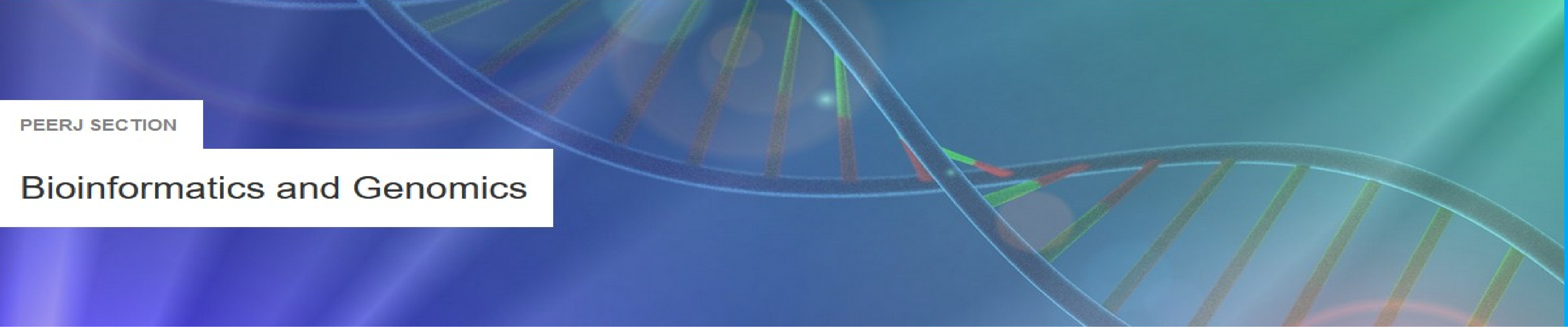

PeerJ
Life & Environment

The reuse of public datasets in the life sciences: potential risks and rewards

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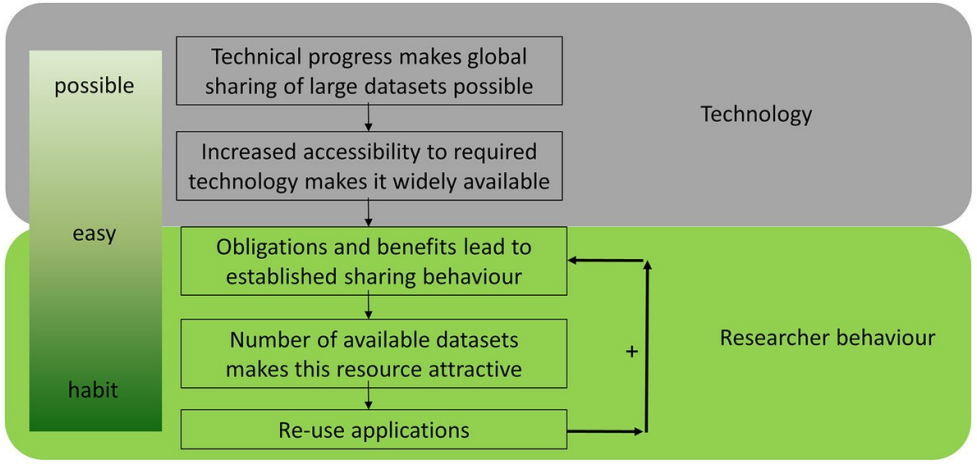
Seminário de Afinidades em Genômica e Bioinformática - Terceiro encontro de 2024

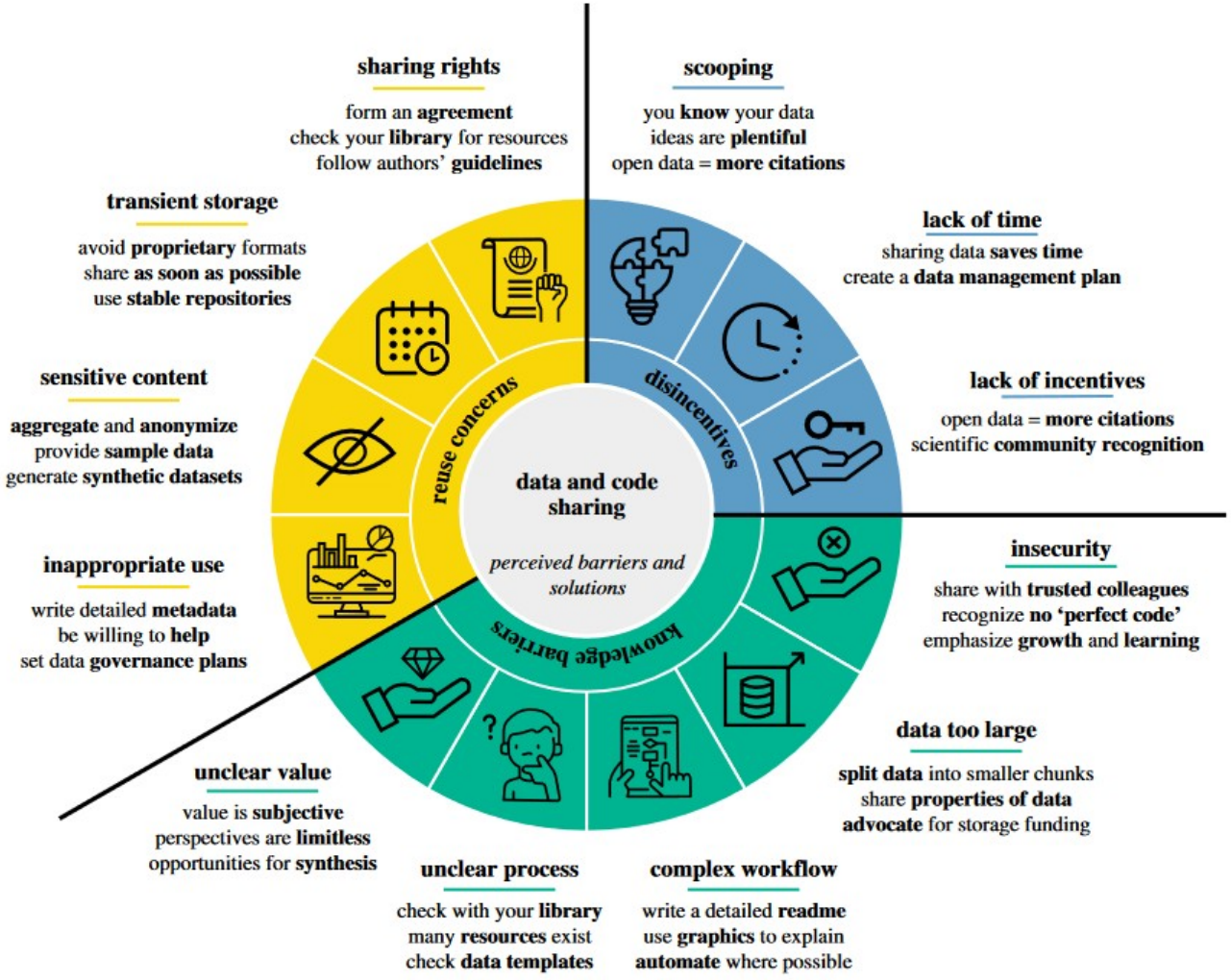
28/08/2024

Big data

- A expansão do “big data” resultou em novas análises para diversos tipos de dados já publicados
- Desenvolvimento de ferramentas de bioinformática para extração de dados já disponíveis:
  - Testes de ferramentas de bioinformática na identificação de padrões
  - Fontes de conjuntos de dados para treinamento de algoritmos de aprendizado de máquinas



Fonte: Sielemann et al. (2020)



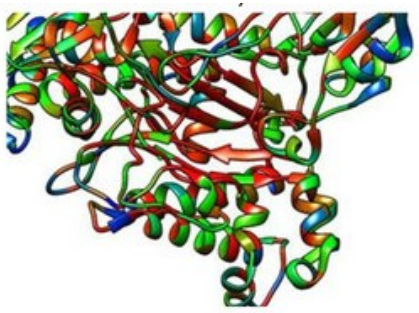
Fonte: Gomes et al. (2022)

Tipos de dados

- Dados primários são diretos e obtidos experimentalmente (sequências, metodologias, grafos, anotações, códigos, medidas, padrões, estruturas, bases de dados primárias)

```
>seq1
ATCGTTTAGCTAGACCTGATG
ATCCGATCGATTACGTG
>seq2
GACACGATCGTCAGAAATGCA
GTC
>seq3
ACGACAAATCATCTCC
```

```
>seq1
MYVRANQEFFK
>seq2
WTSMADCHLKV
>seq3
MGPKLHIGRQEFKLIHYWN
NNG
```



```
for ID in transcripts_per_genes[ gene ]:
        counter = 0
        for element in transcripts[ ID ]:
                if element['type'] == "CDS":
                        counter += element['end']-
element['start']
        CDS_len_per_transcript.append( { 'id': ID, 'len': counter } )
repr_trans = sorted( CDS_len_per_transcript, key=itemgetter('len') )[-1]
repr_transcripts.update( { repr_trans['id']: transcripts[ repr_trans['id'] ] } )
```

