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# Secondary use of health data in Europe

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2	<b>1. Creating an indicator framework</b>
1.1	Background 2
1.2	Research 2
1.3	Drawing on ODI work 2
1.4	Indicators selected for the analysis of the secondary-use-of-health-data ecosystem 4
2.1	Evaluating the policy components 12
12	<b>2. Using the indicator framework to assess maturity of secondary use of health data ecosystems</b>
2.2	Scorecards 14
	Source: ODI 'Theory of change' and manifesto 15
15	<b>3. Validating the Framework and Country scoring</b>

# 1. Creating an indicator framework

## 1.1 Background

This project sought to assess the policy context, across Europe, for secondary use of health data. To do this it was necessary to define a framework that could help compare each country's progress in a consistent manner.

The European Council's 2000 Presidency Conclusions proposed that a process for measuring innovation in policy advances could be used to guide the development of an indicator framework. In particular, the Council recommended that benchmarking processes be used to create mechanisms to compare policies across European member states<sup>[1]</sup>. A benchmarking process involves creating a suite of standard characteristics, or policy components, and measuring each country's policies against a completeness of vision in meeting the particular policy characteristic, and the stage of progress for policy implementation<sup>[2]</sup>. Ideally, a set of benchmarking indicators would refer to a specific policy context or defined set of policy actors<sup>[3]</sup>. Creating an indicator framework, then, to assess European progress towards creating a mature secondary-use-of-health-data ecosystem is a well-regarded and recognised policy analysis approach.

## 1.2 Research

Given the research scope and timelines available for this project, it was necessary to draw on existing work where possible, while also quickly moving to analysing the European context in particular. Initially we employed a desktop research methodology, using terms including 'secondary use of health data ecosystem', 'health data models' and others to review existing work and define a comprehensive framework. This generated limited success, as there is no global framework to describe secondary-use-of-health-data ecosystems. We used existing work to identify key components for defining an indicator framework. Key resources drawn on included:

- 1 European Union (2020), '[Lisbon European Council 23-24.03.2000: Conclusions of the Presidency](#)'.
- 2 Journal of Technology Management and Innovation (2010), '[A Proposal of Indicators and Policy Framework for Innovation Benchmark in Europe](#)'
- 3 International Advances in Economic Research (2009), '[Competitiveness and the Benchmarking of Nations—A Critical Reflection - International Advances in Economic Research](#)'.

- WHO Global Strategy on Digital Health 2020 - 2025<sup>[4]</sup>
- European Medicines Agency Secondary use of health data projects<sup>[5]</sup>
- IDC Research for European Joint Research Centre on secondary use of health data projects<sup>[6]</sup>
- EFPIA policy positions on secondary use of health data<sup>[7]</sup>
- Australian Government Framework on secondary use of health data<sup>[8]</sup>
- US NIH research on developing a secondary use of health framework<sup>[9]</sup>
- UK research on data governance standards for health research<sup>[10]</sup>
- ODI action research projects addressing new models of healthcare data <sup>[11]</sup>

