Introduction

The Annual American Medical Informatics Association Conference was held in Washington DC, from 6 to 10 November 1999. The conference title was "Transforming Health Care through Informatics - Cornerstones for a New Information Management Paradigm." With the exception of the keynote presentation and a few panel discussions, this topic was not generally reflected in the content of most presentations, but then this is often the case with this type of annual event. However, there were several interesting themes that provided a lot of food for thought, the most prominent being consumerism.

The conference had over 250 papers, panels and demonstrations, 45 tutorials, 200 posters, more than a dozen pre-conference evening workshops and a large exhibition of approximately 44 suppliers and organisations displaying a range of health IT related products. At the same time a special Cancer Informatics Tech Expo was held, sponsored by the National Cancer Institution.

The conference was well organised and the quality of the papers and the majority of presentations were good, although it was possible to recognise the more experienced speaker - but then we all have to learn! What was notably different about the conference was the willingness of the American delegates to ask the speakers questions and debate issues after most presentations. This compares with the European culture where 3 minutes of silence is observed when the chairman remarks "any questions"

The way technology seems to have infiltrated into every day tasks is a lot more noticeable in the USA than back home. Every advert or TV programme seemed to end with a web site address for more information. It may have something to do with the lower cost of surfing the Internet in USA.

People and Organisational Issues

Peter G.W Keen, a leading consultant and writer in information technology, gave an excellent keynote presentation. His message was "people, process and technology -
two out of three is not enough." He stressed the shift away from technology towards the consumer. He reminded us that in the past (or present for many of us) the personal computer has been the end point of the distribution of information. Now, however, many consumer appliances, eg mobile phones, are becoming the end point. This will help to make information-processing customer driven. Wireless appliances, for example, will allow information to reach people in any way they choose. Information itself is the commodity. This idea is reinforced by the fact that, in order to woo customers, companies are giving away free appliances. "A free PC with every phone call", might have seemed a little suspect a few years ago.

Keen suggested that the Internet has changed the way we work and may even have invented the customer. In the past, information was controlled by the supplier. Customers are now the people who have the choices and the information to make those choices. In health care this can be seen by the shift of power away from the health care professionals to the patient. His message was "don't fight it"; every thing is becoming personal. The information paradigm is shifting away from information production to information sharing.

The paradigm shift was raised again during an interesting panel debate about connecting patients and physicians via the Web: "let’s put patients' medical records on the Internet and give them access." Patients could; request an appointment or ask a health professional a question, or even view the content of their medical record and view an audit trail of who else had viewed or change their record. The latter would certainly improve the accuracy of that record. There were, of course, lots of reasons put forward as to why this wasn't a good idea. What's the financial return on the investment? How will security and confidentiality be assured? Will making communication easier increase it? What will happen when the physician loses control? All these question had answers and the general view of both the panel and the audience was that access for patients was a good idea.

But what do patients think? The results of a survey indicated that while patients were generally very positive and felt it would make the doctor’s office more accessible, they too had concerns about security. A pilot of 200 patients linked to their physician's office via the Internet proved interesting. The doctor-patient emails resulted in 50% clinical questions and the other 50% administrative. This resulted, rather naturally, in a reduction in phone calls to the physicians' office. Patients however needed reminding not to use it for urgent needs as responses often took 3 or 4 days (Leavitt et al.).

An excellent panel session, entitled "People and Organisational Issues" included Patricia F Brennan. Brennan focused on the patient and outlined the difficulties patients have being patients in the information age. Patients used to know how to be patients - passive, now however they are expected to be SMART. Self assured, Motivated, Aware, Resourceful, and Talented (i.e. knowing what works and what doesn't). However while society is changing and the emphasis on consumerism may have been driven by patients there are still many around who haven't caught up. We were reminded that they are often Scared, Minors, Anxious, Reluctant and Terrified. SMART patients need patient centred systems. These will provide a clinical record, networked communication and consumer health informatics. The key issues of language, outcomes, accessibility and availability were highlighted.
Other panellists highlighted important issues. Dowling, referred to those left behind as the information have's and have not's. Peel emphasised the information paradigm shift by highlighting the necessity of the patient and professional partnership in the drive for change. Friedman, suggested that challenges for leaders in health care organisations were; staying focused, keeping up to date with the rapidly changing information technology scene, and the need to bridge the traditional cultures of professional, scientist, technical staff and managerial staff. As no leaders had all these skills they needed to be team leaders and recognise all four cultures to promote consensus. Unfortunately he missed out the most important culture, the patient culture (Kaplan et al.).

