Patients and clients expect their healthcare to be supported by effective information, decision support and access to a comprehensive evidence base. The National Programme for IT in England (NPfIT) is making tracks towards those expectations. MORE RADICAL STEPS considered issues of requirements and delivery; it did not create a blueprint but collective action plans can be based on the points made by the participants in this initiative.

Elements of the announcements from NPfIT are mirrored in the strategic direction for informatics to support health and care in all the home countries. There is an overarching common will to harness the opportunities presented by considerable current investment to the benefit of patient care.

This year’s MORE RADICAL STEPS think tank and consultation highlight that the new programme offers both major opportunities and areas where confusion, mis-direction, lack of detail and demotivation of the workforce could cause problems if not addressed rapidly. MORE RADICAL STEPS was hosted by the British Computer Society Health Informatics Committee in conjunction with ASSIST; demonstrating the increasing breadth and depth of participation across the UK in informatics to support care.

Yet again, a wide range of experts and interested participants from operational healthcare (public and private), the vendor community, consultant health informaticians and academia gave their time freely. They came together to reflect on key issues brought forward by NPfIT. MORE RADICAL STEPS let them consider and comment on current priority areas, such as:

- Communication of objectives, implications and positive progress from national programmes
- Risks that arise through and/or are being addressed by the national programme
- Actions that will encourage engagement with health informatics by all professions to the benefit of themselves and their patients and clients
- What needs to be done to establish local ownership and effective usage of health informatics solutions
- How the design, development and delivery of fit for purpose solutions can be achieved to support health now and in the future

There were many points of positive progress in informatics to support health, but it was recognised that there are still many issues to sort out. These issues are explicit to NPfIT and very pertinent to the NHS in England but also relevant to those in other areas and working within different models of care. Actions to address the points raised will involve many agencies and many individuals. The mood of the meeting was of enthusiasm to make these major national projects work for the benefit of improved patient care, regardless of traditional boundaries and hierarchies.

The actions outlined in this position paper are necessary to ensure maximum best return on investment in informatics to support health. The recommendations are endorsed by a large part of our community. Failure to consider the items raised, and the spirit in which they were considered, may ultimately further jeopardise benefits to patient care.

The centre pages of this document go into some detail of the points raised. The back page summarises our concerns.

**Definition:** Informatics is the knowledge, skills and tools which enable information to be collected, managed, used and shared to support the delivery of healthcare and promote health.

COMMUNICATION ISSUES

Many of the problems highlighted could be reduced by more attention to communication. The community interested in harnessing informatics for health purposes is very large and can, if engaged, create very significant benefits for care from their actions.

Many organisational changes and informatics developments are complex and their impact is wide ranging. The whole community needs to understand what is going on, what the impact will be and what they can do to help in the process. Communication will need to be fit for purpose, targeted differently for different audiences of public, domain and other external interested parties. Recommendations from participants showed that there is much more to do in this area, notably:

- To issue clear diagrammatic route maps, showing the interoperation of the strands of NPfIT; how they interact with other health informatics activities and what the end points are for each. These maps are needed for each community of practice within our domain – managers, clinicians in primary and secondary care, other professionals and those who deliver solutions to the service.
- To establish effective multi-directional communication between end users, strategic planners and policy makers and service providers throughout the duration of the programme. A "User Group" model may be a way forward, involving front line users, service and solution providers and management from all levels but led ‘by user for user’.
- To ensure understanding and comprehension of information - about patients, policies and protocols - through presenting and retaining information in its context.
- To recognise that organisational changes and realignment of responsibilities, for example from local to (clustered) Strategic Health Authority level will require time and effort to achieve effectively. Targets and schedules may be jeopardised if communication is not addressed as a priority.
- To create a readily accessible corporate repository of knowledge, evidence of good practice and benefits of health initiatives urgently. Even if past history is painful in parts, we must ensure that we know, understand and learn from our ICT, regardless.
- To constrain cascade forms of communication and training that have been proven to elevate ‘Whispers’ to the status of an organisational process; putting at risk competency and understanding of actions and plans amongst professionals. More effective QA processes are needed to ensure that drift is controlled.

