Advisory Board Meeting Minutes, 25 April 2019

Venue: British Computer Society, 1st Floor, The Davidson Building, 5 Southampton Street, London, WC2E 7HA

Meeting Chair: Prof Maureen Baker (MB)

Present:		
Alannah McGovern (AM)	Helene Feger (HF)	Myer Glickman (MG)
Chloe Adams (CA)	Holly Kearn (HK)	Neelam Dugar (ND)
David Watts (DW)	Ian Turner (IT)	Nick Booth (NB)
Don Redding (DR)	Keith Strahan (KS)	Nicola Strickland (NS)
Dr Iain Carpenter (IC)	Kim Bellis (KB)	Obi Amadi (OA)
Dr Ian Rodrigues (IR)	Laura Cameron (LC)	Prof Maureen Baker (MB)
Dr Ian Thompson (ITh)	Laura Fulcher (LFu)	Rebecca Cook (RC)
Dr John Williams (JW)	Lorraine Foley (LF)	Ross Scrivener (RS)
Dr Julian Costello (JC)	Marlene Winfield (MW)	Sophie Randall (SR)
Dr Laszlo Igali (LI)	Martin Orton (MO)	Suzy England (SE)
Dr Michael Thick (MT)	Mike Andersson (MA)	Zahid Deen (ZD)
Euan McComiskie (EMC)	Kathryn Moyse (KM)	
Guests:		
Abby Vella (AV)	Dr Sandy Mather (SM)	Kenneth Harris Jones (KHJ)
Bharat Marka (BM)	Jennifer Noel (JN)	Richard Triffitt (RT)
Dr David Davis (DD)	Katie Thorn (KT)	Samantha Bergin Goncalves (SBG)
Apologies:		
Afzal Chaudhry (AC)	Jeremy Bewley (JB)	Peter-Marc Fortune (PMF)
Ajay Aggarwal (AA)	Joe Noar (JNo)	Phil Koczan (PK)
Alexia Tonnel (AT)	Karen Selby (KS)	Philip Scott (PS)
Ben Bloom (BB)	Kate Brintworth (KB)	Sarah Campbell (SC)
Catriona Davenport (CD)	Lucy Butler (LB)	Sarah Jackson (SJ)
David Riley (DRi)	Luke Readman (LR)	Stephen Goundrey-Smith (SGS)
Debbie Brown (DB)	Mark Golledge (MG)	Steve Casson (SCa)
Dr Brendan O'Brien (BO'B)	Matthew Curl (MC)	Steve Van Wagenen (SVW)
Iain Moppett (IM)	Michael Folan (MF)	Tom Hughes (TH)
James Palmer (JP)	Mohit Khurana (MK)	Usha Grieve (UG)
James Reed (JR)	Natalie Koussa (NK)	
James Sanderson (JS)	Paul Miller (PM)	

1. Welcome

The Chair (MB) welcomes everyone and thanks the British Computer Society for hosting us.

The Chair welcomes our new member organisations and their representatives attending their first meeting: Faculty of Public Health (MG), Health and Social Care Alliance Scotland (ZD) and the Intensive Care Society (SM attending on JB's behalf).

MB mentioned the fact that our membership spans the 4 nations and that we desire to strengthen relationships and commitment from respective governments as most funding currently comes from organisations based in England.

JW from the Faculty of Clinical Informatics (FCI) said a few words. JW noted that MB was key in the setup of FCI. The FCI was established in June 2018, to represent clinical informatics and clinical informaticians. FCI is a multi-disciplinary UK wide body, and it is keen to attract a wide range of professionals. The faculty currently has 350 members and urges anyone who is PSA registered to apply. They have regular rounds of recruitment 2-3 times a year. The FCI are working on defining core competencies and accrediting courses.

No declarations of interest.

2. Minutes, actions of the last meeting and matters arising

Vendor policy - approved.

No errors or omissions in minutes.

