

Towards a New Health and Social Care Information Sharing Architecture



Prof Bill Buchanan, Edinburgh Napier University

James Varga, miiCard

Daniel Moulin and Chris Eckl, Sitekit

Towards a New Health and Social Care Information Sharing Architecture

The Changing Environment



Prof Bill Buchanan, Edinburgh Napier University

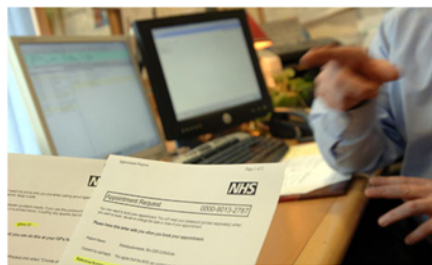
James Varga, miiCard

Daniel Moulin and Chris Eckl, Sitekit

NHS told to abandon delayed IT project

£12.7bn computer scheme to create patient record system is to be scrapped after years of delays

Denis Campbell, health correspondent
The Guardian, Thursday 22 September 2011
Jump to comments (44)



The NHS has spent billions of pounds on a computerised patient record and booking system, which has never worked properly. Photograph: Martin Godwin

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PFI schemes taking NHS trusts to brink of

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Regional Manager
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ORANGE GROVE FOSTER CARE

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Wednesday 21 November 2012

The Telegraph

Patients will view their NHS records online in three years

NHS patients will be given online access to their health records in the next three years under plans to be announced by the Government today.



The move for online health records comes despite the decision by Andrew Lansley, the previous health secretary, to cancel a massive NHS national database. Photo: ALAMY

By Robert Winnett, Political Editor
7:00AM GMT 13 Nov 2012

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PROMOTIONS

HEALTH MOST VIEWED

TODAY PAST WEEK PAST MONTH

1. Flu vaccine effectiveness exaggerated, scientists claim
2. Women suffering liver disease 'because they try to drink like men'
3. Henley hit by 'mutant super rat' invasion
4. The problem with perfection: Is it all right for girls just to be all right?
5. 'Rising tide' of liver disease due to obesity, alcohol and infections, Prof Dame Sally Davies warns

EDITOR'S CHOICE

Rowan Atkinson: Goodbye, Mr Bean?



Doctors' surgeries will have to set up services to allow anyone to see their health files, book appointments and order repeat prescriptions on the Internet.

The new campaign is being spearheaded by Jeremy Hunt, the Health Secretary.

"Looking after their own health, and the health of their families needs to be as straightforward as possible.

"Looking after our health should be easy — in an age where people can do their banking or shopping online, it should be just as simple to view your health records, order a repeat prescription or book a GP



dreich27

11/13/2012 06:02 PM

1) is this in the **interest of people whose hypochondriac and worrying tendencies** are made worse by all the medical information on the internet?

2) how much will it **cost**?

3) what's wrong with the current system where you can **request your records from the surgery**?

4) how will it be **secured a) from hackers b) from your boss c) from your intimidating other half or family member** who is standing next to you at the computer and demanding that you log in?

5) is this going to cause doctors to have to go through your records with a **fine-toothed comb to weed out an ill-advised comment made in 19-when-ever** when the idea that patients could sue or access their records online was very remote.





Thierrytt

11/13/2012 04:00 AM

My partner's doctor here in France hands over the hard copy of any documents to her. This includes notes and letters passed between doctors and other specialists. **He keeps an electronic copy. This means we have all the x-rays, DVDs of MRI scans etc.** He gives a regular print out of any notes made.

The notes are released on the processing of the Carte Vitale which has a photo of the patient.

Other doctors can have access to her records through the Carte Vitale system.

It puts the patient at the forefront of treatment.

When I moved to France from the UK some years ago I obtained a photocopy of my medical records. It contained notes in code which **made no sense to me whatsoever.** I could find nothing regarding hospital treatments, the fact I had broken my leg when 11 yrs old, had my tonsils out etc. No vaccines as a child or adult were noted. **The french doctor said the notes were worse than useless.**

Why is the **NHS** so out of date?

The Telegraph

Patients will view their NHS records online in three years
2015 patients will be given online access to their health records in the next three years under plans to be announced by the Government today.

HEALTH NEWS | Health | Diet and Fitness | Wellbeing | Sexual Health | Pets Health

NEWS | HEALTH | SEARCH NEWS

HEALTH MOST VIEWED

- Flu vaccine effectiveness exaggerated, scientists claim
- Women suffering liver disease 'because they try to drink like men'
- Healthy fat? 'Insistent' report 'off' scientists
- The problem with perfection: Is it all right for girls just to be all right?
- 'Strong link' of liver disease due to obesity, alcohol and infections, Prof Dame Sally Davies warns

EDITOR'S CHOICE

Review: *Admission: Goodbye, Mr Bean?*

The review for *Admission* health comedy, directed by Andrew Lawrence, the principal health secretary to one of the world's most advanced health systems. [Read the review](#)

By Robert Williams, Political Editor
7:55AM GMT 13 Nov 2012

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ivan_opinion

11/13/2012 06:26 AM

NFN – Normal for Norfolk.

FLK – Funny Looking Kid.

GLM – Good Looking Mom.

Who, other than **hypochondriacs, narcissists, neurotics, ME 'sufferers', DLA scroungers and the mentally ill, wants this?** And, for all the groups mentioned, this will only make them feel worse, do no good at all and increase costs. How much will it cost, how secure will it be and how late will it be? **If doctors cannot be frank in the notes, they will end up being defensive and guarded**, which will be bad for everyone. Sadly, **NFN, FLK and GLM** have largely disappeared but this is the death knell.

The truth is, however, that a patient-accessible record system **is essential for the dismantling and selling-off of the NHS**. Alternative providers, doctors and Prince Charles' quacks and businesses run by Hunt and Lansley's mates **will be able to read them, print them, import them and invoice services accordingly**. "Oh, I see you've never had any of my very special water, never tried acupuncture, had this scan." That is what this is about, whether you agree with it or not.

The Telegraph

Wednesday 21 November 2012

HOME NEWS WORLD SPORT FINANCE COMMENT BLOGS CULTURE TRAVEL LIFE FASHION TECH

Health News | Health | Life | Diet and Fitness | Wellbeing | Legal Health | Pets Health

Home | Health | Life | Diet and Fitness | Wellbeing | Legal Health | Pets Health

Patients will view their NHS records online in three years

2015 patients will be given online access to their health records in the next three years under plans to be announced by the Government today.

HEALTH MOST VIEWED

- Flu vaccine effectiveness exaggerated, scientists claim
- Women suffering liver disease 'because they try to drink like men'
- Smoking ban 'no 'smoked' ropes off' recreation
- The problem with perfection: Is it all right for girls just to be all right?
- Strong link of liver disease due to obesity, alcohol and infections, Prof Dame Sally Davies warns

EDITOR'S CHOICE

Review: Adonis: Goodbye, Mr. Bean?

The race for online health records begins, reports by Andrew Laming, the principal health secretary to attend a meeting of the National Association of General Practitioners (NAGP) on 13/11/12

By Robert Williams, Political Editor
7:55AM GMT 13 Nov 2012

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Thierrytt

11/13/2012 05:13 AM

The problem is that the doctors may not be telling the "truth". My partner was **diagnosed as a psychiatric case when she lost use of her legs**. A letter from the neurologist who examined her said she had had an **MRI scan. That had never taken place. All doctors treating her afterwards took that as gospel.**

I reviewed her case and discovered that and **other serious errors by other neurologists, rheumatologist and ophthalmologists.**

In the end I requested the MRI scan and all accompanying tests for **Multiple Schlerosis and every one proved positive**. A review of all previous tests including one when she had lost vision in one eye had pointed to MS.

Maybe knowing the patients can see all the results of tests etc may lead doctors to be more careful. My partner is french and medical records rest with the patient. The doctor keeps an electronic copy.



Towards a New Health and Social Care Information Sharing Architecture

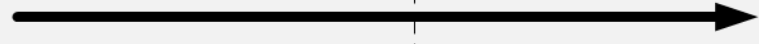
Why?



Prof Bill Buchanan, Edinburgh Napier University

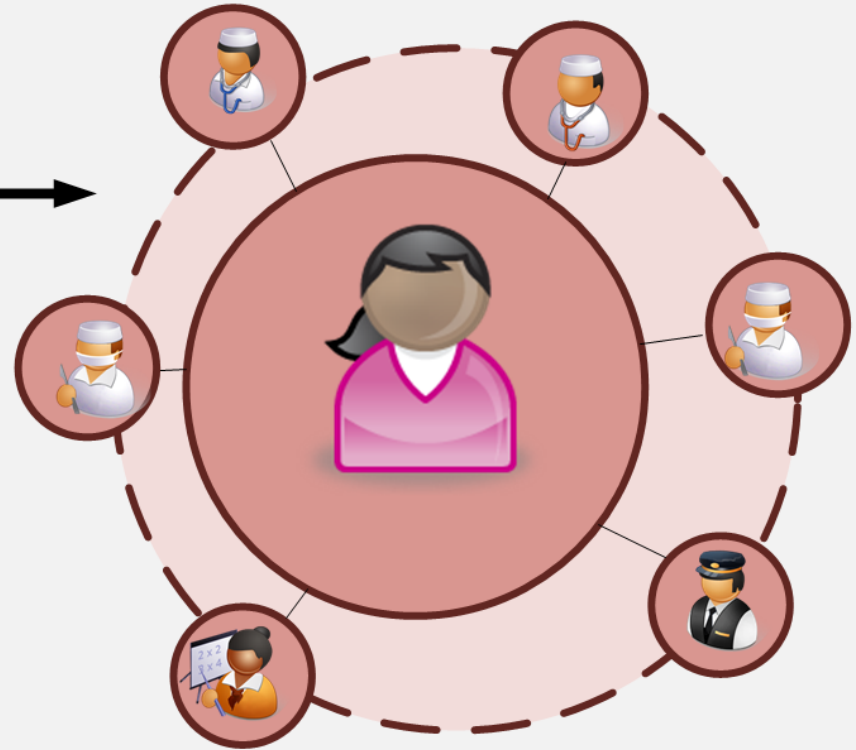
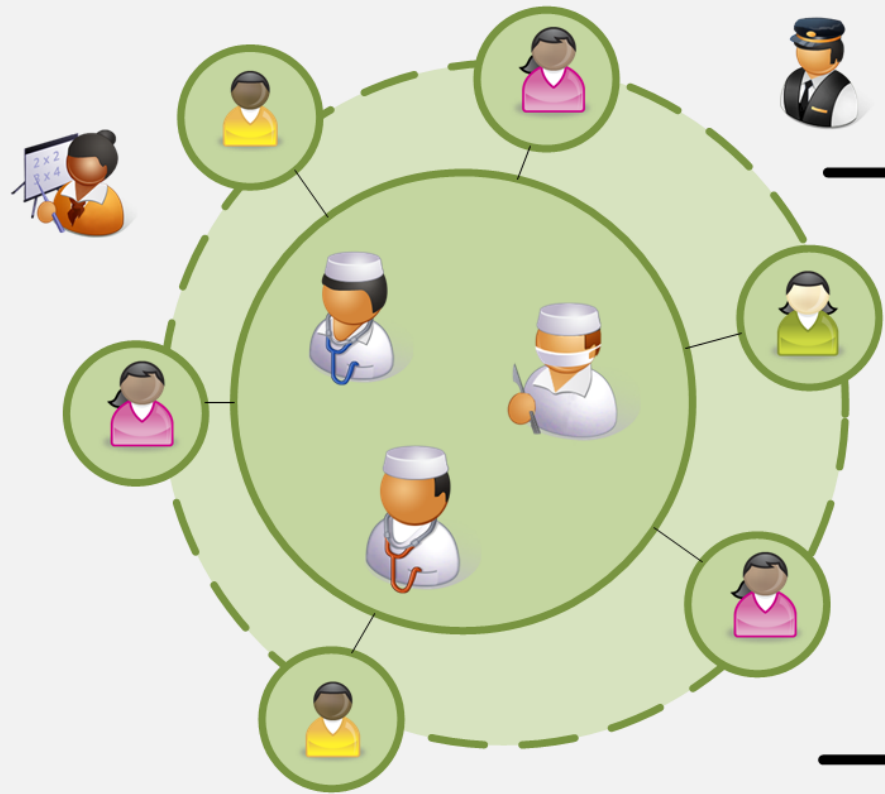
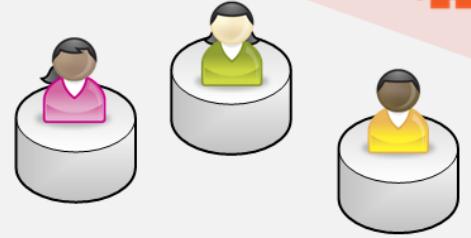
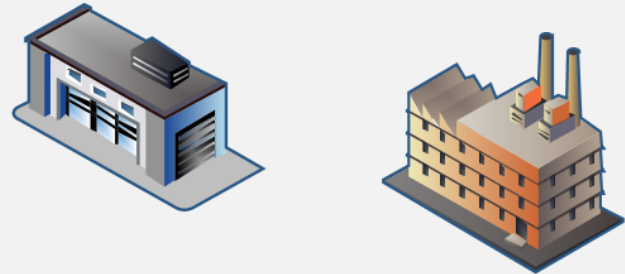
James Varga, miiCard

