

Ethics Review Issues in the Review of Machine Learning Research Proposals

Ethics Review Committee Members Focus Discussion Group

22nd August 2022

Transcript

SPEAKER 1 00:00 And we can begin.

SPEAKER 2 00:04 So good afternoon once again, and I would like to begin with our first question or area of inquiry, I would just like to know what is your current knowledge or understanding of artificial intelligence? In no particular order, but one speaker at a time.... WB, would you like to go first?

SPEAKER 0 00:39 Okay. Thank you. I want to say that my experience with the artificial intelligence, it is a concept that has not really been in existence, but the much or the experience I've had is that you get to occupy a wider space, there is a wider scope that you are able to communicate. You are about to do quite a lot within a short time as opposed to doing it in the primitive way, the old way. So I prefer the artificial intelligence to work with because you can do much within a short time. That's my take.

SPEAKER 2 01:33 Thank you, Prof. C..

SPEAKER 0 01:38 Yes, I think what I would say is, getting machines to actually do what we do, what human beings do, so interacting with them, learning the machine language and getting things done through machines, probably in absence of human interference and so on, which gets most turn around of things faster and, you know, routine things and so on. I think that's what I would say. Thank you.

SPEAKER 2 02:12 All right. Dr. O

SPEAKER 0 02:21 OK, thank you very much. I wish you gave us a scale. On which to rate our understanding. I'm not sure whether you wanted us to define what it is, but I would say that I have quite some experience the issues around artificial intelligence in terms of using machine learning techniques. And also conducting research around challenges with some of these machine learning techniques. So, yes, I would say quite a bit of some experience. Thank you.

SPEAKER 2 03:09 Thank you, but you've not told us, what do you understand by artificial intelligence?

SPEAKER 0 03:17 Wow, OK. I think in my understanding, artificial intelligence is just around using systems that would try to mimic or emulate what we would do as human beings. Either from a cognitive perspective or from a kind of psychomotor use of physical capabilities that we have as human beings, so both

physical and cognitive capabilities and mostly through the experience of learning from data that is available. Thank you.

SPEAKER 2 04:13 All right. Thank you. Mr O

SPEAKER 0 04:23 Thank you. What I would say I understand from machine learning is the ability of a computer to think like a human being and process things like a human being and actually replace the human aspects of doing things. I've not used it much, but in an area of law which we do arbitration and internationally, they managed to reduce a lot of data in a very short time or to analyze, when you are looking for example for a piece of evidence. Analyze data in a very short time and compress it. I wonder which document....

SPEAKER 2 05:12 Thank you very much. Yes. Mr A.

SPEAKER 0 05:21 Thank you. My basic interpretation of AI, I think just involves the use of computers and computer applications to process information or to use information on our own behalf. The way we normally think, the way we normally do our transaction businesses. How we run a statistical analysis. We can use machines to help us in doing those analyses in a faster, efficient way. That is what, in brief, what I think is Artificial Intelligence. Thank you.

SPEAKER 2 06:03 Dr. M

SPEAKER 0 06:12 Yes, I'm here. For me, my understanding of Artificial Intelligence is, to use machines to do what human would have done using their own intelligence? And then the machines also can be able to generate a large amount of data that may not necessarily be generated when humans were supposed to do the same task. So these machines could be used for solving problems, they could also be used for learning and they basically mimic the human mind. So that is my understanding of Artificial Intelligence.

SPEAKER 2 07:16 Thank you very much. Dr PM welcome, and you can introduce yourself and tell us what you understand by artificial intelligence. It's an ambush, but you're the last in this round of questioning. Peter? OK, as Peter catches his breath, I think we can move on to the next question. Dr. P.

SPEAKER 1 07:51 Thank you, so I believe we all sit in the ethics committee in our various institutions. And my question is going to be addressed to us as reviewers, and I would like to know if we've ever had a chance to review to review a protocol that had maybe artificial intelligence or machine learning.

SPEAKER 2 08:39 Dr. P, I think you can give everyone a chance in order so that they are able to proceed. Prof. C, I think just proceed, you are the first on the line.

SPEAKER 0 08:50 Yes. I wanted to talk because I've been a chairman, probably for the last less than five months. It's a relatively new post,

so we haven't had a lot....but the protocols that we have looked at, none of them have involved artificial intelligence. And when I inquired from my older members, they have not had much of anything to do with the AI.

SPEAKER 1 09:19 Yes. OK. Thank you, Prof. Maybe before I go on from here, do you get protocols that are from maybe School of Computer Science coming for review?

SPEAKER 0 09:33 I think they are very minimal. Currently this year, we haven't received any.

SPEAKER 1 09:43 Thank you. The next person I'm going to ask is Miss N..

SPEAKER 3 09:52 Yes, thank you, Dr. P, given that our ISERC is a health-based, we are based at Jarh. That is Jaramogi Hospital, most of the protocols that we receive on our end are basically topics that touch on human issues. Mostly, those are the ones we receive not from these other areas like I.T., we rarely receive such like protocols. But for the ones that we've been receiving at times, we receive protocols whereby the author, the principal investigator is talking of, they'll be using a gadget, a device to be able to reach the respondent or maybe gain information by use of maybe giving the devices to the participants so as to receive back the information that he or she requires. But all that touches on health issues not from outside the health field. Yes.

SPEAKER 1 11:22 OK, thank you. So just to probe a little bit about testing of gadgets, do you.... have you received in the recent past a protocol that wanted to test an already approved application on patients within the hospital?

SPEAKER 0 11:40 Not of rescent, if I can recall the were... there was a time, I think before the COVID pandemic, there was a protocol that touched on similar concept, but I can't really remember the details because again, when protocols are brought unless it is assigned to you as a secretary, then I'll just peruse through and then the chair would give it to the person who is relevant in that field, who understands that section well. But personally, I didn't handle, but I remember there was one with such a requirement. Thank you. Yeah.

