Questions & Answers from the EDCTP Knowledge Hub webinar held on 30 November 2020

#	Question	Answer(s)	Additional follow up answer
		Questions responded to after the webinar	
4	I believe it will be very interesting and clearly visile if we could have a shared classical data sharing sample from start to end and functionality for others to follow and implement in the different networks ....is that possible? thanks	Thank you for the suggestion. There are examples of some of the specific steps of the data sharing process available, but not one whole case study from start to finish (we will bear this in mind for inclusion on the EDCTP Knowledge Hub in the future). It is suggested for now that you explore the resources available in the Data Sharing Toolkit as well as the external resources made available through the Hub (https://edctpknowledgehub.tghn.org/data-sharing-toolkit/collated-external-resources/). Sharing an example through the Hub could be considered for future updates. Additionally, there is a new e-learning course on Data Sharing that just launched so it would be worth looking at the course content (https://globalhealthtrainingcentre.tghn.org/data-sharing/). We will add this link to the resources table on the EDCTP Knowledge Hub.	
13	Great to be here and listen to your talks, thank you very much. Just wondering as I might have missed this bit of info as regards the user community - could you comment if regulatory auhtorities have expressed interest or are readily tapping into these resources & knowledge hub? I`d imagine this could be such a great way to either open (more) collaborative avenues or strengthen timely exchange of information between "regulators" and "researchers"? Thank you.	Thank you for your question. Feedback from regulatory authorities as well as ethics review boards would be highly welcome. EDCTP will share and promote the resources on the EDCTP Knowledge Hub with grant holders of 'Ethics and Regulatory' projects, and would welcome their feedback as well.	
16	Do you filter ressources filtered on documents that fit European regulations on research data, or is it broader ?	External resources provided through the EDCTP Knowledge Hub are kept broad. Note that the views and opinions of authors expressed in these resources do not necessarily state or reflect those of EDCTP. These resources have been collated to allow researchers to access, and easily search for learning materials, guidelines, templates and articles which are free, open access and relevant to the toolkit. Inclusion does not indicate endorsement or recommendation by EDCTP.	
17	How frequently do one review database to search for errors or incomplete access in an environment where access to internet and resources are limited?	Once we've carried out internal testing, we do rely on user feedback, through user groups or the community, to determine issues with the content/functionality. We build these apps and resources with low-resource settings in mind and so try to make them as simple and low-powered as possible. We also try to provide downloadable offline resources where we can. Feedback can be provided through https://edctpknowledgehub.tghn.org/data-sharing-toolkit/repository-finder/repository-finder-feedback/	
18	How can partners from developing countries benefit from Data management capacity building?	Good data management is essential for ensuring the validity and quality of data in all types of clinical research. It is an essential precursor for data sharing. The data management portal has been developed to provide support to researchers to ensure that high-quality data management is fully considered, and planned for, from the outset and throughout the life of a research project. Training resources are and will continue to be made available through the EDCTP Knowledge Hub: https://edctpknowledgehub.tghn.org/training-courses/ Additionally, the following links to the TGHN's Professional Development Scheme, the Process Map and the Training Centre (which has a course on Good Data Management) may be of interest. We will add these to the resources table on the EDCTP Knowledge Hub too: https://globalhealthtrainingcentre.tghn.org/pds/ https://globalhealthtrainingcentre.tghn.org/introduction-data-management-clinical-research-studies/	
19	Is there any kind of FAIR assessment of the repositories in the finder tool? And how does this align to FAIRsharing.org?	In order to interpret the extensive list of repositories recommended by journals and funders, the open access FairSharing ontology was applied to filter by subject areas related to health, based on metadata from re3data.org. Other metadata fields from re3data.org were used to faciliate building the repository finder. This metadata includes the keyword 'FAIR' for those respositories that have been assessed as FAIR within the re3data.org database. See also: https://edctpknowledgehub.tghn.org/data-sharing-toolkit/data-sharing/recommended-repositories/	
20	Question to Sam Driver.....While collecting these information from various portal to come up with final research....what data intergrity issues such as security of the cloud servers for various clinical research withing the global	Is this relating to data security issues around storing research data in cloud repositories? We have added a related article below and will try to locate some newer resources to add to the resources table: https://journalofcloudcomputing.springeropen.com/articles/10.1186/2192-113X-2-13	
24	Do you dowload your tools and apat our study for using?	The EDCTP Knowledge Hub aims to provide researchers with tools and guidance to enable them to conduct high-quality health research. Any templates downloaded are intended for adaptation to fit your needs.	
