, Lewisham

Practice 1 is a large practice with a patient list of approximately 12,500. It is in a mixed socio-economic area and sees itself as a forward-thinking practice. Prior to the start of the project they had been offering RA to their patients for six months. The practice manager sits on the strategic advisory group for the project and allocated us desk space for one day a week.

Practice 2, Lewisham

Practice 2 has a similar profile to that of Practice 1; it has approximately 13,000 patients and is in a mixed socio-economic area. Prior to the start of the project they had been offering records access for a year, in that time they had been successful in recruiting patients to use records access at a rate of 1.78 per week.

Practice 3, Lewisham

Practice 3 is a much small practice with a patient list of approximately 2,000 patients. They have two GPs in the practice and are tight-knit team. They started offering RA to patients in November 2012.

1.3 Intended Improvement

Intervention – Opening up the Record

We were ambitious from the outset that through offering records access to the people of Lewisham and Berkshire East we would spark a nationwide push for RA. We were very much working on a ‘build it and they will come’ approach without questioning our underlying assumptions that:

- The system was working and fit for purpose
- That there was a patient desire for RA

These assumptions came from national evidence as well as the work and experience of the Project Director and other RA pioneers across the country.

As detailed in our early quarterly reports our plan was as follows:

Overall aim: We will improve relationships between staff and people who use health services through the implementation of online medical RA – enabling **more** people to use RA in the **best ways** possible. This will be done through:

Supporting GP practices to 'switch-on' RA – measured by number of local practices switched on. Target is 75% of Lewisham GP practices to be switched on by Summer 2012; 25% of practices in Berkshire East switched on by Summer 2013.

Getting patients to register for RA – measured by increased rate of registration in Lewisham test-bed sites. Target is two practices recruiting at least 10 patients a fortnight within six months of switching on (rate increase from current baseline).

Enabling RA registered patients to better use RA – measurement of use and qualitative research (what helps and what gets in the way) will lead to adapted interventions. Patients at two practices will report on how they use RA; secure messaging; looking at test results; sharing record with family; sharing record with professionals; checking accuracy.

Patients feeling benefits from RA – measured by Patient Enablement Instrument (PEI).

Practices feeling benefits from RA – measured by practices reporting improvements.

Improved relationships between patients and practices/staff.

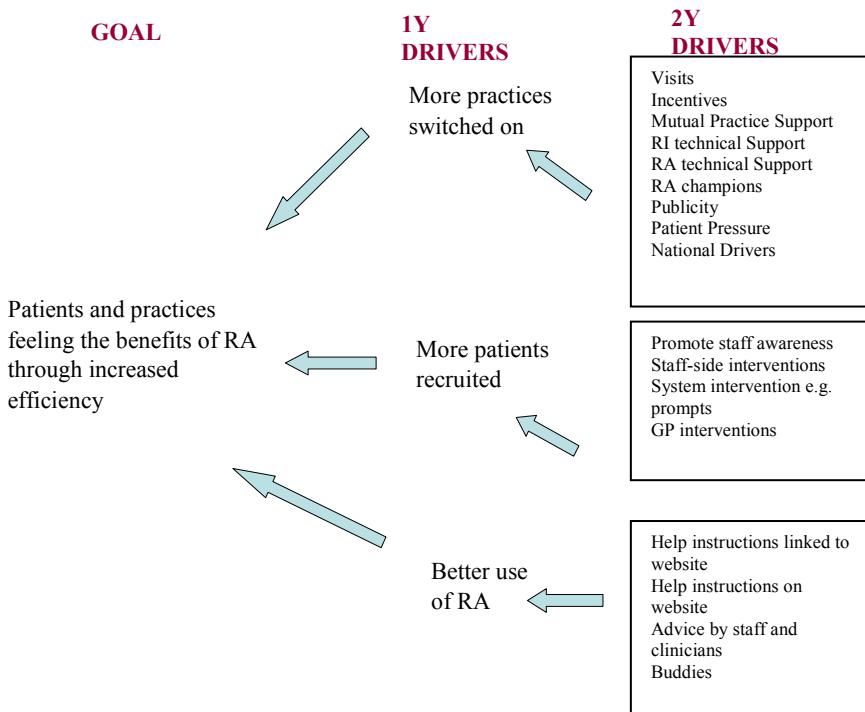
The overall approach can be summarised in the following way:

Better access (practices switching on + patients registering)

-----> Better use

-----> Benefits (to patients + to practices)

-----> Better relationships



In terms of Quality Domains the project aimed to improve efficiency, person centredness, safety and effectiveness. After meeting with the quality improvement advisor (QIA) it was agreed that efficiency would be the main domain on which the project focused. This decision was taken on the basis of previous work done by other pioneers in the country that suggested that offering record access led to efficiencies for the practice and patients and that this was something we could measure.

Factors that would hinder success

The following were documented as risks to the success of the project. Barriers are cultural, organisational and psychological. In particular²:

GPs' fears and concerns

Concerns that people may not use RA appropriately:

- make more frequent and longer consultations
- misunderstand what they read
- possible increased litigation.

Worries about workload:

- managing registration at the desk
- managing more 'demanding' patients.

² Fisher B et al. Record access – the time has come! *BJGP* June 2007 p507–510.

Segmenting the population:

- dealing with people with mental health problems
- issues concerning children and young people.

Losing control:

- sharing decisions safely and effectively
- sharing information means sharing power.

Legal:

- inadvertently breaching the Data Protection Act 1998
- issues around security.

A rare or serious event:

- leak of third-party information or a patient accessing the wrong records.

Organisational barriers:

- a PCT backing out; major reorganisation beyond our control such as GP commissioning; practices confusing this EMIS rollout with that of the Summary Care Record.

Lack of GP leadership:

- for example, reluctance to change or resistance to support.

Patients' lack of involvement:

- lack of confidence or disinterest leading to low take-up of training.

Barriers to implementation of learning and support package:

- poor take-up, it taking too much practice time or not focusing on the key stakeholders.

Slow progress:

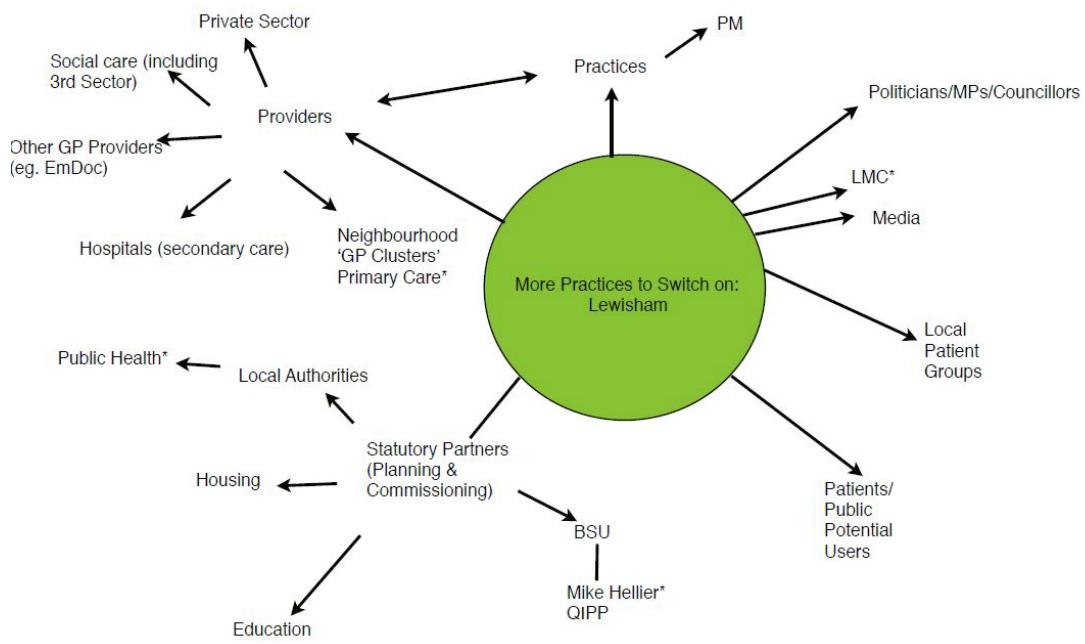
- things taking longer than expected.

Stakeholder map

The stakeholder map below details the key stakeholders we were trying to influence. We set about arranging meetings with local hospital executives, pharmacists, patient groups and GP clusters. At these meetings we'd explain what we were trying to achieve and encourage stakeholders to get involved. This was done at several levels:

- Sitting on the Strategic Advisory Group, attending meetings and giving guidance

- Taking part in promotional activities on our behalf (for example Diabetes UK organised a Diabetes and Record Access mixed stakeholder event where local patients, GPs and decision makers got together to discuss the benefits)
- Receiving and sharing our newsletter among peers and patients



*High Importance

THE FIRST PHASE OF THE WORK

Driving People to Access

In the first year of the project we worked to support practices in Lewisham and Berkshire East to ‘switch-on’ the system and encourage patients to ask for, and use, RA.