3. Chair and CEO Updates

Chair update

Heightening PRSB's profile - twitter

MB highlighted the importance of increasing our reach and influence through tweeting. We need to share the issues passionately debated at the advisory board more broadly and use twitter to further our aims. Members and Advisory Board reps are encouraged to use this medium.

MB informed the advisory board that system sponsorship will be moving from NHSD to NHSX (applies to relationships in England only, no change with other UK nations). We shall maintain our important relationships with NHS Digital. Members are asked to tweet and influence NHSX as opportunities arise. We want to be viable and recognised as an important stakeholder for NHSX from the beginning. We are asking NHSX to send a representative to the next advisory board meeting.

MB encouraged members to tweet and extend the spread of the LHCR survey (aiming for 1000 responses) as it is critical for all professionals and patient/people/carers to have their say and to fully engage in this ground-breaking development.

NICE

Landmark event for NICE to endorse our discharge summary linking our standards to the NICE guideline to create a mutually reinforcing system. MB confirmed that we are hoping to get other standards through the NICE process.

Joint workshop planned with NICE on digital clinical support **10th June**. More details to follow.

NHSX

LF asked the members for their initial perceptions of NHSX, the potential and opportunity and for advice on what we should be saying in any engagement with them.

NHS X feedback:

LFu is worried about how NHSX will avoid organisational bias and cross over with NHS Digital. LFu mentioned two areas; user engagement through their empowered person board and needing press.

KHJ suggested PRSB act as a safe haven for more vulnerable and harder to reach in society as not everyone is up to speed on the agenda.

MA stated that we need more clarity on who is doing what.

EM suggested PRSB should send a communication to members on what NHSX and what the implications are to help people understand it . This could also be an opportunity to explain PRSB's role and purpose.

IC said that the four nations are doing enormous work and that NH X needs to formally engage with them to reinforce the dialogue.

KS questioned where social care fits?

ITh suggested NHSX focus on citizen-based pathways through H&S care.

Strategy

LF told the advisory board that PRSB are planning on updating our strategy but our 18/19 plan is a bit late as there is currently a lot of uncertainty in the system. We will be in touch with member organisations with further information on key changes and a webinar date to discuss our strategy refresh.

RCP – senior digital role

LF notified the members about a job opportunity with our partners the Royal College of Physicians who are recruiting a Clinical Director of Digital Health. This is a great indication that digital is now being considered both key and mainstream. LF urged members to apply or to pass on the job advertisement.

4. Adult Social Care

Introduction to Adult Social Care - David Watts, ADASS representative.

DW director of adult social care in Wolverhampton, provided us with insight into the current climate in social care. DW stressed that the adult social care sector consists of a number of organisations which vary massively in size and services offered, for example there are lots of small providers as well as directly employed personal assistants, unpaid carers etc. Management and responsibility for various services within social care is also dispersed. These factors make Information sharing difficult, discharge planning is particularly problematic. Serious case reviews, discharge summaries not following people back into the community – these all have impacts – key bits of information are missed as there is no consistent way of sharing that information. Investment in infrastructure is necessary.

Policy Direction (social services and digital) - Ian Turner, Care Provider Alliance representative.

IT Chair of the registered nursing home association and a nursing home provider with 300 beds in Suffolk, spoke about the spectrum of digital maturity, with some providers still paper based and others using mainly digital systems. IT mentioned that a lot of information is being shared insecurely on mobile phones without standards. Echoing DW, IT reminded us that provider services are very small on average and that 70% of care homes have less than 20 beds. These smaller homes do not have staff managers or IT professionals so the transfer to digital is challenging. IT spoke about the positive establishment of a new network the Care Software Providers Association (CASPA), which hopes to promote the continued growth of the use of digital technologies and the flow of digital information across the social care sector. IT spoke about some different ways of working care providers have been trialing and mentioned the progress with medicines optimisation in the sector.