Daniel Moulin and Chris Eckl, Sitekit



Industrial Age

Information Age



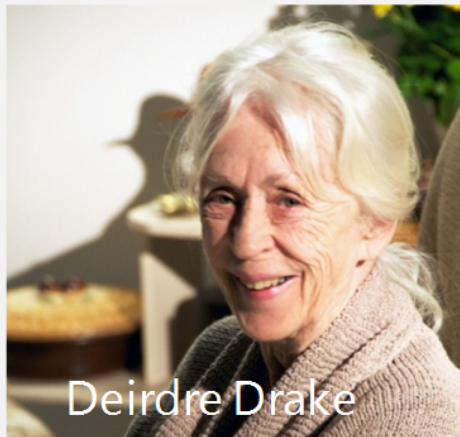
**Centralised, Non-integrated,
Ad-hoc, Clinician Focused, Reactive,
Clinician Control of Records**

**Distributed Patient Care, Holistic,
Patient Focused, Pre-emptive,
More Patient Control of Health**



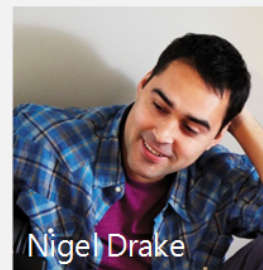
Nurse Kate

- Healthcare Professional.
- Invited user



Deirdre Drake

- Care Subject
- 82 years old
- House bound
- COPD (Chronic Obstructive Pulmonary Disease)



Nigel Drake

- Invited user

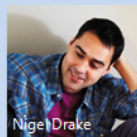


Sam Drake

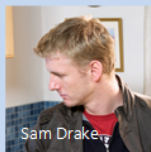
- Site Creator
- Primary Carer



- GP.
- Invited user



Nigel Drake



Sam Drake



Nurse Kate

Assisted Living
(Informal and
Trust based)

Primary Health Care (Formal
and role-oriented) - GP

Secondary Health Care
(Formal and role-oriented)
- Hospitals/A&E


Social Care/Health/etc



Nurse Kate

Technology Strategy Board
Driving Innovation

EPSRC
Pioneering research
and skills



Edinburgh Napier UNIVERSITY

kodit

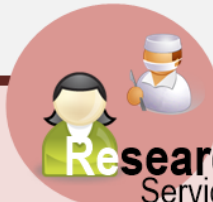
Imperial College London

Chelsea and Westminster Hospital NHS Foundation Trust

CIPHER LAB

GS1 UK

Cloud-based Infrastructure for Clinical Services



Edinburgh Napier UNIVERSITY

Microsoft

HöIP

Trusted Services: Assisted Living

dallas

<sitekit> web excellence

Microsoft

Delivering Assisted Living at Scale

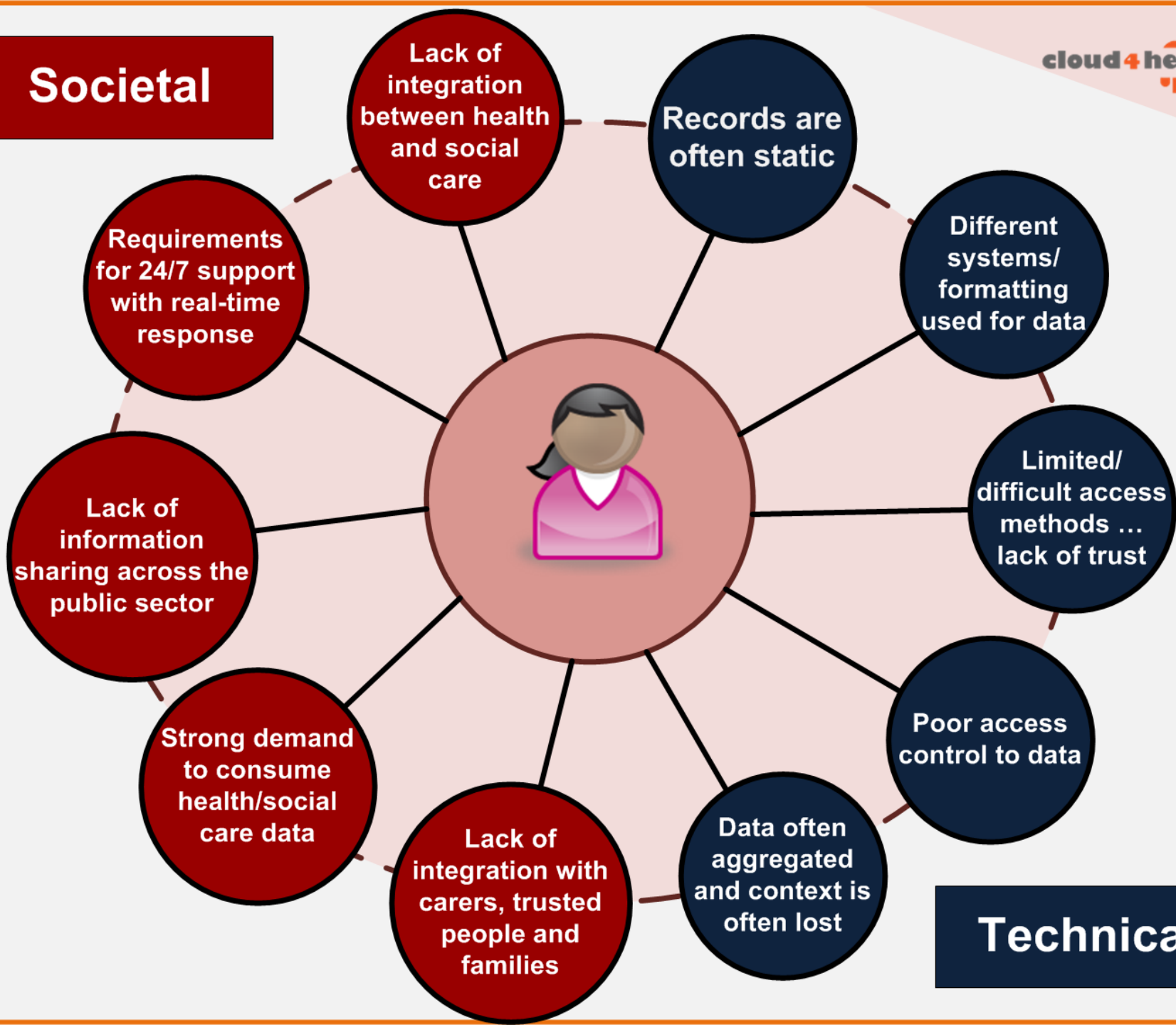
The Scottish Institute for Policing Research

