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Necessity for a global patient co-owned cloud (GPOC)

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Abstract

Background The use of Cloud-based storage of personal health records has increased globally. The GPOC Series introduces the concept of a Global Patient co-Owned Cloud (GPOC) of personal health records. Here, we present the GPOC Series' international survey on the necessity of a GPOC.

Methods Online global survey with invitations sent to health ministries and major organisations. It received answers from health ministries and affiliated advisors of all 193 United Nations (UN) member states, 2 UN observer states (Holy See & Palestine) and 1 de facto UN non-member state (Taiwan) and from 18 major international organisations. The survey examined a dozen aspects encompassing demographics, privacy, sharing, movability, co-ownership, research, company usage, regulation and the necessity of a GPOC.

Results The GPOC Survey elicited responses from 267 individuals from 214 entities, including all UN member states, and major international organisations. Twelve domains were identified, covering demographics, correctness, privacy, commercial use, medical and non-medical research, co-ownership, data sharing, record movement, ownership centralisation, patient rights, environmental concerns, and foundation creation. Results show high agreement on most issues, including support for co-ownership (89%) and movement of personal health records (84%). Disagreement was prominent regarding centralised ownership by the state (64%) and data sharing without consent (85%). Additionally, respondents expressed interest in a neutral, decentralised foundation for regulation (73%) and the environmental sustainability of electronic health records (84%).

Conclusions A Global Patient co-Owned Cloud (GPOC) of personal health records could significantly enhance patient independence and involvement in health management, supported by the near consensus agreement across various domains identified in our survey. This consensus underscores the potential of GPOC to democratise healthcare and align with UN Sustainable Development Goals (SDGs). The survey results demonstrate strong support for GPOC's role in promoting evidence-based patient management, reducing information silos, and fostering ethical data sharing. Moreover, the overwhelming agreement on key principles of co-ownership, data sharing, and environmental sustainability highlights the global inclination for a decentralised, patient-controlled PHR platform. This platform stands to empower patients worldwide, advance precision medicine, and contribute to the global development and dissemination of artificial intelligence in healthcare.

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Keywords Global patient co-owned cloud, Personal health records, Cloud-based health, Artificial intelligence in medicine, Patient empowerment, Healthcare data management, Data privacy, Healthcare accessibility, Medical research ethics, Health information technology

Introduction

The concept of a Global Patient co-Owned Cloud (GPOC) entails a global and securely blockchain protected, globally distributed and patient co-owned platform of personal health records (PHR, ISO/TR 14292:2012).

This has been explored in the GPOC Series [1–4] starting with a systematic review and meta-analysis of the core facets of a GPOC [1]. Then we published a technical article with a GPOC Sandbox, using open-source infrastructures [2]. The series also contains a GPOC Summit [3], and an additional literature review and interview series of the ethics and policies relevant for a GPOC [4]. The co-ownership model, trisected between patients, clinicians, and clinics, enhances patient-centricity, access and control over health information. This promotes autonomy and transparency in healthcare decision-making. This dynamic is crucial as the GPOC evolves into a global substrate for AI deployment and dissemination.

Specifically, the GPOC is a cloud-based infrastructure ensuring global scalability and interoperability facilitating seamless integration with existing healthcare systems. Additionally, advanced technologies such as blockchain, fully homomorphic encryption, and federated learning enable secure data management and global communication, positioning the GPOC as a cornerstone of modern healthcare delivery.

Cloud computing has emerged as a transformative force in various industries, and its importance in healthcare cannot be overstated. With the exponential growth of digital data in the healthcare sector, cloud-based solutions offer the scalability, accessibility, and security necessary for the management of personal health information. Leveraging cloud computing in healthcare has the potential to revolutionise patient care, research, and data management practices [5, 6].

To date, there are relatively few surveys have been conducted in this field, with the largest one undertaken by the World Health Organisation in 2015 [7]. However, the GPOC Survey stands out as the largest ever conducted, encompassing responses from health ministries, their ministers, advisors, and affiliated key opinion leaders. emerged.

Personal Health Records (PHRs) began to receive considerable attention with the emergence and development of digital computing systems [5]. Initially inaccessible to most healthcare institutions, these systems gradually evolved into 'problem-oriented' medical record keeping, enabling the collection and storage of information for decision-making [6]. However, centralised clinical information systems pose significant challenges. These include vulnerability and scalability issues, especially for globalised PHRs [8]. The necessity for a new paradigm of information exchange has emerged, one that facilitates custodianship for patients to co-manage their health data with clinicians [9].

Thus, a shift towards a patient-centric, cloud-based platform enhances autonomy, access, and control over health information [10]. Despite extensive research on various aspects of PHRs, the co-ownership model has not been fully explored [11, 12]. Health data sharing can be improved, but security issues are still substantial [13–15]. GPOC addresses these gaps by providing a secure, interoperable, and scalable solution, promoting both healthcare equality and data integrity. Here, we highlight the major emerging trends in healthcare data management, summarised in a few key bullets:

- *Digital Evolution* From basic digital systems to interactive, modern platforms.
- *Security Challenges* Growing vulnerabilities demand decentralised solutions.
- *Patient Empowerment* Co-ownership models boost autonomy and transparency.
- *Global Integration* Cloud solutions drive global interoperability and innovation.
- *Future Prospects* Healthcare revolution with proactive AI integration.
- *Democratisation* Equitable access and participation in medical decision-making.

The lack of a global healthcare platform for cross-border clinical information sharing creates data silos, that disrupt data governance in global research. When COVID-19 travel passes were issued, a global pandemic monitoring platform was also suggested [16]. The optimal PHR use could be prophylactic with major impact on global health [17]. PHR adoption can lead to measurable improvements in patient satisfaction and significant improvements in global health-related measures [18]. Earlier PHR use during COVID-19 with a global PHR platform would have played a pivotal role in combating the pandemic [16].

Current PHRs are costly and lack interactivity, and their poor design and siloed lack of communication have been linked to health worker burnout [10, 19]. Transitioning to a cloud-based PHR platform shifts the focus toward improving the user experience and interface (UX/UI), facilitating consented sharing among family members and healthcare professionals [20, 21].