Promoting to Practices

Spearheaded by the RA facilitator we worked to secure meetings with practices in Lewisham and Berkshire East. This involved dozens of phone calls to practice managers, the gatekeepers of primary care, to get permission to cross practice thresholds. Meetings were often cancelled, rearranged or forgotten about.

A successful meeting would often be between the facilitator and the practice manager, and occasionally with GPs. The meeting would include the following:

- A PowerPoint presentation outlining the key benefits of RA

- A demonstration of the system
- A question and answer session

This face-to-face contact meant we were able to deal with questions. The most common practice fear was the time that it would take to administer RA to patients.

A few practices were enthused, the relevant decision-makers were in the room and able to give it the go-ahead on the spot. In these cases a date was booked for the facilitator to return and ‘switch-on’ the practice. This gave the practice the time to get ready, brief staff about the initiative and speak to their patient groups.

In the majority of visits the information had to be communicated to other members of the practice in order to make a decision as to whether to offer RA and follow-up was arranged. A few practices refused to take part. Primary care has competing priorities for time and, as it is optional, practices often chose to push RA to the back burner. We learnt

that during the period in which practices are collating their Quality Outcome Framework (QOF) points (from January to April) there is no time or space for anything else.

Promoting to Patients

Once a practice was offering RA, the next hurdle was to encourage patients to ask for, and use, the system. In the first year we deployed several different interventions to achieve this:

- Updated posters in reception, with catchy slogan to peak interest
- Up-to-date leaflets explaining benefits of using RA
- Simplified registration process
- A reception competition – incentivising and encouraging the reception staff to mention RA

to every patient they talk to

- Newsletter articles – we wrote an article outlining the benefits of RA which was circulated to the patient list
- Enhanced website presence – a large banner promoting the RA featured on the practice website
- Having RA prominently featured on the new patient registration form
- Flu jab clinic day – having a team member present at three Practice 1 flu jab clinics promoting the benefits of RA and signing people up on the spot



- Running a stand/workshop at a local LINk event to engage with people in Lewisham directly
- Messages on the Jayex Board
- Producing condition specific information for diabetic patients

We recorded how patients had found out about RA by getting them to indicate on the registration sheet how they had heard about it. We were soon able to see what worked and what didn't; we found that, unsurprisingly, face-to-face contact with the patients worked the best – either recommendation from the reception staff or from discussions with one of the team members at events.

Patient Follow-up

Four months after requesting access to the record we followed up with patients to find out what their experience had been. This was done by sending electronic questionnaires to patients and meant that we were able to start a direct dialogue with them.

High-Level Buy-in

During the first year we also saw it as important to try and gain a foothold on the wider healthcare agenda in Lewisham in order to convince practices to offer RA. At the start of the project we had good support from Lewisham PCT. As time progressed this support was gradually withdrawn. We can only speculate as to why this happened. We believe it was partly due to the dismantling of the PCT as an entity, the mass redundancies and reshuffling of staff meant that our project was no longer a priority and we couldn't be factored into the new regime. Another reason may have been that they felt that our project was too closely tied to the software provider PAERS, of which Dr Brian Fisher is a director. During the first few months of the project, staff at the PCT were happy to share information with us and provide us with any documentation that we needed. Subsequently we requested an updated version of a document that had been provided to us in the first six months and were told 'there is a concern...because PAERS is an outside contractor, there is a potential conflict of interest should we give such detail out'.

CHANGES ALONG THE WAY

When looking back over the last two years the project can be split into two phases. In the first phase we focused on switching practices on (aiming for 75% of Lewisham and 25% Berkshire East), getting patients to sign-up for RA and how to spread the message nationwide. Primarily our efforts were spent marketing the system and offering support to practices in Lewisham and other localities who wanted to offer RA.

Towards early to mid-2012, we realised that we were not addressing the issue of changing relationships and that we had become a marketing project for RA without evaluating our assumptions.

Questioning our Assumptions

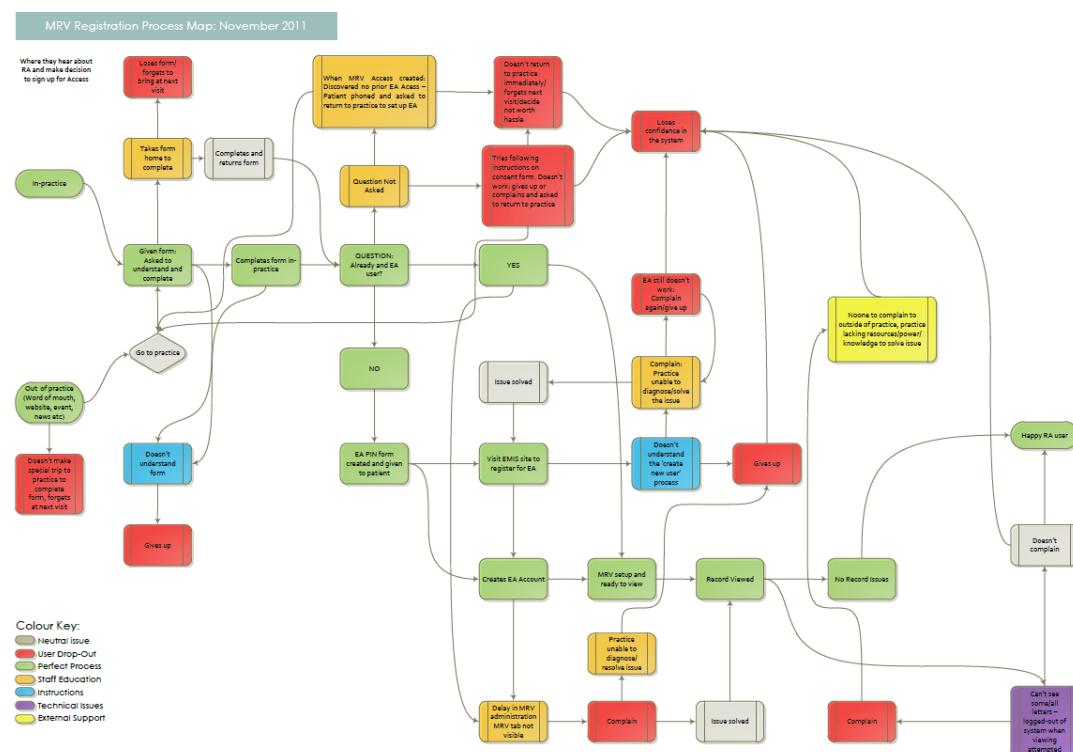
That the IT system was working and fit for purpose

We never questioned that the IT system worked the way that it was meant to and that patients were able to access their record

The first indication that something was wrong with the system came in late 2011 when we had the results of questionnaires sent back from patients who had registered to use RA four months previously. We were expecting a lot of positive feedback, in-line with our assumptions based on others' work, and were in fact bombarded with complaints about the lack of functionality, users' inability to set it up, password issues etc. The realisation that the majority of patients were having difficulties shocked us. Working through the IT system, we found inefficiencies and problems with the registration process.

Medical Record Viewer Process Map

(Please see [appendix](#) for full-scale version)



That there was a patient appetite for records access

Part of our assumptions was that putting up a poster in the waiting room and a leaflet at reception would drive people to request access then go on to use it and have their relationships transformed

We realised that the process was going to be more difficult when we discovered that over 100 patients at Practice 1 who had requested access had not actually had it activated for them by the practice. A key box had remained un-ticked when being processed at reception meaning that those who were interested were not able to gain access. More surprising was that we had no idea that there was a problem, as we had received no complaints – not one patient raised the issue from reception at Practice 1 or from patients who had requested access. This was the first time that we started to question people's motivation to use the system in the first place.

That RA led to increased efficiencies for the practice and patients

We assumed that implementing RA would lead to efficiencies

We had planned to investigate the impact of setting up and running RA on the practice but we were expecting a positive balance on the basis of previous work. However, while this was true for those patients who successfully managed to get access to their record, we discovered that 75% of people who filled in the registration form expressing an initial interest failed to get access to the record. The number of complaints and extra work this created negated any positive benefits to the practice.