miiCard[®]
My Internet Identity

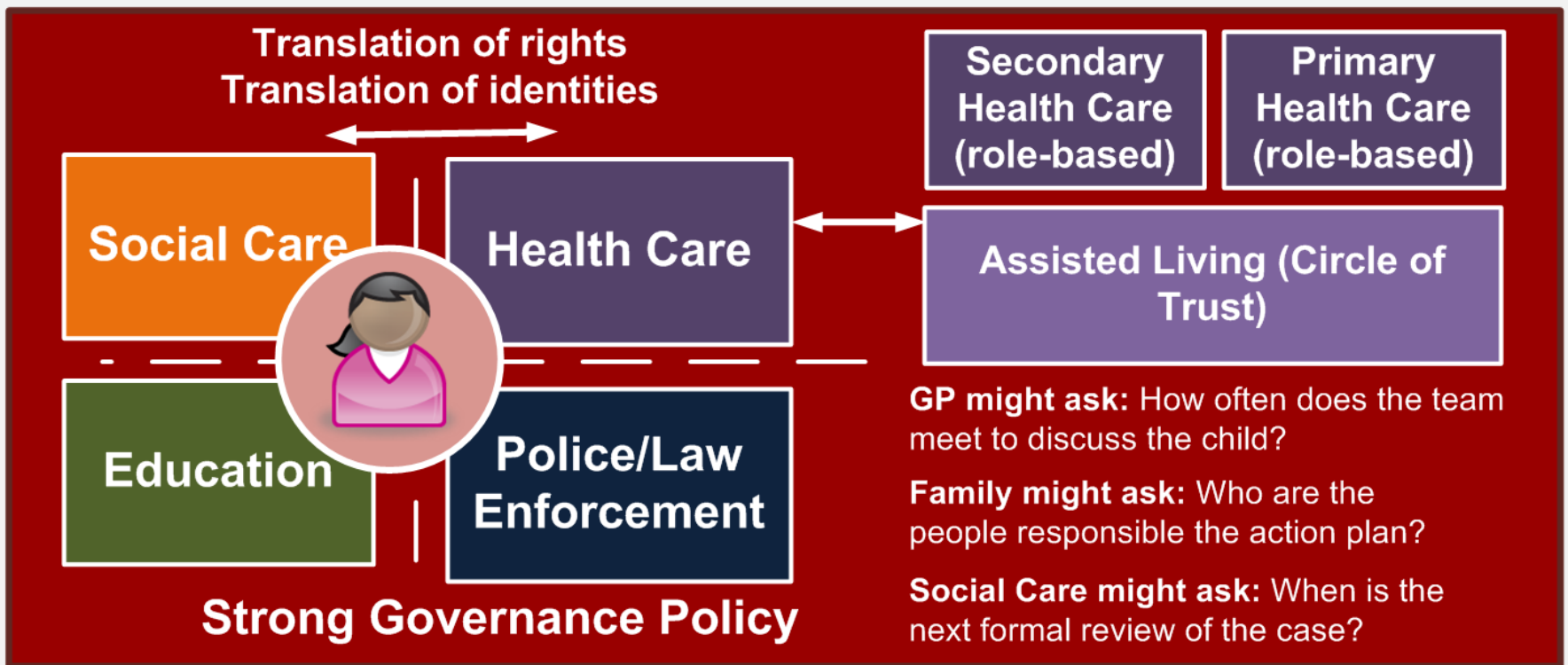
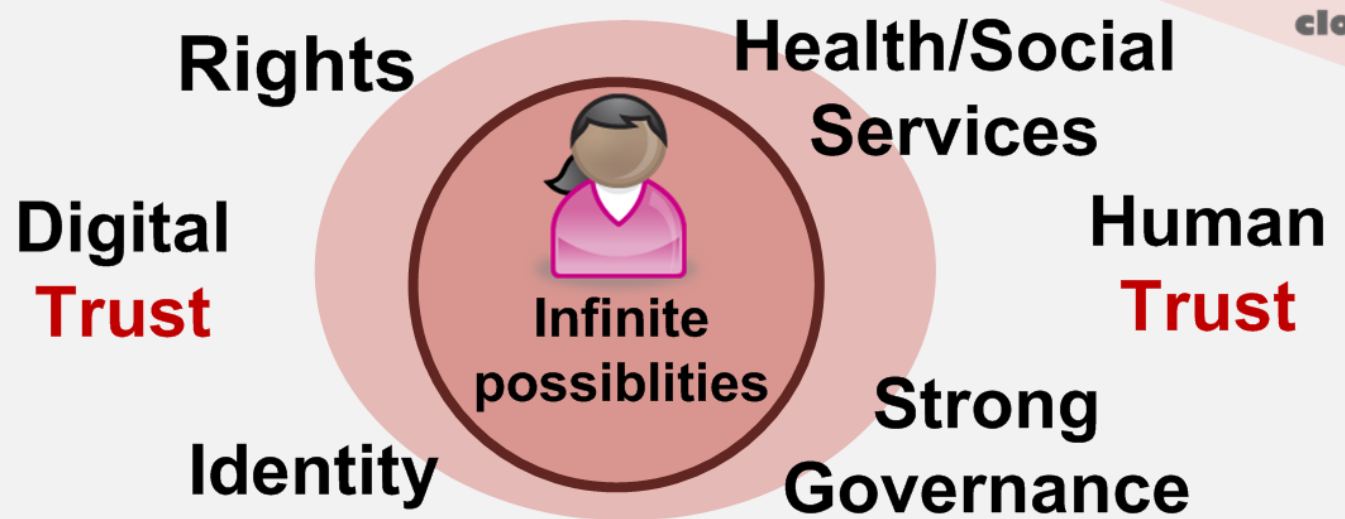
mydex