Despite the extensive research conducted on various aspects of personal health records (PHRs), including accuracy improvement [22], data sharing [23], encryption [24], and management [25], there remains a notable gap in the literature regarding the effectiveness of co-ownership as a model for facilitating healthcare equality, data distribution, and data integrity. Our systematic review and meta-analysis, which analysed 16,000 articles in this field, identified twelve core aspects but did not find substantial research addressing this particular gap [1].

The challenge is ensuring ubiquity, interoperability, security and timely access to the correct information anywhere. Current systems, e.g., EPIC© and CERNER©, are all siloed in their approach to information dissemination. Notably, there is no global consensus or standards for data sharing or migration with the patients. PHR access now changes with the increased need for national alignment, global accessibility and communication [26].

Here we investigate the answers, regarding GPOC, of the key opinion leaders of all the 193 United Nations (UN) member states, 2 UN observer states (Holy See & Palestine) and 1 de facto UN non-member state (Taiwan) with additional input from 18 top-ranked, international organisations.

Results

GPOC survey

We received 100% replies from 193 UN member states, 2 UN observer states (Holy See & Palestine) and the 1 de facto UN non-member state (Taiwan). We also received 100% replies from 18 top-ranked, large, international, governmental, and non-governmental organisations with a total of 214 entities. The survey yielded responses from 267 individual respondents, which were then analysed. Among these responses, 55 (20%) originated from entities that submitted multiple surveys, reflecting instances where more than one key opinion member within those entities completed the survey separately. This occurred in cases where countries or organisations submitted two, three, or even up to five surveys. Importantly, no individual respondent submitted duplicate responses; each survey was completed by a unique person. We meticulously accounted for this scenario in our analysis to ensure accurate weighting of responses.

The breakdown of respondents per entity is provided in (S2), which offers transparency regarding response distribution. Weighting was applied to ensure fairness, accounting for multiple responses from certain entities.

We identified twelve major domains of demographics, correctness and privacy, the use of records by companies, the use of the records for medical and non-medical research, the concept of co-ownership itself, data sharing, movement of the record, (de)centralisation of ownership, rights of patients, protection of the environment and creation of a foundation, see Figs. 1 and 2. For all responses and statistical comparisons see (S2), Tables 1–4.

This Fig. 1 shows the distribution of survey responses categorized into agreement, neutrality, and disagreement for 36 out of 38 survey queries (excluding Q #1 and Q #25 due to their free text and multiple-choice formats, respectively). The maximum response rate observed was 96% for agreement (mean 52%, ± SD 30.5%, CI 43.2–60.2, $p=0.04$), 40% for neutrality (mean 17%, ± SD 9.5%, CI 14–60%, $p=0.04$), and 93% for disagreement (mean 31%, ± SD 29%, CI 23–40%, $p=0.05$). The data were

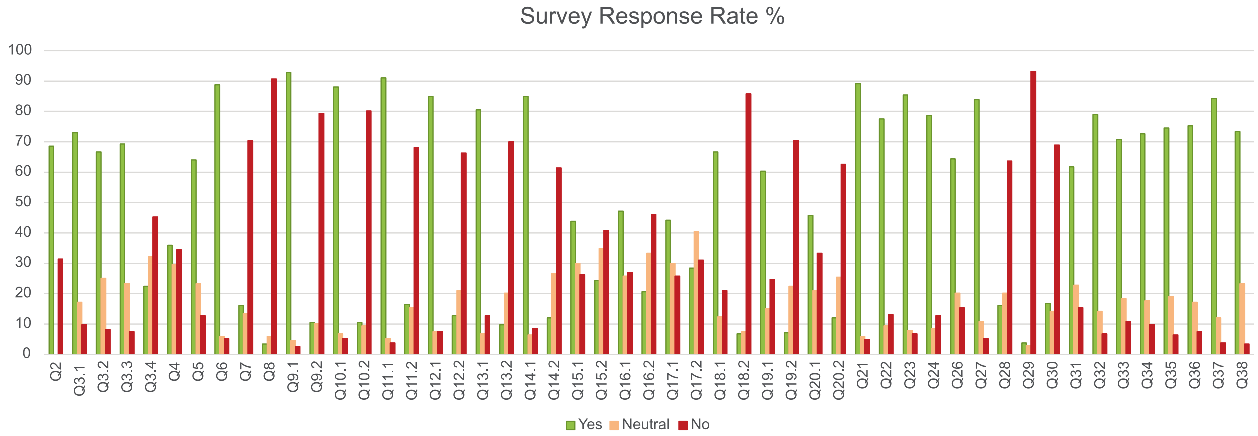
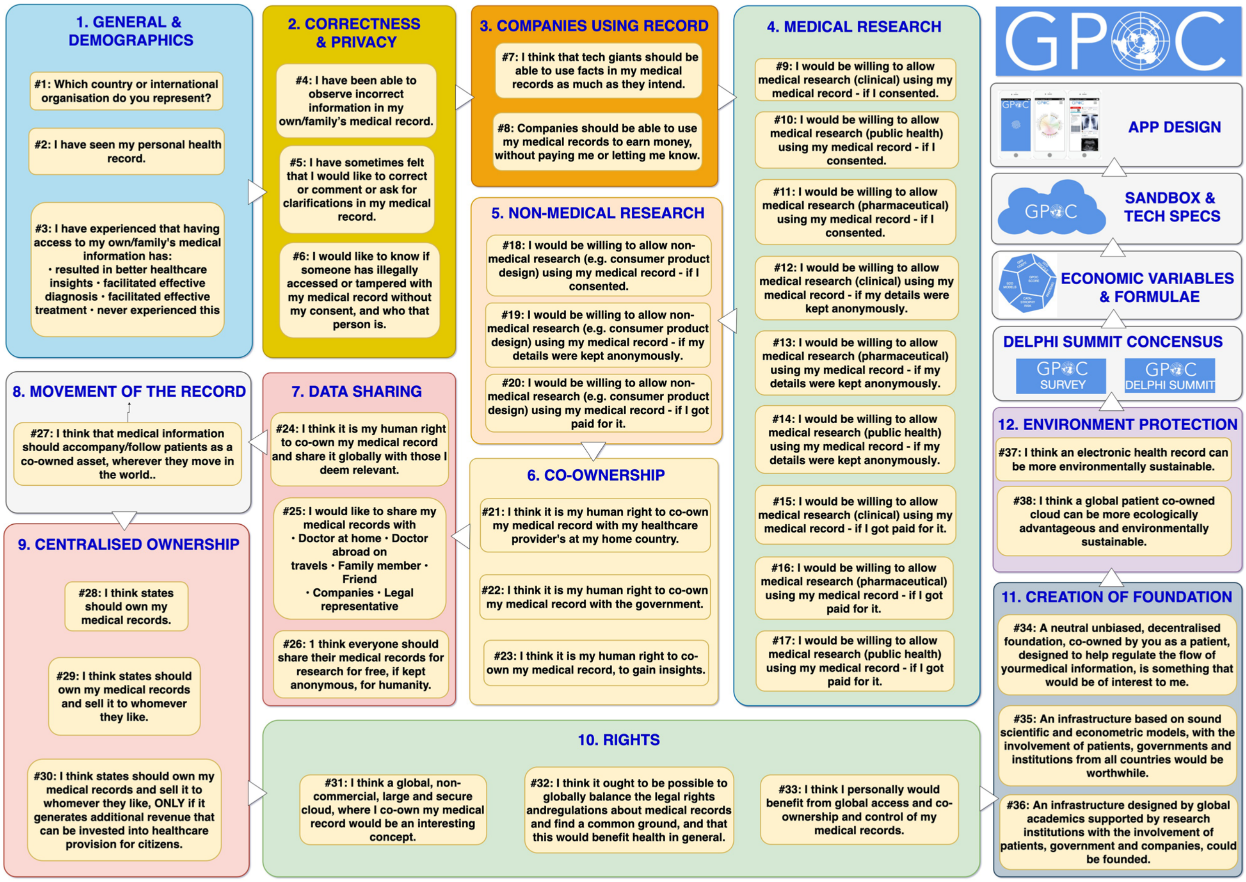


