The Go-Between would like to hear from potential contributors. Articles should be on health informatics related matters and around 250-400 words in length. Copy deadline for Issue 112 is 20 May 2013.

For contributions etc. please write to the Editor (address on back page).

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Mental Health Records On-Line

The Access to Health Records Act (1990) granted patients the statutory right to have access to their health records. Subject to certain safeguards, patients were allowed to see their own health records made after this date and earlier records if they were necessary to understand the later ones. The Data Protection Act (1998) permits access to all health records whenever made, subject to specified exceptions.

People with mental health conditions find the sharing of health records to be acceptable and useful (Essex et al, 1990) yet progress in enabling such approaches to become mainstream practice have been very slow. In a review of patient held records in mental health services (Laugharne & Stafford, 1996) patients generally found their notes useful, informative and felt they increased their autonomy.

The NHS Mandate (Department of Health, 2012) states that the Government expects by March 2015 that everyone who wishes to will be able to get online access to their own health records held by their GP. There is also the expectation that clear plans will be in place to enable secure linking of these electronic health and care records wherever they are held.

Miles Rinaldi and Claire Philpin recently undertook a survey to gain an understanding of the attitudes of psychiatrists in SW London, in terms of the impact of the commitment to make GP records accessible online to patients by 2015, as the attitudes of psychiatrists were not known.

The response rate was 57%. (n=123) Just under a third of psychiatrists were aware of the Government’s commitment to make GP records accessible online to patients by 2015. Yet, when asked as to whether they will choose to exercise their right to access their own health records 63% said they would. A third of psychiatrists were uncertain in their confidence in exercising their discretion to restrict a patient from accessing part of their medical record and, only 35% of psychiatrists thought that patient care would be improved by patients having online access to their GP health records.

Of the psychiatrists that said patient care would not be improved, 53% also thought they may omit certain information from the notes whereas, 58% of psychiatrists that predicted improvements in patient care felt that they would not change their current practice. Significant differences were found between grades of psychiatrists and length of time as a doctor.

Conclusions

The attitudes of psychiatrists reflect the practical conflict between increasing transparency and accountability between doctors and patients, balanced against omitting information from notes which might lead to a lack of transparency and potentially driving some information sharing becoming ‘off record’. There are examples in England where patients are already managing their own personal health records – an online record owned by the patient, allowing them to add and organise personal health information, as well as to integrate health records from different providers, and share this with other individuals and institutions at will.

Accessing health records online requires behavioural change for both clinicians and patients. For clinicians uptake rests on a change in culture and mindset around recovery focused practice, shared care, supporting self-management, and shared decision-making.

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Tweeting in primary care? – see page 2
The use of social media is becoming widespread. Organisations are looking at alternative means of engaging with their clients, customers, members, patrons etc. So what about primary care?

The Royal College of General Practice has produced a Social Media Highway Code based on the following principles:
- Be aware of the image you present online and manage this proactively
- Recognise that the personal and professional can’t always be separated
- Engage with the public but be cautious of giving personal advice
- Respect the privacy of all patients, especially the vulnerable
- Show your human side, but maintain professional boundaries
- Contribute your expertise, insights and experience
- Treat others with consideration, politeness and respect
- Remember that other people may be watching you
- Support your colleagues and intervene when necessary
- Test out innovative ideas, learn from mistakes – and have fun!

Lesley Foote and Helen Simpson report on their experience at Ealing Park Health Centre.

In an effort to reach out to some of our younger, hip, or just generally nerdy patients, one of my GP partners thought we should try social networking to promote Ealing Park Health Centre as a progressive patient-centred organisation. We decided to start tweeting. I was a Twitter novice. In researching what needed to be done, West Middlesex University Hospital Communications lead was particularly helpful. They started tweeting and re-tweeting a few years ago, and gave us some good advice.

The number one rule is to build up your following, he said, by promoting your new service, nurturing followers, and finding the right people or organisations to “follow”. Any adverse comments from people should be treated with respect, he said. There is not much joy in trying to get anything removed from Twitter, so best to counteract any negative comments or suggest that the badly-treated tweeter contacts you direct to discuss an issue. Following his advice a quick policy was written with guidelines on what we should include and what not to - the obvious such as no personal comments, nothing about individuals. We wanted to use Twitter to promote our own services and general healthy lifestyle messages.

The only other GPs I have found on Twitter so far are the celebrities such as Dr Hammond, and a few politically minded individuals speaking for themselves, not their practices. One of our Patient Participation Group members was horrified when I said we were going to tweet. She said she thought we should be doing more important things like caring for patients. I disagree. Practice managers have to diversify. In this brave new world GP practices are going to be competing for patients, and we need to be engaging people in all the different ways on offer. Technology is moving so fast. E-mailing and texting patients have become run of the mill. Patients love to be able to order a repeat prescription by email, to get a text appointment reminder, or book an appointment with a doctor of their choice on-line. So why not start on Twitter.