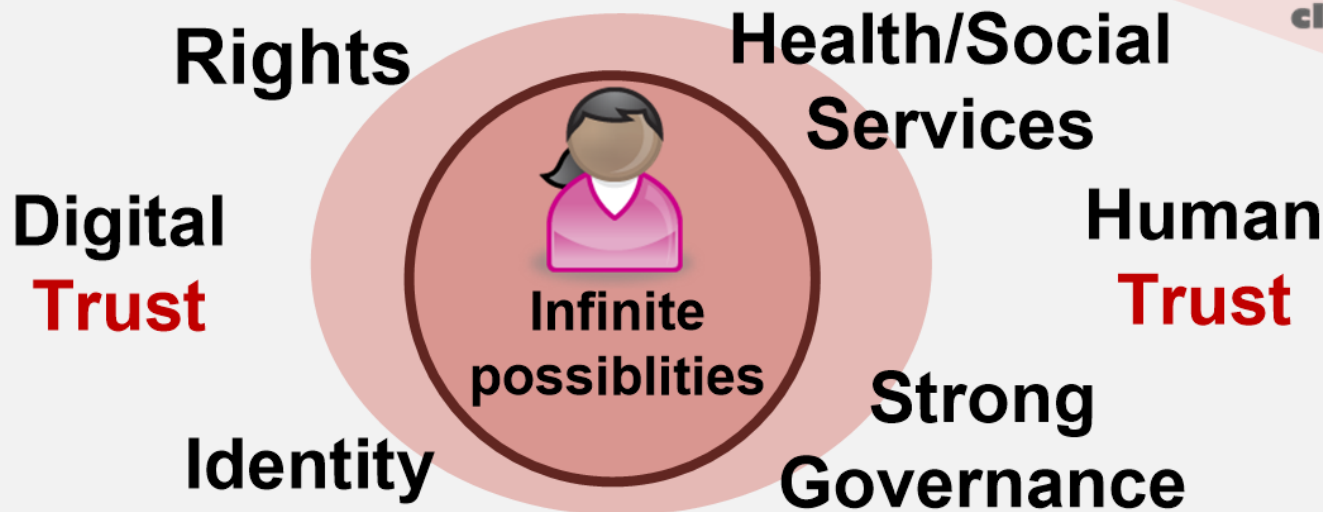
flexiant[™]
utility computing on demand

Societal



Technical





Translation of rights
Translation of identities



Social Care

Health Care

Education

Police/Law Enforcement

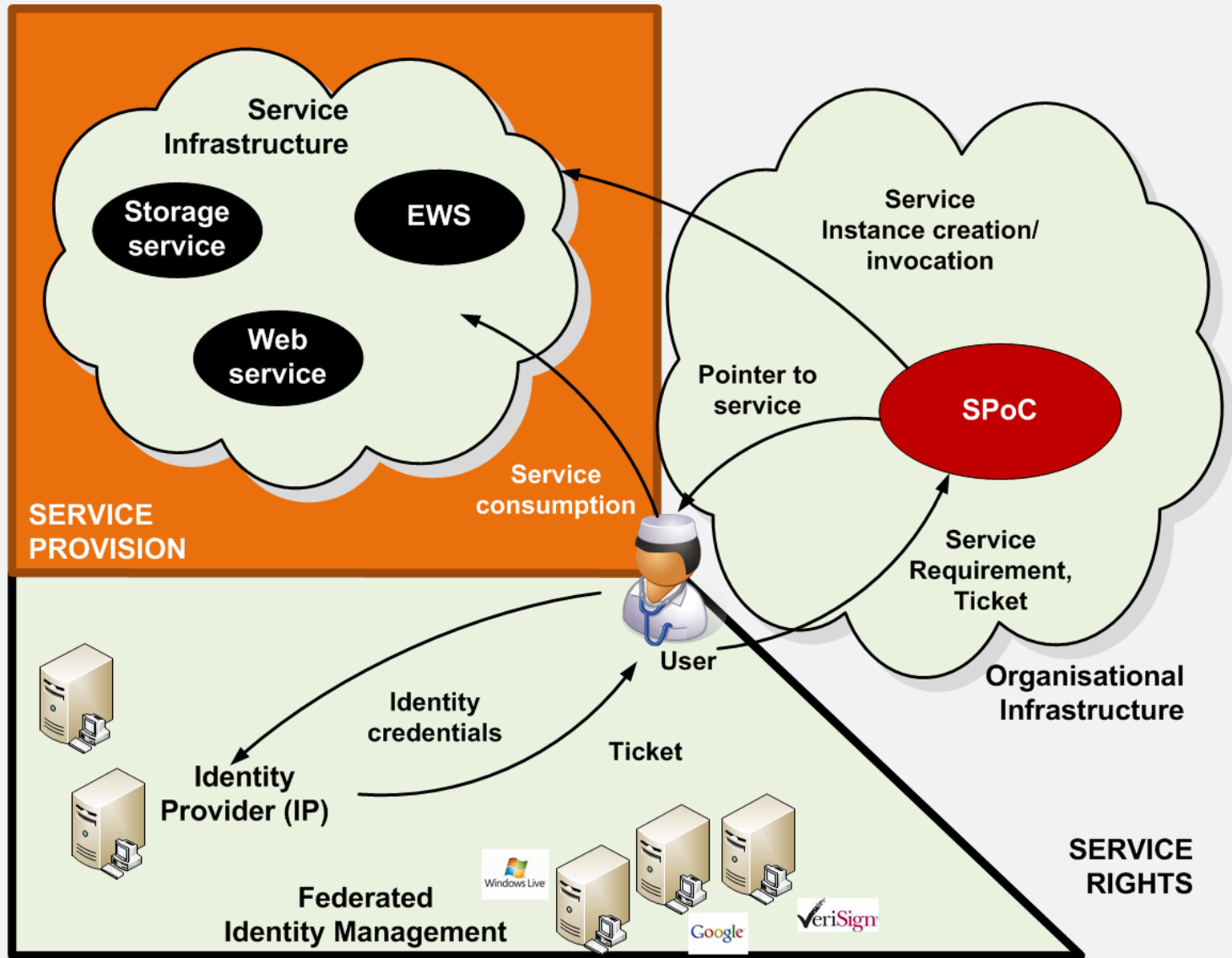
Formal Governance Interfaces



Citizen Integration



3rd Sector Integration



Towards a New Health and Social Care Information Sharing Architecture

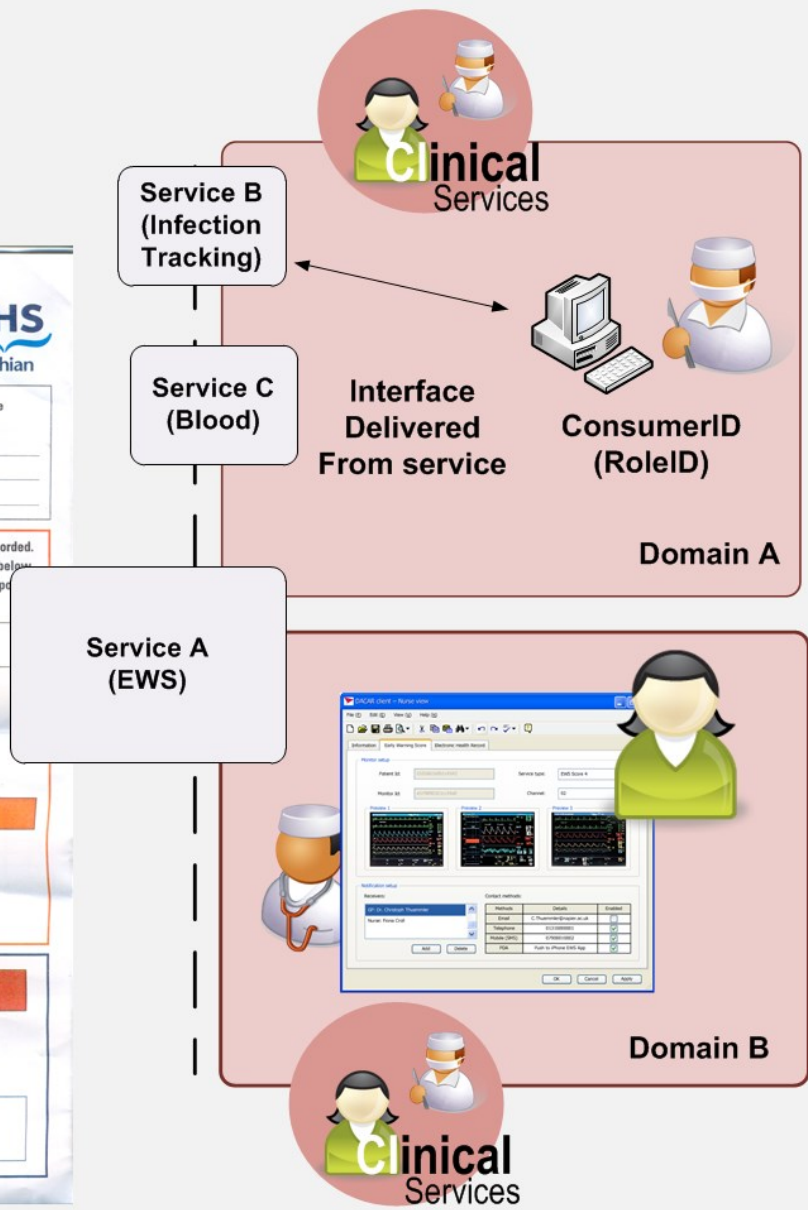
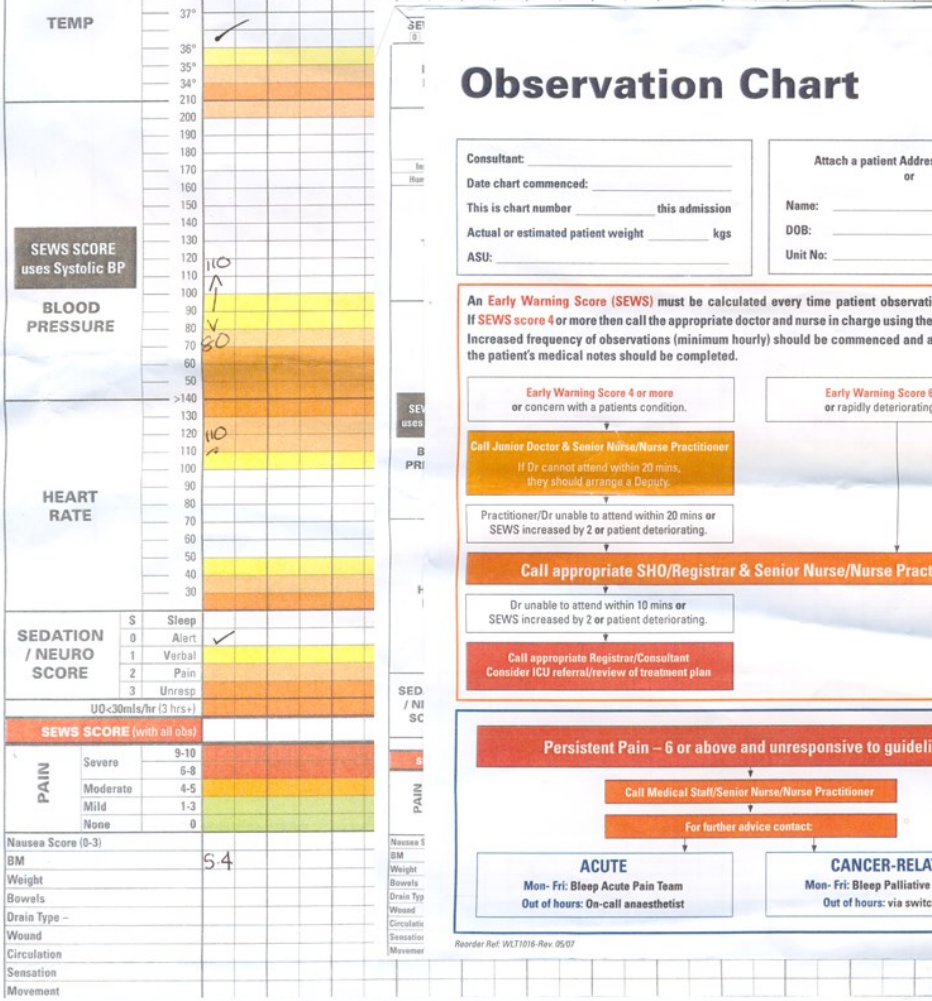
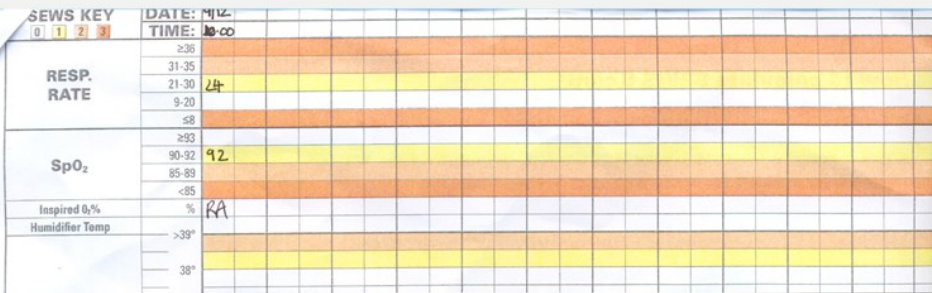
Examples



Prof Bill Buchanan, Edinburgh Napier University

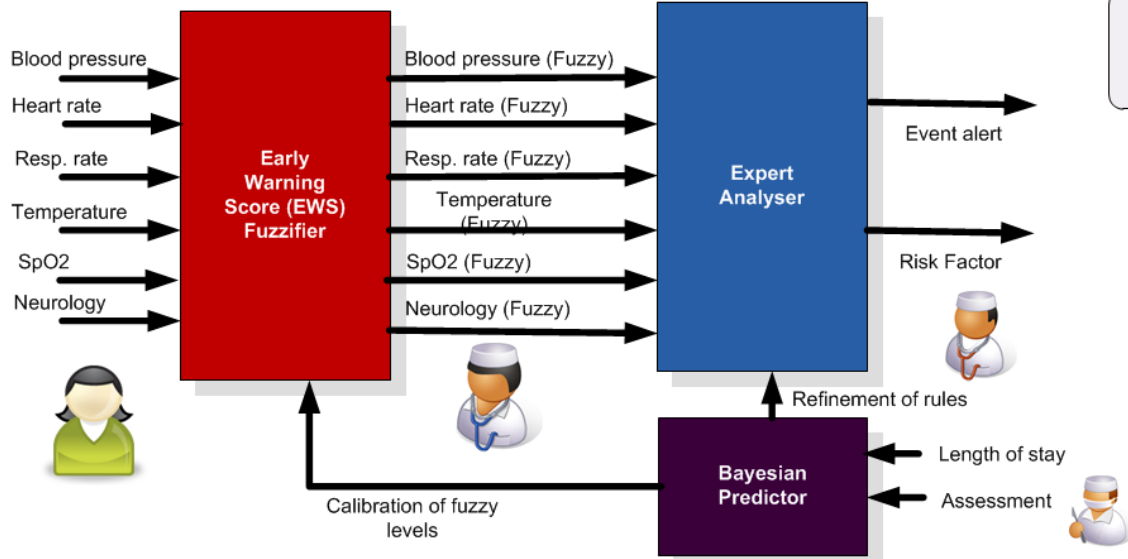
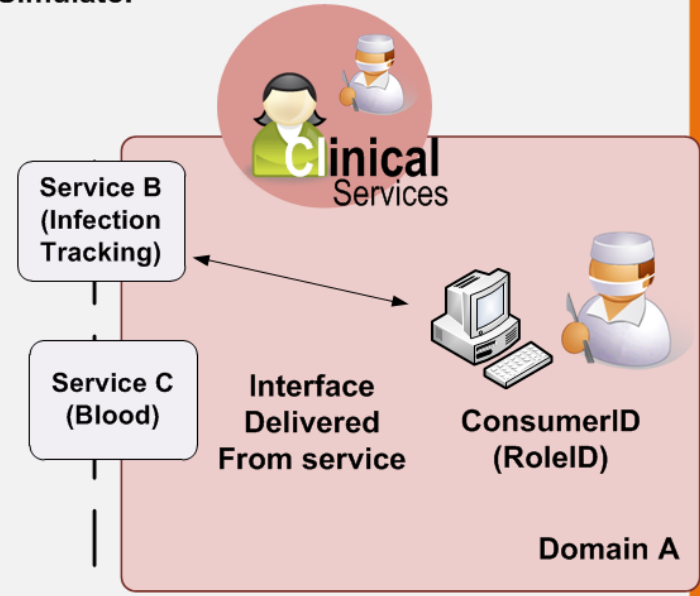
James Varga, miiCard

Daniel Moulin and Chris Eckl, Sitekit

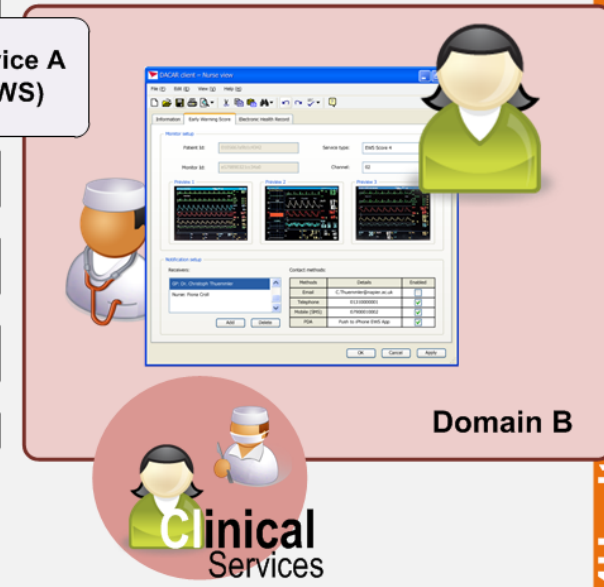




Patient Simulator



Service A (EWS)



