THE OPEN DATA ERA IN HEALTH AND SOCIAL CARE

A blueprint for the National Health Service (NHS England) to develop a research and learning programme for the open data era in health and social care

GOVLAB

www.thegovlab.org/nhs

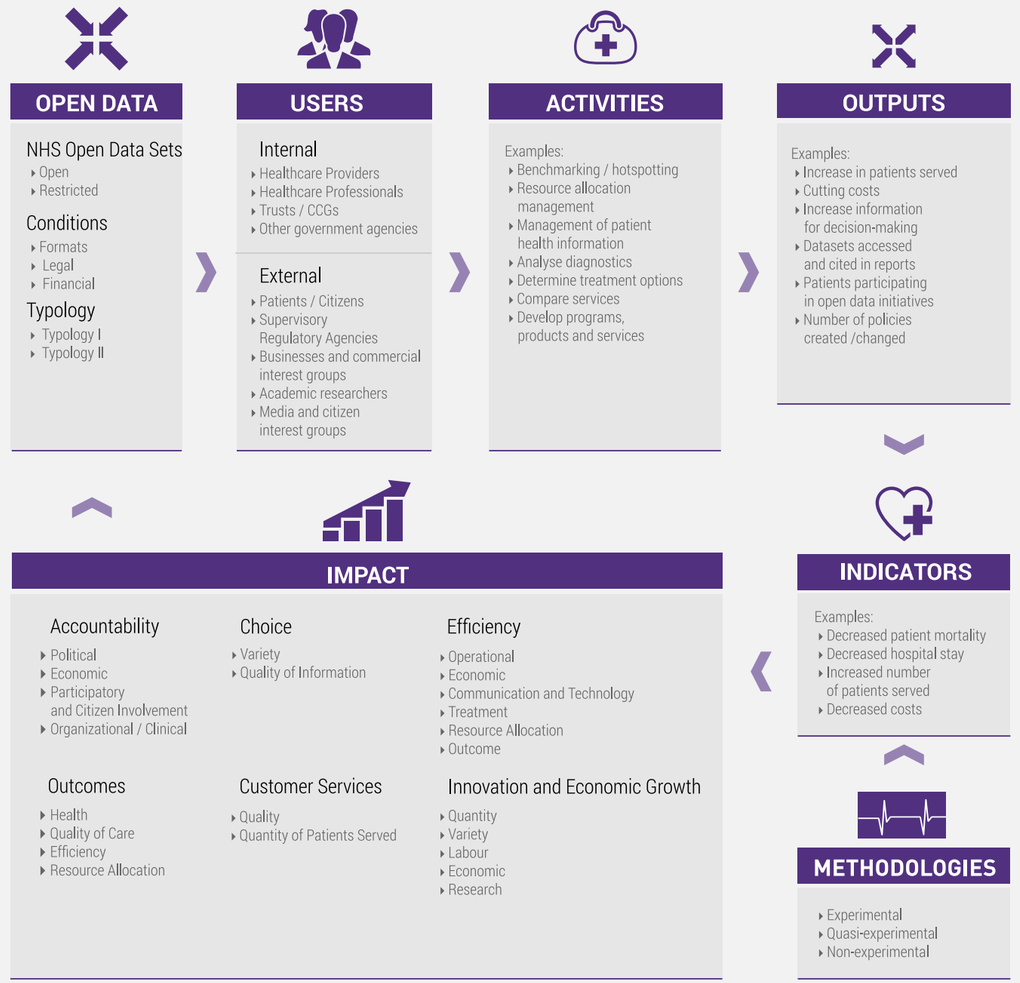
Understanding the Benefits of Open Data

The Governance Lab (GovLab) at NYU worked with NHS England to develop a blueprint for a research and learning programme for the open data era in health and social care, addressing:

- What kinds of evidence can we gather to help measure the impact of open data?
- What methodologies are most effective at gathering actionable evidence?
- How can we use evidence to differentiate and prioritize among various open data initiatives?
- What steps are required to create an environment within which data is used to constantly generate and refresh information and learning?

Understanding the Impact of NHS England's Open Data Program

This blueprint offers a model to help researchers design and understand the impact of NHS England's Open Data Program throughout the process of conceptualization, implementation, and evaluation.



