14th January 2011

**Department of Health consultation – Liberating the NHS: An information Revolution**

1. I write with regard to the Department of Health consultation – Liberating the NHS: An Information Revolution.

2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. Founded in 1952, it has over 42,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline. We are an independent professional body with enormous expertise in patient–centred generalist clinical care. Through our General Practice Foundation, established by the RCGP in 2009, we maintain close links with other professionals working in General Practice, such as practice managers, nurses and physician assistants.

3. The College has responded separately to the consultation on the Government’s White Paper – ‘Equity and Excellence: Liberating the NHS’ and to the five further consultation papers relating to this that have been published. This response should be read in the context of our overall views on the proposed reforms to the NHS.
4. After consultation with our members and discussion by the College’s Council, we published a Framework document outlining our position towards the proposed NHS reforms. This draws attention to the many opportunities GPs have identified within the White Paper proposals, but also to many challenges and concerns that our members have expressed. This document, and all our responses to the White Paper, have been drawn up with reference to the College’s core statement of object, vision, purpose and values:

**OBJECT**

The Royal College of General Practitioners is a registered charity with the Object:

*To encourage, foster and maintain the highest possible standards in general medical practice and for that purpose to take or join with others in taking any steps consistent with the charitable nature of that object which may assist towards the same.*

**OUR VISION**

*A world where excellent person centred care in general practice is at the heart of healthcare.*

Our role is to be the voice for General Practice in order to: promote the unique patient - doctor relationship; shape the public’s health agenda; set standards; promote quality and advance the role of general practice globally.

**OUR PURPOSE**

*To improve the quality of healthcare by ensuring the highest standards for general practice, the promotion of the best health outcomes for patients and the public and by promoting GPs as the heart and the hub of health services.*

We will do this by:

- ensuring the development of high quality general practitioners in partnership with patients and carers,
- advancing and promoting the academic discipline and science of general practice,
- promoting the unique doctor-patient relationship,

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1 See Appendix – The RCGP and the White Paper – A Framework for our Response
• shaping the public health agenda and addressing health inequalities,
• being the voice of General Practice.

OUR VALUES

The RCGP is the heart and voice of General Practice and as such:

- **We protect the principle of holistic generalist care which is integrated around the needs of and partnership with patients**
- **We are committed to equitable access to, and delivery of, high quality and effective primary healthcare for all.**
- **We are committed to the theoretical and practical development of general practice.**

General Response

5. The College has consistently championed the use of information for service development and better patient care. Our Health Informatics Group has produced a number of very important guidance documents, supported by the College and referenced by the Department of Health in this consultation document. These include ‘Shared Record Professional Guidance’\(^2\), and ‘Enabling Patients to Access Electronic Health Records’\(^3\). We refer the reader to these documents for detailed consideration of many of the issues covered by this consultation, including practical guidance for implementation in the primary care setting\(^4\).

6. The College's position is that accurate recording of clinical data is an essential part of General Practice, in contributing to our ability to understand and maintain our own performance and that of the NHS, and in contributing directly to better patient care. We are confident that General Practice is already at the leading edge of accurate record-keeping, and that a key challenge for the shared record proposals will be


ensuring other contributors can maintain the same high standards. We welcome the emphasis in the consultation on information standard-setting, rather than top-down implementation of information systems.

7. The College recognises that patient access to clinical records may be of considerable use to some patients in enabling them to take better control of their care, and will promote shared decision-making, which the College has long supported. We have concerns, though, that this document underestimates some of the dangers and potential drawbacks. There is a danger that expectation of patient access may restrict a clinician’s freedom to include necessary information – for example their judgement that a patient may be a source of danger to themselves or others, technical information which may be unclear to the lay reader, or observations of potential child protection issues. There is also a concern that, without collaborative discussion between patient and clinician, patients may share their records more widely than might be desirable, with outside organisations or, for example, with a carer with whom they may be in an abusive relationship. There are additional concerns around potential for litigation, for example where a patient is able to insert information into their care record and may expect their clinician to take account of this in diagnosis and prescribing. All these matters require closer thought and guidance, and many of our members will require reassurance of this before accepting unreservedly the benefits of full patient access.

8. Our members embrace the use of performance information for benchmarking of services and quality improvement, and recognise that patients have the right to access that information. We strongly support measures to ensure the standards of information that is made publicly accessible, as well as standards for how the information is presented; without such standards, and without careful education in the meaning of the information presented, there is a danger that the use of crude league tables and statistics presented out of context will be harmful to the stability of NHS services and ultimately damaging to patient outcomes.