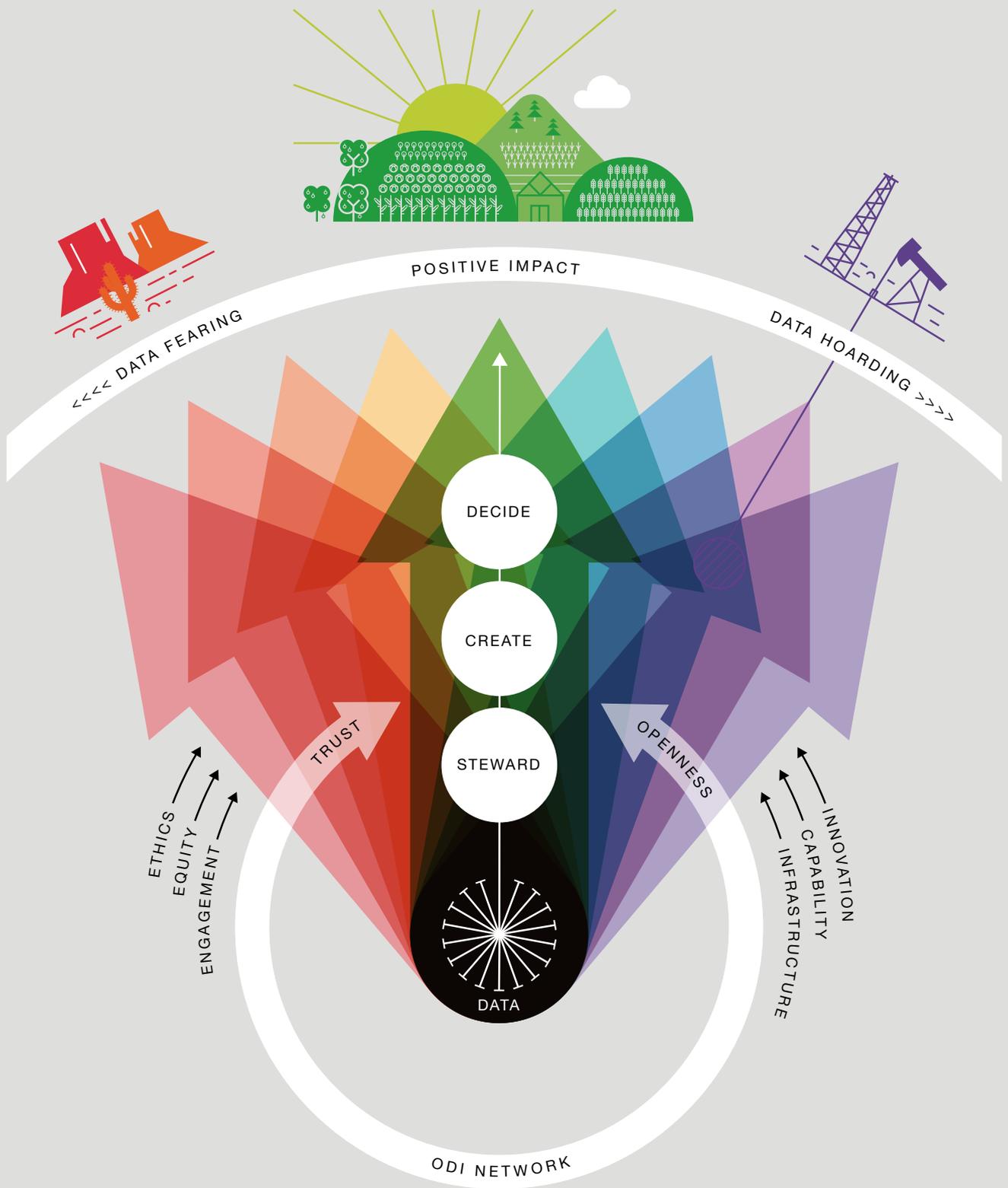
These papers helped provide an overview of the general issues and common challenges in describing a comprehensive secondary-use-of-health-data ecosystem.

## 1.3 Drawing on ODI work

The ODI's theory of change<sup>[12]</sup> explores how an open and trustworthy data ecosystem can be fostered by focusing on multiple data ecosystem components, for use of data for positive impacts as illustrated in the **Figure 1**, below.

