DHACA initial responses to 'Personalised Health & Care 2020'

Purpose

This document is an initial response from the Digital Health & Care Alliance (DHACA) to the NIB regarding the recently-published Personalised Health & Care 2020. Its main purpose is to register DHACA's strong support for the initiative and to seek an early audience with appropriate members of the NIB as we believe our members can make a very significant positive contribution to the successful delivery of the plan.

DHACA

DHACA is an organisation sponsored by Innovate UK with a specific remit to encourage interoperability between health & care systems in the UK, and to encourage sharing of innovation development to reduce money wasted on reinvention. The current 330 members of the Digital Health & Care Alliance ("DHACA") are drawn from across the board of government, academic, large corporate, SME and charity sectors, and include both patient and developer representation.

DHACA operates primarily through (currently) nine Special Interest Groups ("SIGs") which comprise members with particular skills and knowledge relevant to each area. The SIGs are: Benefits & Value, Economic & Business Modelling, Healthcare Education, Information Governance, Medical Apps, Patient Viewpoint, Reference Architecture, Scalability and Self-Care

Summary

DHACA is extremely supportive of the plan described in the paper. As will be apparent from the listing of SIGs above, many areas mentioned are ones where work is already well underway in

DHACA, so we do have value that we can add immediately, as well as the ability to bring in a wide range of expertise from our extensive membership; we are very keen to work with the NIB to make it a reality.

In more detail

What follows are our more detailed initial comments; we welcome the opportunity to expand on them with the NIB.

Chapter 1 – Why do we need to act now?

We were especially pleased to see the recognition that "For care professionals, from social workers to doctors and nurses, the arrival of the digital age has often been experienced not as a force for good but rather as an intrusive additional burden in an already pressured existence." We welcome the opportunity to work with the NIB to help overturn this still widely-held perception.

Chapter 2 – Can it be done?

We welcome the reference to the importance of standardisation, be it formal or by evolution & informal adoption as this is a prerequisite to our drive to improve interoperability between systems.

The challenge of course is getting the balance right between enforced adoption of formal standards and allowing innovation. As digital services are in the early stages of evolving, standards should only be enforced where absolutely necessary, as inappropriate enforcement will stifle innovation, as there's no means to do something different within the strait-jacket of the standards.

Two further considerations are:

- The standards documents must be freely available to read if uptake is to me maximised, especially by SMEs. IEEE, BSI and such like charge very substantial sums to gain access to standards, even as a PDF; this can be a major barrier to someone who wants to have a quick look to see what it's like.

- The standards development process needs to be truly open and inclusive. The process currently set out in the Standardisation Committee for Care Information's (SCCI's) Operating Framework is far from this – it is extremely bureaucratic, and assumes that HSCIC staff will do all the work, only taking input and comment from others. We believe this risks stifling development and innovation. Best practice is to have the standards development done in an industry forum (DHACA would be delighted to assist) and then, if necessary and when pretty-much stable, ratified by a more formal body such as SCCI. This is what has worked very well in the digital TV and mobile phone sectors – some of the recently most innovative digital sectors. In short, we believe that the NHS needs to "let go" much more and let industry and health informatics people work collaboratively as peers. Great things will then happen.

We would add that founder members of DHACA were heavily involved in introducing videoconferencing into Airedale – one of the best practice examples given in this chapter.

Chapter 4 – what needs to change?

A recurring theme in our comments is the issue of standards, as we believe that intelligent application when appropriate is the key to rapid innovation. We are therefore very supportive of the comment: "We will be tight on standards and definitions, and clear on expectations regarding interoperability, but we will support local decision-making on systems, programmes, interfaces and applications."

DHACA's members have enormous experience in determining and measuring the benefits of digital health interventions; we would therefore be delighted to assist the NIB in developing the road-maps and business cases for the resources required to deliver this plan.

Chapter 5 – Enable me to make the right health and care choices

We welcome the assurance on page 21 that all GP records will be available to view by patients through apps and digital platform of their choice by 2015 (although we understood from pronouncements elsewhere that this commitment now only covers SCRs), on p23 that this will extend across all NHS institutions by 2018, back on P21 that NHS Choices is to become single point of access for digital transactions for NHS and that on p22 it says NHS Choices will adopt GDC Identity Assurance service.

In more detail, we believe that all records access and transactional services must be provided via APIs that are accessible by any/all accredited apps. These APIs must be defined in open industry forum as described above, and the specs openly available to anyone. NHS Choices must not have special access – it should be required to use only the same APIs as any other app or web service.

We consider that adoption of GOV.UK Verify (brand name for GDS IDA service) is the right choice – however it will need to be tailored for the ID assurance requirements of the health and care sector.

A particular area of expertise in DHACA is medical apps where we have a SIG already working on flow diagrams to help app developers ensure they have covered all the extensive legal requirements when developing apps, to help them then navigate the CE certifying process, and to help clinicians understand what they need to do before prescribing or recommending an app. We already have significant expertise in understanding what are good, beneficial, apps, and what are not, so we would urge the NIB not to define its own stand-alone "kitemark" all over again – instead we are extremely happy to assist, along the lines of the wider "trustmark" framework that is being proposed by the CDE Catapult and the Information Economy Council.