Fig. 1 Survey response distribution analysis: agreement, neutrality, and disagreement



1. GENERAL & DEMOGRAPHICS

#1: Which country or international organisation do you represent?

#2: I have seen my personal health record.

#3: I have experienced that having access to my own/family's medical information has: • resulted in better healthcare insights • facilitated effective diagnosis • facilitated effective treatment • never experienced this

2. CORRECTNESS & PRIVACY

#4: I have been able to observe incorrect information in my own/family's medical record.

#5: I have sometimes felt that I would like to correct or comment or ask for clarifications in my medical record.

#6: I would like to know if someone has illegally accessed or tampered with my medical record without my consent, and who that person is.

3. COMPANIES USING RECORD

#7: I think that tech giants should be able to use facts in my medical records as much as they intend.

#8: Companies should be able to use my medical records to earn money, without paying me or letting me know.

4. MEDICAL RESEARCH

#9: I would be willing to allow medical research (clinical) using my medical record - if I consented.

#10: I would be willing to allow medical research (public health) using my medical record - if I consented.

#11: I would be willing to allow medical research (pharmaceutical) using my medical record - if I consented.

#12: I would be willing to allow medical research (clinical) using my medical record - if my details were kept anonymously.

#13: I would be willing to allow medical research (pharmaceutical) using my medical record - if my details were kept anonymously.

#14: I would be willing to allow medical research (public health) using my medical record - if my details were kept anonymously.

#15: I would be willing to allow medical research (clinical) using my medical record - if I got paid for it.

#16: I would be willing to allow medical research (pharmaceutical) using my medical record - if I got paid for it.

#17: I would be willing to allow medical research (public health) using my medical record - if I got paid for it.

5. NON-MEDICAL RESEARCH

#18: I would be willing to allow non-medical research (e.g. consumer product design) using my medical record - if I consented.

#19: I would be willing to allow non-medical research (e.g. consumer product design) using my medical record - if my details were kept anonymously.

#20: I would be willing to allow non-medical research (e.g. consumer product design) using my medical record - if I got paid for it.

6. CO-OWNERSHIP

#21: I think it is my human right to co-own my medical record with my healthcare provider's at my home country.

#22: I think it is my human right to co-own my medical record with the government.

#23: I think it is my human right to co-own my medical record, to gain insights.

7. DATA SHARING

#24: I think it is my human right to co-own my medical record and share it globally with those I deem relevant.

#25: I would like to share my medical records with • Doctor at home • Doctor abroad on travels • Family member • Friend • Companies • Legal representative

#26: 1 think everyone should share their medical records for research for free, if kept anonymous, for humanity.

8. MOVEMENT OF THE RECORD

#27: I think that medical information should accompany/follow patients as a co-owned asset, wherever they move in the world..

9. CENTRALISED OWNERSHIP

#28: I think states should own my medical records.

#29: I think states should own my medical records and sell it to whomever they like.

#30: I think states should own my medical records and sell it to whomever they like, ONLY if it generates additional revenue that can be invested into healthcare provision for citizens.

10. RIGHTS

#31: I think a global, non-commercial, large and secure cloud, where I co-own my medical record would be an interesting concept.

#32: I think it ought to be possible to globally balance the legal rights andregulations about medical records and find a common ground, and that this would benefit health in general.

#33: I think I personally would benefit from global access and co-ownership and control of my medical records.

11. CREATION OF FOUNDATION

#34: A neutral unbiased, decentralised foundation, co-owned by you as a patient, designed to help regulate the flow of yourmedical information, is something that would be of interest to me.

#35: An infrastructure based on sound scientific and econometric models, with the involvement of patients, governments and institutions from all countries would be worthwhile.

#36: An infrastructure designed by global academics supported by research institutions with the involvement of patients, government and companies, could be founded.

12. ENVIRONMENT PROTECTION

#37: I think an electronic health record can be more environmentally sustainable.

#38: I think a global patient co-owned cloud can be more ecologically advantageous and environmentally sustainable.

Fig. 2 GPOC survey structure: facets and sequence of questions

analysed using R squared generalised linear regression, yielding an R squared value of 1 and an RMSE of 0.0058 (RMSE = Root Means Squared Error, ± SD = Standard Deviation, CI = Confidence Interval). In summary, the survey indicates high agreement on support for co-ownership (89%) and movement of personal health records (84%). Notable disagreement was observed regarding centralised ownership by the state (64%) and data sharing without consent (85%). These findings highlight the respondents' preferences for decentralised control and consent in managing personal health records, as well as their concerns about state control and privacy.