9. The College has two overriding concerns, which should be considered even when not directly referenced in all that follows. The first is regarding confidentiality. Clearly there are risks to confidentiality in many of the proposals of ‘An Information Revolution’ – these risks are likely to grow even as the benefits of greater information use are realised. Patients and clinicians must be made aware of these risks, and patients must be allowed to ‘opt-in’ where any proposal risks dispersing their personal information more widely. Rigorous standards for data security must be
developed and constantly monitored. See, for example, the Wellcome Trust’s briefing, which the RCGP has endorsed, on ‘Use of patient records from general practice for research’\(^5\).

10. The second concern is that, in pursuing the potential benefits of information technology for the majority of patients, sight must never be lost of the ‘digitally disadvantaged’. There are rural communities who, without vastly improved broadband connections, will never be able to participate in any information revolution. There are those, including some elderly patients who are often more dependent on healthcare than most, who simply do not ‘get’ computers. And there are many with physical and learning disabilities, and other forms of disadvantage, who risk being left behind. Some of these groups can be educated and supported to participate, but for General Practice in particular, the essence of the NHS is in the face-to-face consultation between clinician and patient, and reliance on new technology must not be allowed to detract from this.

**Response to Specific Questions**

11. The consultation on ‘An Information Revolution’ contains 34 questions, to which we have provided answers below:

**Chapter 1**

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

It is noted that information recording and sharing within GP practices currently works very well – but that sharing information beyond the practice will require greater harmonisation of systems and standards for recording to make information more generally intelligible. Clinicians will need guidance on ‘streamlining’ data if it is to be useful, particularly to patients having access to their records and in the context of the ten-minute consultation.

There are gaps in General Practice-derived data to inform commissioning of both primary and secondary care, including data on disease severity, service use and

\(^5\) Wellcome Trust, Towards Consensus for Best Practice: Use of patient records from general practice for research (Wellcome Trust June 2009) - [http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtx055661.pdf](http://www.wellcome.ac.uk/stellent/groups/corporatesite/@policy_communications/documents/web_document/wtx055661.pdf)
outcomes of care. The quality of data for social care is much less secure. Both the accuracy and use of this data for commissioning need extended attention and expertise to be valuable – access to data per se is only part of the story.

There is a major shortfall in the quality of some data from secondary care, where in many cases data is not inputted by clinicians involved in the care of an individual, and data is often not coded appropriately or accurately. There is a need for considerable education and training (for those who input data and for those who make use of it) before this data can be a fit basis for commissioning decisions.

It has also been observed by members of our Patient Partnership Group (PPG) that current information processes are very cumbersome for patients – for example, they often have to submit the same information multiple times to different agencies. In this light, we welcome the principle of recording information once and using it in many ways, as espoused in this consultation.

Our members also recognise and welcome the massive expansion in the availability of healthcare information in recent years through the internet, including sites such as NHS Choices and the NHS Evidence web portal to which the College contributed. There is still a need, however, for standards to guarantee the quality of such information (the phrase ‘kite-mark’ is referenced repeatedly by our respondents), and for information better tailored to individual patients and conditions, to enable self-care and shared decision-making. Along with this emphasis on standards for electronic information, there is a need for investment to maintain the quality of more traditional forms of information – patients who cannot access the internet should not be endangered or disadvantaged by inadequate or out-of-date literature. In particularly, signposting to local services, in all forms of media, should be maintained and expanded.

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

In the context of General Practice, many of our respondents felt that the single most important use of information was to inform about local clinical services and referral routes – and that the primary users of this would be clinicians in consultation with their patients. Better use of information has the potential to provide seamless and efficient care pathways for patients, and ensure equitable access to health and social care for all.
Q3: Does the description of the information revolution capture all the important elements of the information system?
As discussed above (Q2), there could be a greater emphasis on the provision of information about local resources. For many patients and clinicians this will be the kind of information that is most immediately useful. In other respects, the description is broadly coherent.

Some of our members felt that the diagram on page 13 was not entirely successful in attempting to simplify a fairly complex set of proposals.

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?

There are obvious cost implications of any IT strategy, though the College welcomes the emphasis on standard-setting and system-linkage over imposing systems as perhaps a more cost-effective approach. We would urge caution before any major investments in technology, and encourage the testing and assessing of technology and procedures before global implementation, with particular care taken before attempting to transpose systems developed in the urban context to rural areas.

There are obvious potential cost benefits in the improved use of technology – for example, there is much in the referral process which is currently paper- and administration-heavy, and which could be more efficient if done electronically. There is also potential in the use of tele- and video-conferencing to bring clinicians and other groups together more affordably, as understood in business contexts and trialled also by groups within the RCGP, including our Rural Forum, who are in this way able to interact more frequently and efficiently.