SPEAKER 1 12:30 Dr. O

SPEAKER 0 12:36 Thank you very much, Dr P. Maybe, before I comment, maybe probably could explain what you mean by a protocol. I think it's quite used heavily in the health sector. Some of us who are out of the health sector, may not have a clear picture of exactly what you need.

SPEAKER 1 12:58 OK, thank you for that. Now what I mean by a protocol is a proposal that has been sent to IRB for review.

SPEAKER 0 13:09 OK, thank you very much. Now I also want to make it clear that I don't sit in any review board currently. But I have sat in cases where students present proposals or projects that have got AI components and have got machine learning

components, and some of these cases, I think, the data may have been scrapped online or they may have used some gadgets, I've seen the case of a smartwatch... a case where smartwatch was used to collect some data from participants who had agreed to do so. So that's the much of experience I've had with anything close to what you are talking about. Thank you.

SPEAKER 1 14:08 Thank you, Mr. O.

SPEAKER 0 14:14 Yes, I have seen it come through our IREC but personally, I have not reviewed it and if ... such a protocol I wouldn't know where to begin.

SPEAKER 1 14:29 Okay. Thank you. Mr. K.

SPEAKER 0 14:41 Thank you. This issue, research on artificial intelligence, I think, is a new it is that area in Kenya, even in our universities, we have very few proposals that handle this kind of subject. In fact, at the University of Kabianga, being a review member for some time now, most of the... what I consider here, the proposals or protocols that meet the criteria of an artificial intelligence. It's mostly own statistical aspects like database analysis, whereby some investigators are trying to interrogate how to control maybe systematic biases or to predict certain models in a way. So it is not actually from IT or our computer science students. It is mostly from the statistics and applied statistics students. But in general, we have reviewed the statistics aspects, where they are talking about bias errors or even controlling certain statistical monitors. But the one from IT itself, especially bioinformatics being as a subject I think we have not received so far. I think that is as per the information I have upto now.

SPEAKER 1 16:09 Thank you, Dr. M.

SPEAKER 0 16:19 Yes Daktari, as a member of KUREC Committee, I must say that we are privileged to have received, not so many, but at least two of artificial intelligence related kind of protocol. And one was looking at how to detect pre-eclampsia using a smartwatch so that information can be able to be sent to the health care provider as a way of managing the condition as early as possible. The other one was looking at wireless kind of detection model that is going to monitor water loss. So, both the two protocols were submitted and we were able to review the same successfully. Though I must be able to mention there aren't very many of those kind of protocols. That is one aspect that we have to appreciate now, apart from the ethics side, we have also been able to participate in research studies that use different models, different statistical associations, just the way Dr A has mentioned to be able to analyze large data sets so that also can be

		classified under artificial intelligence. Over to you.
SPEAKER 1	18:16	Thank you, Dr. M welcome and we will request you to introduce yourself and then you can share with us if you've had an opportunity to review Protocol or a proposal that had machine learning or artificial intelligence.
SPEAKER 0	18:41	Thank you. Can you hear m Prof C. So far, we have not been able to review such a protocol. But I think we need to prepare in case one comes our way. So that's why we're in the meeting anyway, because we know that we have we are moving into new, new kind of protocols that will come our way. And that's why we're here, but did not had an opportunity to do that yet.
SPEAKER 1	19:13	OK, thank you. Thank you. Back to you, Dr T.
SPEAKER 2	19:21	Thank you very much for your very good responses so far. We want to shift gears a bit to issues of data and let me begin by asking whether we have heard about the Data Protection Act of 2019. If so, have you received any training? And has that helped in the review of protocols that you been involved in? So three questions in one, have you heard about it? Have you been trained and how has the training or lack of it thereof informed how you review protocols? I hope you got that. So in no particular order, let's begin with the Dr. M.
SPEAKER 0	20:19	Thank you so much Daktari... I know you know what you are doing, but anyway, let me say yes, I have heard about the data protection act and I must say that we are privileged to at least initiated a training on the data protection act. So, just in the past few months we were able to organize for a training as KUREC. And we were training our potential applicants on the data protection act, what it entails and how people can be able to handle data. I think that has really improved the way we review protocol, keeping in mind that data is very, very sensitive and therefore we really have to find out how these researchers who are proposing to do different kinds of studies are going to protect the data of their participants. That is very, very important because you don't want to have a researcher collecting data and whenever they disseminate they will be able to link... it's very easy to link that data to the research participants. So that is something that has really improved in our committee. Everyone is very, very cautious and you see reviewers keep asking on the issue of how they are going to protect... how the research is going to protect the participant and if that does not come up very clearly from the protocol, then the protocol will not be able to pass because this sensitive information, personal information that should not be used even by the researcher himself. Over to you, Daktari.
SPEAKER 2	22:23	Great. Let's hear from Mr A.
SPEAKER	22:30	Thank you. I'm aware about the Data Protection Act and. We

0 have been trained by our MOI university IRP and MTRH on data protection, in line with the Data Protection Act. This was particularly important for the IRP because of the privacy and confidentiality of information therein. As well as safeguarding attendees identities or identifiable information, especially in live databases. So for data protection act, yes, we are aware and we have done some training as an

