

Rural Forum response to the “Information Revolution”
David Hogg, 4th December 2010

The RCGP Rural Forum has considered this document in detail, culminating in a teleconference which involved members from across the UK. Unfortunately we found the document to be heavy in rhetoric, and it has raised basic questions which have already been considered at length in previous consultations (with no evidence to date of specific progress).

However, the Rural Forum recognises the importance of participating in the debate on how changes to the NHS will be considered. We therefore offer the following observations.

One key overarching point is the need to rural-proof the plan for any information revolution in the NHS. Rural areas still suffer from disproportionately poor access to IT facilities, including broadband links and local networking, for example decent IT links between branch surgeries. Any move to increase the necessity for IT literacy or access to decent IT facilities in order to interact with the NHS, will further exacerbate the inequalities that rural populations experience in accessing NHS health care.

Technology, especially its use for closing the gaps caused by distance, has a high degree of potential to help rural populations, but the benefits of generic IT facilities cannot be assumed just because the technology makes it possible. Access to and benefits of IT can be very different when compared with urban settings. More sophisticated implementation and development of technology-based solutions must take place. For example, it is widely accepted that teleconferencing cannot replace the core features of first-consultations with hospital specialists. However, there are very real benefits to be realised when selected subsequent follow-up consultations are undertaken by videoconference.

The commitment to the development of IT provision is welcomed. Whilst the frustrations of delays and wasted public money on the IT Connecting for Health initiative remain very much in our minds, there is no doubt that future development of the use of IT in healthcare settings has tremendous potential for patients who live in rural areas. We fully support the prospect of better IT provision in this setting.

Q1: What currently works well in terms of information for health and adult social care and what needs to change?

Access to local health information is increasingly effective, with health boards/trusts providing useful information - from information about services, to guidance on minor illness - on the internet. Where broadband/internet facilities are sufficient, there are many patients of all ages who rely heavily on the benefits that access to web-based information brings.

Better signposting to other agencies is always required, and integrated information to reflect local multiagency services provision has the effect of making this information more relevant, and more trusted.

Whilst centralisation of information may seem desirable, instead some of the best uses of

IT occur when local innovation is allowed to flourish. Developing templates to allow local development of this information is when consistency merges with relevance, and in particular, offering systems to support the use of technological advances, is particularly beneficial to the development of information systems.

Q2: What do you think are the most important uses of information, and who are the most important users of it?

This question is too vague to answer.

Q4: Given the current financial climate, how can the ambitions set out in this consultation - to make better use of information and technology to help drive better care and better outcomes - be delivered in the most effective and efficient way?

Better use of IT offers very real gains to be made in terms of efficiency and savings. The referral process in some areas is still paper-heavy - which causes bureaucratic hurdles and significant delays as such referrals are filtered through various processes. IT offers the potential to adopt more effective "one-touch" processes, such that information is filtered rapidly to those who are more able to respond.

For rural areas, where tele- and videoconferencing is available, there are real gains in terms of time and expense to bring groups together who would normally have significant travelling/ subsistence expenses, especially when those individuals are from rural areas. We use a range of IT solutions within the Rural Forum, and our own experience is that a hybrid of physical meetings supplemented with virtual meetings allows us to communicate within a tight budget and with minimal hassle for our members. We suspect that this hybrid is true of all implementation of IT to improve access to medical opinion.

Q5: Where should the centre be focusing its limited financial resources and role to achieve the greatest positive effect?

In terms of rural populations, IT developers must have relevant experience of the challenges faced in rural areas. We have witnessed many examples in the past where:

1) Urban-based IT solutions have been rolled out to rural areas in the naive assumption that they will achieve equal benefits (problems such as poor broadband speed are one element that needs to be appreciated).

2) Conversely, rural populations should be more easily consulted by the smart use of technology, and we would like to see this occur in the development of the proposed IT revolution.

Consultation questions – Chapter 2

Q6: As a patient or service user, would you be interested in having easy access to and control over your care records? What benefits do you think this would bring?