What we would resist, for vital clinical reasons, would be any attempt to use technology to reduce access to, or the quality of, conventional healthcare services. Email and telephone are useful complements to face to face care, and can be used effectively for some patients some of the time: but the strength of General Practice is that it treats the whole patient, and through the face-to-face consultation can often address problems beyond the patient’s primary reason for visiting. One generally cannot detect distress by e-mail, nor easily correct misunderstandings, or notice the nonverbal symptoms and
signs of child or intimate partner abuse; clearly e-consultations for specific tasks have limits in this regard.

Q5: Where should the centre be focusing its limited financial resources and role to achieve the greatest positive effect?
The primary need is for better communication between systems rather than starting afresh, and the Department of Health’s role is rightly in setting standards for interconnectivity. It is suggested that the appropriate paradigm would be the successful GP2GP implementation, which is a partnership between national standards, supplier implementation and local use.

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?
We agree that many patients would welcome and benefit from having access to their care records – those who take the opportunity are likely to be empowered to take control of their health and make educated lifestyle choices, and enabled to engage in informed discussions with their GP and other clinicians. The ability to challenge content and add information would also be welcome to some patients, though must not take precedence over or obstruct professional judgement.

One concern is that this is likely to be of most benefit to well-educated and time-rich patients, who will by extension be calling upon a greater share of NHS resources, in terms of the technology itself, and, quite likely, clinician time. So this development may, while beneficial in itself, result in a further increase in health inequalities.

We are not clear to what extent the proposals outlined actually offer patients control of their records, since they must always be held by a responsible organisation. We agree with this arrangement, but would suggest that some could find the terminology misleading.

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?
There are potential benefits to the extension of telephone and e-mail consultation for very basic or long-standing/repeating complaints, particularly for patients with mobility difficulties or those, such as in rural communities, living a long way from the practice.
This must always be, however, as a follow-up to face-to-face consultation, which is a vital constituent of primary care. Patients will need to be aware who will be seeing their emails, that these do not form part of the clinical record, and that if a specific recipient is absent from the practice they may not get a rapid response – furthermore that e-mail communication is inherently less secure than some other forms, and care should always be taken in choosing what information to transmit in this way. The usual professional boundaries need to apply – email can be less formal and more personal, which may lead to confusion.

From a practice and consortium perspective, it should be recognised that the use of online or e-mail communication methods may well be more rather than less cost- and time-consuming – as these will be in addition to regular consultations and will likely involve more frequent communication. There is also a concern over the confidentiality of e-mail in particular – patients would need to be assured which professionals would have access to their messages. There are also circumstances in which distant relatives who have power of attorney, or parents who have dispute with child protection plans or access issues, wish to contact the GP. There need to be parameters and guidance over this, because these demands can be complex and difficult to conduct and record.

Once again, risks are that only a section of the population will benefit, not necessarily that with the greatest need, and will therefore use NHS resources disproportionately. Those with hardware or connection disadvantage must not be allowed to lose out. Moreover, some of the holistic benefits of the GP consultation will be lost, as already argued at Q4 above. It is noted in particular that for patients with learning difficulties the online consultation may often not be appropriate, and physical examination essential.

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.

We would reiterate, as discussed at paragraph 2.16 of the consultation, the College’s keen concern for the maintenance of confidentiality of patient records. There should be informed consent from patients before the extension of their confidential information to additional parties. There is a need for widespread education of professionals in all disciplines as to the full implications of confidentiality6. Any non-NHS body controlling or

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6 See Wellcome Trust, Towards Consensus for Best Practice: Use of patient records from general practice for research (Wellcome Trust June 2009) -
accessing health data must be closely supervised. Methods should also be considered (protocols or technology solutions) for restricting access to records on a ‘need-to-know basis’ – for example, a patient’s dentist may not need access to their full medical record. For those with long-term conditions there may be a large number of professionals involved in their care – there should be clear guidance on who is entitled to see what.

We would refer the reader to our Paragraph 7 above, as there are many other risks that need to be considered with regards to the proposed approach to record sharing. In particular we would be concerned that, given widespread patient access, clinicians may be constrained in what they feel they can write in a patient’s record – and either ‘dumb down’ entries that are primarily intended for professional interest or avoid matters altogether which may be relevant to child- or vulnerable adult protection, such as information or opinions about the patient or a family member. There is a genuine fear that some patients may react with hostility to what they read about themselves, however clinically valid – GPs in particular would welcome support and guidance in how to address this concern.

