

Towards a Partnership of Trust

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Abstract: The relationship between doctors and patients is changing as patients live longer but with a greater incidence of chronic disease. An increase in the availability of information about health coupled with the Choice agenda and a patient-led NHS has encouraged patients to learn more about their own health. Patient access to their own GP-held records has led to the development of a Partnership of Trust whereby patients and their clinicians develop a shared understanding of their health and what each do for each other. This could potentially lead to significant patient and clinician benefits ultimately leading to better outcomes for individuals and societies.

Keywords: Records Access, Patient Empowerment, Trust, Doctor-Patient relationship

The traditional concept of the relationship between a doctor and patient is something that has remained relatively unchanged for generations. Generally speaking, this has taken the form of an adult/child, or teacher/pupil relationship. In such relationships the doctor has been the dominant component and the patient the usually passive recipient of the doctor's advice and guidance. Often the doctor was held in awe by the patient and typically there was little or no discussion during the consultation. When feeling ill the patient would visit the doctor and the main concern was to ask the doctor to "make it better" or to be given some medicine to ease the condition. This may partly explain why up to 40% of general practice consultations are for relatively minor conditions that could be managed without the need for a clinician or managed without a specific treatment [1].

However the nature of the relationship between doctor and patient is changing. Modern medicine is enabling patients to live longer but with a greater burden of chronic disease. The incidence of obesity and with it the risk of developing hypertension, diabetes, ischaemic heart disease and cerebrovascular accident [2] continues to rise in the main due to a poor lifestyle, poor diet, lack of exercise and genetic factors [3]. But it is also widely perceived to be readily controllable by the individual [4]. Patients and the medical profession have responded by trying to find pills for every ill [5] with little gain. At the same time, patients are increasingly being managed by teams of people from different disciplines and in different care settings. This may result in patients getting different messages depending on what information the clinician has before him [6].

Searching for a New Relationship

Patients and the general public are now looking for alternative ways to improve their health and reduce the burden of disease [7]. This is partly fuelled by an explosion in the quantity and quality of information that is now available via the internet [8]. However the resulting benefit is tempered partly because “further collaboration, training and evaluation of the information is required”. But where can this come from and how can it be stimulated?

Self help groups such as the Alzheimers Society [9] and Diabetes UK [10] have responded by developing up-to-date web-sites providing information on their respective medical areas. They also try to link patients and their families with research data as well as specific lifestyle measures and other treatments that may help them improve their health and well being. Other groups have turned to alternative medicine [11] to find solace but this still sits uncomfortably next to traditional medicine for most clinicians.

The “Choice Agenda” [12] which enables patients to choose who provides hospital based treatment for them has encouraged the development of a multitude of web-sites [13], [14] to help patients to decide which organisation will best fulfil their needs. At the same time, a generation of people has grown up watching medical dramas depicting fictional medical problems and showing how stressed clinicians and patients or their families cope (eg Casualty, E.R.). This has helped to demystify medicine and enable the public to get a greater understanding of some of the complex problems clinicians and patients sometimes have to deal with. High profile cases in the news, e.g. issues relating to fertility treatment or end of life decisions especially around euthanasia, have further stimulated discussion and debate.

A patient-led NHS [15] encourages patients to take a more active role in the way the NHS delivers services. At the same time, clinicians are beginning to also appreciate the important role patients have in self-managing their conditions. The development of the Expert Patient Programme [16] alongside the introduction of NHS Direct, enables patients to get “instant” advice on medical matters via a telephone service manned by nurses 24 hours a day as well as the NHS Direct web-site and via digital television. [17] More recently the acceptance by the *National Institute for Health and Clinical Excellence* of the value of “pulmonary rehabilitation” [18] has further endorsed the view that patients can, when given the opportunity and some training, enhance their health and well-being over and above traditional medical treatments. Patients whose first language is not English have been given digital recording devices to take away from the consultation to review advice given by clinicians which has been particularly liked by elderly patients and those with memory problems. [19]. Patients have also been given patient-held guidelines to help encourage improved delivery of care. Whilst this has helped to reduce their anxiety, it has not necessarily led to an improvement in outcome [20]. At the same time, the sudden withdrawal of Vioxx from the market as a result of an increased risk of ischaemic heart disease has served to highlight the significant risk some modern medicines can pose despite the regulatory authorities and the best of intentions [21]

What is the Purpose of IT in Healthcare Delivery?

“A modern and dependable National Health Service needs accurate and instantly accessible information. It is vital for improving care for patients, for improving the performance of the NHS, and the health of the nation.” [22]. The National Programme for IT was developed to help bring modern computing systems to the NHS. As the take-up of broadband increases, more people are using the internet seeking information eg the news [23], buying goods [24], [25] or cheap flights [26]. At the same time there has been a plethora of web-sites offering a wide variety of medical information within the NHS [27] and outside it too [28]. But to date the web-sites have offered generic information for a generic audience.