In early 2012 the software provider EMIS was constantly releasing updates to the RA system, most of which led to more difficulties for patients. We had requested that we be informed of known issues as they arose, this failed to happen 100% of the time. At one point the RA system was rendered virtually useless. Furthermore the project had become the main point of contact for practice managers in Lewisham and beyond – instead of practice managers ringing EMIS to complain they were ringing us.

Even when patients did get access, some were disappointed by the failure of some of the functionality. They, in turn, raised these complaints with the practice.

Project Part One to Part Two: Major Changes

In July 2011, one year into the project, we realised that we needed to make major changes to the way in which we were delivering the intervention of RA.

We stopped measuring success by numbers

What: We removed the aim of switching on 75% of Lewisham and 25% of Berkshire East practices and the aim of recruiting 10 patients per fortnight in the two test-bed sites.

Why: It became clear that the complexity of the system was harming the image of RA, instead of practices reporting positive benefits – as we had expected – we were dealing with more and more complaints and a system that, despite our best efforts, was losing functionality on a monthly basis.

We felt that trying to switch-on as many practices as possible was going to be counter-productive.

At the end of 2011 the government announced that all patients in the UK would have access to their medical record online by the end of 2015. This meant that there was little point in trying to design a scalable RA ‘switch-on’ model. It no longer mattered what would convince practice decision-makers to allow their patients to have online access if this was going to be compulsory.

Impact: The impact of this on the project was overwhelmingly positive. We were able to move our focus away from seeking to launch a system that was not ready for mass roll-out and instead focused on what happens within practices once they start offering access. It also led to our development of an in-depth learning strategy, focusing on one practice in Lewisham to assess the level of resources needed to embed a culture in which RA is seen as part of the consultation rather than a technical add-on delivered through reception.

Move away from prescriptive ‘optimal use by patients’ to ‘how using affects relationships’

What: Our initial strategy referred to ‘better use’ by patients, leading to positive benefits, leading to relationship change. We hadn’t, however, agreed what was meant by ‘better use’. The initial definition was that patients clicking on further information buttons or sharing the record with members of their family equated to ‘better use’.

Why: After discussion, and reviewing the results of patient questionnaires, it became clear that patients were deriving a lot of benefits from access, but weren’t fulfilling any of the key indicators that we had identified as signifying optimal usage. We decided that a more appropriate way of assessing ‘better use’ would be to look at the way they felt as a result. Did they feel empowered? Did it affect the way they managed their care? Was the relationship affected?

Impact: By focusing on the outcomes of having access to the record we were able to explore how attitudes changed in our patient cohort.

Part Two – Refocusing the project towards changing relationships

We needed to prioritise ‘fewer practices to achieve greater depth of learning about getting people to use records access to change relationships and improve care’.

Up until this point we had concentrated on convincing practices to ‘switch-on’ RA with the hope that the benefits of it would both distil to patients, clinicians and the practice as a whole. We had gathered useful learning on how to promote it in practices and how they felt about their healthcare as a result. We had successfully changed the relationship between the patient and their healthcare, and in some cases the way they feel about their GP. However, we are unable to say what change, if any, had occurred from the perspective of the GP.

We made a strategic decision to move away from offering RA as a transactional feature, managed by reception, which is passively ‘switched on’. We would try to influence the culture in one practice. We learnt that our previous strategy of targeting the practice manager to allow for the implementation of RA meant that it had been seen as an extra administrative function of the reception staff and not as something with the potential to improve healthcare and change relationships. We had even found that in some practices already offering RA, GPs were completely unaware that the service was available to their patients!

We learnt that in order for RA to be successful in changing relationships, we needed to work in collaboration with a practice partner to effectively implement RA as a key tool to improve patient’s own health management, increase efficiency in the practice and improve the quality of consultations with the intention of changing relationships.

Informed by this, in the second part of the project, we took a holistic approach to implementation which recognised that every area of the practice, from backroom admin staff to GP partners, must be receptive to RA in order for it to be effectively utilised.

Recruiting a Third Practice

In choosing a practice partner to work with in the second stage of intervention work we decided from the outset to be upfront and honest about the limitations of the system and listen to the fears and concerns of all the practice members in order to explore where they come from and how, together, we could overcome them.

This tactic differed from that adopted in the first part of the project. In our experience, GPs have shown the most resistance to RA and therefore, in the first part, we started by looking to win the heart and minds of the practice manager and reception teams. The

plan was to install the service via reception staff then to convince the GPs once it had been embedded further. We have learnt that GPs have continued to remain sceptical in these early switch-on practices, meaning RA has become a technical service solely offered via reception. The main aim of the second part of the project was to gain GP ‘buy in’ from the start. We successfully recruited Practice 3 in Lewisham to take part in the project.

We made clear from the outset:

- **We were not trying to sell them a service**
We emphasised that we were not representing the supplier of the system, but looking to learn how RA can be embedded in a practice culture
- **We used the Health Foundation’s status to promote the project**
- **We made clear what hasn’t worked at other practices**
RA is not a service to be offered solely via reception. Empowered, engaged patients come from clinicians promoting the service
- **We discussed the benefits patients are likely to experience**
Having access to their medical record can empower patients to care for themselves more effectively.
- **A successful study may raise the profile of the practice**
E.g. Positive media attention and a chance to influence government policy
- **Government’s 2015 deadline**
Practice will have to switch-on by 2015
- **Financial reimbursement for time**
A fee of £7,500 will be paid in three tranches of £2,500 (launch, mid-project and completion)

In-Depth Interventions

As part of our work in-depth in Practice 3 we have delivered the following:

- A comprehensive introduction to RA which clarifies the key benefits of a well implemented successful system (i.e. cost savings, improved consultations etc)
- Worked with Transforming Health to offer training through face-to-face workshops that use role-play to enhance practical skills while also collaborating with staff to provide a workshop guide that can be used by other practices
- Practical sessions walking every member of staff through the registration/signing-in/utilisation of the system so that everyone has experience of what the patient journey is
- Brainstorming sessions to establish together what the practice best feels would benefit the patient from RA
- Full training for the entire Admin/Reception department on registration of patients
- Customer service training for the entire Admin/Reception – basics of how to deal with complaints regarding RA (who to/how to escalate issues)

Support for Staff

- Email/phone link through to the project for staff to contact us with any queries
- Information leaflets, information on the website, access to experts in the field
- Financial compensation in recognition of the time spent
- Marketing materials for RA (posters/leaflets)

Support for Patients

- RA champions on site available to talk through issues, help with the registration/sign-in process and offer advice on the best way to utilise RA for their needs
- Readily accessible information (via the website, leaflets in reception, fully RA trained staff)

OUTCOMES

Part One Measures

We started working with two test-sites in 2010 but uptake of access to online records by patients has been very low in these sites. This is primarily because little support has been offered to GPs and practice staff or patients.

To date, all patients (25,500) have been offered access to their records across the two sites via posters, receptionist recommendation, website banners, clinician referral and other means. Around 350 of those offered access went on to request it, and approximately 88 of these went on to access their record (approximately 25% conversion from offering to access).

Patient Enablement Instrument (PEI) questionnaires were sent out to all patients who requested access (350) and around 50 returned the questionnaire. Self Reported Use Questionnaires (SRUQ) were sent out separately to the same group and around 28 returned them. Evaluation measures from these two sites are shown in the table below.

Table 1. Measures Used

Data Collection Tools	Sample Size	Collected by	Output
Initial PEI	44	myRecord Team	Quantitative data
SRUQ	50	myRecord Team	Quantitative data
Patient focus groups to explore feelings towards RA	6 workshops Attended by 35 patients	Diabetes UK	Report produced by Diabetes UK
Patient semi-structured interviews over use and attitudes to RA	5	myRecord Team	Video stories

Part Two Measures

After deciding on a change of direction we met with the Office for Public Management (OPM) to talk through our existing measures and how we could improve upon these to reflect our new ‘in-depth’ approach. With the help of OPM we came up with new ways of assessing our impact.