Additional descriptive statistics can be found in (S2), (Tab: GPOC NEC Fig. 1). All Source Data are available in the article repository on Figshare, https://doi.org/10.6084/m9.figshare.c.7067720.

This Fig. 2 illustrates the sequence of the 38 survey questions presented to 214 entities, categorized into 12 core facets that serve as the foundation for all components of the GPOC Series. These predetermined categories are displayed in chronological order within the survey structure. The main findings indicate a structured approach to capturing comprehensive data across various aspects of the GPOC Series, ensuring thorough coverage and consistency in the responses. In the results, questions Q#1–38 are distributed over paragraphs 1–12, corresponding to the twelve facets. The statistical results for this survey can be found in (S2), Tab 1 ($p < 0.05$), while the original GPOC Survey is available in (S3) for reference, and detailed results are provided in (S4). All Source Data are accessible in the article repository on Figshare, https://doi.org/10.6084/m9.figshare.c.7067720.

1: General & demographics (survey query #1 (Q #1))

A majority (73%) agreed that having access to their own/their family's health records had resulted in better healthcare insights, with two thirds (67%) agreeing that it facilitated effective diagnosis. Additionally, 7 out of 10 (69%) agreed that this facilitated effective treatment and only 22% stated that they had never had access to their health records. When asked whether their experience resulted in better healthcare insights, 17% of respondents gave a neutral answer, 8% stated it facilitated effective diagnosis, 23% experienced more effective treatment and one third (33%) had no experience. Based on the proportional results in other parts of the GPOC-series we assume that the gender balance of the GPOC Survey was approximately 50:50 [3, 4].

2: Correctness & privacy (Q #2–6)

Approximately one-third (36%) of the key opinion leaders, who were asked if they had observed incorrect information in their own/their family's medical records, experienced this. Two thirds (65%) answered that they felt they would want to correct, comment or ask for clarification in their records. The need to be informed about non-consensual illegal access and tampering was considered important by 9 out of 10 of the respondents (89%) with 5% expressing no concern and 6% being neutral about this.

3: Companies using a personal health record (Q #7–8)

A majority (70%) of respondents stated that they would not want companies and tech giants to use their health records without consent. Furthermore, nine out of ten (90%) respondents did not want companies to use their medical records to earn money, without financial compensation.

4: Medical research (Q #9–17)

A majority (93%) expressed that they would consent to the use of their health records for clinical medical research, 88% for public health medical research and 91% for pharmaceutical medical research. Anonymity was preferred in clinical research by 85% of respondents, 81% for pharmaceutical research and 85% for public health.

Regarding the financial incentives for the use of their individual health records in clinical, pharmaceutical and public health research settings, agreements were observed for 44%, 47%, and 47% respectively.

5: Non-medical research (Q #18–20)

Regarding the use of the PHR data for non-medical research, such as consumer product design which could have a social impact on patient wellbeing, two thirds (66%) agreed with non-medical research with their consent. However, six out of seven (85%) disagreed with this research if it would not require their consent.

6: Co-ownership (Q #21–24)

Regarding the concept of co-ownership, a majority nine out of 10 (89%) thought it was their human right to co-own their medical records with their healthcare provider in their home country with only 4.9% disagreeing over co-ownership. A majority (78%) agreed that co-ownership should be with the government, and 85% of the respondents agreed that it was their right to co-own their records for them to independently gain insights. The highest percentage that disagreed was 13% against co-ownership with the government.

7: Co-ownership related data sharing (Q #25–26)

A total of 79% of the respondents agreed on the ability of users to choose with whom their co-owned data should be shared. In terms of who the respondents would like to share their medical records with, a doctor in their home country (49%) or a doctor abroad (29%) were the most popular responses, followed by a family member (16%) or a legally appointed representative (5%). The concept of sharing data for research that would benefit humanity without any monetary incentive, provided that anonymity would be maintained, was preferred by 64% of the respondents, and 15% were against this notion.

8: Movement of the personal health record (Q #27)

The ability to move a medical record so that it accompanies the patient as a co-owned asset wherever they move in the world or if the individual becomes displaced as a refugee reached 84% agreement. This was the crown statement of the survey, and only 3% disagreed.

9: Centralised ownership (Q #28)

A majority (64%) disagreed with centralised ownership of medical records by the state, 20% were neutral and only 16% agreed with state ownership of health records. Regarding the state owning the record and selling the data to whomever they liked, 93% disagreed on this subject, and only 3.8% agreed. Of the respondents 69% disagreed with centralised ownership by a state that would use the patient's records to generate revenue to be reinvested for the benefit of citizens. In contrast, only 17% expressed agreement with state-owned health records and the state's ability to sell patient data to generate added revenue for reinvestment in healthcare provision.

10: Rights (Q #29–30)

The concept of a global, non-commercial, large and secure cloud that offered them the ability to co-own their medical records would be an interesting concept to which a 62% majority agreed. However, circa 1 in 7 (15%) were opposed to this concept. Notably, four out of five (79%) suggested that it would be possible to globally balance the legal rights and regulations about medical records and find a common ground to benefit health in general. A minority of respondents, 1 in 15 (6.7%) disagreed with the concept of a non-commercial GPOC. Finally, a majority of 71% answered that they would personally benefit from global access and co-ownership of their medical records with 11% disagreeing with this specific question. Notably there was no difference between the forms of government.

11: Creation of a foundation (Q #31–36)

To facilitate the regulation of such a global patient co-owned cloud, a three-fourths (73%) agreed that they would prefer a neutral, unbiased, decentralised foundation, co-owned by patients designed to help regulate the flow of medical information. Furthermore, a majority (75%) also agreed that the infrastructure needed to achieve such a global patient co-owned cloud for medical records needs to be based on sound scientific and economic models, with the involvement of patients, governments and institutions from across the world. A majority, three out of four (75%) agreed that the design of the infrastructure could be achieved under the auspices of global academics supported by research institutions with the involvement of patients, governments and companies. Moreover, in a summit the foundation alternative was discussed [3].

12: Protection of the environment (Q #37–38)

A majority (84%) agreed that electronic health records must be environmentally sustainable, and three of four (73%) agreed that a GPOC can be ecologically advantageous.

