InterPARES
Trust

Public trust in online records: The case of the UK care.data programme

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21 Archival Colloquium / International Symposium
Born Digital in the Cloud: Challenges and Solutions
In cooperation with InterPARES Trust
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Introduction

- Study question & objectives
- The UK care.data programme
  - aims & timeline
- Findings
- Conclusions in the context of public trust in access to & use of online records

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Research question & objectives

- What lessons about professional & public trust in online records can be obtained from a study of the care.data programme?
  - To take a 360° view of stakeholder views of trust in online records
  - To develop a reproducible methodological approach using analysis of public discourse
  - To identify issues for managing digital records which contain personal data

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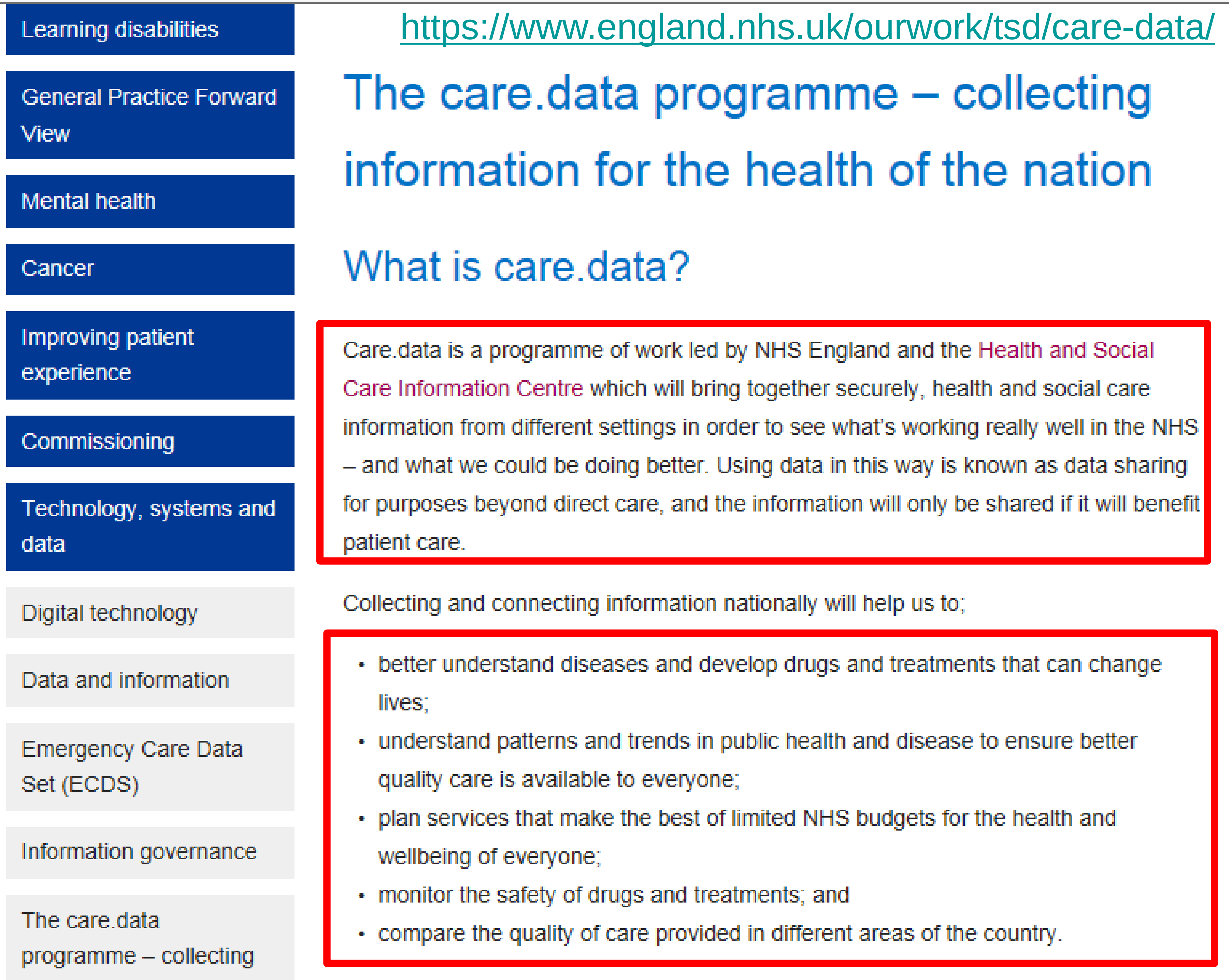
https://www.england.nhs.uk/ourwork/tsd/care-data/



- Learning disabilities
- General Practice Forward View
- Mental health
- Cancer
- Improving patient experience
- Commissioning
- Technology, systems and data
- Digital technology
- Data and information
- Emergency Care Data Set (ECDS)
- Information governance
- The care.data programme – collecting

