

IFLA E4GDH & HBS webinar: Combating digital health inequality in the time of coronavirus Full transcript

Anne: Hello and welcome to the webinar. My name is Anne Brice. I'm the Head of Knowledge Management at Public Health England, and also the convener for the IFLA special interest group on Evidence for Global and Disaster Health. IFLA is the global voice for the library and information profession and it believes that people, communities and organizations need universal and equitable access to good quality information.

In these unprecedented times providing information also assumes that people have access to the digital technologies, and to the skills with which to navigate them. It therefore gives me great pleasure to welcome our speaker today Bob Gann. Bob is an independent consultant specializing in digital inclusion and combating digital health inequalities. He works as a Digital Inclusion Specialist for our (UK) National Health Service, working with partners such as NHS Digital, with Public Health England, Digital Communities Wales and is well known, I know, across the world. Bob trained as a health librarian and was also Strategy Director for the NHS website for many years. So without further ado I'd like to hand over to Bob to lead the webinar from now on, thank you.

Bob: Thank you very much Anne. It's an absolute pleasure to be with you this afternoon. It's 3 o'clock in the afternoon here in England on a beautiful, sunny Spring day. Most of the experiences and initiatives I'm describing in the webinar are from here in the UK but I hope those are of relevance to you, and you'll get ideas and I hope maybe inspiration from some of those. Please do share experiences in your own countries and use the chat box to do that and it would be fantastic to share some of the work that you're doing in this area.

I'm speaking to you from my kitchen in the medieval cathedral city of Salisbury in the southwest of England. Salisbury is well known worldwide for its beautiful Cathedral and for the Neolithic monument of Stonehenge, which has been standing for I think nearly 5,000 years. When I go on my walk in the morning and I look at some of these things that have sustained and are still there - what those monuments have seen - it gives me great inspiration and hope for some of the things that we're going to get through. I also think that in a way our lives have shrunk to a very hyper local world when we are socially distancing in our own homes and the immediate environments.

But on the other hand we are in touch with colleagues all over the world through these kinds of forums and these kinds of technologies. and I was really excited as the registrations came in, just to see where colleagues were joining us from and I think there are 36 different countries involved in this webinar. Not all of you are here live, although I see there are a good number, a very good number, live. Some of you will be seeing the webinar in the recorded form, perhaps because of the time difference. I imagine colleagues in New Zealand where it's like 4:00 in the morning will be viewing the recorded version so you have both those options.

The world that we've all become very used to is a world in which we're online. We're online shopping for essential supplies and food, we're keeping in touch with family and friends, we're working from home, many of us are taking part in classes either for education or for recreational purposes. It's the way in which we apply the benefits and financial support. It's how we manage our own health remotely and it's how we access reliable health information - and that's been increasingly the case for the past few years, but suddenly it's become absolutely essential. It's the way in which the world is surviving in lockdown, the way in which the world is surviving in social isolation.

But just imagine what it's like if you're not online and not able to do all those things - and that is the situation for a very large number of people. These figures are obviously a little approximate, I'm not

really sure of the data sources for some of these figures, but I think the broad-brush is correct that apparently there are around 4.5 billion people in the world who are active Internet users and about 4 billion unique mobile phone users. So the majority of the world is now online, but that still means that 40% of the world isn't. If you look at that infographic you can see that in countries or continents like Africa and Asia, the majority of the population is not online. In Europe about 80%, in the Americas slightly less. So that the kind of picture.

We know quite a lot about the online states of my own country in the UK - and here in the UK, about one in five of the population either are not online at all - and that's about 8% of people are not online at all, have never used the Internet - and about 22% of people may perhaps just about be able to switch on a computer but they lack the essential digital skills they need for everyday life. And who are those people who are digitally excluded? They are very likely to be older, to have lower income, to have a lesser level of education, and maybe homeless or insecurely housed. They're exactly the kinds of people who experience health inequalities and perhaps have the greatest need for health services are the people who are most excluded from the ability to access those services.