- 4 WHO (2021), '[Global strategy on digital health 2020-2025](#)'.
- 5 Eg EMA (2020), '[Electronic Health Record: Access, Share, Expand Project](#)'.
- 6 IDC / The Lisbon Council (2020), '[Update of the European Data Market SMART 2016/0063 Story 6 – The Secondary Use of Health Data and Data-driven Innovation in the European Healthcare Industry](#)'.
- 7 Including European Federation of Pharmaceutical Industries Associations (EFPIA) (2019), '[Position Paper Safeguards framework for secondary use of clinical trial data for scientific research September 2019](#)'.
- 8 Australian Government, Department of Health (2018), '[Framework to guide the secondary use of My Health Record system data](#)'.
- 9 Journal of the American Medical Informatics Association (2007), '[Toward a National Framework for the Secondary Use of Health Data: An American Medical Informatics Association White Paper](#)'.
- 10 Journal of Medical Internet Research Publications (2020), '[Toward the Development of Data Governance Standards for Using Clinical Free-Text Data in Health Research: Position](#)'. Paper
- 11 ODI (2020), '[Applying new models of data stewardship to health and care data](#)'.
- 12 Open Data Institute, 2018, '[Theory of Change](#)'

**Figure 1:** The ODI's theory of change for encouraging an open and trustworthy data ecosystem



The ODI believes that an open and trustworthy data ecosystem has the following key components, as outlined in the [ODI's manifesto](#):

- **Infrastructure:** Sectors and societies must invest in and protect the data infrastructure they rely on. Open data is the foundation of this emerging vital infrastructure.
- **Capability:** Everyone must have the opportunity to understand how data can be, and is being, used. We need data literacy for all, data science skills, and experience of using data to help solve problems.
- **Innovation:** Data must inspire and fuel innovation. It can enable businesses, startups, governments, individuals and communities to create products and services, fuelling economic growth and productivity.
- **Equity:** Everyone must benefit fairly from data. Access to data and information promotes fair competition and informed markets, and empowers people as consumers, creators and citizens.
- **Ethics:** People and organisations must use data ethically. The choices made about what data is collected and how it is used should not be unjust, discriminatory or deceptive.
- **Engagement:** Everyone must be able to take part in making data work for us all. Organisations and communities should collaborate on how data is used and accessed to help solve their problems.

This model for data ecosystems can be applied to any jurisdiction, sector or domain. Here, we've used it alongside our analysis of country-level policy environments for secondary use of health data in the European region, to explore 'What does good look like?'

## 1.4 Indicators selected for the analysis of the secondary-use-of-health-data ecosystem

**Table 1** below describes each of the indicators and how they were selected, the alignment with the ODI's manifesto, and the evidence base that suggests why each indicator is relevant. Discussion of the limitations and suggestions from validation activities to improve the indicator are also given.

**Table 1:** Overview of indicators included in secondary use of health data framework

Framework Component	Success indicator	ODI Manifesto area	Evidence base	Limitations and proposed enhancements identified through validation
<b>Burden of Disease registries</b>	National illness and disease registries have been established with >75% of relevant patient population data recorded	Infrastructure	The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country	Due to limitations in available data and the scope of this research, strict measures such as calculating >75% could not be undertaken, and measures of quality of the data collected and reported were not assessed. As with all dataset indicators, deeper analysis would be useful to create a directory of known datasets, and measure each for their quality, completeness, and regularity of reporting
<b>Biobank and genomic data centralisation</b>	Established biobank and genomics database centralised all structured diagnostic results	Infrastructure	The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country	As with all dataset indicators, deeper analysis would be useful to create a directory of known datasets, and measure each for their quality, completeness, and regularity of reporting
<b>Patient health records</b>	Interoperable formats and standards for EHR are adopted and records are able to be shared securely	Infrastructure	The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country	Validation suggested that complete information of the entire patient's treatment route is gathered and stored in the health records and should be included in future assessments.  As with all dataset indicators, deeper analysis would be useful to create a directory of known datasets, and measure each for their quality, completeness, and regularity of reporting