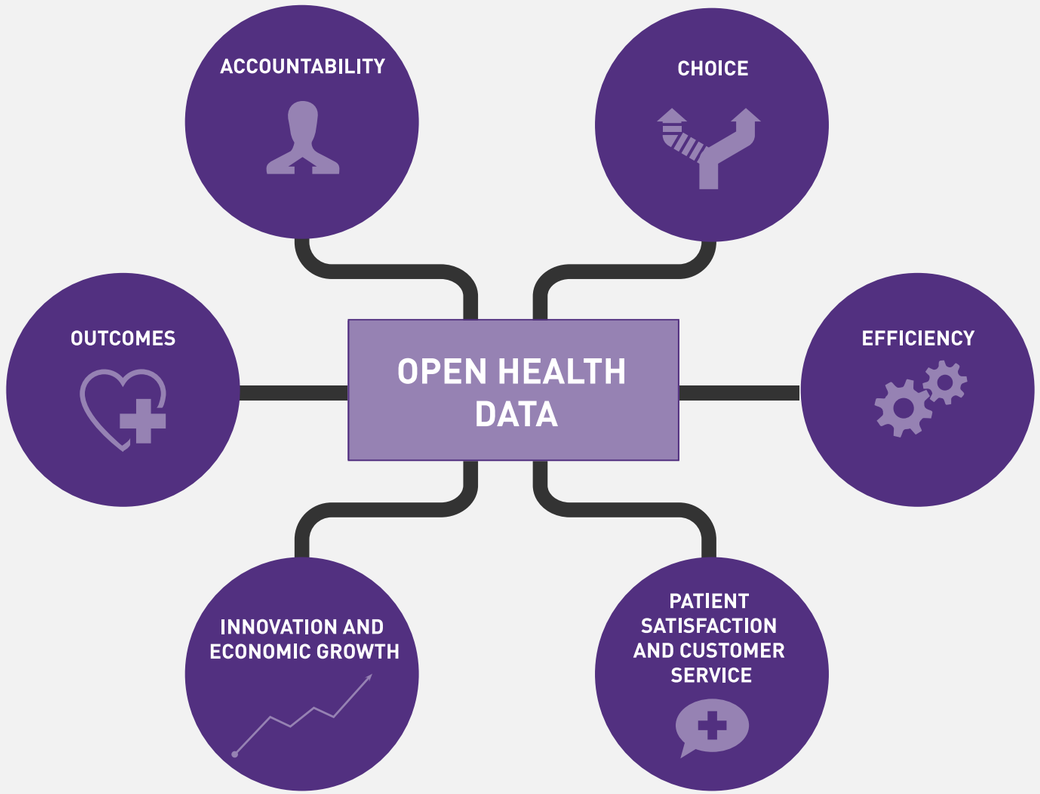
The Value Proposition behind Open Data

The blueprint starts from the assumption that open data seeks to:

- Hold healthcare organizations and providers **accountable** for treatment outcomes;
- Enable patients make **informed choices** from among the healthcare options available to them;
- Improve the **efficiency and cost-effectiveness** of delivering healthcare;
- Improve treatment **outcomes**;
- Educate patients and their families and make healthcare institutions more **responsive**;
- Fuel new healthcare companies and **innovation**.

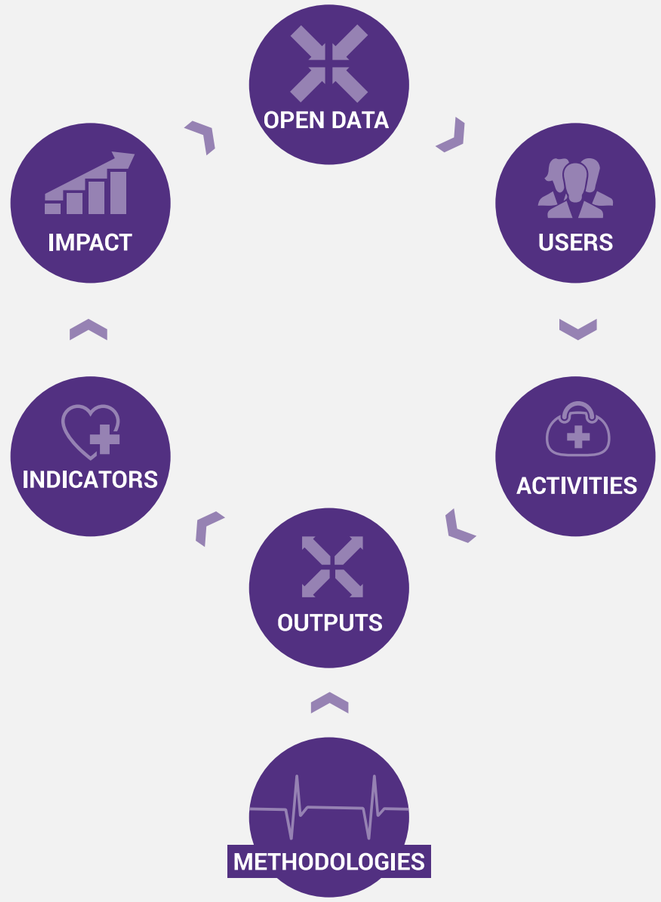
The blueprint was guided by two overriding principles regarding open data deployment:

- To focus on results, determining impact and effectiveness. Allowing for clear attribution of outcomes resulting from the use of open health data.
- To integrate metrics into the design from the outset for systematic use at each stage of the open data management cycle: planning, implementation, monitoring, reporting, and evaluation.