PDBe
Protein Data Bank in Europe

- Dados derivados são dados de meta-análises e processados (publicações, bases de dados curadas)

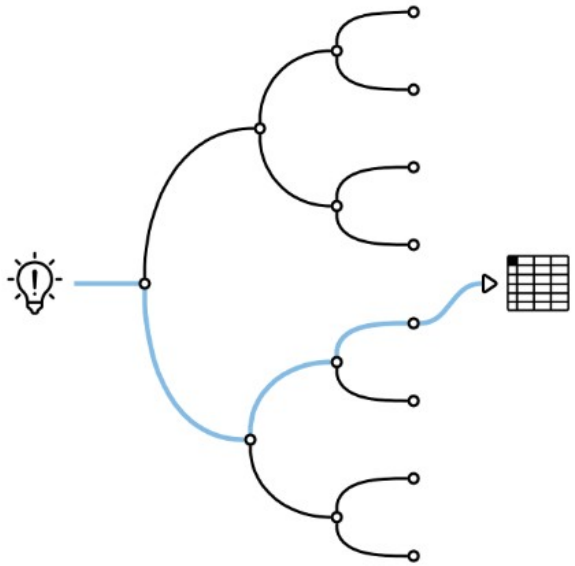
InterPro

KEGG Kyoto Encyclopedia of Genes and Genomes

Fonte: Sielemann et al. (2020)

Potenciais

- O estabelecimento de normas de compartilhamento de dados devem ser introduzidas por obrigações nas publicações, incluindo descrição e padronização



Fonte: Borghi e Van Gulick. (2022)

	Project Planning	**Data Collection and Analysis**	**Data Publication and Sharing**
Data Management Activities	• Data Management Planning	• Saving and backing up files • Organizing files • Formatting and describing data according to standards • Maintaining documentation and metadata	• Preserving data and other materials (e.g. reagents, code) • Assigning persistent identifiers
Open Science Activities	• Planning for open (e.g. including data sharing in consent forms)	• Using open source tools • Using transparent methods and protocols	• Sharing data • Publishing research reports openly (e.g. open access publishing).
Reproducibility-Related Activities	• Preregistering study aims and methods • Using appropriate research designs (including sufficient statistical power)	• Preventing methodological issues (e.g. p-hacking, HARKing) • Implementing quality control measures	• Preventing publication bias • Following reporting guidelines

Fonte: Borghi e Van Gulick. (2022)

Potenciais

- A padronização exige precauções:
  - A integridade da fonte deve ser verificada
  - Possíveis vieses devem ser analisados
  - Todas as informações relevantes devem estar disponíveis (metadados)
  - A integração de dados só pode ser realizada com dados semelhantes
  - A qualidade deve ser alta (Phred scores, comprimento e pareamento de sequências, contig/scaffold N50, etc)

Name	Explanation	Prevention
Allocation bias	Systematic difference in the assignment of participants to the treatment and control group in a clinical trial. For example, the investigator knows or can predict which intervention the next eligible patient is supposed to receive due to poorly concealed randomization.	- Randomization with allocation concealment
Attrition bias	Attrition occurs when participants leave during a study that aims to explore the effect of continuous exposure (dropouts or withdrawal). For example, more dropouts of patients randomized to an aggressive cancer treatment.	- Good investigator–patient communication - Accessibility of clinics - Incentives to continue
Confounding bias	An artificial association between an exposure and an outcome because another variable is related to both the exposure and outcome. For example, lung cancer risk in coffee drinkers is evaluated, ignoring smoking status (smoking is associated with both coffee drinking and cancer). A challenge is that many confounders are unknown and/or not measured.	- Randomization (can address unmeasured confounders) When randomization is not possible: - Restriction to one level of the confounder - Matching on the levels of the confounder - Stratification and analysis within strata - Propensity score matching
Immortal time bias	Survival beyond a certain time point is necessary in order to be exposed (participants are “immortal” in that time period). For example, discharged patients are analyzed but were included in the treatment group only if they filled a prescription for a drug 90 days after discharge from hospital.	- Group assignment at time zero - Time-dependent analysis may be used
Information bias	Bias that arises from systematic differences in the collection, recall, recording, or handling of information. For example, blood pressure in the treatment arm is measured in the morning and for the control arm in the evening.	- Standardized data collection - Data collection independent from exposure or outcome (e.g., by blinding of intervention status/exposure) - Use of objective measurements
Publication bias	Occurs when only studies with a positive or negative result are published. Affects meta-analyses from systematic reviews and harms evidence-based medicine	- Writing a study protocol and preregistration - Publishing study protocol or registered report - Following reporting guidelines

Fonte: Schwab et al. (2022)

Planning
1. Specify your research question
2. Write and register a study protocol
3. Justify your sample size
4. Write a data management plan
5. Reduce bias

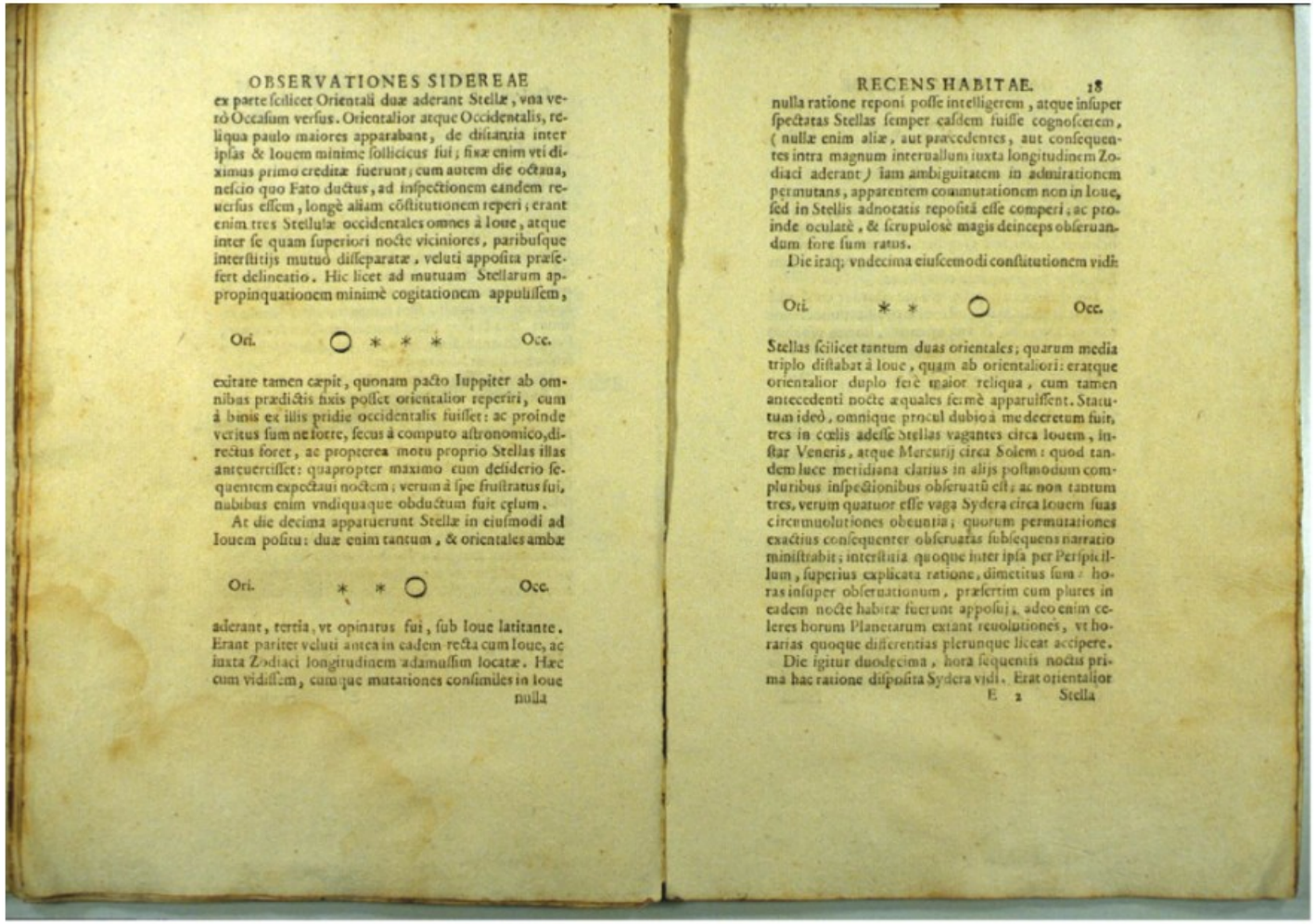
Execution
6. Avoid questionable reseach practices
7. Be cautious with interpretations of statistical significance
8. Make your research open