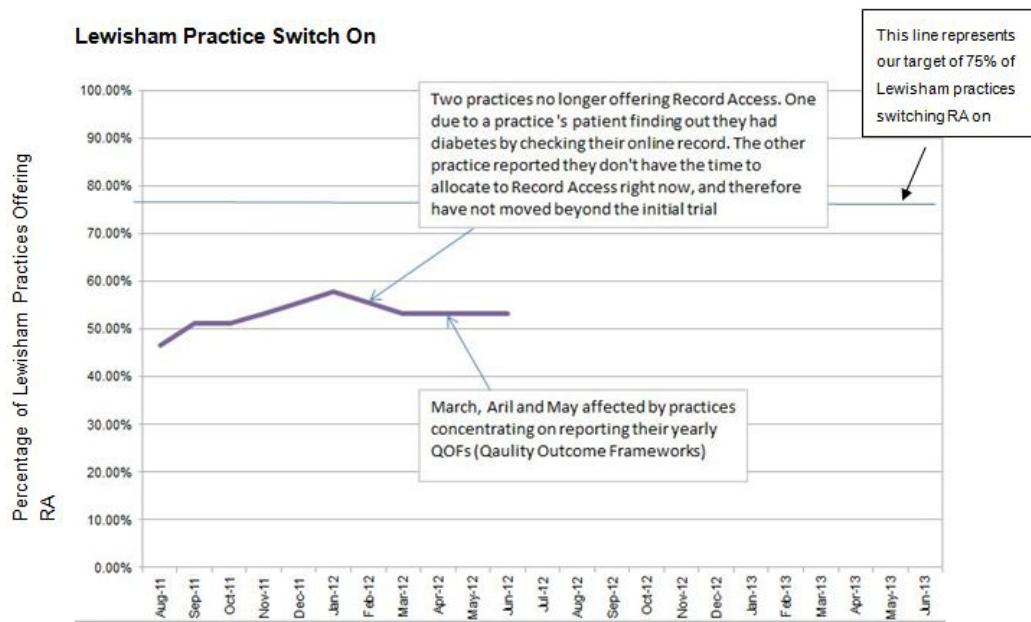
Table 2. Part Two Measures

Data Collection Tool	Sample Size	Collected by	Output
Updated PEI questionnaire to include a few key questions from the SRUQ and a few new questions about relationships	79	myRecord Team	Quantitative data
Patient interviews	8	myRecord Team	Qualitative data
GP post-consultation feedback	Unable to complete	myRecord Team will liaise with GPs.	GPs to complete the checklist after each consultation with a diabetic patient who has accessed their record
Baseline GP/Staff interviews	Mix of GP, practice manager and reception staff	OPM, as part of Wave 2 data collection	Qualitative data
Post-intervention GP/Staff interviews	Mix of GP, practice manager and reception staff	Interviews to be undertaken by OPM as part of Wave 3	Wave 3 to be collected in March 2013
Interviews with practice who switched off records access	1	OPM	Qualitative data

Outcomes – Part One

As mentioned previously in the first part of the project we focused on ‘switching on’ practices and patients, we worked to increase the numbers of practices and patients using the system.

Practice Switch-on

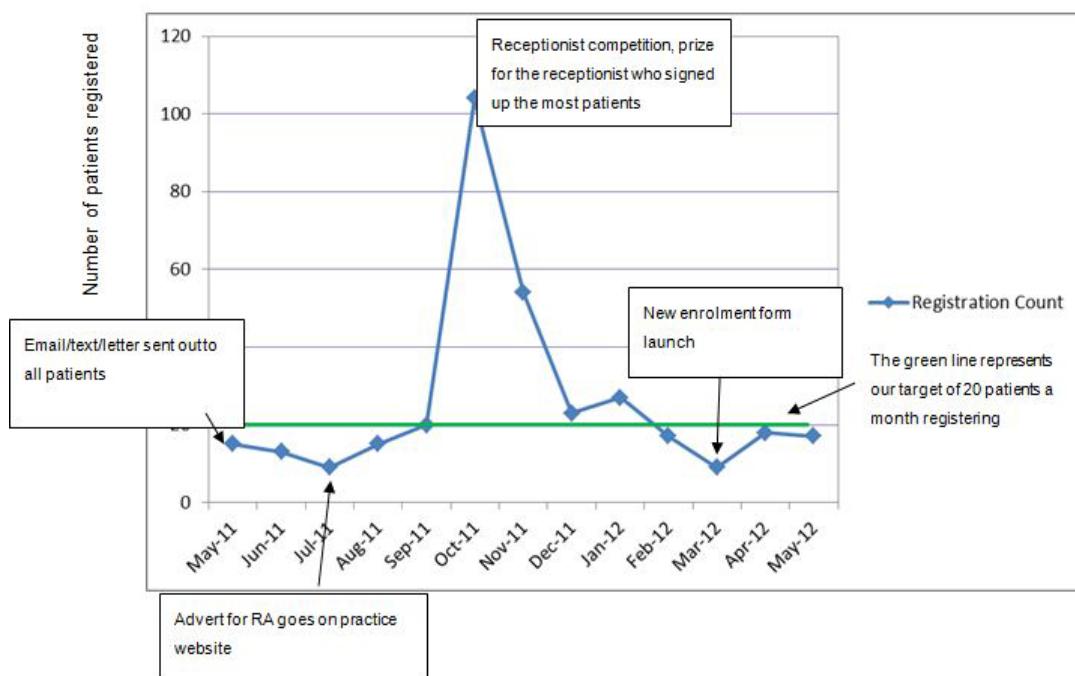


This graph shows our results in encouraging practices to offer RA. Our aim was to have 75% of practices in Lewisham offering RA by summer 2012. Data run to July 2012, where we made the strategic decision to stop focusing on switch-on. At this point 24 of the 43 practices in Lewisham were offering RA; subsequently this number fell to 17.

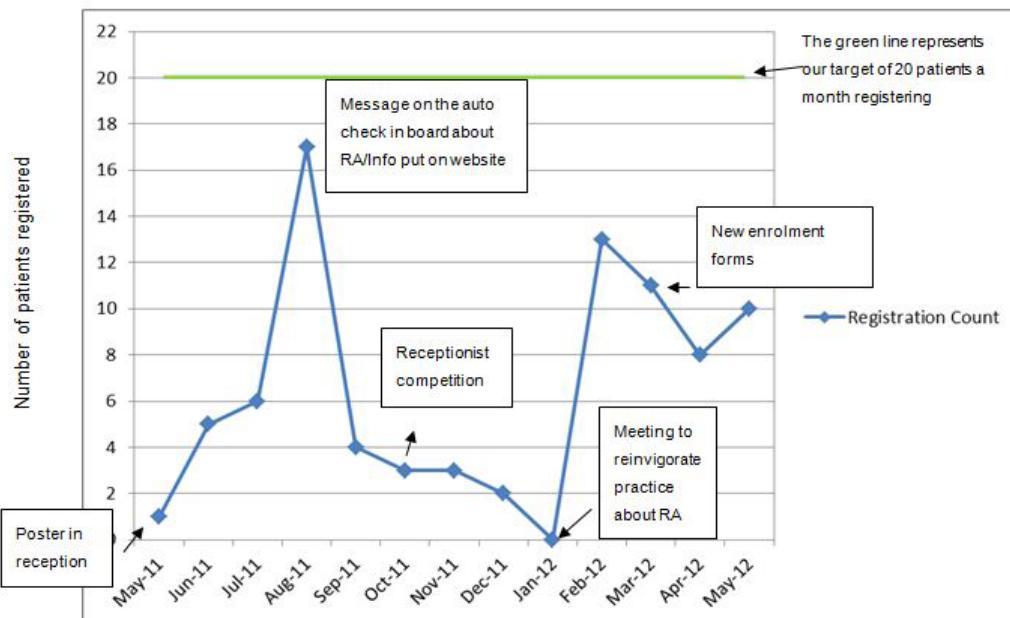
Patient Switch-on

Our aim for patient switch-on was to encourage 20 patients a month to sign up for RA. Although we achieved this rate at Practice 1, we started to realise that our numbers were meaningless as high registration was not turning into usage. The technical problems as detailed before contributed to this, as did a lack of patient motivation to persevere through difficulties. Although we had 400 patients we estimate the actual number who actively use this to be much lower. We had previously thought the number to be around 25% of patients who fill in the registration form; however recent changes to the RA system mean that people's access is being cut-off so this number could be even lower.

St Johns Patient Registration



Hilly Fields Patient Registration



Halfway through the project we noticed that the drop-out rate was very high among those people signing up for access – around 75% – we rang 244 patients to understand why this had happened and their motivation for requesting access in the first place.

Telephone Interviews

After realising the drop-out rate was so high we systematically rang patients who had filled in the RA registration form and asked them the following questions:

- A. Have you used the system?**
- B. Did you find it useful/what are you using it for?**
- C. Did you/are you having any problems?**
- D. What was your initial motivation for signing up?**

We tried to contact 244 patients who had indicated on the registration form that they were happy to discuss RA. Over a three-month period we successfully spoke with 187 patients who had requested RA to understand their experience.

