A summit on a Global Patient co-Owned Cloud (GPOC)

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Abstract

Background During the last thirty years the world has benefited from the increasing adoption to cloud-based storage of personal health records. The concept of a Global Patient co-Owned Cloud (GPOC) of personal health records is presented in the GPOC Series, which contains a systematic review and meta-analysis, a global survey among 100% of the UN member states and a technical sandbox environment. GPOC contains patient co-ownership of personal health records. The global survey showed a consensus for the realisation of a GPOC.

Methods Here, we present a Delphi styled GPOC Summit. It also contains a final vote, that validates the results of the previous GPOC Survey. Hence, the Summit contains both multiple rounds of discussion and a voting.

Results At the GPOC Summit a unanimous consensus for patient co-ownership of the personal health records was expressed. The majority of participants underlined that GPOC may benefit global health, transfers of the personal health records globally and the dissemination of evidence-based medicine across the globe. The plausible advantages for patients, both refugees and travellers and for developing economies were underlined. GPOC, as a large substrate for global medical artificial intelligence research, was highlighted. There was unanimous positive interest for GPOC. The GPOC Summit agreed on patient co-ownership of personal health records. This collective agreement underscores the potential of GPOC to enhance global health outcomes, facilitate seamless exchange of health data, and advance medical research worldwide.

Conclusions The summit emphasised the potential benefits of GPOC for diverse populations and economies, highlighting its potential role in improving healthcare access and infrastructure. Moving forward, coordination with relevant initiatives could enhance interoperability and standardisation in healthcare data management. In conclusion, the GPOC Summit represents one step towards realising a patient-centric, globally accessible healthcare ecosystem, with possible implications for the development and global adoption of AI-driven healthcare solutions.

Keywords Global patient co-owned cloud, GPOC, Personal health records, Medical ethics, Health policies, Medical regulation, Cloud-based health, Artificial intelligence in medicine, Key opinion leaders, Summit

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Introduction

A few decades ago, the feasibility of a global, cloud-based, trustless, decentralised, multi-stakeholder, co-owned and secure cloud for healthcare was not technically possible.

The concept of a Global Patient co-Owned Cloud (GPOC) encompasses a global and securely blockchain protected, worldwide distributed and patient co-owned platform of personal health records (PHR, ISO/TR 14292:2012). To date, no publications have presented the development of a co-ownership model on a global scale.

The GPOC-Series [1–4] explores this topic, starting with a recently published systematic review and meta-analysis of the core facets of a GPOC [1]. Furthermore, the necessity of the concept was investigated with the GPOC Survey, that showed a global concensus [2]. This is the basis of the technical and mathematical presentation, which emanated in a GPOC Sandbox environment [3]. Moreover, the series contains an additional literature review and interview series of the ethics and policies relevant for a GPOC [4]. For a chronology of the GPOC Series, see Fig. 1.

Here, we present the GPOC Summit. It contains: 1) initial individual interviews with each participant, 2) repeated rounds or sessions of discussion between the delegates when preliminary statements are expressed,

and 3) a final voting procedure. Thus, the Summit emanated in an exit poll confirming the results of the previous GPOC Survey. The latter received answers from all key opinion leaders of 193 + 3 United Nations member states and 18 international organisations relevant for global health.

The summit delegates ($n = 15$) echoed the results of the survey ($n = 214$, of which 196 countries and 18 organisations and a total of $n = 269$ participants) and confirmed a unanimous consensus for its assumed feasibility and necessity and possible global health advantages. The concept was discussed and emanated in a vote on the core of the GPOC concept. This voting was the final step within the Summit. The survey gave exact Likert scale numerals, and the Summit completes with citable statements from the delegates. The free discussion led to analyses of complex subjects. Among others, the alternative of a foundation for a GPOC was discussed and appeared to be an option with delegate consensus.