SPEAKER 23:08 How have that impacted your reviews?
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SPEAKER 23:13 Yes, but the question in terms of review is now on protocols related to now bioinformatics which and like ... are abit few and sometimes even the IRB members may not have a good understanding of these, so they are some challenges which I think we shall talk about it later. Thank you.
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SPEAKER 23:34 All right. Thank you.
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SPEAKER 23:38 Dr T, before Mr A goes, I was just wondering, he mentioned, that they have had data protection training. Maybe how long ago did this happen Mr. K? I cannot hear you.
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SPEAKER 23:57 Your muted Mr A.
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SPEAKER 24:00 Yes, some nine months ago.
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SPEAKER 24:03 OK, so my next question would be ever since you had that training have you... has it been helpful to you when reviewing proposals that are sent to you, especially in the area of how to manage data?
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SPEAKER 24:21 Very helpful, of course, in the first, what I consider, in ensuring the principle of autonomy among participants of research, we actually check whether they got... data protection has actually been assured. Especially their privacy and confidentiality. Any identifiable information which may not have been safeguarded. We always make sure that it should be safeguarded and we review protocols specifically in mind with data protection. Yes.
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SPEAKER 24:55 OK, thank you.
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SPEAKER 24:57 Thank you. Thank you for the follow up question. Yes, Prof. C.
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SPEAKER 25:05 Yes. I have, of course, heard about the act, but I will admit I have not had any real training in it's application and so on. And I would really wish I could be trained. I think we have been all the same reviewing protocols generally, and this is an area where I think we find most issues arising from the protocols that we receive. And we always, of course, ask for more clarification than all of these. So I think probably a training would make us a bit more efficient in that area or useful, thank you very much.
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SPEAKER 25:49 OK, thank you. WB. The question is, have you heard about the Data Protection Act? Have you been trained and...
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SPEAKER 0	26:02	I want to say that I've had about it. And as ISERC, we've never had any training. But just going back to the basics. Privacy confidentiality in relation to data is very, very key. So what we've been doing as an ISERC we ensure privacy. We don't usually ask in any sense the identity of a researcher. Instead, we can just apply or rather use the id's for identification, identifying one protocol to the other. But we don't use names of researchers. So we protect data. It's lockable. When we have any information, It's not accessed by any person, but only authorized officers can access data, is in our possession. But I would request that if there's any opportunity for training, then we would consider our ISAAC. Thank you, back to you.
SPEAKER 2	27:27	Okay, thank you very much. We WB... Let me hear from Peter. Do you have something to add? I know your chair has spoken, but you may have something to add.
SPEAKER 0	27:42	Not really Daktari, can be heard?
SPEAKER 2	27:45	Yes, you can.
SPEAKER 0	27:47	Yeah, because I'm traveling... so I am trying to connect as I travel. Like what my chair said, I believe we.... I have heard about the act, I've read about it but I think we still need to have some training so that we can connect It's application, especially when it comes to review of protocols and those... of things. So I would really urge if there is an opportunity we could.... I've actually read about it. I've picked out the act, I have read about it. But I need that extra training so that I can be able to see in a real sense, how we can apply that... there is a law that is guarding data and their are prescriptions in that law, so we don't have a choice, we really need to apply it in our ISERC's and as we review protocols as well. Thank you, Dr T.
SPEAKER 2	28:45	Thank you. Mr. O.
SPEAKER 0	28:51	Thank you, Dr T. Before I directly answer the question. Maybe unrelated thing I wish to say is I've never been a participant in any proposal or protocol and the way Dr. P spoke about informed consent, I was convinced that I could give this consent. I am so happy about this. Another time I will not have given my consent. I never used to give my consent on the ... to do anything. You did it so well Pamela, and I wanted to learn, that's ok. So data protection act, yes, I think the only time I get to be very, very happy is now because this is my area, am a lawyer. If you have not heard about a new act, then your friends will laugh at you I have heard about it, I know about you and I was privileged to be chosen to train the Kabarak University IREC on data protection. Just the overview. So yes. What maybe I can say and I've heard it being mentioned by Mr. K. We need to do

more because we have just said, there are some challenges. We really need to do more but for the overview, yes. Just to add, that It's vital to know this act, number one. And number two, the fines associated with breach of any of those things in the Act, for example, confidentiality is so huge that you really just must not only be trained on it but comply with it as an institution. One percent of your turnover, just for not complying. Imagine that. Thank you, Dr T.

SPEAKER 2 30:50

Thank you for those insights. Dr O

SPEAKER 5 30:56

Thank you very much again. Yes. I heard about it, and I've not only heard, I've read about it the entire act. And I've been fortunate enough to have a two weeks training in the act, at the center for intellectual property and IT, ... and Strathmore University. And, I've also had the opportunity to have it incorporated in my postgraduate information security and data management class as one of the areas that we need to go through. So yes, I'm familiar with the act. What this has enabled me to do is actually when I'm looking at postgraduate student proposals, then, the principles, the data protection principles can become very important. And then the custody and the disposal of the data collected becomes very key to handle. You realize some of us who look at postgraduate proposals, especially the questionnaires, you will find some questions that are asked for the sake of it. And if you ask the student, Is this really relevant for what you want to do? So that makes it very important for principles like data minimization, just collect what you need for this purpose and things like anonymization ... and all those important principles. So at least these days, I check them even with the students proposals and especially their questionnaires which they used to collect data. Yes. Maybe I stop at that point. Thank you.

SPEAKER 2 32:57

Thank you. So now, a general question to all of us is how has the Data Protection Act, I know Dr. O has already started in that direction, change the way we should do research? I'm asking this because if it has changed, then probably we change the way we need to review protocols. So you could probably answer the two questions in one. How has it changed or will it change the way we do research? and the way we review protocols? With that in mind? So Dr. O already got started on that one. Anyone else? Some thoughts on how it has changed research and the review of protocols.

SPEAKER 0 33:49

Dr T, probably will allow me just to share a few thoughts, and then I asked to leave because I have another meeting at exactly four. OK. You, you realize that, the act does not really started hitting us hard, and I think people are still not taking the act seriously, but I guess it is coming, and we really have to take it it very seriously as just as Mr O the

lawyer would tell us ... a lot of litigation would start appearing in our Courts of Law about violations of this act. I'll give you a typical example where you still see people sending mass emails with a lot of other people's information without their consent, and that's challenging. But back to your question about how it is going to change, I think it's really going to change the way we handle data generally right from the time we are collecting that data, the way we process that data, are we process it within the restrictions of the law and more importantly, how we keep that data. And what are the mechanisms that we have for disposing of that data because again, we should not keep data for longer than the period it is useful or needed to be used. So how to dispose of this data will be very important. So I think even from a research perspective., we'll have to start getting more serious with the way we handle data even for us who supervise students, even the way our students handle data, probably will have a task of educating them on some of these requirements. Thank you.

