BSC Health and Care Executive

BCS, The Chartered Institute for IT

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By E-Mail:

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Dear Will,

BCS response to the output from the Interoperability and Population Health Summit

The purpose of the BCS is to make IT good for society. Health and Care is one of the four societal challenges (alongside Capability, Education, and Personal Data) that the BCS is championing through leadership, communities and excellence. Our industry wide membership allows BCS to bridge expertise between sectors and share best practice, coupled with having a health and care focused community of digital leaders and Informatics professionals we are well positioned to be a critical friend driven by our shared goal to create a better future for the health, care and wellbeing of society.

Having sought the feedback of BCS Health and Care Members and as the Chartered body for IT / Computing in the UK, we welcome this open approach and the opportunity to provide a consolidated and reflective response to the "Target Architecture - Outputs from the Interoperability and Population Health Summit" document.

The context to the Summit is of course the serious state of the NHS and care system in England, brought about by the increasing pressures and demands made upon its services. We believe investment in technology and information, coupled with adaptive change, is one of the key ways to alleviate the current crisis. We must also stress, as Prof. Bob Wachter does, that successful IT implementation and adoption is as much of a people challenge as it is a technical challenge; we will continue to lead the professionalism agenda through initiatives like professional registration, through Fed-IP, for health and care informaticians and the development of a values and purpose driven community of clinical and non-clinical informaticians.

Executive Summary

A Target Architecture is clearly needed to help resolve the present failure of meaningful connection between care in acute providers and care in the community. We believe that a holistic, system-wide, architecture would provide a coordinated approach that should help deliver substantive benefit and value to the health and care of citizens. This would also allow all parties to make decisions in their day to day work that will aid progress towards this target.

The stated aim of the document was to enable "data to flow across the health and social care system to support the provision of the best possible care to our citizens." The intention is good, and the document presents an essential first step towards a Target Architecture, but we want to constructively highlight what we believe to be some necessary improvements. We feel in its current form it presents a hybrid of requirements, aspirations and assertions that mix business, data and technical concepts.

Specifically, the next version needs to address issues in the following areas:

- **Problem statement:** Redefine the problem statement and the specific business need the Target Architecture is seeking to address.
- **Concepts:** Be very focused on the introduction and description of concepts used. For example, 'Learning Health and Care Systems' and 'The Purposes of Information' were under-explored. Additionally, the key layer diagram missed many dimensions such as time course, population size, disclosive risk and patient safety criticality amongst others.
- **Clarity in expression**: For example the use of a sustainability example of patients waiting years, the national data lake, and the scenario in Appendix 1 (which was very hypothetical) need a more nuanced approach and more development to demonstrate they are grounded in the day to day experience of NHS and care system staff.
- **Consider international standards, and reuse of existing work more widely:** The focus of the document is on national (but not international) standards and principles which are presented as unique. However, many appear to be well known in places such as the Scottish Health system and this shows a missed opportunity to learn from others experience.
- **Architecture:** The next version of the Target Architecture diagram could draw on outputs from the International Standardisation arena that have already considered record and service architectures, functional models of PHRs, privacy by design and other areas.
- **Next steps:** We provide commentary on each next step outlined in the document. This includes the need for NHS England/Digital to be clear on the current roadmap to inform local investment decisions, implementability, the precise types of data envisaged, the legal basis for data sharing, and the need for local and national approaches to interlinked.

The Annex to this letter elaborates on each of these aspects as raised by BCS members, but it would not claim to be an exhaustive treatment. In conclusion, our view is that the outputs of the Summit as presented in the draft report require substantial improvement, but we recognize and welcome the open approach in sharing and consulting. The community of members within BCS are eager to contribute constructively, and we would like to offer to host workshops and / or panel discussions to further develop thinking.

Yours sincerely

David Evans, Director, Policy and Community

Andy Kinnear, Chair, BCS Health and Care

Stephen Kay, Vice-Chair for Standards, BCS Health and Care

Cc:

- BCS Health and Care members
- Jonathan Jeffery, Health Programme Manager, BCS

Annex A – BCS critique of Target Architecture

This response is structured under five headings, each section addressing the report's findings. Its structure mirrors those areas that have raised significant concerns.