32	in future that is		
33	Good Evening Can you enlist the emerging trends in Clinical Data Management?	You may want to read the following White paper from the Society for Clinical Data Management (SCDM):https://scdm.org/6588/. This paper is discussing how, amongst others, emerging study designs, regulations and technology innovations are reshaping the role and profile of clinical data management.	

38	is there a way for low income country to submit their article cheaply or even for free in these repository ?	Repositories are intended for data storage rather than articles. Some repositories charge costs for storing and sharing data while others are free of charge. This depends on the repository selected. Members of The Global Health Network can submit articles for publication on the platform. Membership and publication is free. Please see: https://globalhealthtrials.tghn.org/articles/	
39	Hi all		
44	Question to Francine Ntoumi.....What were the challenges you experience with accessing paper (manual) data collection especially in rural areas where technology is a problem....please from data collection to data analysis as this will enable the global health network to come up with strategies to meet these challenges in future...	This question has been forwarded to the speaker and will be updated with the response.	
45	Sorry I'll have to drop off to get to another meeting. One very important consideration I feel needs to be factored into any data sharing policy/agreement will be the role of the IRBs. In my setting, there are 2 main misconceptions (1) data sharing makes it difficult for IRBs to perform their primary fucntion which is to protect study participants and (2) the motive behind this might be solely to discredit the work done	Thank you for your question. Feedback from regulatory authorities as well as ethics review boards would be highly welcome. EDCTP will share and promote the resources on the EDCTP Knowledge Hub with grant holders of 'Ethics and Regulatory' projects, and would welcome their feedback as well. We are also looking into how to incorporate this perspective into any future events.	
47	The cultural aspects of data sharing - can one elaborate more on this/concerns and key aspects in another webinar since this has been touched upon today again, and as well ? Thank you?	Thank you for your question. We will look into how to incorporate this into any future events.	
48	How is it possible to sponsor research project for public health institutions.?Haruna, National public health laboratories	This question does not relate to the webinar but you are welcome to contact us for further information.	
50	i have aquestion,with this data sharing and management,the key target here is the patients details and maybe on the clinical issues,what of if the data is hacked can we be sued for that	The EDCTP Knowledge Hub is not a repository in and of itself. We would advise that you refer to the individual respositories for advise on how these issues are handled.	
51	Encouraging access and use is as important as providing access. Large anount of data sit unused in repositories that are not exploited. EDCTP could consider funding shemes that would lead to this data being used. A good user-friendly interface is also important.	Thank you for this suggestion. The focus of our efforts so far has been on gathering and providing information on the various repositories available and to help researchers with determining through a decision tree which is the most appropriate to use for their purposes. We do not provide an opinion on these repositories or recommend one over the other, but could certainly consider what EDCTP could do to help facilitate the use of data that has been openly shared through them.	
52	Why do ethics committee and other institutions refuse data sharing and how to change the culture of data sharing?	Thank you for your question. Feedback from ethics review committees and regulatory authorities on the EDCTP Knowledge Hub would be highly welcome. EDCTP will share and promote the resources on the EDCTP Knowledge Hub with grant holders of 'Ethics and Regulatory' projects, and would welcome their feedback as well. We are also looking into how to incorporate this perspective into any future events.	
53	Are there systems in place for data quality checks, to enhance data validity?	TGHN will perform a quality check on the information provided on the EDCTP Knowledge Hub, but will not monitor the quality of data shared on any of the repositories listed as this is beyond our remit.	
55	Do you have any mobile app (data collection tools) so as to support during process of data collection?	A few years back TGHN carried out a review of Data Management Systems. We are currently updating this review: https://globalhealthtrainingcentre.tghn.org/articles/data-management-systems-your-views-needed/	
56	What steps are taken through thisinitiative to protect the rights of local communities on sharing indiginous knowledge?	EDCTP has participated in the TRUST project, a 3-year EU funded project and a global collaborative effort to create and enhance trustworthy, responsible partnerships in international research. One of the main outputs was a Global Code of Conduct that is now used by the EC, EDCTP and other funders to foster ethical research and equitable partnerships. The following resources will be added to the resources section of the EDCTP Knowledge Hub: - Global Code of Conduct (https://www.globalcodeofconduct.org/) - Ethical guidance on community participation: towards empowerment in collaborative research - Book: Case studies (Ethics dumping) - Book: Equitable Research Partnership	
57	Please this question is to Jennifer. About the community engagement. What if the community is not willing to give out or get involved or engage in the data you want to collect. And how sure are you that the community is going to give you a correct data.	This question has been forwarded to the speaker and will be updated with the response.	