Primary Care Informatics

Another panel focused on Primary Care Informatics, with presentations from Canada, USA, Australia and Britain. The content of the latter was by far the most advanced. The other countries talked about national statistics, what should happen, and what couldn't happen and why (i.e. the reimbursement system for primary care physicians was a disincentive for health care - let alone information collection). Britain however described their IT strategy, its relevance to patients in primary care, and present usage of primary care computing. It was rather pointedly suggested by a member of the audience that the other countries needed a primary care strategy before they developed their IT strategy for Primary Care (Hausam).

Another panel session reported on usability studies in primary care informatics. The most interesting presentation was again from Britain and included the evaluation of Prodigy - a decision support system for drug prescribing in general practice. It was a good example of a clinically useful information system that GPs, if you could get them to use it the first instance, were pleasantly surprised at how useful it actually was. New decision support systems for chronic disease management were now being considered.

The lack of usage of IT in the USA and Canada in primary care was surprising, given the high profile of information technology. Reasons given included high cost, lack of computer literacy and confidentiality concerns. What can be done? Ziemkowski, one of the panel members suggested that ultimately software should be usable without training and described heuristic analysis (http://www.useit.com/papers/heuristic), involving or serving as an aid to learning, discovery or evaluation. This form of analysis asks the question, does the system look or act as expected? Ziemkowski suggested that this form of analysis could be a useful aid during system development. Usability tests included training required, learnability, efficiency, memorability, errors and satisfaction. (Mullins et al.)

Consumer Health Informatics

A topic that was well explored, particularly in papers, was consumer health informatics. Many papers described projects that were interesting, thoughtfully introduced and provided real health care benefits for a specific client or patient group. The key questions one must ask of consumer health informatics are: Do patients want it? Will patients use the information to benefit their health? What are the disadvantages? And last, but by no means least, how will consumer health informatics impact on patients relationship with health care professionals?
**Do patients want it?**

A number of papers suggested that patients were willing to make use of the growing consumer health information industry, but only certain groups of patients and when they perceived the information to be needed. This will limit its benefits until ways can be found to support those who do not or cannot use it.

The Medical College of Wisconsin created a consumer health information resource. This web site contained searchable articles on a variety of health topics and an e-mail newsletter. In its first six months it had 7,490 subscribers, over 200,000 page views were made per month, and the key cluster of topics chosen were 1. Arthritis/Backpain, 2. Cholesterol/Heart Disease/High Blood Pressure, 3. Heart Disease/High Blood Pressure/Stroke, 4. Weight Control/Womens Health (Barnas et al.).

One project described the use of email to deliver patients their A&E discharge summary and allow them to ask questions about follow-up management. The presenter challenged the audiences' assumptions by giving an example of where one anecdote was worth a thousand facts. The clinician involved in the project thought twice about offering the opportunity of sending a homeless patient and their child their discharge summary via email. They were amazed when the patient replied that they would like to receive it via email as they had been looking for an excuse to use the computer in the homeless person's shelter. (Mandl et al.).

Although expanding rapidly, until everyone has access, the Internet can only be one potential source of information. The National Cancer Institutions (NCI) Cancer Information Service (CIS) has, for several years, provided information and support, via the telephone, to cancer patients, their families, the general public, and health professionals. The information provided helps their understanding of disease, treatment options, and survivorship issues. In addition to the telephone service the institute has a website. This not only provides information on cancer issues but also has informed many callers of the existence of the CIS. In a 6 month period, 7% of callers to the CIS had learnt of its existence from the Web. While these may, or may not be, additional callers their profiles hold interesting clues to the type of person who uses the Internet and for what. The callers were; more likely to be family and friends of patients, less likely to be seeking information on prevention or risk factors, less likely to have a brief call with the information specialist answering their questions, less likely to have used CIS in the past, and more likely to be white, better educated and male (Fleisher et al.).