Problem Statement

The Executive Summary of the Target Architecture document specifies the Problem Statement as "What is the Target Architecture that will support delivery of the Paperless 2020 ambitions that enable us to:

- bring together care information related to the patient in near real-time[1] at the point of care
- create a normalised view for the citizen and those involved in their care
- perform near real-time analysis tailored to the needs of the population as well as enabling decision support for an individual
- to achieve more precise targeting of interventions for citizens as part of their care"

There is the strong feeling from the BCS members who responded to the consultation that this problem statement is an inaccurate reflection of the real problem; the failure of connection between care in the community and acute care intuitions

The report does say that the problem statement as given leads to a wider set of questions. However, both examples of such questions were limited to issues of scalability, presumably intentionally, as these areas are the ones mainly discussed in the 'solutions' section later in the Summit's report.

The whole feel of the document is not improved by reference to the ambitions of 'Paperless 2020', a title which sets the aspiration bar low in terms of delivering personal care. The '2020' attribution is itself a problem, raising impossible expectations and we address this timing element later in this response.

The bullets and language that comprise the above problem statement, for example 'normalised view', are not explained or contextualised and the priority is only implicit in the sequencing of the list. It is not clear how these bullets should relate to each other, nor how they are dealt with in the Summit's proposals. At the very least, there are differences in the immediacy of any impact for the day to day business of patient care that are not addressed.

It is not clear that social care is specifically mentioned and unless that position is made crystal clear from the outset, then the opening reads like old 'NHS Health' and is in danger of wasting time and effort on something not required. Our consultation with members provided insight. *Work on the Innovate UK ALIP interoperability programme ultimately failed because the complexity of the financial responsibilities is such that co-working is dis-incentivised".*

Another comment re-enforcing these ideas, stating: "*The fundamental problem with the scoping of this document is that this is wrongly assumed to be 'NHS health' not 'person health'".*

[1] "near real-time" meaning that information can be accessed and used in an actionable period by citizens and professionals

Concepts in the proposed solution(s)

Within the context part of the document it is stated that:

> "A number of key concepts were discussed at the summit to address the problem statement set out in the executive summary".

The two key concepts presented are '"Learning Health and Care" Systems' and 'The Purposes of Information'. Both of these are important concepts but they are treated in too superficial a manner.

Learning Health & Care System (2.7 – 2.12)

This is a relatively old idea that is linked with the idea of organisational learning. It was taken up previously in health authorities, but was not successfully implemented and there is no clear roadmap that describes how to make this happen in the future. The repetition in the content of the Summit would suggest that the lessons from failed implementation were not learnt. An example of this is the proposed role of the EHR in the learning.

Converting data to knowledge is not a simple matter either. The complexity of data is made clear in the excellent book 'Big Data, Little data, No data' by C.L. Borgman. Although Borgman has a different scope and intention, the central topic and her depth of understanding are directly relevant to questions posed by the Summit's problem statement. The Summit report seems to imply that data to knowledge conversion is a straightforward process; if so, then they are mistaken and the Summits' proposed approach will not be able to deliver.

The following excerpt from the report introduces the terms 'latency' and 'two-delay' as explanation to a further quote that expresses nothing new. The fact that the references are not fully explained does not raise confidence.

> "A key metric of learning healthcare systems is the associated latency, this being a "two-delay" problem - data captured to data being available and then also data available to action being taken. "Current health data reuse is too little, too late, at too high a cost of information management."[2] "

Some of our membership felt that there was a failure to acknowledge the distinction between data re-use and re-purposing, with the latter carrying with it the additional burden that contextual and process metadata must be made available alongside the source data.

Furthermore, organisational learning must take notice of organisational culture. On the positive side, the Summit was an opportunity to share and learn from the experience of many. As one BCS attendee said:

"the summit for me represented a moment in time where a group of people were desperately struggling to make progress in this space came together to try and inch it forward".

The experience on the ground varies significantly from area to area and it is critically important that the this is shared and appreciated. Variability and good practice are essential components for stoking the development of any Target Architecture.

[2] Methods Inf Med 6/2015

Purposes of Information (2.13 – 2.20)

The figure in the draft report is introduced before the explanation of the 'Layers'. Furthermore, it is simplistic as the layered model implies dimensional characteristics across the five layers without articulating what this dimension refers to.

It also seems that the idea of semantics, interoperability and meaningful sharing is being played down. It is not clear that these ideas are understood in terms of the proposed architecture and we were unsure how this relates to the Interoperability measurement activity. There are many models in existence within interoperability frameworks. It is not clear whether the extended one given in the Summit report emerged from the workshop, or is grounded on another model.

Clarity of intent

There is a danger that the current confusing set of concepts, terms and reasoning will be carried forward. Reducing the use of jargon and following chains of argument through to the end will go some way towards rectifying this.