In particular, safeguarding of children is an extremely important and sensitive area for data capture and data sharing for GPs. GPs provide ongoing care for vulnerable children, their siblings, parents and household contacts. However, information about such children is poorly captured at present. Approximately 10% of children are exposed to some form of maltreatment by carers/parents each year, yet codes reflecting concerns about maltreatment are rare in GP records. Interviews with GPs suggest a reluctance to record explicit concerns because parents and eventually the child him/herself have access to their records. There are also sensitivities about social care having access to GP data, even to participating in multidisciplinary team meetings within the practice when vulnerable children are discussed. On the other hand, social care (and education) are sometimes very poor at keeping the GP informed of welfare issues and seem not to recognise the pivotal role played by the GP in managing vulnerable families over the long term, or the importance of the GP record as the repository of information about welfare issues that have a major impact on immediate safety and long term health.

A specific area in which guidance is needed is the scanning of Child Protection conference reports, which may contain third party information or allegations, into the

computerised GP medical record. The present guidance in the RCGP/NSPCC safeguarding toolkit is that such reports should be scanned in full into the child & siblings’ notes, and a note referring to them in parents’ and carers’ records. There should be parameters to what children and those with parental responsibility can see. There is also ongoing work by the RCGP Multi-site Audit group on rationalising Child Protection Read Codes. The group have serious concerns about the imposition of SNOMED codes.

GPs will also need reassurance that they will not be vulnerable to litigation or media pressure should, for example, a patient add information to their record which the GP subsequently fails to take account of in diagnosis and prescribing.

Lastly, patients will need education if they are enabled to share their records with individuals and organisations of their choice – education in the full implications of data security and confidentiality, and support, for example in the case of a vulnerable patient whose carer or family member should not always be assumed to have their best interest in mind.

Q9: What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?
As mentioned earlier, information on local resources, including relevant support groups and other information sources, should be made much more easily available, either directly to the patient or through their GP. Condition-specific online information is useful, so long as quality is assured, it does not take the place of face-to-face contact, and provision is made to include those without web access.

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?
Our respondents valued information about conditions and treatments, as well as availability of local services. Some did wish to see more information about outcomes from particular types of surgery and particular surgical units, as well as information on the quality of nursing and medical care, and wished this kind of information could be more easily obtained. However, others were concerned that the imposition of ratings-based ‘TripAdvisor’ style information on the quality of healthcare could be misleading and lead to heightened inequalities rather than increased quality all round, which is what patients really desire and deserve.
Members of our PPG reported using websites such as NHS Choices. Others, however stressed the continuing importance of more traditional information sources, such as local newspapers and leaflets provided through sites such as local surgeries and Sure Start centres, and word-of-mouth through family and friends and the personal knowledge of trusted local doctors. These sources are particularly important for those without easy access or ability to use electronic resources.

**Q11: What additional information would be helpful for specific groups - e.g.**
- users of maternity and children’s health services;
- disabled people;
- people using mental health or learning disabilities services;
- the elderly;
- others?

In the case of those with mental health problems or learning disabilities, the key issue is the methods of communication used. Information delivery must be tailored to specific needs – here above all a one-size-fits-all approach to information will not work.

People using these services will especially benefit from information about side effects of medication, alternative therapies and the availability of benefits.

It is suggested that there are lobbying and support groups available for all these groups – but other groups who may also be especially vulnerable, because often largely invisible within society, include homeless people, travellers, new migrants and asylum seekers. Consideration should be given to how we make information available to these groups.

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

There is a need for coherent and accessible information for carers – on how to obtain support (financial and emotional, as well as options for respite), on limitations of care (what may and may not be expected of them) and what to do if patients refuse care. Many carers suffer significant health problems because of their caring role, and it is essential to support these needs as fully as possible. Peer support networks can be particularly useful to carers, and there are potential benefits to be found in internet-based networking of carers.
There are likely to be particular issues for carers of older disabled children facing the transition into adult services and those caring for patients with end-of-life care needs or with dementia.

It needs to be recognised that carers may themselves be subject to disability or disadvantage – carers include those with substance misuse or mental health problems, and people who do not speak or read English - and efforts should be made to communicate with them using language and technology that they can access.

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?

As before, the primary need is for signposting to support groups and other forms of help, provided electronically but also through more conventional sources.

Members of our PPG tell us that they do value information being available about specific conditions, including reliable information about new treatments and research studies, the likely course, symptoms and management methods for the condition and links to other people with similar conditions.

People with long term conditions and physical disabilities may well be those to get the most benefit from the potential for electronic communication with their GP and other clinicians. At the same time, they may also particularly benefit from a regular, named practice contact who can ensure prompt attention.

