Royal College of Psychiatrists
Consultation Response

DATE: 14th January 2011

RESPONSE OF: THE ROYAL COLLEGE OF PSYCHIATRISTS

RESPONSE TO: Liberating the NHS: An information revolution

The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and is the professional and educational organisation for doctors specialising in psychiatry.

We are pleased to respond to this consultation. The lead author(s) for this consultation were Dr Joe McDonald and the Service Users and Carers forum. The consultation was prepared by Richard Meier from the College Policy Unit.

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Draft response to Liberating the NHS: An information revolution

Consultation questions – Chapter 1

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

The system of manually kept records currently works well. They are required to be detailed, particularly in a mental health setting; should an untoward incident occur (suicide or harm to others in the community) such records are vital for use at Coroners Court or a Criminal Trial.

The following are areas where improvements could be made:

- Patients and carers should be provided with telephone numbers in order that they can make immediate contact with hospital/secondary care services if they need to.
- The use of telephone or text reminders to people regarding appointments should be increased. However, punitive measures when people don't make an appointment are counterproductive and inappropriate and should be avoided.
- Since professionals are often communicating complicated, emotionally-laden information that is unfamiliar to patients, there is a need that they become more sophisticated in the way in which they provide information. Research into the communication of information in mental health services is scant, and the College would welcome greater research focus on this area.
- Too often patients are sent appointment letters starting that they have an appointment to see a healthcare professional but which contain no, or little, explanation of who the healthcare professional is, what might happen next or what the consultation might be like. Such paucity of information is particularly of concern to people experiencing mental ill health, and services should do more to prevent people who are

experiencing great distress or who are at the greatest point of crisis having to deal with such uncertainty in regards to their own care.

- An increasing proportion of data collected adds little to the quality of patient care, either being defensive in protecting Trusts from charges of negligence, or collecting outcome data of dubious validity. This ultimately detracts from the quality of care as less time is available for assessment, treatment and communication. Any data collected should be demonstrably worth the time this takes away from direct patient care.
- Much of the duplication in information requirements from patients and carers is due to inadequate joining up of information systems between primary and secondary care and between health and social care. Greater focus is required on these interfaces.
- In order to avoid duplication in administration time, electronic patient records need to be available at patients' homes and off-site from a main hospital's information system. This requires hardware and communication networks to be improved.

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

One of the most important uses of information is to inform clinicians, patients and carers about treatment options and the quality of available services.

While we welcome the general thrust of the proposals contained in this consultation, we fear that professionals' need for information about the quality and range of services available for carers and service users, whether provided within or outside of the NHS, has been somewhat overlooked.

Q3: Does the description of the information revolution capture all the important elements of the information system?

The description of the information revolution is of a process. However, a key element of whether such a process will work effectively and efficiently is the quality of information recording undertaken by numerous staff at a variety of levels and abilities; at present, there is no real discussion in this section of this process whereby information, especially from service users and carers, is to be gathered and processed. A description of the information revolution which does not explicitly reflect the need for training of staff in information recording, and the monitoring of the quality of information recording, runs the risk that systems and processes will be put in place which allow for important information not be recorded in the detail that is required; or that important information is lost amongst a vast amount of less relevant information. The implications for patient safety in this respect are considerable.

The description also focuses exclusively on patients' care records being the primary source of data; however, patient-reported outcome measures and views from external bodies are important potential sources of information.

Is it beyond the scope of this question to query how the data will be abstracted from different forms of data collection in different systems by different organisations to allow comparisons without a national detailed template for every specialty produced centrally?

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?

It will be extremely difficult in the current financial climate to achieve the revolution in information set out in the document, not least because the

systems for collecting that information are currently non-existent in large parts of the country.

See also our response to question 5.

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

- On the development and wider use of standardised patient satisfaction measures.
- On providing the necessary resources to ensure that adequate systems and incentives are in place to produce reliable data at the point of entry, in care plans and in care records, and for the regular updating of as and when appropriate
- On addressing the fact that practitioners need to be allowed the time to work with service users and carers collaboratively to produce care plans; this aspect of the proposed revolution – the effect on practitioners' activities – is somewhat overlooked in the document.
- On connecting the existing social care, primary and secondary care record systems.