60	i beleieve if we all understand clearly the rationale of data sharing, then they will adhere	Thank you for your comment.	
61	There is limited data sharing and paucity of data from the Gambia, what are the chances of being engage in such research and have access to such data sharing tools.	The EDCTP Knowledge Hub and its data sharing resources are freely accessible to anyone, regardless of location or background.	
62	As the process for data collection will be launched, what level of confidentiality will be used to run away from public consumption? or else will it be more voluntarily?	This question is not entirely clear to us. Please feel free to follow up via https://edctpknowledgehub.tghn.org/feedback/	
66	do you plan to have a french version of materials and tools available	Currently the materials are only available in English, but we are looking into the possibility of translating the EDCTP Knowledge Hub into Portuguese and French in the future.	
69	I am looking to data management couse. should i ask for one?	Training resources are and will continue to be made available through the EDCTP Knowledge Hub: https://edctpknowledgehub.tghn.org/training-courses/	
70	How will political interference be delt with in order to facilitate the programme in the host/ target countries?	This question does not relate to the webinar but you are welcome to contact us for further information.	

71	do you plan to have a french version of materials and tools available in the EDCTP knowledge hub	Currently the materials are only available in English, but we are looking into the possibility of translating the EDCTP Knowledge Hub into Portuguese and French in the future.	
72	Shouldn't we join and build onexisting platforms and softwares for data sharing? The most contraproductive way to sharing data is if everybody organization develops its own new way of data collection. To this end, which platform is the one most promising and used?	Please note that the EDCTP Knowledge Hub is not a repository in and of itself and we are not developing our own new way of data collection. Rather, it serves the purpose of gathering and providing information on the various repositories available all in one, easily accessible place, in addition to helping researchers to determine through a decision tree which is the most appropriate to use for their purposes. We do not provide an opinion on these repositories or recommend one over the other. See https://edctpknowledgehub.tghn.org/data-sharing-toolkit/data-sharing/recommended-repositories/ for the top 10 repositories that featured most frequently in our review of funder/journal recommended repositories. Additionally, according to a clinical trial data sharing 2019 cross-funder consultation published by Wellcome Trust, MRC UK, Bill & Melinda Gates Foundation and Cancer Research UK in February 2020, the most well-known platforms for sharing data were CSDR, UK Data Service, Figshare and the Open Science Framework. For more information, see https://wellcome.org/sites/default/files/clinical-trial-data-sharing-what-weve-heard-from-researchers.pdf	

Questions responded to during the webinar

1	Can we have all the video after presentation ?	A reminder that the recording, materials and presentations will be shared here: https://edctpknowledgehub.tghn.org/training-courses/webinar-edctp-knowledge-hub/	
2	Can we set up a team network after this presentation with people involved today ?	This is a great suggestion - we will be added some additional community group function to the site so that users can connect to one another in discussion groups. There will no doubt be interest in taking forward joint work amongst your peers. A reminder that the recording, materials and presentations will be shared here: https://edctpknowledgehub.tghn.org/training-courses/webinar-edctp-knowledge-hub/	
