Supplement 1 (S1): Additional Ethics-Policy-Reg GPOC Review Documentation

For the *Systematic Review and Meta-Analysis for a Global Patient co-Owned Cloud (GPOC)*, see this article published separately and its supplementary material for search strategy etc.
Lidströmer N et al, *Systematic Review and Meta-Analysis for a Global Patient co-Owned Cloud (GPOC),* Nature Communications, DOI: 10.21203/rs.3.rs-3004559/v1
And the supplement documents of the article:
Documentation of search strategies_Niklas*, made in collaboration with the Karolinska Institutet librarians, and also the PRISMA checklist:* ***PRISMA_2020_checklist.GPOC***

Two facets of *co-ownership* and *security* a handful of articles with the highest relevance to the article *Review of the Ethics, Policies and Regulations of a Global Patient co-Owned Cloud (GPOC)* were extracted. These articles had not been further elaborated in the original article to avoid any overlapping.

The GPOC Additional Literature Review

The above-mentioned *Prospective Register of Systematic Reviews* (PROSPERO) registered and *Preferred Reporting Items Systematic and Meta-Analyses* (PRISMA)-guided systematic review and meta-analysis is more stringent that the additional review. However, below follows the search queries, key words, problems statements and search terms used in this additional review. It was also supported and, in its selection, guided by the GPOC interview series, see supplement document ***Ethics-Policy-Reg GPOC Interviews***. The interviews sought to answer the same three groups of search questions, but also encompassed a wider and informative scope.

Based on the above-described systematic review and meta-analysis key terms were selected. Then MeSH term search was performed and cross referencing made to previous meta-analysis. Hence, the additional review is a combined systematic and narrative review.

Key problem statements with personal health records (PHRs)

1) No or limited patient access
2) No patient ownership
3) No explicit right to share
4) No integration or interaction across platforms
5) Ineffective user interfaces
6) Expensive, too expensive for many health economies.

Search Strategy and Keywords

Database**:** *PubMed (MEDLINE)* only

1. Formulation of clear, well-defined, answerable search questions

1. *Overarching question*

1.1 Can an artificial intelligence (AI) empowered and blockchain protected Global Patient co-Owned Cloud (GPOC) of personal health records (PHRs) be a solution to the *six above problem statements*?

2. *Problem statement specific sub questions (naming the six problems in words, to make it clearer)*

2.1 Can GPOC solve the problems with no or limited patient PHR access, ownership and sharing rights?

2.2 Can GPOC solve to lack of integration, interaction, effective user interfaces and the high costs and security issues with current PHRs?

3. *Focused question*

3.1 Can there be a *global consensus* on the ethics, policy and regulations for a GPOC?

4. Identified primary concepts and gathered synonyms

#	**Searches with keywords**
1	Personal Health Record*
2	PHR* or EHR* or EMR* or EMRS*
3	Electronic Health Record*
4	Health Information System*
5	Clinical Decision Support Systems*
6	Medical Record Linkage*
7	Medical Records System*
8	Patient Portal*
9	PHR AND Ethics or PHR AND problem*
10	Computeri#ed or electronic or personal or personali#ed or health* data* or health* record* or medical record* or patient record* or pharmaceutical record*
11	Clinical decision or clinical information or decision support or health information or medical information
12	Medical Record Linkage* or Patient* Portal* or Personal Health Information
13	Patient Ownership
14	Health Personnel
15	Patient Participation
16	Patient Access
17	“PHR sharing” or “health data sharing” or
18	Multi-ownership or ownership or “PHR ownership” or “health data ownership”
19	Policy or Policies
20	AI or AIM
21	Artificial Intelligence
22	Cloud Computing
23	Data Management
24	Information Dissemination
25	"Information Storage and Retrieval"
26	Machine Learning
27	Blockchain*
28	Artificial Intelligence Dissemination
29	“AI substrate” or “AI training” or “AI research”
30	administ* or custod* or dissemination or distribution or extract* or govern* or link* or manage* or retrieval* or source* or sharing* or steward* or storage*
31	“Fully Homomorphic Encryption” or FHE
32	“global consensus” or “regulatory consensus” or “policy consensus” or consensus
33	Cloud-based or “cloud-based PHR” or “cloud-based personal health record”
34	Global or globally AND integration or sharing or moving or migration
35	Computer Security
36	Confidentiality

37	Ownership
38	Patient Access to Records
39	Patient Right* or Human Right* or Right* Declaration
40	Legislation or Jurisprudence
41	anonymi#ation or blockchain* or block chain* or co-own* or coown* or cybersecurit* or de-Identification? or deIdentification? or encrypt* or jurisprudence or law* or legal or legislat* or ownership* or regulation* or secrecy or secur*
42	computer or cyber or data or breach* or compromising or hacker or virus or viruses or worm*
43	data or information or masking or protection
44	patient* or property right*
45	patient or data AND privacy

In the above are the primary keywords for the search concept. The keywords relate to each other as seen in the row groups. Synonyms have been gathered and have been limited in order to not expand the scope and keep the review balanced.

5. Located subject headings (MeSH)
Usage of Medical Subject Headings (MeSH) in the search to cover word variations, word endings, plural or singular forms, or synonyms. Some of the topics or concepts had more than one appropriate MeSH term. Some concept did not have any MeSH term.

6. Combined concepts using Boolean operators AND/OR
Boolean operators (e.g., AND, OR, NOT) were applied in the search string.

7. Refined search terms and search in PubMed
The review was limited to English literature and to PubMed only.

8. Applied limits
Results were limited to articles written in English. Only publications less than 5 years old (2018-2023).

For philosophical aspects, i.e., to quote original sources on basic ethics statements from the enlightenment period, e.g., Immanuel Kant, the origins of universal rights and UN Declarations, exceptions were made.

Searches were also limited to accessible open-source publications.

Only fully published peer reviewed articles were included.

9. The results were organised in twelve subgroups

1. Relevant Human Rights Declarations
2. Ethical Principles
3. Co-Ownership
4. Privacy Aspects
5. Policy Aspects
6. Security Aspects
7. New Technical Solutions and Ethics
8. Initiatives by Regulatory Bodies and Organisations
9. An Overview of Global Regulations (w/ Table 1)
10. The Global PHR Market (w/ Table 2)
11. Artificial Intelligence Integration
12. Future Challenges