Model Healthcare Community

Health Consumers' Tour:
Friday 26th February 2010
Office of Medicare Australia
Canberra

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Contents

          Purpose of this report
          Background
          Information source
          Main findings
          Conclusion
          Recommendations

Introduction   4
          Model Healthcare Community Tour

Discussion   5
          Secondary evidence from consumers
          Facts seen from an alternative view – the consumer point of view

Conclusion   8
          Support for the concept

Recommendations   9
          First step limited funding time
          Resistance to change
          Single definition of E-Health
          Quality of information   10
          Exclusion of consumers on E-Health matters

Appendix 'A'   **Consumer Secondary date collected**   11

          'B'   **Minister's Media Release 18 Jan 2010**   12

          'C'   **iSOFT report synopsis Dec 2009**   13

Executive Summary

National E-Health Transition Authority (nehta) held a day for consumers' and consumer representatives for numerous NGO's from around Australia to attend an organised tour at the Canberra offices of Medicare Australia.   The nehta tour was tightly structured and limited to a pre ordained time frame set by the nehta management.

This report is from the consumer experience and is supported by additional observational (qualitative) data from another consumer who completed the tour with on the same day.
Qualitative Consumer Data Appendix 'A'

E-Health has been at the vanguard of the new vision to deliver public health in Australia.
The expectations are that it will take us from the current models of record keeping which are based on best practice of medicine in the mid reign of Queen Victoria into the modern period of 2010 and beyond using best practice of modern electronic 'E' capabilities.
Consumers who were guests on the nehta tour were provided with a well rehearsed presentation of the first step towards achieving a true E-health system.

The presentation used the umbrella terminology of E-Health and actually used many very different components that will go to make up 'E-health'. However, what was on display and what has been achieved was limited to a narrow field of endeavour that will have to go to make up E-Health as a whole. This was a single component part but not the whole of E-health prototype.

What has been achieved and was on display on the tour was that component part of E-health which will provide a single identifier for the patient. This has always been a fundamental foundation upon which to build a new system of record keeping. The introduction of this single unique patient identifier (UPI) was outlined on the nehta tour. This UPI will produce a sudden, dramatic and significant improvement in all patient care around Australia and so from a consumer perspective is unreservedly welcomed.
The Minister of Health and Aging, the Hon. Nicola Roxon MP, visited the display in January 2010 and was very positive in her media release of 18th January 2010 on what had been achieved.
Media Release by Minister Appendix 'B'

What was stated and on display was positive and in the opinion of the author should have the support of health consumers. However, there remained concerns around a number of fundamental issues which should be a cause of some unease to health consumer group of stakeholders.

What has been achieved and were on display was a huge step in the right direction.
However, aspects adjunct to what was on display raised a number of concerns, but it would be a matter of being careful not to throw the baby out with the bath water. Greater consumer representation and closer involvement in all stages from planning onwards needs to happen in order to optimise the full potential of E-health

Introduction

This report is to communicate the information provided by the National E-Health Transition Authority (nehta) from the point of view of health consumers.

On Friday, 26th February 2010 a group of health consumers' from around Australia were brought together at the head office of Medicare Australia, in Canberra. We were given a guided tour of the current work of nehta. The tour was highly structured and followed tight time lines. There were a number of display booths each with an accompanying operator demonstrating that aspect of the intended new system of patient single identifier.

All tours that day witnessed by the author appeared to be limited to health consumers. People invited to join these tours were requested to arrive at the offices of Medicare Australia at staggered intervals. The first tour of health consumers started at 10.00AM.
The next tour was scheduled to start at 10.15AM and this was followed by subsequent tours that were scheduled to commenced 15 minutes apart. This has a multiple effect of keeping the groups together and limiting the amount of time any group could spend examining or questioning aspects of any one booth as there was always another organised group immediately behind you who needed to be accommodated. Questions could be asked but we were reminded that most of the questions would be addressed by subsequent parts of the tour or we could ask questions at the end of the tour. This had the effect of limiting spontaneous questioning by the tour participants. Questions were allowed and all questions raised by consumers were responded to.