The summit discussions emanated in a range of expressed possible advantages with a GPOC for global health. The positive impact for travel medicine, vaccine development, catastrophe relief, and displaced refugees was highlighted. The delegates expressed enthusiasm for what a large global GPOC substrate of PHRs could mean
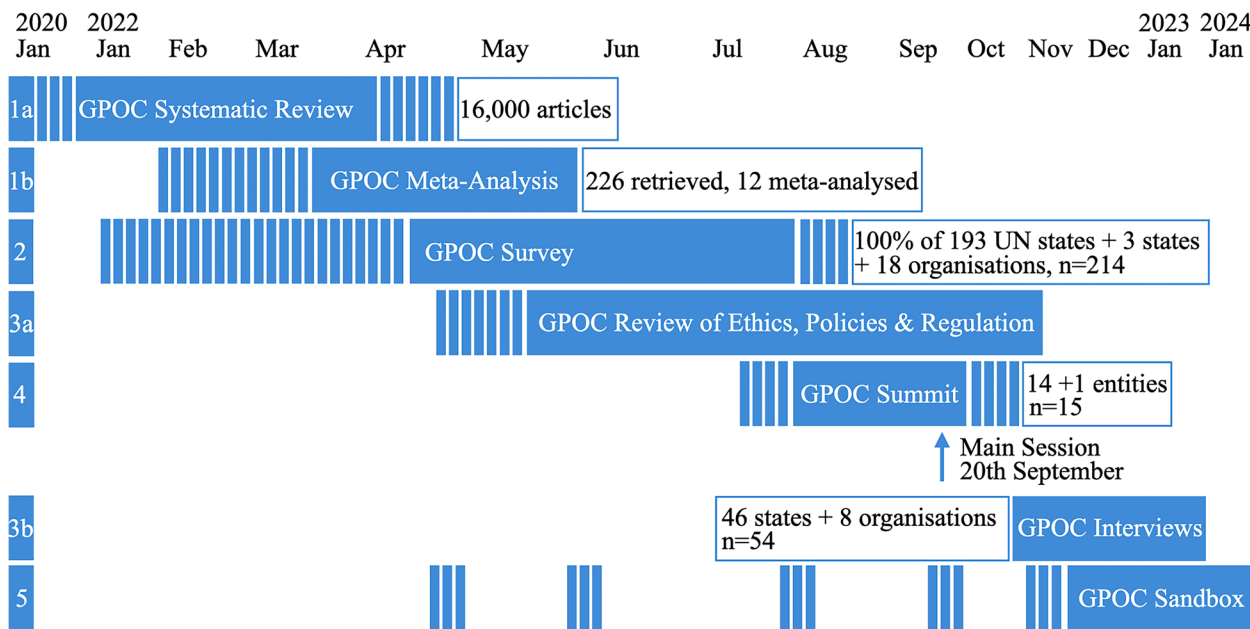
Fig. 1 The Chronology of the GPOC Series. In 2020 the structure of the series' five parts was planned, and the coming studies were conceptualised. The GPOC systematic review and meta-analysis were carried out in the first half of 2022. This study was recently published [1]. The following GPOC Survey required long preparations and networking to successfully invite all entities. The survey was closed in August 2022, with 100% of the 193 UN member states and three other states and 18 organisations participating [2]. From June, data for the review and inquiries on ethics, policies and regulations were assembled in parallel with an interview series [4]. The main session of the GPOC Summit occurred on 20th September 2022. The GPOC Sandbox was finally constructed, based on all the insights from the entire GPOC Series [3]. For details and Source Data, see the respective publications

for both global research and development of artificial intelligence in medicine and for its global dissemination.

Results

Participant characteristics

The fifteen delegates represented their respective countries' health ministries, as in some cases the health ministers and in other affiliated advisors or experts. The participating states were Belize, Brazil, Czechia, Denmark, Finland, Honduras, Kenya, Maldives, Norway, Palestine, Saudi Arabia, Sweden, Taiwan, Tanzania and the EndFGM (International Organisation against Female Genital Mutilation). Notably, the delegates came from countries with different characteristics including democratic, market and personal freedom indices; population size; geographic location; form of government; wealth distribution; crime rates; disease panorama; and many other indicators. However, they could all provide their unique perspectives on the potential of GPOC. Thus, with this spread, it is perhaps even more interesting that the enthusiasm was shared and that a consensus on this subject matter was reached. For a complete list of participating states and organisations in the GPOC Series, see (S1).

At the summit, 8 delegates were women and 7 were men. The Summit participation also mirrored the 50% GPOC Survey gender balance. For the participating states and organisations and the summit place in the GPOC Series context, see Fig. 2.

General feedback scoring

At the GPOC Summit, fifteen delegates with a total of 165 votes participated. For an overview of the results, see Table 1. All the participants responded to all the feedback questions and statements. The first section sought general feedback on the GPOC Survey:

1:1. General feedback on a Likert scale of 1–5 for the quality of the invitation, presentation, and structure of the GPOC Survey in general, with an average of 4.5.