Regarding gender balance the GPOC interview series has an exact 50% gender balance [4], and the GPOC Summit also precisely mirrors the GPOC Survey [3].

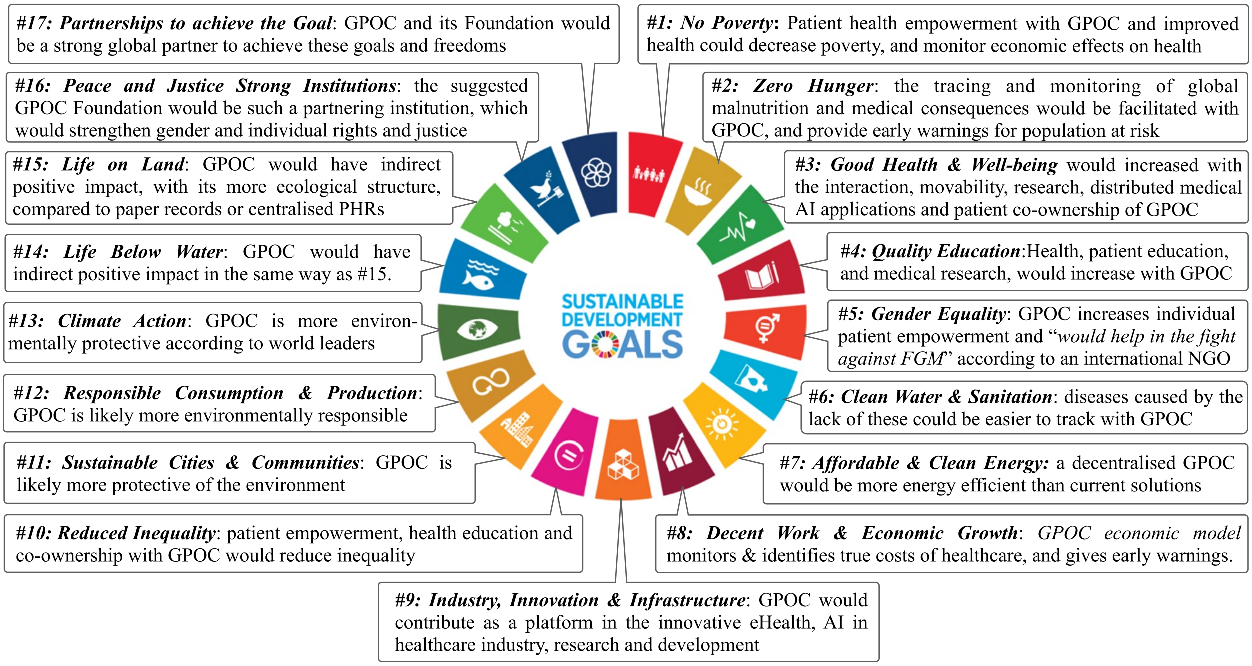
For a detailed presentation of the results, please see (S1-S2).

Discussion

The findings from the GPOC Survey highlight significant support for patient-centric care and the empowerment of individuals to access their own medical records. Clear majorities among leaders worldwide, ranging from two-thirds to more than 90%, expressed consensus across all twelve measured core facets. The high response rate from 100% of the ministries and leaders of the 196 states and 18 organisations underscores the importance of these results. The GPOC Survey is supported by a systematic review and meta-analysis for GPOC modelling for future research on an ideal cloud-based solution [1].

In line with the 2030 Agenda for UN Sustainable Development Goals (SDGs) and its aims for global partnership, a Global Patient co-Owned Cloud (GPOC) could have significant implications for multiple SDGs (see Fig. 3). Our survey revealed that close to six out of seven respondents (84%) believe that a GPOC could identify the true costs of healthcare, contribute to economic growth (SDG #8), and provide early warnings. Additionally, a majority of respondents recognised the environmental benefits associated with implementing a GPOC.

No global health communication platform currently exists. It would need to ensure privacy and consent. During the recent COVID-19-pandemic, the design of a



#17: Partnerships to achieve the Goal: GPOC and its Foundation would be a strong global partner to achieve these goals and freedoms

#1: No Poverty: Patient health empowerment with GPOC and improved health could decrease poverty, and monitor economic effects on health

#16: Peace and Justice Strong Institutions: the suggested GPOC Foundation would be such a partnering institution, which would strengthen gender and individual rights and justice

#2: Zero Hunger: the tracing and monitoring of global malnutrition and medical consequences would be facilitated with GPOC, and provide early warnings for population at risk

#15: Life on Land: GPOC would have indirect positive impact, with its more ecological structure, compared to paper records or centralised PHRs

#3: Good Health & Well-being would increased with the interaction, movability, research, distributed medical AI applications and patient co-ownership of GPOC

#14: Life Below Water: GPOC would have indirect positive impact in the same way as #15.

#4: Quality Education:Health, patient education, and medical research, would increase with GPOC

#13: Climate Action: GPOC is more environmentally protective according to world leaders

#5: Gender Equality: GPOC increases individual patient empowerment and "*would help in the fight against FGM*" according to an international NGO

#12: Responsible Consumption & Production: GPOC is likely more environmentally responsible

#6: Clean Water & Sanitation: diseases caused by the lack of these could be easier to track with GPOC

#11: Sustainable Cities & Communities: GPOC is likely more protective of the environment

#7: Affordable & Clean Energy: a decentralised GPOC would be more energy efficient than current solutions

#10: Reduced Inequality: patient empowerment, health education and co-ownership with GPOC would reduce inequality

#8: Decent Work & Economic Growth: *GPOC economic model* monitors & identifies true costs of healthcare, and gives early warnings.

#9: Industry, Innovation & Infrastructure: GPOC would contribute as a platform in the innovative eHealth, AI in healthcare industry, research and development

Fig. 3 Impact of a GPOC on sustainable development goals (SDGs) global monitoring platform, achievable in a centralised or decentralised way was discussed [27].

