Reflections from a Northern Ireland perspective

Adele Graham PHA
• Not going to describe in any detail the various initiatives you have seen here.

• Will talk about some of the things I think we in the North are doing well and some where we have a way to go.

• Finish with some of the broader issues and directions of travel or prevailing winds.
Public Health - a busy landscape

Knowledge  Community-development
Monitoring  Empowerment
Evidence  Inequalities
Health  Service-development
Small-area information  Comparative-data
Protection  Disease-registries
Evaluation  Community-planning
Screening  Research
If we think about the Public Health information /knowledge system as if we are building a house

— but this is a house with lots of different tenants
Some good foundations

- One unique number on all main HSC systems
- Good death and birth registrations
- Within HSC core systems mainly common across Trusts
- Postcodes are widely used.
- An agreed and tested deprivation measure (2010)
- Census (even if only 10 years) in 2011 and 2021
- NISRA process of out-posting statisticians to government Depts
- NINIS for small area data
- Local academics (COE, UU, QUB)
Things that are advancing well (my view)

- The plumbing – HSC wide networks (BSO)
- The bathroom – Health protection – lead PHA with good PHE links
- The windows - NINIS – NISRA with PHA and DHSSPS. Other specialist areas such as CYPSP
- The Aga - The data warehouse for HSC data - lead BSO with HSCB and now wider prioritisation group and Honest Broker
- Individual rooms
  - Cancer Registry – NICR (PHA funded) linked with Irish and other Cancer Registries
Things that are advancing well ctd

Health inequalities monitoring / NI Health survey (DHSSPS)
Self harm registry (PHA – all Eds covered – link with Cork)
Northern Ireland Longitudinal study (QUB and NISRA)
Confidential enquiries (PHA)
R&D strategy – (PHA)
Primary Care data – now have good prevalence data (HSCB)
Prescribing data – (BSO)
Campaigns – development and evaluation (PHA)
Individual initiatives with RoI – (CAWT, IPH etc)
Where do we have a way to go?

- Screening – operational systems good but only now getting into downloading data and further analysis and linkage (PHA)
- The corridors - Data standards and definitions – particularly in community and voluntary
- Impact/Outcomes measurement and VFM/ SROI
- Private Sector and C&V data
- Clarity about who to ask for what data?
- Knowledge exchange and sharing evidence
- Data linkage
- Closer engagement with the IT system design and implementation
- Structured ways to engage people and record it
- More professional engagement in data collection systems
- Using the data we have!

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Looking over the fence from our garden

The UK always seems to be ahead of us in Northern Ireland
• England has scale and the legacy of topic specific observatories, wide comparative data.
• Scotland – long history of work of ISD and record linkage well established.

• But facing similar base line reductions and many common issues going forward.
What do the gaps have in common?

- They tend to sit between organisations.
- No-one organisation is leading on them.
- Because we have no agreed strategy or road map.
- Each bit of the system tending meet its’ own needs.
The wider context

For the purposes of talking I have to separate them but many of these issues are closely linked.
Access to data

• Tension - Open data and Data Protection/ disclosure controls/ ICO

Or as a data provider maybe
more like this
As data providers we need to get more comfortable and clearer re the real constraints, risks, issues. We need to streamline access systems. Disclosure controls – guidance and risk assessment.
Public and Professional Trust

NHS Care.data information scheme 'mishandled'
By Chris Vallance
PM, BBC Radio 4
18 April 2014 | Health

It's barmy to hand our health secrets to Google - the world's greediest snoper, writes STEPHEN GLOVER
Published: 01.30.5 May 2016 Updated: 01.40.5 May 2016

UK data watchdog threatens legal action against dementia charity
The Alzheimer's Society faces potential £500,000 fine for various security failings.
By Kelly F突然： Jun 7, 2016 1:45pm GMT

56 Dean Street fined £180,000 by ICO

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### Overall trust scores - mean scores

"Please tell me on a scale of 0-10 how much you personally trust each of the institutions below. 0 means you do not trust an institution at all, and 10 means you have complete trust."

<table>
<thead>
<tr>
<th>Institution</th>
<th>Trust Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your GP surgery</td>
<td>7.07</td>
</tr>
<tr>
<td>The NHS</td>
<td>6.72</td>
</tr>
<tr>
<td>Academic researchers and universities</td>
<td>6.51</td>
</tr>
<tr>
<td>Online retailers, for example, Amazon, Asos and play.com</td>
<td>6.27</td>
</tr>
<tr>
<td>The Police</td>
<td>6.20</td>
</tr>
<tr>
<td>The ONS</td>
<td>5.95</td>
</tr>
<tr>
<td>Charities</td>
<td>5.95</td>
</tr>
<tr>
<td>Supermarkets</td>
<td>5.72</td>
</tr>
<tr>
<td>Your local authority</td>
<td>5.22</td>
</tr>
<tr>
<td>Internet companies, such as search engines and social media</td>
<td>5.19</td>
</tr>
<tr>
<td>Telecommunications companies, such as mobile phone companies</td>
<td>4.74</td>
</tr>
<tr>
<td>Banks</td>
<td>4.67</td>
</tr>
<tr>
<td>Insurers</td>
<td>4.24</td>
</tr>
<tr>
<td>The British government</td>
<td>4.22</td>
</tr>
<tr>
<td>The media / the press</td>
<td>3.60</td>
</tr>
</tbody>
</table>

### Differences within differences – not all sceptics the same

Which of the following views, if any, comes closest to why you do not want commercial organisations to have access to health data under any circumstances?