Total number of patients we attempted to contact	244
Total contacted	187
Number of patients who had accessed their record	99
Number of patients who had not accessed their record*	88

Motivation for Enrolling for RA

Although we think about RA as being a separate function of the online system to the transactional elements (appointments and repeat prescriptions) patients in the sample viewed them as one and the same. We asked all patients, both those who have successfully used the system and those who hadn't what their primary motivation was for enrolling in the RA scheme and got the following responses:

Main Motivation	Number of Patients	%
Appointments	52	28
Repeat prescriptions	15	8
Test results	14	7
Might be useful in the future	22	12
Curiosity/access to details	59	32
Better health	5	3

management		
Other**	20	11
Total	187	100

**'Other' consisted of answers such as 'suggested by reception', 'don't know', and 'no real reason'

The majority of patients, 54%, who signed up for RA had no real reason for requesting access (might be useful in the future, curiosity, other). Forty-three per cent had practical reasons in mind, such as repeat prescriptions, test results and appointments and a very small 3% requested access to their medical record in order to better manage their health.

Patterns of use

Patterns of use of the system relate to patterns of use of the practice and their health conditions, for example, patients who indicated to us they had long-term conditions also stated they used RA and other facilities such as ordering repeat prescriptions more frequently.

*Problems registering

Reason for not Accessing Record	Number of Patients	%
Technical difficulties	21	24
Busy	30	34
Forgot	9	10
No longer interested	3	3
Don't actually need it	18	20
Others	7	8
Total	88	100

Eight-eight registrants of the system, 47%, did not log in after registering at the practice. Many because they failed to see the need for it or had been too busy to attempt logging in. Moreover, many were discouraged by the technical problems and convoluted procedures to access the website.

During the course of these telephone interviews patients also shared with us the following remarks:

...My main motivation was to be able to access my records...Although I had technical issues the first time I tried to use the system, I have found the system to be great!

...I understood that technology is changing, so I was willing to accept it and was curious to find out what it is all about....I have been able to look at my test results and my records without making any calls to the surgery. I do find the system useful...

...I wanted to better manage my health. Through record access, as someone who suffers from multiple health problems, I can see if I could have picked up certain conditions or symptoms earlier and how they fall into one place. Information on my health would be useful for my applications for my mortgage, life cover, critical illness cover etc. I also have trouble with my legs, heart failure and so on.

...I wanted to find out about my medical details and check if they are correct. In fact, after getting record access, I had managed to inform the practice about discrepancies of my records and that had been fixed since...

...I thought it to be very interesting to see my medical records. This is especially because I had an accident last year that injured my spine, causing severe back pains. Sometimes, I might feel depressed and it is good to be able to see what's going on...

...The system is very useful and I signed up because I thought it was a good idea. You get to be 'marginally' in charge of your life and health... In particular, I find the information sheet on the system quite helpful and through immediately accessing my test results online I need not worry unnecessarily and bother the practice about it...

Online Patient Surveys

Total number of surveys sent	226
Number of responses	44
Number of patients who had accessed their record	25
Number of patients who had not accessed their record	19
Number of patients opting out of survey	6
Number of incorrect email addresses	22

From the phone interviews and online surveys we have gathered some anecdotal evidence of a change and a ‘more equitable’ arrangement between patients and their healthcare providers. A survey was sent to all patients who had filled in the registration form, though this does not indicate use of the record, which included the question ‘Do you feel any different towards your GP or medical practice since having access to your medical records?’ This was sent to every patient at Practice 1 and Practice 2 four months after filling in the registration form.

The question was optional, in total 32 patients chose to respond. Fourteen patients answered ‘no’, six indicated that they hadn’t been able to view the record and 12 patients responded positively (see below).

‘Do you feel any different towards your GP or medical practice since having access to your medical records?’

Positive Patient Responses

Am impressed with it – saves having to try to call for results, repeat prescriptions etc.

I like to have the choice of doctor when booking appointments online, and choose a convenient time that suits me.

Yes I think it's a brilliant initiative to be able to see my records. It reflects the dynamic nature of the practice and commitment to transparency.

Yes, I have the opportunity to see what's been written about me. It improves (or not) the credibility of the staff I've met so far.

Am impressed with it – saves having to try to call for results, repeat prescriptions etc.

Yes, it provides an opportunity to check they have correct records, so it's reassuring for me.

I like to have the choice of doctor when booking appointments online, and choose a convenient time that suits me.

It is useful to be able to check what is recorded

I think it's more transparent and less paternalistic than in the past. I like to feel that I am trusted with the information

Yes, its good progress, well done – makes life easier!

Feel it to be forward thinking, helpful and up to date.

I believe it to be a good idea, to promote communication and let the GP focus on those patients that need more attention and explanation

I appreciate the ability to refer back to the record and to check test results. It is very much an empowering tool.

I think access to any records is a good thing and it gives me confidence to see what is said in surgery is put on record. My only disappointment is that the records do not go back far enough and some sections i.e. letters are not accessible...

During a focus group held with six patients who had accessed their record from our test-bed sites the group reported the following:

[They] agreed that having access to the information on their records gave them more power and made it easier to challenge HCPs (Health Care Professionals) when they felt that things weren't right. They all agreed that the system increases patient power by making the relationship more equal between HCPs and their patients. It stops you

*feeling like you're being 'kept in the dark', 'puts you on an equal footing' and makes you feel more included in decision making about your own health. One participant also suggested that it helps you to help the system do the things it is not as good at, such as sharing information. Another participant said records access helped prevent 'mushroom management – being kept in the dark and fed a lot of s**t'.*

Outcomes – Part Two

In-depth at Practice 3 and Relationship Change

At the end of 2012 we enthusiastically started working with Practice 3 in Lewisham. As a small practice with a patient list of 2,000 and two GPs we were confident that we could use our initial learning to influence the culture in the practice and successfully implement a 'RA friendly' environment in which relationships would evolve and patients would feel empowered. Our thesis was thus: convince the members of the practice that RA was a positive intervention that they should support and the patients would, with guidance from peer support and their clinicians, maximise the benefits for themselves.

We were hoping that we would be able to successfully report that we had patients using their record in collaboration with their GP; however this has not been the case. Eight people have registered to use RA at Practice 3; however we are not able to report on their usage or outcomes. Of those eight, four were unable to register online and didn't understand how to complete the registration process, two did not wish to talk to us about it, one managed to access the record but there were no test results and the letter's wouldn't open, and we were unable to speak with the final registrant.

It is very clear to us that without a working system that allows patients to clearly and simply check their record, and have trust in the safety of such a system, pursuing relationship change is fruitless.

Practice Switch-Off

Despite our work in Lewisham we have seen the number of practices that have been offering RA decrease over the last 12 months. In this period the technical capabilities of the system have declined as have the number of practices choosing to offer the service to their patients. At the high point of the project there were 24 practices offering RA, at our most recent assessment we judge this to be 17. However, we know that as recent updates have been made to the EMIS GP software it is possible that even fewer have the capability to offer it to their patients.

We contacted a number of practices who had switched-off RA to ask them why they had made the decision to do so; of the seven switched-off practices only three had the same practice manager in place when RA was switched-on. A GP in one of them agreed to discuss their reasons for discontinuing access on the basis of anonymity of the practice. The following is a shortened transcript of an interview regarding a Lewisham practice switching off RA and why.

Format: Open-ended questions intended to explore GP experiences and attitudes, through interview

Responses: Free text

Participant: Lewisham GP

Rationale for Participation

What was your rationale for participating?

[We were] encouraged... to participate and there was some funding attached as well.

What did you expect the process to be?

We were always very nervous about it, I think partly because of the types of patients that we have. We have many patients who live in the council estates; it is a relatively deprived area. We were concerned about how much they would understand, and if the notes would be used for the wrong purposes and security...From my own point of view, I have had some experience with patients getting a hold of their notes and reading things and not understanding them and it causing lot of concern. I have had some really awkward consultations because patients saw things in their notes that they shouldn't

have seen. The notes weren't screened properly [The GP is referring to their past experience with sharing paper notes].

How long elapsed before you switched the service off?

Not long at all, we were not interested. I can't really remember the details. Our big concern was that the information wasn't going to be understood. And then we had our own security worries as well.

Initial Experiences

What was the impact on the practice and its staff?

Never really did much of it, we heard of other places going forward...we were worried about the time and extra workload.

Could you have dealt with them [the impact] better if you had known in advance they might happen?

...It is something that is coming over the next years, every GP is supposed to be able to sign up for patients to access. It is coming, but I have these memories of patients horribly upset reading things that they shouldn't have done. Notes are a lot more, how do you put it, well written now than years back. There were some quite hurtful letters out there. Another thing that put me off tremendously was the fact these were unscreened, what patients were being given. We had patients who were really really upset. Again this is going back...I remember one girl who was given the paper packet and she was brought to tears because she found out that her mother had been sectioned and she had been fostered. That kind of thing from reading a handwritten card that no one else had bothered to read. There are bombshells in these packets.