**Table 1:** Overview of indicators included in secondary use of health data framework

<p><b>Medicine / pharmaceutical registers</b></p>	<p>National registers are maintained, including adverse drug reaction registers</p>	<p>Infrastructure</p>	<p>The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country</p>	<p>Validation suggested that in addition to the stated success indicators, it is also important to stress access to the data, ie that stakeholders can make inquiries and get (pseudonymised) data for analyses.</p> <p>As with all dataset indicators, deeper analysis would be useful to create a directory of known datasets, and measure each for their quality, completeness, and regularity of reporting</p>
<p><b>Patient reported outcomes data</b></p>	<p>Interoperable formats and standards are created for patient reported outcomes</p>	<p>Infrastructure</p>	<p>The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country</p>	<p>As with all dataset indicators, deeper analysis would be useful to create a directory of known datasets, and measure each for their quality, completeness, and regularity of reporting.</p> <p>This measure was included in part as a ‘stretch’ indicator, as in practice, few jurisdictions globally are mature enough to have incorporated patient reported outcomes data as a standardised dataset</p>
<p><b>Science/clinical data</b></p>	<p>Scientific studies, observational studies and clinical trials data are available and sharing of data enabled</p>	<p>Infrastructure</p>	<p>The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country</p>	<p>As with all dataset indicators, deeper analysis would be useful to create a directory of known datasets, and measure each for their quality, completeness, and regularity of reporting</p>
<p><b>Insurance claims data</b></p>	<p>National registers on social health insurance claims are maintained and published regularly</p>	<p>Infrastructure</p>	<p>The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country</p>	<p>As with all dataset indicators, deeper analysis would be useful to create a directory of known datasets, and measure each for their quality, completeness, and regularity of reporting</p>

**Table 1:** Overview of indicators included in secondary use of health data framework

<p><b>Employment sickness and social security data</b></p>	<p>National registers on illness and sickness including social security financing and costs of illness on workplace participation are maintained and published regularly</p>	<p>Infrastructure</p>	<p>The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country</p>	<p>As with all dataset indicators, deeper analysis would be useful to create a directory of known datasets, and measure each for their quality, completeness, and regularity of reporting.</p> <p>In some jurisdictions, for example, these are separate datasets, whereas in other countries they are combined, so it is challenging at the level of research scope available to measure the exact maturity</p>
<p><b>Personal and health technologies data</b></p>	<p>National systems for standardising, collecting and reusing personal health data from wearables, fitness trackers, remote patient monitoring and software as a medical service are described, with citizen participation</p>	<p>Infrastructure</p>	<p>The project reference group advised on nine key types of datasets that could be leveraged for secondary uses, and project researchers were requested to assess whether these datasets were available and regularly reported within each country</p>	<p>This measure was included in part as a ‘stretch’ indicator, as in practice, few jurisdictions globally are mature enough to have incorporated personal technologies and wearables data as a standardised dataset</p>
<p><b>Real World Data (RWD) infrastructure</b></p>	<p>All RWD captured in consistent standardised formats with advanced data curation systems in place enabling exploration, cleaning, enrichment, and standardisation</p>	<p>Infrastructure</p>	<p>Described as essential in:  <a href="#">Opportunities for RWD, RWE Generation and Evaluation of Therapeutics, NCBI Bookshelf,</a>  <a href="#">FDA, RWE PROGRAM,</a>  <a href="#">Global strategy on digital health 2020-2025</a></p>	<p>N/A</p>
<p><b>Real World Evidence (RWE) infrastructure</b></p>	<p>Health technology assessment (HTA) bodies and policymakers have established a clear framework for the use of RWE in decision-making</p>	<p>Infrastructure</p>	<p>Described as essential in:  <a href="#">Opportunities for RWD, RWE Generation and Evaluation of Therapeutics, NCBI Bookshelf,</a>  <a href="#">FDA, RWE PROGRAM,</a>  <a href="#">Global strategy on digital health 2020-2025</a></p>	<p>N/A</p>