- They cannot be trusted to store the data safely (20)
- I don’t agree profit should be made from NHS data, even if there are benefits (18)
- Commercial organisations cannot be trusted to put society before profit (16)
- They might sell data onto another commercial organisation and you cannot control where it ends up (13)
- If commercial organisations access the data, they could manipulate it and this is unfair (8)
- They may try and market products and services to me (8)
- There might be negative consequences for me or my family (6)
- They may re-identify me even though names and personal information might be removed from the data (2)
- There might be negative consequences for the community (2)
- Even if they misuse the data they won’t be punished (2)
- Other (2)
- Don’t know (4)

49% of people asked this question aligned with reasons related to things that could harm them or their family.

46% aligned themselves with social reasons: that commercial organisations having health data could negatively impact society.

### Table 2: Low trust in an institution in general vs. low trust to use data appropriately

<table>
<thead>
<tr>
<th>Institution</th>
<th>Low trust generally (0-4)</th>
<th>Low trust in data (0-4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your GP surgery</td>
<td>11%</td>
<td>14%</td>
</tr>
<tr>
<td>The NHS</td>
<td>13%</td>
<td>17%</td>
</tr>
<tr>
<td>Academic researchers and universities</td>
<td>12%</td>
<td>22%</td>
</tr>
<tr>
<td>Charities</td>
<td>21%</td>
<td>35%</td>
</tr>
<tr>
<td>Online retailers, for example, Amazon, Asos and play.com</td>
<td>15%</td>
<td>38%</td>
</tr>
<tr>
<td>The British government</td>
<td>49%</td>
<td>46%</td>
</tr>
<tr>
<td>Supermarkets</td>
<td>23%</td>
<td>42%</td>
</tr>
<tr>
<td>Telecommunications companies, such as mobile phone companies</td>
<td>40%</td>
<td>54%</td>
</tr>
<tr>
<td>Internet companies, such as search engines and social media</td>
<td>32%</td>
<td>54%</td>
</tr>
<tr>
<td>The media / the press</td>
<td>59%</td>
<td>68%</td>
</tr>
</tbody>
</table>

### Chart 3: “Overall, which of the following statements is closest to your view?”

A. "We should share all the data we can because it benefits the services and me" / "...
   (No safeguard added) 33%
   ...data is anonymised and I can’t be identified 50%
   ...I can opt-out if I choose 52%
   ...there are heavy fines and possible prison sentences for anyone caught misusing the data 49%
   ...there are strict controls on who can access the data and how it is used 46%

B. "We should not share the data as the risks to people’s privacy and security outweigh the benefits"
   44%
   28%
   34%
   33%
   32%
How important this is – work steam in England called ‘Build and sustain public Trust’
EU data protection regulation passes in Brussels giving citizens right to be forgotten online

You now have the right 'to be forgotten'

Zlata Rodionova | Thursday 14 April 2016 | 1 comment
Recovering costs- From HSCIC website May 2106

- **Data Access Request Service (DARS)**
- To request access to data please contact us to discuss your requirements or visit our new DARS online(Opens in a new window) portal.

- **Data products and services**
- HSCIC can provide access to a wide range of [data products and services][133kb](Opens in a new window) through DARS and we make a [charge][79kb](Opens in a new window) to cover the costs of managing your application, processing data and providing access.
- Please note that the way in which we deliver access to data has radically changed over the past 18 months.
- **Changes in legislation coupled with growing public concern over the appropriate use of data have led to the need for greater rigour and transparency when dealing with requests for data.**
- Aligned to this, we are striving to improve the quality of the service we deliver to ensure data access requests are dealt with in a timely, efficient and transparent manner.
- **As such, a revised cost recovery structure is now in place.**
Big Data and data mining

The focus on using administrative data systems where possible along with the increased availability of data from e-health applications mean we need better ways to analysing large quantities of data routinely including visualization.
Ever increasing demands

- New levels of geography for community planning
- Special interest groups and inequality issues
- More emphasis on stakeholders / PPI
- More and more data
- How to prioritise?
Last but definitely not least – ‘Purple people’ and developing and keeping the necessary skills
We need people, technology and infrastructure

...AND THIS EXPENSIVE DEVICE IS THE "DATA-HEAP 5000". IT GENERATES 200 PERFORMANCE REPORTS AN HOUR!

LOOK AT THE LEVEL OF DETAIL. ISN'T IT IMPRESSIVE?

WHAT DO ALL THE NUMBERS MEAN?

NOT SURE...THE TEMP WHO PUTS THE DATA INTO "EXCEL" AND CHANGES ALL THE HEADINGS IS NOT HERE TODAY.

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Events like today are important to learn from each other and see examples of good practice and I am sure like me you have come away with new ideas and contacts and an appreciation of some of the work going on.

Thank you

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Inspirational quote: Benjamin Franklin (1706-1790)

An investment in knowledge pays the best interest.

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