KTN
the Knowledge Transfer Network

Engaging with the UK Digital Health Industry: Getting Health Data Analytics onto the Map

Sheffield 14th March 2016

Healthcare opportunities

1. Better care through patient-specific prediction:

- Patient need and global epidemiology
- Pharma needs to engage via ABPI
- Understanding what does behaviour change? Some are proxies
- Find out what are the really significant signals?
- Sentiment analysis of social media- detection prediction
- Using social media to collect data & feedback analysis
- Devise coherent- hypo thesis & association between cause & effect
- How much is enough data? Collect data, filter relevant
- Identify relevant metadata
- Interrelated indicatives- composite measures
- Avoidable admissions-detecting signals in the data
- Ensuring more appropriate information governance

2. Learning health systems

- Handling conflict between sets of data
- Person-centric data complete, comprehensive needed in order to predict
- Outcome based database
- Real-time data collecting & real-time analytics
- Identifying the gold standard of care
- Monitoring , encouraging compliance to retirement & life styles
- Empower the patient to ‘flag’ their data needs to the system
- Opportunistically collected data

- Measure integrated care – patient path & treatment decision
- Lobbying role for UKHDAN to bring industry & academics together
- Methodology of benchmarking
- Small incremental steps towards getting rid of fragmentation

3. New insights from integrating non-traditional data

- Devices at home hive/canary care?
- Co-production of care
- Patient reported outcomes
- Managed access fund CDF + real world SACT
- Can bring in other health determinates such as economic socio cultural factors
- Opening up data to right partners -> appropriating data in timely + meaningful manner ensuring lands' right place
- Greater cross- disciplinary + cross public sector engagement private
- Changing care coordination

4. New models of technology-enabled care

- Future: re-organising traditional structures of healthcare delivery & Ai IBM Watson eg. Algorithmic driven diagnoses + access data /examples
- Greater personal ownership of health outcomes + wellbeing
- Support/incentive personalised health budgets
- Better ability to determine indicators that deliver better healthcare outcomes
- Current: using available data to drive insights for care-> trends not individual events
- Care should always be delivered in p……

5. Characterising human phenome

- Finding different groups where treatment effects differs
- Treatment efficacy depends social context- understanding social context
- Comparative data-people like me how I rank vs others like me
- Interaction with personalisation
- This needs reworking and explain better
- Monitoring NAS health support groups to mental health patients & characterising sequence of episodic intervention

6. Personalising care

- Setting personal goals- really important
- Patient reported and defined outcomes
- Consumer opportunity – self management
- Extending the personal consultation by digital means

- Data analytics process linked to actionable intervention & communications channels organisations
- Right care- why not consumer facing?
- Patient activation
- Need for co-design of systems patient engagement
- Before engagement need access then inform
- Democratising health
- Access through offer sectors insurance, supermarkets, telecoms etc
- Tailoring message to level of understanding of user
- Need incentives for system to share data
- NHS is part of the problem
- Skills gap in case coordination
- This is a new market opportunity
- Self-configurable systems
- Personal health budgets
- Person at the centre
- Getting the balance right between sharing everything and need to know
- Up to date & meaningful metrics for patient engagement
- Cross-sector learning metafused
- Stratification of patients for communication
- Patient-reported experience outcomes – population evidence of effect (eg drugs) vs individual effect
- Dealing with co-morbidities
- Need for evidence about the way patients use info
- Care should always be delivered in partnership degree of autonomy may depend on condition

Data science challenges

1. **Dealing with missing ,unreliable and corrupted data**

- Disagreement which source is correct?
- Signal detection AE reporting
- Requirement to record data in particular form & standard
- How do we get correct/reliable data through asking appropriate questions
- Disconnected organisational =/= data challenge but institutional one
- Medicines homecare (data gaps)
- Minimise missing data + increase collection of relevant data
- What is the purpose of re data? 99% good for statistics bad for direct care
- Purpose the data was collected

2. **Integrating heterogeneous data sources**

- Common data standards OMOP

- Preparing the data what do I need to answer my questions?
- Disagreement between linked data sources
- Governance to link data whose organ's remit is this?
- Disclosure central
- Data management tools + systems from other sectors (retail financial astronomy digital marketing automotive)
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3. Characterising complex temporal structure

- Enabling individuals to access their own longitudinal data
- Change from static & episodic data to clusters & sequences
- 'Lag' between activity /intervention
- Meditation analysis
- Analysing sequences of actions & behaviours
- Interdisciplinary approach eg. statisticians, computer science
- Plotting the life course in data= connections between various factors & poor health – individual patterns