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?

Having total access to their care record will enable service users to see what is recorded about them and 'challenge' anything they feel is incorrect or has been misunderstood.

The bringing together of records might begin to address the situation whereby people who live with mental health problems tend to have less access to treatment for physical health problems.

However, service users and carers have strong concerns about the lack of security and possibilities of abuse from electronic care records systems. In light of well-publicised, recent data confidentiality breaches by Government departments, the public remain justifiably concerned about who else might access information (e.g. insurance companies, finance providers etc.). There are real concerns about information in records that it might not be appropriate for the carer to see – such as personal information relating to a relative or carer. The issue is mentioned in the consultation as 'as exception', but within the area of mental health it is a genuine and general concern for family members and we would want to see specific safeguards spelt out in order to address this issue.

There are also occasions when health and social care professionals want to share thoughts (hunches about potential risks of abuse for example) that would be to the detriment of patient well-being were they to be transparently available.

Service users who have made Advance Directives will benefit from this being noted on their care records since they will therefore have a degree of assurance that their wishes will be known to practitioners and services caring for them.

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?

Being able to communicate with doctor and other health care professionals on-line has the potential to facilitate routine communication concerning

medication, appointments etc. and perhaps less routine communication. Service users who feel that they are becoming unwell may find it beneficial to be able to communicate with their GP and other health and care professionals online.

Online communication could also contribute to the development of greater egalitarianism in the health service since access and communication are often used as barriers that reinforce differential power relations. However, a system in which emails are not responded to (by an individual rather than by an automated response) has the potential to exacerbate patients' mental health problems. The Government is keen to increase patients and service users control over their experience of health and social care services, and it will be important that system overload – which is a not unlikely outcome, especially if e-communication proves very popular with patients and service users – is avoided. It will also be important to clarify who will read e-communications and what systems are required to ensure that such communications are read and responded to in a safe and timely manner.

Notwithstanding the above, however, face-to-face contact is important for many reasons, not least, the therapeutic relationship. Furthermore, many people do not have access to a computer, and/or may find e-communication problematic due to literacy or language difficulties. The preference for either face-to-face or electronic contact is very much an individual matter and arrangements should be worked out collaboratively between the service user and the service provider.

It will also be important not to underestimate the potential for hugely increasing the administrative burden on clinicians should they start to receive queries by email about all aspects of patient care.

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.

There is little threat to health and social care professionals of patients having direct access to their own records, but the risks to loss of confidentiality and third party information are considerable.

See also response to question 6.

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

- Face to face, or telephone, contact with a health professional rather than electronic or printed material, when this is wanted by patients or service users.
- While the provision of electronic or printed material may be useful and welcome in certain circumstances, services should not see such provision as an end in itself, but rather should follow-up those provided with information to see if it has been effective in reducing stress and anxiety – and offer alternatives if it has not helped.

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?

Information about individual teams rather than only at a trust-wide level; information conveyed directly to the service user and carer by a consultant; evidence-based information, and information concerning best practice, such as is available from the Royal College of Psychiatrists, mental health charities and NICE guidelines.

Local databases of services available across health, social care and the third sector.

As a general point, the College is uneasy about the appropriateness to health and social care of the analogy – contained in 1.2 – regarding rapid price comparison of electricity providers. The prospect of health and social care providers (from independent, statutory and voluntary sectors) cold-calling patients, carers and service users to persuade them to switch their care to another provider is a bleak scenario. The ability to switch between providers whilst important in increasing competition amongst providers would be unlikely to improve continuity which is valued in the context of therapeutic relationships between patients and clinicians.

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?

See response to question 1. In addition, we believe that information should be available regarding the outcomes achieved by individual healthcare professionals.