Centralised systems can neither adapt to the globalisation of vast volumes of siloed patient information, nor support global PHR data volumes. Hence, the optimal use of decentralised PHRs could help prevent global health information decohesion and have a major impact on global health [11]. GPOCs could therefore facilitate better health (SDG #3) on multiple levels. These range from improved pandemic tracking, global health platforms, overviews, medical research, patient empowerment, interaction and education. GPOC would also impact innovation (SDG #9) with AI, eHealth, and research. It may enable epidemiological monitoring of pandemics and malnutrition (SDG #2) and give health empowerment to fulfil the goal of no poverty (SGD #1).

This figure demonstrates the potential impact of a Global Patient Co-Owned Cloud (GPOC) on the facets of the 17 United Nations Sustainable Development Goals (SDGs). GPOC has the capability to directly or indirectly influence most SDGs, highlighting its potential role in advancing global health, education, and environmental sustainability. The analysis shows significant intersections where the GPOC could contribute to achieving these goals, underscoring its relevance in global health policy. All Source Data for this analysis are accessible in the article repository on Figshare, https://doi.org/10.6084/m9.figshare.c.7067720.

According to the survey three out of four respondents agreed that having access to their own/their family's medical information would have resulted in better healthcare insights. Moreover, the majority deemed it their human right to co-own their medical records, to gain insight. Notably, participants were willing to share their PHRs for research, if they were paid for it. Here it is worth noting that all the survey statements were first person singular. Separate legislation for leaders and people is hence hard to motivate. Possibly GPOC may also improve health education in the population. (SDG #4) and improved healthcare (SDG #3).

The current PHRs are expensive and non-interactive, and studies have highlighted their poor design, which can cause health worker burnout. A well designed PHR should be simple, to allow users to manage and share data. Others further note that sharing can be to family [17, 24–26, 28–31] and friends [9, 32] and to a professional [20, 32–34] researcher [34], pharmacist [34], or insurance company [33, 34]. As we identified in our survey, half of the respondents advocated for sharing with doctors in their home country, doctors or healthcare providers abroad when travelling (30%).

Economically, the main cloud companies are considered to be generating significant profits without incentivising patients for the use of their datasets. PHRs outsourced to third-party cloud service providers can cause severe security issues and increase the risk of malicious usage and leaks [35]. Clearly, concerns surface in relation to reports on the pseudo-consent given by patients for their data. This might lead to the psychological profiling of patients thereby influencing patient purchasing habits. Fairly surprisingly, publicly available non-PHR data, can now also be used to profile and gain healthcare insights through artificial intelligence, prompting policymakers to consider regulation [36]. A GPOC would eliminate some of these issues, foster an evidence-based approach and allow us to study the economic impacts of data-driven information co-ownership. The survey revealed that a clear majority (73%) preferred the described GPOC Foundation and that 75% agreed with the suggested GPOC structure. We further explored the creation of a GPOC Foundation as a consensus solution. Furthermore, delegates at the GPOC Summit discussed the ethics and legality of information misuse without any compensation to the patient [3].

To date, no current regulatory, consensus systems exist to provide an effective patient inclusive global platform. We show that it is possible to create a GPOC model and that a majority of nations, and major international health organisations, support its development. A GPOC foundation has never been considered and cannot be traced anywhere in the scientific literature. We have further explored the ethical and regulatory requirements for a GPOC, and we have suggested that patient co-ownership of health data could be considered a new human right [4].

In the survey, 89% of respondents regarded it to be a human right to co-own their PHR with their healthcare provider, with less than 5% disagreeing, and 78% agreed that co-ownership should be with the government. However, disagreement with government involvement in the co-ownership concept peaked at of 13%. In addition, 85% indicated that their human right to PHR co-ownership stemmed purely from their ability to gain insights. Since there seems to be a consensus among opinion leaders worldwide to consider the patients' co-ownership of their health data as a new human right, will this affect the UN charter, i.e., will we have a new human right entity?

While initial resistance from health professionals against patient empowerment has been documented [10], the overarching trend towards transparency, access, and patient-centred care continues to shape the evolution of medical information management.

New technologies are now available for all to support clinical decision making with the patient's involvement [37]. With these technologies and AI-empowered PHRs, we enter an era of deep medicine, making healthcare more human [21].

PHRs are legally binding medical documents. It is the clinician's responsibility to ensure the accurate documentation of findings to safeguard practice, allow continuity and reduce litigation. New interaction scenarios emerge. Who becomes responsible if there is a data breach or when new information is updated, is it the doctor or the patient? Who amends any errors in the record and how is this reviewed, and how is probity facilitated to avoid legal repercussions? Currently, a novel approach is not accepted by most healthcare systems. However, data protection regulations with other ethico-legal challenges and practical considerations provide many compelling arguments for considering new PHR models for health data management.

A clear nine out of ten majority wished to know details about security breaches, including the identity of the intruder. Three-fourths of the respondents indicated that PHR access affected their healthcare in a positive direction, with increased insights. Since the state's opinion leaders have these clear ideas about security, rights and access, this might affect legislation in the foreseeable future.

Most participants, 70%, did not wish for companies to use their PHRs freely, without them being asked to give consent. There was very strong resistance, at 91%, to letting companies earn money on PHRs. Hence, this resistance may be mirrored in future regulations.

A majority wished to contribute to medical research, if it were anonymous (85%), if they consented (93%) and if they were paid for it—for instance 47% wanted payment to participate, and 41% disagreed. To a lesser extent than for medical research, the participants were willing to contribute to non-medical research, if it were anonymous (60%), if they consented (67%) and if they would be paid (46%). The difference for non-medical research is more pronounced. When asked about non-medical research without their consent, 85% disagreed, 70% disagreed with this research if their details were not kept anonymous and 61% disagreed with this research if they were not paid. Therefore, it may be anticipated that this will be reflected in future patients' rights and regulations on reimbursement for the use of patients' PHR contents. Maybe we will see a microflow of payment to patients when PHRs are used for research?

A global patient co-owned and interconnected cloud would facilitate a large research substrate. The GPOC survey has shown the willingness to participate, share and get paid for such research. Moreover, the willingness to share data with family, professionals, friends and healthcare providers has also been demonstrated. There is now a new online service paradigm that permits its users to share their health data [36]. Modern PHR software allows patients or caregivers to exchange or share their health data with others, e.g., other patients or healthcare professionals. The suggested co-ownership would also give the patient the right to migrate with the PHR contents and share it with those deemed relevant. Especially in zones where people are displaced or are travelling globally, there is a need to facilitate the cross-border movement of the PHR.