One paper, which described a study providing adolescents with access to an online support group, concluded that Internet TV set-top devices provided a feasible alternative to Web access for some patient groups. This however should be coupled with education and a dedicated television and phone line (Johnson et al.). A plea to provide affordable information to those less likely to use the technology was made in one paper which reported on a study, which examined cancer patient's use and satisfaction with a touch screen information system in Scotland. The study found younger broadsheet readers were more likely to find the system easy to use. Older tabloid readers were more likely to find the content new and relevant. They concluded more effort should be made to provide affordable information to older, generally less literate and technologically less literate groups in suitable locations (Pearson et al.). These are likely to be the people who need the health information more.
Will patients use the information to benefit their health?

One or two papers reported useful benefits from using the technology. One explored the relationship between lay conceptualisation of health and illness and how they translated this information into action and knowledge sources. It was recognised that treatments are more effective if received quickly and early consultation with health professionals is dependent on a patients' knowledge of symptoms and their likelihood of taking action based on that information. As experience moulds patients' perceptions of health and illness, even when symptoms of a particular disease were known, in this case acute myocardial infarction, decisions about actions were strongly influenced by variables such as anxiety and uncertainty. The authors recommended providing information as clear, simple, personalised instructions on how to respond to symptoms including simulation, scenarios and role play (Cytryn et al.).

One paper described the development of a web-delivered multimedia health education programme designed to improve body satisfaction, a probable risk factor for the development of eating disorders in young women. The program included psychoeducational content and a news group for communication. The outcomes for the participants were positive. Involvement in the programme improved body image and reduced other attitudes that predispose to eating disorders. It was also discovered that anonymity was not important in a self-help group. Participants posted photographs of themselves which, they felt, helped to develop a sense of community (Dev et al.).

One paper reported a study that used the web as an educational tool to reduce postoperative pain following ambulatory surgery. Of the total study population of 195 patients, 52% already had access to the Internet, and a total of 85% of the study population accessed the resources made available over the web. The majority found it helpful (Goldsmith et al.).

What are the disadvantages?

If patients are to make efficient and effective use of the plethora of health information available on the Internet, they must be able to access it, determine the quality and relevance of that information to their particular situation, and be able to comprehend that information.

Almost anyone can put almost anything on the Internet. Fallis suggested that inaccurate health information on the web might cause a problem of credibility and safety. Consumers could either not believe that accurate information is accurate or may act on inaccurate information. Valid and reliable measures of the accuracy of information on health web sites are required.

Web sites could provide the information people need to judge some aspects of the accuracy for themselves but at present this is not often done. Stanford University Medical School reported the results of an analysis of pages retrieved from 97 unique sites on breast cancer. Only one page revealed all four basic publishing elements of authorship, references, disclosure and currency. All separate elements were revealed in less that 41% of sites (Shon et al.).

One paper described the development of a self-assessment method for patients to evaluate health information on the Internet. Fours useful categories were used as a framework for the assessment including content, design, communication and credibility (Jones). Other Internet accuracy support was offered by Oregon Health Science University who have developed a prototype system that responds to a
consumer’s health query by returning a list of web pages that are ranked according to the likely quality of the page content (Price et al.).

Even if all the information on the Internet was good quality and useful, it can and does, often take time to find it. The issue of terminology has crept slowly, but surely, into consumer health informatics. The National Library for Medicine has recognised the increasing difficulties faced by users to find relevant information in the large information space that they are now forced to navigate. Retrieving too much information, no information, or information that is not relevant to their question causes frustration. An analysis of the new resource, MEDLINE plus, was described in a paper. This resource is intended primary for consumers of health information. The site organises information according to common health topics such as asthma, cancer and heart attack. Further work continues on the development of the site and to explore the development of a terminology server whose goal it is to mediate between user terminology and terminology as it is reflected in a variety of medical information resources (McCray et al.).

How will consumer health informatics impact on the patient's relationship with health care professionals?

Few papers reflected on this question, however, one did describe a system that offered a combination of consumer and physician support. ‘Charlotte’s web’ was designed to support patients, collect and maintain family health history, and help physicians interpret that information to identify patients most at risk of common diseases (Cohn et al.).

Conclusion

Consumerism is well and truly on the health care agenda in the USA and indeed elsewhere in the world. The ability to support consumerism is greatly increased with recent advances in information technology such at the Internet. It is possible, with a little innovation to, provide people and patients with information in an easy, convenient way at all stages of the health and illness continuum. The provision of information is not the only advantage. Communication can also be supported. Easy access to experts from people’s homes and communities, where most healthcare takes place, is possible. Informed choice, involvement in decisions, and improved access to health care are all enhanced.