We particularly welcome proposal v. as we have been hugely impressed by the mental health apps developed by our members – these have an opportunity not only to enable diseases to be diagnosed & monitored electronically, they can also treat people electronically. Intriguingly many providers claim that treatment gives better results when done online than face:face – one reason for this is that there is a record of the consultation that patients can rerun afterwards, should they wish to, to ensure the key messages are absorbed.

We note also in proposal v. a reference to "rapid trials", a topic that DHACA has been working on with Professor Jeremy Wyatt of Leeds University, an acknowledged expert in this field. At our request he has produced a proposal to develop a technique for rapid trials of medical apps using the

'A/B testing' technique developed by the banking, insurance, travel and online shopping industries for rapid app appraisal. He is all ready to start working with us when we can find the funding!

Other DHACA SIGs could also assist too, most notably Reference Architecture, Economic & Business Modelling, Information Governance and Self-Care.

Chapter 6 – Give care professionals and carers access to all the data, information and knowledge they need

As mentioned earlier, we were pleased to see on p27 a reference to limiting standards only to where needed.

On p28, reference is made to apps recording and transmitting clinical data, and clinical decision support systems using this data. Medical Device regulation is of course governed by European law and has huge impacts here; it cannot be sidestepped. Most of the app industry doesn't understand it. There is therefore lots of Fear, Uncertainty and Doubt which needs clarifying & resolving if successful apps are be used across the NHS. Many apps clearly do not meet the MEDDEV 2.1/6 definition of a Medical Device, however some important ones certainly do. DHACA already started on this with published guidance, however we recognise the need to go much further in order to remove perceived barriers, whence the work of the Medical Apps SIG referred to earlier.

DHACA (via its SIGs) could beneficially be involved in many of the proposals on pp29-31, 34-35.

Chapter 7 – Make the quality of care transparent

We are very excited to see the proposals to develop the MyNHS website as a way of encouraging clinicians will to take personal responsibility for the care that they provide. DHACA would be delighted to input into the development of priorities for the development planned for finalisation in March 2015.

Chapter 8 – Build and sustain public trust

DHACA welcomes the proposals to build and maintain public trust.

The Information Governance SIG would welcome the opportunity to be involved in the proposed development of a roadmap for moving to consent-based information sharing (proposal iv, p41).

We would further suggest that the re-launched IG Toolkit (proposal vii, p41) needs to be app-friendly. DHACA could help – specifically the Reference Architecture and Information Governance SIGs.

Chapter 9 – Bring forward life-saving treatments and support innovation and growth

DHACA greatly welcomes your objective of establishing England as one of the world's leading centres for innovation in digital health and care services. Our commercial members would obviously particularly welcome it, although our public sector and patient representatives will benefit hugely too.

We would naturally therefore welcome the opportunity to be involved with many of the proposals on pp44-46 – e.g. ii, iii, viii, ix, x.

One of our members, the Bradford Digital Health Enterprise Zone and associated CDE Catapult Local Hub would add particular value to proposal vi.

Chapter 10 – Support care professionals to make the best use of data and technology

We consider the choice of Mersey Burns as an exemplar to be a particularly appropriate choice. Rowan Pritchard-Jones, the leader of the Mersey Burns innovation, has addressed DHACA-attended events three times to date, to enable us to learn as much as possible from the development and marketing of this truly outstanding app.

DHACA's Economic & Business Modelling SIG would especially welcome being involved with proposal iii and p49 (framework contract for digital strategies etc.).

Chapter 11 – Assure best value for taxpayers

DHACA welcomes the objective of this chapter.

We particularly welcome the proposal to align existing national programmes with the core outcomes of the document to maximise their cost and clinical benefits, and your proposals for the termination of ineffective investments. We would be delighted to assist.

Stressing again DHACA's interest in standards, we welcome the proposed publication of security and interoperability standards for common services to be purchased directly by care providers, such as email, to allow them to connect to the national infrastructure and provide confidence for inter-organisational transactions.

Chapter 12 – How can we make it all happen?

DHACA is dedicated to open systems, so we greatly welcome, especially, the commitment to default to open by working in the open and ensuring all new source code is open and reusable.

As the issue of 'kitemarking' apps is again mentioned here, we would suggest again that there is no need to develop yet another standard for apps to meet. The picture is, again as mentioned earlier already very complex with apps potentially legally being required to meet medical device, data protection and consumer protection legislation. We would suggest instead that the MHRA might be staffed up, particularly to police the medical apps world and ensure that apps commonly in use in high risk areas, such as dosage calculators in hospitals are appropriately certified if they are medical devices.

In our discussions with GPs, they have indicated a particular welcome for an efficacy measure for medical apps which DHACA has already previously suggested would best be developed by NICE, a suggestion also agreed by senior NICE personnel such as Prof Mike Kelly. We would be delighted to pass you the research we have done on this topic and work with you, if you wished, to build a system acceptable to GPs that as far as possible enabled the benefits of apps and drugs to be evaluated comparably so, say, a GP could decide whether a mental health app or an anti-depressant drug would be more effective for treating depression. We would suggest based on comparing costs that that would save the NHS substantial sums, too.