Supplement 1 (S1): GPOC Summit 2022 Final Transcript

The summit consisted of 12 sessions in total. The ten ones recorded and transcribed. The others have been annotated. All will appear collected below. The readings of the questions by the GPOC Speaker have been deleted for increased readability. Hence, we have focused on the citable statements from the participants.

Instructions for the transcript

• Nearly all sessions were held in English and transcribed in English.

• The sessions with Norway, Sweden and Finland were held in Swedish, why the transcription is incorrect. The correct wordings have been annotated manually as with the unrecorded sessions.

• A gender symbol ♀ or ♂accompanies the country name. There were 8♀ (women) and 7♂ (men) participating in the summit. In other words, nearly equal. Since the invitation to the summit may mirror the survey in other aspects, it may also indicate a 50% participance of women and men across the globe.

• Words like “umm” and internal irrelevant discussion or content of private nature have been omitted. Filling words and verbal noise have also been deleted.

• All unnecessary from the GPOC Speaker, co-hosts have been deleted to increase readability

• The original file contained 200 full A4 pages of text. The below is a more legible and relevant, hence cleaned version, so that the participants' quotable statements appear much easier.

• The session with Brazil was held on Thursday 15th September and all the other 14 representatives had sessions on the 20th September.

• The session with Brazil was annotated manually and not recorded.

• The contents of all summits, regardless of recorded, transcribed or annotated manually, have been pasted below in one united all assembling file.

•In all of the text below, the quotable sentences, citations, have been highlighted.

• A bullet point "•" has been inserted before the quotable succinct text, which appears in italic.

• As a final instruction: only the CITATIONS (•) remain now in clear and legible text below, starting on the next page.

• The first portion of the citable country statement appears in bullet points.

BRAZIL (1) ♂

• The usability of a PHR must be as simple as Facebook

• The current PHRs are badly designed, with bad UX/UI

• There are many hindrances in the form of many different legislatures around the world - these must be harmonised for a GPOC

• The international banking sector have more money, but have managed to become global, for all types of transactions

• It is important how to finance a GPOC - it won't come free, it will cost a lot

• Maybe it could be tried with a GPOC for the EU, or the Nordics, and see how it works, and then expand to the rest

NORWAY (2) ♀

• This is personal liberty in a nutshell.

• This is the future of healthcare

• Some countries could pay more - this is a way of helping the world.

• With GPOC we can assist developing countries, it is like human aid to all citizens of the World.

SWEDEN (3) ♀

• The system must be well-built, robust and have no security leakages

• The whole World health would benefit from a huge Facebook like AI-EHR-PHR personal, secure and safe global medical record system, synced and continuously updated with the latest AI - there will be so many updates every year.

• All humans should have subscription freely from birth

• Login with their DNA from birth and they should own it

• We agree with Finland that this is a global project exclusively for free and democratic states, when it comes to its regulatory statutes' creation, technical construction, maintenance and supervision. Autocratic states could misuse this.

• Democratic and human rights values should spread with a GPOC, and not be worked against with the misuse of such a system.

• Such a platform, with refined AI, must be regulated in the right way. We agree with Finland about the risk, if in the wrong autocratic hands.

FINLAND (4-5) ♀♂

Both participants from Finland will be fused here.

• The use and access to technology in patient data protection are the key elements.

• Safety and robustness of the system are very important.

• Only a well-built system will be able to gain trust.

• Not all countries have the capacities to build this platform – the leading AI-nations must take the lead and distribute it.

• The distributed, not hierarchical, not central, safe, blockchain like way of building this, is the way to do it.

• Some key academic institutions in the Nordics, USA, England, and other democracies, note the democratic and transparent freedom loving aspect here, can and should take the lead.

• There is always a danger with medical information in the wrong hands, such as autocrats, so it is important who maintains such a platform, and how it is regulated.

BELIZE (6) ♂

• This is a great initiative, and we are more than happy to collaborate in any way possible

• We must make this a reality.

• As a Specialist of Intensive Care and internal medicine based and currently the president-elect of the Societies of Intensive Care and Critical Care Medicine, it will be my pleasure to collaborate.

• This would benefit emergency and intensive care unit (ICU) care.

• Security is very important.