There are however key issues that need to be considered. Confidentiality, or lack of it, was frequently mentioned even though the greatest risks are likely to be from within the health services. Accuracy and consumers’ ability to judge the plethora of information means educating patients in how to critique information. Knowing how to critique information however is only possible if you have it. Providing new ways of delivering information can just emphasise the existence of the information have's and have not's. However, I would suggest that all these issues present a challenge, whether or not we have the technology. With more openness and communication comes different risk, but equally different possibilities. Overall a useful, enjoyable and well organised conference. Well worth the trip across the Atlantic.

References

All references are to: Proc AMIA Symp 1999
Barnas G.P., Kahn, Jr. C.E. Assessing Consumers' Interests in Internet-based Health Information, p.1018
Cohn W.F., Kinzie M., Barrett J.R., Julian M., Einbinder J.S., Pelletier S.L., Knaus W.A. The Development of a Web-Based Family Health History Collection Tool, p.1042
Fallis D. Inaccurate Consumer Health Information on the Internet: Criteria for Evaluating Potential Solutions, p.1055
Goldsmith D.M., Safran C. Using the Web to Reduce Postoperative Pain Following Ambulatory Surgery, p.780-784
Johnson K.B., Ravert R.D., Everton A. Internet TV Set-Top Devices for Web-Based Projects: Smooth Sailing or Rough Surfing? p.535-539
Jones J. Development of a Self-Assessment Method for Patients to Evaluate Health Information on the Internet, p.540-544
Kaplan B., Brennan P.F., Dowling A.F., Friedman C.P., Peel V. Panel: People and Organizational Issues: Towards an Agenda of Key Issues for the Turn of the Century.
Leavitt M., Skinner R., Gibson D. Panel: Connecting Patients and Physicians via the Web: Pushing Aside the Frosted Glass Window.
Mullins H., Purves I., Ziemkowski P.J., Holbrook A. Panel: Usability Studies in Primary Care Informatics: Searching for Useful Answers to "Everyday Problems".
Shon J., Musen M.A. The Low Availability of Metadata Elements for Evaluating the Quality of Medical Information on the World Wide Web, p.945-949
Additional reports.

Note: These reports are in rougher, less edited note form.

Jean Roberts
Chair, medinfo2001 Organising Committee

Introduction

Nancy Lorenzi, Professor of Organisational Development, Cincinnati and current SPC Chairman opened the event with some statistics – pre-congress tutorials were 20% oversubscribed and 33% of the attendees were newcomers (although it was unclear whether this was to tutorials or full congress). There were 1890 registrants by the first day, which grew to 2200 during the period. The event was 12 tracks over 2.5 days with an Open Plenary the day before and Closing debate and Awards ceremony afterwards. There were 670 submissions which were refined down to 42 tutorials, 96 papers and panel discussions, 18 evening workshops and 200+ posters. Additionally, there were 37 focused National Cancer Institute ‘Technology Expos’ which were mounted in the exhibition area, which also contained 40+ exhibitors in mostly small curtained shell scheme layouts. Over 17% of attendees were ‘non-US’, but that included Canada and Mexico.

She reported that the Programme had for the first time been a totally electronic process this year. In reporting this years AMIA activity, she noted that AMIA had hired professional lobbyists to input their views on HIPPA (and other US privacy legislation).

Robert Wittes, Deputy Director of the National Cancer Institute (one of the US National Institutes of Health) reported a number of initiatives that he called ‘Big Biology’, relating to genomes and controlled trials in the cancer domain. He highlighted the conceptual, technical and sociological challenges inherent in such work.

Interestingly, and emphasised in the subsequent main body of the programme, was the AMIA Students Award to a paper on Consumer Health, an emerging pressure area.