In **section 2.4** sustainability is mentioned. However, it is not clear to what it is referring and the description of new models of care and its expected outcomes does not seem to logically support such a concept without further detail. Arguing that "Users of the health care system are no longer prepared to wait weeks, months or even years to discover individual outcomes or describe collective performance" is not a strong justification. Users may be more demanding now, but surely none have ever been prepared to 'wait years'.

Clarity was also reduced by the use of jargon via terms such as 'two-delay', 'diameter of trust', and 'data lake'. The latter was seen as particularly unhelpful, with one person commenting:

"*The national data-lake concept is, at best, poorly described. A data lake runs the risk of being a dumping ground (data-swamp) of data that is poorly characterised and almost impossible to re-use or repurpose meaningfully."*

Determining the approach to supporting local learning health and care systems must be done concurrently with supporting national analytics and insight across various stakeholders. Consequently, the architecture needs to facilitate the creation of a national "data-lake" that is based upon the information held at a regional level and to be able to perform near real-time analytics and provide insight at a national level.

Some felt the appendix of process and actors in the Summit's report was unrealistic and not in line with the rest of the document. In addition, the lack of money being appropriated to problem areas meant that there was little incentive for the kind of changes outlined in this section to occur.

Again, the choice of material and its criticism reflects on the issue of clarity for an intended reader. The inclusion of Appendix 1 presumably is intended to ground the architecture and to explain its contribution. Unfortunately, it cannot bridge the gap between the coal face of day to day need in the NHS and the blue sky view from the Summit.

International Standards & existing work

In **section 3.9**, emerging principles from the Summit are presented as being new, whereas most are preexisting to some degree. There is a need to consider work in Scotland in this area as they have at least 5 years practical experience that the English system could learn from.

The document as it stands presents a selective view of the problem and does not make enough reference to wider standards. A case in point is the area of standardisation. One comment points to the need for defined standards and an appreciation of complexity and implementations in other domains:

"The NHS (and beyond) must be coordinated in any approach, not have multiple systems and work to defined standards in partnership with local provision. They (we) must learn from previous mistakes and move forward to make IT good for society"

When mentioned at all in the document, standardisation is almost always mentioned in the context of national standards. Other areas in the document omits consideration of standards altogether, for example **section 3.26** on the process between data governance and delivery. In the area outlining next steps, the lack focus is still apparent as it avoids the idea of a 'learning system' as shown in the following:

> "To urgently accelerate the definition of the *national* standards - both in the common set of interfaces and also the national datasets required, as well as the delivery roadmap for 'do-once' national infrastructure capabilities based on open standards and open source approaches.
>
> To investigate the optimal delivery approach for "standardised components" and also *national* procurement frameworks to drive consistency in the capabilities delivered and create appropriate market dynamics."

International standards and perspectives are mainly ignored in the output and the BCS believes this to be a detriment to establish a working system going forward. Open standards and open source approaches need to be clarified too.

Architecture

There are numerous architectures in the International Standardisation arena that might be considered for adoption and our members were unsure where the Target Architecture diagram come from. If it was from the Summit, the text in the report does not show clearly how it was compiled. If it was from another source, the rationale needs to be addressed.

One member commented on this asking:

"Why are we defining the architecture and prescribing that this needs to be coterminous? Surely the focus should be on allowing these communities to be supported by appropriate services, where each of these services are defined with respect to clearly articulated and standardised service contracts. The underlying architecture should be irrelevant to these communities."

There were also concerns with **section 2.12**, with confusion as to whether it was saying that mature architecture needs to include a catalogue of terms.

In general, the graphics and diagrams are not particularly clear, with an example being elements of the proposed target architecture chart **Figure 3**. Examples such as this again strengthen the plea for more clarity and explanation if they are to have any value for the new reader.

The Summit report says that these platforms should operate on principles of "Privacy By Design". We would argue that it would probably be more accurate to say that the delivery and configuration management of these platforms and services would take a 'Privacy by Design' approach, since this is not a feature of steady state Business as Usual (BAU) operations. Again, we would point to the on-going work being done in this area particularly in mainland Europe.

Finally, in response to **section 3.25** which read:

> "An alternative approach would have been to look to provide new centralised data services for local and regional population health management. However, this does not take into account the significance of establishing trust and instilling local confidence in the confidentiality, security, agility and flexibility in nationally delivered data services."

The following comment sums up many concerns:

"There is a big difference between a centrally hosted data service and a nationally delivered one. The first simply refers to the underlying data management service (or services) that are put in place whilst the second refers to the business rules and policies that are enacted to disseminate the data. They are quite different architectural constructs."

BCS Response on Next Steps and Considerations

1. To engage on the proposed target architecture with the attendees of the interoperability summit and then to wider stakeholder groups.