So why are people digitally excluded? Probably four main areas - and I'm grateful to HIFA for running some discussion on their health care information forum asking people around the world why people in their countries aren't connected online - and I think broadly sometimes it's about access. It's about people not being able to afford devices, not owning devices, perhaps not being able to afford data so there's that access issue. There's an issue around digital skills and that might be basic digital skills - things like just being able to use a computer keyboard, or do a search, or download an app but also information literacy skills. The ability to distinguish between good quality information and bad, and I'll come back to that in the later part of the presentation. There's some barriers around communication, particularly around language. The language of the Internet is English, and if you're not able to speak or read English you are excluded from a significant body of online information. You may have disabilities that mean you can't use a device, or you might have a sensory impairment that means you can't see or listen to information. But increasingly I think people are acquiring devices, they are developing skills, technology is easier to use now with simple touchscreen technology. More and more - and there was an interesting review of this in our UK consumer digital index some two years ago suggesting that - increasingly it's lack of interest, lack of motivation and lack of trust. Broadly we are not delivering for people digital health information and digital services that are sufficiently compelling and meaningful for them to overcome some of those barriers around motivation and trust.

And the ability to access services and information digitally has become acutely important as health information is increasingly digital. Now these references are in an article that I had published last year in the IFLA Journal, it's in the resource list that accompanies this presentation, but broadly 80% of Internet users have searched for health information, one in 20 Google searches are for health information, there are over 300,000 health related apps, and a million people every day visit the NHS website that I used to be the strategy director for and that's gone up considerably in coronavirus and I'll come back to that.

And if people are going to be able to access that kind of health information digitally, they need digital health literacy skills. And digital health literacy is a multi-faceted kind of literacy. It includes traditional literacy, so being able to read, being able to understand numbers - a lot of health information is about numbers, it's about doses and about risk - and if you're not numerate, that's pretty hard to understand. It's about using health information in your everyday life, to address a health problem. So health literacy is about computer literacy, being able to use devices; it's about information literacy and understanding things like privacy, security, how your data's being used; scientific literacy, distinguishing between good quality evidence and bad; and media literacy,

understanding what might be a good source of published information and what might be a piece of fake news - and I'll come back to that as well.

And I think it's really, really important that we don't regard health literacy as just an issue and just a problem for individuals. I think if we say it's all about a problem for people to sort themselves out and get literate, that we won't solve the problem. We also need to be making sure that our organizations are digitally health literate as well - and I'm very taken by this model that looks at what a health literate organization might look like (and there's a reference to this in in the resource list available with the webinar). A digitally health literate organization is one that supports its patients and its carers to build their digital skills. It provides a digital infrastructure, so for example free public Wi-Fi - and we've put free public Wi-Fi into every National Health Service building in the UK in the last three or four years. It co-produces information, so it works with service users to produce information relevant to them. It takes the risk of digital exclusion into account when it's planning services. Crucially it develops the digital skills of its workforce, and it has a knowledgeable and committed digital leadership. I think that's a pretty good checklist for looking at how digitally literate our organisations are, and to recognise we need to develop organizational digital health literacy as well as individual health literacy.

So we know that people with low health literacy make greater use of the services and experience worse health outcomes. And as those services are increasingly delivered digitally, we risk widening health inequalities further and I think it's worth going back to a concept from the early 70s called the inverse care law Julian Tudor Hart, who was a GP working in Wales, developed this concept of the inverse care law where people who have the most need for health services have the worst opportunities for accessing them - and this was in a pre-digital world. I think now we've reached a position where we have a digital inverse care and the people who most need health care services are least likely to be able to access them digitally. Now in a country like mine in the UK, we might feel quite complacent about our digital connectivity compared with some countries in the world. I think recently we had a visit from Philip Alston who's the UN Special Rapporteur on extreme poverty and this caused some political resistance in the UK - that the UN was sending somebody to look at poverty in the UK. and he made a couple of really important statements I think. That overall in the UK roll out broadband may be high but many poor and vulnerable households are not online, and secondly that digital assistance has been outsourced to public libraries and civil society not-for-profit organisations at a time when their budgets have been severely cut.

But what we do have in the UK is an extremely rich foundation for digital inclusion. Particularly we have a network of what we call UK Online Centres. So there's 5000 of these centres based in community settings like community centres, cafes, around half of them are in libraries, and they provide safe supportive environments where people can go to access technology and build digital skills.