How did patients react to the service being switched off?

I don't think they even really noticed. We work in quite a deprived area, don't have people from social class 1. That's not really been our issue.

Attitudes

Do you feel the concept of RA is a good thing?

I think it's too big a question to give an absolute yes or no answer. There are definitely people who can and will work well with access to their notes but also there is a proportion who won't. When you're average class 1 with degree, acute skills then yes I could imagine it's a great help to be able to look at test results and things. Now, what we get are a lot of patients coming in with the hospital clinic letters because they get copies of them. And quite often, they bring it with them saying that they got it by mistake

because actually they don't realise that it's actually theirs. And then others get upset, because they don't understand and can't remember. And then there are great big long words that they don't understand and want me to interpret it. Patients getting clinic letters if anything has increased our workload. I don't want to be patronising, but not everyone can understand these letters. I had one just this morning, a patient had an MRI report and even I was struggling to figure out what the abbreviations were.

Future Intentions

Would you consider providing access in the future? Why or why not?

But it is something that is coming I know that. I definitely have two minds about it. There are some things that are useful, but I think the past is probably better left there and to look at the future. You wouldn't believe some of the letters that have been written in the past.

Would you recommend access to other practices?

I think it would have to be on a limited basis, I would need to have someone explain what it is from the outset, and so expectations are more realistic. The other things that go with deprivation are complaints. That's also in there, like no win no fee kind of stuff. It's never an absolute and certainly there are letters arriving every week from solicitors wanting patient notes, so there is certainly going to be vulnerability. But some patients are complaining more anyway, it is the way the culture is changing we better get used to it...I suppose it's been too many changes too quick really. The timetable is really quite tight to get this in and up and running...These things arrive with not the resources to follow them through. And if it goes out half baked, like not really, it will cause more problems. The pressure is on to get this up and running in 2 years, 2015.

Part Two Outcomes – Measuring Relationship Change – Enhanced PEI

It took us a long time to agree on a measure to accurately assess the relationship change as a result of patients having access to their medical record. As well as conducting interviews with patients to assess how they feel it has changed their relationship, with the help of OPM we developed a ratified instrument, the PEI 2 to look at how having access to the record changes the patients relationship with their own healthcare (questions 1–6) and their relationship with the GP (questions 7–9). While we have been unable to compare the outcomes from our original test-bed sites with that of Practice 3,

we feel that nevertheless there is some demonstration of ‘changed relationships’ in particular the way the patient feels about the relationship with their own health.

The sample was sent, in March 2013, to every patient who had filled in the enrolment form for RA at Practice 1 and Practice 2 and indicated they were happy to be contacted.

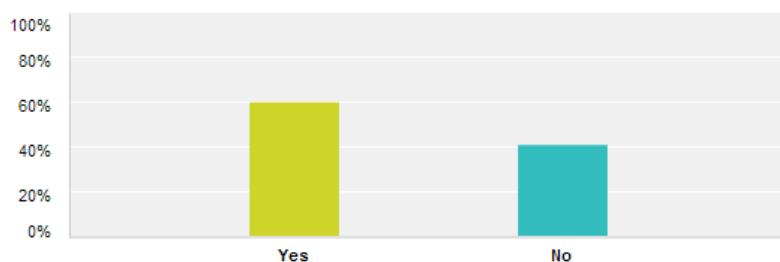
PEI Sample

Total number of surveys sent	354
Number of responses	79
Number of patients opting out of survey	6
Number of incorrect email addresses	24

Of those who responded to the survey, we found that 41% had not looked at their record

Have you looked at your record since registering for access?

Answered: 79 Skipped: 0

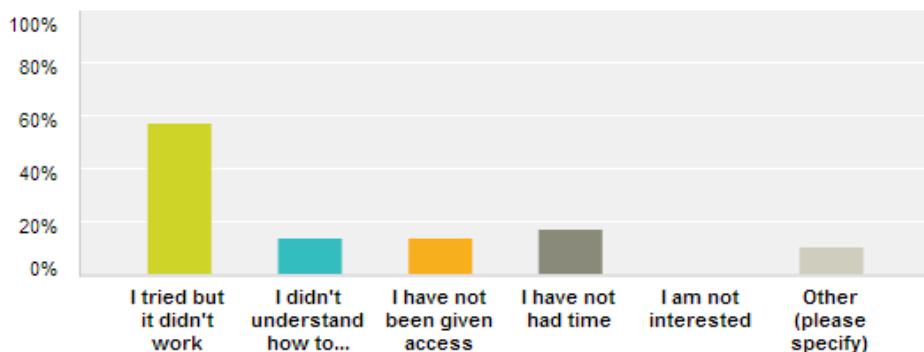


Answer Choices	Responses
Yes	59.49%
No	40.51%
Total	79

Of those who had not viewed the record we found that most had tried, but failed.

What has prevented you from accessing your patient record?

Answered: 30 Skipped: 49



Answer Choices	Responses	
I tried but it didn't work	56.67%	17
I didn't understand how to access it	13.33%	4
I have not been given access	13.33%	4
I have not had time	16.67%	5
I am not interested	0%	0
Other (please specify) Responses	10%	3
Total Respondents: 30		

'Other responses'

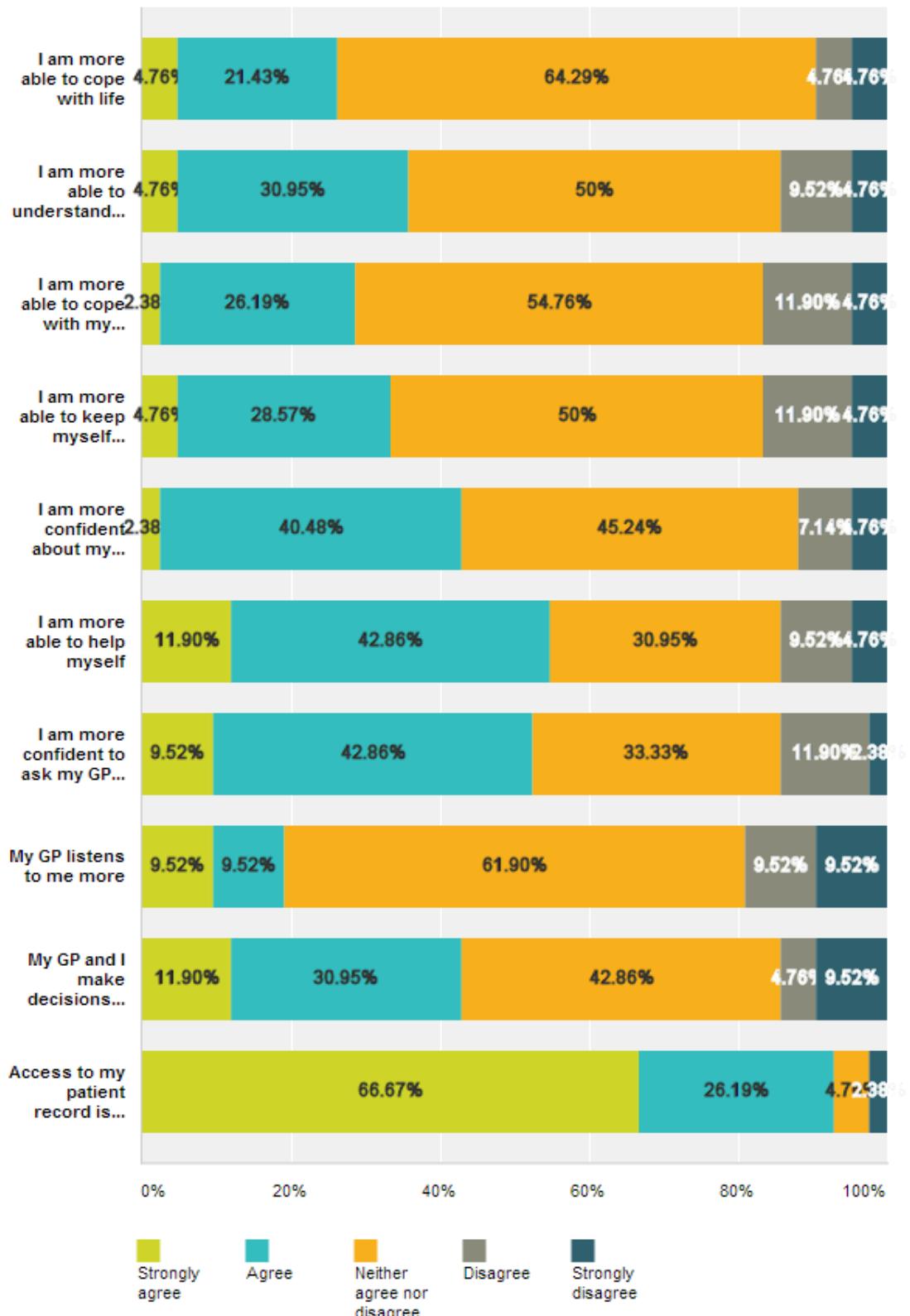
I have had no need.