Reporting
9. Report all findings
10. Follow reporting guidelines

Fonte: Schwab et al. (2022)

Potenciais

- A manutenção de dados favorece também a integração de dados de diferentes fontes:
  - Fornecem análises necessárias para hipóteses que não podem ser testadas por conjuntos únicos de dados
  - A reutilização de dados supera limitações financeiras de muitos grupos menores para o delineamento de experimentos complexos, uma vez que a geração de novos dados pode ser custosa e laborosa



OBSERVATIONES SIDEREAE

ex parte scilicet Orientali duæ aderant Stellæ, vna verò Occasum versus. Orientalior atque Occidentalis, reliqua paulo maiores apparabant, de distantia inter ipsas & Iouem minime sollicitus fui; fixæ enim vti diximus primo creditæ fuerunt; cum autem die octaua, nescio quo Fato ductus, ad inspectionem eandem reuersus essem, longè aliam cõstitutionem reperi; erant enim tres Stellulæ occidentales omnes à Ioue, atque inter se quam superiori nocte viciniores, paribusque interstitijs mutuò disseparatæ, veluti appositæ præfert delineatio. Hic licet ad mutuam Stellarum appropinquationem minimè cogitationem appulissem,

Ori. ○ * * * Occ.

exitare tamen cæpit, quonam pacto Iuppiter ab omnibus prædictis fixis posset orientalior reperiri, cum à binis ex illis pridie occidentalis fuisset: ac proinde veritus sum ne forte, secus à computo astronomico, directus foret, ac propterea motu proprio Stellas illas antecurrisset: quapropter maximo cum desiderio sequentem expectaui noctem; verum à spe frustratus fui, nubibus enim vndiquaque obductum fuit cælum.

At die decima apparuerunt Stellæ in eiusmodi ad Iouem positu: duæ enim tantum, & orientales ambæ

Ori. * * ○ Occ.

aderant, tertia, vt opinatus fui, sub Ioue latitante. Erant pariter veluti antea in eadem recta cum Ioue, ac iuxta Zodiaci longitudinem adamussim locatæ. Hæc cum vidissem, cumque mutationes consimiles in Ioue nulla

RECENS HABITAE. 18

nulla ratione reponi posse intelligerem, atque insuper spectatas Stellas semper easdem fuisse cognoscerem, (nullæ enim aliæ, aut præcedentes, aut consequentes intra magnum interuallum iuxta longitudinem Zodiaci aderant) iam ambiguitatem in admirationem permutans, apparentem commutationem non in Ioue, sed in Stellis adnotatis repositâ esse comperi, ac proinde oculatè, & scrupulosè magis deinceps obseruandum fore sum ratus.

Die itaq; vndecima eiusce modi constitutionem vidi:

Ori. * * ○ Occ.

Stellas scilicet tantum duas orientales; quarum media triplo distabat à Ioue, quam ab orientaliori: eratque orientalior duplo fere maior reliqua, cum tamen antecedenti nocte æquales fermè apparuissent. Statuam ideò, omnique procul dubio à me decretum fuit, tres in cœlis adesse Stellas vagantes circa Iouem, instar Veneris, atque Mercurij circa Solem: quod tandem luce meridiana clarius in alijs postmodum compluribus inspectionibus obseruatũ est: ac non tantum tres, verum quatuor esse vaga Sydera circa Iouem suas circumuolutiones obeuntia; quorum permutationes exactius consequenter obseruatas subsequens narratio ministrabit; interstitia quoque inter ipsa per Perspicillum, superius explicata ratione, dimetitus sum: horas insuper obseruationum, præsertim cum plures in eadem nocte habitæ fuerunt appositi; adeo enim celeres horum Planetarum extant reuolutiones, vt horarias quoque differentias plerunque liceat accipere.

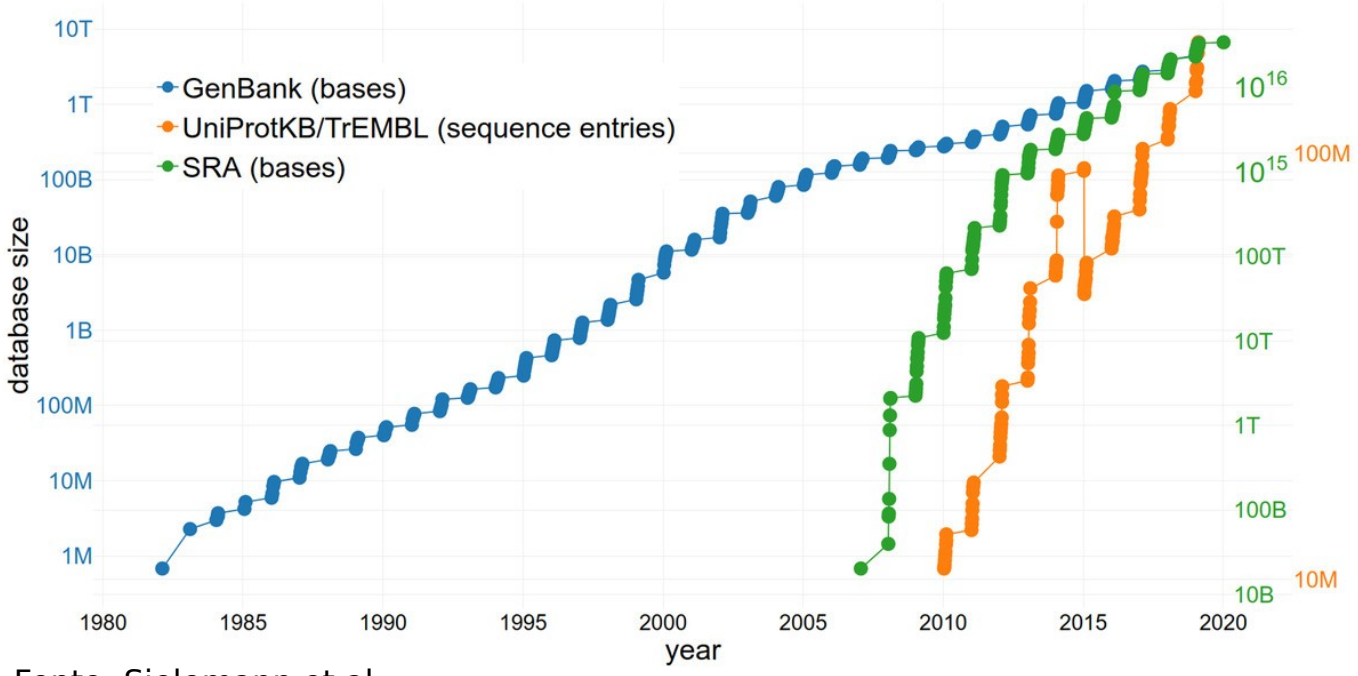
Die igitur duodecima, hora sequentis noctis prima hac ratione disposita Sydera vidi. Erat orientalior

E 2 Stella

Fonte: Goodman et al. (2014)