SPEAKER 1 36:07 Dr. O Thank you. Before you leave, I just want to say that I caught something that you said concerning the amount of data that sometimes we collect, you know, some of this data that we collect for the sake of collecting. I think this is something that has gone on for a very long time, and this Data Protection Act is going to protect all of us because you realize that we produce a lot of information that can be used to incriminate us or even stigmatize us. The other thing that you know, that you have also brought out very clearly is the privacy and confidentiality. I think in our setup, sometimes we don't know what should be private and confidential, and we tend to do the mass emails like you've said and you find one thread that has so many people's details. And if I want to track you, I can quickly track you. And when it comes to data collection, we heap all these things together. We don't care about how we store it. I know one time I asked a student to indicate that they would store the data in a lockable cabinet, and everyone laughed. And I said, Where do we normally keep this data in our day to day life? So I like the, you know, examples that you've given, especially for us in the teaching institutions as well as in IRBs, because when we look at these protocols, we'll be looking to make sure that this data is protected. Thank you.

SPEAKER 2 37:38 Thank you for the additional insights, Dr. P. Let's hear from the rest. How is it changing research? And thank you, Dr. O, for taking your time to be with us. We may follow up with the remaining questions on a different session. We have three questions, and we will still seek you out for them. So thank you so much. All right. Thank you. So anyone else wants to take a shot at this? How is it changing research and the review of these protocols? Mr A

SPEAKER 0 38:17 I think the review of the protocols, the IRECs then have to be much more diligent and much more strict, and then they have to develop new forms to be filled, at many different stages, not just maybe at the time of submitting a proposal or the protocol to IREC. And it may well be that other forms have to be developed before even the the researcher brings their applications to an IREC. For example, if they're saying they're going to be using data or samples which are already available in their lab. How did that lab itself collect whatever sample or data which was there? That data or samples which was in a certain lab was itself subject to data protection prior to that collection? So that the researcher is coming to IREC and saying, I have this proposal, I'm going to use data which is in a certain lab or in a certain database already, I want consent for my proposal. But then, does the researcher have consent of the data that they are going to use? And had those people who have given their samples or any other data consented to it being used for a research purpose? So, much more stricter application of the forms of the consent prior to even coming to an IREC. Thank you Dr T.

SPEAKER 2 40:06 Hmm. Very good insight there. Go ahead.

SPEAKER 1 40:09 Mr. O, you've brought out something that is critical, especially in large datasets and even when we collect data because a lot of times we seek for consent for the immediate use. But we keep this data and we don't tell the participants that there may be a probability for this data to be used again at a later time as secondary analysis for existing data. So I like the idea that you've brought that when we think about consent, we need to think of what type of consent we are giving. Is it just for this? And then we discard the data and what could be the implications for this. And if we are keeping the data, how then should we seek for consent so that another person may use this consent? I think that is very important. Thank you.

SPEAKER 0 41:02 I just want to add on to what Mr. O has mentioned with regard to the review of protocols. Now in the recent past, we used to have protocols that are experimental in nature. And most of these protocols would just go largely because we see that there isn't really much risk. And we see that they are not really collecting human data directly. But recently, after the Data Protection Act, we realized that we have question where the research is obtaining the material that they are going to use for this experiment, that is number one. And we also are in the process of reviewing our tools so that we incorporate the material transfer agreement aspect. We know that that is given in a different department altogether by the government. But then, considering that material can be moved from the country to another country, but then these experiments that are being done in the lab,

you say someone has gone to KEMRI, they have gotten some isolates or they have gotten something, those have been obtained from individuals somewhere at some point. Now we want to know whether that particular individual gave consent. That material that they donated to that particular organization can be used by other researchers, so we need to see that broad consent being availed by this researcher. So it is not just a matter of saying that we will go to this lab and pick some, you know, some material from there and come to our lab and you know, and do the experiment. Then the other aspect that has largely been lacking from this kind of protocols is the aspect of how those materials that have already been used for experiments can be discarded. They just mention about preparation, culture and then blah blah blah, and then they stop there. They don't tell us how they are going to discard that material, how they are going to protect that data because that information can be traced to someone. So it has to be very well protected. So that has really improved the way we look at different protocols, not only those ones that have artificial intelligence, but largely all protocols that come our way. We really emphasize on the issue of consent, we really emphasize on the issue of data safeguards that has to come out clearly regardless of what kind of study an individual is doing. Thank you.

SPEAKER 44:22

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Ok, go ahead.

SPEAKER 44:23

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I think Dr. M, you've brought up a very good discussion. We should not look at data from the surface. We need to dig deeper to try and understand if there are other things that would be harmful to the participants if not addressed. And that is the reason we are here today because a lot of times when we think of artificial intelligence, we tend to think about machines and we think that the data, you know, we are just getting data. It is not going to affect an individual, but that data can affect my livelihood. That data that we get may affect, you know, may stigmatize me. For example, if I'm doing a prediction about something maybe development of a congenital disease, then I may be together with my offspring, maybe stigmatized because people know that if you marry from this family, the probability of you getting disease X is going to be this way. So sometimes the data, when we think about data, it might look like a very harmless thing. But when we probe and go deeper, we find that there's a lot that we need to scrutinize to make sure that we are protecting those that are coming in. So I like that you have brought that up, and I want us to go back now to the you know, machine learning just a little bit so that we can finish this discussion. Thank you.

SPEAKER 45:54

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All right. Thanks so much. Just any final thoughts, ... on what is changing because of the Data Protection Act. Just your

thoughts.