1:2. For specific components, questions, or issues that could have been improved, twelve participants voted for no improvements, two suggested some changes to the question structures and one wished for more answer options.
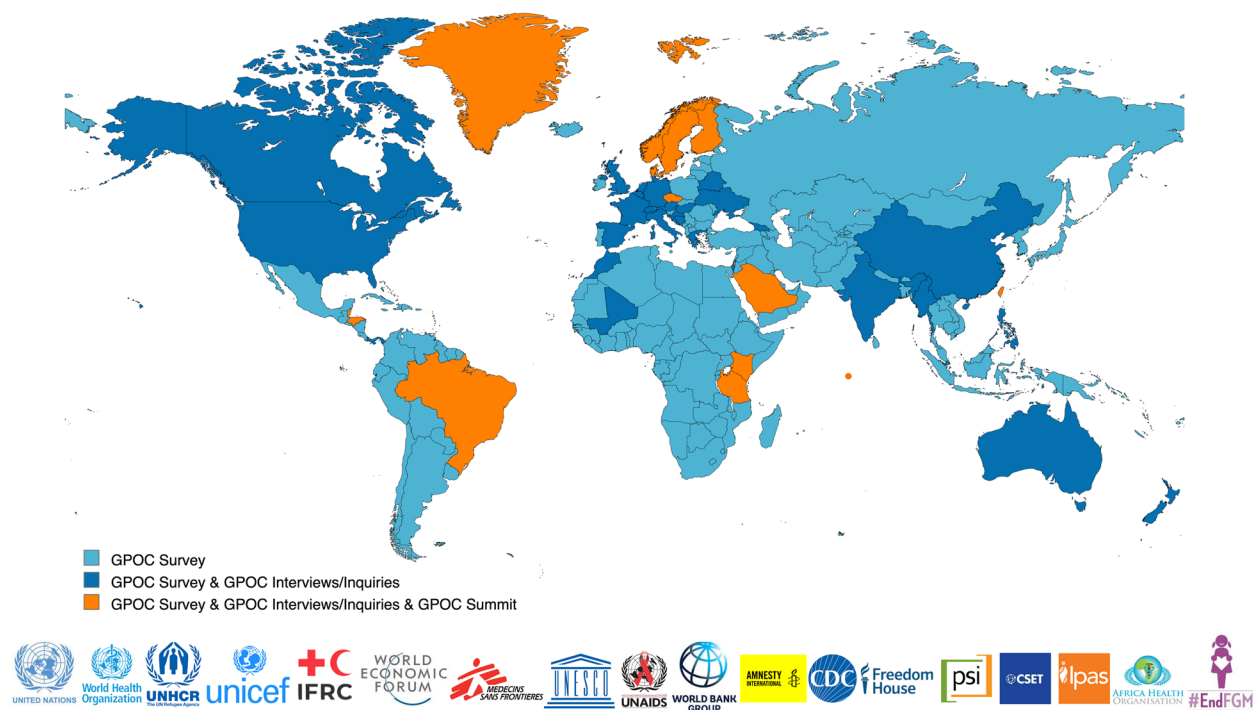
Fig. 2 The GPOC Summit and the Outreach of the GPOC Project. Global map of the expanse of the GPOC project. The GPOC Survey received answers from 100% of the UN member states, observer states and one de facto independent state ($n=196$) depicted in light blue. It also encompassed 18 major international organisations with logotypes shown. The states that also participated in the GPOC Interview Series or Inquiries are depicted in dark blue, and with eight organisations ($n=54$). Orange depicts the states that participated in the two abovementioned and also in the GPOC Summit ($n=14$) and one international organisation (EndFGM). Source Data files available on Figshare, https://doi.org/10.6084/m9.figshare.c.7067714