Communications should be made readily and equitably accessible and understandable to all (including commercial partners); to ensure that efforts are not wasted. A distinct and unique website should be created for this major NHS programme. Material should also be available in other forms and not be buried in remote archives as the programme moves on.

GENERATING TRUST AND ENGAGEMENT

Over many years, NHS informatics developments have suffered from being under-utilised by their potential users. This has sometimes been because of inappropriateness for purpose, lack of adoption, mis-understanding of capability and ‘imposition’ of requirements from either one or both of the provider and client side. Concerns about health informatics are sometimes ill informed. Promoting positive messages, where valid, will help to increase trust in the solutions provided.

There is a wealth of experience in ‘islands’ of development across the UK. MORE RADICAL STEPS participants recommend that good developments and new innovative systems be displayed in a ‘Vision Centre’ (real and virtual), so that potential users can see what is possible and assure themselves where this would be of benefit to their organisations. The Vision Centre(s) could also be used for benchmark testing, awareness raising and training in new systems.
Similarly, all possible steps should be taken to recognise and capture experience to date in informatics to support health. If best practice and negative experiences were collected then in due course it would be possible to make failure to consider, use (or act on) stored material be seen as negligent practice. Collected historic wisdom must not be lost to the corporate NHS. Channels of communication about matters related to health informatics must be kept open and receptive to ongoing comment, question and dialogue.

Computing-related activity has not been seen as mainstream to healthcare delivery and management to date, but is in fact crucial to underpin effective care. The position of informatics should be stressed to empower decision makers to take steps to harness its capability, notably through:

- The centre taking action now to engage operational clinicians in determining how informatics will best be used in health; in order to avoid an escalation of issues in future phases of the programme
- Ring-fencing protected time and resources available to allow all necessary staff to raise their competency in informatics, including making cover available for such developments
- Stimulating cultural change that will break down tribal barriers to using records created by other clinical professions; thus taking steps towards realising power from holistic clinical histories
- Ensuring that clinical involvement in informatics is enhanced and integral to day to day working, without which few health informatics systems will perform up to their promise
- Promoting well-publicised audits of useful and useable information and what it can be used for will reassure sceptics that available content is necessary, sufficient and managed in a sensitive way. Current confusions over person-identifiable and pseudonomised data needs allaying
- Multi-media communication of intent, progress and benefits of informatics initiatives may inform more interested parties about ongoing activities, and it will also reduce the defence of ‘No one told me’
- Recognising that it is more realistic to expect people to adequately review a well-structured electronic record (EPR) than a poorly structured set of paper notes

On the other hand, commercial service and solution providers can increase the power of their offerings by:

- Becoming more aware of the complexity of the NHS and the environment in which it operates
- Ensuring that their client-facing staffs have appropriate qualifications and professional registration. This will add to the likelihood of valued dialogue, fit for purpose solutions and reciprocal respect for each party.
- Developing mature, non-adversarial relationships with their clients and those using their solutions which go beyond the letter of their contractual obligations and add to the richness of dialogue about the specification of prospective functionality and service requirements

All parties (commercial, strategic and operational) should recognise that there will still be competition for scarce resources and priority implementations. It is suggested that conflicts should be resolved at the level of a natural community; which may in practice frequently not be the level at which contracts were signed.

Some operational care initiatives currently encourage negative diverse fragmentation in informatics terms. There is very real potential for current National Service Framework specifications to create silo-based duplication, incompatibilities and factional suspicion if steps are not taken to create synergy and common purpose, especially in terms of Integrated Care Record Services. Supporting generic cross-cutting processes like the Single Assessment Process and Care Pathways could increase the impact and credibility, and thereby trust, in the worth of health informatics.
STANDARDISATION AND LOCALISATION 
HAVE THEIR PLACES

Attempting to establish a monopolistic solution across the loosely federated NHS even within one country or cluster of Strategic Health Authorities is viewed with considerable concern. The MORE RADICAL STEPS participants recognised certain areas for standards and others where customisation may bring larger rewards:

- Standards are required to represent workflows unambiguously across multiple care providers working together on joint pathways and programmes
- Further and earlier dialogue is required to resolve differences in comprehension about what clinicians feel they want and how their requirements are interpreted by informatics providers, in order to reduce the chance of costly failure and recovery actions
- Effort should be put into realistically challenging the loop which suggests ‘Modern is good; IT is modern; therefore IT is (always) good’. Clear specification and agreement of apriori criteria for good would avoid painful and damaging mud-slinging and retribution after the fact
- It must be recognised that care is commissioned and provided from sources that may be outside the NHS family. All parties regardless of origin should be convinced of the benefits of working to common standards that do not jeopardise the opportunities to deliver appropriate care and support

NPfIT and many other informatics initiatives in health require commitment, dedication and extensive resources from all parties. To avoid mis-understanding, a clear Route Map of what is required from local operational care providers (and what they will get in return from) participating in an informatics implementation should be drawn up and agreed in advance. As local organisations transition from their existing informatics position to the ‘new order’, care must be taken not to introduce errors through the conversion process, especially in novating applications and data content to other platforms.

In due course, the agenda for health informatics will be extended. This will raise more questions for the mid to long-term about which there should be thought now, including:

- How to turn the programme of procurement into a programme for delivery
- How to ensure that any locally indicated informatics products and services outwith NPfIT can be introduced and managed synergistically
- How to design contracts that facilitate a collaborative relationship with contractual robustness between NHS communities and their *Service Providers that will allow for and positively embrace changing requirements in the future at acceptable cost

DELIVERY AND FUNCTIONALITY

Informatics developments do not happen overnight nor can they be delivered without risk, too rapidly, or in isolation from operational practice and without cognisance of the political climate. This section of the MORE RADICAL STEPS describes recommendations that come from the sometimes cathartic experiences and knowledge of participants.

- The National Programme goal of establishing system phases so that benefits can be seen as early as possible is to be welcomed
- There is an implicit requirement and real need to ensure that operable NPfIT developments are rendered operational as soon as possible. This will require explicitly funded research, introduction of procedural change and comprehensive end-user empowerment on a much greater scale than is currently envisaged, described or resourced
A balance has to be struck between the need for standardisation on best practice and a flexible accommodation of innovation so that health services can evolve and improve over time.

The rationale behind some initiatives given central priority is seriously questioned; providing a threat to staff motivation, informatics credibility and the likelihood of a successful implementation of the national agenda. These include:

- Investment in the ‘Data Spine’ concept is questioned because typically only 1% of the data relating to a subject (patient / client) is currently in the hands of organisations outside the home patch. However there do appear to be reasons for its introduction for supporting Emergency Medicine.
- The concentration on e-transfer of prescriptions, as opposed to those acknowledged as having significant clinical priority and benefit, such as e-prescribing.
- The concentration on e-booking

If the national requirements were specified as a simple minimum specification with a framework of common terminology and accuracy of data attribution, leaving room for interpretation, we would get closer to fit for purpose and local ownership.

Activity profiles purporting to describe care delivery performance must not be taken at face value without clinical and contextual interpretation. Recent ‘Star Rating’ furore could have been substantially avoided by consideration of the figures in context.

Fragmented and confused funding structures for central data collection and provision of local data for personal care should be resolved. Current practices are not conducive to effective delivery of comprehensive records and activity profiles to describe actual organisational performance.

Care delivery will increasingly be provided from a mixture of public and private sources, and all necessary steps should be taken to facilitate consistent use of informatics to underpin effective health and social welfare. It will not be feasible, desirable or successful to impose NHS information structures and processes on other sectors without multi-party consideration of the implications of such a scenario.

A ‘thin-client’ electronic summary Emergency Medical Record will be increasingly needed to support organisation-independent care delivery from a mixture of public and private sources. Effort should therefore not be invested in promoting a “Thick Spine” to replace electronic patient records (EPR) systems. Harmonised strategic and tactical views on informatics support to encompass all sectors are needed to succeed.

The inability of the NHS to allow patients to easily schedule non-urgent procedures to fit with other commitments and to know reliably when urgent procedures will take place cause real problems for patients and their carers. There is a problem with the naïve view of politicians that booking in the NHS is just like airline booking. Substantial improvements in the quality and efficiency of services would flow from e-Booking done properly.