Chapter 3

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

GPs already use information about care services to support and advise their patients, and this is a vital part of primary care which can be enhanced by more accurate data and by information technology solutions. It is anticipated that a far greater volume and quality of information from all health and social care sources will be a vital tool to aid GP commissioners. This must also include access to public health information, as currently produced by PCTs and the regional public health observatories: these datasets need to be retained if the public health function moves into Local Authorities.
We would argue that the primary role of information about delivery and outcomes of specific services is not so much its utility to patients in helping them make choices – we would expect that only a minority of patients would ever use information in this way – but rather the ‘push’ that public availability of data gives to providers, and their ability to benchmark their activities and identify areas of strength and weakness.

Some patients use outcome data - members of our Patient Partnership Group stressed that they read carefully the reports issued by service providers that they interact with, as well as the Care Quality Commission (CQC) reports on their performance, and also value information on patient experience. However, the main value of public data is probably less about individual choices than the competitive functions between providers – though this can lead to biases in self presentation as well as acting as a useful source of comparisons.

Q15: What additional information about outcomes would be helpful for you?
Many GPs would welcome timely, accurate and comparative data about their own activity in order to monitor themselves and help them work towards best practice. GPs already use such information, for example on prescribing levels, and find it useful.

There is concern however, as expressed in our response to the consultation on proposals for a Health Outcomes Framework\(^2\), that there is currently a lack of clarity in proposals, and that outcomes must only be used as an indicator of quality where they are under the direct control of the care provider. The danger is that some outcomes may be used as a measure of quality when they might more accurately be regarded as a measure of need, reflecting underlying factors in local communities.

Q16: How can the benefits of seamless and joined up information be realised across the many different organisations (NHS and non-NHS) a service user may encounter?
As discussed above, General Practice leads the way in collecting comprehensive data. When secondary care and other organisations record data as effectively, and standards for interoperability are established and implemented, including universal use of the NHS Number, the potential is there for information to be a vital tool in assisting commissioning

for service development and, at the level of the individual GP and patient aiding more effective referral.

A vital part of this will be the availability of public health information – this can be a powerful driver to commissioning, but only if there is effective communication and data-sharing between commissioners and local authorities.

**Q17: For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?**

The use of information across organisational boundaries, and hopefully the coordination of care which will follow, will be of use to most service users, but particularly for those with long term conditions, who may currently experience distress and frustration at the lack of ‘joined-up thinking’. The co-ordination of care across different organisations is particularly important in chronic co-morbid conditions.

**Q18: What are your views on the approach being taken and the criteria being used to review central data collections?**

The proposals appear justifiable and proportionate, though as stated above care needs to be taken, when compiling national outcomes data, of the distinction between outcomes as measures of quality and outcomes as measures of need.

**Q19: How could feedback from you be used to improve services?**

We welcome opportunities for patients to provide feedback on their general practice and other healthcare services, and agree that this can be of use in guiding service development as discussed in the *Liberating the NHS: Transparency in Outcomes*. With specific reference to the use of Patient Reported Outcome Measures (PROMs), we have expressed previously our reservations about their accuracy and efficacy, and would press for much greater trialling before widespread and expensive implementation. It is vital to avoid crude ratings-based systems and the kind of skewed information gathering (wherein only aggrieved patients are motivated or encouraged to contribute).

We also note the necessity that feedback be collected anonymously and analysed independently, to avoid unnecessary and distressing patient-clinician conflict.

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8 RCGP 2010, Response to Liberating the NHS: Transparency in Outcomes (p9)-
GPs themselves would welcome improved options to offer feedback to other clinicians and services – for example the ability for rapid access e-mail feedback to care pathway leads.

Q20: What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?
Local patient groups (such as the proposed Local HealthWatch) have a role here, both in providing/coordinating feedback themselves and in leading campaigns to encourage others, particularly hard to reach groups, to provide feedback.

Principles that apply to all feedback methods is that they need to be confidential, easy to do and accessible, and you need to be able to demonstrate that feedback is listened to and results in change.

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?
As stated above, the need is for anonymised, accessible and easily understandable feedback systems. Then there needs to be a culture of open discussion and regular reviews of practice within organisations. If NHS and social care staff have confidence that the information collected is accurate, fair and representative, they will be far more likely to support changes based upon it.

Q22: Which questions, if asked consistently, would provide useful information to help you compare and choose services?
Members of our PPG stated that they would value information about the effectiveness of specific treatments and specific care teams, and patient views regarding the quality of care, including attitudes of staff and fitness of facilities.

More generally, the College reiterates its strong preference for evidence-based measures and its rejection or crude and misleading ratings systems.