PALESTINE (7) ♀

• In Palestine we've been working on similar projects for a long time in order to gather all of the medical records of patients in a safe way. Let's say for example in blockchain, so that nobody has access to it that can misuse it or use it in the wrong ways or the privacy of the patients is very important.

• Also the medical records could be very beneficial in providing our benefiting healthcare worldwide because it will provide data to scientists in order to have advancement in many diseases such as cancer, nervous system diseases.

• This is very important, but we need to play this right to provide security and safety for the patients.

• We need to gather all this information and create a great legal framework in order to put some regulations in order to preserve this.

TAIWAN (8) ♀

• I believe that in the survey there were many aspects which we have experiences about.

• So first I would like to congratulate you for your hard work and make it a global united collaboration and that is the only thing I would like to emphasise.

• The conclusion is that I do agree fully politically to this.

• Its justified infrastructure I think is a neutral, collaborative welcoming environment, and it is very important that we can put a global effort into this.

KENYA (9) ♀

• People would trust GPOC more if kept separated from political influence.

• Here people do not trust governments or official health authorities, so an independent body would be more efficient.

• This, if frees-standing, would be excellent for developing and poorer countries, so that really all people get access to the latest and best healthcare AI and technology

• The development pace of healthcare can be more even, and people can reach this through GPOC from everywhere

• It would be important to separate GPOC from the political field completely. It does neither have be associated to WHO or UN even.

• It should be an independent institution, with academics and the patient.

• It is important that people can trust GPOC.

• In Africa we have a tendency of not trusting large organisations.

• Academic involvement makes it more trustworthy, than if politically based.

• GPOC should be a decentralised platform.

• There is a lot of corruption - here we need political goodwill.

• GPOC must be independent.

• Political involvement makes it hard to execute – look at our recent elections, or the vaccination campaigns, and people's trust towards the government. There have been issues, just because the vaccine came from the Government. People are suspicious just because of that.

• Governments have often proved to be trustworthy in countries with corruption – hence, people are afraid that their data could be stolen and used for something politically motivated.

• I would suggest focusing on the academic side of GPOC and involving academics.

• People would build trust in an independent body, more than when a minister of health tries to build trust.

• This suggested EHR platform could be of pivotal importance – it can lead to earlier diagnosis – the issue in our country is really late diagnosis.

CZECH REPUBLIC (10) ♂

• Telemedicine is an important player in this field.

• Security and privacy are pivotal.

• The patients should have co-ownership of their data

• In Czeck Republic you have have access, but you need to pay to get all the data

• It should be free for all and digital in the cloud

• A GPOC would have enormous impact in the distribution of care to poorer countries

• It would give the whole World access to medical AI

• The ideal would be a GPOC will integrated PHR and AI

• From my experience in my country the EU funding for the telemedicine projects is horribly misused.

• There are a few organisations getting funding for certain projects and the leaders of those projects are misusing these funds.

• There are no clear control mechanisms to monitor the providers of the funds. We must implement control mechanisms here.

• There are several good examples within medical devices, AI, automatic radiological image descriptions, e.g., in MRI, and preventative applications, such as melanoma detection and many more, which could be integrated with the GPOC platform

• In our country we have partnered with insurance companies, to cover the cost for a dermatoscope process, to scan the skin, and at a low cost for the patient.

• Anybody should be able to access and download such applications, and then the AI would be more accurate – same with GPOC.

• This platform is good for second opinions in medicine.

• Integrating AI in patients' health records is way more doable because patients will love it. It's definitely a big help because a majority of the population do not have their health records.

• Here you can pay for a paper copy – sometimes there is not even an electronic record. We are a bit behind.

• In effect the patient should have co-ownership to the medical record, but it is a bit of a shady area in our legislation, meaning that it belongs to the patient and the doctor, but that the patient must pay to get it.

• This should be free, as in the Freedom of Information act.

• The patient should have personal access directly and co-owning it in the digital GPOC.

• This would be a huge help for patients in my country.

HONDURAS (11) ♀

• This is basically one of the first with this type of baseline.

• The GPOC study has a high-level type of survey.

• I think that there could be a common regulatory ground for the GPOC.

• GPOC could also contain vaccination guidelines, clinical suggestions that are applied worldwide, but context specific and flexible enough.