SPEAKER 0 46:10 Yes, thank you. I think what is coming up is that, of course, initially we used to be very casual about data, but now we have these Act in place. We can see the seriousness. And that also goes for the IRECs. I think we need to be protected by being properly trained because what we pass and any protocols we pass and any subsequent use of any data is going to come back to us. And with the awareness in public now about issues and the law and their rights, I think we need to be very careful now. And the IRECs need to really be properly armed, you know. Thank you very much.

SPEAKER 2 47:02 Thank you. The reality is beginning to come closer to us. I'd like that perspective. WB.

SPEAKER 0 47:14 Yes, I want to contribute by saying that because the Act is in the public domain, I think, researchers are becoming more and more keen when handling data, and this has really helped because issues that have been overlooked in the past, like the earlier speaker said when it comes to material transfer, there cases that we intercepted at one point whereby an investigator was kind of shipping some of the samples to a foreign land for further analysis. And when we got to know this, we had to stop the process because anything going out or anything being transferred from point one point two, there must be some protection, there must be safety, there must be a consent signed. And that one really brings a lot of sanity to the scope of science. Again, I believe with this, we are going to improve so much because there will be few issues or legal issues that normally come up as a result of data are not being handled well. And that is my understanding. Thank you.

SPEAKER 2 48:52 Thank you, for this, a very, very good insight, WB. OK, so, Mr K, you have something to add on to that before we move on to the final set of questions.

SPEAKER 0 49:06 Not new as such, my only contribution is on the question of whether we are implementing the Data Protection Act 2019. In my humble view, this is more of a boardroom thing. There's no systems in place for monitoring the violations of the protection of data. Most of the IRBs in Kenya, including NACOSTI, which is actually the one delegating the authority. They have not put in any new measure to make sure the compliance of data has been set. We are still using old model in IRBs, despite the Data Protection Act. So, and if you just...very well, It has very nice English about general risk of that, safeguarding, security etc., but how do we manage that? There is no mechanism of monitoring any violation of these, as we speak, I have never heard any person who has been brought before a court of law in violation of any privacy. Maybe on Safaricom issues and etc, but not on research and Bio-informatics subject. And another issue is based on the general problem of monitoring of research in

Kenya. We know that IRBs, normally look at the proposals, make sure that we have these very nice language of protecting the data, using whatever mechanism, but immediately we give the authority, the approval, nobody cares whether that person is actually adhering to it. No one comes and check when you are collecting data, to check whether you are actually adhering to what you have written in your beautiful protocol. And another issue related to that is we don't know disclosure of information, as we give out information, some words can hurt other subject participants and there's no mechanism of knowing the psychological impact of this, as well as among the investigators themselves, especially postgraduate students, where we do a lot... they do a lot of research. Do we say we can collect unnecessary data the way I have heard from some of the panelists? I don't know whether there is a useless data. The question is, is it relevant to the subject that you are trying to investigate, even if you collect irrelevant data, but you can still assure safety, and it doesn't cause any harm to the participant in any way, I still find that OK. So in Data Protection Act, it is still a boardroom issue, It has not been implemented, even prosecutors I don't know if they really understand this thing, but in terms of IRBs and implementation of this, I think we have a long way to go. We don't know, even transfer of materials, continued, consenting... For instance, one point consent is different from continued or broad consent, is different from continued consenting... We have no information on that as such, and there is no mechanism of knowing... So the issue is, data Protection Act is still in paper. In practice, I think we need to do a lot... Thank you.

SPEAKER 1 52:25 Dr T, if you may allow me... thank you for the insights that you've given us, Mr. K, maybe my question would be why do you think we have very beautiful papers with very little implementation?

SPEAKER 0 52:44 Generally, we have a culture in Kenya of not funding researchers well. Even IRBs are not adequately funded to monitor the implementation of this research protocols. And then training of these principle assistants, some of us are thinking we are actually very good investigators. We know these things, but when it comes to implementing, we are actually doing the opposite. So what is in the ground is different from what is actually required. That is what I think is contributing to this. And at the same time, the level of education in our populist who are normally our study subjects who we collect data from, some of them do not even know whether we are violating their rights, we normally ask them in our consent form. You are free to answer any question and you are also free not to answer some. But in essence, some investigators will go ahead and make sure

that all information is gathered.. is filled up and so that you don't have any missing data. So we have a culture and we need to change our mindset, as well as financing the implementation and research in general. That's what I think. But for new subjects like bioinformatics, even the investigators themselves or the reviewers do not understand that subject, for instance, computational dataset analysis, we don't know whether a model that has been developed for predicting say a certain disease or any other condition could have been done in a way that we can say that it can offer data protection. I think that's what I.... It's complex, and that is what I can say for now.

SPEAKER 1 54:41 Thank you. Maybe the last question to you, Mr. K, do you think training, for example, training the Research Ethics Committee on the basics of some of these things, for example, bioinformatics or even in machine learning and artificial intelligence and then training, maybe the artificial intelligence developers on the basics of what they need to include to make their work ethical? Do you think it would solve some of these problems that you have raised?

SPEAKER 0 55:18 Thank you. That's a very good question. These problems mostly can be reduced significantly by training and making sure that the investigators, including the reviewers and even the funders of research, are trained to have adequate information, adequate knowledge on this subject. Without training, we will not be able to even safeguard or to ensure that these data protection is adequately done or even to guide the postgraduate students and sometimes undergraduates on some of the ways in which we can ensure that this kind of information safeguards are taken in place. Sometimes out of some professors, some academic staff who are not aware about this, and they only know their subject, but actually safeguarding the information, they have no idea. So training is actually significant in reducing some of this challenges.