Person lead integrated care (about me) - Keith Strahan, social care representative

KS, social worker by background, principle clinical lead for social care at NHS digital spoke about the importance of joining up the various health and care services that support an individual. KS listed some opportunities for joining up care – the local health and care records (LHCRs) programme, local sustainability and transformation partnerships (SDPs), Integrated care systems (ICS') and primary care networks (PCNs) and emphasised the role social care has to play in all of these. KS stressed that information must flow two ways, for example care homes hold information that would be useful for GPs. The Sutton red bag which goes with the patient includes standardised information that is hopefully updated and will follow the patient home. The Sutton red bag programme has now been digitised. KS prompted us to look at Sutton and see the useful information traveling from social care to Clinicians. Potential for a new standard. KS also spoke about the national reasonable adjustments flag which is a flag in medical records to indicate someone might have a significant need (physical sensory disabilities and relevant conditions) is about to be piloted in the summary care record viewer soon.

NHS digital social care programme

The NHS digital [social care programme](#) is focusing on improving digital maturity in the adult social care provider sector, funding good practise across the country, so far 40-50 sites have been recognised for doing really good work. KS also spoke about the programme's procurement which the Care Provider Alliance won for a new website called digital social care.

KT explained that the [website](#) will go live in beta service at the beginning of May, hosting guidance for care providers on the data protection toolkit and secure email accreditation as well as offering a digital maturity assessment. The website will fully launch in June.

Social care digital pathfinders

KS brought a [funding opportunity](#) to our attention. Funding is available for existing projects focusing on standards or data taking place in adult social care providers based in England. The funding aims to help providers scale up these projects over a two-year period. The application deadline is **5pm**, Wednesday **22nd May** 2019. KS suggested that at the end of the 2 years there is potential for PRSB collaboration with standards or guidance to support implementation.

5. **Case study**

The importance of about me information – Samantha Bergin Goncalves, Carer

SBG demonstrated the importance of about me information in the context of her son Shane (21) by showing us his RIX wiki. Wikis are personal websites that can be used to create multimedia person-centred plans for people with learning disabilities and those responsible for their care.

SBG emphasised the importance of people understanding Shane as a person and that the family demanded that those supporting them considered Shane's aspirations too.

SBG showed us the digital tool that contains Shane's about me information. SBG has found that sharing small pieces of information like this avoids distress for Shane, unnecessary Doctors' appointments etc. SBG told us that they also store Shane's documents on the wiki, which would physically be boxes full of paperwork, digital storage makes things like certificate expiration easily viewable.

SGB explains that digital storage of information detailing Shane's aspirations has led to better support. SBG says that when the importance of their work in helping Shane becoming an independent, mobile adult is communicated those supporting his care can help him achieve these objectives but without understanding the positive and negative impact of the care you give and receive, mistakes can happen. Before SGB used videos and photos, in the context of Shane's mobility the family would have to speak to the school, look at the physiotherapists case load, organise a visit and hope someone is taught how-to put-on Shane's stints properly.

Other benefits SGB listed were image storing, SGB keeps digital copies of Shane's previous x-rays so in the instance that he sustains an injury, the professional caring for him can see what 'normal' looks like for Shane. A digital tool also means that

information necessary for Shane's care is accessible without his parents needing to be present. A digital tool that contains all Shane's information avoids, potentially distressing, repetition. The multimedia function allows Shane to act as an active self advocate and he can demonstrate things that he has worked on and achieved.

SBS insisted that the barrier to poor behaviour is poor support. Sharing this vital information is key to his wellbeing. Huge thanks to the social care team and to Sam for showing us a practical example of where we can go.

6. Wales

Nationally relevant standards work in Wales – Rebecca Cook, Head of Information Design and Standard Development at NHS Wales Informatics Unit

RC from NHS Wales informatics unit has led on data standards development and assurance for fourteen years. RC is also the programme lead for SNOMED terminology implementation across Wales and Chair of the UK board that governs the products and services NHS digital provides to the UK. RC's team do standards development for Wales.