What if patients could be given patient-specific information to help link themselves to their health record and to the clinicians looking after them?

www.renalpatientview.org has been developed as a joint venture between renal patients, their clinicians and the laboratories. It enables patients to see their diagnoses, treatments and test results and share these with anybody anywhere in the world. More recently EMIS [29], a clinical supplier for general practices in the UK and PAERS [30] have developed a system that enables patients to access their full GP-held record over the internet without prior filtering. This includes seeing full notes of consultations, all results of tests as well as any letters or other documentation that has been attached to their medical record.

NHS CfH is about to start the early adopter implementation of the NHS Summary Record [31] via the Spine and enable this information to be seen via Health Space [32]. This will enable patients to record their personal demographic details and some medical values e.g. blood pressure and smoking status. It will also allow them to see a summary of their medical information e.g. current medication and list of allergies once these are available on the Spine. It will also allow patients to book appointments for hospital care or diagnostics e.g. CT scans or MRI scans at a time of their choice that providers can offer. These developments will further encourage patients to use the internet as a means of finding out more about their own health, what choices there are available and even to register their choices. The user experience is much more centred on the needs of the patient and not that of the system as has traditionally been the case

How does enabling patients to see their medical records over the internet lead to a Partnership of Trust?

Simply enabling patients to access medical records over the internet will not lead to better health outcomes. Patients need to feel there is some value in the record that could then benefit them. This “value” comes directly from the doctor-patient relationship or perhaps more correctly the clinician-patient relationship which recognises the important role nurses and other allied health professionals play in delivering health-care. If this is a strong relationship, where each party feels an equal partner, then they are more likely to share their ideas, concerns and expectations. “Shared decision making” may be regarded as an aspect of “patient centeredness” and can enhance

patient autonomy as well as being associated with more positive consultations without increased anxiety [33]. The clinician can bring to the consultation his or her experience and knowledge of the medical world whilst the patients can bring their experience of the symptoms of the disease and how it is affecting them. Together they can build a “partnership”. But for this partnership to be beneficial, it needs to provide something for each party. Trust is that basic commodity. The clinician needs to trust the patient who is telling them all they can about their illness whilst recognising that patients have their own agendas and may only tell them what they feel comfortable with. Similarly the patient needs to trust the clinician hoping that they will be given all the relevant information about their illness in a form they can understand. By accessing the medical records, the clinician is in effect telling the patient what their understanding of their illness is and what the plan of action may be. The patient is able to access this information, agree with it or refute it or identify any mistakes that may co-exist and then respond by determining what course of action to take. The more information there is, the greater the trust this breeds between the two parties. Trust can be broken and partnerships can split but when a Partnership of Trust is formed, it can create a synergy that enables the clinician and the patient to feel more in control and more at ease with their disease and enables patients to feel less ill (personal communication with patients of AH). A Partnership of Trust can exist without access to health records but this could be a false partnership that could result in great distrust if abused. Harold Shipman, the mass murderer is thought to have killed more than 200 patients during his career. He did this by amassing large quantities of diamorphine deceptively from patients to use against his victims and demonstrated how dangerous this can be if such a trust is misappropriated and a patient is unable to let others see what is happening. Record access for the patient enables a very open relationship and helps to prevent such a calamity from ever occurring again.

How can a Partnership of Trust help patients to achieve better health outcomes?

The underlying assumption is that patients wish to get better and feel less ill (although this is not always the case especially in a country with a well-developed welfare system). But to gain better health outcomes, patients need to understand their health better. That means gaining a better understanding of their health parameters eg blood pressure, body mass index, cholesterol, mental health status and knowing what these health parameters mean and what is normal for them.

Identifying what is normal for people can be problematic. [34]. Often the context is more important than the value itself. For instance, understanding the significance of a lipid profile depends on whether or not the blood test was taken fasting, the sex of the patient, their diabetes status, whether or not they suffer with ischaemic heart disease and what their blood pressure and smoking status is. It is also affected by their ethnic status and whether or not there is a family history of heart disease. As time goes on, we are likely to identify other risk factors which will further help to stratify risk. Clinicians may be able to identify these factors and use “risk calculators” or other tools to help patients to categorise their level of risk. Trying to explain this risk to patients and perhaps more importantly identifying what factors can be altered (e.g. smoking status or weight) to reduce that risk may help patients to modify their health risk and improve their health outcome. The Partnership of Trust is critical in enabling this because patients will need to change the way they live their lives in order to reap the rewards.