Table 1 GPOC Summit Results Overview: Final Votes and Averages

Question	Keywords #	1–5 average	Votes
1:1	General Survey Feedback	4.5	15
1:2	MCQ Improvements	-	-
	Layout	-	-
	Question Structure	-	2
	More Instructions	-	-
	More answering options	-	1
	Nothing to improve	-	12
2:1	GPOC Concept in general	4.4	15
2:2	Balancing of rights & health benefit	4.3	15
2:3	Personal gain of PHR co-ownership	4.5	15
2:4	Interest in a GPOC foundation	4.5	15
2:5	GPOC creation being worthwhile	4.3	15
2:6	The feasibility of a GPOC foundation	4.3	15
3:1	GPOC benefit for own country or organisation	4.6	15
3:2	Headquarters such as with UN, WHO, Red Cross	4.0	15
3:3	Suggested GPOC framework	4.5	15
1:1–3:3	Overall average	4.5	15 (165)

Overview of the GPOC Summit results with 165 votes from 15 delegates. Averages based on: Strongly disagree (1), Disagree (2), Neutral (3), Agree (4), Strongly agree (5). For final votes see (S2). For *p*-values see (S3). Source Data files available on Figshare, https://doi.org/10.6084/m9.figshare.c.7067714

Scores on the GPOC Survey's Six Foundation Related Statements

The second section sought specific feedback on six of the statements of the survey, which were related to the GPOC concept in general, the harmonisation of regulation globally, possible global health benefits, co-ownership, and the alternative with a global foundation:

2:1. I think a global, non-commercial, large and secure cloud, where I co-own my medical records would be an interesting concept, i.e., about the GPOC concept in general, giving an average of 4.4 (of 5).

2:2. It is possible to globally balance legal rights and regulations about medical records and find a common ground—this would benefit health in general. This gave an average of 4.3.

2:3. I think I personally would benefit from global access and co-ownership and control of my medical records. Average 4.5.

2:4. A neutral, unbiased, decentralised foundation, co-owned by you as a patient, designed to help regulate the flow of medical information interests me. Average 4.5.

2:5. An infrastructure based on sound scientific and econometric models, involving patients, governments & institutions from all countries is worthwhile. Average 4.3.

2:6. An infrastructure designed by global academics supported by research institutions involving patients, government and companies, can be founded. Average 4.3.

Scoring on a possible foundation

The third section sought guidelines from the delegates for a possible future GPOC foundation:

3:1. My country or organisation would benefit from having access to or contributing to a global patient co-owned cloud (GPOC) foundation. The average was 4.6.

3:2. The foundation should be headquartered in a country or region, such as the United Nations, WHO, or the International Committee of the Red Cross. Average 4.0.

3:3. The foundation framework, legislature, and governance should be inter-organisational, patient co-led, and involve academic institutions. Average 4.5.

Written free text feedback segment of the summit

The fourth and final section of the Summit was a freely composed written 'word-bubble', where all 15 delegates answered the final question; Are there any specific

Lidströmer *et al. BMC Digital Health*   (2024) 2:51

Page 5 of 10

subjects or feedback you would like to give us, or which you would like to bring up at the GPOC Summit on the 20th of September? The quotations are referred to in the discussion and presented in full in (S2). Table 1 summarises the key questions from the summit.

Free summit discussion and transcript analysis

The Summit also provides room for free discussions about the GPOC concept and related matters. All discussions are recorded and on the written transcript, natural language processing (NLP) is performed in the form of sentiment analysis as exemplified in Fig. 3. Figure 4 shows a selection of spoken quotations from the summit delegates. For the complete transcripts, see (S5).

In depth interviews and discussions

While the GPOC Summit aimed to gather diverse perspectives on the concept of a Global Patient co-Owned Cloud (GPOC), it is important to acknowledge certain limitations inherent in the study design. One limitation pertains to the relatively small sample size of Summit participants, with only 15 delegates attending the open session. Despite efforts to invite a broader range of participants, scheduling constraints and other logistical challenges limited the overall participation rate.

To address this limitation and ensure comprehensive insights, in-depth interviews were conducted with select delegates who were unable to attend the Summit. These interviews were recorded and analysed using similar methodologies employed during the summit sessions. While this approach helped compensate for the limited participation, it is important to recognise that the perspectives gathered may not fully represent the diversity of opinions within the global health community.

Additionally, the use of natural language processing (NLP) techniques for transcript analysis introduced another potential limitation. While NLP offers valuable insights into sentiment and thematic patterns within discussions, its effectiveness may be influenced by factors such as language nuances and the accuracy of algorithms used.

Despite these limitations, the Summit provided valuable insights and generated meaningful discussions on the feasibility and implications of the GPOC concept. Future research efforts may benefit from larger and more diverse participant samples, as well as continued refinement of analytical techniques to ensure robust and reliable findings.