• Guidelines and regulations need even to be adapted to subnational level.

• Not every country has these regulations.

• GPOC could spread or give legal rights and regulation, but this could be a double-edged sword, because the rules are not in place yet, but this new regulation could be an opportunity to help – and we need to create these rules.

• For GPOC regulation there should be a very strong component of co-creation.

• This must occur within the regions and national and subnational level.

• Often regions are provided with guidelines, and capacity building, but no funding.

• The PHR ownership must enter the agenda.

• Sometimes whole regions are blocked in this development, because of lack of knowledge or technical capacity.

• Patient self-empowerment and the notion that, "we do this ourselves" – that you have in GPOC, and I like this idea.

• This could spread to many countries – it is better than many countries reinventing the wheel.

• The ideal would be many different headquarters, which could facilitate resource mobilisation. And making administrative procedures more seamless. A headquarter in one single place could be isolated. With several GPOC locales you would read the "last mile" type of countries, and they would benefit more. And it could be more cost effective.

• Compare with Spotify – they have some kind of headquarter, but they operate everywhere – GPOC could have the same cloud-based system.

• In Honduras there is a large cargo train going North – and people are fleeing for their lives from here, from corruption, organised criminality, gang violence, physical jobs that are really dangerous with no workers' protection. They risk their lives and limbs to jump on that train to flee. And only really fit people can make it. This is the reason we have so many amputees.

• I have worked with this at a hospital here - we had amputees from Honduras who were attended to in Guatemala or sometimes in Mexico. Sometimes they had their medical record, a physical one, i.e., a printed one. But they never matched our records. Sometimes they were electronic and sometimes physical. The formats were different, even though we are neighbouring countries – there is no harmonisation.

• Many regions do not have data regulations in place, or infrastructure to support EHRs. GPOC is the opportunity to make it concrete and to democratise health. To improve technologies and achieve EHRs, and improve access

• Regulation is definitely a conundrum.

• In Latin America, in many regions, we don't have data regulations in place, not only for health apps, but for data in general. And what happens is that, since many of our countries are dependent on international aid, whoever provides the aid provides the regulation as well. We hence need to comply with (the regulation from) where the aid comes from. With US funding we usually need to comply with US regulation. The same with the EU.

• We are subjects to foreign, and different, regulations

• Another layer of complexity to our own national processes, which is performed with very low technology.

• We are hence subject to different regulations, different providers, different fundings, different languages and nothing is standardised.

• A GPOC could simplify our administration and help our technology shortage.

• These international regulations should be in place as soon as possible - they should have been working for decades now.

• When in place – can all adapt to them? What can we replicate and how can we change them?

• There is a huge need to harmonise the medical records. But when it comes to trying to implement this GPOC idea it will be very tricky. The main reason why we have no harmonised regulations, and even economic treaties across countries and regions, is because we have so many different levels of development and economic capacity within the very same region. There are enormous differences between, e.g., Honduras and Costa Rica, and they are only 700 kilometres apart, not ever far. We compare our level of development to those of Panama or Mexico

• Perhaps neighbouring countries could really benefit from a harmonised region.

TANZANIA (12) ♂

• The GPOC Survey was self-explanatory, and everything was clear.

• When the governments are involved in these projects, they're able to manoeuvre, which can be very risky. It can compromise the privacy of the patient. So it may not be the best idea to involve them.

• Regarding companies, it really depends on which companies we are talking about. Sometimes there have been companies, which have taken advantage of people's private information and actually exploited them for their economic gain.

• GPOC would be in the public interest, and should stand free of large corporations, e.g., the large pharmaceutical industry.

• There is a significant risk these health-related projects, like GPOC, are concentrated and end up isolated, only targeting some beneficiaries with some services or information. Coming from Africa, I know too well how these global or UN initiatives end up only being in Geneva, with no direct contact with the most vulnerable and affected population in Africa, which then doesn't make a lot of sense.

• Hence, regional presence or distribution of efforts across the continent would really be useful, e.g., a specific office for Africa or even a specific office for sub-Saharan Africa, which of course we know is affected by so many different health issues.

• So, even if GPOC needs to be headquartered somewhere, it must be minimal and symbolic, and the real services or information must be local and accurate.