SPEAKER 1 56:27 Thank you Mr. K, so I'm going to continue this conversation and ask the rest of the participants about capacity-building, especially for machine learning and artificial intelligence and in terms of data protection. What are some of the things that we need to put in place to ensure that we just don't have good papers and bad implementations or anything that you feel can be done for us to be able to protect our participants better? And this is open, we can have anyone, you know, give us their insight, other than... Mr. A here has talked about training, what other things can we do to capacity build so that we better understand maybe data protection and even maybe artificial intelligence and machine learning and better protect our participants?

SPEAKER 0 57:28 Dr. P, If you allow me, I just wanted to speak for few seconds on still the data protection act. The consent when given, Ok,

under the Act... The consent, when given should be as easy to withdraw as it was easily given. So that, for example, in our scenario here today, I have given the consent... during the course of this focus group discussion, I can easily say, guess what Dr T, Dr. P, I don't want to continue with this interview. And that would be OK. And maybe later you will give me a number to see how far can my data be used or etc. So let me give you an example of Java, very simple example which we will tie in to what we have said. If I buy a cup of coffee from Java, I'll get a message there and it will tell me kindly rate our services, great, good, bad, fair etc. I'll answer, and it will at the end say if you don't want to receive this message, and I'm sure this happens to any other service providers, just press stop. So I can press stop and I'll no longer be able to give my data or my information. As Mr. K said, most of our data subjects are illiterate, if they give consent. One, you as the researcher will give a very good run down, just as Dr. P has said here, of what consent, what they will do, but they will not even know whether their rights are being violated. So, one is education. But for them, even if they give their consent, how easy is it for them to withdraw that consent along the line? So it should be easy under the Act. The last thing, under the Act, I really want to say is that the Act majorly dwells on the right to privacy, which is a constitutional right, which was provided by the constitution of Kenya 2010. So the Data Protection Act, only came in to actualize, yes boardroom still kind of thing, but only need one person, just one to sue an institution or even a person or an organization and everyone else will follow, so we would rather be safe than sorry because the fine is hefty and as you know our Kenyan Judiciary is very vibrant. Anything that touches on the Constitution's right to privacy is a fundamental right. They will enforce it very quickly. So that is for the previous question. So then, with that interruption, kindly, Dr. P give us the question again. I know the others have understood theirs. I would like the question again. So I think about it.... Thank you

SPEAKER 01:00:2
1 8

Thank you, my question was capacity building, what do we need to do for us to understand maybe data protection, machine learning and to capacity build for us to be able to review this proposals to ensure that we are protecting ourselves, as well as our participants in the research studies that we are carrying out. I know Mr. K had talked about training being very important. Anything specifically that you'd want us to train because training is wide, is there anything specific? Is there any other, you know, innovative ways to help capacity build us, as you know, Research Ethics Committee so that we are not passing things blindly and harming us as well as our participants.

SPEAKER 01:01:3

If I can... maybe to add.. I don't know if.... its not different

0	1	<p>from what I have earlier said. But training and continuous training is the way forward in this matter, especially one way of increasing this number of trainees and people who are in authority in this subject, like the reviewers and students, is to do more workshops on these subjects, including more on highlighting on data protection act and even on training on issues related to computer protection, privacy, confidentiality issues. We can do in workshops. And Education, if you check even curricula of our medical schools, curricula or even schools of public health curricula and even IT schools, computer science schools. Most of their curriculum not emphasize much protection and this data protection thing, I think, because you find that most of the research experts e.g professors and others who are in this subject and are experts in these computer things, when it comes to data protection, they miss even when we are reviewing their protocols. So I think we need to improve even in curriculum development on that subject. And I don't know whether we also outside the training, we need to involve the media to sensitize the public so that even the research participants can know that I have some basic rights. How do we use the media, the print TV and even the radio kind of public communication to help the public to understand the data protection? How can I, if I choose to participate in this study, for instance, where being part of the millions of participants like datasets can be can be developed? How can my rights be protected? How can I be assured my autonomy? How do I get full disclosure of information for me to make a decision? Those are the things that we need, even for the members of the public where we derive most of our study population from, you know, and I think we need to bring in different stakeholders, the media, the academia, the regulatory bodies, and then we need also NACOSTI to be more active. NACOSTI i think is a sleeping giant in this matter, and most IRBs are actually on their own. They are doing things on their own, they have no policy guideline from the regulator NACOSTI, and with that, I think we can improve. Those are what they think for now. The ways in which we can improve other than the continuous training. But the most important is training, training and training. And we need to target the training to people with different education levels, with different interests and with different understanding of these subjects. I think for now that is it. Thank you.</p>
SPEAKER 1 0	01:05:0 4 01:05:0 6	<p>Thank you, Mr. K.</p> <p>Dr. P, something small to add on what my brother has just talked about targeted training is key, and I was thinking in this dimension that to increase this capacity, can we try, because the trainers may not be as many to reach all the</p>

regions or all that to be trained, can we work with the TOTs that we identified TOTs from different regions so that when they're trained on these, especially on data protection and ethics. Generally, ethics related to all research. This same people can reach out even to the community to sensitive them on matters concerning their rights. And I think this can really have an impact because like if we have research trainers say from NACOSTI or from whichever organization, they may not be able to reach as bigger numbers as we may want, so TOTs can really inject some good sense of information to the larger population. That was my addition. Thank you, Miss N. Any other additions? Yes, Prof.

SPEAKER 01:06:3
1 6

SPEAKER 01:06:5
0 1 Yes, thank you. I think I agree with the previous ... this especially with the AI area being very new. I think, and of course the data act. I think we should have more training as the ISAAC members, because most of our members where we get the the protocols from also depend on us to actually educate them on what is required. I think more regular trainings is very welcomed....

SPEAKER 01:07:1
1 6 Prof, please check your speaker. Thank you.

SPEAKER 01:07:3
0 8 Hello, can you hear me now?

SPEAKER 01:07:4
1 3 Fairly better. It is better, yes, better now.