3	Thank you.		
5	am requesting if possible they share with us the presentation after the webinar, thank you.	A reminder that the recording, materials and presentations will be shared here: https://edctpknowledgehub.tghn.org/training-courses/webinar-edctp-knowledge-hub/	
6	is his open access freely?	Hi - yes this is a free to access resource	
7	How interactive is the protocol development tool? Or are their persons willing and ready to guide a novice through conception, development and piloting the trial protocol?	The Protocol Development tool will be covered extensively in the next webinar, scheduled early next year. This webinar is focusing more on data mgmnt and data sharing, thanks	
8	Thank you for that you will share recording materials and presentations with us!	A reminder that the recording, materials and presentations will be shared here: https://edctpknowledgehub.tghn.org/training-courses/webinar-edctp-knowledge-hub/	
9	how can one access certificate of attendance from the the global health network website	For this webinar there will not be a certificate available due to the volume of attendees - however please do look out for furture workshop sessions that The Global Health Network organises	
10	kinly reshare the previous screen showing the procedure	You can find the resources referenced in the presentation by visiting: https://edctpknowledgehub.tghn.org	
11	Will you include latinamerican countries in the project?	EDCTP's research funding covers sub-Saharan Africa however this EDCTP knowledge hub is open to all researchers globally	
12	Thank you	Most welcome	
14	Does EDCTP have a data repository?	EDCTP does not have its own data repository. Instead we would like to refer researchers to the repository finder on the EDCTP Knowledge Hub to identify a suitable one: https://edctpknowledgehub.tghn.org/data-sharing-toolkit/repository-finder/	
15	Question to Sam Driver....What were the data systems used while collection data for your surveys..? We have various data collection tools and most clinical researchers use various systems like REDCap, KOBO Collect, Open MRs etc...What future plans do you have in place to ensure that Clinical Research used one platform and what challenges will this give despite enforcing future rules	live answered	
21	Can students currently studying in the final year of Pharm-D, MBBS, BDS or DPT who wants to perform research on a particular project and be the part of EDCTP?	There are no current EDCTP calls for proposals open and so it may be better to make contact with research groups in your country/region to see if they have funding opportunities or research posts available that could support you. Please see the EDCTP project portal https://www.edctp.org/edctp2-project-portal/ for information on our current projects	EDCTP has a fellowship programme for sub-Saharan African researchers at various stages of their career. Please refer to https://www.edctp.org/funding/calls-for-proposals/
22	demonstration was too fast but nice	Many thanks apologies we dont have more time today to cover everything - a reminder that the recording, materials and presentations will be shared here: https://edctpknowledgehub.tghn.org/training-courses/webinar-edctp-knowledge-hub/	
23	on this data magement can we use android to access it or its only applicable software	Hi this is a web browser based tool currently - it is possible an app based version could be developed in the future. Great question thanks	

25	Do you have plans to support clinical research in Kenya	EDCTP already supports clinical research in Kenya and our calls for proposals are open to participants from all sub-Saharan Africa. We fund clinical research projects through open and competitive calls for proposals - you can find current funding opportunities on the EDCTP website: https://www.edctp.org/funding/calls-for-proposals/	EDCTP supports several clinical research projects in Kenya. you can find details of these on our website in our project portal by searching by country https://www.edctp.org/edctp2-project-portal/. We fund projects via calls for proposals open to all countries in sub-Saharan Africa
26	Thank you very much for your presentation. Does EDCTP provide training in data science? Secondly, apart from sharing your own data, how can you access published data?	EDCTP grants support training, specific to the project aims. We do not offer specific training in data science but we collaborate with partners such as TGHN to provide tools and resources. You can normally access data via the publications which indicate the data source	
27	Can we get this webnar's presentations?	A reminder that the recording, materials and presentations will be shared here: https://edctpknowledgehub.tghn.org/training-courses/webinar-edctp-knowledge-hub/	
28	In the context of COVID-19 today, what should be the best strategy to obtain community engagement related to clinical studies participation?	live answered	also check our features on the www.ctc.africa
29	Please, is it possible to have the full presentation at the end of the webinar ? So interesting! Thanks!	https://edctpknowledgehub.tghn.org/training-courses/webinar-edctp-knowledge-hub/	
30	thanks please consider that as amajor tool in data sharing	Many thanks	
31	Does the EDCTP Knowledge Hub provide the guidance for site selection also? Can EDCTP Knowledge Hub accessible freely?	The knowledge hub is freely accessible. You may be able to find more information on site selection in the main TGHN resources	
34	Can Asians be the part of it and Will there be any fellowship programmes for Asians in the future?	currently the EDCTP2 programme has a focus on sub-Saharan Africa only	
35	What is the motive for data sharing? what has been found relevant to engage in data sharing? how participants are going to benefit from data sharing? what if the data used in other way instead of targeted?	Many thanks for the question	
36	I am from Burundi, Public health advocate and i am quite aware of the EDCTP contribution to Clinical research(PRDs, tropical neglected diseases etc..)However, it seems Burundi falls in silent zone. Do you have plans to support Burundi.	EDCTP provides research funding in response to open calls for proposals and we cover many countries in sub-Saharan Africa but you are correct that we have limited activities in Burundi. We hope that some recent calls (networks of excellence and EDCTP-CDC joint call) may lead to projects, collaborations or opportunities to support research in Burundi.	