In the 10.15AM tour group made up of some ten people few of the questions raised were answered in direct terms of YES or NO followed by a detailed explanation. A number questions put to the staff were responded to with;
'that is a very good question and if I can ask you to just hold that for me I think it will be answered as we move to other booths.' The results were the spontaneity and context of the questions were lost and the author could not a recall a single question that was addressed later.
Another frequently used response to questions was: 'It would be possible'.
The author's understanding was that this types of response to questions as neither a YES nor a NO but that all things are possible. A cleared communication of; 'I don't know'. Or, 'I will look into that and get back to you.' would have been productive.
Another response to questions from consumers' was, 'That would be up to the local provider.'

At one point the tour guide referred to the system we were looking at and explained it would link in with iSOFT. iSOFT is a computer system in commercial hands which has being sold to a number of hospitals around Australia.
Hospitals state responsibility, nehta functions a Federal responsibility.
I knew something of iSOFT as I attended a briefing by them in Perth on 9th December 2009 and completed a report. Following the information about the use of iSOFT I asked if the unique patient identifier (UPI) would be used when an ambulance was called to attend a patient out in the community. Not for the first time during the tour the answer to the question was; 'That would be up to the local provider.' Had the nehta representative delegated to inform we consumers had a knowledge of what iSOFT was about the simple answer would have been NO.
iSOFT report Appendix 'C'

Discussion

The lack of engaging in meaningful ways with the consumer tour group to their questions around E-health, the whole picture, and the presentation of E-Health the UPI was of concern. This could be an example of a disconnect in that the presentation was explicit and limited to E-Health the UPI and not a foot out of place from that. While consumers looking at E-health understood a much wider range of issues that would have to be addressed and tried to introduce those questions without success. These stakeholders, the consumers were not a group who could be misdirected with ease in response to their questions. Whatever the reason for this display of inability to appropriately respond in depth to questions from the group I did felt as consumers and major players we were entitled to expect interaction at an informed level but that was not always obvious on the tour.

The particular stock reply, 'That would be up to the local provider' was used to answer a number of the questions I raised.
'Will the system carry patient end of life directives? IE do not resuscitate'
'When an ambulance is called with the UPI be used as part of the ambulance information?'
As iSOFT was used as an example the answer to both questions was No.
It could be the iSOFT had amended its programme since 2009 to address these patient issues and if not that the person doing that section of the nehta tour actually had not been informed what iSOFT would do but were only told their system would be used with the UPI.

The tour was by design limited to run to a tight time schedule. It was not a matter that the various guides gave the appearance of wanting to hurry away from any booth. There was a real pressure to keep moving as the group behind were also moving to take your group's space and they in turn were forced to move by the next oncoming tour group.
When one paid attention to all of the tour experience it appeared to split into the formal and informal parts. The formal was the rehearsed delivery of each booth visited. Of itself the information was instructive and delivered at a professional level. The informal was that element that was not scripted. That provided an insight into the programme as a whole. As a member of the tour group listening to the questions from other members I felt I heard a lack of confidence and an exposure on the part of the system's agents to have an in-depth understanding of the product which was E-Health as a whole and at times a limited appreciation of the concept of patient single identifier away from the learned script they delivered.

Another consumer member of the tour group I was on expressed reservations about what the purpose of the event. I felt as consumers we had higher expectations of what new information would be imparted to us.

What the National E-Health Transition Authority (nehta) did have on display was a system that appears to be a done deal and now it's a matter of getting that information out into the community in the best possible way. By word of mouth and at the grass roots level is the most trustworthy way a getting a message out into the community. They have that identified correctly; we the consumer representatives are the best system of dissemination information. We need to protect that by making sure we are never used to disseminate misinformation.

What was on this tour was not the package which has to be E-Health.
This was foundational to the possibility of establishing the full package that will be E-Health.
It was the putting in place of a single unique patient identifier (UPI).
Critical to improving even the possibility of good health care delivery will be this step into the modern age of electronics and computer systems.

iSOFT previously referred to will seek to address this existing major problem of a UPI. From the report, appendix 'C' it should be obvious that what is being sold will only give that protection to patients, clinicians and hospital administrators to a single institution.
The introduction of UPI's will not, at this stage, give the hospital across the street any of the patient medical records. But, the new system of UPI's will tell the hospital across the street they are dealing with this patient and will properly identify that person. That will importantly apply to test results ordered from the same pathology labs for the same patient but from different hospitals. It appears outside of the agreed planning the pathology testing by using the single UPI they, the patient and treating clinicians will benefit because no matter where the tests are ordered from they will be, can only be, assigned to that single person using that UPI.