The care.data programme – collecting information for the health of the nation

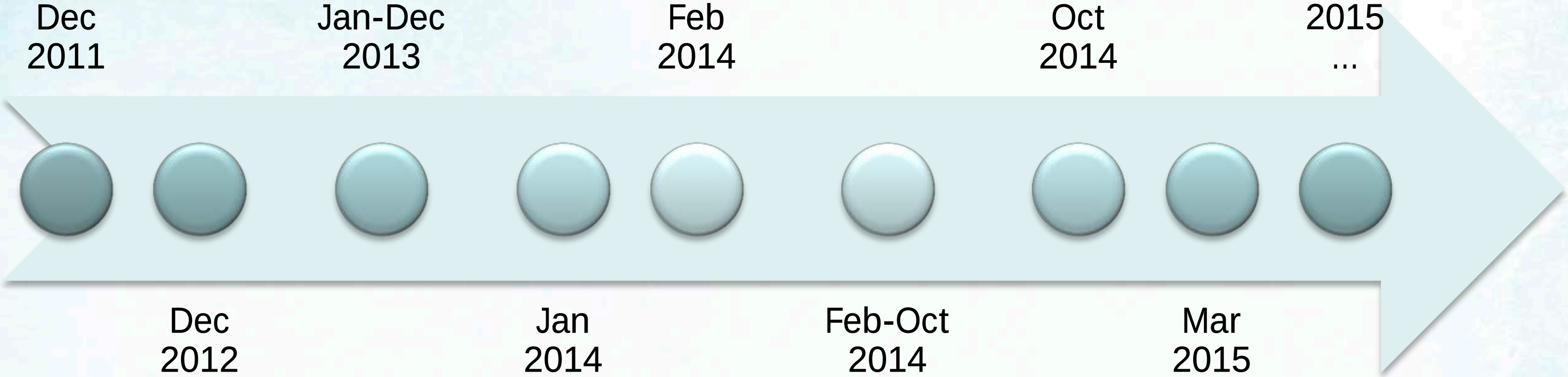
What is care.data?

Care.data is a programme of work led by NHS England and the Health and Social Care Information Centre which will bring together securely, health and social care information from different settings in order to see what's working really well in the NHS – and what we could be doing better. Using data in this way is known as data sharing for purposes beyond direct care, and the information will only be shared if it will benefit patient care.

Collecting and connecting information nationally will help us to;

- better understand diseases and develop drugs and treatments that can change lives;
- understand patterns and trends in public health and disease to ensure better quality care is available to everyone;
- plan services that make the best of limited NHS budgets for the health and wellbeing of everyone;
- monitor the safety of drugs and treatments; and
- compare the quality of care provided in different areas of the country.

Care.data timeline



Dec 2011

Dec 2012

Jan-Dec 2013

Jan 2014

Feb 2014

Feb-Oct 2014

Oct 2014

Mar 2015

May 2015 …

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Care.data timeline

Story of government consultation to automatically include patient data in clinical research with patients able to opt-out

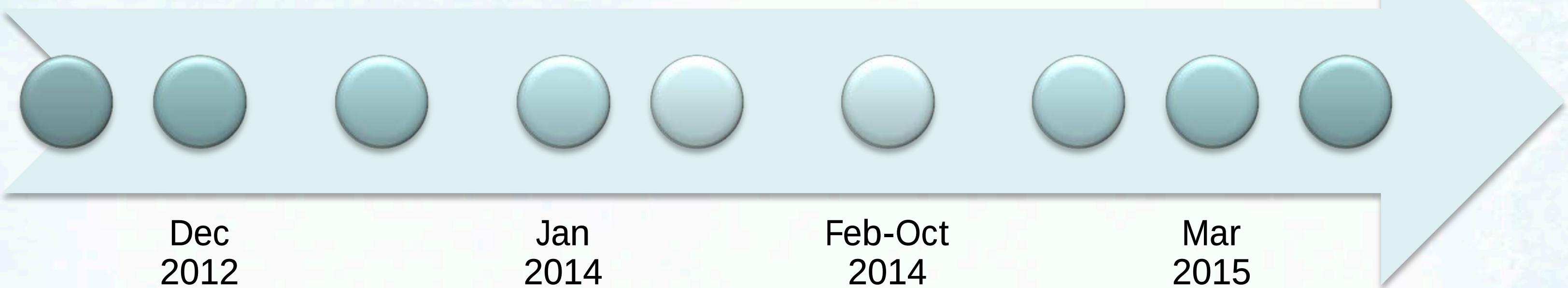
Privacy groups and health professionals are concerned and start action & lobbying

