1. Considering income and charging

No charge for access

Equal charge for access, or different?

An argument for …

Charging might put off potential organisations from using the data – meaning research doesn't happen (where it might have if there was no charge). This could have a negative impact on the potential to create research outputs and economic benefit.

Charge a set fee for use, regardless of the 'type' of research user (public or commercial) and the financial gain that might arise from that usage.

An argument for against…

Charging should happen to cover the costs of operating, maintaining and developing the asset. Without charging the asset might not be maintained, which would stop any benefits emerging at all.

Charge differing rates for use depending on type of user and the expected financial gain to be made from that usage – the higher the financial gain, the higher the rate for usage.

2. Considering types and levels of transparent reporting

Depth of information provided (arrow pointing down)

Basic details

Extended details

Full details

Public registries of projects	Individual usage reports	
A collaborative project is using a subset of population data (just people under 18 years) to look at childhood asthma	Actively you log-in through an app (e.g. NHS App) to access: e.g. Depersonalised data about you has been used in 54 studies this year	Passively, a letter / data usage statement sent to your house, telling you: Depersonalised data about you has been used in 54 studies this year
Extended detail, plus a requirement to make the summary findings available	Log-in through an app (e.g. NHS App) to access: e.g. Basic details, plus a list of those studies, with the names of the principal investigator	A letter / data usage statement sent to your house, telling you: Basic details, plus a list of those studies, with the names of the principal investigator

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NHS

Academia

Commercial

To what extent…

…should the benefits go to those who actively produced them

NHS organisations that have invested in this type of data asset should keep the investment and knowledge, because it rewards the decision to invest in data and research, and it will incentivise other regions to do the same.

Academics should continue to try to publish this research in the top-rated journals because it is how they get the most academic impact for their work, even though the findings are often not freely available to the public.

Companies that invest in doing R&D incur considerable cost and commercial risk (the research might not lead to any product). When there are successful products developed they should reap the full rewards: acting as an incentive to others and making the investment worthwhile.

…should the benefits be distributed widely across society

NHS organisations (or regions) should give the proceeds of investment to the NHS as a whole. Places like London have used national funding to invest in the infrastructure, so everyone in the country should get a share of the benefits.

Academics should publish the information in places that are open to everyone, because the work is based on access to a public data asset, and it is often funded through public grants.

Companies' products are developed using a public asset. This is a joint effort and so companies shouldn't make an excessive profit from the NHS. The NHS should benefit from some of the commercial success, either by getting reduced prices for the product or a share of the profits.

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Proposal 1

Requester	UK-based University
Reason for access (to be conducted in a safe setting)	Conduct research to understand circumstances where patients visit A&E for problems that could have be managed by a GP. The research can be used to develop solutions to divert unnecessary A&E visits to GPs.
Summary of potential benefits	**Primary benefit**: • Reduce A&E waiting times by reducing unnecessary visits. • Researcher receives grant award (to conduct the research and improved status from publications). **Additional benefit**: • Save costs for the NHS. It is more costly to treat patients in A&E compared to GP surgeries.
Type of data to be accessed	Depersonalised data for all patients who had one or more A&E visit over a 12-month period, including: • Clinical information (reason for the visit to the A&E department). • Administrative information (time spent in the A&E; reason for discharge). • Patient information (age group, gender and ethnicity).
How is the data accessed?	• The university must submit application to the NHS explaining benefit to health and social care in the UK. • This is reviewed by an independent body that includes patient representation. • The university must also fulfil certain criteria to access the data, such as showing evidence that the data will be hosted in a secure environment. • Once approved, the university is sent an extract of the dataset (i.e., all unnecessary data points are removed).
Proposed commercial agreement?	The university pays a fee of a few thousand pounds to the NHS.
Potential risks?	• Because the dataset is sent to the university it is difficult to control who has access to it (although the NHS audits any security claims). • The researchers could use the data to inform other research projects, although this would be against the terms of the agreement
Decision making process?	Data for all NHS patients is automatically included in the dataset, although an opportunity to opt-out is offered.