**Table 1:** Overview of indicators included in secondary use of health data framework

<p><b>Adoption of open standards</b></p>	<p>Health data policies confirm the importance of using open standards for health datasets and ministries of health are committed to their adoption</p>	<p>Infrastructure</p>	<p>Essential for open standards: ODI, <a href="#">What are open standards for data?</a>, <a href="#">Open Standards for Data Guidebook</a></p>	<p>N/A</p>
<p><b>Legal framework for sharing of secondary use of data</b></p>	<p>A legal framework is articulated that builds on the protection of personal data to enable the use of de-identified data to benefit society</p>	<p>Infrastructure</p>	<p>Described as essential in:  <a href="#">Framework to guide the secondary use of My Health Record system data</a>,  <a href="#">Position Paper Safeguards framework for secondary use of clinical trial data for scientific research September 2019</a>,  <a href="#">Toward a National Framework for the Secondary Use of Health Data: An American Medical</a></p>	<p>N/A</p>
<p><b>Evaluation framework for health technologies</b></p>	<p>A robust, ethical, and community-participatory Health Technology Assessment process is adopted across Europe and in each Member State</p>	<p>Capability</p>	<p>Recognised as an essential element in:  <a href="#">Update of the European Data Market SMART 2016/0063</a>,  <a href="#">Position Paper Safeguards framework for secondary use of clinical trial data for scientific research September 2019</a></p>	<p>N/A</p>
<p><b>Investment in EHR systems</b></p>	<p>Training is resourced and incentives are available to healthcare institutions and data ecosystem stakeholders to encourage adoption of standard and data sharing, including use of EHRs</p>	<p>Innovation</p>	<p>Investment in EHR was considered a foundational element that can enable innovation. It is essential that EHRs are available in a reusable format that can be anonymised, aggregated and used for secondary uses. As discussed in: <a href="#">Towards trustworthy health data ecosystems</a></p>	<p>Validation noted in some jurisdictions, data sharing of EHRs is expressly forbidden, making this indicator impossible to meet</p>

**Table 1:** Overview of indicators included in secondary use of health data framework

<p><b>Secondary use of health data policy is a national priority</b></p>	<p>Specific policy is developed that recognises the value of secondary use of health data and all stakeholders are encouraged to participate in ecosystem networks, with strategic investment available to foster best practices</p>	<p>Innovation</p>	<p>Goal of project is to measure whether secondary use of health data policy is specifically described at country and European-levels</p>	<p>N/A</p>
<p><b>Equity considerations addressed</b></p>	<p>Policies recognise the uneven distribution of health resources and seek to leverage secondary use of health data to address inequity</p>	<p>Equity</p>	<p>Availability of secondary health data disaggregated by subpopulations facing greatest health inequalities is recognised as an essential component in planning and delivering equitable healthcare: <a href="#">Equity-Oriented Toolkit</a>.</p> <p>In addition, research has identified that drawing on secondary use of health data can help design therapies and health interventions for sub-populations that may not have had large enough sample sizes in existing clinical trials to identify opportunities for more personalised healthcare: <a href="#">Patient Segmentation Analysis Offers Significant Benefits For Integrated Care And Support</a></p>	<p>N/A</p>
<p><b>Privacy regulation</b></p>	<p>Robust privacy regulation is in place that allows appropriate industry access and use of high quality health care data within agreed privacy constraints</p>	<p>Equity</p>	<p>European GDPR context: <a href="#">Position Paper Safeguards framework for secondary use of clinical trial data for scientific research September 2019</a></p>	<p>N/A</p>

