Health data access industry checklist

This checklist is designed to help data custodians understand the needs of SMEs in the life science industry.

UK BioIndustry Association

Pricing structure

Excellent

Comprehensive, affordable and clear pricing publicly available. Complex project pricing available within 2 weeks of submitted proposal.

Acceptable

Clear pricing for most common use cases (this can be available on demand but should be quick and easy to access). Complex project pricing available within 2 weeks of submitted proposal.

Difficult

Unclear, unaffordable or bespoke pricing, over 2 weeks to ascertain a project price, pricing dependent on third parties

Turnaround time

Excellent

Commitment and delivery of 2 months or less turnaround time from submission of a simple project with required information, to granting access (i.e. company can start the data science). Clear guidance if a project is likely to be exceptional and take more time, and why.

Acceptable

Commitment and delivery of 3 months or less from project submission with required information, to granting access.

Difficult

No commitment on turnaround time, delivery over 3 months, unclear guidance on required information to enable a simple review.

Transaction efficiency and predictability

Excellent

Clear guidance on how to apply and what is acceptable. Published flowchart of process with requirements, dependencies and timings. Documentation not exceeding 10 pages, nor taking one FTE more than a day's work to complete. Customer support doing initial internal review before they go to formal review to highlight any obvious issues, and responding meaningfully in 2 days.

Acceptable

Clear guidance, published flowchart, documentation not exceeding 20 pages or 2 FTE day's work. Customer support able to answer simple questions within 3 days.

Difficult

Unclear guidance, no publicly available details of process or timelines, lengthy documentation requiring specialist input. Slow (>3 days) or unresponsive customer support. Difficulties in access can lead to third parties offering paid support.

SME access metrics

Excellent

UK SME data access applications and projects are tracked and completed projects are a KPI for the system.

Acceptable

UK SME data access applications and projects are tracked.

Difficult

UK SME data projects not tracked, one-off projects are presented as system success.

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Single front door

Excellent	Acceptable	Difficult
All data enquiries, applications and approvals available through one website and one team who can handle and redirect questions as needed.	Central service that understands and can reliably predict how to interface with the system to deliver data science. A simple process to combine applications for linked and national data. Application details can be re-used or shared between the different processes.	Separate front doors for regional data or data types, no system ownership for bringing together the data discovery or application or approval processes.

National scale linked data

Excellent	Acceptable	Difficult
Data available for research nationally across linkable datasets.	National linked data available for a predictable price and turnaround time, except in well-known areas where clear technological or data quality barriers prevent it (i.e. not governance issues).	Unclear or unpredictable process for linking data nationally or across datasets.

Technical

Excellent	Acceptable	Difficult
Standard of secure data environment (SDE) is clearly published, including level and flexibility of compute, and support for end users. IP protection for those using SDE.	SDE standards available on request, including IP protection. Support available on request.	No published information of what will be available in environment or guarantees on security. No or unpredictable support for users.

Meta data availability

Excellent	Acceptable	Difficult
Full searchable catalogue of meta data available to search online, with flexibility in search terms and standard data dictionaries.	Limited meta data available, restricted search, or non-standard data dictionaries.	No or unsearchable meta data available.

Developed by the BIA's Data, AI and Genomics Advisory Committee data subgroup.