RC informed us that through the welsh clinical portal, they can access pathology results regardless of where they were taken and the GP record across the whole of secondary care in wales. Single sign-on to systems in wales allows access to the master patient index so they can securely identify the same patients.

There isn't a clinical data repository in Wales yet, but this is being worked on and will focus on allergies and adverse reactions in the first instance. All the information goes into a data lake for analytics feeding AI systems etc.

Document metadata standards

The Welsh Care Record Services contains over 19 million documents, accessible across organisational boundaries in Wales. They are indexed for retrieval via the Welsh Clinical Portal. They were strict recording demographic information to ensure that documents absolutely belong to particular patients. They are now refining the metadata model specification; and will make sure these are compliant to the standards. RC asked whether they should reject documents that do not meet the criteria. Is this a clinical risk? Or a risk that we can't attribute it to a patient because the quality is low?

RC mentioned information governance constraints around information sharing. The consent model is so important as Wales do not have the opt out programme. Wales are currently working on a data promise - what they will and won't do with people's data.

In wales they have a delivery arm, if they are going to use a standard, they test it.

Welsh government funded clinical informatic nurse leads across Wales to work with RC and team who gathered 60 different inpatient forms across wales to look at what they captured. They reduced a 60-page document to a 14-page document. This is being piloted on wards to test whether they are recording the right information. So far, this has saved 10 minutes per admission for nurses. NHS Wales informatics unit

are now delivering the digital version of these standardised nursing documents, aiming towards tablet use at the bedside.

RC remarked that district nurses have been standardising their information also, the chief nursing officer was keen to strip away any idea of community as different.

Wales are determined that SNOMED ct drives implementation rather than mapping occurring after the fact, they have developed a maturity matrix to support this. They are also working with NHS Digital and a terminology service. NHS Digital are the authoring/ master server and Wales and other regions each have hub or team servers.

LI asked RC whether Wales thought about using modern tech for databases and stated that the future in healthcare is graph databases.

RC responded that she would need to defer to her tech architect to answer fully but that they will be putting the documents in one store rather than in several services.

MT noticed that there had been no mention the NHS number

RC told us that to get an NHS number in Wales you must register at a GP practise or be born in Wales and that they don't have the ability to allocate a temporary NHS number when an individual doesn't have one. This situation means that they can't be used as the primary identifier until temporary NHS numbers can be distributed.

MW asked whether RC thought there will be some more interoperability with the English, Welsh, Scottish and Northern Irish systems seeing as Wales are working closely with NHS Digital?

RC stressed that there are different political drivers in the countries but said that in terms of the colleagues she works with, interoperability is the driver. RC notes that colleagues in north Wales do more business across the border than they do in Wales. Due to this, RC said that standards and guidance commissioned in England must align with Welsh architecture, otherwise they can't implement or use them.

MB thanked Rebecca and suggested that updates at regular intervals would be helpful.

Action: Have four nations representatives present regularly at advisory board meetings.

7. Completed standards

Digital Medicines information

MB introduced the session, mentioning that feedback from the previous meeting was that our session on the digital medicines project was too technical so this time round we decided to offer the patient's perspective.

RT member of the RCP patient carer network and citizen rep on the project provides this patient perspective. He spoke about HIU's closure and the necessity of continuing to ensure the patient voice is heard. RT commented that the LHCR survey was quite physician focused and asked PRSB to think about how we engage meaningfully with patients.

ITh went on to talk about the project's specifics, explaining that the key thing was to prevent the time-consuming manual transcription that exists on any transfer of care, freeing up pharmacist time for other patient-facing activities. The aim of this technical piece of work was to allow this information to be shared and understood by a machine, enabling the medications reconciliation process to be aided in this way. Most importantly this must be validated by a prescriber, being able to use this for stock control is an added benefit.

RT believes that patients will now be assured that the clinician has accurate information about their medication.