**Table 1:** Overview of indicators included in secondary use of health data framework

<p><b>High level of trust in data-informed healthcare</b></p>	<p>A high degree of willingness by the public to consent to reuse of their health data for research and personalised healthcare goals is observable</p>	<p>Ethics</p>	<p><a href="#">Towards trustworthy health data ecosystems</a></p>	<p>Validation suggested that this indicator could be more strongly linked to secondary use of health data, for example, by stipulating the use and value was generated from secondary use implementations. Validation also suggested that “high degree of willingness” to be defined specifically.</p>
<p><b>Ethical / accountability framework for secondary use of health data</b></p>	<p>Clear reporting, methods of redress and consequences are defined and resourced</p>	<p>Ethics</p>	<p>Clear ethical frameworks are recognised as an essential component of health data ecosystems: <a href="#">Position Paper Safeguards framework for secondary use of clinical trial data for scientific research September 2019</a></p>	<p>Validation suggested that meeting regulatory requirements of accessing and processing data should also include deleting the data after the conduct of analysis</p>
<p><b>Sustainable and trustworthy data institutions</b></p>	<p>Strategic investment in data institutions that can steward data infrastructure and report on implementation and capabilities</p>	<p>Infrastructure</p>	<p>Data institutions are recognised as an essential part of health data ecosystem infrastructure: <a href="#">Healthcare Research and Analytics Data Infrastructure Solution: A Data Warehouse for Health Services Research</a>,  <a href="#">Institutions, infrastructures, and data friction – Reforming secondary use of health data in Finland, Ville Aula, 2019</a>,  <a href="#">Applying new models of data stewardship to health and care data [report] – The OD!</a></p>	<p>N/A</p>

**Table 1:** Overview of indicators included in secondary use of health data framework

<p><b>Public/patient participation</b></p>	<p>Investment to support facilitation and participation of citizens and healthcare communities in decision-making</p>	<p>Engagement</p>	<p>Recognised as an essential element in secondary use of health data systems by: <a href="#">Toward the Development of Data Governance Standards for Using Clinical Free-Text Data in Health Research: Position Paper</a>,  <a href="#">Framework to guide the secondary use of My Health Record system data</a>,  <a href="#">Update of the European Data Market SMART 2016/0063 Story 6 – The Secondary Use of Health Data and Data-driven Innovation</a></p>	<p>N/A</p>
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# 2. Using the indicator framework to assess maturity of secondary use of health data ecosystems

Policy components and their respective success indicators were considered by how they align with the Open Data Institute’s six manifesto points for an open, trustworthy data ecosystem. For example, in this analysis, the policy component “legal framework for sharing of secondary use of data” aligned with the ODI Manifesto area “Infrastructure: Sectors and societies must invest in and protect the data infrastructure they rely on. Open data is the foundation of this emerging vital infrastructure.”

Table 2, below, provides an example of a policy component with its associated success indicator.

Policy component	Success indicator description
Legal framework for sharing of secondary use of data	A legal framework is articulated that balances the protection of personal data and the use of de-identified data to benefit society.

Table 2: Example policy component and success indicator

Table 3 below gives an example of a policy component and its respective success indicator organised by ODI manifesto area in parallel. Overall, there was strong alignment with the ODI manifesto points.

Policy component	ODI manifesto point	Success indicator description
Legal framework for sharing of secondary use of data	Infrastructure: Sectors and societies must invest in and protect the data infrastructure they rely on. Open data is the foundation of this emerging vital infrastructure	A legal framework is articulated that balances the protection of personal data and the use of de-identified data to benefit society

Table 3: Example integrated ODI framework

## 2.1 Evaluating the policy components

For each policy component, we identified current policy work, institutional supports, and strategic initiatives at both the European-level and at country-level. These activities were then evaluated or scored against two measures:

- What is the quality of policy activity for this indicator?**  
 The evaluation range for activities is: having only limited aspects of the success indicator (low); aligned intent but missing key aspects (medium); fully comprehensive (high).
- What progress is being made on implementation of policy for this indicator?**  
 The scoring range for the policy implementation stage is: not started (0); defined (1); planned (2); pilot initiatives (3); scaled-up implementations (4).

As an example, **Table 4**, below, demonstrates this evaluation methodology applied to one of the policy components and its success indicator.