What is now on offer through nehta is that step to protect all the participants, none more important that the patient, that with this new UPI both hospitals will know it's the same patient and pathology tests will also have the assurance they are responding to the same patient no matter where they are, in any hospital or at a doctor's office.

The material passed out included statistical details, some of which were compelling and some were not. Examples of how the introduction of UPI's will help issues of the following;

- "Chronic disease affects 1 in 7 Australians and is a cause of mounting healthcare costs."
  I read this and found it confusing. How will at UPI reduce the numbers of Australians suffering from chronic disease and so reduce costs?

- "Medicare prescribing errors are estimated to cost $380 million per year in the public hospital system."
  As in all of the material presented, and the tour itself, I would have liked to see this as patient focused or at least patient inclusion. This is extremely important to patients. Errors in prescribing medicines are a triple blow to patients;
    - *You are ill and you are not receiving the correct medicine to either relieve your symptoms or treat you to recovery.*
    - *The wrong medicine has been given to you and this may well make you more ill especially as being sick your immune system will probably be weakened.*
    - *Money wasted in this way takes away funds from our health system that could otherwise be used to provide high health care and delivery of health care services.*

  We continue to have this disconnect between patients and their health care system. A disconnect that has not limited itself to patients in isolation. The disconnect also presents itself between the health system on the public hospital administrators/ clinicians/patients Health consumers always need to be included at every step of the way because they have a distinctive point of view which will not necessarily be reflected by the other stakeholders.

- "25% of a healthcare provider's time can be spent collecting information"

- "And up to 18% of medical errors are from an inability to access up-to-date patient records."

  From the consumer point of view, this statistic is stunning. Will this new nehta material we have all been updated on address this issue around patient records? No it will not. The tour we were on were told this UPI will in no way have anything to do with patient records. One assumes at least not yet and not as it stands now.   What nehta has on offer and will only speak about in very narrow terms is the UPI. Having this truly improved approach to health, the UPI, will in no way address access to up-to-date patient records as it stands at this point. In fact the connecting of patient information and patient records is so far down

the time line as not even to be a consideration now. The UPI will in a very limited way give improved access to addressing this burden of unavoidable malpractice. With the UPI the treating clinician will know, or should know, that the patient records in front of him/her applies to the patient in from of them. The UPI must, but at this time has not been, connected to that the treating clinician will have all of that patient medical records before him/her and upon which they will rely in part for diagnosis and treatment decisions.
At part of our tour we were told:
*"A doctor **will not** be able to access your medical record, only your UIQ."*
At another point we were told:
"Medical records – this is not in the scope of the E-Health at this time."

Conclusion

The National E-Health Transition Authority (nehta) tour demonstrated a positive move to a much needed overhauled in our public health system. From the point of consumers it has moved us in a significant direction to improve outcomes for the health and safety of all patients'.

From the perspective of other important stakeholders, the clinicians, pathology testing, administrators, health departments of government the positive consequences will be in the probable reduction of adverse events, squandering of time in unproductive cross-references, huge savings in greater productivity and returns on each dollar spent while actually lifting the quality in the delivery of health care in Australia.

What was on display was well designed but remains a single aspect of many more component parts with will have to come together to make up the whole which will be E-health.

Recommendation

That the different stakeholders embrace this program of unique patient identifiers (UPI) to lift the quality of health care delivery in Australia and endorse this first step towards a fully functioning E-health system.

This first step in E-health is set up with funding to Medicare Australia up to 2012. That is a concern as the time frame is so limited. With the best will in the world and every effort made by those charged with its design and implementation the reality is that we have to accept that it is likely to create some problems while solving existing ones. With every new system it will take time to see unexpected issues come to light. That will provide the opportunity to make the necessary adjustments to make the system even better. It is with some unease to know that Medicare Australia has a start with such a restricted time of two years. This new system should be funded in terms of decades to implement. Hand in hand with that government should start to insist on mandatory accountability, delivery of outcomes, monitoring of policies while seeking to identify and remove token people not implementing this E-Health.