4. Marriage of human and machine

- Involvement of artists and creatives in data visualisation
- Must follow trends in personal tech
- User experience must evolve not design and ossify
- New infographics are absolutely critical
- Using behavioural economics approaches to motivate users
- Data=> information/information=> knowledge
- User-central design
- Interfaces that learn
- Behaviours change=psychology
- Filtering for relevance is a key challenge= what is actionable by the user?
- Create the opportunity for users to share their approach
- Social networking as part of the community pathway
- Personal health assistant- but needs comprehensive knowledge
- How can individuals choose from complex options and revoke choices
- Dashboards
- What's the incentive for anyone to address this
- Brining in creatives
- Fundamental unsolved problem
- Need data visualisation hackathons
- Mobile devices basically allow consent through engagement
- Self-service- metrics visualisation cohorts
- Prominence of points solutions=-lack of analytic integration
- Carry bridge- talking about symptoms with selected groups= how can the individual choose
- Need to draw in experts not currently engaged in #BUdatabases

- Must follow trends in personal tech and be open

5. **Identifying subgroups**

- Identifying relevant data
- How to present the analysis
- Educating clinicians about the meaning of risk
- Empowering patients to flag their data needs to the system
- Analytics about the individual to provide useful data to the individual
- Tailoring information to individuals+ their characteristics treatments/drugs that will work or not
- Cohort identification predictive modelling

What are the Barriers and Enablers?

Poster1:

- Overview of available data
- What is a sustainable business model for companies in healthcare?
- No ecosystem that supports new entries to market
- Fragmented analytics
- Fragmented data landscape- where is it? Who is responsible? How to link?
- Cultural reticence to share with industry
- Culture of conservatism of resistance to change
- Market forces do not encourage sharing of data in a social healthcare system
- Challenges in mixing publicity of privately provided services
- Unified political will across defined geography
- Can't deploy without evidence- can't get evidence without deploying
- Access to data- knowing what exists getting access once you know
- Patient granted permissions to share data +determine use (single agreement)
- Co-produce/shared revenue models
- City-region open platforms- core services open API
- (in)Ability of NHS to create + engage with markets at scale
- Developing open platforms to share data
- Minimum standards for new systems
- Reducing costs are increasing choice
  Combining products and services may be the way forwards

Poster 2:

- Enabler: National networks KTN
- Enabler: KTN to bring diverse groups together
- Enabler: emergence of alternative provider/new business models
- Enabler: Health AND social care

- Enabler: Devolution Manchester
- Enabler: Group collaboration
- Data quality
- Enabler: Data VIZ (UI)
- G Cloud
- Enabler: STPs
- Enabler: activated SME community
- Enabler: local health economies
- Enabler: patient voice
- Enabler: hackathons for co-discovery and co design, bringing diverse groups together
- Enabler: SBRI funding
- Enabler: standardisation across software systems and/or move APIs for integration
- Outcomes based healthcare
- AHSN activities eg. digital health and wellbeing ecosystem In Yorkshire
- Creative England interactive healthcare fund
- NHS adoption facilitation competitions and programmes
- NHS test Bed learnings
- Learning from rural healthcare provision
- Enabler: patient groups IR engaged correctly
- Short termism
- Barrier: NHS think they own data
- Barrier: The daily mail
- Getting data from private health providers
- Barrier: Lack of positive motivators to adopt new practices & products
- Barrier: Morale in healthcare professions
- Payment by activity
- Barrier: Lack of commercial models
- Barrier: Pseudonymisation
- NHS architecture
- NHS lack of engagement with innovations businesses (DIY solutions?)
- Org. inertia
- CSV's
- IG
- HSCIC
- Acceptable use of data
- Needs dual approach to finding
- HSC IC Blockages
- Barrier: Lack of expertise in using big data tools
- Lack of gainshare

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Birmingham 17th March 2016

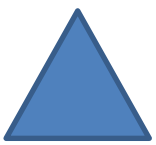
Healthcare opportunities

1. Better care through patient-specific prediction:

- Risk stratification
- Degree of confidence in prediction
- Early warning scores
- Predictive analytics
- Moving to community
- Where does the data come from primary care SUS?
- Planned intervention in rent-time
- Data-driven triaging

2. Learning health systems

- Continuous feedback
- How does the action happen?
- Real-time data
- Comparative benchmarking
- Tracking infectors disease
- Need for culture change- annual budges-> lack of agility
- Understanding the planning cycle
- What works for real people at the ideal
- Reimbursement charges slowly and is this a barrier to change? eg. GPs warfarin clinics
- population



cost Individual

3. New insights from integrating non-traditional data

- Missing Wellness & Fitness
- Social networks; Socio-economic data
- Hospital design ' in hospital' 'virtual beds'
- Extra Care
- Useful to plan a design services dependent on local SES (Social Econ Status) manage elderly bed block
- Helping individuals learn sharing their feeling with the system