Discussion

The GPOC Delphi Summit contains a vote as its final step. The summit contains an excerpt of the participants of the GPOC Survey. The chronology of the GPOC Series, is outlined in Fig. 1. The invitations for the GPOC Summit. The invitations were sent out one month in advance and fifteen delegates participated. The consensus results from these delegates provide an indication for future discussions. These could take place in other international fora, e.g., within the World Economic Forum (WEF), to which the summit was submitted for external validation. Additionally, the Red Cross (ICRC) in Geneva
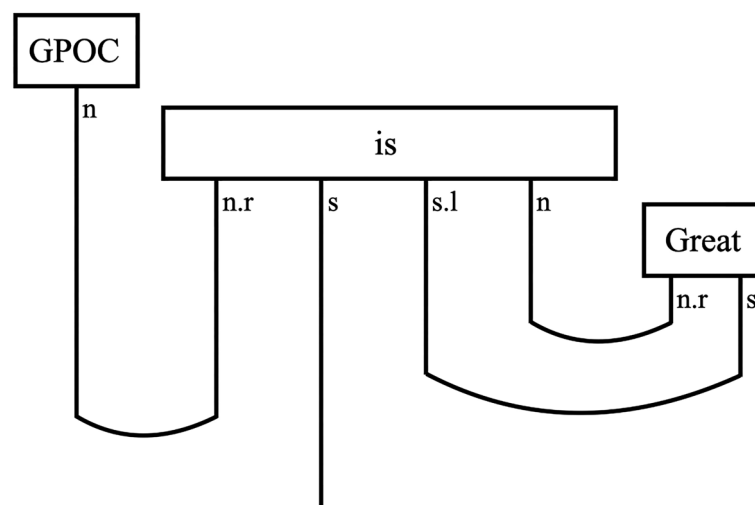
Fig. 3 Natural Language Processing on the Summit Transcript. We performed Natural Language Processing (NLP), in the form of sentiment analysis, on the Summit transcript, which contains all spoken words of all its sessions. Example use of Quantum Natural Language Processing using Lambeq from Prof Bob Coeke [5]. The results were incorporated into the sandbox environment of GPOC [3]. Source data files available on Figshare, https://doi.org/10.6084/m9.figshare.c.7067714
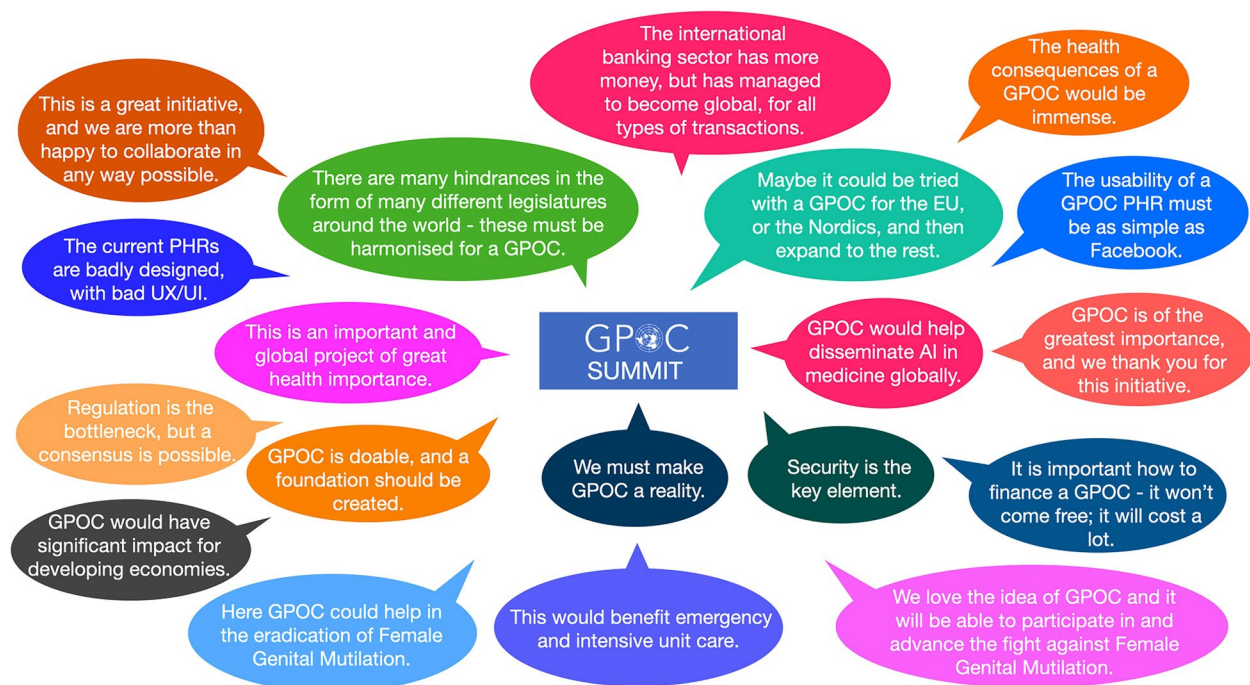
Fig. 4 Delegate Quotations at the GPOC Summit. A selection of delegate quotations from the GPOC Summit. For a full list of spoken statements see the final transcript in (S5). For details on the above quotations, see (S2). Source Data files available on Figshare, https://doi.org/10.6084/m9.figsh are.c.7067714