Resistance to change:
When an international accounting agency were recently charged by the WA Government with a review of value for money spent with NGO's the accountants identified as a first priority to achieving change the need to adequately address the issue of change itself. How people working in the system, government and non government, handled change. How change was often sabotaged by the failure to appreciate the need to identify and assist those for whom any change will be seen as personally threatening.
Mr. Ken Baxter will/has released in the first week of March 2010 a report to the DoHA focusing of new health care within Australia. In his report in part he wrote of the concern to change that can be expected by the ranker and sloth of some bureaucrats in the health system.
In all of the presentation by nehta in no part did it address this essential and real impediment to implementing any part of a new system. The natural resistance what will have to be addressed from within in order to achieve any form of a good outcome.

'E-Health' needs to have a single agreed definition.
Within the current Australian health systems there are 5 official different understandings of what e-health is, and as many combinations of writing E-health is currently in use.
One defined group of medical providers recently held a national workshop to debate E-health.
Their E-health ,as they defined it, was the use of telephones and or emails to communicate with patients'.
This National E-Health Transition Authority (nehta) has not gone far enough in defining up front what they identify under their use of the banner, 'E-Health'. What is on offer is not the full E-Health as I and many others understand E-health to encapsulate. Through responses to consumer questions while on the guider tour nehta staff did make it very clear that what was on offer was the unique patient identifier (UPI) and no more. E-health is much more that only the establishment of UIP's and that has been built into the current system on display. To their great credit someone, or some committee, have also incorporated into our Australian UPI international unique patient identifiers and those have already been put in place and are now protected.
As part of the UPI the numbering all will start with '800'. This is the unique national/international identifier that this belongs to Australia only.
The next part of the UPI will have '0'. This again will be the unique national/international identifier that this belongs to Medicare Australia.
One has to take pride and appreciate the forward planning that has gone into this planning.
Issues of privacy to be resolved aside, this is a great forward step in patient health delivery for Australia. However, this is a step. It is not the package. It is the foundation upon which the rest of E-health will have to be built.

There were concerns around the quality of the information provided. These concerns touched on the use of statistics.

Written on the wall of one of the booths was;

"consulting with consumers 82% of all Australians support the introduction of e-health."

Are we to understand that 100% (every living person in Australia) were asked this question and 82% were in favour of e-health?

As a health consumer I want to see the details of the pool of people that every statistic is based on. I then want to see the questions. Then I can draw a proper conclusion as to the significance of this survey.

There was room for improvement in the presentation and delivery of information on the E-Health tour. A clear statement that what was on display was a single component part of that will be E-Health as a whole. That this was the foundational part of that whole and only this aspect, the UPI was up for discussion would have assisted. Greater consumer involvement from planning forward has to be standard practice to every piece of work engaged in by the DoHA and all government departments. A current example is:

 E health – national coordination and alignment – assessing strategies, priorities and alignment .

They will meet in Sydney 14 -15 April 2010 (http://www.national-ehealth.com/overview.php)

This looks like another possible important component part of the E –health system. Where is the consumer engagement and involvement in the planning of this? From enquiries made I understand a member of staff of CHF (Consumers Health Forum of Australia) will deliver a paper. We need to be more that observers or single presenters in all debate around E-health.

To even attend as an observer would cost some $3,000 plus travel and accommodation.

How can any serious body having input to government about the health of people still exclude those very people?

Appendix 'A'

....
The story boards of the whole My Community appears aimed at the Health Provider- GP's especially, as they are the ones who get to CHOOSE if they join the whole concept and get a IHI -P no. Whereas we health consumers get a number automatically allocated.

Because it is voluntary for health providers and health organisations to join into the scheme, universal improvements in safety and quality may therefore not be forthcoming.

What impact will this have on our records when we do get to the stage of an e- Health Record? How complete our individual health records are may be very uncertain due to this.

 There is certainly a large area of information about IHI's which needs to be made clearer to consumers, who may be expecting this is their e-Health Record..

(name withheld on request of consumer)

Appendix 'B'

THE HON NICOLA ROXON MP Minister for Health and Ageing MEDIA RELEASE

18 January 2010

E Health to Deliver a Better, More Efficient System

Patient care will be improved and inefficiency in the health system will be cut by new e-health legislation soon to be introduced by the Rudd Government.

Today I visited Medicare Australia to see firsthand how the secure e-health system currently being developed will work for patients and health care professionals.