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

- Information particular to carers would include information on carers' rights, about confidentiality and its limits, benefits, separate peer and other support groups, advocacy services, as well information and

training in how best to contribute to the recovery of the person they care for.

- The range of services available to support themselves and the person they care for, and a named individual who will help them navigate their way through these resources.

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?

Information about where to access training – such as the Expert Patient Programme – as well as contact details for support networks, in order to be better able to self-care.

Information regarding means of contacting health professionals – without having to go through centralised primary care hubs or through GP surgeries – should problems arise with self-care or when patients feel that self-care is no longer their preferred option.

An electronic NHS condition management website that holds information on mental and physical conditions.

The cost-benefit implications of different interventions – for example telecare and the need for social care.

Information sources that are tailored to the needs of people with reduced mental capacity.

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?

Patient satisfaction, patient-identified goals, social outcomes (e.g. employment and housing) and symptom improvement, together with patient safety measures.

Q15: What additional information about outcomes would be helpful for you?

Clinical and quality outcomes from local services with regional, national and even global comparisons.

Service user and carer feedback, service user reported outcomes, service user and carer assessments, and experience records.

Comparable data on outcomes regarding different mental health disorders.

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?

Seamless and joined up information has to be weighed against the confidentiality needs of the patient, and this is a difficult balance to strike. Such availability of information could potentially lead to great improvements in patient care and reduced duplication by different organisations, but is a huge undertaking an almost certainly beyond any government to achieve. Ultimately the solution is a technological one, though would also require great coordination from the centre that appears to be against the thrust of the strategy.

It is essential that robust and effective arrangements are in place for patient consent and or pseudonymisation for any proposed use or disclosure of patient information for all NHS purposes not directly related to the care of that individual. Valid consent arrangements should normally be required for remote access to a patient's records, for example the Summary Care Record, for direct care.

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

- People with mental health problems (including those with dementia)
- People with learning disabilities
- People who misuse substances
- People with dual diagnosis or multiple morbidity
- People with mental health problems who have physical health problems
- People with physical health problems who have mental health problems
- Young people involved with child and adolescent mental health services who are moving to the care of adult mental health services
- People involved with working age mental health services who are moving to the care of older people's mental health services

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

The approach is a good one as it enables comparison across all services; it will also facilitate the comparison of outcomes of specific illness and identify which areas are outperforming others.

We support the collection of the Mental Health Minimum Dataset.

A problem in Old Age psychiatry is the lack of data that is being collected that can be used centrally, as reported in The Healthcare Commission's report 'Equality in later life'.

The issue may therefore be much more about improving the range and quality of information that is not yet collected.

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

Through the analysis of patient satisfaction and patient reported outcome measures being used to support change and improvement.

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

An NHS version of feedback/ratings websites would result in more feedback from families and carers.

Development of service user and carer fora; the proposed local HealthWatch bodies might be a valuable source of feedback from service users and carers. Developing an equivalent in mental health to Maternity Service Liaison Committees might also be a useful way of encouraging meaningful feedback from those using services.

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 with a number of the questions in this consultation, this covers such an enormous area that it is impossible to do justice to the question in the space

(and timeframe) allowed. However, as a general principle, holding services to account for the outcomes they deliver (whether through bodies such as the National Commissioning Board and Care Quality Commission) will be a powerful incentive in making them more responsive to feedback.

In addition, Trusts should be encouraged to use innovative approaches (such as having service users act as 'mystery shoppers') and to commit to report feedback from service users at Trust Board Level.

Furthermore, the NHS needs quality IT systems which allow rapid feedback, and these are not yet in place.

NHS services and staff are hindered by having little incentive to improve care and often perverse incentives to keep care at the minimum quality required. More time should be devoted to considering carrots rather than sticks.

A culture of seeking consent and the recording of consent for any proposed use of patient identifiable information needs to be encouraged through training , professional development and incentives such as the Quality and Outcomes Framework and the development of information standards.

Q22: Which questions, if asked consistently, would provide useful information to help you compare and choose services?