MO told us that Taunton and West Suffolk are testing the guidance, West Suffolk are looking at the medications reconciliation and transferring information in and out of the hospital (with Cambridge). PRSB has done the assurance of this work with a wide range of clinicians through webinars. PRSB are now in the process of coming out to members for endorsement, once we have endorsement and have the testing running, existing standards can be updated which will enable this technical guidance to be fully workable.

RT remarked that patient input was better than was expected with such a tech focused project.

MB mentioned that when this was commissioned to PRSB, there was an emphasis on swift delivery. Maureen commended colleagues for delivering in such a short time, whilst retaining rigour.

JW was happy to hear of the progress and said that the emphasis on the need for human intervention on transfer of care is encouraging as it is of critical importance when responsibility for prescribing transfers from one professional to another.

Ambulance handover

DD reminded us of the background of the ambulance handover project, when first looked at, there were some standards but lots of paramedics used paper based and verbal exchanges and there wasn't an interoperable digital record. There was not enough operational or strategic by in and the work was never fully signed off. In December 2017 the team proposed to finish off this work by creating a shadow ambulance data set which has now been commissioned and ambulance steering group meetings are taking place. There is now a set of content that can be sent from the ambulance and electronically transferred and live streamed to any department.

The standard aims to enable the sharing of clinically relevant information to contribute to the longitudinal record and the ongoing care of the patient, through real time patient access. Getting the work flows right will improve clinical safety and reduce costs.

DD explained that the project is running slightly behind as getting hold of the clinical group has been quite challenging. DD urged the members to discuss this piece of work with colleagues to help encourage implementation.

DD announced that the standard will be published soon, once NHS Digital have found organisations to do first of type.

NT informed DD that Taunton are keen to do first of type.

IC noted that one of the big challenges was getting the ambulance services involved as there are 12 ambulance services in England with substantially different agendas.

DD mentioned that there is a group for ambulance service directors which does create some alignment as does the NHS England ambulance group with the implementation of the data set etc.

NS asked whether this is a product and whether industry is involved?

MO responded, telling members that this is a PRSB product and that industry have contributed to the consultation. MO informed us that NHS England and NHS Digital are responsible for the implementation.

NS said that in radiology they have been using standards for decades and they tell the companies already out there that they must follow the standards.

DD replied saying that they are waiting for the right time to tell suppliers, it is a chicken and egg but maybe this is the shell.

ND told us that she is very passionate about industry involvement and engaging with suppliers prior to setting standards. The suppliers are there and willing to adopt but often the funding isn't there. The process described is live and does work.

MT reiterated that the industry is not the problem, the user is not the problem, but it is the middle bit that is the issue.

MB agreed, saying that this is the gap in the system that needs to be addresses.

DD confirmed that is really important in this ambulance space, with lots of different systems, contracts etc. He noted that the difference is that they have buy-in from the ambulance improvement programme and the national ambulance data but that they are going to need to do the same for all types of ED.

MT urged DD to start engaging suppliers now rather than later.

KHJ advised that the mechanisms are in place to enable this and that NHS Digital would mandate this standard and any other standard for use. He stated that it is the funding processes and prioritisation of the standards that are the issue.

DD suggested revising the final report to consider the comments from this group.

MB agreed.

Action: revise ambulance handover final report to consider comments from the advisory board members.

8. Work programme update

HF told members that PRSB's comms activities have been generally positive, increasing our profile and levels of engagement. We have published a new video with patient representative Catriona Davenport, speaking about the positive benefits digital records will have for Mother's: https://theprsb.org/2019/02/mothers-view-maternity-records/. We are soon to publish another podcast about End of Life Care and are in talks with SBG around an 'about me' podcast. If you have any ideas for episode topics or want to put yourself forward, please get in touch: info@theprsb.org.

HF informed the advisory board that we were at the digital health rewired programme and showcased work around implementing standards, where there was lively discussion about implementation. HF said that we are also working with digital health to take a piece of work to their summer school.