Simply telling people to do something will not work – they need to feel how important the change is and to feel that it is something achievable and worthwhile. This does not happen spontaneously: both parties have to work hard to learn to trust each other and in so doing respect each others' views whilst trying to move towards a common goal. Once this is reached, a Partnership of Trust is engendered which can then help the patient and the clinician to develop a bond that helps each to move forwards productively. – the patient gets a better understanding of their health and may feel more empowered; the clinician feels more valued by bringing his knowledge and experience forwards and enabling the patient to feel more happy and less ill.

What are the benefits of the Partnership of Trust?

By developing a Partnership of Trust, a more open relationship is formed where there is less hidden between the clinician and the patient. Giving patients access to the medical records further cements that relationship and helps to ensure that the expectations of the patient are matched by what the clinician can deliver. As new encounters happen and more information becomes available the records will continue to further develop the plan which can continue to be agreed by both parties. This empowers both clinician and patient by informing, enabling and ultimately sanctioning a course of action that can be adhered to and recorded for review at a later date. This leads to an improvement in the knowledge of both parties of each others' situation, helps to improve the skills to understand each other and may even change the attitude each has. Over time, both will learn to communicate better as further trust is gained, become more responsive to each others' needs and hence enable more timely interventions. But more importantly for both parties, the contact becomes more productive and more efficient with greater ability to develop the relationship in a way suitable for both parties. The Partnership of Trust enables both parties to decide when and where and even how to meet – in person face-to-face, over the telephone, electronically via e-mail or other secure web-messaging service or by paper. At present only the clinician can write to the medical record but for this to be an equal partnership, the record may become either a two-way communication channel or a separate channel may be used for clinicians to be “allowed” to view the patient held record, something that does not exist in the UK but does exist in the US (Personal Health Record).

While knowledge is one of the keys to forming a Partnership of Trust, another is the possession of the skills necessary to apply that knowledge for the benefit of the partnership. Many of the required skills may already be possessed and practiced by the partners - honesty, candour, tact, discretion, courtesy and mutual respect. Others may need to be developed. Patients, for example, may need to gain the confidence to ask questions of the doctor if he or she does not understand what is being explained about the condition, its cause, effects or treatment. When patients feel trusted by the doctor, patients are more ready to express their worries without being concerned about being disbelieved or dismissed as being silly. In addition to this, an informed patient, after some discussion of the condition with the doctor, may feel it necessary to question the conclusions reached by the doctor. In this circumstance, courtesy and tact will be particularly important on the part of the patient when raising the issue and the doctor who responds to it. Both need to recognise that it is possible and legitimate to disagree without the intrusion of any tension or offence between them.

The medical record consists of a wide variety of descriptions of symptoms, signs, diagnoses and treatment plans. Over time these may join up to provide a “clinical pathway” highlighting the journey a patient makes as they move from one stage of management to another. Tools are beginning to be developed to help clinicians to manage patients along clinical pathways derived from standards previously agreed. An example is the Map of Medicine [35] which NHS CfH has adopted. It is not clear how such a tool may be deployed. But in theory patients might be able to see such a pathway and assess their progress along it. As time passes, further tools may be developed for patients to help them at points where there may be choices for different courses of action. These are points in the clinical pathway that the patient and clinician may want to discuss things to help decide the optimal treatment plan.

The clinical pathway may stimulate discussions on when a patient or clinician may choose not to follow the ideal care pathway. There may be times when the ideal care pathway cannot be followed because the service is not available or not accessible to the patient close to home or simply has not been considered. This could stimulate the patient and clinician to take an active role within the local health community to help bring forward such services or at least ask why they are not available. This will help the health service to be more responsive to the needs of the patient and clinician whilst recognising that all services cannot always be made available to all people all the time in a constrained service. It does however encourage patients to get involved in such things as Patient Participation Groups [36] or on health committees to ensure their voice is heard and that decisions are made taking into account patient’s views. This is even recognised in the World Health Organisation report “Preventing Chronic Disease – a vital investment” [37].

Denmark already leads the world by enabling all its citizens to see medications and results of blood tests on-line [38]. This helps to stimulate a healthy Partnership of Trust. It encourages patients to see their clinician when they really need to rather than as a routine visit just to find out what is happening. This also means that the clinician can spend more time discussing the implications of the condition or treatment rather than just re-iterating the contents of a letter or informing the patient of a test result. The patient and clinician can then discuss the implications of the results rather than just the tests themselves.

As a Partnership of Trust is established, what can we go on to hope to achieve?

