Session 1:
Patient data and information part 1 - what we know

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- 25th May is a key date for data protection rights
  - Implementation of the General Data Protection Regulations (GDPR)
    - Lots of web resources out there…..

  - The new National Data opt-out
    - A number of roadshows are underway, organised by NHS Digital
    - NHS Digital website has been updated
    - https://digital.nhs.uk/services/national-data-opt-out-programme

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- Data Protection Bill
    - MPs debated the Second Reading of the Data Protection Bill in the House of Commons on Monday 5 March 2018.
    - Now at Committee stage in the Commons.
    - (n.b. Have your say")
- Sets out how the UK would apply the derogations available under the GDPR
- Updates the laws governing the processing of personal data by the intelligence services
- Aims to ensure that the UK would be able to freely exchange data with the European Union post-Brexit
- Will repeal the Data Protection Act 1998.

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- The Association of British Pharmaceutical Industries (ABPI) (1/4)
- October workshop "Commercial access to patient data" at IQVIA
  - ABPI & AstraZeneca jointly presented the session “How does the pharmaceutical industry use patient data?”
  - Some communication problems around informing the patients about the outcomes of the projects where patient data has been used
  - Q: why are patients refused entry to some drug company events and meetings?
  - A: Some meetings are not for the ‘public’, which is why entry may have been refused as it is not permissible to ‘promote’ prescription only medicines to the public.
  - Commented: as patients provide the data, they are not ‘the public’

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- The Association of British Pharmaceutical Industries (ABPI) (2/4)
- 20 March AMRC/ABPI Conference, Patients First: Pioneering Partnerships
- Key focus of the day was the need to involve patients at the start of research projects and recognise that patients are experts in their field. Patients' frustration at the barriers to engagement with pharma was made clear.

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- The Association of British Pharmaceutical Industries (ABPI) (3/4)
- 20 March AMRC/ABPI Conference, Patients First: Pioneering Partnerships
- At the end of the Conference, Mike Thompson, the CEO of the ABPI said he was taking away two specific priorities:
  - the need for the way the industry does research to change
  - the need to look at the Code of Practice - the ABPI are in the process of recruiting for a role that will specifically work on what the code can do, rather than can't.

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- The Association of British Pharmaceutical Industries (ABPI) (4/4)
- Keynote Speaker and panellist at the ABPI Annual Conference, April 2018
  - Vocal support for a stronger patient voice
  - “Is the ABPI Code of Conduct now a block to patient inclusion?”

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- Data sharing between NHS Digital and Home Office
  - Chronology described on the use MY data website in Data News Stories
  - use MY data members were polled on the contents of the letter from DH
  - Short report available, and sent to follow-up inquiry being managed by Public Health England
- **Summary of findings**
- There was unanimous agreement amongst members (either strongly agree or agree) that patient confidentiality should be respected by ensuring that medical information about a person is properly protected.
- Members largely agreed that sharing data was important, but that medical data should be properly protected.
- Members felt much less certain that patients would have a reasonable expectation that data should have been shared in this instance.
- Contrary to views stated by the Home Office and the Department for Health and Social Care, it was the strong view of members that sharing of data in the investigation of criminal offences had significant implications for public confidence.

Memorandum of understanding on data-sharing between NHS Digital and the Home Office: call for evidence

PHE Publications gateway number: 2017793

Introduction

Public Health England are seeking views on the impact of data-sharing arrangements under the memorandum of understanding on the health and healthcare-seeking behaviour of migrants, specifically:

> *"What is the public health impact of the Memorandum of Understanding on data sharing between NHS Digital, the Home Office, and the Department of Health, particularly on health seeking behaviour and health outcomes of the migrant population?"*

This response, from use MY data members, looks particularly at the key points relating to this case, taken from the most recent letter between the Home Office, Department of Health and Social care and the Health Select Committee.

We used an online questionnaire emailed directly to members, and left this open for just one week. The results of that questionnaire are supplied here as evidence to Public Health England, as summary findings and as detailed response to questions.

Further details and any questions relating to this evidence submission can be directed to:

Alison Stone, Coordinator, use MY data

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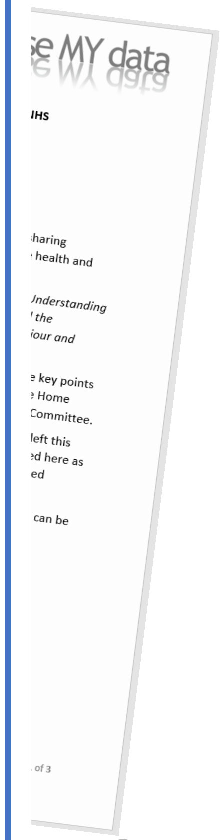
> “As a health informatics professional and a cancer patient, I was appalled to hear that this MoU had been agreed between NHS Digital and the Ministry of Justice. I am an advocate for the use of anonymised patient data for research purposes but this action severely undermined my own trust in HMG as a whole, and of NHS Digital in particular, as a trustee of my personal and confidential data.”

use MY data member



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- Public Health England lung cancer data release to William Wecker
  - Response from PHE to use MY data on the website
  - E-response to the BMJ (Paul Affleck, Chris Carrigan)
  - https://www.bmj.com/content/360/bmj.k293/rr

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- Publication: Data for Public Benefit
- Published jointly by Involve, the Carnegie UK Trust and Understanding Patient Data
- New research highlights there are big differences in how public services define public benefit and risk with regards to data sharing..
- “Includes a framework to help organisations better evaluate these benefits and risks. This framework will help professionals weigh up the purpose of sharing data against the potential for harm and help public service providers have conversations with the public about data sharing.”
- Access via the use MY data News page

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- Local Health and Care Records Exemplar bids
  - A small number of regional health and care collaborative communities across England have been invited to bid for national investment in shared health and care records.
  - The regional collaborations will compete to become one of five new Local Health and Care Record Exemplars (LHCRE), each potentially receiving up to £7.5m in national investment, which bidders will be expected to match fund
  - Each regional LHCRE will build on existing local work on shared records to further develop joined up regional health and care information reference sites, focused on improving direct patient care

For all other news stories……

- See the use MY data website “News” snippets (the post-it notes)
- Also the extended news pages
- And in response to members requests, watch for a more news-focused front page soon…

A movement for patients, relatives and carers. Harnessing the patient voice to build confidence in the use of patient data for research and analysis.

Data for Public Benefit

Report shows differences in how public services define benefit and risk of data sharing

New Data Animation

Farr and Connected Health Cities animation about data and University research

Select Committee report

Report published on the data-sharing between NHS Digital and the Home Office

A movement for patients, relatives and carers. Harnessing the patient voice to build confidence in the use of patient data for research and analysis.

Data news stories

This is a short set of items for information or interest, providing a short briefing, plus links where these are available:

The Health and Soccial Care Commitee - Report published on the Memorandum of understanding (MoU) on data-sharing between NHS Digital and the Home Office (15 April 2018)

The Health & Social Care Committee published its report on 15th April, on the Memorandum of understanding (MoU) on data-sharing between NHS Digital and the Home Office.

The Committee has emphasized the damage the MoU is doing to patient care and confidence in