SPEAKER 01:07:5
0 0 Yes, I think what I was mentioning is just to reiterate that the trainings should be more regular in this new emerging areas of AI and of course the data act. This is of course to our advantage the IREC, as well as to our members because we have to come and educate them on these... so that their protocols are inline with what is required. The other thing which was mentioned was that most IRECs are working under a very difficult ... especially in terms of resources....

SPEAKER 01:08:2
1 9 Please move closer to the mic. Prof.

SPEAKER 01:08:3
0 5 And therefore, I think we should advocate for more funding and resource building up within the IRECs. Thank you very much.

SPEAKER 01:08:4
1 7 Thank you, Prof. Any other thoughts? Dr M.

SPEAKER 01:09:0
0 0 Yes Daktari, I'm following the discussion. And i think training is the way to go, especially in the area of artificial intelligence. This is something that has been there, but it is now something that is now coming out in the open. I mean, intelligence has been there for a very long time, but now people are beginning to get aware that this is the new way in which people can be able to do things. And there are so many protection issues around artificial intelligence that a layman may necessarily not be able to be aware, may not be

aware of, and therefore we need to be able to do a lot of training. Training for ISERC, training for the community members, they need to know they are rights, just the way WB has mentioned. And all together, we can be able to be well-informed around the area of artificial intelligence just to know where your data... your information is going to and who is going to handle it. That is, for me, I feel that is a very big challenge in the area of AI because that information is not usually clearly given. But you see information is being collected about you, OK? And the fact that you don't know where the information is going to and who is going to use it, and whether it is going to be safe, so that things that when you think of you, you just get scared. But again, if people are well educated in the area of AI, then I think it can be. It can be very good. Thank you, Daktari.

SPEAKER 01:11:0
1 3 Thank you, Dr. M. Mr. O.

SPEAKER 01:11:0
0 6 As regards Artificial intelligence, I think it's not just the IREC or the researchers who should be trained. It should also be the subject, OK, because it's going to involve them and you have to tell the person who are researching about that, what's going to happen here is that a certain machine is going to take information and make a decision. And the guy will ask you, OK, so what about if it make that mistake? I don't know whether you've explained to him that, well, this machine will to make a mistake. But I don't know, can I trust my information with a machine? So I don't know. Those kind of thing... the average person here, a person would go to school and has a university degree some even don't know what AI is ... I know what it is, I don't know how it works. So, the subjects themselves, also have to be sensitized that a machine is going to be something on your behalf... on behalf of me, I'll take this data put it in a machine, the machine will decide XYZ. That is my take. Thank you.

SPEAKER 01:12:1
1 8 OK, thank you, Mr. O. I don't know if I've left anyone out. OK, then maybe I'll ask two questions right now together. The first question would be would it be helpful to review our current protocols or our current application forms so that they can capture some of the things that are relevant for, you know, artificial intelligence or machine learning? And the reason I'm asking this is because artificial intelligence is going... is fast infiltrating the health care. A lot of things are being used now in health care that use artificial intelligence. And just like Mr. O has said, we have a lot of data being churned out from healthcare, they are the ones that are being used for prediction. Should we then tailor our application forms to capture some of the specific things in machine learning? And then my second question is, would it be helpful to train the ISERC members on the basics of machine learning and artificial intelligence? Two questions.

SPEAKER 01:13:4
0 1 Maybe I'll go first on those questions. My answer for both is yes. Why, yes, it is, because, as you know, science evolves. And right now, we are at that point where we are no longer looking at the human interaction, human offering service to human. AI has been introduced. So yes, AI has to be incorporated in our review form. And again, following the mandate, the new mandate of ISERC. We need to be able to review these protocols that may come our way. It is not only specific to one category of protocol, we may receive different kinds of protocols. We may decide to send to the ISERC of WB a protocol in IT in a specific condition that is being managed in their health facility. How are they going to handle that particular protocol? OK, so we need to generally review the form to capture all aspects, all ethical aspects in research. Regardless of which kind of research is going to be conducted, so that includes AI. What was the other part? Training of ISAAC?. Yes, ISERC members need to be trained. Not everyone knows what artificial intelligence is. And not all ISERC may have a person who is familiar with machine learning or artificial intelligence, so therefore every ISERC member needs to have an idea of what to look for when they, you know, when a protocol of artificial intelligence comes their way. So not only waiting for an IT person. So, in our ISERC, If our IT person is not there, so what happens? We refer the protocol to somewhere, to another ISERC. So that training is very important for ISAAC members. Thank you.

SPEAKER 01:15:5
1 9 Thank you, Dr. M. Any other person? Your thoughts on incorporating changes to our application protocols and training in AI for ISERC members. Mr. K, what are your thoughts?

SPEAKER 01:16:3
0 0 Yeah, thank you. A review of the protocols to incorporate this subject, I think is overdue. It is very, very important. I highly recommend. And if you check, if you do assessment of the current protocols that we are using, it is totally insensitive to these new data protection. So we need this. And in aspects of training the ISERC members, I think it is important so that we can all be in a position to detect this subject to another level because without training, we shall have what is called information symmetry where others know, the IT guys know, and then the non-IT fellows doesn't have any information. I think so that... to me, what I can call a consensus point and for better implementation, I think training is very, very important and to emphasize the first point, there is an urgent review, maybe a stakeholders meeting of all the IRBs so that we can review these things and even harmonize on what should be in the review documents on when we are approving research proposals so that even different institutions.... as we speak right now, they have different ways of reviewing. I think we need to standardize and incorporate artificial intelligence and even other systems I.T.

related, so that we can be able to assure data safety. Without this, I think it is virtually... it is almost impossible.

SPEAKER 1 01:18:1 Thank you. Thank you. Mr. K. Mr. O.