Q23: What will help ensure that information systems - and the data they collect - are appropriate to support good commissioning at different levels, including decisions by individual patients, GP practices, GP consortia, service providers, local authorities and the NHS Commissioning Board?
As already stated, agreed standards for quality and interoperability of data, to bring secondary care and social care services up to the high level of General Practice, as well as access to the public health data to be held by local authorities, will be vital to inform commissioning decisions. At present we are concerned that the quality of data in secondary care in particular is not adequate to the task.

The Atlas of Variation can be a useful tool, but once again commissioners will need to understand where variations in outcomes reflect differences in need rather than differences in quality of service.

Chapter 4
Q24: How can health and care organisations develop an information culture and capabilities so that staff at all levels and of all disciplines recognise their personal responsibility for data?

The vital need is for high standards of data quality across organisations, so that information is complete, confidential and accurate, and adheres fully to the requirements of the Data Protection Act. This data needs to be processed by professionals with understanding of its context and meaning and who can extract useful lessons. All of this requires education and training – of those who input clinical data, those who extract and aggregate it, the commissioners and managers who use it, and the patients who are expected to make choice based upon it. Only through education will the vital importance of usable data be understood across the organisation.

Q25: As a clinician or care professional, how easy is it for you to find the evidence you need to offer the best possible care and advice? What could be done better?

At the moment GPs often depend to a large extent on their local knowledge – in part because, as already stated, information from secondary care is currently often flawed and incomplete, and not easily accessible.

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?

There are suggestions that greater use of speech-recognition software could encourage more consistent record keeping – however the drawback of this is that often too much data can be recorded – making records much harder to use for clinicians and, potentially, patients.
As stated above staff, particularly in secondary care settings, will need education in accurate and confidential record keeping, and no doubt IT systems that run effectively, and are tailored to their needs and easy to use will encourage more comprehensive use.

Strong guidance on what data is to be recorded, along with the principle of recording data once but using it in many ways, should help minimise the burden of record keeping for staff, and most likely make the data recorded more efficient and useful.

It may be hoped that effective record-keeping will have an observable impact on clinical workload, which may in turn incentivise good record keeping – if this is not the case, it is hard to see how record keeping will be accepted as anything better than a burden for staff.

Q27: What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?
As stated at Q24 above, information management professionals need training in the context and meaning of the data they process in order to extract useful learning outcomes. Information without interpretation will not in itself be successful in raising standards in the NHS.

Chapter 5
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?
The College recognises and supports the principle of ‘presumption of openness’. However a potential drawback, as alluded to throughout this response, is the danger that without educated interpretation data may be used to give misleading impressions – for example raw outcome data on mortality rates used to assess quality of services without accounting for the complex differences in needs of local populations.

For service users, and by extension for those who commission the services for them, a challenge will be to manage the demands and expectations that may come as a result of this openness. Giving patients’ choice of services, and information on which to base that choice (especially if the information is unmediated) may lead to hard-to-predict fluctuations in demand, and possibly disappointment for some patients. By extension, the
opportunity should be taken by professionals to use openly available information to raise the standards of services across the board, so that all patients will have confidence in their local services.

Professionals, and patients, will also be keenly concerned to avoid over-complexity in information systems, and ensure that the key need for confidentiality is maintained.

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

We welcome the suggestion that data and data providers will be quality assured. Though there are benefits in having a range of providers, tailoring material to specific audiences, the dangers of misleading and misinterpreted information being directed at the public are manifold – there may be costs in litigation and loss of goodwill between public and professionals. As a rule, we urge a preference for quality rather than quantity in the provision of information. Bearing this in mind, it is likely that GPs will make use of such information providers, both in supporting their own clinical decisions and in providing additional support to their patients.

**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?**

As stated above, the College would support quality assurance of information providers, as there are many dangers of an unregulated market here. In this context, we note the success of the discontinued Information Management and Technology DES for General Practice in improving and demonstrating data quality.

Clinicians, and commissioners in particular, will rightly demand the highest quality in the information provided to them if they are to make accurate and well informed decisions that develop and improve services.

Patients would benefit from clear identification of the level of endorsement for the information they receive, so that they can know when what they receive is a trusted source rather than being subject to commercially-motivated distortion.

**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.

Access to the internet has increased exponentially in recent years, but it is understood that there are always likely to be people who are unable or who need extra help to access information resources. It is critical that we not use the information revolution as an excuse to take away more traditional forms of information, and the services (from public libraries to SureStart centres and advocacy services) which act as supports and signposting for these groups of service users. These groups will need additional investment in education to support them to access technology, and should always have assured access to face-to-face consultations.

There are, of course, ways in which technology can be used to help and advance these otherwise disadvantaged groups. For example, call reminder services can be useful in reducing did-not-attend rates for patients with learning disabilities and their carers, and adaptive technology can enable many patients with disabilities to access computers.