held a conference with the research team on the optimal evidence based criteria for a GPOC Summit.

In the discussion on a possible GPOC foundation the delegates underlined the need for transparency of the structure, founders, decision makers, activities and core values, regardless of whether it became part of an already existing international organisation or was created from scratch. In 2016 the world's ten largest international medical research foundations, out of over fifty identified, were deemed to need increased transparency [6]. Often no basic information, i.e., on decision-making processes, funding, distribution, or reporting, was available. The site www.healthresearchfunders.org aims for international health foundation transparency [6]. Hence, a new GPOC foundation would need a review of the applicable legal status. A GPOC would be governed by international law. Global organisations are subject to both national and international laws [7]. An extensive review encompassed reports on comparative foundation legislature, regulation, structure and economies—The Comparative Highlights of Foundation Laws. It presents the operational environment for European foundations [8]. A comprehensive global review was presented through the Global Philanthropy Report [9].

The realisation of a GPOC would require multilevel partnering and coordination internationally. A prominent example of an existing effort is the *International Patient Summary* (IPS) [10]. The initiatives could synchronise on standards, research and technology to use limited resources economically. Discussions have also been held with The Red Cross (ICRC) which uses the Red Cross Health Information System (RCHIS) and the app *RedSafe* – a collaboration here could also be valuable [11].

The GPOC Summit provided in-depth explanations and clarifications of the corresponding GPOC Survey questions. The repetitive discussion rounds in the Summit sessions hence closed the loop in a Delphi manner. The Summit gave indications of the political will and attitudes towards the GPOC concept.

Governments and other organisations may be able to provide healthcare qualitatively and efficiently and at lower cost with cloud computing [12–14]. Several nations, e.g., Singapore, Japan, and South Korea have used cloud computing to create national PHR databases. These are now in use for both monitoring risk groups, providing improved ground for telemedicine and providing genetic data for research. All are drivers in the economy [15].

The adoption of cloud-based PHRs not only offers cost-effective solutions for healthcare provision but also has the potential to bridge the digital divide by providing access to essential health information and services in

regions with limited infrastructure, thereby promoting health equity and inclusivity across diverse populations [16].

Delegate comments regarding the impact on humanity, particularly mentioned the elderly people and people with disabilities. These comments exemplified the anticipated potential benefits of GPOC. It could be a platform for individuals to access and manage their personal health records, regardless of geographical location or physical ability. Thus, it could improve healthcare accessibility and quality of life for vulnerable populations.

Eventually only fifteen delegates participated, out of the 214 entities (with 269 answers) in the survey. This is only 7%, and hence only indicative. Furthermore, there is an imbalance towards the EU and the Nordics. However, there was unanimous positive interest. This may indicate the need for a broader summit, sponsored by a larger international organisation.

Some few countries have passed legislation on national PHRs. The European Commission decided 29th April 2024 on a European electronic health record exchange format to unlock the flow of health data across borders [17]. A key question is how people would otherwise be incentivised to participate. In essence, the conundrum is how GPOC could disseminate without state funding and initiative. The alternative on an international foundation was discussed at the Summit. However, the opinion that "people would not trust this if it came from the politicians" was expressed by an African health ministry representative. The idea that eventually the market may decide this, and then the political assemblies will be forced to act was also expressed. Additionally, public awareness campaigns highlighting the benefits of PHRs in improving health outcomes and empowering individuals to take control of their healthcare may encourage participation.