Professional staff mobility between care organisations is considerable. Staff who use informatics tools in their day to day work would be capable of operating more effectively if all basic system operation was more consistent. For example screen layouts and logon procedures should be consistent regardless of environment, applications systems or service providers.

The UK must not lose sight of the European requirements it is subject to. For example, the EU requires networked identification of patients entitled to cross-border treatment by 2005. The current specifications do not address this either for UK patients treated abroad or other nationals requiring treatment in the UK.

In addition, there is strong evidence that growth in citizens’ self-management and third party advice improves their own health. Current systems do not appear to accommodate functionality to capture these valuable elements of a full clinical care history; this must be addressed in the mid-term to ensure complete records are available throughout.

It is hoped that by taking actions such as those outlined above, we will ultimately reach a position where Chief Executives do not worry about where their data comes from and are confident in its fitness for purpose, quality and validity to support their care delivery and management business needs.
RISK MANAGEMENT COMES IN MANY FORMS

Risk may affect healthcare delivery from many angles. Realistically, response to possible litigation has increasingly to be taken alongside managing expectations in advance and educating clients about realistic outcomes from challenging procedures. There is risk in too much haste or development that is too slow. The NHS needs a balance between organic evolution and forced growth, and NPfIT has to be encouraged to take that route.

Informatics solutions must provide proper support to clinicians in the way they manage needs and priorities for each individual patient. For example, National Service Frameworks are intended to guide a clinician through the most appropriate care pathway in a flexible manner, recognising the individuality of the patient/client. Informatics solutions must be a catalyst not an inhibitor to appropriate care. NHS staff should not abrogate their responsibility to be part of the delivery of high quality care by assuming that NPfIT will solve all the management problems of the NHS without their participation.

There are questions and perceptions presently that, if addressed, would reduce risk to systems deployment and effective use and ultimately could have a positive effect on the outcomes of patient care.

- Where is the body that is ultimately responsible for awareness raising, training and education of all professionals on whom informatics will have an impact. Without an informatics–literate workforce we will not get the best out of systems deployment
- If full funding for change management is not forthcoming, even from multiple sources, then the likelihood of substantial returns on informatics investment is very limited. NPfIT will require unprecedented business process re-engineering in order to deliver
- Estimates of four to eight times current planned investment were suggested as necessary to carry out necessary professional training, organisational systems redesign and realignment to support a successful NPfIT. Until any other figure is ratified, the potential for NPfIT to have a substantial impact on care remains at serious risk
- Health informatics staff continue to vote with their feet and are demotivated by the lack of recognition and long term potential for them within the service. Further guidance and substantive contracts would be most welcome. The establishment of the UK Council for Health Informatics Professions (UKCHIP) as a voluntary registration body will go some way to meeting the formal need for recognition in general and the issue of National Occupational Standards will clarify the position re employers
- The risks surrounding patient/client and person-identifiable data consent issues should be addressed firstly across sensitive clinical areas, thus developing good practice principles that will be relevant across the whole spectrum of care
- People in the field who also speculate that timescales are driven more by political expediency than a feasible reality, consider many of the targets unachievable. Further revision of dates and requirements to avoid being seen to fail politically will not be accepted at grass roots this time
- Participants expressed a willingness to scale and schedule requirements to a level at which they could definitely be delivered and afforded

Success in NPfIT terms is necessary but not sufficient to success in overall NHS terms. Successful implementation of NPfIT needs to be judged on its impact on the quality and form of care delivered for and by the NHS and not simply on improvements in technical infrastructure and more cost-effective procurements.
Not all risks will occur in the same way at the same time in all places. The MORE RADICAL STEPS participants endorsed the establishment of Rapid Reaction Teams to be called off from a central pool when problems arose or advice is required; for example for contract negotiation, legal issues and the unintended consequences of technology.

The current situation is not the only risk area. MORE RADICAL STEPS participants scanned the horizon and looked at future NPfIT phases, and made the following observations.