Health records contain information which hitherto has been mainly for fellow clinicians to see. The “copying letters to patient” initiative [39] has encouraged clinicians to change the style of writing to ensure patients can also understand what they have written. Otherwise patients may come back to them for further clarification. As patients begin to realise they have the right to access their medical records and the technology becomes more widely available, more patients will request access to their full medical records. Clinicians will need to respond by enabling patients to see records that they understand. This style will gradually develop as the Partnership of Trust shapes the skills and attitudes of the clinician as well as the patient. The clinician may have to adjust by being more prepared to enter into meaningful discussions with patients; to allow patients to participate in decisions about choice of treatment; to present information to the patient which may be unpleasant or potentially upsetting, honestly, and with full candour; to recognise that some patients are competent to make and

record some of the more straightforward indicators, such as blood pressure, blood sugar, and to regard these as useful additional information, if appropriate; to recognise and accept that in some cases a patient may actually know as much, or even more than the doctor about a medical condition. Long term chronic conditions may stimulate patients to research their complaint in considerable depth. In other cases an obscure or rare condition might also stimulate extensive studies on the part of the patient. This situation may be difficult to concede by some doctors but its recognition does help to enhance the Partnership of Trust. Patients, too, may need to modify their approach to the clinician. For some there may be the need to overcome the natural or traditional reticence to engage in genuine two-way discussions with the doctor; to become better informed about their medical conditions, together with the initiative to find ways of doing so; to ensure their medical record is correct and free of error [40]; to cooperate with the doctor by taking more responsibility for their own health and welfare; to keep a close eye on dates and be proactive in making appointments for regular tests, etc., without having to be reminded; to become more involved in the activities of the practice. Patients can gain a better understanding of the workings of the health services in general and of the practice in particular. Patients have already started to help stimulate such discussion and debate [41], [42]. As this develops further, other interested groups e.g. Diabetes UK or the Alzheimers Society may produce specific advice for patients and clinicians to help further support the relationship between patients and clinicians. Groups such as the Patient Information Forum [43] are also likely to become more influential in supporting the transition of the patient from a passive recipient of care to an active partner.

Health Space [32] enables patients to store basic medical information such as current medication, allergies, blood pressures and peak flows. This facility will need further development so that complete medical information is available to help patients and clinicians to be aware of all information that is stored about their health in all care settings. This will help to stimulate many different Partnerships of Trust between many different clinicians, acknowledging the multi-disciplinary nature of modern healthcare.

The internet, like illness and disease, does not have national boundaries. People are now travelling further afield for business and / or pleasure. As the prevalence of chronic diseases continues to rise, many of them may have conditions that need to be managed whilst they are away from their home. They will therefore need access to high quality information about their own health and about the healthcare services specific to the country they are visiting. UK based web-sites may not be appropriate when in Africa or the Far East. But how can an individual know that the information they are receiving abroad is appropriate? How can the clinician whom they trust give appropriate advice about where the patient can get appropriate information whilst abroad? The World Health Organisation may have a role in developing standards for stimulating discussion and debate amongst member countries and relevant organisations to help produce a quality marker so that patients and clinicians can easily identify and use the information.

Clinical software to date has been largely focused on the needs of the clinician. This is not necessarily conducive to encouraging a Partnership of Trust. The next generation software needs to be developed for both patients and clinicians together in partnership so that it will encourage patients and clinicians to further develop and improve the clinician-patient relationship. This will support clinicians and patients to learn from each other and develop further mutual respect whilst recognising the critical role patients have in attaining better outcomes for themselves. This will be even more

important as healthcare organisations move away from simply treating disease to promoting health and well-being and ultimately happiness. Already evidence is accruing that electronic health records contain sufficient information to help patients to identify the level of their personal cardiovascular risk [44]. Seeing this personalised information will encourage patients to consider their personal risk and plan life-style changes for reducing that risk.

Clinicians are concerned about the conflict of helping patients to self manage whilst enabling professional responsibility, accountability and contextual factors that drive behaviour such as consultation length [45]. Anecdotal evidence suggests that the time taken is typically much less because all information is to hand for the patient to see prior to the consultation. The frequency of consultations decreases but the quality of the consultation improves as the discussion focuses mainly on the implications for the patient as opposed to merely informing the patient of the results of tests or other communications that have been received. This however needs to be further researched and formally evaluated.

Ultimately it is hoped that a Partnership of Trust will support an open policy for patients and clinicians to feel comfortable with sharing all information that is available. Information unjustifiably locked in patient-sealed envelopes (preventing the clinician from seeing) or clinician-sealed envelopes (preventing the patient from seeing) [46] could build distrust and harm to both patient and clinician. It is however recognised that sealing may be necessary in some circumstances for a healthy relationship to exist e.g. the minutes from a child protection meeting. There needs to be a balance between enabling an open relationship whilst recognising the need for withholding some information so long as this is to the advantage of the clinician-patient relationship. A local Health Care Record Board made up of local clinical leads, managerial leads, information governance leads and patients could be an important group to manage and perhaps police the utilisation and development of patient access and clinician access to health records.

We hope that enabling patients to readily access their medical records will lead to an improvement in the health outcomes of individuals. In societies where patients have this facility they can enjoy living and celebrate the benefits of having information about their health linked with high quality information. This in turn will help them to continually improve their health as well as their relationship with their clinician: a true Partnership of Trust.

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