Potenciais

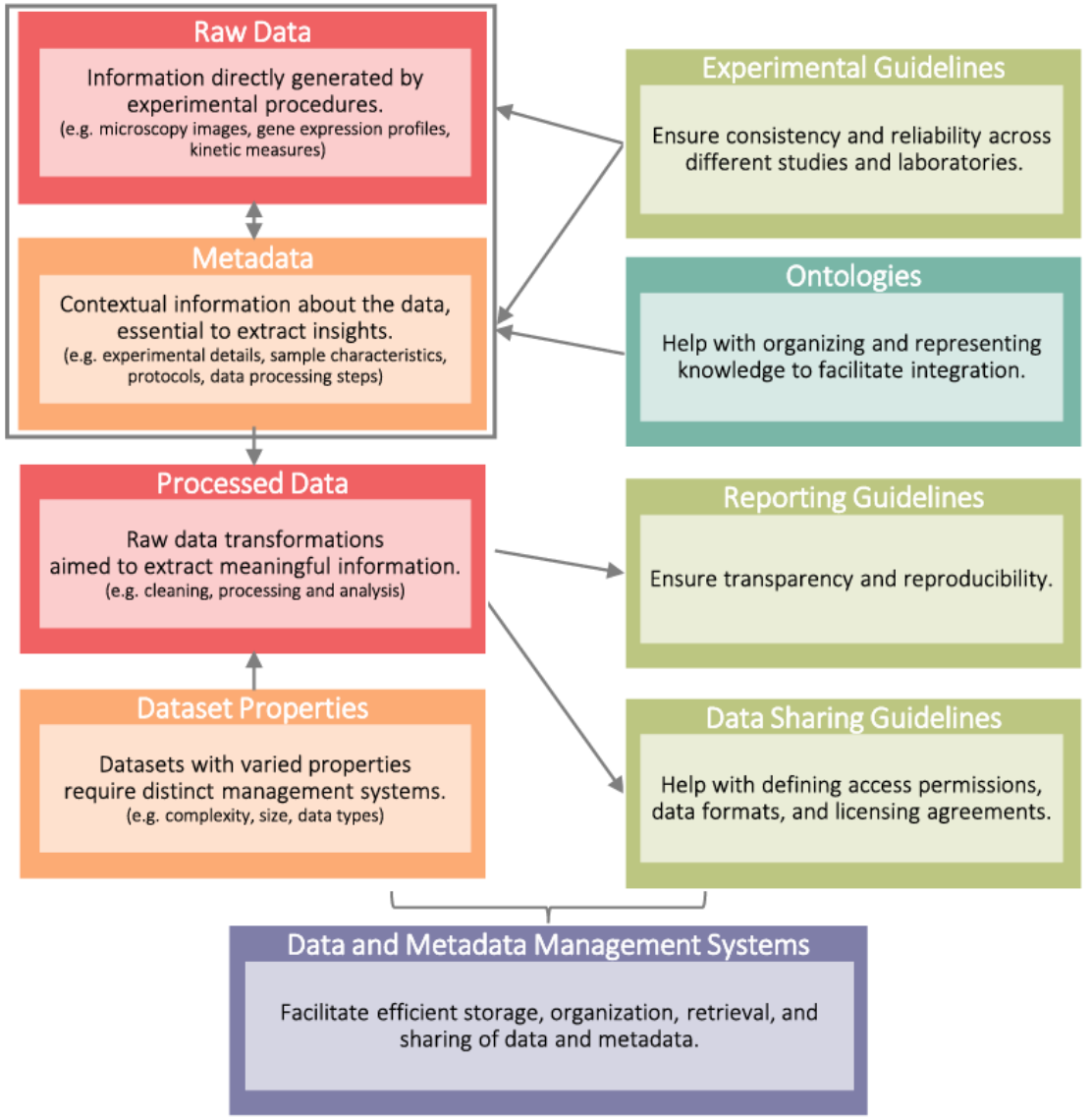
- A disponibilização pública dos dados previne a perda de informação e a geração de conjuntos redundantes e/ou duplicados:
  - Manutenção concisa das bases de dados
  - 20% das publicações de metagenomas entre 2016 e 2019 não são acessíveis ao público



Fonte: Sielemann et al. (2020)

Potenciais

- A reprodutibilidade da reutilização de dados pode ser melhorada pela padronização, documentação e organização de fluxos de trabalho:
  - A integração de diferentes fontes envolve a comparação entre fluxos de trabalho distintos, variáveis indevidamente registradas, apresentações não unificadas, e falta de disponibilidade de dados brutos
  - Exige uma curagem manual
  - Padronização do formato de linguagem e arquivos (XML, FASTA, FASTQ, SAM/BAM)



Fonte: Cunha-Oliveira et al. (2024)

Potenciais

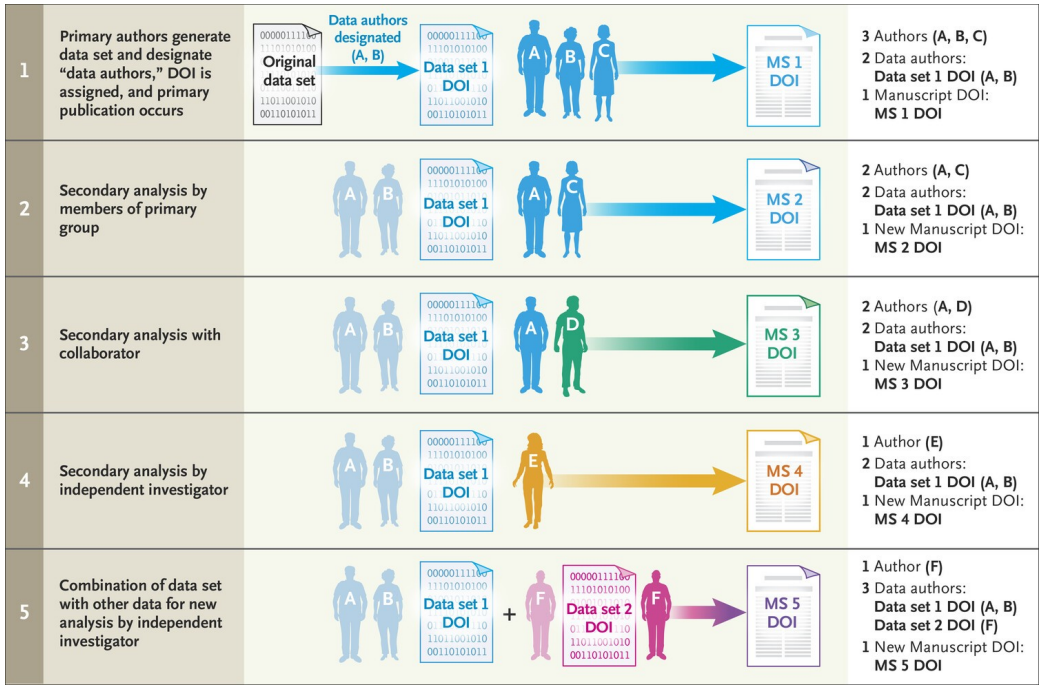
- Existem guias para a padronização do compartilhamento de metadados:
  - Findable Accessible Interoperable Reusable (FAIR)
  - The Transparency and Openness Promotion (TOP)
  - Open Data in a Big Data World (Open Data in a Big Data World, 2016)
  - Beijing Declaration

FAIR Principle	For Infrastructure	For Researchers
Findable	Data and metadata should be easy to find by both humans and computers. In practice, this means that data should be assigned unique and persistent identifiers, described using rich metadata, and registered or indexed in a searchable resource.	Research teams should implement standardized practices related to organizing files (e.g. standardized file naming conventions) so data can be found when needed. When data is made available to others, it should- whenever possible- be uploaded to a repository that assigns a persistent identifier (e.g. DOIs, RRIDs, etc) and describes datasets with standardized metadata. Complete and high quality metadata should be added so data can be discovered and linked to related resources (e.g. related paper DOIs, author ORCIDs).
Accessible	There is a clearly defined method for accessing the data. Data should be retrievable by its identifier using a standardized protocol that is open, free, and universally implementable. Metadata should be accessible even when data is no longer available.	Data is available through a clearly defined process. Members of the research team should be able to access raw data, intermediate products, and other research materials. When data and other materials are made available to others, there should be a clear path to gaining access. The terms by which the data will be made available (e.g. to whom, when, and for what purpose) should be articulated and abided by.
Interoperable	Data should be usable across a range of applications and workflows. Data should use formal, accessible, shared, and broadly applicable models for knowledge representation.	Data should be structured in a standard way so it can be easily combined with other similarly structured datasets. In practice, this means implementing a range of practices such as describing and organizing data (e.g. applying appropriate metadata, maintaining data dictionaries) and saving files in open or non-proprietary file formats.
Reusable	Metadata and data should be described following relevant community standards and have clearly defined conditions for reuse including a machine-readable license	Data should be saved, organized, and described with its future (re)use in mind. A future user may be a member of the research team who is returning to the data after a period of several months or years or another researcher who is (re)using the data for another purpose.

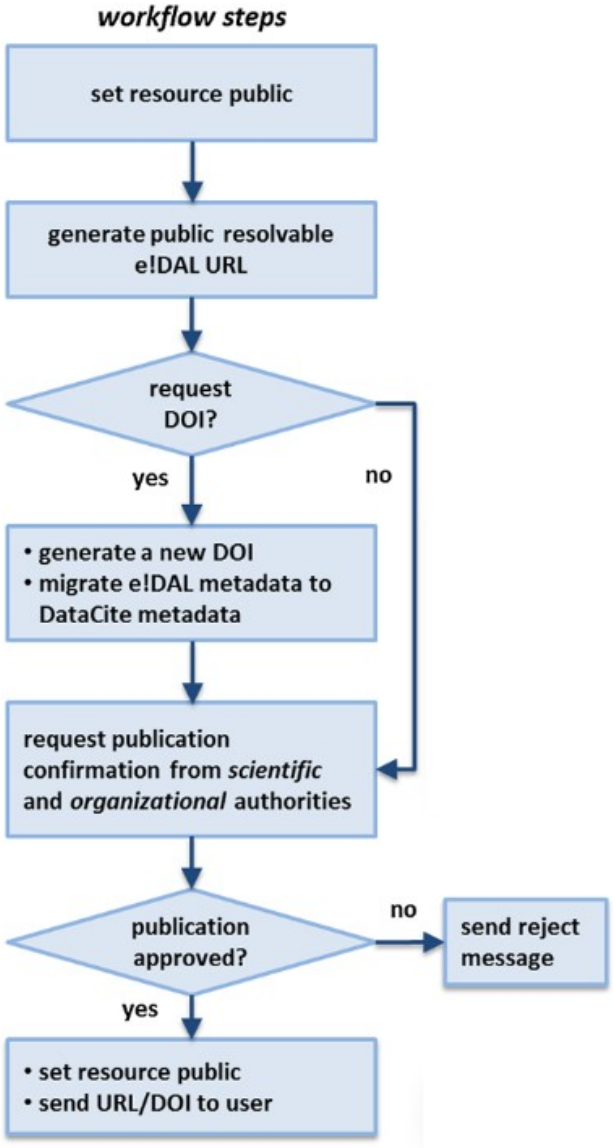
Fonte: Borghi e Van Gulick et al. (2022)