Keynote: Peter Keene

The Keynote Plenary, Peter Keene, gave a refreshing and fact-packed outsiders view on health informatics. He is a decision support guru, and author of ‘The Process Edge’. Notable soundbites included: ‘the focus is shifting from technology to distributed computing for users, particularly customer-preferred tools – a paradigm shift to customer sophistication’, ‘wireless is fundamental to health service provision and the future linkages’, ‘Windows is the last revenge of the KGB’, ‘charges for phone calls will disappear (in the US) within a year’, ‘the Internet is a joy to the hypocondriac’. He stated that the focus on information production will shift to information sharing, for example drkoop.com, and a community collaboration model for sharing information. He likened the browser to a ‘Store front’ in the first stage, thereafter everything including business to business transactions become personalised, having been segmented into professional and sales activities. The shift, he said, is
from control to access, and because physicians (in the US) have not addressed the fragmentation of their service, they have lost their autonomy and position.

He stated that Silicon Valley was currently 5-7 years in advance of commercial practice. It will be necessary to look at the supply chain logistics to resolve and customer-supplier conflicts, and to assess competitor strengths. He likened medical systems to fiefdoms that are paying the price for lack of architectures. He identified 1999 as a pivotal year when technology and markets have come together, giving massive opportunities for medicine and healthcare, if our ‘disproportional cost base’ can be solved. His concluding message was that only radical change makes big success – so do not tinker around the edges’.

Comments on papers delivered

Human Factors and Care Guidelines
Miller et al (Yale)— gave a 1996 example of immunisation and vaccination, exploring what is an incomplete record (overall 97% errors due to data quality). The speaker was looking at drug doses recorded and extrapolating backwards to fill the gaps (14% were incomplete, 2% actually had not enough time spaces to implant missing doses).

(S29) Intellectual Property and Protection : Is the Internet really free?
Stensaas (University of Utah Medical Centre, Salt Lake City – an excellent contributor. In the US, copyright statements need to be different now that web-based sharing of materials goes on, also because of the existence of multi-media (CD-ROM) therefore increased discretion, litigation, legal proceedings emerging. Because of the perception of the lucrative potential of the web, people do not contribute materials freely – the textbook culture remains!!

LUMEN (Loyola University system) – had 4 million hits, 90K users per month, but ‘published books are put behind firewalls for their own students. For clinical photos, the speaker (Chandrasekhar) suggested ‘respectful use and credits’.

Legally, Alison Bunting stated, anything pre-1923 is public domain. Fair use can be copyright free for educational purposes and the Digital Millennium Copyright Act has now come in (October 1998) which amends Article 17 to implement WIPO.

Encyclopaedia of clinical clip multi-media – Slice of Life / Byte of Life from UoUtah. Indicated that any photo of a patient (that might be identifiable) must have an express release.

(S48) Consumer Health Information Innovations – a demonstration session

1. The HeartCare programme.
Professor Patti Brennan and team (U of Wisconsin) presented WebTV use into the home. A good demonstration of using the web to reassure and inform the ‘vulnerably ill’. WebTV was used to connect homes to a WWW-based cardiac (surgery) rehabilitation service. The service curently contains discharge brochures on healthy behaviours. The info is patient-centred and tailored on discharge to what is needed by the individual including a ‘filtering’ of data to their desired level of scientific data. The service makes good use of available material which is amended by a nurse to include patient specifics. Human-computer interface issues (ie of usage and useability) include the nuances of proprietary webTV and the need to alter the
hypertext version to be compatible with these differences. Must be careful of using fancy fonts that did not show consistently on every type of configuration. Good points were made about cultural sensitivity that is necessary in designing any citizen materials, for example – English as not first language, suggesting buying things or using luxury ‘tools’ to those low and un-waged, or ‘walk to the Mall (Shops’) to a home-bound person. Before introducing the system, the presenters felt a literacy check might have been useful to pitch the language at the appropriate level for both scientific capacity and whether the vernacular had to be used as communication medium. Another problem with webTV is that the system calls itself up periodically and adds about 10 mins per week to your expected phone bill!

2. The HealthAware programme through Brigham and Womens’ Hospital, Boston Kogan said the project aims to provide consumers with an integrated web-based service for health, wellness and healthcare information. Proactive service that assesses risk and then allows user to connect to any services indicated as necessary. Core tools to develop such as service were reported as there will be further roll-out to other clinical content areas in due course (current areas include sports injuries advice). Highlighted the need to set all content at the 7th grade literacy level (??age 12) in order for it to be understandable by potential audiences. There are also AMIA-drafted guidelines on how email communication between doctors and patients should be transacted. The feedback so far is that the consumers do like the service and they trust the content.