A necessary development, before information access to all can be assumed, is the universal availability of broadband internet. This is particularly a problem for rural areas, where the benefits of electronic information might otherwise be the most profound.

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?
We note that the proposed are extremely complex sets of data, and have some concerns that, if published in their raw form, without information about context, especially the context of local health inequalities, they may be subject to harmful misinterpretation. We would welcome, though, the publication of regular analyses of these datasets, and their widespread availability to researchers.

Chapter 6
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?
The challenges – but also opportunities - for rural communities have already been referred to. The information revolution will not succeed without the extension of broadband internet to these communities.

The challenges for those with learning disabilities have also been alluded to – all the emphasis on patient feedback must not exclude them by default. With care this can be addressed – for example by careful phrasing of surveys and tailored use of technology.

The same is true for other groups subject to health inequalities – black and minority ethnic groups, the elderly, the economically disadvantaged, those with substance misuse or mental health problems, travellers, migrants and sex workers – all may have significant and specific health needs, but be less able to access information resources, unless sustained efforts are made to direct those resources to them.

With regards to sustainability, it should be recognised that, in the great majority of cases, access to electronic information will be ‘as well as’, rather than ‘instead of’ use of the conventional face-to-face consultations, and on the whole GPs would not wish to see it be otherwise. The NHS should retain its human face, but use the opportunities of technology to improve the quality of, and access to care.

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?

The will to implement these proposals will be critical – there needs to be a clear chain of responsibility, from the local to the central, to ensure that these changes actually happen.

As argued above, proposals must be implemented fairly and efficiently and with a constant view to patient confidentiality – they depend on the ‘buy-in’ of so many staff within the NHS, and so many service users. If they are perceived to be unfair, or to generate data for data’s sake, or to be unsafe, they may well not succeed.

One issue that has not been raised at all is the potential impact of these proposals in border areas, between England and Scotland and England and Wales, where primary and secondary care may have to deal with multiple systems of referral.
12. We gratefully acknowledge the many contributions of College members, and in particular members of the College Council, our Patient Partnership Group, Health Informatics Group and Rural Forum in formulating this response.

Yours sincerely

Professor Amanda Howe
Honorary Secretary of Council
Appendix: The RCGP and the White Paper – a Framework for our Response

1. Background

The Government published its White Paper on its plans for the NHS, ‘Equity and excellence: Liberating the NHS’ in July. Following on from the publication of this document, four further consultation documents were released. These are:

- Commissioning for patients
- Transparency in outcomes – a framework for the NHS
- Increasing democratic legitimacy in health
- Regulating healthcare providers.

There is an obvious challenge for the RCGP as a UK wide body, as the current White Paper specifically applies to the NHS in England. However, Council on September 10th 2010 agreed that the RCGP should debate the implications, and should respond to the consultation with a constructive critique from all countries and Faculties to reflect members’ concerns to the government, in a way which will maximally influence their eventual policy implementation. Further testing of membership views up till the close of the consultation, will form the basis of our written and verbal efforts over the next period to influence the definitive outputs of this policy challenge.

This Framework is based on an overview of members’ responses, set in the context of the College’s vision, purpose, values and priorities. We have used these to evaluate whether the reforms proposed are likely to enhance or jeopardise our core values, which are that:

- We protect the principle of holistic generalist care which is integrated around the needs of and partnership with patients
- We are committed to equitable access to, and delivery of, high quality and effective primary healthcare for all.
- We are committed to the theoretical and practical development of general practice.

2. Consultation responses

The largest numbers of comments grouped around the following issues.

2.1 Opportunities for:

i. greater influence by GPs on patient care and health services, through direct leadership and greater input to the Department of Health;
ii. overall benefits to patients if instigated effectively;
iii. better use of local knowledge for appropriate resource allocation and strategic planning;
iv. streamlining resource use, less wastage and duplication;
v. a crucial role for the RCGP in setting standards, leading by example, sharing good practice, disseminating information, setting standards for clinical pathways and
services (in collaboration with other Royal Colleges) and providing training to skill members up for leadership and commissioning.

Other opportunities flagged by senior officers include the opportunity to work more closely with local government, joining up with social care and public health; delivering even better education and training for nurses and for GPs – including extending the period of GP training to deliver GPs with appropriate knowledge and skills; and potential for better workforce planning. Council emphasised real opportunities to work more closely with patients, and to develop stronger links with colleagues in specialist practice.