Potenciais

- Autores podem ser beneficiados pelo fornecimento de dados de alta qualidade e com boa anotação:
  - A prática deve fomentar as citações e reconhecimentos adequados
  - Podem resultar em citações adicionais para um mesmo conjunto de dados



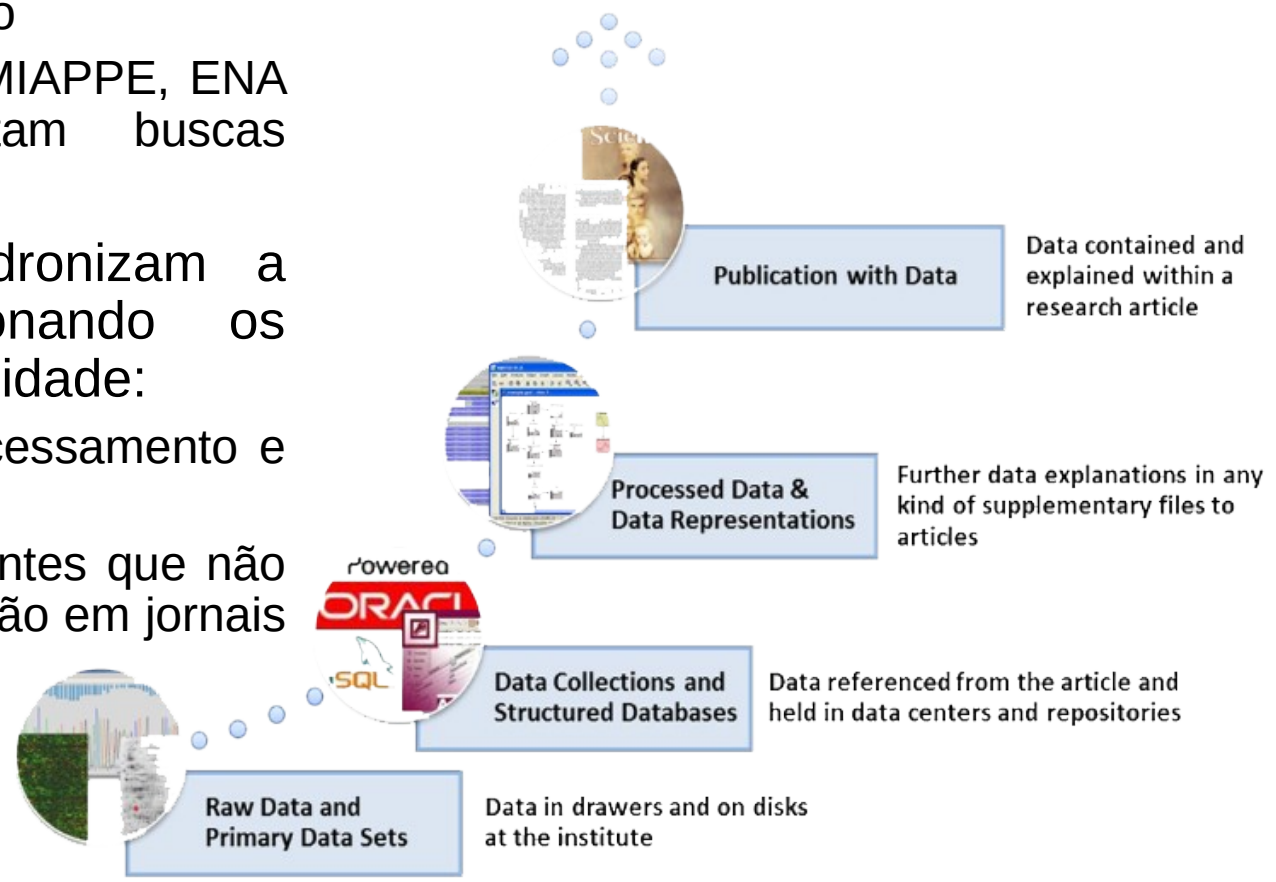
Fonte: Bierer et al. (2017)



Fonte: Arend et al. (2014)

Potenciais

- A padronização exige uma curagem manual:
  - Cada projeto apresenta vocabulário próprio
  - Padronização de metadados (MassIVE, MIAPPE, ENA e SRA) e de vocabulário facilitam buscas automatizadas
- Jornais de dados (*data papers*) padronizam a submissão dos metadados, solucionando os problemas associados ao controle de qualidade:
  - Descrição dos métodos para coleta, processamento e verificação dos dados
  - Permitem a publicação de dados importantes que não são suficientes para compor uma publicação em jornais comuns.



Fonte: Arend et al. (2014)

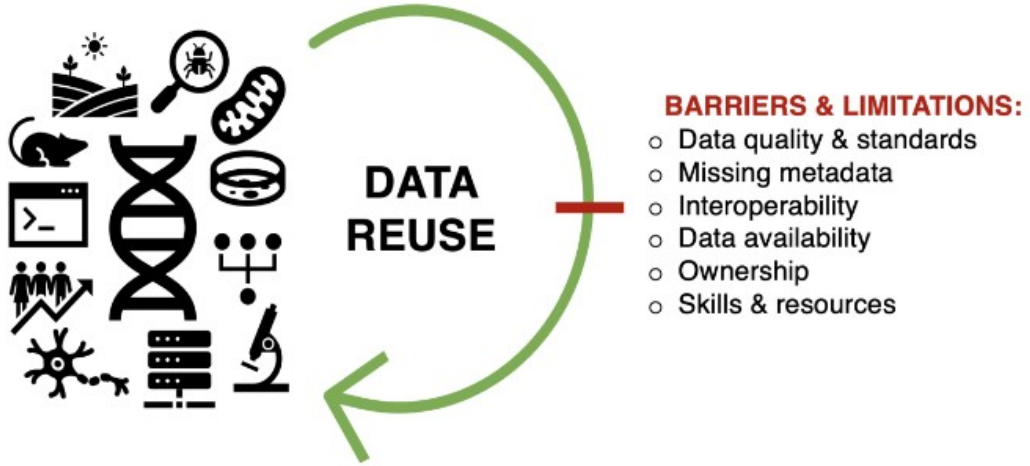
Ética

- Direitos de uso:
  - Reuso justo (para novos propósitos)
  - Reprodução de estudos prévios com dados publicados
  - Reuso injusto (plágio)
- Parasitismo de pesquisa:
  - A reutilização deve gerar novos resultados, e não apenas impulsionar publicações anteriores.
  - *The Research Parasite Awards* premia autores que adequadamente reutilizaram dados

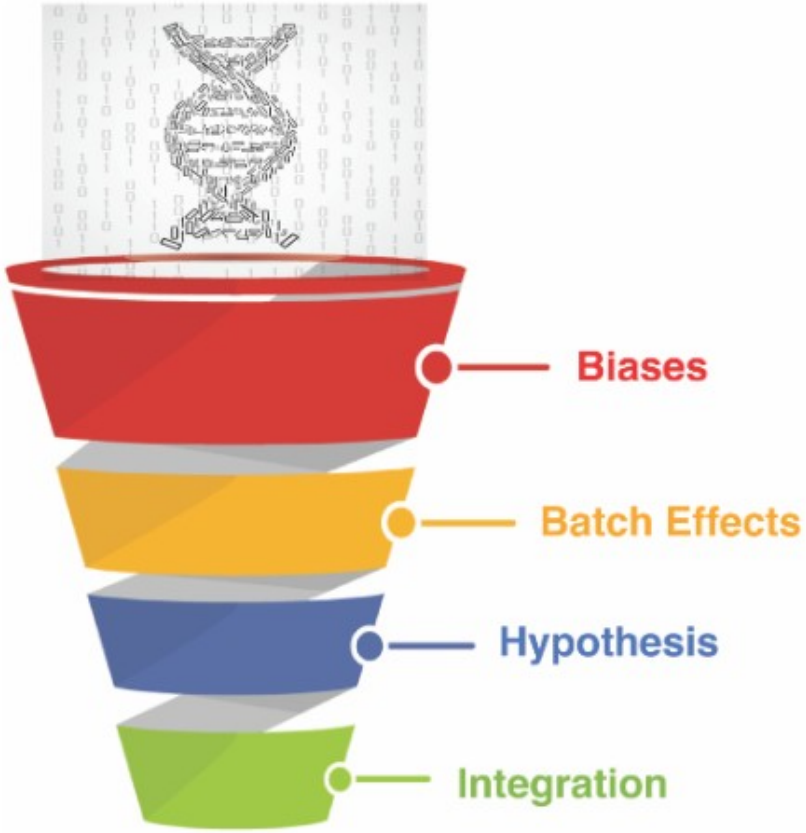
Fonte: Greene Laboratory (2020)