(S54) Goldsmith and Safran (Beth Israel Deaconess Medical Centre, Boston)
The speakers showed that having access to web-based information reduced (perceptions of) postoperative pain – pains that they categorised as ‘mild’, ‘discomfort’, ‘distressing’, ‘horrible’. Their findings were borne out by Jostette Johnson (S66, Uni o Wisconsin) re Self Assessment Method for Patients to Evaluate Health Information on the Internet.

Kukafka (Dept Med Informatics, Columbia (New York) reported potential barriers to the use of informatics by the elderly, particularly in a MIHeart project in this case. Contact can be made for more details if required for DH R&D project.

(S68) Triangulating on Informatics Teaching, Learning and Objectives.
Reported surveys – useful background
http://www.aamc.org/newsroom/reporter/aug98/msop.htm
http://omie.med.jhmi.edu/ewg

Craig Scott (Washington, Seattle) – provided what could be useful material to feed into the Virtual Classrom developments for the NHS, in terms of surveys from graduate competencies in informatics when exiting medical schools.

(S80) Technologies for Learning and Teaching
K. Caton et al from Oregon - Evaluating a Virtual Learning Centre, containing course builder, course editor, forum within a faculty … an ongoing development. Curriculum transformation is not easy and a nested problem of literacy levels. Working with commercial partners (see web sites http://www.educause.edu, http://www.ECollege.com ). Big problems from the modern pool at the Uni
Hovenga (Australia) suggested that mounting a 4-day multi-media course telematically was same price as hiring a conference centre (and bringing people to it) for the course.

Cimino, from the Albert Einstein College in the Bronx used web-concept as a Virtual Library, with pre-selected web references, medical literature pieces, searches and Medline access integral. The total minutes spent searching for material did not vary whether the computer was used or not!!

*(S95)* Policies to promote educational and health information quality on the web. AMIA Educational Working Group discussion – collective discussion on what exists, qualifying as:

- Provenance and parentage
- Authority (authors, creations, educational versus commercial, affiliations, declared commercial interests)
- Audience
- Content and scope
- Currency
- Design ‘fitness for purpose’ (technical, architecturally, editorially)

Quality is in the eye of the beholder. Should also include:

- Accessibility for disabled
- Opportunity to consider content or meta-content (not wade through data-treacle)
- Transparency (any inherent biases).

Question – should ‘accreditation bodies assess quality or accredit the tools that will allow others to systematically judge the content? It was suggested that AMIA (etc) should provide Portal Sites to confirm authority rather than list the authors / board who had assessed the material (or else they could be persecuted)
Paper presentations and panels

S24 – McGee and Wu, Harvard Medical School – ‘A process and programming design to develop virtual patients for medical education’
Looked at production of ‘Virtual Patient’ multimedia clinical simulations – one of few papers to look at real costs of producing such materials (important as increasing moves in this direction by many organisations). Said that first case cost approx. $160K, but subsequent ones approx. $100K each, and about 2.25 months. Have team involvement (akin to Open University model) of clinical educators, media specialists, programmers and admin., as well as advisory group and evaluation feedback. After case selection, there is intensive script writing (no media production at this stage) to produce design document (approx. 200 pages) with all details for production of materials, filming etc., then move on to media production.

S35 – Gassert, Staggers, Hovenga; chaired by Milholland. Panel on ‘Informatics competencies and curricula for registered nurses’.

Staggers: is a need for informatics competencies – service job descriptions include informatics requirements – US healthcare leaders emphasise the need. Re: integration of competencies in US – not especially positive findings or good job done so far in US – cited literature by Johnson 95, Carty & Rosenfeld 98, Austin 99. Different authors emphasise different types of skills in the literature (computer literacy, information resources, patient-centred info., general NI skills and knowledge). Past work – most studies looked at nurses at BN level – little empirical work on needs of bedside nurses or those in training. Therefore, no current and comprehensive competencies so far developed in US.