The demonstration clearly showed how useful tools like electronic health records, medications-management systems and electronic clinical messaging (discharge, referrals, pathology, and prescriptions) will help improve delivery of health care – particularly when patients are being cared for by multiple providers.

The first step in creating an e-health system will come into effect in the middle of the year when unique healthcare identifiers are assigned to all health consumers as well as to health professionals and the organisations that provide health care in Australia.

The unique healthcare identifiers will be available on a secure system, operated by Medicare Australia.

These identifiers will be provided in addition to Medicare numbers, as a further step to ensure the security of the system. Legislation to underpin this work – the Healthcare Identifiers Bill 2010 - will be introduced to Parliament in the first half of this year. The draft legislation is available for comment at www.health.gov.au/ehealth/consultation.

The Rudd Government is committed to continuing implementation of eHealth to support a more effective health system, and the Council of Australian Governments provided $218 million to fund the National E-Health Transition Authority to 2012.

Today I also held a roundtable consultation with eHealth organisations and professionals to discuss the Reform Commission's eHealth recommendations.

The views of these key eHealth stakeholders are important as we consider the NHHRC recommendations, and in developing strong foundations for Australia's eHealth - such as unique 'healthcare identifiers' and secure messaging standards.

Today's roundtable was the Government's 91st consultation across the country to road-test the National Health and Hospitals Reform Commission's proposed reforms.

All Australians are also able to send in their comments and contribute to the national debate on our health system via the yourHealth.gov.au website.
For all media inquiries, please contact the Minister's Office on 02 6277 7220.

Appendix 'C'

Synopsis of the iSOFT presentation 9th December 2009

On Wednesday, 9th December 2009, iSOFT (in collaboration with WA Health) held a briefing on their new computer programme to be used in many hospitals in WA.
The briefing was identified as part of the eHealth system. My expectation was that I would learn something new about the national implementation of a single eHealth card and its systems. That this eHealth system will be patient focused and in a major way be for the benefit of patients' and focus on good patient outcomes to diagnosis and treatment. This was an error on my part. The iSOFT computer software presentation was hospital administrative focused with the intended benefits to administration better exploit resources.

In my opinion this presentation from iSOFT was a good infomercial of their product to potential and new purchasers. The product is a computer software programme that will take over from the current PAS (Patient Administration System) and TOPAS (The Open Patient Administration System).

*** a personal and subjective opinion*
*As a member of the general public it was for me like hearing how good Pepsi was and it was going to replace Co-Cola. Of concern was the understanding that this new commercial enterprise will give hospital administrators <u>more of the same</u> old style computer programme system. The public hospitals in the CBD of Perth at this time, using current computer programs, are unable to exchange patient medical records between public hospitals. This just purchased new computer program will **still not** connect patient information between hospitals in the same city. Connections have **not been built** in to exchange patient information, and **no single identifier** for a patient is covered outside of each separate hospital. Neither of these substantial negative impediments to patient health and safety appear to have been addressed.*

This new 'upgrading' of the administration system looks much like the existing system in important ways. Of apprehension on my part is the apparent replication of the existing system around patient records, privacy, health and safety in medical treatment and the failure of all appropriate clinicians', administration managers and patient themselves have good access to the patient's medical history and medical records.

Throughout the entire presentation I attended I did not hear a single reference as to how iSOFT would aid patients let alone if it would improve the hospital experience for patients'.   There would appear to be a paradox in our new patient focused health system that introduced iSOFT without prior inclusion of health consumers.

Not having immediate access to the entire patient files can and does compromise patient health and medical outcomes.   At a section in which the audience were told of the outstanding manner that iSOFT will control all patient files there was a question from the floor.
If a patient is scheduled to have an operation in one public hospital but has an emergency and that operation is done in another public hospital will the system advise the original hospital to cancel the operation as the patient has already been treated?
The answer was, 'it ***could.***' That was the full body of the response. 'It could.'
I understood that for additional cash input the new system could, but does not now, be changed so as to share patient information. To do this they will have to start with the **single unique patient identifier.**

I got the impression we were listening to a business plan discussing product not people.
Of note there is **no inclusion for the system taking and monitoring patient complaints within the new system.**

It is the business and the concern of health consumers and potential health consumers how large slabs of the Health Budget is spent, especially when that money is for 'upgrading' an administration system which looks very much like the existing system. For a new health focused system such as

Western Australia has recently embraced it would appear a paradox that the same health system could entertain spending money to introduce a new system which replicated many of the disadvantages of the current system. Not having instantaneous access to accurate records of the complete patient files immediately can and does compromise patient health and medical outcomes.