Limitações

- A revisão por pares geralmente não envolve a avaliação dos conjuntos de dados e sua descrição:
  - A qualidade dos dados é questionável quando são de responsabilidade pública
  - Metodologia e design experimental incompletas
  - Propagação de ruídos nos dados com a reutilização
  - Os conjuntos de dados não são normalizados, impedindo a integração



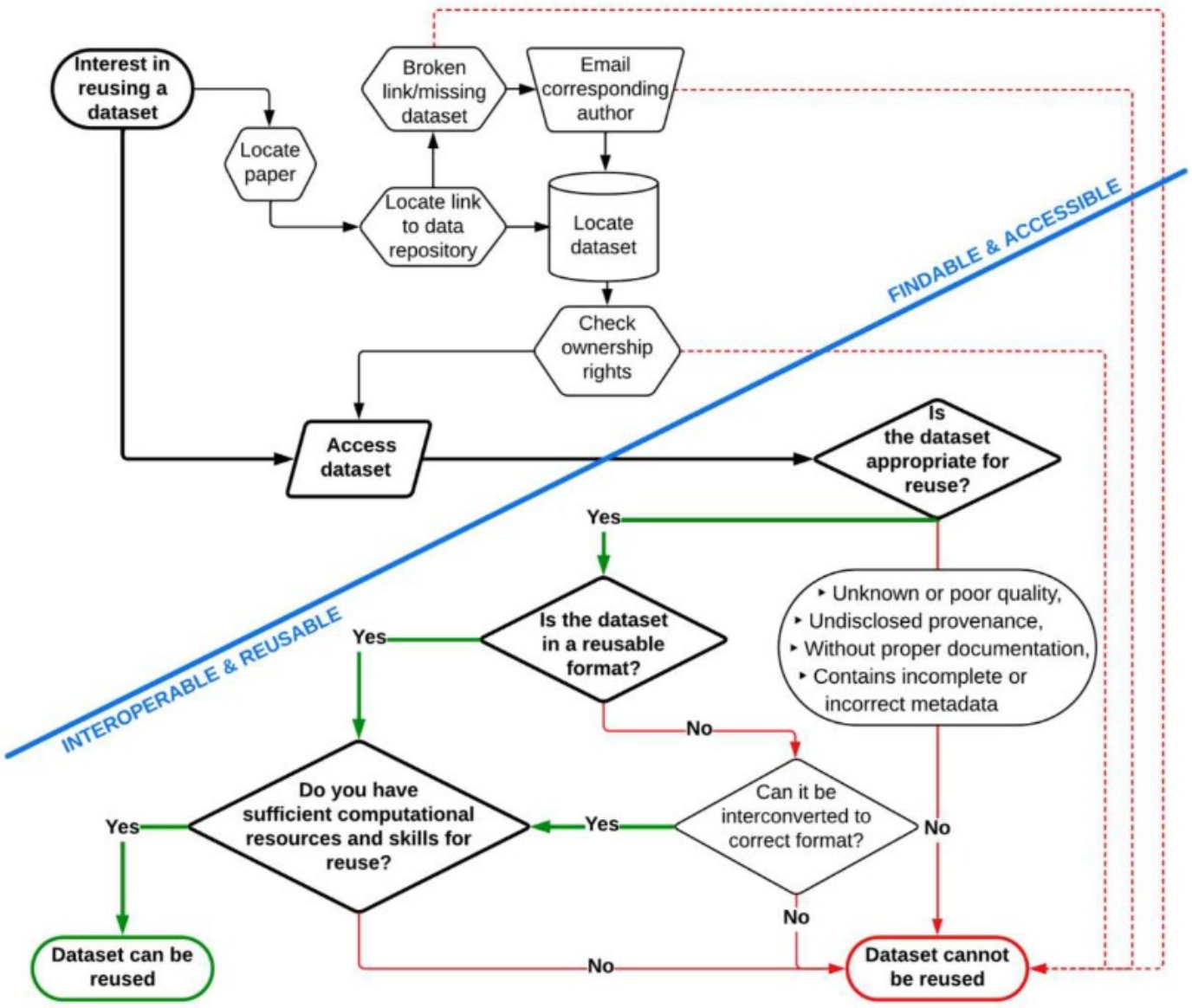
Fonte: Hafner et al. (2024)



Fonte: Raman et al. (2021)

Limitações

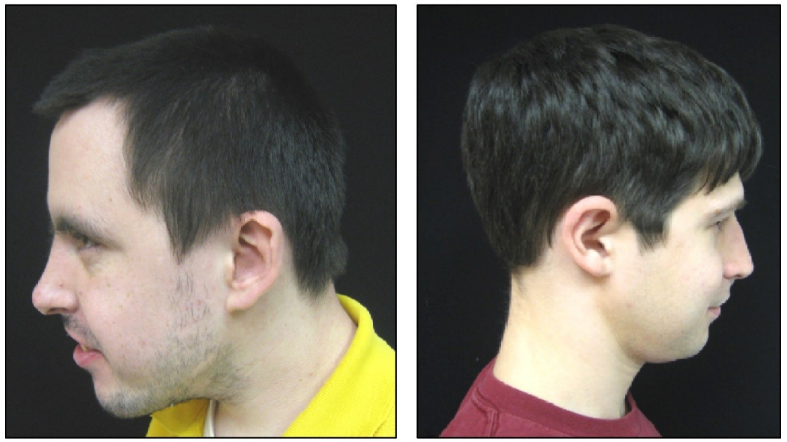
- Sequências podem ser depositadas com identificadores diferentes, impedindo sua integração e escondendo possíveis informações.
- A anotação não é padronizada, possibilitando a inserção de um mesmo conjunto de dados com diferentes identificações
- A montagem de genomas baseada em dados públicos podem ser prejudicadas pela presença de contaminações não identificadas
- Falsos positivos em experimentos podem não ser identificados em dados públicos



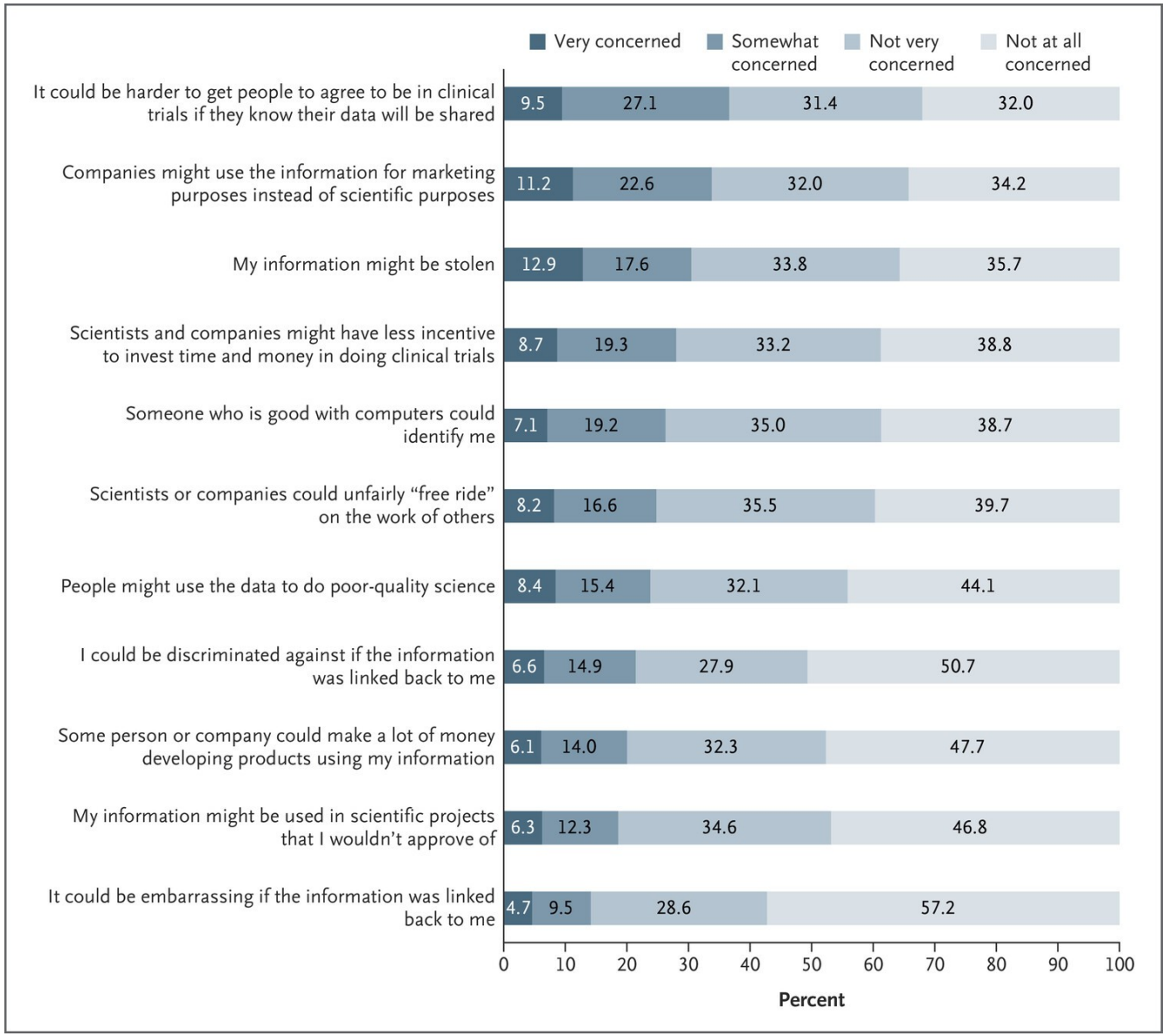
Fonte: Hafner et al. (2024)