The abovementioned PHR exchange format was discussed at the summit. The delegates speculated that GPOC could become a unified platform for storing, accessing, and sharing PHRs globally. This would promote data accessibility and standardisation. The participants expressed that with a collaboration among healthcare providers, researchers, and technology developers, GPOC could accelerate the development and validation of AI-driven healthcare solutions. Such a platform could integrate ethical and regulatory frameworks. Thus, GPOC could ideally ensure the responsible use of AI in healthcare. With and equitable access to advanced diagnostic tools and treatment recommendations, GPOC would empower healthcare providers worldwide to deliver timely and personalised care. In this way the platform could address global health challenges and reduce disparities. At the summit it was also suggested that GPOC could support capacity building and

education initiatives. It was also speculated that GPOC may enhance healthcare professionals' AI literacy and skills, strengthening workforce readiness for AI-driven healthcare transformation on a global scale.

A motivation for the summit was also that it sought to further analyse and scrutinise the survey, but it also sought to provide a more in-depth examination. Not only does it echo the survey, but it also expresses a vivid consensus and an indication for further debate.

One of the main driving forces of GPOC is to make the voice of the patients heard because it is missing in the PHRs. Since we are all patients, on purpose all questions in the GPOC Survey, Summit, and Interviews were always in the "I"-form. In this way we hoped to force legislators to think how they, as patients, would like to have it all organised. In other words, not to think about one standard for "the people" and another for themselves.

Finally, it may be relevant to elaborate on the practical meaning practically of patient "co-ownership." The co-ownership refers to the right to access, share, store, move and even getting paid for one's encrypted PHR for medical research or other use. The right to contribute to the PHR is also an articulated component – in this way the voice of the patient can be heard in the record. Additionally, with the Internet of Things (IoT), patients will be providers of data influx into the PHR from their owned medical monitors and other devices. Patient co-ownership emphasises the importance of empowering individuals to actively participate in managing their healthcare data and ensuring that their privacy and autonomy are respected.

Conclusion
In conclusion, the GPOC Summit marks one step in the journey towards realising the vision of a Global Patient co-Owned Cloud. The Summit, with its diverse participation, provided insights and consensus on the assumed feasibility and plausible benefits of GPOC. The summit delegates came with examples of potential benefits from GPOC. Future efforts could profit from coordination with initiatives such as the International Patient Summary (IPS). A future and larger summit could be hosted by an established international organisation. Moving forward, GPOC may bridge healthcare disparities and advance global health research. Its role in facilitating the development and global dissemination of AI in healthcare may be important for global health.

Methods
Ethical considerations
Participant recruitment was conducted through official email invitations sent by the first author using the Karolinska Institutet email platform. Invitations were

Lidströmer *et al. BMC Digital Health*   (2024) 2:51

Page 8 of 10

extended to health ministries and organisations participating in the international GPOC Survey, totalling 214 entities. Written informed consent and assurances of confidentiality were obtained from all participants. For the "open" Summit held in September 2022, delegates consented to audio and video recording, as well as the use of their quotes and identification of their represented state or organisation. Ethical approval for the GPOC Series, including the Summit, was obtained from the Imperial College London University Research Ethics Committee (IRAS Project ID 310441), see form UPR16. Informed consent was obtained from all participants 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.

Methodological rigour
The Summit employed various methodologies, including participant selection mirroring the GPOC Survey and a rigorous Delphi process, which involved multiple rounds of communication to achieve consensus among experts [18].

Data collection
The data were collected online using Microsoft Teams and Mentimeter. All interactions were video recorded, resulting in 12 h of footage for the open GPOC Summit in September 2022. Transcripts were analysed using natural language processing (NLP) methods, with additional analyses conducted using ChatGPT4.0 and Microsoft Word. Measures were taken to ensure validity and reliability, including pilot testing of instruments and interrater reliability checks.

Participant selection
Participants were selected based on predefined criteria to ensure relevance and expertise. While the current Summit focused primarily on health ministries and international organisations, future iterations may consider diversifying the participant pool to enhance its validity and generalizability. The 214 entities in the GPOC Survey were invited via email and followed up with LinkedIn messaging one month in advance. 148 responded they would attend, and 15 eventually attended.