The following lists the various categories that the new system will address and give improved control.

TOPICS ADDRESSED IN THE BRIEFING:

- Patient Admission
    - iSOFT solution
    - Description of WA Health project
- In Patient
    - Referral
    - Waiting List
    - Admission
    - Theatre
    - Clinical Coding
    - Bed Manager
    - Dashboard
    - Document Management/Scanning
- Outpatients
    - Clinics
    - Scheduling
    - Queue Management
    - Appointment Notification – SMS
    - Dashboards
- Management Tools
    - Billing
    - Eclipse
    - Dashboard/Reporting/Alerts
    - Document Management/Scanning
- Medical Management

- ED
    - Functionality
    - iCHARTPro
    - dashboards
- User Interaction
    - Vantage Point
    - Summary View

We were told by the first presenter that under iSOFT:

- PAS & TOPAS would become redundant
- The new system would be used in 13 hospitals
- In those hospitals iPM would replace existing systems
- J Pharmacy was presently being rolled out by iSOFT at 22 hospitals (This is also known and identified as E-pharmacy by other users)
- EDIS was in 9 hospitals
- There were i CM in 13 hospitals

I am concerned on many levels by this news that the WA Dept of Health has embraced this administration expenditure under the cloak of eHealth, the new national system.
The new E-health is patient centred, this is not. From the information provided, iSOFT is administration focused in *tracking* patients while processing them from entering to exiting the designated facility.

At the briefing [09/12/09] this new, and I assume very, very expensive administration software is much of what we already have with our current health system will by design **still** not to communicate patient details outside of each building let alone around the State or interstate.

From the information provided,
13 hospitals will have the new iSOFT programme.
- How many public funded hospitals are there in WA?

  o More than 13?

  o What is to happen to hospitals not included in the 13?

  o What of patients attending those hospitals?

  o Will those patients be disadvantaged?

In the presentation there was no mention that any private hospital system was, or would be, involved in taking up this new software of iSOFT.
In the new E-Health, we are looking at a single national system that empowers patients' and treating clinicians' by improving reliable instantaneous communications of all of the facts of that person's medical history. This will improve patient health and safety.
 The briefing 09/12/09 appeared to have very little to do with that goal.

We were informed that;
- The new system would be used in 13 hospitals
- J Pharmacy was presently being rolled out by iSOFT at 22 hospitals

Why was there an apparent anomaly in the figure where 13 hospitals would operate with the new iSOFT programme but there were 22 hospitals that would use another of their software packages of j Pharmacy?
If the new system by iSOFT is so good why will 9 hospitals not have the whole package?

IMP implementation covered;

- Bed management.
    - The right bed of the right patient.
    - There was also identification of virtual beds. As the term alludes to these were managing beds and patients in real time but where was no real bed for the patient.
- Managing patient queuing out of ER

An idea I did think had merit was the creation of a ***transit lounge*** where admitted patients waiting beds could wait and also be used for exiting patients.

The improved data entry of the new software which included an automatic correction as demonstrated. There will be box for the patient's title. Mr. Mrs Miss Etc
If you type in 'Mrs' and later when the GENDER BOX has to be filled in and you put male then the new system will automatically go back and correct the TITLE BOX and change that to read Mr without referencing the data input person.
I did not see that feature as a benefit. In fact I saw this as a potential for a serious error. The gender is not just a social nicety; it actually revolves around patient safety. Correct patient identity is of primary importance in avoiding mistreatments in medical applications. I would have hoped when the system identified a difference it would be highlighted and a person investigate the difference and then make the correction. For safety the system could not precede until a manual decision was put into the system.

The iSOFT presenters then provided an in depth description of the features of the programme and how it will manage a hospital. Outside of this limited e-Health we are engaged in discussions of a new and potentially great revolutionary leap into a patient centred health care system. It was disappointing to appreciate money was currently being spent in replicating many aspects of an existing system along with its existing problems.
For a new health system being embraced by the WA Dept of Health that ***'will be patient focused'*** this new acquisition [iSOFT] is singularly not patient focused.

That was this consumer considered impression from attending the briefing.