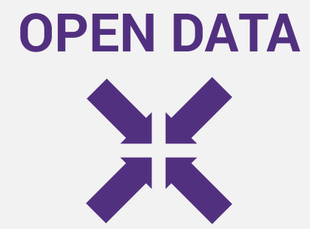


To accelerate the use of data, we need to gather more evidence on the value of open data

The Conceptual Framework for Open Data in Healthcare Seeks Answers to a Set of Questions



Input: What open data set was used?



Open data comes in a variety of types.

- What dataset was used in the initiative?
- What were the conditions of release? Was the dataset published in machine readable format?
- If the dataset contains personal information, did it fulfill the legal conditions required?
- What type of data was used? Was it financial, administrative, statistical/diagnostic, or audit data?
- Who was the initial target of the data when it was collected? Was it collected for health practitioners, the hospital system, or patients?

Users: Who is using the data? What is their relationship to the NHS?

USERS

- Internal users include those working within the healthcare system. Open data released by NHS subagencies can be used across the NHS system more fluidly.
- External users interact with open data from a position that is partly or completely external to the NHS, such as patients, journalists, and entrepreneurs. The release of open data can be used by external users in a variety of different ways.

Activities: How is the data used?

ACTIVITIES

For what purposes is open data being used? Different user groups will use open datasets for different reasons.

- A hospital within NHS may use an open dataset released by another hospital, to better understand their differences in spending.
- An entrepreneur may use open data create a business related.
- A researcher might use open data to better understand potential outcomes from different treatment options.

Outputs: What was the value produced by the open data initiative (activity)?

OUTPUTS

Different users and activities will generate different outcomes...

- The hospital's output could be the amount of money saved.
- The entrepreneur's output could be the business created and the money saved collecting data for the business.
- The researcher's output could be the results from their research that integrated open data.

Indicators: To what end?

INDICATORS

Establishing indicators helps determine whether the activity helped to achieve the long-term goals of the NHS. While outputs are often quantitative, indicators build on these outputs to make judgments, such as:

- Decrease in waste and fraud (from the output of $ of dollars saved).
- Strengthening public-private partnerships (in the creation of a new healthcare-serving business).
- Improvement of treatment outcomes (due to research that suggests one treatment method over others).

Methodologies to Measure Impact

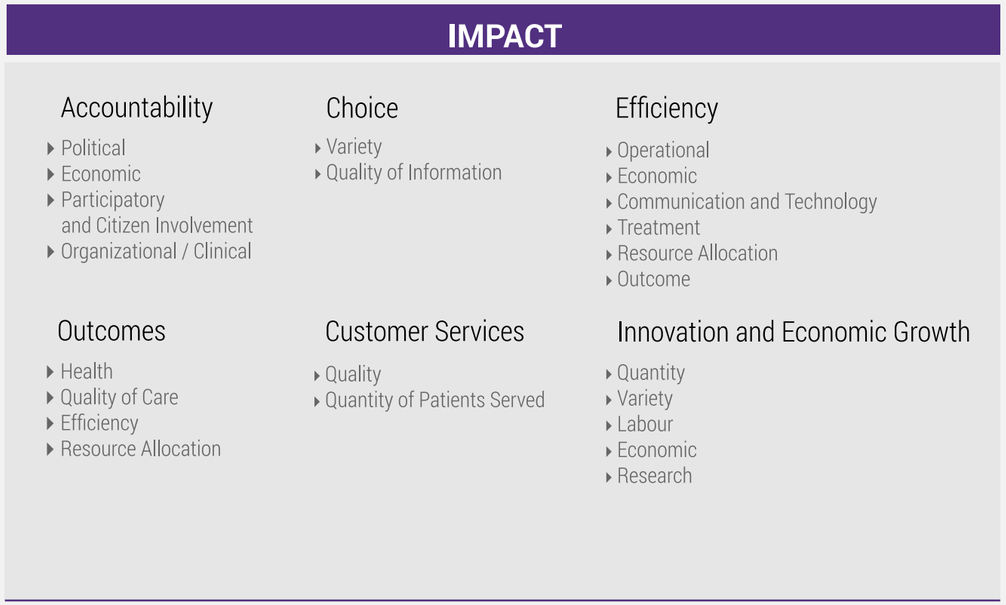
METHODOLOGIES

To measure impact several tools exist. such as:

- Experimental methods – For example, measuring change in wait times following open data initiatives.
- Surveys, interviews and questionnaires – To assess whether the activity increased qualitative variables, such as quality of life.
- Site download rates, number of mentions of open data in academic papers – to assess whether the open data being released is being used.