Towards a New Health and Social Care Information Sharing Architecture

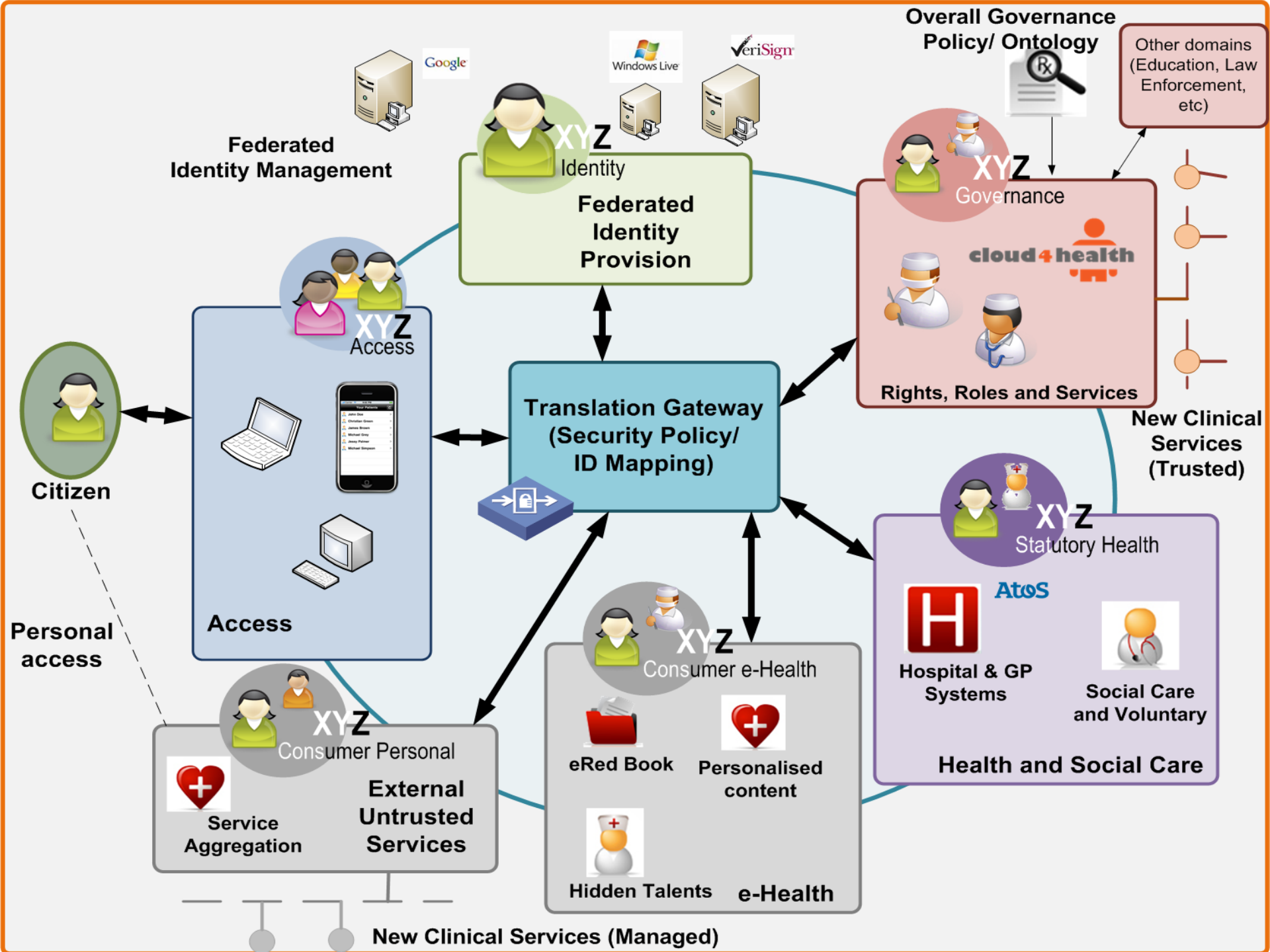
Current and Future



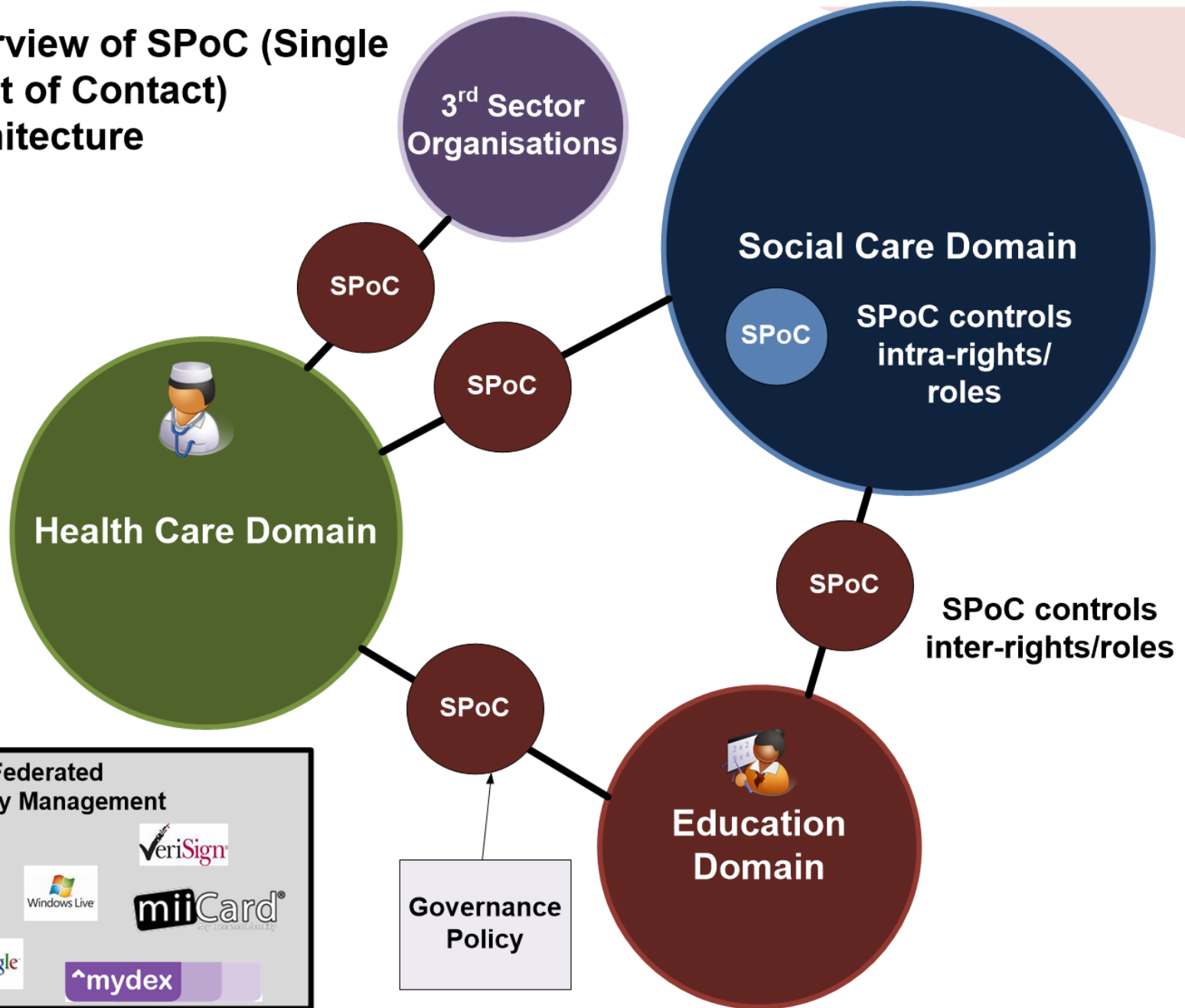
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James Varga, miiCard