LHCR – core information set standard

HF provided a summary of the core information standard project for the advisory board. Explaining that this work was commissioned by NHS England and the remit was to define what is a key set of information. HF spoke about our definition of 'core information', which is the information that could potentially be shared and is needed for care depending on role, situation and what the individual wants shared. How this is presented will be driven by systems. HF reminded the advisory board that the consultation is still live, encouraging involvement in the survey. HF informed the room that the intention is to publish by late may and then go into procurement and piloting - by the LCHRs in the first instance. We have been working closely with NHS England with regards to information governance. Who will have access to it? How can certain information be shared/ not be shared? We need to work will our colleagues to see what this looks like and how we can tell that story.

Patient lead for the core information set standard LFu wanted to explore social media to engage people who were not available to partake in the consultation during the day. LFu ran a tweet chat on Tuesday, the outcomes of which revealed that unanimously people have felt the about me section is incredibly important for a variety of reasons to reinforce expectations. LFu used a personal example to illustrate this, stating that most people with her diagnoses are 50 years older than her so the fitness expectations are very different.

Digital medicines information standard published beginning of next week. NHS England and NHS Digital helping publish this – medicines optimisation meeting next week – showing a join up in the system.

Academy survey – clinical leadership and engagement

HF spoke about the project PRSB and Academy of Medical Royal Colleges are working on, funded by Health Education England to consult with the medical professions to unveil some of the frustrations and barriers to engaging with digital as well as insights into how some might view digital as enabling their role. Clever Together has been appointed to develop the consultation and a steering group with senior leaders from several of the medical colleges has been established. HF informed the advisory board that the plan is to go out to consultation in June and to produce a final report and launch after the summer holidays.

EMC asked whether the academy was funding this.

HF responded that the PRSB and the Academy have commissioned this piece of work.

EMC said that it was important to involve other health care professionals, not just medics, as he expects outside of medicine that the barriers would be very different. EMC assured that CSP members would be desperate to inform us of the barriers that are stopping them.

RS mentioned the building a digital ready workforce (HEE) programme.

MB responded saying that the work first involved nurses, now medics and then so on and that she doesn't think the work should be devalued because it is not all encompassing. MC stated that she is personally frustrated that this work has taken a very long time.

DD said that most of the clinical informatic leadership posts are inhabited by medics. DD has just joined a cohort as he believes we need to be working with emerging leaders through the digital academy cohort 1 and 2.

EMC suggested lobbying.

JW thinks that any lobbying should come from the faculty, with others support.

Endorsement policy

MO explained that we have revised our endorsement policy to make sure we are involving people more actively and earlier which we hope will make things easier for people; the policy was sent around and we welcome back any comments.

Transfers of care

MO updated us on the projects progress. He explained that the full electronic transfer will be tested in June and that there has been significant progress with GP providers. GP suppliers have signed contracts with NHS Digital and providers can now send their messages to the test harness and GPs can join these together and do the piloting. This is a key step in allowing the key messages to flow in transfer of care. Some providers have started to send messages in the full format e.g Alder Hey Children's Hospital in Liverpool demonstrated the ability to send the discharge to their regional care record.

Pathology standard assurance

MO informed the advisory board that PRSB are working with NHS Digital on a pathology standard. We have delayed the consultation to make sure the standard is written in standard English and further revise the information model. When further funding is confirmed, we hope to go out to consultation.

KHJ explained that NHS Digital are waiting for the formal letter to come through next week then funding will be confirmed.

Actions from Advisory Board meeting – 25th April 2019

Date	Agenda Item	Action	By Whom	Status/Comments
25/04/2019	6. Wales	Have four nations representatives present regularly at advisory board meetings.	Alannah	Ongoing
25/04/2019	7. Completed Standards – Ambulance Handover	Revise ambulance handover final report to consider comments from the advisory board members.	Martin	Completed