Progress is slow. We are into our third week @EPHC_W5 and have 6 followers so far. But great news today - our first patient follower!!

Now to think of some interesting and pertinent things to say in less than 140 characters.


Paperless Referrals

The NHS should go paperless by 2018 to save billions, improve services and help meet the challenges of an ageing population, Health Secretary Jeremy Hunt said in a speech back in January.

On the way towards this 2018 goal, the Health Secretary wants to see:
- By March 2015 - everyone who wishes will be able to get online access to their own health records held by their GP.
- Adoption of paperless referrals - instead of sending a letter to the hospital when referring a patient to hospital, the GP can send an email instead.
- Clear plans in place to enable secure linking of these electronic health and care records wherever they are held, so there is as complete a record as possible of the care someone receives.
- Clear plans in place for those records to be able to follow individuals, with their consent, to any part of the NHS or social care system.

By April 2018 - digital information to be fully available across NHS and social care services, barring any individual opt outs.

Whilst the Choose and Book service enables referral letters to be sent electronically not all referrals are via the Choose and Book service: there are referrals from education, to and from social care, and between secondary and tertiary services.

Sending a document electronically – typing, converting to pdf (portable document format) or scanning before onward transmission – whilst “electronic” and improving communications is not true seamless working. Receiving a pdf document will usually require the recipient to re-key data potentially causing unnecessary delays, possible transcription errors and an opportunity for efficiency savings. Integration engines and portal technology are available and developing. So may be the goal of lean seamless electronic referral (and discharge) processes are now within grasp.


Caldicott Review

Dame Fiona Caldicott has concluded her second review of information governance in health and social care. On 26 April the Report “Information to Share or Not to Share” was published.

People using health and social care services are entitled to expect that their personal information will remain confidential; feeling able to discuss sensitive matters with a doctor, nurse or social worker without fear that the information may be improperly disclosed. These services
cannot work effectively without trust and trust depends on confidentiality.

However, there is also an expectation that professionals share information with other members of the care team, who need to co-operate to provide a seamless, integrated service. Good sharing of information, when sharing is appropriate, is as important as maintaining confidentiality.

In 1997 the Review of the Uses of Patient-Identifiable Information, chaired by Dame Fiona Caldicott, devised six general principles of information governance that could be used by all NHS organisations with access to patient information. The principles have stood the test of time, however, over recent years there has been a growing perception that information governance was being cited as an impediment to sharing information, even when sharing would have been in the patient’s best interests. In January 2012 the NHS Future Forum work stream on information identified this as an issue and recommended a review “to ensure that there is an appropriate balance between the protection of patient information and the use and sharing of information to improve patient care”.

The Review considered issues around people’s lack of access to their own records, which can often impedes care and recovery. Caldicott recommends that all communications between different health and social care teams should be copied to the patient or service user. There should be ‘no surprises’ for the patient about who has had access.

A target in The Power of Information – the Department of Health’s Information Strategy – said people’s access to their care records should be improved, with individuals gaining electronic access to their own care records where they request it, starting with GP records by 2015 and social care records as soon as IT systems allow. The Review thinks this right of access should cover hospital records, community records and personal confidential data held by all organisations within the health and social care system. It believes that access should become available within the next decade.

Caldicott also recommends that an audit trail of everyone who has accessed a patient’s personal confidential data should be made available in a suitable form to patients via their health and social care records.

The Review found that when it comes to sharing information, a culture of anxiety can permeate the health and social care sector. Managers, who are fearful that their organisations may be fined for breaching data protection laws, are inclined to set unduly restrictive rules for information governance. Front-line professionals, who are fearful of breaking those rules, do not co-operate with each other as much as they would like by sharing information in the interests of patients and service users. There can often be a lack of trust between the NHS and local authorities and between public and private providers due to perceived and actual differences in information governance practice.

The Review found a strong consensus of support among professionals and the public that safe and appropriate sharing in the interests of the individual’s direct care should be the rule, not the exception. It also looked at the problem confronting staff who have to distinguish between an individual such as a relative legitimately seeking information about a patient’s progress and a person making improper inquiries. It recommends protocols to assist in good decision making and procedures for informing and helping people if mistakes are made.

The Caldicott Review sets out how the use of personal confidential data for clinical audit can be managed within the law.

In the 12 months to the end of June 2012, there were 186 serious personal data breaches were notified to the Department of Health. Most involved the loss or theft of data, but almost one-third concerned unauthorised disclosures. The Report states that there should be a standard severity scale for breaches agreed across the whole of the health and social care system. The board or equivalent body of every organisation in the health and social care system should publish all such data breaches, as part of the quality report in NHS organisations or as part of the annual report or performance report in non-NHS organisations.

Consideration is also given to the implication for data security of people’s increasing use of social media. Although not changing any principles of confidentiality, there may be a need for greater vigilance among health and social care professionals as they switch from the personal side of their lives to the professional side.