37	Question to panelist......Moving forward with Data management portal...how will EDCTP ensure that all clinical trials data collected has standard way of data collection in resiporatory such as standard data dictionaries , standard databases and standard data collection systems as this will fastract Data analysis and the end of study .....John Hongo	EDCTP expects its funded clinical trials to conduct research to international standards including in data collection and sharing, hence we are supporting initiatives such as this to assist researchers	
40	Jeniffer's talk will stir discussions among African scientists and policy makers. A lot remains to be desired. Thank you Jeniffer.	Many thanks	
41	Was Slide 24 skipped on purpose?	I am unsure as the slides have been provided by the speakers and collated before the session so there may have not wanted to include that slide	
42	Very good presenataion made here and are an eye opener to me!.have tried to apply for funding opportunity for EDCPTP funding but have not received any feebback.These could be 2-3 years back.Kindly advise.	Please contact the EDCTP secretariat outside of this webinar and let us know the reference number of your application	
43	It will be nice to have the full presentation at the end of the webiner	A reminder that the recording, materials and presentations will be shared here: https://edctpknowledgehub.tghn.org/training-courses/webinar-edctp-knowledge-hub/	
46	Thanks Dear Pauline for your resourceful response. I personnaly have been in contact with national institute of public health and seems they are open to receive any support, guidance, coaching or mentorship on how to actually join the EDCTP networks of excellence as well as well the funding/application process. Would appreciate to talk more about that if relevant conatcts were shared. Thanks.	You can find the details of the networks on our website here: http://www.edctp.org/projects-2/edctp2-projects/edctp-regional-networks-2015/ and this will give you details of who to contact at the networks. The coordinators of the networks are the best people to contact to find out about joining. Hope this helps	
49	Question to Rob Terry......What measures will EDCTP put in place to ensure eqitable platform between rural setup and urban setup sharing of data in future despite the challenges you presented such as technological , social etc.....	live answered	
54	I am from India. We have Clinical trails going on especially tuberculosis. Does edctp. Has it's presence here How can we involve with edctp	Researchers from anywhere in the world can participate in EDCTP proposals, working with European and sub-Saharan African partners to jointly develop knowledge, research data, and leading scientific teams and networks. However, participants from outside sub-Saharan Africa, the European Union or one of the Countries Associated to Horizon 2020 are not automatically eligible for funding and should fund their own participation in the project. This funding can be from any source. Potential participants from these countries are therefore encouraged to contact research and innovation funding organisations in their own country to seek support for their participation in EDCTP Calls for Proposals.	EDCTP supports research in sub-Saharan Africa and so our funding is open to researchers in Europe, SSA and countries that are associated to H2020. India is not included but we do have some projects that include partners in India.
58	how to encourage institutions to accept in this data sharing coz we tried and its difficult to convince them to share	we have to provide an incentive on benefits of data sharing includes IPs and products etc	
59	What steps are taken through this initiative to protect the rights of local communities on sharing indignious knowledge?	EDCTP is a partner in the TRUST project which has produced guidance on this issue http://trust-project.eu/the-project/about/	

63	is implementing the data sharing as a part of contract by funding bodies would be helpful in solving that problem?	EDCTP as part of H2020 expects projects to share data as part of the grant agreement	
64	Please again to Jennifer. Please how do you get communities to engage in your data collection. What tools are you going to use?	Baffour- i am not an expert in community engagement but i would encourage you to speak to the experts in the field. These are just recommendations from the commitee	
65	I applaud this great move in the direction on bridging the gap on Clinical research knowledge.

How does your team plan to win the policy makers and influencers especially in regions where clinical research is on lowest scale and much attention paid to practised medicine? | this is one of the reasons why weare conducting the prioritization execersize. we are working closely with the African union and hope that through the heads of state ad minietsrrs of health we will reach the policy makers | |
| 67 | Please are we getting certificates for this workshop? | No certificate is provided due to the high number of participants | |
| 68 | Please Trudie Lang and Sam Driver.....i would like to have your contact for future.....sorry for using this KEMRI Kenya | please do share your interest via the platform or via info@theglobalhealthnetwork.org many thanks | |