National & professional press coverage exposing problems and concerns

Dec
2011

Jan-Dec
2013

Feb
201



Dec
2012

Jan
2014

Feb-Oct
2014

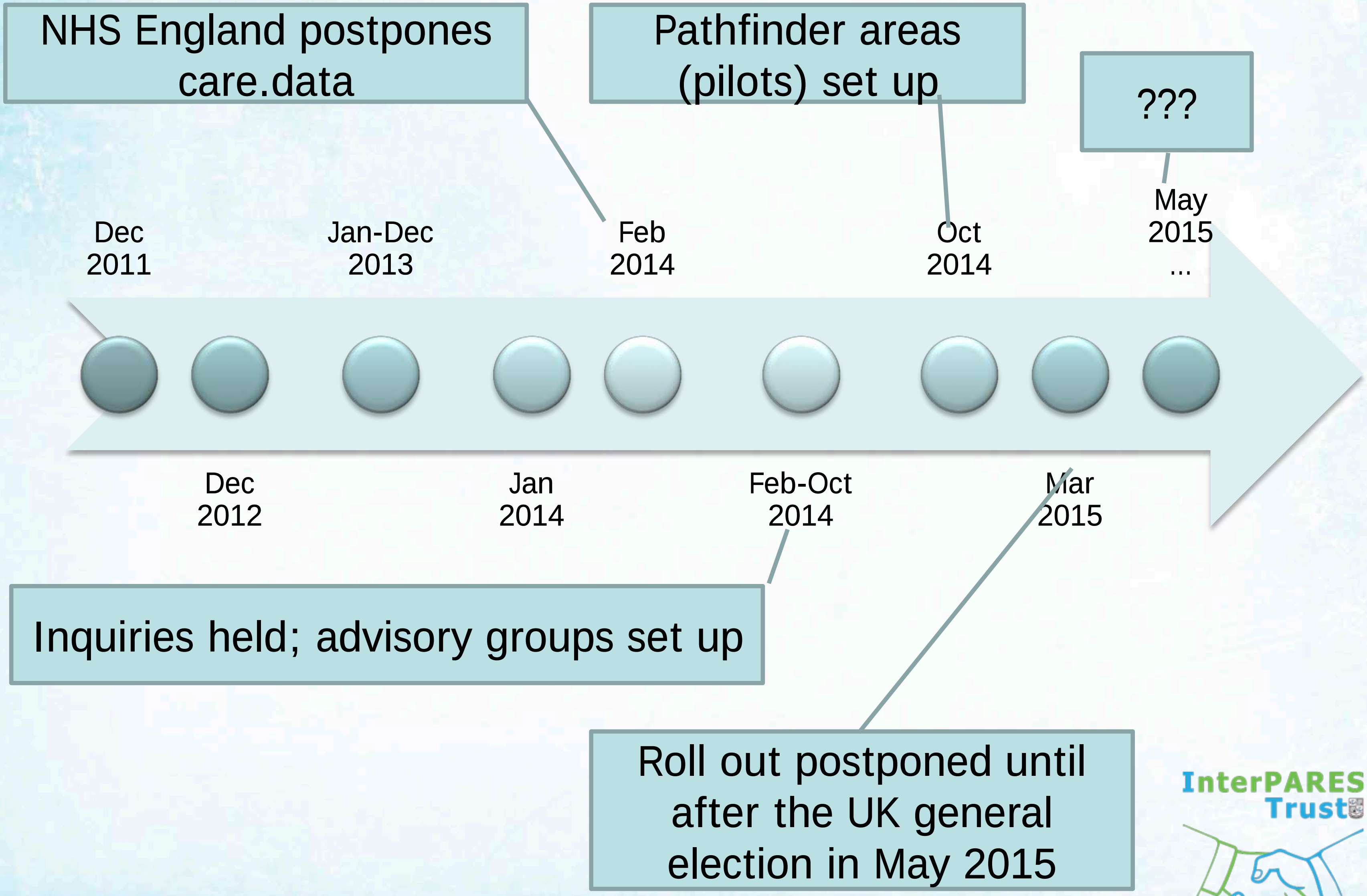
Mar
2015

Care.data listed in NHS England planning guidance to surprise of health professionals

Flawed public leaflet campaign

Concern and discussion of problems goes mainstream, e.g. 38 Degrees national petition

Care.data timeline



NHS England postpones care.data

Pathfinder areas (pilots) set up

???

Dec 2011

Jan-Dec 2013

Feb 2014

Oct 2014

May 2015 ...

Dec 2012

Jan 2014

Feb-Oct 2014

Mar 2015

Inquiries held; advisory groups set up

Roll out postponed until after the UK general election in May 2015

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Findings

- Poor governance
- Lack of clarity / agreement about purpose
  - what data? why is it needed? who can access it?
- Benefits to health research
  - clear benefits but who is trusted to use it for research?
- Benefits realisation compromised
  - opt-out consent

Findings

- Lack of consultation and poor communication
- Informed consent process flawed
- Data security procedures perceived as being poor

all of these were key to achieving trust

Conclusions

- Crisis of public trust
  - Could the crisis have been averted by good governance?
- Embedded within wider distrust of government, NHS management and commercial organisations
- Context is critical

A case example of public trust in online records – The UK care.data programme. *Final Report.* InterPARES Trust Project EU17. 2015. https://interparestrust.org/assets/public/dissemination/EU17_20150802_UKCareDataProgramme_FinalReport_Final.pdf

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