4. New models of technology-enabled care

- Reassurance for patients (particularly for older patients)
- Perception of data ownership and psychology of share data
- Psychology of disease

5. Characterising human phenome

- Where do you draw the line in tracking activity?
- Strategies for managing risk vary by individuals
- Phenome 'Twins'
- Different methodologies for capturing mortalities
- Precision medicine
- Frailty
- Related to personalising; helping individual to understand influences on the health
- Contextualising health data

6. Personalising care

- Trust
- Data integrity
- Personally held record
- Projects
- Office of life science
- Landscaping
- Information governance
- Personalised stratified medicine
- Frailty
- Intelligent assistant that learns about yon
- Personal choices influence feedback realistic feedback
- Patient records
- Tailor content
- Information governance
- Need for personal assistant to collaborate with the wider health system
- Ethics & litigation
- MHRA BSI: digital health & care alliance
- Role of evidence: deploy>>risk>>evidence

- Information Governance – Uni of Bradford Data Mutual
- Someone referred to Sheffield website (FRAX?)
- Identifying big hitter key parameters to follow
- Hub of all things HAT
- Comorbidities
- Bring your own device
- Patient access to their own data presented in a way they understand
- Consent, unintended consequences
- Linkage between systems: Interoperability not a challenge (ref: Dalas ifocus)

Data science challenges

1. **Dealing with missing ,unreliable and corrupted data**

- 6 dimensions – Data quality
- Missing data may be informative
- Need to understand the health effect
- Standardisation
- Understanding the reliability of data sources
- No model is perfect but some are useful
- Marrying perfect & imperfect data
- Information from talking to the patient
- Checking the problem of coding variation
- Media perception of data sharing
- Appropriate & safe data sharing
- Open data institute
- Common nomenclature – standardisation

2. **Integrating heterogeneous data sources**

- Probabilistic linkage
- Only the machine can see the patient data
- Standardising variation in measurements between devices
- Educating people about sharing data implications
- Identifying the reliable source of data so health care professionals can rely on it
- Text mining free text

3. **Characterising complex temporal structure**

- Data external validation/ avoid ‘over fitting’
- Validation
- Identifying all the appropriate things to monitor
- Need the right tools to measure the right things
- Challenges in attitude over the life course
- Reference values ‘sets’ normal ranges
- Computational power of vary large datasets
- Unsupervised learning eg accelerometer Data

4. **Marriage of human and machine**

- The less visible the better
- Infographics UX/UI interactive
- Stuart Anderson Edinburgh University
- Evolutionary algorithms
- What's happening to me/What is likely to happen to me
- Nudging of gaming
- Interfaces that evolve
- Complex dashboards- break into manageable elements
- How diagnostic tools evolve over time
- Decision-support targeted to the individual at the role
- Access to data – Caldicott Review
- Generative vs discriminating models
- Salient decision making signals UX/UI
- Communication/sense – making/data/ For Key stakeholders(personalisation)

5. **Identifying subgroups**

- Validation
- Risks of over interpretation
- Validation predicting outcomes

What are the Barriers and Enablers?

- Lack & sustainable business models
- Understanding the effect & linkage
- Trust
- Apple/google connecting with EMIS (enabler?)
- EU legal framework that prevents mobile phone companies using data for a different use case
- EMIS etc. are driven by commercial values
- Users are enabled citizens – dynamic consent
- Barrier: filtering junk information
- Data quality
- Potential to drive health inequality
- Can we detect AF
- Truly informal consent
- Information spread across different systems/stakeholder
- Accessing data-sharing
- Lack of focus on specific outcomes
- Standards vs innovation
- Ethics of choosing operating points (FP vs FW)

- Explosion of data if derived data is stored
- EMIS are beginning to open their APIs
- Single information governance for aggregated databases
- Can connect lots of people in a standardised way
- Ambient monitoring & wearables can help NHS to interact with patient
- Cloud based systems Hadoop
- Stakeholders engagement of key data holders
- Rules & bureaucracy of data sharing
- The NHS thinks they own the data (but they don't)
- Barrier: same data is paper-based
- Barrier: reverse financial incentives
- Fear of technology is making people redundant
- Information governance
- Public perception thank to the media
- Information about data
- Enabler: 'virtual' consent
- Face time for medical consultations
- The worried well
- Barrier: access to data
- Barrier: problems with agreement to share data
- Limited budgets are encouraging innovation
- BBC analogy 11k taxis/couriers per week to move tapes around to end-to-end IP
- Blocking: disincentive to change systems: Ivory Towers eg it systems in hospitals
- Technology can be a barrier- eg monitoring the data for 'big' analytics
- Patients know best: have a consent model – understanding the effects of linkage
- The worried well
- Protecting existing systems to stop change happening
- Data is not 'open' with suitable safeguards