   Response: We hope that the BCS response will help to catalyse the debate and start a process of convergence towards a useful architecture, whilst openly admitting that there is some way to go. The wider audience would be aided by more clarity with less jargon. There was also a suggestion that it could take the form of a Wikipedia-style piece that could be frequently and easily updated.

2. To consider the approach and guidance on supporting the self-organising groups and their scale to establish learning health and care systems.

   Response: This opportunity should be used to build and improve relationships between the different stakeholder groups and to ensure learning is not restricted. This is not a short-term fix and expectations have to be managed with solutions being realistic. There needs to be a better understanding and justification of community size, scale, capability and capacity to deliver.

3. To outline the leadership and delivery expectations that would need to be in place locally to ensure that this implementation can be achieved and benefits realised.

   Response: It depends what is meant by implementation here. We do not believe one size fits all, nor that the local needs or capabilities and the level of maturity will be the same throughout England. It should be an evolutionary approach to adoption rather than wholesale reorganization.

   Cost/benefit analysis of options for such a critical public investment would be of use too as value for money is essential as resources are scarce. The implementability of regional platforms, whilst challenging, is possible to achieve if resources are made available. But as one contributor said *"there is not any money anywhere in the NHS now, it's bloody hard going."*

4. Further work in outlining the information governance implications of the target architecture, including taking account of the work to develop anonymisation guidance/standards and incorporating privacy by design in early stages.

   Response: Clarification on what type of data the report is referring to is necessary. The assumption that rich data is not needed nationally, mentioned in **section 3.13,** is unsound and researches and health experts would not want to get data via regional platforms. There is also a belief that the report underestimated the likely influence of regional politics when it comes to NHS England being able to implement change.

5. To outline the local ‘design guide’ for regional platforms - including the key capabilities needed and which ones will be delivered nationally.

   Response: Security and Information Governance are not addressed at depth in the document outside of NDG work and there is a real need to look into this in further detail potential legal ramifications.

6. To urgently accelerate the definition of the national standards - both in the common set of interfaces and also the national datasets required, as well as the delivery roadmap for ‘do-once’ national infrastructure capabilities based on open standards and open source approaches.

   Response: It is not obvious who will accelerate the definition of standards. It will also likely prove difficult to implement numerous regional platforms with different vendors and timescales while trying to hold together the national picture too.

7. To investigate the optimal delivery approach for “standardised components” and also national procurement frameworks to drive consistency in the capabilities delivered and create appropriate market dynamics.

   Response: We should call on NHS Digital to publish a roadmap of the national enablers as soon as possible, so local investments can be made with confidence of what's available when. There is also a realisation that we ought not to aim for perfection, or let unsuccessful work drag on, when there is such a need for rapid implementation.

8. To work with the NIB portfolio, its programmes and the EAB on the implications of the target architecture. This includes further definition of the national capabilities and also detailed architecture definition for different uses cases on sharing of citizen provided data.

   Response: Answers in this area could use more detailed architectural thinking. Members could envisage a model with local data platforms supporting point of care or population health analytics for example. This was more difficulty when it came to seeing this feeding this into a wider national picture. Although it is surely possible, more questions need to be answered around how it would work and how we can be confident of its success.

9. To outline next steps in moving towards the target architecture and the minimal viable approach needed for lower mature localities whilst taking account of market and innovation implications.

   Response: National and local must work together. This will involve high levels of emotional intelligence, actions to back up words, investment and delivery locally where it makes sense to do so and investment and delivery nationally where it makes sense to do so, all in a coordinated manner.

10. To outline the emerging needs for evolving national functions e.g. outcomes-based re-imbursement models, risk-based approach to quality regulation and the implications on the target architecture.

Response: We would support this, but would stress the need to learn from neighboring nations, particularly Scotland. A commitment to use international standards where appropriate should be made.

Conclusion

A recent press report ('The *i* Paper', 12th January, 2017) carried the following:

"The Government has set various targets for 2020 on finance, staffing levels and patient care. However, Simon Stevens said:

> *"Debate about 2020 this and that misses the point.*
> *In the here and now, there are very real pressures.""*

This quote seems to crystallise the different perceptions of NHSE and NHSD and directly relates to the BCS critique of the Summit's problem statement. The response given to Next Steps (9) above supports the idea that it is not one or the other, but both local and national working together, that must occur in order to move forward and ensure the best opportunity for success in a short timeframe.

We would argue that the Target Architecture must therefore have a plan and a published timescale, taking into consideration the variability and maturity of existing systems. It must be seen as a realistic, collaborative venture that delivers value.