Gassert: NACNEP recommendations to include informatics competencies in the curriculum – but to do so, need to know what they are. Competencies abstraction from list of 1159 items to provide three categories – computer skills, informatics knowledge, and informatics skills. Eventually reduced to 313 unique items (?but do these reflect NI practice) Identified 4 levels:

- Beginning nurse (qualified) – has fundamental information management and computer skills – uses existing information systems and available information
- Experienced nurse – has proficiency in a domain of interest (but not NI – eg clinical expertise) – is highly skilled in using information management and computers – sees relationships among data
- Informatics specialist – advanced preparation and additional skills/knowledge specific to informatics – integrates components of NI and uses skills of critical thinking etc.
- Informatics innovator – conducts research and generates theory – leads advancement.
The 313 items were assigned to the 4 levels, and lead to 306 final items. This forms a matrix to be used for Delphi-type validation. In the items, many computer skills statements at lower levels, but move to information skills (esp. research) for higher levels.

Hovenga – discussed NIGHTINGALE preoject and IMIA WG1 recommendations.

Question that sprung to my mind – do these competencies address telehealth/nursing, what will be an emerging field.

S52 – Panel on ‘Consumer participation in informatics research and development: ethical, social, methodological and political challenges’- Jadad et al.
Collyar (Patients advocates in research) – what do people want from medical/health information? – we can often forget why we are doing things due to focus on technical aspects – public/patients want providers to CARE for and about them – doctors in US good technicians but not trained well in people skills – patients/public do not want to CONSUME healthcare! and service orientation needed but not commodity orientation.
Eysenbach – talking from researcher perspective – studying importance of Internet on public health and evidence-based, interactive patient information systems. Says R&D needs to be targetted to problems that are important to people – issue of finding ‘representative’ consumers. (Article in Archives of Dermatology)
Jadad – is consumer involvement in research desirable? – is it possible? – is it necessary? – does it make a difference; do more good than harm? – (how) can we measure it?
- are methodological challenges – results patchy and few validated tools.
- Oxford Pain Internet Site – gives systematic reviews on pain relief
- Cochrane Consumer network
- is doing work on new ways to present scientific information - eg interactive, evidence-based stories for children
- is there a new breed of consumer-researcher? (rise of monetary driver for Internet consultations).
Goodman – commodification of healthcare is an important ethical question.
Gyde – increasing ill health among the poor – therefore need for health information to be received by and understood by those most at risk.

S61 – Panel on ‘Report of the 1999 Annual Spring Congress: health informatics education’
Gassert – talked about informatics for healthcare professionals – undertook a needs assessment, which identified 4 trends:

- changing role of the patient – empowerment, access to information, technodivide
- trends in higher education – critical skills, resource versus content approaches, lifelong learning
- integrated delivery systems – evidence-based practice, data sharing/standards
- trends in technology – convergence, miniaturisation, bioinformatics.

- which lead to needs for health informatics education in the future – evaluation of information – confidentiality issues – on-demand/just-in-time/online systems – faculty use of technology – point of care information.
- discussion of fundamental skill sets – computer literacy, privacy & confidentiality,
ethics and legal issues

*S95 – Panel ‘Policies to promote educational and health information quality on the Web’*
Very popular session (as were all on the themes of patient health information issues) - room full to capacity
Report from work of AMIA Educational Working Group – which gave rise to 6 principles.

- How to promote quality – options include:
  - Setting a good example
  - Evaluating and providing feedback
  - Creating criteria for evaluation
  - Creating policies to enable evaluation
  - Endorse existing policies

A suggestion from panel that they were going to explore AMIA kitemarking of web sites. This seemed a rather dated discussion that raised few new issues and did not seem at the leading edge of thinking in the area.

**CARING (Capital Area Roundtable on Informatics in Nursing) Luncheon**
Guest speaker at the luncheon was Russell Jones, SAIC Healthcare Solutions – ‘What every healthcare professional needs to know about information security’.

Computer security, data protection and confidentiality are never easy subjects to get across to people or to make interesting. But Russell did an excellent job, through appropriate anecdotal materials.

The session addressed a range of security issues, and the general importance of the topics, within the context of recent US legislation (HIPAA).

Started from the premise that ‘people will find a way round a system if it prevents them from doing their job’ (and one has to ask, if this is the case, what does it say about the nature/design of the system and any real user involvement in specs?)

Looked briefly at patient safety issues, financial and criminal penalties and possible effects of healthcare organisations’ accreditations by not complying with standards, and financial implications of security. Looked at threats, vulnerabilities and risks to organisations, providing examples of some recent incidents. Talked about internal and external security threats due to networks, and about client-side issues, before briefly providing some technical solutions including biometrics and public key infrastructures.