SPEAKER 0 01:18:2 Thank you Dr. P, Will it require change? Yes. And for me, of course, beginning with the second one, you have to train the members first, so that they know what kind of questions to develop in the current protocols. If you don't train them, then how will they know what to include the protocol? Because the IREC members are the ones, who are going to be users, so to speak. They are the ones who are going to be testing whether such a protocol meets a certain threshold. So they have to be trained first in order to inculcate into the current protocols, which have to keep up with the changing times. I would like to really agree with Mr. K, who was saying that after the training Because we are an extension of NACOSTI, OK, we are their agents. We are the ones who do work on their behalf. It is better to have the IRECS harmonized to a very large extent across Kenya so that any researcher, who goes to any IREC knows that if I go to X, I'll get the same amount of.... the proper treatment as I would go to Y because we are really an extension of NACOSTI. And of course, the issue is funding as Mr K earlier said. But thank you. That's that's my contribution.

SPEAKER 1 01:19:5 Thank you, Mr. O. Prof. C. Your thoughts?

SPEAKER 0 01:20:1 I think the issue of training is very paramount. What I would, of course, one of the reasons is that AI is now cross cutting all areas of So I think ISERC people should be aware of the basic of AI. Of course we are teaching from our point of view of the ethics, right? And it's not that we are coming to get a certificate in AI, you might scare some people away, you know. So, I think it will be from that point of view, including, of course, the data Act.... it is a very important aspect which I think it has been played down or neglected upto this moment and we have now seen the seriousness of that Act and the consequences it might bring to ISERC. So, I think training is long overdue. Thank you very much.

SPEAKER 1 01:21:2 Thank you, Prof. C and Miss N

SPEAKER 3 01:21:2 I just want to say that large and by we, I wish that we start this training as soon as possible as yesterday all ISERC to be trained. My concern is if individuals are taken to boardroom trainings meetings, sometimes from experience, it remains. The information remains with the individuals because when they go back, they'll are overtaken by other assignment and they forget to give feedback. And that is why, in my earlier statement, I categorically said that if we can have trainers of trainers so that within reach, we can have people to train almost every ISERC that every member gets to understand

what concerns the particular protocol that you undertake, what concerns the data that is in our custody and also reaching out to the larger community and give them the information. What is theirs, what belongs to them so that we are all at per. Yes. And the training, should start with us especially the nine who have been on this platform. Yes. Thank you. That is well noted. Back to you, Dr T.

SPEAKER 01:22:5
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SPEAKER 01:23:0
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Yes, thank you, I have been listening, wonderful engagement, yeah, I think you have exceeded our expectations. The depth of your contributions, the passion, I don't want to add much because we want to digest this, but that said, in normal concluding when we proposed to start with this study, we had that feeling that you have just confirmed. But in research, you all know that you don't go with your feelings, you don't go with the intuition, you need to collect data to confirm those intuitions, those feelings, those imaginations. If I may say so, your now much confirmed, and even added on to what we thought. And I mean, we feel validated in terms of indeed, this is an issue that needs to be addressed. This is something that is important, you have confirmed that beyond all reasonable doubt. So, WB has given us a very good concluding remarks. And we just go from there. She has read our minds. We will check, how did she manage to do that? Or maybe we were in the spirit... Our intention is to extend an invitation to you who have taken your time to join this focus group, to have the front row seats in the first training that we shall hold. Remember, the training is part of a study, so you are probably going to be invited to be ... on what may in future rollout to all members of ISERC as a fundamental training on artificial intelligence and data protection. And we would be glad to have you there because you will also help us to develop those tools we have discussed. Those tools that will help us do that review that we are seeing, there's probably a gap. So this means you are now part of a team, and I hope you're feeling it that way, you are part of the making of that bright future that we hope to have. So when you extend the invitation to you and please be gracious enough, we'll give you notice. We are hoping to do so within the first two weeks of September. Hopefully, you may begin telling us, but we hoping first weeks of September and it would be residential, so we will facilitate your coming and you're going, you're staying depending on how far you come from. We'll give you all the details. So in that event or that engagement, we shall have the other side of the story also present. We shall have people whose bread and butter is Artificial Intelligence. Yeah. All they know is AI. And they have no idea what is ethics, but they know AI. And you know ethics, and maybe not so much of AI. And we are going to learn together. We are going to

mingle. We are going to cross pollinate and come up with something that should work for that common purpose. So giving you just a little bit of a preview or a trailer of what is coming up. Immediately, we are done with that particular engagement. We shall then pilot those tools and when they are ready and good to go, we disseminate them at no cost to any ISERC that wants to use them. We have engaged NACOSTI already, we have shared with them this plan and we had hoped that they will be part of this journey. We are still hoping that there will be, if not at the training, maybe at the validation, but essentially we have already engaged them and we hope that they will be able to also own up these kind of initiatives and give them some impetus and maybe even validate the tools for us and encourage the adoption. So just to clarify that we are not doing this without the knowledge of NACOSTI. We know the critical role they play, of course, they have given us a permit to do this and we hope that they will even do more than that. So those are the closing remarks. Expect our invitation in a few days. Everybody saying after the elections, we also join in saying after the elections... We should expect an invitation. And yeah, that would be it for me. Let's pray for a very peaceful election and we have our different inclinations. But at the end of the day, we would love to continue with this kind of peaceful interactions without the tensions that are there right now. So I'm just urging us that let's not forget our other responsibility and to pray for this country and to be part of the solution. I don't know if anyone has other closing remarks. I didn't exactly mean to be final. Those were my closing remarks, but any other person can now, just say something.... we essentially are done with the focus group. But if anything, you think you have remembered, some suggestion, some parting shot. You're welcome in no particular order. Anything that's relevant to the discussion. Let me be the first sheep. First of all, congratulations. This is a very novel study which... when i even checked.... When I was trying to familiarize myself with this, it was actually.... I found that it is very nice, I think we need to encourage more research like this and it helps to solve most.....

SPEAKER 01:29:3
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