Limitações

- Dados clínicos impactam os pacientes envolvidos e devem ser devidamente assegurados para reutilização
  - Pacientes não devem ser identificados
  - Dados genômicos (risco de privacidade para a progênie)



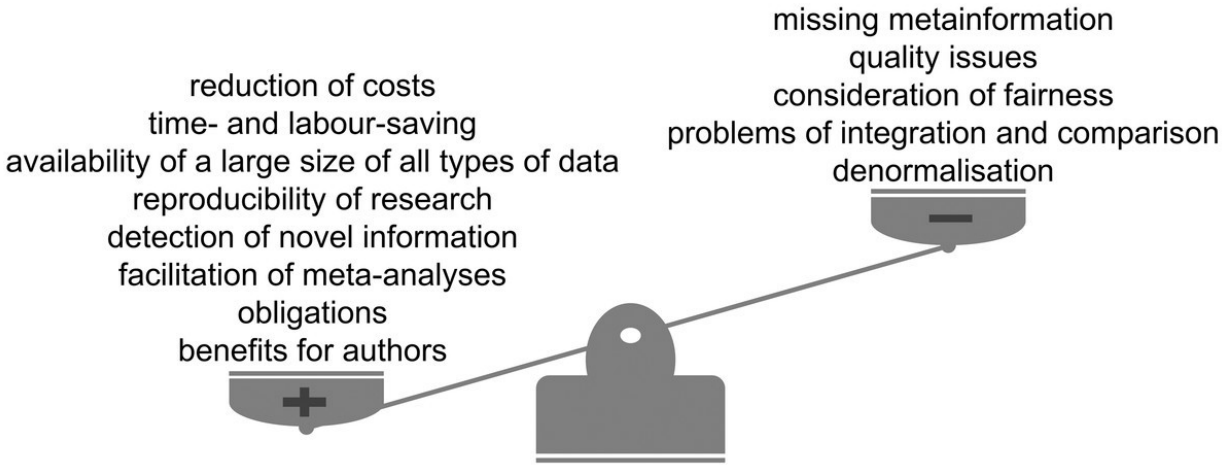
Fonte: McDonald-McGinn et al. (2011)



Fonte: Mello et al. (2018)

Balanço

- Benefícios:
  - Redução de custos
  - Redução de trabalho manual
  - Disponibilidade de diversos tipos de dados
  - Reprodutibilidade de trabalhos
  - Detecção de novas informações
  - Facilidade em meta análises
  - Benefícios aos autores.
- Precauções:
  - Perda de informação
  - Perda de qualidade
  - Uso justo de dados
  - Problemas de integração e comparação
  - Falta de normalização



Fonte: Sielemann et al. (2020)

Exemplos

PMID	Title	First Author	Journal/Book	Publication Year	DOI
28480475	Clinical Data Reuse or Secondary Use: Current Status and Potential Future Progress	Meystre SM	Yearb Med Inform	2017	10.15265/IY-2017-007
26094821	Archetype-based data warehouse environment to enable the reuse of electronic health record data	Marco-Ruiz L	Int J Med Inform	2015	10.1016/j.ijmedinf.2015.05.016
30306916	Data Reuse Through Anesthesia Data Warehouse: Searching for New Use Contexts	Lamer A	Stud Health Technol Inform	2018	
29281658	Attitudes and norms affecting scientists' data reuse	Curty RG	PLoS One	2017	10.1371/journal.pone.0189288
26308551	Changes in Data Sharing and Data Reuse Practices and Perceptions among Scientists Worldwide	Tenopir C	PLoS One	2015	10.1371/journal.pone.0134826
29063535	Update on Data Reuse in Health Care	Safran C	Yearb Med Inform	2017	10.15265/IY-2017-013
31164775	Credit data generators for data reuse	Pierce HH	Nature	2019	10.1038/d41586-019-01715-4
24109559	Data reuse and the open data citation advantage	Piwowar HA	PeerJ	2013	10.7717/peerj.175
30961905	A review of attitudes towards the reuse of health data among people in the European Union: The primacy of purpose and the common good	Skovgaard LL	Health Policy	2019	10.1016/j.healthpol.2019.03.012
23289463	Reuse of public genome-wide gene expression data	Rung J	Nat Rev Genet	2015	10.1038/nrg3394
31426840	Clinical trial data reuse - overcoming complexities in trial design and data sharing	Wilkinson T	Trials	2019	10.1186/s13063-019-3627-6
28002728	Expanding the Immunology Toolbox: Embracing Public-Data Reuse and Crowdsourcing	Sparks R	Immunity	2016	10.1016/j.immuni.2016.12.008
30573830	Proteomics data reuse with MassIVE-KB	Doerr A	Nat Methods	2019	10.1038/s41592-018-0283-9
23508969	CistromeFinder for ChIP-seq and DNase-seq data reuse	Sun H	Bioinformatics	2013	10.1093/bioinformatics/btt135
29881734	A Data Quality Assessment Guideline for Electronic Health Record Data Reuse	Weiskopf NG	EGEMS (Wash DC)	2017	10.5334/egems.218
26769124	SPIRIT: Systematic Planning of Intelligent Reuse of Integrated Clinical Routine Data. A Conceptual Best-practice Framework and Procedure Model	Hackl WO	Methods Inf Med	2016	10.3414/ME15-01-0045
29758095	Reuse of public, genome-wide, murine eosinophil expression data for hypotheses development	Grace JD	J Leukoc Biol	2018	10.1002/JLB.1MA1117-444R
30895574	Impact of Electronic versus Paper-Based Recording before EHR Implementation on Health Care Professionals' Perceptions of EHR Use, Data Quality, and Data Reuse	Joukes E	Appl Clin Inform	2019	10.1055/s-0039-1681054
32160189	Data sharing, management, use, and reuse: Practices and perceptions of scientists worldwide	Tenopir C	PLoS One	2020	10.1371/journal.pone.0229003
31594947	Compendiums of cancer transcriptomes for machine learning applications	Lim SB	Sci Data	2019	10.1038/s41597-019-0207-2
24395549	Drug risk assessment and data reuse	Iyasu S	Pharmacoepidemiol Drug Saf	2014	10.1002/pds.3518
26137488	Toward a Literature-Driven Definition of Big Data in Healthcare	Baro E	Biomed Res Int	2015	10.1155/2015/639021
30342679	Harmonics of Big Biomedical Data to characterize temporal variability and seasonality of data repositories: Functional Data Analysis of data temporal evolution over non-parametric statistical manifolds	Sy^ec C	Int J Med Inform	2018	10.1016/j.ijmedinf.2018.09.015
27374120	The harmonizome: a collection of processed datasets gathered to serve and mine knowledge about genes and proteins	Rouillard AD	Database (Oxford)	2016	10.1093/database/baw100
29677919	From Data Extraction to Analysis: Proposal of a Methodology to Optimize Hospital Data Reuse Process	Lamer A	Stud Health Technol Inform	2018	
22733976	Methods and dimensions of electronic health record data quality assessment: enabling reuse for clinical research	Weiskopf NG	J Am Med Inform Assoc	2013	10.1136/amiajnl-2011-000681
30957010	Three controversies in health data science	Peek N	Int J Data Sci Anal	2018	10.1007/s41060-018-0109-y
28906267	Evidence-Based Guidelines for Interface Design for Data Entry in Electronic Health Records	Wilbanks BA	Comput Inform Nurs	2018	10.1097/CIN.0000000000000387
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[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
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32521555	Factors Influencing Problem List Use in Electronic Health Records-Application of the Unified Theory of Acceptance and Use of Technology	Klappe ES	Appl Clin Inform	2020	10.1055/s-0040-1712466
21346966	Development of automated quality reporting: aligning local efforts with national standards	Dykes PC	AMIA Annu Symp Proc	2010	
24808228	Efficient acceleration of mutual information computation for nonrigid registration using CUDA	Ikeda K	IEEE J Biomed Health Inform	2014	10.1109/JBHI.2014.2310745
32418147	Development, implementation and preliminary evaluation of clinical dashboards in a department of anesthesia	Laurenti G	J Clin Monit Comput	2020	10.1007/s10877-020-00522-x
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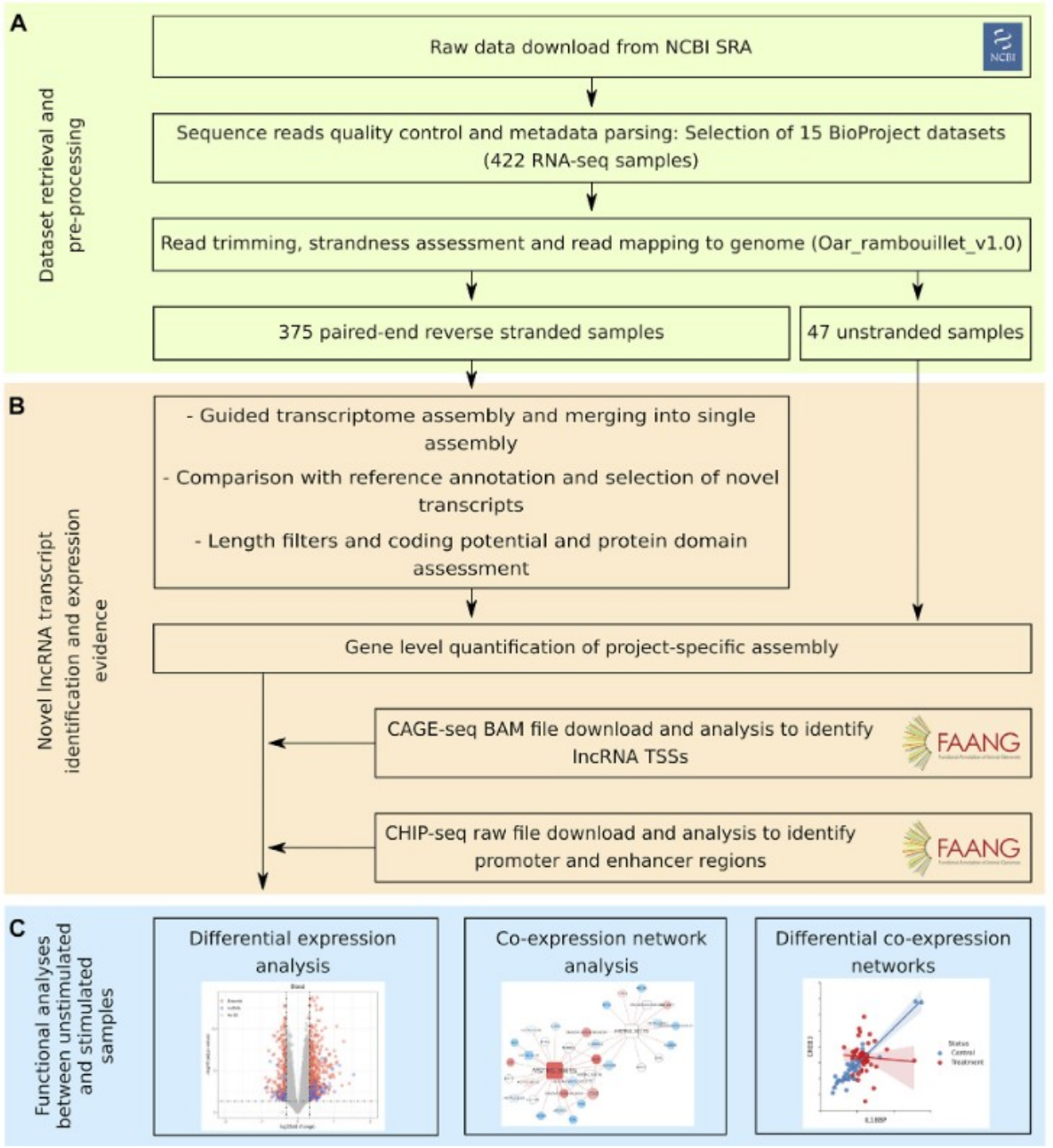
Fonte: Sielemann et al. (2020)