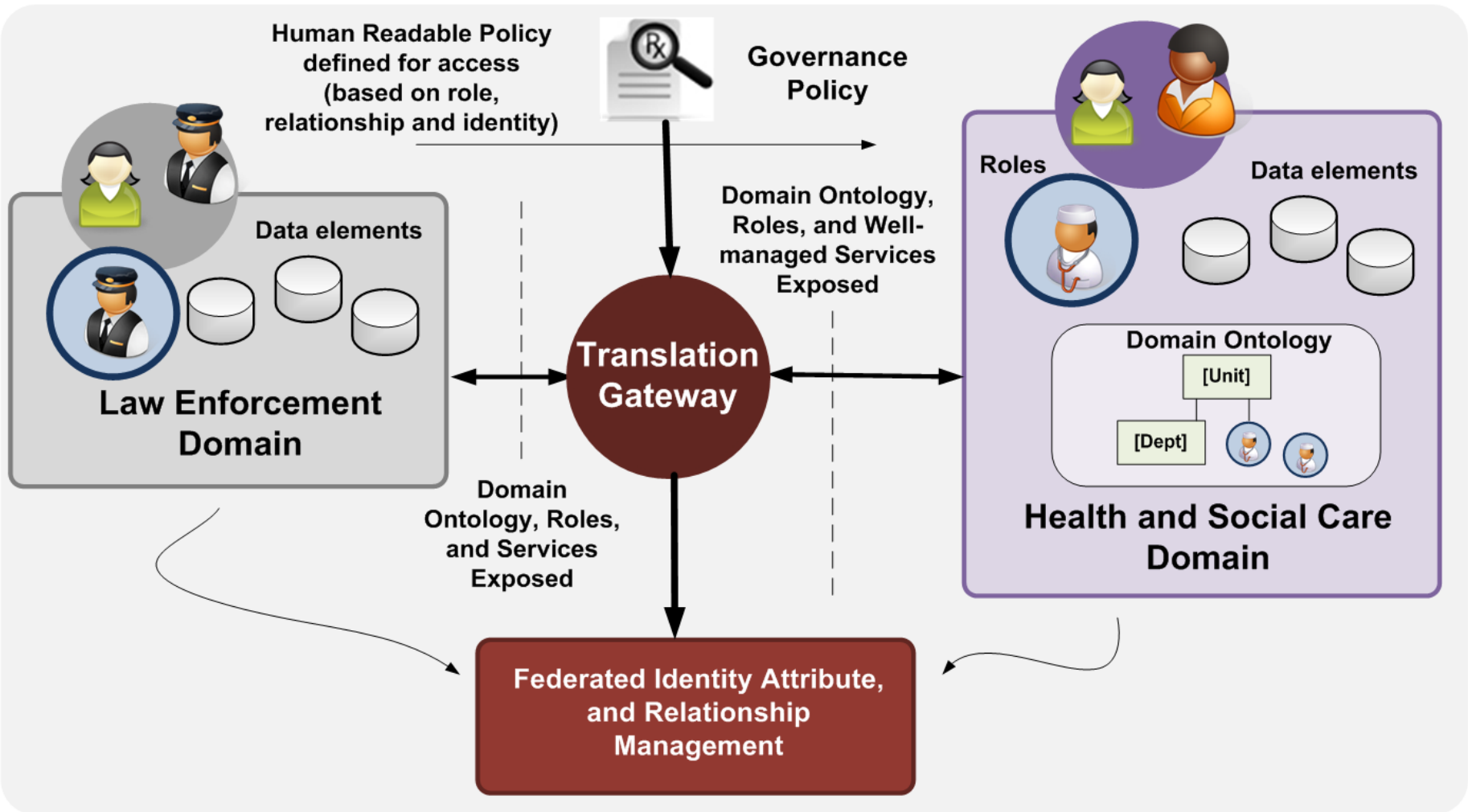
Daniel Moulin and Chris Eckl, Sitekit

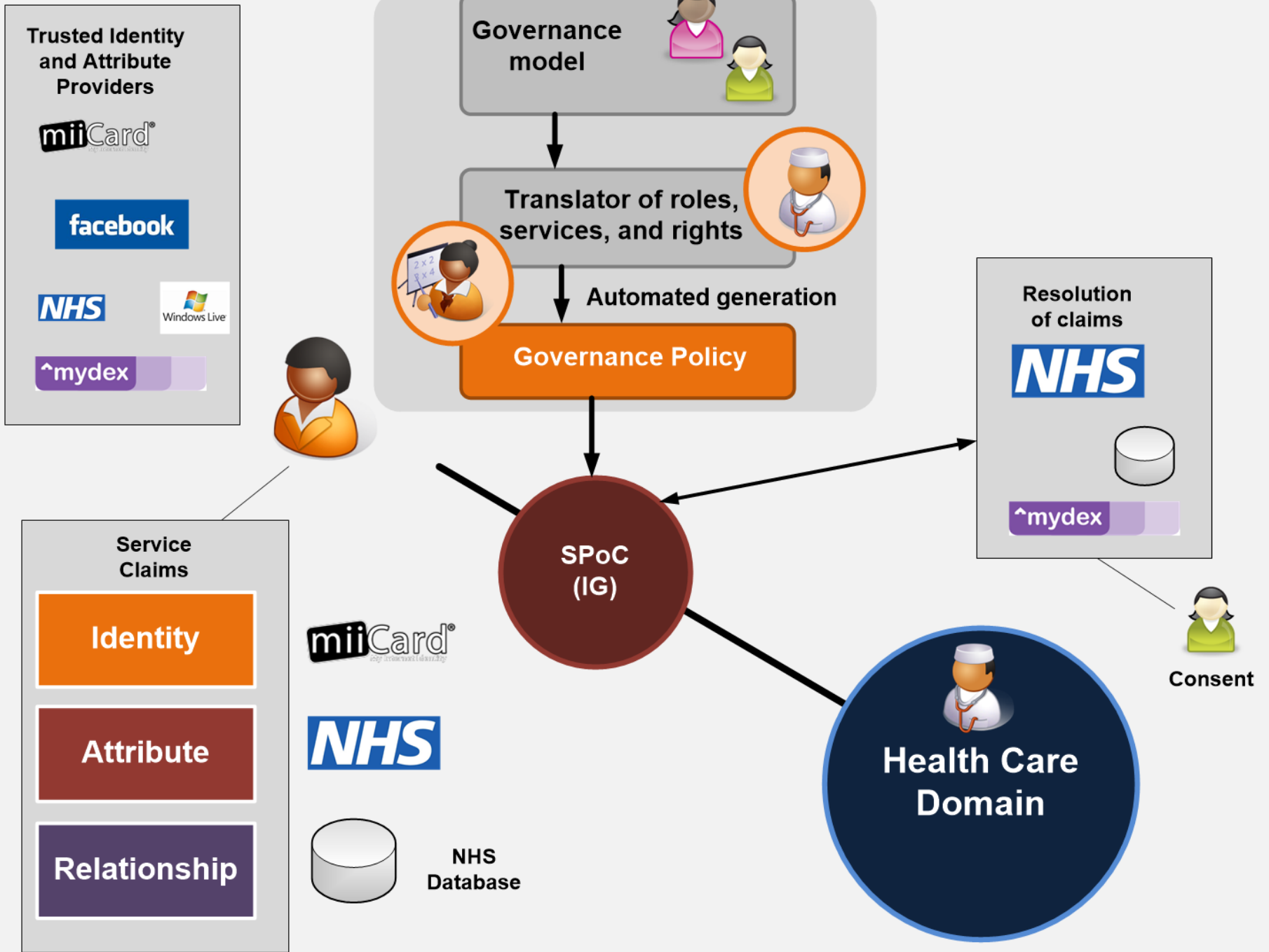


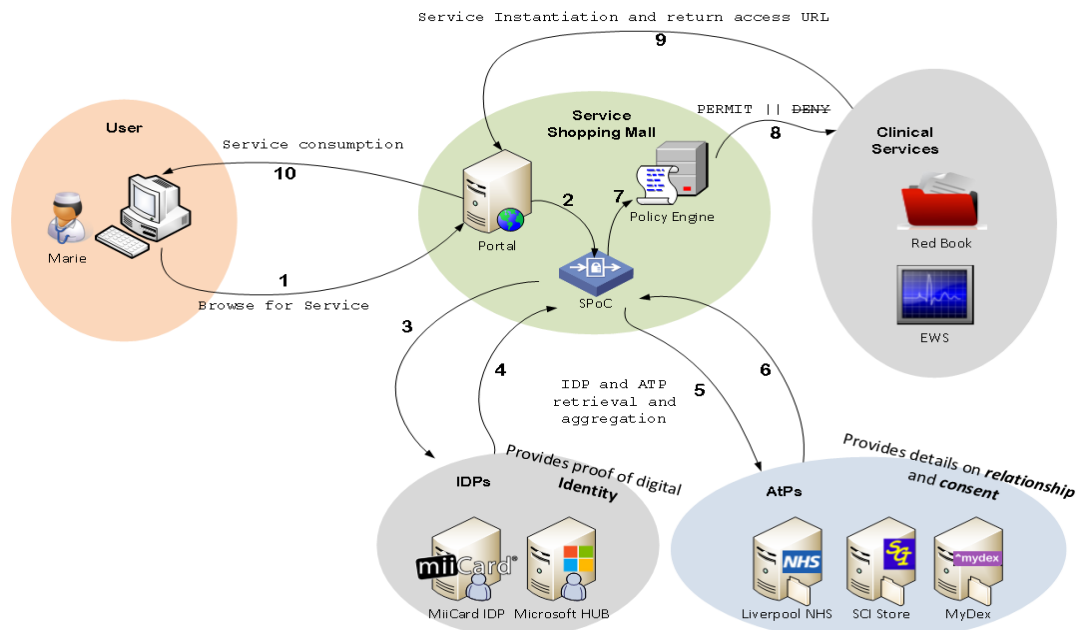
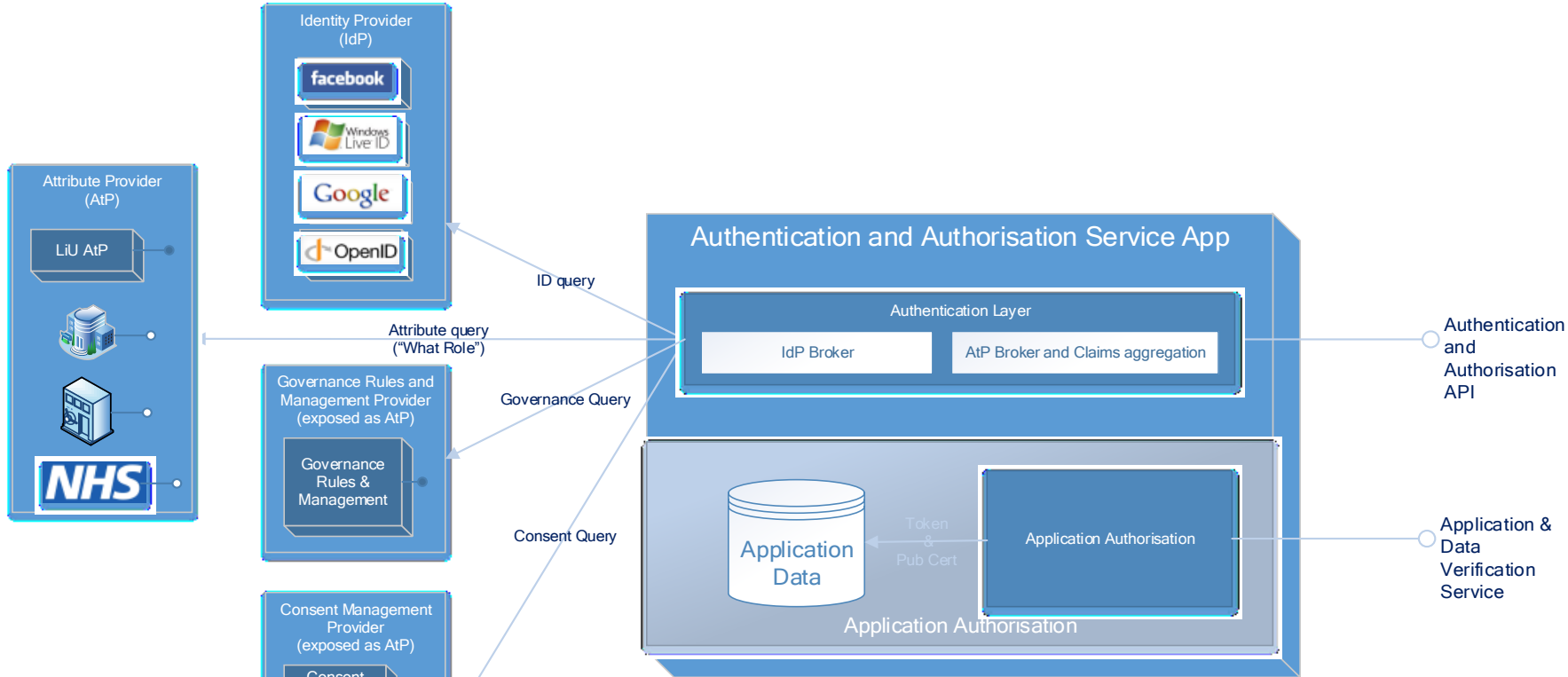
Overview of SPoC (Single Point of Contact) Architecture