To exemplify with a hypothetical scenario: during the COVID-19 pandemic, GPOC could have facilitated rapid and secure exchange of patient health data across borders, enabling timely coordination of healthcare responses and resource allocation. In the GPOC Summit article these topics and scenarios were further discussed [3].

The currently siloed healthcare data limit the development of large pipelines for global AI for health. If patients can appropriately opt in and consent to sharing their PHR content for insight discovery and be compensated for it [12], it would be more in line with a GPOC concept. Increased patient involvement might have impacted the fact that now 20% of patients report finding a mistake in their PHRs, where 40% of these were regarded as serious errors [38].

Lastly, the exponentially growing internet energy consumption is predicted to reach over half of the world's energy output in the early 2030s, The vast amount of data in a global PHR cloud will be a large contributor, as was evidenced by the World Health Organisation (WHO) Third Global Survey on eHealth in 2015 (GOE_Q144) [7].

The GPOC concept can also be seen in a wider perspective of scientific complexity [39]. The fact that the physical conditions now allow for a technical realisation of a GPOC allow for a new field of 'social physics' [40].

Ethical challenges

The implementation of GPOC raises critical ethical issues concerning data privacy, ownership, and transparency. These include regulating patient co-ownership, integrating AI ethically, and ensuring robust privacy protections. Addressing these concerns, GPOC utilises advanced technologies like blockchain and fully homomorphic encryption to secure patient data while promoting transparency through its co-ownership model. For a comprehensive exploration of the vast field of ethical dimensions and the global lattice of regulation and guidelines, we refer to the GPOC Ethics article, dedicated to these issues [4].

Limitations

While this study aimed to investigate the perspectives of global health ministries on the necessity and potential benefits of a Global Patient co-Owned Cloud (GPOC), several limitations should be acknowledged.

First, the study focused exclusively on obtaining insights from health ministries and relevant organisations. While this approach ensures engagement with key decision-makers who have the authority to enact change, it may not fully capture the diverse perspectives of the general population. However, this targeted approach was intentional, aiming to prioritise the voices of stakeholders with the power to implement systemic changes in healthcare.

Second, while the survey achieved a remarkable 100% response rate from all 193 UN member states and 18 major health organisations, it is important to recognise that this sample may not represent the entirety of global viewpoints. The survey reached these entities through various channels, including diplomatic contacts, cabinet advisors, and UN channels. This unprecedented level of engagement underscores the significance of the findings within the political and policy realms.

Furthermore, the decision to allow health ministry representatives to respond to the survey using "I" statements was deliberate. By framing the questions in this manner, the intention was to encourage respondents to empathise with the perspective of patients and consider the implications of healthcare policies for individual experiences. While this approach may have deviated from traditional survey methods, it aimed to bridge the gap between policy-makers and patient-centred care.

This survey represents one facet of a complex landscape, and further research exploring the perspectives of broader populations may be warranted in the future. However, for the purposes of this study, the focus on health ministries and related entities provided valuable insights into the attitudes and considerations of key decision-makers in shaping the future of healthcare.

While this article primarily addresses the necessity and potential benefits of a GPOC, it is important to note that other aspects, such as ethical, regulatory, feasibility, technical, policy, and security considerations, were explored in separate articles within the GPOC series. Here we discuss how GPOC can be implemented globally in a way that is accessible equitably. Interested readers are encouraged to refer to these related works for a more comprehensive understanding of the GPOC concept.

Final remarks

In conclusion, the GPOC Survey highlights the need for a global PHR platform, with co-ownership and patient independence and involvement in managing their health. This could benefit many conditions and medical research and make the PHR globally accessible. Here, we show that it is feasible to bring together key opinion leaders to discuss data management for patients, clinicians, and organisations, highlighting the need for continuous scientific study. Doing so can reduce information silos, allow consent for data sharing and support data-driven evidence-based patient management. Moreover, ethical data acquisition based on the GPOC can unveil the full potential for precision medicine and help to eventually democratise healthcare for those in underprivileged economies in line with the UN SDGs. The GPOC model would become an important contribution to individual freedom and would place personal health information science front and centre of the world health agenda. The overall vision is that a distributed decentralised international patient co-owned and controlled cloud will facilitate the construction of a borderless data platform to support ethically sound, evidence-based practice. Thus, patients around the globe could be educated, engaged and take control of their health destinies and identities through co-ownership. The GPOC concept might have an impact on research, the development of artificial intelligence for healthcare, patient empowerment and global health.

Methods

Ethical approval for the survey was obtained from the Imperial College London University Research Ethics Committee. The survey questionnaire was developed using Microsoft Forms (Microsoft, Redmond, Washington, United States, 2022). Prior to distribution, all participants provided informed consent in accordance with the guidelines outlined in the Nature Portfolio participant release form. A written consent declaration can be found in (S5).

To ensure broad participation and representation, a multipronged approach was employed for respondent recruitment. Initially, all the target entities were identified, and four thousand emails were dispatched to diplomatic offices, representatives, and ministries of health worldwide. Then when solid contacts were established the most relevant target body was invited. Often this entailed prolonged contact via email, LinkedIn and WhatsApp messaging and phone calls. The questionnaire, consisting of thirty-eight questions presented with a 5-point Likert scale response format, was distributed via email to all 193 (+3) ministries of health, embassies, and relevant United Nations entities.

The survey, encompassing 38 questions was designed to measure all the twelve aspects, originally measured in the systematic review and meta-analysis article, and mirrored in the ethics review and interview series article, as well as in the summit article. For further details, refer to these articles separately.

Our original intention was to investigate the opinions of world leaders, i.e., the people with the power to change the world scene in this area. Hence, we deemed that the focus of the present should be the health ministries of the world, i.e., their ministers, advisors and affiliated relevant key opinion leaders.

All questions were strategically selected to delineate the central themes of the survey and gauge respondents' perspectives on the concept of a GPOC. Thus, we strived to arrange the questions thematically and list them with their intrinsic relations and associations. Thus, we also identified a possible crown question, identified as Question 27, around which several other cardinal questions were arranged. This was done to stratify the responders' interpretations of the concept.