We have some online training resources to help people with basic digital literacy and then to move on to do other things like improving their health online or developing their role as digital champions helping others like them - and again these resources, links to the work of these centres, is in the resource list for the webinar. We in the National Health Service worked with UK Online Centres and with an organisation, a not-for-profit called the Good Things Foundation, to fund a national program over the past seven years where we supported half a million people in the UK to engage in national programs to improve digital health literacy skills and to take more control of their own health. And we did an evaluation of that program and what we found was that people were able to, having learnt digital health literacy skills, people were able to self care better and to reduce their dependence on health professionals for minor ailments. They were less lonely and isolated, they said they save time and they said they save money - and I think what that's demonstrated is an

investment in digital health literacy and digital skills can have major payoffs for individuals but also for the health care system.

And we moved on from a programme focusing essentially on digital skills, to looking at some of the other ways in which people might be digitally excluded. It's not just about lack of skills. So we did a set of pilots in socially deprived centres to try and gain a better understanding of the barriers to digital health literacy and developed some co-created solutions working with patients and carers and members of the public to develop initiatives like social prescribing - where health care professionals would prescribe a non-medical intervention, something like exercise or gardening or arts - and prescribing to digital health resources or prescribing to Digital Inclusion support was an important part of that. Or developing high street health hubs where local organizations would get together and set up a local drop-in hub where people would go and access health information resources. Good Things Foundation, our partners in that work, have published a fantastic set of tools / "how to do it" guides for those interventions. There's a link to that on the slide but again it's also in the resource list.

So I was going to give this webinar anyway following the article in the IFLA Journal, but as we planned the webinar suddenly we were in a world of coronavirus and digital inclusion suddenly became so much more crucial and relevant so I'll move on and just round up the presentation with just some examples now of how libraries and other community organizations are tackling digital exclusion, enabling people to use digital resources in the time of coronavirus. I'm going to focus in those four main areas.

Firstly tackling fake news and misinformation. Now we know how much misinformation there is around coronavirus, people thinking 5g is the cause of coronavirus. We had an appalling example in the UK where people opposed to 5g burnt down the phone mask that supplied one of our new hospitals. We've seen influencers on social media spreading some of those kinds of misinformation.

And there's a really important role for our Library and Information Services in tackling misinformation so we have organizations like Public Health England, our health education and knowledge services providing good quality evidence around coronavirus. We've got things like the World Health Organization mythbuster site, we just had a really interesting formulary of evaluated apps around coronavirus and also staying healthy during social isolation launched in the UK last week. All of these again in the resource list.

And I'm really pleased to see how important the NHS website, where I used to lead strategy development for, has become during the virus. Our Prime Minister Boris Johnson (there) gave his daily press conference with the NHS website on his podium and that led to an increase, doubling of the activity on the NHS website so it went from a million visits a day to two million visits a day and almost all those new visits were to coronavirus content.

So there's a big thing around good quality information. I think there's also really great examples of libraries and other community organisations beginning to mobilize community resources. We have three interesting examples there. We've got an initiative in the UK at the moment called DevicesDotNow where businesses are donating devices which are then being supplied to the 1.9 million households in the UK who are not connected. We've used an app, which is mainly used for emergency responders in emergency services, to recruit 3 quarters of a million volunteers who help deliver shopping and medicines to people who are socially isolated. We've had a technology fund where people have bid to do really rapid technological innovation around coronavirus. So examples of very rapidly using digital technology to mobilise large armies of volunteers and innovators.

We've seen libraries step up and do things really differently. Lots of industries have started doing different things, so we've got Burberry fashion house making gowns and masks, we've got French alcohol and perfume manufacturers making hand sanitizers, and we've got libraries which are closed to the public using their 3D printers to churn out protective equipment. So a really interesting change of function for libraries.

But of course just because library buildings are closed, it doesn't mean library services are closed and in fact what we've seen is a real upsurge in people in the UK registering with libraries. Apparently over 120,000 new people have joined their public library in the last three weeks and have been using the library to access ebooks. We've got a new thing called the National Shelf Service, a bit like our National Health Service, where librarians are making daily recommendations for reading - and just yesterday a new national initiative was launched to combat loneliness in social isolation and libraries are really important sponsors of that.