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Proposal 2

Requester	US-based technology company
Reason for access (to be conducted in a safe setting)	• To develop an artificial intelligence (AI) algorithm that can help detect signs of breast cancer in an X-ray of the breast. • The algorithm would reduce the number of radiologists needed to review the breast X-ray – currently two radiologists are needed to review each image. The algorithm would mean only one radiologist is needed for the review. • The algorithm may be as good as a radiologist, but potentially even better, which would help improve diagnosis. • If the algorithm works, the company plans to market it as a product around the world.
Summary of potential benefits	**Primary benefit**: • Better and faster detection of breast cancer (could reduce the risk of missing signs of cancer and delaying subsequent treatment). **Additional benefits**: - Reduced waiting times for diagnosis (the UK has a shortage of radiologists, expected to worsen in the future). - Reduced cost (using the algorithm could reduce radiology costs for the NHS).
Type of data to be accessed	Thousands of depersonalised images collected from multiple NHS hospitals that have been reviewed by NHS clinicians (Note: very large datasets are needed to train AI algorithms).
How is the data accessed?	• The images are first depersonalised at the NHS hospitals, before being transferred to the external commercial organisation, who will use the images to develop the AI algorithm. • To access data of this kind, the company must fulfil certain criteria to be approved by the NHS, such as showing evidence that the data will be hosted in a secure environment.
Proposed commercial agreement?	The company pays the NHS a fee for access to the data. In addition, if it is successful in developing the algorithm and turning it into a product, it will provide free access to the product to every NHS hospital for 5 years. After this period, NHS hospitals will have to pay to use the algorithm.
Potential risks?	• The technology company might fail to develop a working algorithm. • After the initial 5-year period, the product might become very expensive for the NHS to license. • Because the dataset is sent to the requester, it is difficult to control who has access to it.
Decision making process?	Requires several levels of approval and governance including from participating NHS hospitals and a national ethics assessment.

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Proposal 3

Requester	UK-based large pharmaceutical company
Reason for access (to be conducted in a safe setting)	• To identify suitable participants for a clinical trial of a new drug. The hope is that the drug will manage blood sugar levels for patients with Type 2 Diabetes. • The drug has shown significant potential to be more effective than the current best treatment on the market. Access to this data could will help them identify suitable patients quickly and (if the drug works) bring it to market sooner.
Summary of potential benefits	**Primary benefits**: • Improved outcomes for people with Type 2 Diabetes (reducing the likelihood of complications such as kidney disease and nerve damage). • NHS patients might get access to the drug sooner than if the trial was held overseas. **Additional benefit**: • Reduced cost for the NHS to treat complications of Type 2 Diabetes (diabetes being one of the most costly conditions in the UK).
Type of data to be accessed	NHS registry of people with Type 2 Diabetes who have previously consented to being contacted about drug trials.
How is the data accessed?	• The company will not have direct access to clinical data. A clinical lead from the NHS will work on behalf of the company to recruit patients and run the trial. • Trial data is then analysed by the NHS based on the company's requirements and only the aggregated results of the analyses are shared with the company.
Proposed commercial agreement?	The company pays the NHS a fee for access to the data and £100,000-200,000 pounds for support of the drug trial (including analysis of the trial data).
Potential risks?	The drug may be less effective than existing treatments and never reach the UK market.
Decision making process?	Each individual patient has to consent to be included in the registry and to be contacted for drug trials.

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Applying conditions to satisfy stakeholder expectations

1. Income and charging

2. Level of transparency

3. Distribution of benefits

What others?

What charges should be made to research projects to access data: should there be any charges at all, and if so, are these equal for all parties?

How should we make clear what research is taking place: what type of record of projects should be made available, and to what level of detail?

What should be done with the outputs of successful research: how should we consider access to, and distribution of, the outputs of successful research from a population data asset?

What other issues are important to the public: what do you think should be part of the operating model of a fair partnership?

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