I didn't know I had signed up.

The whole process was aggravated and the stuff unhelpful so I just gave up.

Patients who had indicated that they'd looked at their record (59% of respondents) were asked to answer 10 questions designed to assess how having access to their record had changed their relationship with their own healthcare and with their GP. They ranked the statements from strongly disagree to strongly agree.

PEI-Ranked Statement Results



26% agree/strongly agree with the statement: I am more able to cope with life

36% agree/strongly agree with the statement: I am more able to understand my illness

29% agree/strongly agree with the statement: I am more able to cope with my illness

33% agree/strongly agree with the statement: I am more able to keep myself healthy

43% agree/strongly agree with the statement: I am more confident about my health

55% agree/strongly agree with the statement: I am more able to help myself

52% agree/strongly agree with the statement: I am more confident to ask my GP questions

19% agree/strongly agree with the statement: My GP listens to me more

42% agree/strongly agree with the statement: My GP and I make decisions together

92% agree/strongly agree with the statement: Access to my patient record is important to me

These are striking responses. It is unusual to see that a single intervention at the same time helps at least a quarter and sometimes over half of respondents to:

- Cope better with life and their illnesses
- Keep themselves healthier, help themselves and feel more confident about their health

The majority of responses cluster around ‘neither agree nor disagree’. This does not mean, however, that RA is, for example, making a patient less confident to ask questions, or less able to help themselves. It is merely a reflection on the mixed group of individuals who are using records access. We know from discussions with patients that the majority of our users are people who signed up out of a general interest to see their records rather than with a primary health purpose in mind (see Main Motivation table page 23), furthermore the average (mean) views of the record per patient in this cohort is 3, this is over a period ranging from three months to a year. Only three of the 44 respondents stated that they used the record on such a basis they couldn’t accurately judge the number of times they had accessed the record:

More times than I can possibly recall.

At least once a week.

Certainly more than 10.

Changing relationships

It is also striking that we can detect a change in the way GPs and patients relate to each other. It seems that, as a result of RA, the GP listens more and the patient is more confident to ask questions.

THE LEARNING

Challenge not overcome

Despite our best efforts, we were unable to positively improve the technical system although we were able to improve guidance and share how best to work around it.

Changing Relationships in Primary Care

Time and resources are precious and it is difficult within a general practice population to convince stakeholders that things need to change. We found that once you are able to start a dialogue towards change other contextual factors can get in the way:

The existing culture in a practice can help or hinder relationship change

This is something that seems obvious now, however working with a new practice that has a very different culture and ecology to our existing sites highlighted this for us. Practice 3 is very positive in its outlook and this helped immensely. It has meant that, although some members of staff may have initially been resistant to the idea of offering RA, they listened to us and were open to learning about it.

This positive culture is key to implementing systems and practices in order to try and change relationships. In Practice 3 they are open to the idea that things could be done differently, and that there may be other ways of working. This gave us good foundations to work from in order to influence attitudes towards RA. Through individual conversations with staff we have been able to use this positivity to have meaningful discussions. In particular one member of reception was able to understand the benefits of RA when we discussed with her about her sister whom she helps care for. She could see that having access to her sister's record could have a direct impact on the ability of her and her mother to help care for her sister. When we told her that is was available in her sister's practice she commented that she was going to go and help her get signed up.

Being able to identify with the possible applications also made her think about others with Practice 3 that would also be able to benefit from access.

We are working in a very target-orientated sector, where something as abstract as relationship change is challenging for GPs to focus on

The primary care system seems to militate against change. Practice 3, with whom we are working in-depth, has been particularly uneasy with both low numbers of users and our quest for a deeper understanding of their and their patients' experience. For us this feels like a reflection of the way the primary care system operates. Perhaps an unintended consequence of the QOF system is that it can relegate patient individuality and need in favour of hitting numerical targets for financial recompense. In our experience we feel that this aspect of primary care financing has a negative impact on trying to change relationships through implementing Quality Improvement initiatives such as RA. The drive from the practice manager, as we have witnessed in other test-bed sites, to 'sign-up' as many patients as possible clouds the real, less easily quantifiable, target: changing relationships between the patient and the practice.

We believe that paying attention to the subtleties of who is using it; why they are using it; how it's making a difference to their lives and relationships is a far more important and meaningful pursuit than producing large numbers to report back; For Practice 3, and our other test-bed sites, this is a difficult concept to convince them of. Nowhere is our failure to communicate this to Practice 3 more clear than when asked by OPM what we thought success would be: we said, '10 patients using record access and feeling like their relationships had changed' and Practice 3 said '100 (out of 132) diabetic patients signed up'.

The novelty of RA makes it difficult to accept.

At Practice 1, during the first year of the project, we were successful at modelling the QOF approach and launched a reception competition. The rules were simple; the receptionist who signed up the largest number of patients won a prize. Unsurprisingly it was successful. Surprisingly, to us at the time, approximately 75% of those people who had filled in the form never went on to look at their record and, furthermore, half of the people who had filled in the form didn't even try. In the wake of this we attempted to contact all registered patients to try to understand why our large volumes of registrants

weren't producing the same fantastic patient stories as witnessed in other pioneering RA practices around the country. We came to this conclusion: offering people access to their record is so new, so different from the way we expect health to be delivered in the UK that such an approach might not produce anything more than superficial data that tell us nothing about relationship change or our success other than, 'we were very good at convincing others to fill in forms'.

Engagement Issues

The reality has been very different. Our experience of, trying to drive change in primary care has been tough. Technical issues aside, our biggest hurdle has been engaging with healthcare professionals. Our experience suggests that time pressures in primary care are so overwhelming that the idea of adding another 'non-essential' time pressure for clinicians to consider is a big ask. As part of trying to engage with Lewisham clinicians we conducted a borough-wide survey of their opinions of RA, below is a selection of responses.

GP Quotes

In principle I have no problem with patients seeing their medical records, but I think it may cause a lot of extra workload for GPs, who are already experiencing huge workload demands, with patients wanting clarification of medical language used in notes – I already spend quite a bit of time explaining the contents of hospital letters to patients, and I am concerned this will be an extra workload for GPs with no patient benefit in terms of increased health outcomes.

The majority of patients would not want access and equally would not want ownership of their own health. For the motivated patient it could be a great tool to help managing their health.

I do not agree with this initiative, I feel it will hugely increase the worried well. I am always happy to discuss any concerns patients have about their health, medical records etc, but I think that it has potential to do a lot more harm to patients if there is no health professional guiding them through their records – and of course, we do not have the time to do this.

Generally I am very positive, have used a lot with some patients, my only major concern is that it is seen as a low priority by the majority of GPs when I talk with them

My concerns; because of a lack of understanding of medical terms and tests, patients will be booking appointments/emailing wanting decoding/explanations, how will you get round this, without creating more work for clinicians. I am not sure what demand there is for this. In General Practice patients can have access to their notes but very few ask to see their notes. It is usually when there is some kind of dispute or litigation involved.

The number one concern from clinicians was that offering RA would lead to extra workload and time pressures. Truth is, in our experience, offering this system of RA does increase the practice workload. It was very difficult for us to therefore balance this fear with the positive benefits as we haven't been able to adequately demonstrate that they are there for the majority of patients. GP practices are privately run businesses and if this cost/benefit analysis doesn't add up then new initiatives, no matter how great they might be, are unlikely to prove successful.

The Government's commitment to patients having access by 2015 bypasses the need to have clinicians on board for RA to be made available. However, in our view, failure to engage them will lead to it being seen as nothing more than a transactional service and the real benefits that it can bring to some patients will be lost.