Thirdly we're seeing community organisations enabling safe remote care. Before coronavirus, online and virtual consultations were becoming more and more common, and those virtual consultations spared patients the cost, stress, inconvenience of travel - and of course they've become the way now in which most people access health care services. I saw a friend of mine who's a GP [community doctor] when I was out for a walk yesterday and we had a short conversation, socially distance apart, and he told me that 80% of his work now is telephone and video consultation. In Wales there's been a rapid rollout of a video consulting platform called Attend Anywhere, and that's been rolled out within a matter of weeks but crucially my colleagues in Digital Communities Wales have been providing digital devices to people particularly in care homes who would otherwise be digitally excluded so that they can access that virtual consultation.

And we're beginning to see a lot of evidence about the effectiveness of virtual consultations coming out very rapidly in consumer friendly ways. I really like this set of guidelines in a really easily usable form that's come out from Barts National Health Service Trust in England and the University of Oxford. That team, with Professor Greenhalgh in the University of Oxford, are doing a lot of rapid evidence reviews including a recent one about face masks so really great to see that kind of pace of knowledge being developed.

And then finally some of our most vulnerable people in the healthcare system at the moment are people living in care homes. A lot of people who are at high risk, they are isolated, they're not having any visitors - and we're beginning to see some really creative ways of people being able to keep in touch through digital technologies. Again Digital Communities Wales, but also some other organisations including some down in Cornwall, are supplying care homes with voice-activated devices - Alexa, Google Home etc - and they're fantastic for people who lack digital skills or lack dexterity, can set up spoken reminders for appointments etc, access websites apps. And we've made all the content on the NHS website available via Alexa so people who can't search for information very easily using traditional digital means can just ask for that information online - and that's proving very popular with older people.

And then another really important and interesting thing I think around care homes and again a great project with Digital Communities Wales - they've been providing virtual reality health headsets for people isolated in care homes to get in touch with a wider world, a world beyond the confines of their own space. And before the lockdown they were doing wonderful work with school children from local schools going in and showing older residents how to use these virtual reality headsets.

And I just for my very last slide give an example of what I think is the best example of a library service really stepping up to the challenge of COVID-19. And this is in Leeds, and this is a large city in

the North of England where there's an initiative called 100% Digital Leeds. It's a multi-agency initiative with budget from a range of organizations led by Leeds Libraries - and 100% Digital Leeds has an action plan around tackling COVID-19. There are people from 100% Digital Leeds on the webinar, they may be able to provide further information via the chat box etc but what they're doing is they have a grant fund where they're providing funding to not-for-profit organisations for digital equipment, data and connectivity. They're distributing iPads to socially isolated people, from a tablet lending scheme. They have a digital champions training program that they're delivering via videoconferencing. They're signposting to digital tools and resources including free online training. They are encouraging and facilitating the adoption of self-management tools like apps for people with breathing difficulties, and they are auditing digital access across the city to see where help can be best provided because in the old world many people were using public access Wi-Fi in places like libraries and cafes and on the street and they're not able to do that anymore and they're cut off - so just identifying what's been lost in the COVID world and where we might be able to provide help most effectively.

So I'm going to stop there. There are some resources available with the webinar, by all means email me directly after the webinar, or follow me on Twitter. You might be particularly interested in two practical guides that we produced - one for England, one for Wales - telling you how to do it with digital inclusion and digital health literacy. Loads of great examples of case studies, videos, practical guidance that you might find helpful in your own countries but equally we would be fascinated to learn more about how you've been able to do it locally where you are and let's self learn together and defeat the virus.

Blessing: Thank you Bob. We've got 14 questions. I'm not sure if we'll be able to go through all of them. So some have got some commonality and some are a bit different. And I can see that some of the participants have already started answering and giving resources as well - and we really welcome them. So the first question Bob is how significant are political obstacles to digital inclusion - for example the blockage of social media and news sites by some governments?