- Transition from older to new systems is bound to generate data loss, but it must be recognised that even a 1% loss may be crucial
- Penalties intended for breaching confidentiality in the NHS cannot currently be applied similarly to the private sector. If we are to effectively work cross-boundaries then this situation must be harmonised
- What happens to the status of any functional specification with regard to NHS ownership after the development of solutions from it
- There is a need to future-proof the design of systems to avoid built-in obsolescence.
- The long term principle of NPfIT-contracted solutions should be ‘open source’ and non-proprietary, albeit with contract-duration exclusivity for the NHS and parties authorised by it. Systems should be flexible enough to accommodate reasonable local requirements without code changes, and to support innovation
- Corporate learning from developments like primary care informatics should be captured (perhaps as an element of the published NHSU corporate university commitment) and used to inform current and future initiatives
- NHS must move forward with interlinked comprehensive planning models like NPfIT and not revert to LIS/LDP models where each stood alone and provided little synergy

None of us wants to ‘take the fall’ if NPfIT does not deliver. We must be able to take all possible steps to create success, avoid failure and public outcry. We must work together or risk spending the money but not delivering the solutions. We are faced with a once-in-a-lifetime opportunity; we must not just plan to avoid failure.

Patients want their data to follow them throughout any and all of their care and are currently surprised when it does not. The MORE RADICAL STEPS position statement is intended to offer some recommendations on how healthcare providers may move closer to this goal.

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Hosting organisations

BCS Health Informatics Committee (BCSHIC) is a large community within the British Computer Society and is made up of geographic groups addressing health informatics, specialist profession-specific groups and a strong mix of constituent liaison bodies. In addition to informatics professionals working within national healthcare delivery and research facilities, the HIC represents clinical professionals and health managers with a significant interest and involvement in informatics to support health. Its activities, for example in national congresses, international activity and formal expert commentary can be found at www.bcshic.org

ASSIST is a national organisation established to provide a network for those involved in ICT in health and social care. The provision of a professional association is part of delivering a sense of identity, standards and common purpose to ICT staff. ASSIST works closely with NHS organisations to influence policy development and the HR aspects of the National Programme. Further details of their activities, branches and purpose can be found on www.assist.org.uk.
SUMMARY OF MAJOR ISSUES

This section highlights significant ways that could assist the National Programmes to make a positive difference. Informatics developments do not happen overnight nor can they be delivered without risk, too rapidly, or in isolation from operational practice and without cognisance of the political climate. No one sector in one country can resolve all the issues. It will take considerable effort from many agencies and all of us collectively.

Overall Issues

1. There is risk in too much haste or development that is too slow; the NHS needs a balance between organic evolution and forced growth in its informatics.

2. More attention must be given to communication. The community interested in harnessing informatics for health purposes is very large and can, if engaged, create very significant benefits for care from their actions. Utilise multiple media and target communication differently for different audiences.

3. Few health informatics systems will perform up to their promise unless clinical involvement is enhanced and integral to day to day working. Unless full funding for change management is forthcoming the likelihood of substantial returns on the informatics investment is very limited.

4. Standards are required to represent workflows unambiguously across multiple care providers working together, both in and outside of the NHS family.

Specific Issues

- Promote health informatics as crucial to underpin mainstream care delivery and management; ensure clinical and managerial involvement
- Establish a distinct and unique website for the National Programme for IT
- Recognise and capture the experience to date in informatics to support health; learn from the worse and develop the best
- Resolve conflicts at the level of a natural community
- Generate trust and increased worth from high impact joint informatics solutions supporting care pathways and singles assessment plans
- Balance standardisation and flexibility so the NHS can innovate, evolve and improve over time
- Develop mature, non-adversarial relationships between health clients and commercial service and solution providers
- Make basic system operation more consistent regardless of environment, applications systems, vendors or service providers
- Never take statistics at face value without clinical and contextual interpretation.
- Create, recognise and support an informatics–literate workforce
- Value the role of Health Informatics specialists
- Take actions to ensure CEOs are confident in their data
- Establish central Rapid Reaction Teams to counter unintended consequences of technology

We must work together or risk spending the money but not delivering the solutions. We are faced with a once-in-a-lifetime opportunity; we must not just plan to avoid failure.

**Success in NPfIT terms is necessary but not sufficient to success in overall NHS terms.**

Comments on this or any other informatics topics that support health, by emailing radicalsteps@amicconf.demon.co.uk. Also look at www.bcshic.org and www.assist.org.uk for ongoing expert commentary on HI in general.