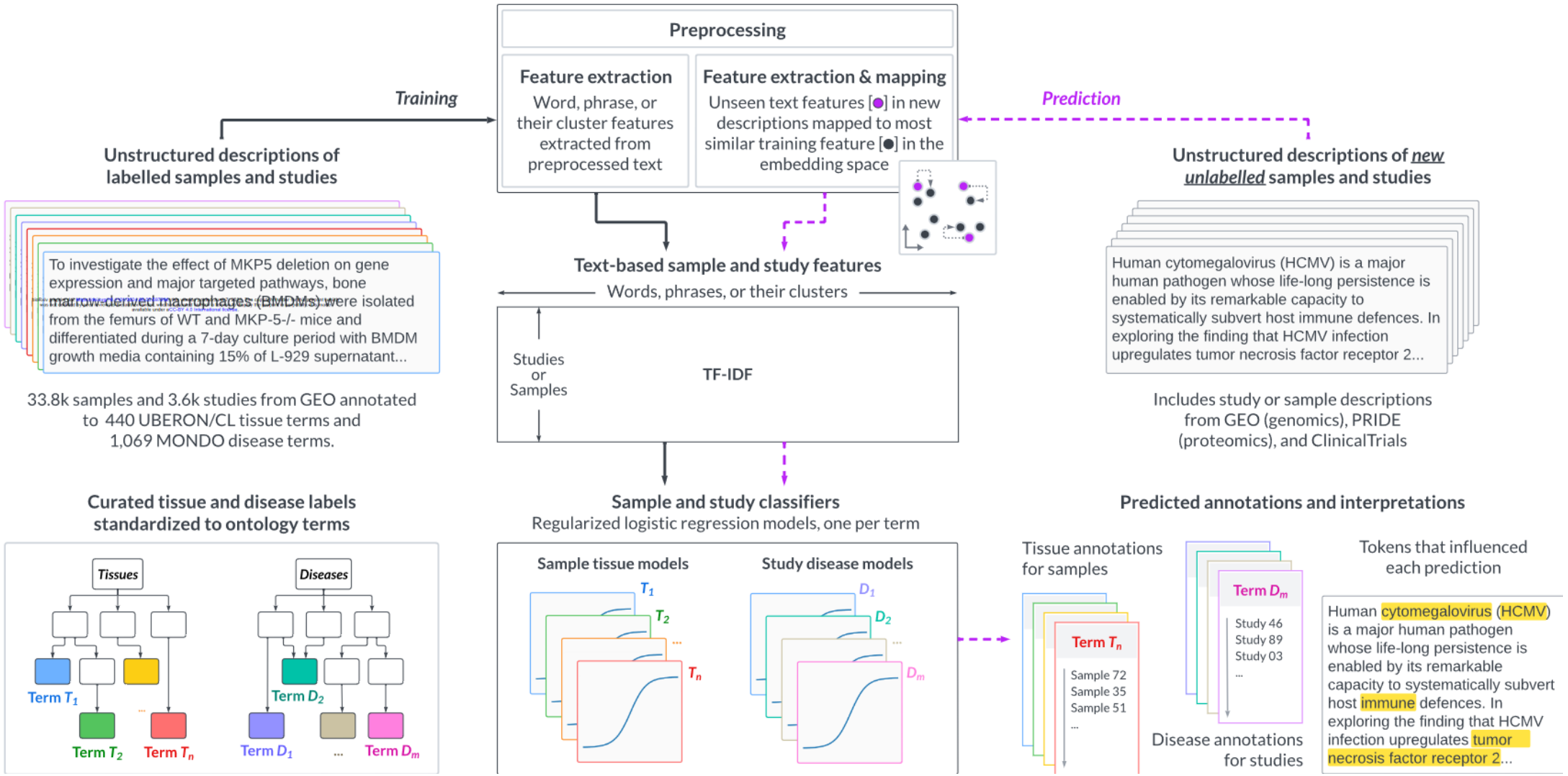
Exemplos

- Utilização de diversos conjuntos de dados de amostras do sistema immune de ovinos
- Identificação de lncRNAs associados à resposta immune em ovinos



Fonte: Bilbao-Arribas e Jugo (2022)

Exemplos



Fonte: Yuan et al. (2024)

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