For a comprehensive overview of the survey questions, including their formulation and structure, please refer to (S1) showing the rational of the survey structure, (S2) the GPOC table with statical analyses, (S3) the GPOC original survey as it appeared to the participants, (S4) the GPOC Survey results in detail.

Limitations and representation

The survey received responses from all 193 United Nations member states and three de facto or de jure independent states, along with contributions from eighteen international organisations crucial to global health. However, despite the method managing to secure responses from all nations, there may be a bias towards responses from administrative capitals and potential underrepresentation from subnational regions. The survey method prioritised engagement with health ministries, and formal invitations were sent to intended recipients through multiple communication channels as described earlier. However, identifying the exact representative within each ministry was not always possible. While responses often came from health ministers directly, in other instances, they were provided by delegated individuals such as cabinet advisors or senior administrators. It is important to note a demographic bias towards societal elites, including those with significant influence, economic power, and social status. Nevertheless, targeting this group was deliberate as they possess the authority to effect change and represent their respective nations or organisations effectively.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s44247-024-00133-5.

Supplementary Material 1: Table 1. Statistical Analysis and Indicators of the Global Patient co-Owned Cloud (GPOC) Survey. Table 1 presents the statistical analysis and indicators derived from the Global Patient co-Owned Cloud (GPOC) survey, comprising 38 questions. The table includes three groups of columns: 'Mixed,' 'Country Based analysis,' and 'Organisation Based analysis.' In the 'Mixed' group, statistical measures such as the number of observations (Obs), parameters (Parms), Root Mean Dquare Error (RMSE), R-squared value (R-sq), F-statistic (F), and *p*-value (P) are provided. For the 'Country Based analysis' and 'Organisation Based analysis' groups, the statistical measures include RMSE, R-squared value, F-statistic, and *p*-value. Additionally, the table includes calculations for 11 indicators related to health expenditure, population, migration, and GDP. These indicators supplement the analysis and provide valuable context for understanding the survey results. They are not the primary focus of this article but contribute to the comprehensive analysis of the GPOC survey data. (S2).

Supplementary Material 2: Table 2. Illustration of Survey Responses. Table 2 provides an overview of survey responses collected for each question (Q1-Q38). The leftmost column (A) lists the questions, while column B ("Variables") presents the exact survey questions in chronological order. Columns C to E display the number of "YES" responses, with column C showing the count (n), column D showing the percentage (%), and column E showing the cumulative percentage. Similarly, columns F to H represent "NEUTRAL" responses, and columns I to K represent "NO" responses. (S2).

Supplementary Material 3: Table 3. GPOC Survey Details and Regression Analysis Using R. This table presents detailed survey responses and regression analysis using the statistical software R. The leftmost column (Column A) contains grouped survey questions, while Column B includes 8 indicators (Ind1-Ind8) along with a constant (_cons) at the end. The analysis focuses on the preparedness or willingness of countries and organisations to adapt to a GPOC concept, calculated as the GPOC coefficient. The remaining columns (Columns C to K) display the regression analysis results for the mixed group of countries and organisations. These include coefficients (D), standard errors (E), t-values (F), *p*-values (G), and 95% confidence intervals (H to K). The constant (_cons) represents the intercept term in the regression equation. It indicates the baseline level of the dependent variable when all independent variables are zero. While this table provides additional insights for the general overview, it extends beyond the scope of the current article. More detailed calculations, including those presented in GPOC ECO Tables 1-2, are part of an econometric article and are referenced here for context. (S2).

Supplementary Material 4: Table 4. Illustration of the Survey Clusters. This table offers an illustration of the variable clusters derived from the GPOC survey responses. Each cluster represents a thematic grouping of survey questions covering various aspects related to the Global Patient co-Owned Cloud (GPOC) concept. Column A (Variable Clusters) describes the twelve thematic clusters, including General and Demographic, Privacy, Companies using records, Medical Research, Non-Medical Research, Co-Ownership, Data Sharing, Movement of the record, Centralized ownership, Rights, Creation of a Foundation, and Protection of Environment. Column B lists the 38 survey questions in chronological order, grouped according to their respective clusters. Columns C-E provide the percentage distribution of YES, NEUTRAL, and NO responses for each survey question within its corresponding cluster. The rightmost part of the table contains visual representations or summaries of each cluster's characteristics. (S2).

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Authors' contributions

Niklas Lidströmer (NL) conceived the background research, idea and concept. NL and Joseph Davids (JD) designed the survey structure and questions. NL researched and conducted all necessary global networking. NL managed all diplomatic channels, and ministerial key connections. NL performed data collection and harvested survey results. NL and JD performed the data analysis. NL assembled and structured the source data for the analysis. All authors (NL, JD, Mohamed ElSharkawy (ME), Hutan Ashrafian (HA), and Eric Herlenius (EH)) contributed to the data interpretation. HA and EH provided critical intellectual input throughout the study. All the authors conducted the statistical analyses and contributed to the interpretation of the results. NL wrote the manuscript with input from all the co-authors. NL made all the revisions of the manuscript with input from EH. All authors critically reviewed and approved the final version of the manuscript. NL created all the figures and the featured article image and assembled all the source data into a repository on Figshare.

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Availability of data and materials

The data generated in this study are provided in the Supplementary Information**.** Source data are provided with this paper. Source data and raw data generated in this study, have been deposited in the article repository on Figshare, https://doi.org/10.6084/m9.figshare.c.7067720.

Data availability

The data generated in this study are provided in the supplementary information. Source data are provided with this paper. Source data and raw data generated in this study, have been deposited in the article repositories. All data are free to use and available on the repository without restrictions, https://doi.org/10.6084/m9.figshare.c.7067720.

Declarations

Ethics approval and consent to participate

Ethical approval for the GPOC Series was obtained from the Imperial College London University Research Ethics Committee, IRAS Project ID 310441. Prior to distribution, all participants provided informed consent in accordance with the guidelines outlined in the Nature Portfolio participant release form. The Human Ethics & Committee Consent Declaration is available as a related article file.

Consent for publication

All participants gave informed consent in writing to appear and be quoted in this publication. Individuals who are showing their human faces in the featured image consented in writing, as shown in the Consent to Publish Declaration & Featured Image Licence Information related article file.

Competing interests

The authors declare no competing interests.

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