This must be an explicitly opt-in system. We were gravely concerned that there was very little consideration in the document with regards to protecting confidentiality. This is an absolutely essential component of any move to make care records available electronically. Failure to satisfactorily address this will simply result in massive challenges, as service users become untrusting of the system, and professionals need to be convinced that the information they

submit is subject to strict and consistent information control policies.

There are many situations when it is entirely proper for information to be with-held from patients either fully (to cause unnecessary harm) or until appropriate explanation can be given in a suitable environment. Specific situations include areas of child protection and mental health where patient expectations must not be raised further than what can be legally and morally delivered.

Q7: As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?

The doctor-patient relationship, and the value of a personal consultation, are frequently devalued or misunderstood by non-practitioners. In addition, there are significant risks in creating new tiers of hypochondriasis, not least in the associated financial cost (with little consequent benefit) that this brings. Many patients who engage with the NHS are actually in vulnerable groups, due to extremes of age, poor financial resource, poor comprehension of English or due to other reasons that prohibit easy access to health care. Online communication with professionals can be appropriate in some specific circumstances, but we believe that there is no equal replacement for the benefits in a true face-to-face consultation with a healthcare provider. The benefits of a physical examination and interpretation of subtle non-verbal communication must not be forgotten when planning IT-based solutions.

Q8: Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document.

This seems like an obvious question, some of which has been answered above. Confidentiality (and autonomy in terms of whether to opt-in to a shared IT system) must remain at the forefront of any decision to implement online healthcare records.

Q9: What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?

Often patients cannot be adequately supported outwith the bounds of a physical consultation. There must be adequate safety-netting and signposting to alternative forms of assistance. In terms of providing online information, it is best to avoid creating stress or anxiety in the first place.

Q10: As a patient or service user, what types of information do you consider important to help you make informed choices? Is it easy to find? Where do you look?

A paradox exists between using popular resources (such as Yahoo or Google) whilst ensuring that personal records are maintained within a completely separate domain that confers the autonomy and trust in confidentiality as described above. We often use review-based systems (such as TripAdvisor) for non-healthcare purposes, but the dangers of transferring such systems into the NHS are well documented elsewhere, and we would resist any move to introduce such ratings-based information within the healthcare - particularly the rural practice - setting.

Once again, patients have the right to expect safe, confidential, effective and appropriate treatment. Many patients do not wish to have choice added to this equation, as they assume that the first four tenets are adhered to in the first instance.

Q11: What additional information would be helpful for specific groups - eg.

- users of maternity and children's health services;
- disabled people;
- people using mental health or learning disabilities services;
- the elderly;
- others?

This is a very broad question, too much so to offer a concise answer.

Q12: What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?

Peer support is particularly relevant to carers, and internet-based networking of carers has some great potential benefits.

Q13: What are the information needs of people seeking to self-care or live successfully with long-term physical and mental health conditions and what support do they need to use that information?

Again, this is a very broad question to answer.

Consultation questions – Chapter 3

Q14: What information about the outcomes from care services do you (as patient, carer, service user or care professional) already use?

Generic national-based standards are increasingly used. We are against the use of ratings systems as they are too infrequently accurate at giving realistic impressions of professional-patient relationships, and are open to significant unwarranted abuse.

Q20: What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?

As already stated, there are many inherent dangers in this approach. In general, structured, qualitative feedback can be most relevant, especially when obtained from a random selection of service users. The introduction of ratings-based systems or skewed information gathering (such that only aggrieved patients would be likely to contribute) would be resisted by most of our members.

Q21: What are the key changes in behaviour, systems and incentives required to make the NHS and adult social care services genuinely responsive to feedback and how can these be achieved?

This relies on trust being created in the systems used to glean this feedback in the first place.

If the systems ensure that constructive, truly representative and relevant feedback is obtained, responsiveness to these systems will more likely follow.

Q26: Clinicians, practitioners, care professionals, managers and other service provider staff will be expected to record more data and evidence electronically. How can this be facilitated and encouraged? What will be the benefits for staff and what would encourage staff to reap these benefits?