Application of Governance Policy







Proposed Architecture for DALLAS Living It Up

Towards a New Health and Social Care Information Sharing Architecture

miiCard - My Internet Identity' Card

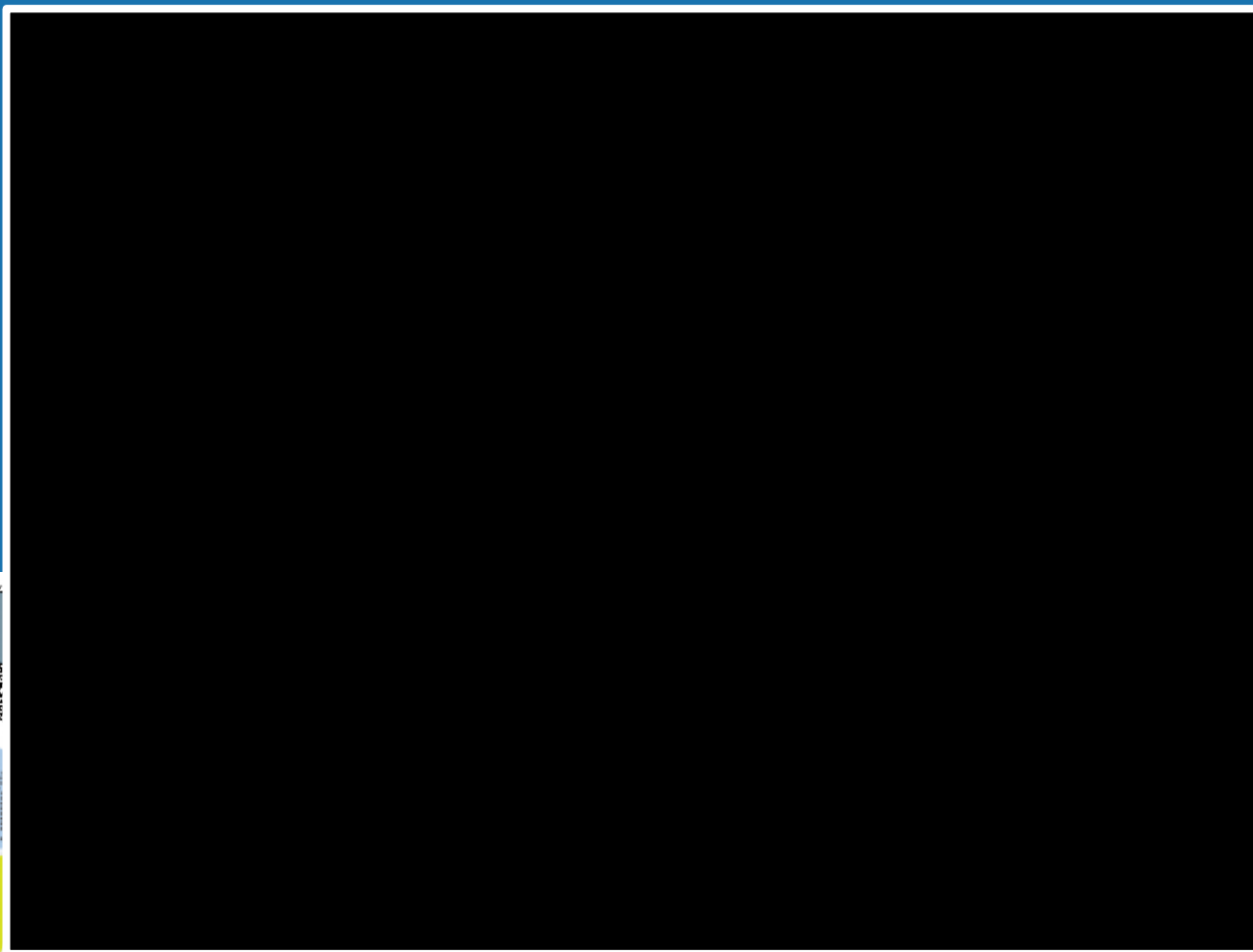


Prof Bill Buchanan, Edinburgh Napier University

James Varga, miiCard

Daniel Moulin and Chris Eckl, Sitekit

miiCard IN 2 MINUTES



PURELY ONLINE IN MINUTES

Set up your miiCard and **verify** your identity

one time set-up
In 5-10 minutes

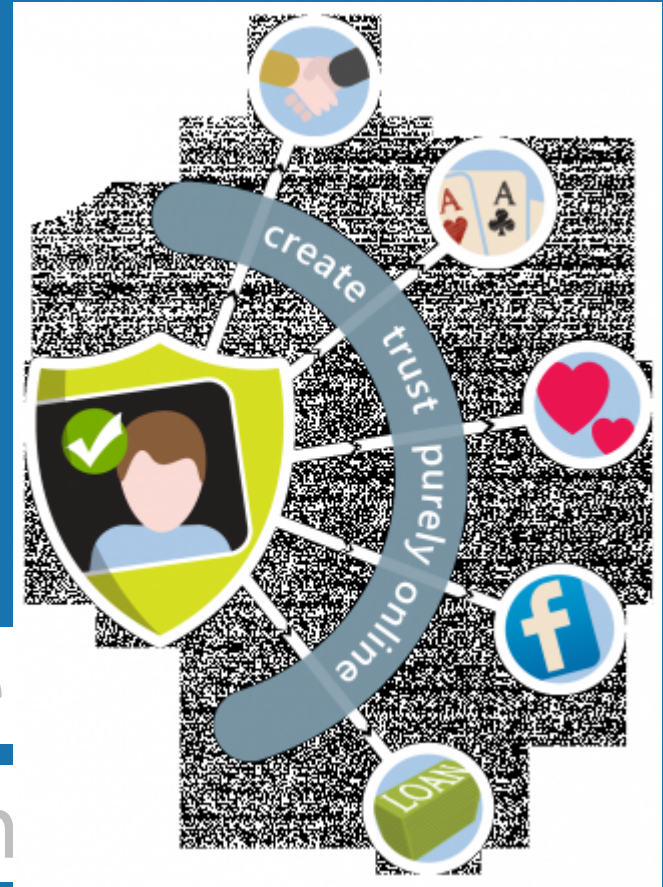


bank-level security
protects your Identity and information

Bring Your Own Identity (BYOID)



- Retail Banking
- Consumer Finance
- Online Gaming
- High Value eCommerce
- Online Dating, Recruitment



HIGH TRUST

expert physical document check

bank account



LOA3

— ID Verification
("you are you")

knowledge-based assessment

online passport

online driving license

credit reference

mobile number

LOA2

— Data Validation
("info about you")

social accounts

email address

LOA1

— IDP (Identity Provider)
(Authentication Services)

LOW TRUST



Data

Attribute Providers

miiCard Attributes
- Verified Name
- Verified Email
- Verified Mobile
- Financial Profile
- Reputational Trust Score
etc

Bureau

Credit Reference Agencies

Data Application Interfaces (API)
Data Validation

Services

Identity Providers

miiCard Secure Token Services
- OAuth
- OpenID
etc

Windows Live ID
Google
Facebook
ConnectMe

Authentication
- 2-Factor Authentication
- Location
- Voice Biometrics

Authorisation
- Claims Based

Trust

Identity Proofing

miiCard Verification

Document Verification
- Drivers License
- Passport

Identity Verification



Participating Site
(Relying Party)

Towards a New Health and Social Care Information Sharing Architecture

Cloud-based Personal Health Records



Prof Bill Buchanan, Edinburgh Napier University

James Varga, miiCard

Daniel Moulin and Chris Eckl, Sitekit



incisor

11/13/2012 02:30 PM

Some years ago I was written to as part of the now aborted **NHS patient records programme.**

I was told that a **"summary care record"** would be created for me (unless I opted out) and that **it would be accessible by me.**

I decided to ask (via a phone number which was provided) whether and how I would be able to **view my children's records.**

I was told that this would **probably not be possible**, but perhaps would be **if I asked a GP to show me.**

This seems to me to say a lot about the **attitude of the state and the NHS to their "customers".**

The Telegraph

Home News World Sport Finance Community Blogs Culture Travel 100% FASHION TECH Wednesdays 21 November 2012
Home > Health > Health News

Patients will view their NHS records online in three years
NHS patients will be given online access to their health records in the next three years under plans to be announced by the Government today.



The news of the NHS's health records strategy was leaked by Andrew Lansley, the previous health secretary, to a senior Conservative MP's national newspaper.

By Robert Woollam, Political Editor
7:58AM GMT 13 Nov 2012
Print this article
146 views
Facebook 14

PHOTOGRAPHY

HEALTH MOST VIEWED

- 1. The vaccine effectiveness exaggerated, scientists claim
- 2. Women suffering liver disease because they try to drink like men
- 3. Menstrual pain by 'instant super ref' machines
- 4. The problems with perfection: Is it all right for girls just to be all right?
- 5. 'Walking talk' of liver disease due to obesity, alcohol and sedentary life: Prof. Denise Sully Davies warns

EDITOR'S CHOICE

Review: *Millennium: Countdown, My Best?*



e redbook

Your child's digital health record

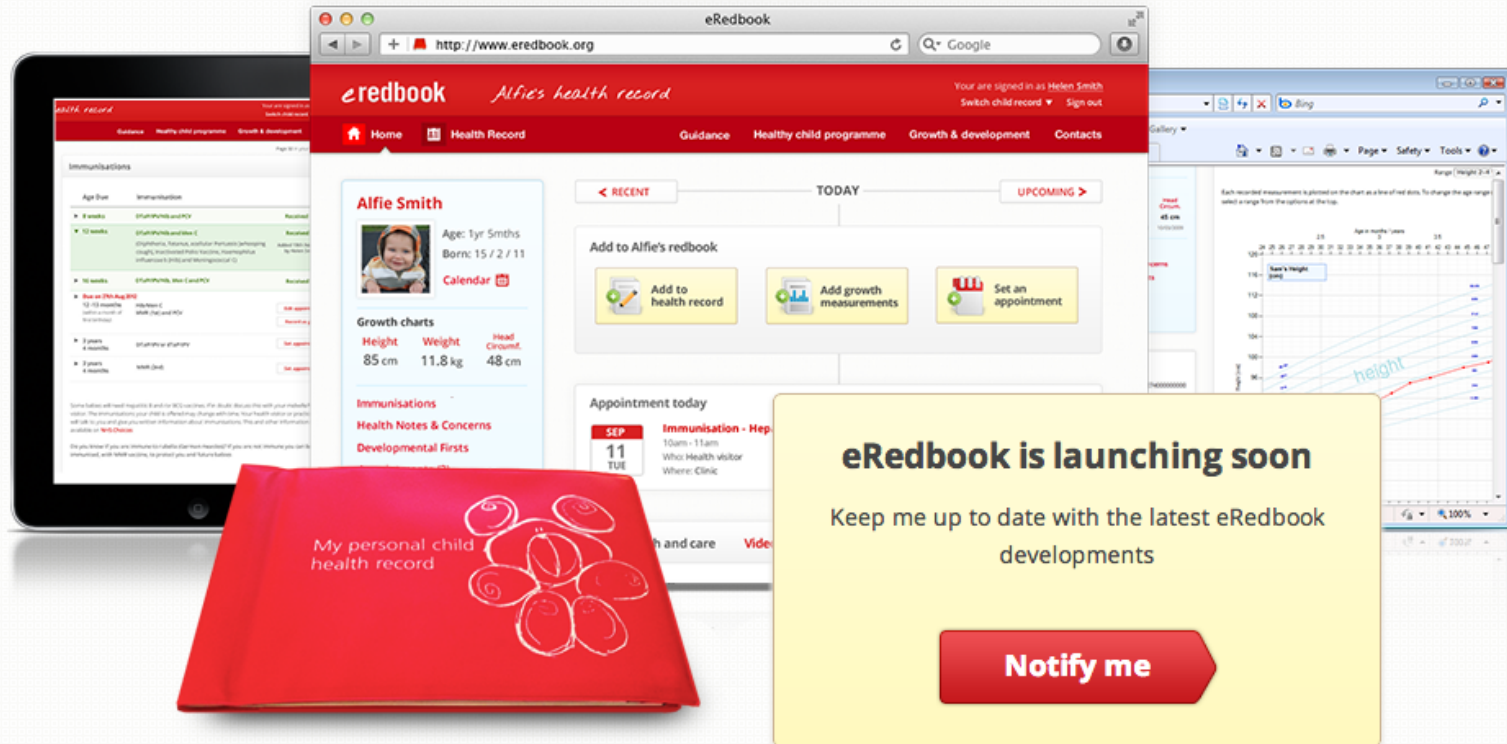
Sitekit

Tuesday 4th December 2012

Dan Moulin – Project owner



The online version of your personal child health record



Organise health care

Plan ahead for all the important **health reviews, immunisations** and **appointments** with your health visitor or doctor.

Keep a secure record

Keep your own **personal notes** and photos of your child's **growth and development**.

Useful reminders

Note important health care **questions** to ask a health professional and **receive email reminders** for appointments.