• I would not vote for it to be headquartered in the US like the UN or in Geneva like the WHO – it must be much more spread. It must be relevant to the local. It must be distributed.

• Headquarters are basically about this thing nowadays.

• Despite all attempts of infiltration with advanced technology, the patient information must be kept private and made accessible to the patients, it must be relevant and when necessary instructive for the patients.

• It is also interesting how the settings and infrastructure could be adapted to the population of Africa, which is not exposed to technology, and may not be able to navigate so well. This is something we should consider for patient information protection.

MALDIVES (13) ♂

• This widespread archipelago nation would need a GPOC.

• It must be obvious who manages the security.

• It would be good if this is an open-source data construct.

• Would be good for research, health-state of nations etc.

• We need to use newer tools so that we can develop technologies that will support co-ownership.

• Could also be useful for the vulnerable part of society, e.g., the stress element of forced migration, social pressure that brings people to move, and therefore lose their access to their own data.

• Maybe there could here be some kind of international health access card.

• This platform could offer more holistic data.

• This would best be set up as a foundation.

• With digital ID and financing this could be a meaningful and powerful tool for risk insurance.

• Maldives has a very fragmented morphology of its territory; hence we would benefit from GPOC. We have no continuum of the land.

• There should hence be this repository with all the data for somebody, an umbrella kind of cloud data available for everybody, would be of the greatest interest.

• There are many subjects for anticipatory governance and policy making on several issues, which you must interpret.

• You could imagine if you had this for the entire hospital supply and service chain.

• And for our hundreds of islands a GPOC would make it unified and accessible.

INTERNATIONAL ORGANISATION AGAINST FGM (14) ♀

• We strongly agree with the suggested foundation principles of GPOC.

• While fighting FGM, my organisation is working for the total eradication of it, it is required to have accurate health information.

• It's very important to have accurate information to be able to but only work with the right people that are affected by FGM and monitor the figures.

• I want to be talking about other figures in 20 years from now, that my work mattered, for the decreasing and ultimately eradication of FGM.

• I believe that having access to medical records with GPOC, would give a lot to activists against FGM.

• The accurate information would hint which communities to target and let us work with the right people, while fighting FGM.

• Such an electronic health record would really help with early prevention of FGM already in Europe and even across Africa.

• This system could alert healthcare professionals how to care about these girls and women.

• It is very sensitive to talk about FGM for someone deciding to share their story. Some may have undergone it and experience serious complications of FGM.

• There must be ways to regulate the information on such as system, having the needs of these victims in mind.

• A GPOC would be able to involve the people that could give first-hand information about FGM.

• Medical records with sensitive info, such as FGM, may give rise to fear about what this information will be used for. Though many of the patients that have undergone FGM may be very open to share this information if the incentive is to benefit the greater good, of fighting against the FGM. Other are very sensitive for their own personal reasons. The must be involved and before dissemination information.

• If making GPOC information public, the sensitive info must firstly be very guarded, and secondly patient should be involved and give consent.

• I share my personal experience, and it is important that others also are aware of the intention of the information sharing.

• For example myself - I was willing to share my story about FGM - because I knew that others would be inspired to share theirs, as you have been able to see.

• Here GPOC could help in the eradication of FGM.

• There can be a replication of story sharing.

• It is important that the medical institutions, involved in GPOC, have this in mind - the victims of FGM that have gone through unimaginable circumstances.

• GPOC health records would be beneficial in the fight against FGM.

• Our organisation represents the voices of millions of girls.

• The financial, micro-economic model of GPOC, could spark the willingness of sharing very personal information, which would help in the fight against FGM.

• The reimbursement model for the patients, who are co-owning their data, could financially support people telling their story. It could be encouraging.

• The numbers may multiply so that more people come forward and tell their story. So if there is an option to get paid – this would be a great motivating factor.

• It is important to collect this information from this group of people, for educational purposes too.

• GPOC statistics will help in the fight for better health here.

• A GPOC foundation would be able to stand up for victims of FGM and other atrocities.

• There could be courses on which human rights values that GPOC stands for.

• THE GPOC foundation could go one step further and with its medical records create a transformation.

• Contribution medical institutions collecting GPOC information could provide statistics, which could help these courses.