Policy component	Success indicator description	What is the quality of policy activity for this indicator?	What progress is being made on implementation of policy for this indicator?
Legal framework for sharing of secondary use of data	A legal framework is articulated that balances the protection of personal data and the use of de-identified data to benefit society	<p><b>At EC-level:</b> Medium  <i>(There is a range of legislation applicable to balancing personal health data for secondary use including the new Data Governance Act, which proposes ‘altruistic use of data’ and the General Data Protection Regulation (GDPR) which preserves privacy, but no clear legal definition of secondary use of health data is given, nor are guidelines available to explain how privacy laws and wider social good value should be balanced)</i></p>	<p><b>At EC-level:</b> 3. <i>(There are a number of pilot initiatives being conducted by a range of stakeholders but none have yet been evaluated sufficiently to create a legal framework or set of principles that can be applied across all of Europe)</i></p>
		<p><b>At country level (eg France):</b> High <i>(The French Data Protection Act Reference Methodology MR004 states that if research does not directly involve human beings, patients can be informed that data may be reused for scientific purposes. Where in doubt, an ethical body assesses research use)</i></p>	<p><b>At a country level (eg France):</b> 4 <i>(Legislation is in place, guidelines are available to define how decisions are made and an ethics board is in place to assess decisions between private use and benefit to society where it is in dispute or unclear)</i></p>

**Table 4:** Example of policy component evaluation

## 2.2 Scorecards

For European-level analysis and for the 29 countries in scope for this project, a comprehensive scorecard for the policy framework was created. We mapped the 22 policy components and their respective success indicators against the ODI manifesto areas, and applied an evaluation of both the quality of the policy activity and the stage of advancement of the implementation for each one. We conducted desk research and analysis to draw up the scorecards, and then used small-group workshops with industry stakeholders to validate and refine our findings.

For each country and for Europe overall, each indicator was then calculated as a score based on the completeness of vision for progress of implementation. Scores for each indicator were then tallied to create an overall score out of 88 for quality and an overall score out of 88 for progress of implementation; for more granular analysis, scores were also calculated as percentages.

As with any such analysis, the approach that we've taken has limitations, which we highlight here to aid with the interpretation of the results:

- The implementation scores evaluate the extent to which policy-makers have invested in implementation of the policy, but do not evaluate the effectiveness of that implementation, nor its impact. So, for example, policy activity might be evaluated against the framework as high quality – which means that there are comprehensive policy statements on the topic – and as having scaled-up implementation, but the nature of that implementation might still be flawed.
- The policy indicators are not evenly distributed across the ODI's manifesto areas for open and trustworthy data ecosystems: for example, the Infrastructure policy area has 13 indicators while the Ethics policy area has only two, so jurisdictions that have invested in data infrastructure policy while neglecting data ethics policy might still score highly overall. One option for mitigating this imbalance would have been to weigh scores across each manifesto area: however, this might lead to a different kind of skew or imbalance in the results, since not all the tools or interventions needed to support open and trustworthy data ecosystems are policy tools.
- The policy indicators evaluate the readiness of the policy environment in the jurisdiction, but do not evaluate other key considerations for implementation and impact – such as the economic, political, and social environment. We have provided some of this context in the country profiles (see Annexes) which include data on country GDP, population size, GDP per capita, and Gini co-efficient for in-country inequalities. The extent and distribution of positive impact from policies to do with secondary use of health data will be dependent on these and other factors.

# 3. Validating the Framework and Country scoring

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The indicator framework was initially validated with the project reference group during the research collation stages of this project.

Feedback was sought from industry stakeholders on the validity of framework indicators, the country-level findings collated in their scorecards, and the metrics calculated (completeness of vision score and implementation progress score) generated by the research team.

Overall, validation did not identify any components that were missing, nor query the high-level groupings and categorisation of the indicator framework.