Focus

- Clinical Engagement
- Ease of use
- Standards compliance
- Engaging



- Usability - User Centred Design
- Clinical Engagement – Paediatrics, Health Visiting, Midwifery, GP, Parent
- Standard Compliance (RCPCH)



- Secure, scalable and robust, health data storage
- Consumer mediated data exchange:
 - With clinicians
 - With friends and family
 - With devices

Some PHR Definitions

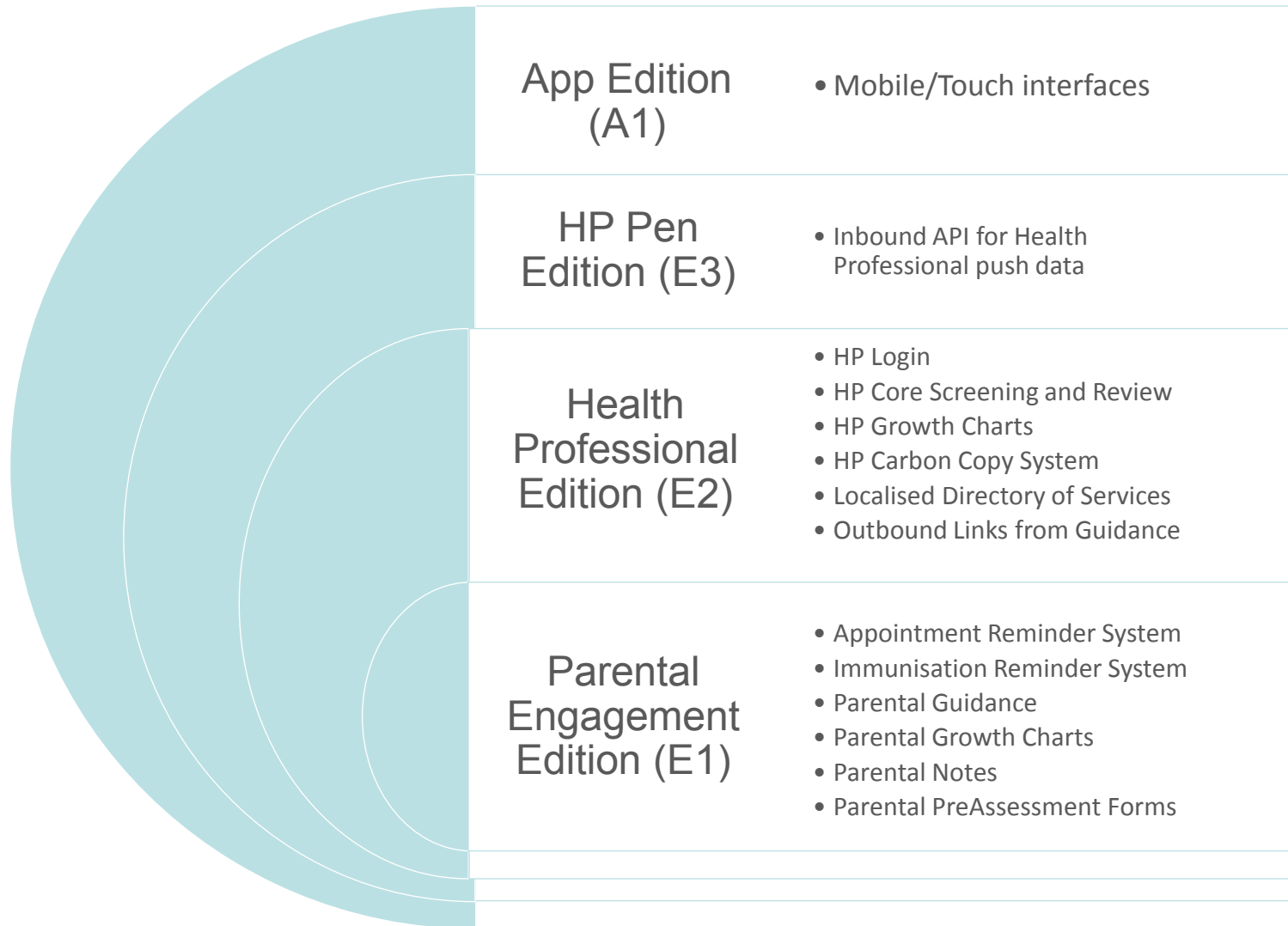
The Healthcare Information Management and Systems Society have defined a Personal Health Record as follows [2007] :

*An electronic Personal Health Record ('PHR') is a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools. The **PHR** is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations.*

The Medical Library Association/National Library of Medicine Joint Electronic Personal Health Record Task Force also examined the state of PHRs in an extensive review in 2010. After scrutinising various existing classifications, they provided the following working definition:

*Electronic personal health record (**PHR**): a private, secure application through which an individual may access, manage, and share his or her health information. The **PHR** can include information that is entered by the consumer and/or data from other sources such as pharmacies, labs, and health care providers. The **PHR** may or may not include information from the electronic health record (**EHR**) that is maintained by the health care provider and is not synonymous with the **EHR**. **PHR** sponsors include vendors who may or may not charge a fee, health care organizations such as hospitals, health insurance companies, or employers.*

eRedbook Editions



Mark Johnson



Age: 18 months
Born: 16/05/2011
Calendar

Growth Charts

Height	Weight	Head Circum.
78 cm	11 kg	45 cm
16/10/2012	16/09/2012	16/05/2012

- Immunisations
- Health Notes and Questions
- Developmental Firsts
- Appointments
- Health Reviews

Contacts

Family doctor
Dr. John Lewis 07700 900000

Health visitor team
Mr. Sam Maguel 07700 900099

< RECENT

TODAY

UPCOMING >

Add to Mark's eRedbook

Add to health record

Add growth measurements

Add a appointment

Next appointment

SUNDAY **Monthly checkup** Edit Delete
 14:07
 Venue: portree
 Added by sarah johnson

Questions

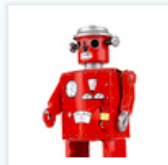
+ Add a question

Is this a question? Yes it is Edit Delete

30 November 2012 Added by sarah johnson
This is a question

Developed a rash Edit Delete

Felix Moulin



Age: 27 days
Born: 06/11/2012
Calendar

Growth Charts

Height Weight Head Circum.

- - -

Immunisations

Health Notes and Questions

Developmental Firsts

Appointments

Health Reviews

Contacts

Use this space to save important clinical contacts. You have not yet added any contacts [Add contacts](#)

< RECENT

< TODAY

UPCOMING

Upcoming appointments

Appointment



Hearing screening Edit Delete

09:54

Added by Dan Moulin

+ Add a appointment

Book soon

Full physical examination

6-8 weeks old

[More details](#)

Due

Contact GP practice to arrange an appointment

Set this appointment

1st set of immunisations

8 weeks old

[More details](#)

Due

Contact GP practice to arrange an appointment

Set this appointment

Appointments you need to book are part of the **healthy child programme**

Mark Johnson



Age: 18 months

Born: 16/05/2011

Calendar

Growth Charts

Height	Weight	Head Circum.
78 cm	11 kg	45 cm
16/10/2012	16/09/2012	16/05/2012

[Immunisations](#)

[Health Notes and Questions](#)

[Developmental Firsts](#)

[Appointments](#)

[Health Reviews](#)

Contacts

Family doctor

Dr. John Lewis 07700 900000

Health visitor team

Mr. Sam Maguel 07700 900099

Guidance for parents

NHS approved information sources

If you would like to read more about baby and child health guidance, the following websites contain Department of Health approved guidance and content:

NHS choices Child health 0-5 and Pregnancy and baby guides.

NHS Direct NHS Direct, 24 hour support and advice.

When to call the doctor

Small babies' illnesses can become very serious very quickly. You know your baby best. Don't wait too long if you are worried. Ask for help when you feel you need it.

A very ill baby may be unusually sleepy, have breathing difficulties, be much less active, take less than half the normal feed in the previous 24 hours, have less than 4 wet nappies in the previous 24 hours, feel hot when looking pale.

If you notice any of these contact your doctor at once and find out what to do next. If you cannot talk to a doctor quickly, then take your baby to the hospital or phone 999 for an ambulance. If your baby/child has a rash, see 'spots and rashes' and meningitis guidance information.

Child safety

- Home safety 0-12 months
- Home safety 1-2 years
- Home safety 3 years
- Keeping your children safe in the car
- Protect your child from

Feeding your baby

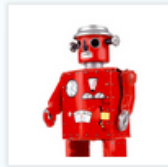
- Feeding your baby
- Information for breastfeeding mothers
- Breastfeeding
- Bottle Feeding
- Solids

Healthcare

- New baby review
- Can your baby hear?
- When to call the doctor
- Can your baby see?
- Looking after your child's teeth and gums

[Home](#)[Health Record](#)[Healthy Child Programme](#)[Growth and Development](#)[Guidance](#)[Contacts](#)

Felix Moulin



Age: 27 days

Born: 06/11/2012

[Calendar](#)

Growth Charts

Height	Weight	Head Circum.
-	-	-

Immunisations

Health Notes and Questions

Developmental Firsts

Appointments

Health Reviews

Contacts

Use this space to save important clinical contacts. You have not yet added any contacts [Add contacts](#)

Growth and Development

When to measure growth

Normally your baby needs to be measured only as part of your routine appointments with a health professional.

Age	No more than
2 weeks to 6 months	Once a month
6-12 months	Once every 2 months
Over 12 months	Once every 3 months

[Read more about the growth charts and measuring your baby](#)

The growth charts

The charts in the eRedbook are a guide to how your child is growing. It compares your child's length and height with other children of the same age. It also shows how quickly your child is growing.

[Read more about interpreting the growth charts](#)

Further information about baby development

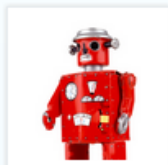
If you would like to read more about baby and child health guidance, in particular the development of your baby as he or she grows, the following NHS approved sources may be of interest:

Developmental firsts

Babies want to explore the world around them. Your baby grows and learns faster in the first year than at any other time. There are many things that all babies and young children do, but not always at the same age or in the same order. You can use the eRedbook to record when your child does things for the first time.

[Track Felix's development firsts](#)

Felix Moulin



Age: 27 days
 Born: 06/11/2012
 Calendar

Growth Charts

Height Weight Head Circum.

- - -

Immunisations

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Immunisations

[+ Add immunisation](#)

Healthy Child Programme

Age Due	Immunisation	
▶ 8 weeks	1st set of immunisations	Book appointment
▼ 12 weeks	2nd set of immunisations	Book appointment
	DTaP/IPV/Hib and Men C (Diphtheria, Tetanus, acellular Pertussis [whooping cough], Inactivated Polio Vaccine, Haemophilus influenzae b [Hib] and Meningococcal C)	
▶ 16 weeks	3rd set of immunisations	Book appointment
▶ 12 months	Booster immunisations	Book appointment
▶ 13 months	1st dose MMR vaccine and booster immunisations	Book appointment

Other immunisations

Date Given	Immunisation
No Immunisations Found	

Questions

Towards a New Health and Social Care Information Sharing Architecture



Prof Bill Buchanan, Edinburgh Napier University

James Varga, miiCard

Daniel Moulin and Chris Eckl, Sitekit



murwald

11/13/2012 12:17 PM

Oh good because [...] doctors always look at me as if I am asking to look at the bloke's down the road when I ask to look at mine

It should be an absolute priority to see your own records whenever and wherever you want to

Regarding the title of this piece considering how badly most NHS IT systems are designed, implemented and function it probably means that you log on and the correct page comes up three years later.



stelvio

11/13/2012 08:45

There is no money.
This is the new "Cones Hotline"



philclark60

11/13/2012 12:17 PM

Patients will view their NHS records online in three years

NHS patients will be given online access to their health records in the next three years under plans to be announced by the Government today.