Scoring methods
Summit scores were averaged based on a 5-point scale ranging from "Strongly disagree" to "Strongly agree." The scores were averaged based on: Strongly disagree (1), Disagree (2), Neutral (3), Agree (4), Strongly agree (5). Voting was achieved using Mentimeter (Mentimeter AB Tulegatan 11, 113 86 Stockholm, Sweden). STATA 13

(StataCorp. 2013. Stata Statistical Software: Release 13. College Station, TX: StataCorp LP) was used to calculate the p, and significance was set at a $p < 0.05$.

Data collection
The data collection methods included recorded interviews and discussions, with video recordings facilitating delegate identification. All participant input and discussions were documented in (S1-S5) for transparency.

Analysis techniques
The analysis involved the use of Microsoft Teams and Python-based tools such as Qiskit and Cirq for data pre-processing and analysis. Quantum Natural Language Processing (QNLP) algorithms were employed to extract insights from the summit transcripts. Statistical analysis conducted using STATA. The Summit was executed using Microsoft Teams (Microsoft, Redmond, Washington, United States, 2022). Qiskit (version 0.31.0), Cirq (version 0.12.0), and Python (version 3.10.2) were used for data pre-processing and analysis. These tools allowed the implementation of Quantum Natural Language Processing (QNLP) algorithms and the processing of the Summit transcript to extract insights, which were then integrated into the Sandbox environment of GPOC for further analysis or application.

External validation
External validation of the summit structure and findings was sought through peer and expert review processes. The organisations such as the World Economic Forum and the International Committee of the Red Cross (ICRC) were consulted to validate the methods and findings.

GPOC summit networking, follow-up, and recording techniques
The GPOC Survey facilitated a global network of health ministries and organisations, with follow-up interactions facilitated through social media platforms. The open GPOC Summit held in September 2022 consisted of twelve sessions over two days, recorded and transcribed for analysis. The data generated in this study are available in (S1-S5) and deposited in the article repository on Figshare (https://doi.org/10.6084/m9.figshare.c.7067714).

The Summit consisted of twelve sessions in total for two days to match all the time zones of the world. These were recorded with 840 min of HD video, transcribed and annotated. Nearly all sessions were held in English. The sessions with Norway, Sweden and Finland were held in Swedish and transcribed into English. Unnecessary words (humming, coughing, or half sentences without meaning) and irrelevant discussions (initial greetings

Lidströmer *et al. BMC Digital Health*   (2024) 2:51

Page 9 of 10

and courtesies, and personal introductions) before or after the proper summit. Filling words and verbal noise were also deleted. The cleaned file is available in (S5). The session with Brazil was held on Thursday 15th September 2022 and all the other 14 representatives had sessions on the 20th September 2022. The session with Brazil was annotated manually and not recorded.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s44247-024-00112-w.

Supplementary Material 1: S1_Overview of Participating States and Organisations in the GPOC Series.

Supplementary Material 2: S2_GPOC Summit Word Bubbles.

Supplementary Material 3: S3_GPOC Summit Votes.

Supplementary Material 4: S4_GPOC Summit Results.

Supplementary Material 5: S5_GPOC Summit Final Transcript.

Authors' contributions

Niklas Lidströmer (NL) conceived the background research, idea and concept. NL and Joseph Davids (JD) designed the summit topics. NL invited all the delegates from health ministries and health organisations from around the world. NL, JD, and Mohamed ElSharkawy (ME) participated in pre-summit sessions with, e.g., the ICRC, and sought external validation from several experts. NL chaired all the rounds of Summit sessions. JD and ME participated in several of the final rounds of the summit sessions. NL collected data with video recordings and manual and automated annotations. NL, JD and ME performed the data analysis. NL assembled and structured the source data. JD and ME performed Quantum Natural Language Processing. All authors (NL, JD, ME, Hutan Ashrafian (HA) and Eric Herlenius (EH)) contributed to the data interpretation. HA and EH provided valuable 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 to the manuscript with input from EH. All authors critically reviewed and approved the final version of the manuscript. JD and ME created Fig. 3. NL created Table 1, Figs. 1, 2 and 4, Supplement S1-S5; and related files and assembled all source data into a repository on Figshare, https://doi.org/10.6084/m9.figshare.c.7067714.

Availability for data and materials

No datasets were generated or analysed during the current study.

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.

Consent for publication

All participants have consented 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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