Some comments were received querying the definition of specific indicators. These were adjusted slightly based on this feedback, but overall, have been incorporated into the limitations and validation notes in the above **Table 1**. That is because, while the indicators in some instances could be improved, the overall feedback related to the scope of the project. For example, the project reference group requested that the assessment include an analysis of nine key datasets. Ideally, an indicator framework would first list what individual data items make up that dataset ('burden of disease registries' is quite broad: which registries are essential to include in the assessment?, for example, and if the country had, say, 80% of those registries in place, what score would they be given? etc), as well as the data governance aspects of those datasets (assessing quality; completeness of the dataset, for example, in some instances, only a small proportion of the population is measured; regularity of reporting; standardisation of data format, etc). This level of analysis was beyond the scope of the research project, but an ideal indicator framework would measure at that level of detail.

There is a degree of subjectivity that was applied to the indicator framework by the lead researcher. In each case, the researcher was assessing the identified health data policy documents and applying a score for completeness of vision and stage of implementation. While this was the subjective view of the researcher, as there was only one researcher reviewing all documentation, the scoring is considered consistent across the countries reviewed.

Validation feedback was essential in uncovering differences between the desktop research undertaken and the implementation experiences of in-country affiliates. Often scores were adjusted by affiliates who were able to guide the researcher to understand that while the policy describes one scenario, in practice, implementation had not progressed, or had resulted in different strategies being used.

Overall, the indicator framework components in their entirety did not meet with disagreement.

## Source: ODI 'Theory of change' and manifesto

The ODI was co-founded in 2012 by the inventor of the web [Sir Tim Berners-Lee](#) and artificial intelligence expert [Sir Nigel Shadbolt](#) to show the value of open data, and to advocate for the innovative use of open data to effect positive change across the globe. The ODI works with companies and governments to build an open, trustworthy data ecosystem. Bringing about sustainable behaviour change within companies and governments that hold and use data via specific programs, advocacy and supporting peer networks is fundamental to the ODI approach.

Through this model, the ODI has built partnerships with Microsoft, Luminata, the Wellcome Trust, Bill & Melinda Gates Foundation, the World Bank, and others to help shepherd new approaches to open data ecosystems that enable data to be used as a common resource for social good. A key strength of the ODI's model is that it can work across a wide range of sectors, and can develop a common language and series of cross-sector toolkits that support the development of data ecosystems. These resources are being adopted in a wide range of contexts and use-cases, including enabling Covid-19 data sharing<sup>[13]</sup>, fostering data agreements and common tools for industry stakeholders on antimicrobial resistance<sup>[14]</sup>, and encouraging new business and market solutions for physical activity and wellbeing.<sup>[15]</sup>

The ODI has six manifesto areas for an open, trustworthy data ecosystem:<sup>[16]</sup>

- **Infrastructure:** Sectors and societies must invest in and protect the data infrastructure they rely on. Open data is the foundation of this emerging vital infrastructure.
- **Capability:** Everyone must have the opportunity to understand how data can be, and is being, used. We need data literacy for all, data science skills, and experience using data to help solve problems.
- **Innovation:** Data must inspire and fuel innovation. It can enable businesses, startups, governments, individuals and communities to create products and services, fuelling economic growth and productivity.
- **Equity:** Everyone must benefit fairly from data. Access to data and information promotes fair competition and informed markets, and empowers people as consumers, creators and citizens.
- **Ethics:** People and organisations must use data ethically. The choices made about what data is collected and how it is used should not be unjust, discriminatory or deceptive.
- **Engagement:** Everyone must be able to take part in making data work for us all. Organisations and communities should collaborate on how data is used and accessed to help solve their problems.

This approach allows readers of this report to evaluate relevant policies and policy opportunities using concepts and vocabulary about the data ecosystem that is established and influential across several domains or sectors beyond European health policy.

13 ODI (2020), '[Applying new models of data stewardship to health and care data](#)'.

14 ODI (2018), '[Case study: Antimicrobial resistance and data](#)'.

15 ODI (n.d.), '[Health and physical activity](#)'.

16 ODI (n.d.), '[Our manifesto](#)'.

