

# Recommendations for policymakers concerned with health data

Despite large investments in big data, we are far from realising the anticipated revolution in personalised healthcare. Nevertheless, the increasing drive towards digitisation means that it is essential to improve the use of routine health data in England. Presented here are a number of recommendations on how best to do so.



## Establish systems and incentives to encourage secure data linkage and sharing for research in England

- Encourage visible national leadership to promote data linkage and sharing e.g. through the UK Institute for Health and Biomedical Informatics Research
- Have mandatory data linkage and sharing standards including considering standards of interoperability and future proofing for data sharing when setting up a new dataset
- Generate performance metrics to improve quality, transparency and standardisation of data linkage and sharing practices for research
- Encourage public understanding of and feedback on use of these datasets for research through regular consultations



## Increase capacity for data linkage and sharing by public organisations

- Ensure adequate capacity for data linkage and sharing within data providers, including developing innovative approaches to data linkage in special populations
- Encourage hosting of researcher placements within all data provider organisations
- Diversify the organisations that are able to act as trusted third parties for data linkage, while ensuring appropriate standards of information security and governance



## Streamline procedures to enable appropriate and efficient access to routine health data for research

- Have a national catalogue of datasets collected by each major data provider with notes and a key to understand the variables collected and data quality. This should include datasets not available for external research, with the reason for lack of availability given
- Publish a roadmap for researchers on how to access all routine health datasets, including a contact point for help. An example is shown in the document *Obtaining data from NHS Digital for health research – a guide for researchers* published by the MRC, NHS Health Research Authority and NHS Digital

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- Standardise data access and permissions requirements across similar routine health datasets
- Consider allowing re-use of newly generated linked EHR datasets for a broad purpose, as determined by data providers using a risk-based approach



## Improve transparency and communication around routine health data access and use between data provider organisations and researchers

- Publish a national showcase of examples of research using different linked EHR datasets
- Have a platform for sharing of codes, algorithms and methods to analyse routine health data
- Encourage development and use of publication standards for research using routine health data, such as the RECORD statement
- Promote dynamic feedback systems between data users and providers to incorporate on new data linkages, feedback and comments on existing datasets and extracts



## Provide better support for researchers working with routine health data

- Provide high quality training for data users on research tools, methods, information governance and processes for accessing and using routine health data for research
- Improve the ability of university research offices to support researchers applying for approvals to work with routine health datasets

For the full report visit [here](#).

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