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Engaging with the UK Digital Health Industry: Getting Health Data Analytics onto the Map

Newcastle 23rd March 2016

Healthcare opportunities

1. Better care through patient-specific prediction:

- Lifestyle to food
- Predicting problems in advance
- Early diagnosis/risk profile
- Education of the young
- Designer sensors for an individual co-morbidity
- Combine with health education
- Understand 'big data' around individuals socio-economic status
- Identifying the 10% who account for 40% of cost
- Forecast when problems are likely to occur
- Focus on long term conditions
- Focus on 10%. 80% cost of long term conditions

2. Learning health systems

- Issue is not rapidity but timeliness and assurance of action
- Apps for patient feedback which can be acted upon
- Stratification of risk
- Prioritise appropriately rapid
- Measuring the right outcomes e g getting back to work
- Patient experience important
- Implantable sensors with a feedback loop
- Measure outcomes not activity
- Value based outcomes
- Needs the right data to measure it

3. New insights from integrating non-traditional data

- Difficult to get data out of NHS – impossible to get it in
- Breath sensor- personalised to individual need
- Learning from other industries
- What is really happening to people in the wild
- Post-surgery sensor in joints
- Socio economic data
- Sensor (bio compatible to track recovery after surgery)

4. New models of technology-enabled care

- How are people rewarded for engaging
- Decision support: supporting co-production
- Community can flag the need for an intervention
- Educating the carers & community
- Tax breaks for informal carers
- Better involvement of community pharmacies
- Business incentives for pharmacies (not just prescriptions)
- Mental health of carers
- Ecosystem of providers –including health care professionals
- Need an 'All about me 'view
- Wellness Programmes for corporate programme
- Need for a system – wide approach
- Whose job is it to make sense of it all for the individual?
- Building are what we have develop & add value
- Pathway redesign to address 'big ticket' items
- Need for integration – how will integration engage
- Integration needs to emerge
- Using & integrating technology
- There are barriers to the 'system' accepting the data
- Civic platforms – current evidence suggests few repeat visits

5. Characterising human phenome

- Integrating genomic &environmental data

6. Personalising care

- Charities are better than NHS
- Diabetes UK + Tesco tie-up
- Do everything possible outside the surgery (stats)
- Timely feedback to patient-should go to healthcare team
- Getting engagement with the system right- eg access to GP
- Measure stats in Boots – should go into HER & produce alerts to healthcare team
- Reduce the number of goals – focus on what is important
- Electronic Passport for diabetic patients
- Persistent communication

- Self-service 24/7 will increase uptake – will it?
- The journey-> communication
- Helping the patient to interpret the data
- Does the patient drive healthcare inequality?
- Is this a worried well thing?
- Gamification
- People have different motivations
- Tie-up between Tesco and Diabetes UK – seamless capture of data
- Untapped potential of social media

Data science challenges

1. **Dealing with missing ,unreliable and corrupted data**

    - Managing uncertainty property
    - More intelligent alerts-data model may be unreliable
    - Industry standards
    - Paper based records
    - Manual recording intelligent checking based on patient history
    - Automatically cleaning data but not missing signals

2. **Integrating heterogeneous data sources**

    - Is it the right place to put it?
    - Don't throw away potentially valuable data
    - Don't make the barriers for medical devices too high
    - Rating data services emerging property
    - Automated trip advisor for data
    - Risk exists already accept this
    - Metadata age & proven once etc of data
    - Refresh rate- is a measurement current?
    - Effective meta-data services

3. **Characterising complex temporal structure**

    - Beyond steps
    - What's normal for me?
    - Monitoring devices that only read out when integrated
    - Most important challenge to solve
    - Need for meta data
    - When is no signal a signal
    - Most important challenge to solve
    - Currently only crude comparisons available

4. **Marriage of human and machine**

    - Different visualisation & tools depending an role
    - Need for appropriate language
    - Different tools for different users
    - Actions need to be guaranteed for the really important

5. **Identifying subgroups**

    - Dealing with evolving structure
    - Lots of correlations in the data
    - Including managing data
    - Techniques are mainly translational space