More information:

care.data

In March the NHS England (formerly the NHS Commissioning Board) announced the creation of the care.data programme. Over the course of the next few years, NHS England will establish a new, modern data system for the NHS in England: care.data, its purpose will be to provide timely, accurate information to citizens, clinicians and commissioners about the treatments and care provided by the health service.

The aims of care.data are six-fold: first, to support patients’ choice; second, to advance customer services; third, to promote greater transparency; fourth, to improve outcomes; fifth, to increase accountability; and finally, to drive economic growth. The underlying data within care.data will all be collected as part of the care process. For the first time, these data will be linked for all patients nationwide along the entire continuum of care.

Hospital Episode Statistics (HES) have long been the backbone of hospital reported activity dating back to the 1980s. But HES is limited in scope and now seems dated. A key element of care.data will be Care Episode Statistics (CES), which will provide commissioners with data from across primary, secondary and tertiary care, as well as community health services and social care.

Since most NHS consultations occur in primary care, it is vital that data from GP systems be incorporated as soon as possible. One of the first goals of care.data, therefore, will be to expand HES so that it becomes Care Episode Statistics (CES). This expansion will ensure that commissioners can obtain a more complete and balanced picture of the care being delivered to NHS patients, since the information will now be linked across primary and secondary care. An analysis of linked data is essential for commissioning integrated care, which in turn is essential for reducing fragmentation in the NHS. The first new building block of the care.data service will be the inclusion within CES of primary care data drawn from GP practices.

A data set will be developed with the help of clinical commissioners. The data set will be requested from GP practices for submission to the Health and Social Care
Information Centre, via the statutory safe haven. The patient identifiable components will not be released outside the safe haven except as permitted by the Data Protection Act. GP Practices will be able to provide the data utilising the centrally funded and secure General Practice Extraction Service (GPES).

care.data is expected to deliver the following benefits:
- Improved monitoring of outcomes through linkage between primary and secondary care
- Improved monitoring of performance through linkage between primary and secondary care
- Earlier diagnosis of illness through the identification of the number of patients with secondary care activity for a disease recorded in QOF
- Improving the contribution of primary care to wider outcomes
- Improved data quality
- Monitoring and understanding trends
- Predictive modelling
- Evaluation of preventive services and interventions
- Analyses of variation.

More information:

News in Brief

Proposal to Extend IC Powers

The Ministry of Justice has launched a public consultation on extending the Information Commissioner’s powers to enable him to carry out mandatory audits of organisational compliance with the Data Protection Act 1998. Responses must be received by 17 May 2013. Proposed powers include Information Commissioner: to access any premises; to inspect and copy information and documentation; and to observe the processing of any personal data. See: https://consult.justice.gov.uk/digital-communications/ico-assessment-notices.

Information Economy Strategy

The Government has set out a vision for the future of British industry and committed to a long term, strategic partnership with industry. The Information Economy is one of 11 sectors where partnerships are being developed, with the following aims:
- Be long-term in focus: developing a vision for the sector and what needs to happen from both Government and business to get there
- Be co-created with industry: committing both business and Government to specific actions to maintain and develop long-term capabilities
- Take a ‘whole of Government’ approach: looking across all of Government to identify barriers and levers which have the biggest impacts and align these to deliver growth
- Engage across the totality of the sector: working with industry and identifying actions which benefit businesses across the whole supply chain whether they are large, medium or small

The Information Economy Strategy is due to be published in May 2013. This call for evidence is one of several means of dialogue with industry suppliers and users as part of preparation for the strategy.

Primary Care Info 2013

This year’s Primary Care Information Conference takes place on 5 and 6 June at Cheltenham Race Course. Subtitled “Waving Not Drowning in the IT Pool” the event is for anyone with an interest in primary health care data systems and information management. Discounted rate for BCS Members. See: http://www.phcsq.org/prices-and-on-line-booking/

A&E Indicators

The Health and Social Care Information Centre (IC) recently published Provisional Accident and Emergency Quality Indicators for England, experimental statistics by provider for December 2012. The report includes:
- Left department before being seen for treatment rate
- Re-attendance rate
- Time to initial assessment
- Time to treatment
- Total time in A&E

See: http://www.hscic.gov.uk/catalogue/PUB10740

Mental Health to link to HES

The Health and Social Care Information Centre (HSCIC) is for the first time providing a linkage of the Mental Health Minimum Data Set (MMHDS) to Hospital Episode Statistics (HES), as directed by NHS England. This will enable the analyses of acute patient pathways for mental health service users in England, assess equality of access and identify opportunities for service improvement. Patient identifiers are removed and replaced with a pseudonym that protects the identity of individual patients but allows the records to be linked. See www.hscic.gov.uk/HESMHMDS.

Diary

8 May 13  BCS Sussex: “Where is the UK IT Industry Going?”, Sussex University
(https://events.bcs.org/book/643/)

(https://events.bcs.org/book/575/)

06 – 07  Primary Care Info 2013, Cheltenham Race Course
(http://www.phcsq.org/prices-and-on-line-booking/)

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