2.2 Concerns

There were many queries about the lack of detail of how the reforms might impact on services and the workload for practices, and a significant numbers of comments on the risks of these reforms to the NHS in England, as follows:

vi. Rather than efficiency savings, both financial and human resources would be diverted away from clinical care and quality improvement into issues around commissioning and resource management. The extent and speed of the reforms risk destabilising both the interpersonal relationships and economic basis of local health economies at primary and secondary care level.

vii. Local diversification will be likely to increase rather than reduce health inequalities.

viii. GPs will be seen as the purse-holders: this could reduce public trust and decrease their ability to advocate for patients, and they will be blamed for failures and cuts in services.

ix. Many GPs currently lack time, skills and capacity for commissioning – this will need addressing urgently.

x. The reforms open a door to increased involvement of the for-profit private sector in the NHS, and tax payers’ money will be diverted into private companies and their shareholders. This could be seen as the break up of the NHS with some private companies ready to take over the provision of services.

xi. The reforms take the health service in England further away from the health services in the other UK countries, although the training for GPs remains the same.

3. RCGP Council Debate

In the light of these findings, and of the content of the proposed reforms, Council had an extensive debate which is reflected in the following statement:

“The Royal College of General Practitioners exists ‘To encourage, foster and maintain the highest possible standards in general medical practice, and for that purpose to take or join with others in taking any steps consistent with the charitable nature of that object which may assist towards the same’. We are committed to equitable access to, and delivery of, high quality and effective primary healthcare for all: and to protecting the principle of holistic generalist care which is integrated around the needs of and partnership with patients. We are an independent professional body with enormous expertise in patient – centred generalist clinical care. We shall make every effort to influence the outcomes of these reforms in a way that reflects the core principles of excellent general practice, which has already been shown in international research to be highly effective and efficient.”
We note the opening paragraphs of ‘Liberating the NHS’:-

- “The Government upholds the values and principles of the NHS: of a comprehensive service, available to all, free at the point of use and based on clinical need, not the ability to pay.

- We will increase health spending in real terms in each year of this Parliament.

- Our goal is an NHS which achieves results that are amongst the best in the world”.

In principle, the RCGP welcomes all opportunities which bring the expertise of GPs into effective roles for developing and improving services that meet the needs of our patients. We also welcome initiatives which allow a more effective patient and public voice within the NHS and those which enable people to play a greater part in society; that includes overcoming health inequalities. We believe that GPs can assist in the effective and efficient use of NHS resources, and wish to play an active role in reducing waste and duplicated effort. We accept the need to plan and deliver our services according to evidence based outcomes and public health needs.

GPs already have strong partnerships with other clinical specialities, and the possibilities for more collaborative commissioning and integration of clinical care are welcome. We value the expertise of effective management and want to retain this for the NHS. We also welcome the emphasis on a stronger patient voice, and any ways in which we can improve health outcomes, especially for those disadvantaged by personal and socioeconomic circumstances.

However, some of our members are not convinced that the scale of the changes proposed is justifiable, especially in the context of cost reductions. They are concerned that the proposed scale, pace and cost of change will prove disruptive; and that the proposed reforms may not achieve the stated aims because they will divert effort, costs and human resources into complex commissioning and local decision making. Some members are also concerned that GPs will be held responsible for shortcomings in services, and that this will disrupt public trust in the crucial doctor-patient relationship which underpins effective uptake of services and clinical interventions. Fundamental to those members’ concerns was that the ability of the NHS to provide a high quality service should not be jeopardised by irreversible changes to the infrastructure of the NHS, including imperatives to offer choice and an increased dependency on private providers.

Other members, particularly at the start of their careers, welcomed the opportunities for increased potential to influence services to patients and the wider community.

4. Next Steps

We have consulted with our members on the White Paper and supporting documents and will continue to do so. We shall respond in detail to these by the deadlines, and will include there the many other points already made by members and Faculties, and debated at Council. In particular, we shall highlight the need for the government to provide clearer details on how these reforms will reduce rather than exacerbate health inequalities, as the existing evidence base on commissioning suggest there is little impact on inequalities, and increased local variability can lead to disadvantaged populations being further marginalised.
We shall also emphasise our concerns about the diversion of GPs away from clinical work into managerial and leadership roles, and the long-term implications for workforce capacity of these new roles. We expect that we shall be involved in further discussions with government, and that our views and concerns will be taken into account.

Whatever the outcome of the consultation, we shall uphold our values, work closely with patients, other health professionals, and other Colleges to retain and develop excellent primary care for all. We shall offer leadership and guidance to members as they seek to deal with the consequences of the NHS reforms. We shall also provide guidance, education and training opportunities, and ensure the sharing of good practice to assist our members to develop the necessary skills to lead effective clinical primary care within the context of GP consortia and commissioning groups if these pass into law.