Engagement and Changing Relationships at Practice 3

When working with Practice 3, as previously discussed, we adopted a different approach to change management. We didn't try to sell them on the benefits but have taken them on a more supportive change journey. Offering them information, listening to their thoughts, running workshops – all the while gently poking them to see information sharing as something good that they should be doing. We have seen a change already with one doctor at the practice. When we first visited with the GPs at Practice 3 one member of staff was visibly shaken and concerned about the prospect of their patients being given RA. At one point they were almost in tears while describing all the different pressures that the practice was under and their fear that this would compound the situation. We felt it was very important to hear them out, not to try and have all the answers, but validate these concerns and make it clear that we would work together to

minimise the risks. This initial reaction can be contrasted with their attitude at our most recent workshop with the practice where the same GP actively engaged with the task at hand and after the session even took us into their office to show us an idea they'd had for an improvement to the patient record. We learnt that to engage with the clinicians at Practice 3 they needed the time and space to come to terms with what was being asked of them, to feel that they were in control of the situation and that they had our full support.

Time is Money

We have been able to affect change at Practice 3, the critical point is that they were not enthused or evangelical about RA to begin with; the main reason that they took part and were prepared to listen was because we reimbursed them for their time and effort with £7,500. It is doubtful that they would have taken part in so many workshops or given it a go without this incentive, which, to a small practice is substantial. We recognise that when trying to push for change there are practical things that can get in the way, and finance is a critical element of this. We ran workshops with every member of the practice staff; we sat down and discussed the fears and worries on an individual basis across the practice, we made sure that everyone got the attention they needed. Some workshops lasted 20 minutes, others lasted for hours. However, we believe that without this financial recompense there is very little motivation for practices to dedicate time to extra learning, especially learning that falls outside of a direct route for financial gain for the practice, such as QOF points.

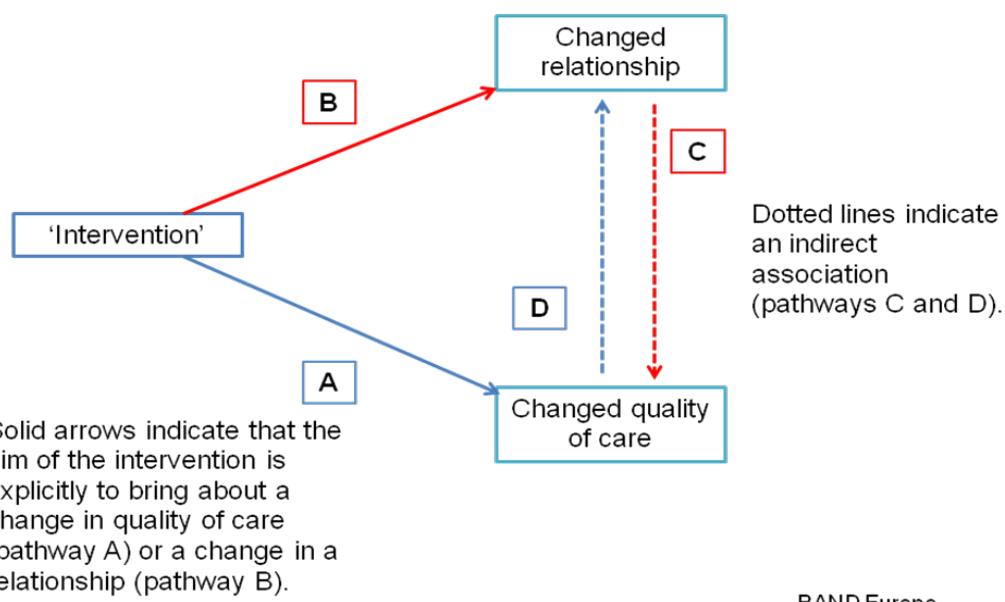
Technical Barriers

The lack of a fully functioning system, as detailed previously, was the largest barrier to this project. We were never able to fully observe and understand how and if relationships change because of RA. There were times when it stopped working completely and everything had to be put on hold while we attempted to find fixes to issues. At times it has been incredibly frustrating and has meant that a large amount of our time and effort has been spent trying to get both practices and patients using the system, rather than focusing on the outcomes of use. Had the system been fully-functioning then our original ambitions were realistic aims to have.

Link between interventions, changed relationships and quality of care

The diagram below shows a very clean, logical relationship between the three components. While we aimed to deliver an intervention that both changed the quality of care and changed relationships, our experience is that it is not as clear-cut as the diagram suggests and this perhaps oversimplifies the process.

We have struggled with the concept of a ‘changed relationship’, what qualifies as a ‘changed relationship?’ Do both parties need to be aware for it really to be called a change? We have delivered an intervention that, in many cases, one half of the clinician/patient relationship – the clinician – is unaware of. So if the patient then feels differently does this suggest the relationship has changed? Can the care then really be improved if the person who is primarily responsible for the delivery is unaware?



Challenges to sustaining the work

As we have discussed, our work has been based on delivering a technical system into primary care. Unfortunately due to the shortcomings of the system, in some cases we have been unable to sustain the work even during the course of the project. There are three fewer practices offering this to their patients than when we started, and unless improvements are made to the current system further practices will switch-off as they

will not have the time or the resources to handle complaints, especially if more and more people start requesting access. If an updated version of the current system is released, and centralised support for patients offered by the software provider, sustaining RA in those places where it already exists will be a much easier proposition.

To highlight how much of a challenge it has been to get GPs to see this as ‘business as usual’ it is interesting to hear, RA pioneer, enthusiast, project director and part-time GP, Dr Brian Fisher’s experience of offering it to patients in consultations

I have begun practicing as a GP in a practice that now offers record access. Despite my personal interest and commitment to it I have found it hard to think about offering access during the consultation. I get totally bound up with the patient and their presentation and their problem. I offer many different kinds of solutions: prescribing, leaflets, online solutions – but I still have difficulty remembering record access. It’s not surprising that other clinicians with less of a passion to the field find it difficult to remember to discuss it as an integral part of care.

THE OVERALL IMPACT OF THE PROJECT

It has been difficult for us to disentangle the theory of RA from the technical system that we have had to use.

We have been able to demonstrate that access to records, even with a clunky system that doesn’t always work:

- **Does improve the service for some users (see Positive Patient Responses, section 3 and PEI Results section 3.1)**
- **Enables patients to feel more confident and more in control of their health**
- **Seems to support patients in becoming more confident in dealing with their GPs**

Imagine the possibilities when the offering is improved. In a recent email from a patient – writing to complain about letters not working – they shared with us the following:

Hope the project is still going well have found even difficult access handy this past couple of months, the Professor treating me @ Guys does not give out much info to patients. Thanks in anticipation.

Lewisham Patient, March 2013

We have been able to outline key interventions that CCGs will need to take into account to make RA a reality.

We have tools that will help CCGs and the government's next steps in preparing the UK for RA.

Our website is available as a resource for everyone: www.myrecord.org.uk

This ‘rough with the smooth’ sums up our experience of RA and giving people who want and need it access to information. Through speaking to patients in focus groups, informal chats, interviews and the PEI results we know that even if done badly it still has a positive benefit for some, as illustrated through patient interviews, if not for all users.

Although our impact hasn't been felt as deeply or as widely as originally hoped, we believe that the project is making a positive difference to those people who have been able to access the system and see their records. We can confidently say that having access to their medical records, electronically and in real time, has had a transformative effect on their life and their relationships with their GP and their own health.

In conclusion, let the patients speak for themselves:

[click here](#) to hear Diana's story:

I suffer from significant health problems...I have real problems getting out of the house, that meant that engaging with the general practice in any form was very difficult, I also have problems with the telephone so even ringing to make an appointment or find out the results of test was almost impossible... now the system has come in... I can use it to find out things about my healthcare such as the results of tests of whether letters have been sent or received concerning my healthcare... So in practice it has meant I'm using my general practice for the first time in years...

[click here](#) to hear Storm's story

For around two years I've been registered to use the online record access...I was one of the first to sign up, my motivation was efficiency I was away from London for work... and I wanted to know immediately when results came in...it gives me the steering wheel when it comes to managing my own healthcare...it makes a huge difference...the amount of time I have to spend when I do see medical professionals, that time, I'm already pre-informed myself so I can speak to them on a level and we can get further spend the precious time you have with medical professionals well and manage to get the best out of them

[click here](#) to hear Chris' story

My main reasons for signing up were practical... One thing to bear in mind is that people use computers for everything... so it seems pretty obvious that we ought to do that for things like medical records...what the online access has done for me is it's made me feel much more involved in my own care so, I can go in there look at any kind of details of my medical record, that means you're much more informed... that really is a benefit...the one thing that has changed is that I now feel so much more involved and it now feels like a collaboration when looking after my health...

[click here](#) to hear Aileen's story

...It does make it easy to make appointments and access your files... I thought it would be good to save time...when I used to ring it was engaged continually from 8 o'clock to half past... My family wondered when I first said that I was going to go online, but they see now that it's a benefit...

APPENDIX: MEDICAL RECORD VIEWER PROCESS MAP