This completely relies on the logistics of entering this information being addressed. Slow logins, poor/interrupted connections, or clumpy irrelevant input forms (which are already found in many healthcare settings) would be the biggest initial challenges.

The benefits of the information gathering will - if truly beneficial - become obvious to the team through the impact that it has on their clinical workload. Conversely, if benefits are not experienced, this will quickly stifle attempts to encourage greater use of these systems.

Q28: The ‘presumption of openness’ in support of shared decision-making will bring opportunities - but may also generate challenges. What are the greatest opportunities and issues for you a) as a care professional? or b) as a services user?

This has been covered above. The core aspects of the GMC’s “Good Medical Practice” infer the presumption of confidentiality. The above statement is a potential conflict with this. Shared decision-making is facilitated more effectively in the way in which professionals engage on a personal level with their patients.

Q29: What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?

The GP-held healthcare record must be subject to the highest level of stringent security, and access based on strictly regulated “need to know” basis. The credibility of GP-held and GP-endorsed information must be realised, with supplementary information clearly branded as other levels of endorsement. Confusion between information/recommendations from your GP and from other sources must be avoided.

Q30: Would there be benefits from central accreditation or other quality assurance systems for information providers and ‘intermediaries’? Would factors such as cost and bureaucracy outweigh any benefits?

There must be clear identification of different levels of endorsement for information that patients receive. It is widely and continually reported that the GP-patient relationship is held with the highest degree of trust in the vast majority of patients, and this must not be abused or hijacked by those with vested interests. However, this does also offer the opportunity to stratify health information that patients can access, from an NHS perspective, and provide better signposting to higher quality information.

Q31: How can a health and social care information revolution benefit everyone, including those who need care most but may not have direct access to or know how to use

information technology? This might include those who do not have access to a computer or are remote and can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages. It must be accepted that some of these groups will not benefit directly from the information revolution, and will continue to rely on quality GP-patient consultations without any personal access to the elevated levels of information proposed. More attention must be placed on the importance of improving rural access to broadband facilities, and subsequent policies must be rural proofed as current Government policy demands.

Q32: Are there other datasets that you think could be released as an early priority, without compromising individuals' confidentiality? Would there be any risks associated with their release - if so, how could these be managed?

Scotland has enjoyed the benefits of the Emergency Care Record - providing details of a patient's latest prescriptions from their GP. There have been some issues in terms of autonomy of inclusion, however at the acute-care level, it provides good, filtered access to the medication record only.

Q33: The information revolution can deliver many improvements. What are particular benefits or other challenges - including sustainability, business, rural or equality issues - that need to be considered in developing the associated impact assessment?

Most of these have been covered above. Approximately 1/3 of the UK population lives in a rural area, and a range of peripherality exists within these areas. Many benefits of information technology have already been implemented, and the information revolution document outlines more which - in theory - could do much to improve the access and experience that rural patients can achieve from the NHS. However implementation must be careful, sensitive and relevant, and erosion of the fundamental doctor-patient relationship must not be a side-effect of the changes proposed.

Access to broadband must be improved as an absolute priority. The challenges of decent broadband connections in rural areas, have been well documented and many of our members in rural areas experience the difficulties of this on a daily basis. The information revolution simply cannot occur in rural areas without significant commitment to investment and pragmatic implementation of an adequate network infrastructure.

Q34: Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?

Issues of compatibility don't seem to have been addressed. This is a big issue on several different levels - between primary and secondary care, between medical and allied professional areas (such as pharmacies), between trust/board regions and also across borders. The last issue was raised specifically by some of our members who live close to the borders with Scotland and Wales, and the challenges they face in dealing with some referrals fitting in with protocols and procedures not just in neighbouring regions, but countries.

*We also wish to highlight that efforts for information provision must not preclude the core role of the NHS: to provide good quality health **care**. Of course, information provision is implicit in this, however patients rightly expect good quality **care** first and foremost.*

Submitted on behalf of the RCGP Rural Forum 5th December 2010.