Impact: To add what value to the NHS as a whole?

- Did it increase **accountability** within the NHS? and/or
- Did it facilitative **patient choice**? and/or
- Did it increase **efficiency** of services? and/or
- Did it improve treatment **outcomes**? and/or
- Did it improve **customer service**? and/or
- Did it result in **innovation** and **economic growth**?



Potential Challenges and Barriers

Open data presents opportunities, but also challenges. The blueprint outlines challenges that need to be overcome in the areas of:

1
CULTURAL AND INSTITUTIONAL BARRIERS

2
PRIVACY

3
STANDARDS AND INTEROPERABILITY

4
GOOD ANALYSIS

Recommendations for Creating an Open Data Learning Environment

Build an Open Data learning capacity and culture

- ✔ Document the evidence for the use of open data
- ✔ Institutionalize action and learning about open data
- ✔ Solicit calls from the academic community in relevant domains
- ✔ Pose challenges and offer incentives for the use of open health data

Engage the public in defining metrics

- ✔ Develop a citizens' open health data panel (similar to Hackney's online citizen panel) to review metrics on a regular basis.
- ✔ Facilitate user-led design exercises to better understand how open data can support stakeholders' work and ultimately improve people's lives.
- ✔ Design and implement online mechanisms such as ratings and feedback tools to gauge public opinion and solicit insights from citizens.

Stay Focused on What Really Matters

- ✔ Develop NHS Open Data Stories that will allow stakeholders to share how open data improved people's lives in real time.
- ✔ Use surveys, social media, and sentiment analysis to learn what dimensions of healthcare improvement are most important to the public, and ensure that success metrics and indicators capture those priorities.

Develop a Common Assessment Framework

- ✔ Set up an annual meeting/listserv/monthly hangouts on open health data research to trade best practices and ideas.
- ✔ Create a directory (perhaps in wiki format) of other assessment frameworks across countries and sectors. Such a directory would also include a list of key contacts and organizations.
- ✔ Use online and offline meet-ups and other approaches to create a culture that encourages knowledge sharing and collaboration with other organizations.

Stay flexible and adaptive in measuring impact

- ✔ Build a research community centred on studying the impact and implementation of open data programmes
- ✔ Evaluate research programmes for effectiveness
- ✔ Use a mixed methods approach to assess impact

Share what is learned (including failures) with everyone

- ✔ Conduct regular audits and evaluations of open data programmes
- ✔ Communicate findings horizontally within departments, and to the general public
- ✔ Encourage conversation with open data community members to learn from and share findings with other researchers

Build a research and expert network on open data and its use

- ✔ Build capacity around methodology to study the impact of open data through engaging the research community in debate
- ✔ Organize meetings (either online or offline) with experts
- ✔ Create an advisory board to assess open data programmes

Develop an open data health ecology map

- ✔ Establish an inventory of open datasets currently available
- ✔ Develop a data dictionary with terminology, taxonomies being used, and definitions of common terms
- ✔ Centralize the open data inventory, creating a site map of existing datasets for ease of access

Publish, Integrate and Fine Tune the Open Data Conceptual Framework

- ✔ Develop an interactive version of the conceptual framework that can be annotated.
- ✔ Create an expert, online advisory network to vet and review the conceptual framework.
- ✔ Create channels for feedback and review by various stakeholders.
- ✔ Research and evaluate similar frameworks used in other sectors or countries and build on insights or lessons learned.
- ✔ Build on the Memorandum of Understanding between the United States' HHS, and the NHS, and include impact assessment as a joint activity undertaken by these two countries.

Engage Stakeholders in Shaping the Open Health Data Programme

- ✔ Set up a wiki, forum, or combination of online tools for stakeholders to provide this feedback.
- ✔ Develop a subcommittee of the Open Data User Group to focus on health data specifically.
- ✔ Hold roundtables with different groups of stakeholders--health-related businesses, advocacy groups, and patient groups--to help shape government policy on the release of open health data.

How to contribute to the framework

Add your feedback to the report on **Medium.com**

Contact us at **OpenHealthData@thegovlab.org** with your comments, suggestions and feedback.

THANK YOU

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