Questions which elicit data on the following areas:

- Staff/patient ratio at all levels of skill-mix
- Skills and experience of staff
- Clinical and quality outcomes
- Results of any external investigations or inspections, as well as internal audits
- Whether services have been accredited, for example by the National Accreditation Systems run by the Royal College of Psychiatrists

- Therapeutic activities on wards
- Recent history of drug prescribing, kinds of drugs and whether prescribing drugs is increasing or decreasing, proportionately
- Whether there is protected time for therapeutic work and is it used effectively
- Caseload of community mental health staff
- Range of services available for carers
- Range of treatments available
- Range of follow-up services available
- Quality of environments
- Waiting time for first appointment
- Number of untoward incidents – adjusted according to patient complexity
- Number and content of compliments/complaints
- Staff turnover
- CQC rating.

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?

The involvement of Royal Colleges, amongst others, to advise on appropriate, specialty-specific, outcomes measures.

The involvement of clinicians in the development of systems is vital to their future usefulness.

Health and well-being boards will have to be adequately resourced – financially and in terms of expertise – in order to carry out their duties with regard to JSNA effectively.

Management budgets for GP consortia will have to be sufficient to allow for adequate assessment of patient population need.

This will have to be centrally directed to allow adequate / meaningful comparisons to be made for intelligent commissioning.

The highest standards of Information Governance, including appropriate security provision and monitoring, are essential for public confidence in permitting the use of their information for their care or for essential public health and NHS management purposes.

Consultation questions – 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?

Support staff in the practicalities of data collection – for example avoiding duplication or parallel running of paper and electronic records. Incentivise good performance rather than just penalising poor performance.

Training will need to start in medical schools and the development of medical informatics as a specialty needs to be supported in the same way that other new sciences have been supported in the past.

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?

It is relatively easy to obtain evidence of the best possible care using the internet but as yet there is no good decision support software linked to clinical systems.

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?

Providing increased time per patient (but thereby reducing productivity).

Q27: What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?

Every healthcare organisation should have a clinician with dedicated time and support for informatics and IT.

Consultation questions – 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 opportunity will exist for a more open dialogue between the care professional and the service user.

Care plans can be checked to see if they reflect the participation of the carer as partner in care.

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

Patients, carers and clinicians may have concerns that the collection of data may become an end in itself, rather than as a tool to inform the commissioning and delivery of health and social care services.

It will be important that systems are in place to ensure that any focus on large-scale data collection does not result in a lack of responsiveness to individual patients' needs.

Furthermore, there should be adequate resources available to train healthcare professionals in the collection of data and to ensure that this activity is incorporated as seamlessly as possible into clinical practice rather than disrupting or supplanting usual clinical practice.

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 is a danger that such large amounts of data of variable quality will be used for media purposes whose interest is in an interesting story rather than a factually accurate representation of the true picture in complex health and social care issues.

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 cannot 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.

- There is a significant risk that the information revolution may potentially increase the discrimination against patients who are most mentally ill as some will be unable to use the opportunities that such changes would bring and there could thus be an inappropriate shift of focus and perhaps even resources to the more IT competent and articulate patients. Preventing this potential perverse outcome would cost money.
- Support to develop patients' and carers' IT capabilities. For carers, this could be proactively offered in the context of carer assessments, and it could be promoted in all service user venues and meetings.
- The innovative use of IT, such as healthcare professionals treating people in the community being provided with laptops and portable printers.
- Development of the mental health advocacy system could obviate some of the problems identified in this question.

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?

Anonymised data from the Mental Health Minimum Dataset. However, the interpretation and presentation of statistical data is a highly complex area. How will the Government ensure that data is presented in a way that is useful and meaningful to patients, carers and clinicians?

Consultation questions – 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?

Although there are overall benefits in having access to accurate data and reducing duplication, there are also (often over-looked) considerable additional administration required of clinicians to maintain electronic systems that reduce productivity. These should be assessed in pilots.

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 greatest challenge, though also the greatest potential benefit, will be in integrating data across health and social care, and primary and secondary care.

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