Bob: OK we had a general election in the UK back in December and - without making a party political point - the manifesto of our Labour Party, our Socialist Party, included the provision of free Wi-Fi to everybody as a public utility. And that was pretty extensively criticized, it was mocked as barmy Bolshevism I believe one of our newspapers called it, and suddenly in the world that we're in now it doesn't seem such a crazy notion and being online is (as I said right at the beginning of the call) the way in which we will survive through this crisis and I think political attitudes to both provision of digital information and digital connectivity as a utility have changed a lot. Much greater support, and I hope that's sustainable beyond the virus.

Blessing: Thank you Bob, the second question was that you mention that 60% of the global population are active Internet users. How do we define active Internet users? Dwindling income and affordability is one of the factors enhancing digital exclusion in my country at the moment. How can we also bring the government's attention to such a problem? So this is a two pronged question - the first one really looking at how we define active internet users and the second one looking at bringing the government's attention to problems of inequalities in income.

Bob: Yes I don't know what was (I should maybe have looked into this in more detail before the webinar) but usually, well I mean we would define in the UK as an active Internet user somebody who wasn't just able to access the internet but was able to have sufficient broadband to be able to do activities of everyday life and to have the digital skills to be able to do those things. So going back to the UK example, it was 80 percent of people who were active digital users, probably a greater number than that who were able to access the internet but not able to use it effectively and

certainly that was a theme that came through very much in the discussion on the HIFA forum. A number of people from lower and middle-income countries were saying that they might have some kind of access to technology but not sufficiently good connectivity to be able to do many other things we want to be able to do in the modern world. Particularly things like virtual consultation which are quite bandwidth heavy so I think it's partly about connectivity, it's partly about skills. In terms of governments well I mean it's the kind of a slightly facile cliche to say not wasting a good crisis but one thing for all the tragedy around coronavirus, it has very much emphasized the importance of digital connectivity to the world as we must live in the future. It's not just the world that we live in through the current crisis but the new world we live in afterwards and I am very confident that governments will be - and will have to be - much more focused on how we live as a society perhaps for quite a long time - maybe forever more - in a much more digitally connected way and less of a physically connected way.

Blessing: Thank you Bob. The next question - I'll include this one as there are a couple of them around how can we empower or support people who speak English as an additional language to use digital platforms, especially during this pandemic?

Bob: Yes, as I said in the presentation, one of our problems is that English is the language of the internet and most of the information around coronavirus is still in English - although I'm sure there are many good examples in other languages and some of the organizations I'm sure that you're working with in your own countries will have many good examples of information in languages other than English. And it's not only an issue for countries where English isn't their main language. It's also a big issue in our own country as well. In fact I was listening to something on the radio this morning where people from black and minority ethnic groups in England have been much more heavily impacted by coronavirus than the white population. And there's a number of theories about why that might be but one of the reasons is that the lack of information in our own minority languages in England around coronavirus, and the exclusion of those populations from public information campaigns. So I would really welcome examples in the chat box of content in languages other than English and how we can make those more widely available or better known.

Blessing: Thank you Bob. The next question is I think the fourth theme around how we can support the elderly during this time of the pandemic and to get their health literacy skills updated.

Bob: Yes, OK yes I mean I think that's just so important people who are, I mean we define in the UK at the moment people being over 70 being at particular risk, so it's that sort of population. A population who are least likely to be online, a population who haven't grown up so much as younger people using the Internet at work and maybe - as I said in the presentation - people in settings like care homes so there is a particular challenge there. I think there's a number of things that we can do. We do have a number of online courses and tools that can help older people to develop their digital skills and digital health literacy - but of course you need to be online already to access those courses in the current environment. We used to provide them in a drop-in environment with support in a library or a UK Online Center but friends and relatives can sometimes help you to do those kinds of courses so there's that. I think there's provision of technology to older people - so some of those things like the devices loan schemes that we have in place through DevicesDotNow and some of the initiatives like 100% Digital Leeds. So making sure older people have got the technology. And then there's using technology like voice recognition. I think that's a very good example where firstly you're using a technology where you don't have to have the ability to use a keyboard, you can use it if you've got some impairments in your mobility and dexterity but also where you can access good quality health information so I think our deal where we've provided the NHS website via Alexa is an example of where it can be particularly helpful to older people.