• I love the idea of GPOC and think that the foundation will be able to participate in and advance the fight against FGM.

SAUDI ARABIA (15) ♂

• I find GPOC an interesting idea, and I think I personally would benefit.

• I love the whole idea, and the most important thing is the governance as well as the implementation plan. These two need to be robust to execute, because there are great ideas that never see the light.

• There needs to be an umbrella of one of the international governing bodies or internationally recognised bodies like the United Nations or WHO to receive the credibility and trust from health leaders around the world. It needs to be a collective.

• The participating countries need to draft a governance framework, and implementation plan, so that they are responsible for the implementation and the execution and take the responsibility upon their shoulders.

• GPOC does not need a new law or regulation, if this initiative comes from a well-recognised body like the United Nation or WHO, because most countries, if not all, are committed and already have regulations to follow.

• At least the member states need only to accept the recommendations and initiatives coming from these international bodies, so we do not need to instate a new law or regulation, if this is hosted or owned by the United Nation of WHO.

• In our country we don't have laws that prevent or prohibit or allow, getting compensated for your own electronic health records.

• Now we have the idea of owning your medical records, but nothing is mentioned about making an outcome from it. This is likely something new for most countries.

• I would be really interested to see what other countries have in their regulations about this and how they made the regulations fit within their healthcare system structure and current regulations. So that it cannot get abused, modified, or falsified to benefit illicitly.

• Wherever there is money people try to get the best out of it for their own benefit. Therefore, governments are hesitant to either allow or prevent this in state regulations. This is true especially in countries where they have unified health systems. Here the health care is

provided free of charge to their citizens. Then it can be tricky to regulate. It is also a different story when you have an insurance-based system, especially when you don't get taxed to pay for your unified healthcare.

• All I'm saying is that the initiative would need acceptance by the countries, whether patients can get compensated or not, there might be some discussions at the country level whether to adhere to this.

• But as you know, not all countries follow all recommendations by WHO or United Nations. But there is a minimum set of requirements or obligations of countries that they need to adhere to.

• The GPOC initiative as a whole, as an idea is really worth exploring, and would receive more acceptance if it came from an internationally recognized body like the United Nation or WHO, but the payment for your own medical record might require further discussion at the country level.

• Yes, you have the freedom to use your own medical record. Absolutely. And to get access to it, similar as to any other data, not health related, e.g., personal data. Your data at the government financial data, you have full right to access and use it for your own benefit. However, monetizing this might need further regulations. But I am talking about Saudi Arabia, basically.

• Currently we do not have a regulation on how you monetize your personal financial demographic data that you own and have full access, and free to use it the way you want. But monetizing it is a different story.

• And possibly, we may have experience of “monetizing” clinical trial data that pertains to you - you could have participated in a clinical trial and got paid for it. There are regulations for this. These regulations need certain requirements in terms of informed consent, fair compensation, reporting to certain regulators, and auditing under certain regulations, but this

applies only to clinical trials. Now we're talking about monetizing all health-related data of someone outside a clinical trial, which is a more controlled environment. This must be subject to further auditing and scrutiny. It is a little different situation, and in fact, we do not have regulations yet. This does not mean we can't do it if allowed by law. It does not mean that it is going to be allowed. It just means that it needs to be discussed, evaluated and we have a regulatory body in terms of data here in the Kingdom, called Sedaya and it regulates all related data with regards to Saudi Arabia.

• I think that we could learn from the clinical trial experience, when creating new regulations. But the situation in clinical trials is different to a large medical record system. A clinical trial is more controlled and of smaller scale, and it is subjected to more scrutiny and auditing.

• Clinical trial record keeping regulations also entail fair compensation. You cannot pay somebody $10,000 to get into a clinical trial, but what is considered to be a fair compensation for their time. It needs to be discussed at a different level when you want to generalise it to all health-related data. The clinical trial involves medications or medical devices or food supplements, and it needs also to be approved and reviewed by the Saudi FDA, which is the governor for these health technologies. And there is also an ethics committee and specific institution to perform the audit. It is important with long term follow up. There are certain issues with the clinical trial itself, e.g., dropouts.

• I hope GPOC ultimately sees the light.

• And I'm hopeful that this will definitely result in the overall benefit of not only patients, but institutions as well as.