Blessing: Thank you, we've got two questions here that speak to each other. The first one: is there any evidence that people who are active Internet users are more informed in terms of basic health knowledge as compared with others in the same country who are not connected, after correcting all confounding factors? Which leads to the second question. Are people who are active Internet users more vulnerable to misinformation, are they more likely to believe false rumours about COVID-19 as compared with unconnected people? Are they more likely to be conspiracy theorists?

Bob: Yes, couple of really good questions. So on the one about digitally active users and whether they are likely to have better health outcomes - I think one of the problems obviously is the confounding factors, that people who are digitally active users are likely to be less socially deprived, they're likely to be younger, they're likely to be better educated so those factors in themselves might mean that they have better health status. So I think the causal relationship between digital inclusion and health status, it's not an easy one. However there is research, and there's some examples in my article in the IFLA journal, around this and there's also the evaluation that I referred to in the presentation where we looked at people before they'd had digital inclusion support - so before they'd had digital skills training particularly - and after. And we found that when people had had the digital skills training, (they) were more digitally engaged, were more digitally confident, more digitally health literate. That they were not only the things I showed on the slide - which were things like less GP consultations for minor ailments - but also some evidence of things like greater level of physical activity, some reduction in mental health symptoms, some of those kinds of things. I think it's difficult as the questioner suggested to separate the other factors but there is evidence, and increasing evidence, that simply being digitally engaged and digitally confident leads to better health outcomes. The question about whether being an active information user makes you more exposed to misinformation. Well yes absolutely. If you're online and you're particularly accessing social media, you are exposed to misinformation in ways that people who aren't online will be shielded from. So being online is not an undiluted benefit. There are people who are gaining enormous benefit from being online, but there are also people who are being exposed to misinformation. So I think initiatives like the WHO Myth Busters resource - now I saw recently that Facebook are linking to the Myth Buster site where they think they're detecting misinformation on Facebook - so those kinds of things hopefully are beginning to mitigate some of that risk.

Blessing: Thank you so much Bob. We've got a lot of questions and we've taken note of all of them. Looking to the time, I'm going to handover back to Anne.

Anne: Thank you Blessing. Bob, do you want to move on to the next slide. Yes certainly. Great, thank you. I just want to say a couple of thank-yous. First of all, I'd like to thank IFLA HQ for helping us plan and set up the webinar, and for helping us use the new technology, the new software platform. I'd also like to thank, a special thank you, to Neil Pakenham-Walsh for all of the support he's given to the special interest group and also for, as Bob mentioned, running the discussion on the HIFA forum before the event. And for those of you who haven't come across HIFA - Healthcare Information for All - do follow that up and and join. A very rich source of discussions.

I'd like to thank everybody in the special interest group working group. Blessing and Maria for helping co-host and sort the technology out, but also Caroline for all the work she's done on all of our evidence-based resources but particularly to Emma for everything that she's done for the SIG and basically these events wouldn't happen without her. But finally I would just like to thank Bob again for a really interesting and a splendid session. We are really grateful for him too, for being involved with us but I'd also like to thank you all too. Do look out for our further events in this webinar series. As we've said, the recording will be made available and we'll also try and publish the questions and the answers. So just to finish, I attended a virtual theatre performance last weekend and they managed to unmute everybody at the end of the session so that they could give the presenters a round of applause. So I'm going to try and do that now just so that we can thank Bob.

At a very minimum then those of us who are presenting can clap - so I just like to ask everybody to give Bob our thanks. OK right so I'm going to hand back to Emma now to close the session and again thank you all very much for attending.

Emma: Thank you and just to say that there are many messages of thanks that have come through in the chat box as well so we'll be sharing those with Bob - and as Anne said we've captured the questions we didn't get to, this is our first webinar with using the zoom webinar software so it's been very interesting learning and we'll look at how we can keep the conversation going. So as Maria has posted, the recording, the slides and the resources will all be made available on our web pages. Some of them are already there. And we hope to see you at our next event but thank you everyone for engaging and many thanks again to Bob. OK I'm going to stop the recording now if I can work out where the button is and thank you all again.