UK Association for Accessible Formats UKAAF

UKAAF webinar, 2 August 2022

Sophie Randall in conversation Transcript

Roger Firman
Hello. My name is Roger Furman from the UK Association for accessible formats. Thank you for joining us.

I'm very pleased that Sophie Randall, Director of the Patient Information Forum, is our guest. Very warm welcome Sophie.

Sophie randall

Thank you, Roger.

Roger

Sophie, you started your career as a journalist specialising in public health. Was this your plan, and if so, what fired your interest in this particular area?

Sophie

Well, I suppose like lots of things, when you first start working, it was a bit of an accident. I certainly always wanted to be a journalist, and I took on a temporary admin job at a publishing house. It was a first step in and I managed to persuade them, eventually, after a lot of begging, to take me on as an editorial assistant. So in a way, I fell into it and it was a

magazine for environmental health officers who work in local government.

There are certainly some issues that really captured my imagination and interest quickly. So although it's wider issues of public health, it was issues of housing and health, both public sector and private sector housing, and at that point air quality, and people really starting to think about the impact that air pollution from cars was having on children with asthma and things like that. This is back in the 1990s. So that really captured my interest and started getting me interested in issues of health inequality.

Roger

Being a journalist - and you've already mentioned that you were engaged in those particular activities - was there anything else you thought that you were going in a more unexpected direction just by being in the work environment and discovering things about where that was leading you?

Sophie

Yes, where I worked was a weekly magazine and it was a News magazine predominantly, so we covered everything that local government can cover from barking dogs, to night noise patrol, to health safety, to major pollution incidents, major food poisoning outbreaks. Mad cow disease was a big thing at the time and I didn't come from a science background and I found myself covering a lot of policy but also talking to quite a lot of scientists and even medics and academics.

I think what I found out then was that people are really happy to explain things that are complicated if you bother to ask them, and if you say oh, I don't understand, they can then find a way to explain it in a way that other people can understand more easily. And actually I think that was a really useful lesson to bring to health information because I think that's one of the problems that quite a lot of healthcare professionals have. The health system has its own language and its own jargon. Because of

that early training, I never had the problem of saying, oh, I don't understand that, but I think also it was a really good grounding in working with people from all backgrounds. And when you are in a Council flat with somebody who's got cockroaches everywhere through a district heating system and you see the impact the stress has on someone's mental health as well, it really made me understand those links between physical and mental health. And we also did other work for organisations like The WHO and we did a public health magazine for the new countries, the emerging democratic states that had come out of the former Soviet Union and one of the big topics then was Chernobyl, and I was having these conversations with The WHO, and we were looking at children's leukaemia and they were saying, “but you can't say that is caused by Chernobyl. We don't have the evidence, the hard evidence on causality” But it's so obvious. “Until we've got the studies, You can't do it.” So I think it really taught me some hard lessons around evidence but also sometimes, maybe, we do need to take a precautionary approach when something is really clearly staring us in the face in terms of health and causality. So yes, lots of interesting lessons that were transferable into health information.

Roger

You then moved into health information, what was the catalyst for the next step?

Sophie

I think as often happens, life changes. I'd become a mother, I had young children, so the slog of doing weekly magazines and late press days became a little bit more difficult. And I saw it in commuting to London and I went for a job in a medical publishing company. And I thought right, I'm going to do that jump now from public health to medicine. But the other thing that really interested me about that job was the opportunity to work with different formats because that was probably at the end of the 1990s and before that, everything had been very much print based. The new organisation I went to work for, was doing things in audio, it was using CD-ROM. It was starting to do some of the early e-newsletters and that was really fascinating to me. The opportunity to work in other formats as well as making that jump from just writing about

public health to much more medical areas as well, so yes, I think it was those two things combined that attracted me.

Roger

As Director of the Patient Information Forum, what attracted you to that position?

Sophie

Well, I was already a member of PIFF, so I knew the organisation really well. So once I had worked for the agency for a few years I set up my own agency and did that for around twenty years. I think one of the best things about the Patient Information Forum is it's such a broad Church of people who work in different sectors who are all really committed to producing quality health information.

I had in my time running the agency, been very interested in issues around health literacy involving users, and finding out what type of information they want, trying to make information more accessible to other people and also to really broaden the reach and the type of people that health information both included in its development, and also who it then targeted for making it more accessible. So that was really interesting to me, I'd learned a lot from Pif. So my interest in health inequality had been maintained.

When the job came up, I thought well this is a great place to bring my experience of working in this industry for twenty-thirty years and be able to make a bit of a difference in more campaigning at national level on the availability of health information with like-minded people. And I think that's the thing about PIF, it's a small organisation where people come together to try and promote the best practice in health information possible.

Roger

Could you perhaps fill in some more background about what PIF is, what it does, who it represents, and its place within the sector?

Sophie

Yes. The patient Information forum is twenty-five years old and we are a UK-based membership organisation. We represent people involved in health information and support from all sectors, so that could be some of the massive national charities like McMillan, or Cancer Research UK, right down to some really tiny single-handed charities, but it also ranges from large NHS bodies like NICE to local NHS trusts or individual GPs, also private sector members as well. So we have memberships from the Pharmaceutical industry, from some big organisations like Bupa UK, right through to some very small tech start-ups that are offering specific health information services, particularly now health information has changed so much. PIF exists to bring all of this expertise from across the UK together and say, OK, So what is the best practice in health information? What do we need to do to make sure that everybody has access to information they can trust so that they can make informed decisions about their health and care, but information in a way they can access, use, and understand. I think that's the really crucial part of what we do.

We have four strategic pillars: Quality; Integration; Expertise; Inclusion.

Quality of information, what makes high quality information is evidence-based, it's user friendly. Those are the two top criteria when we asked the public what they felt. There are ten criteria for our quality mark for health information. We also provide a lot of training. So we have a whole expertise function where we produce best practice guidance. We offer CPD accredited training to members and we do a series of webinars so people can share best practice. We also work on the integration of health information. So how people get health information and when they get it on their journeys and in what formats, and obviously that has become so diverse. Health information can be anything now from a social media post right through to a large book, and everything in between. Finally, we also work on inclusion, so that's everybody in our vision. We're trying to campaign for information to be accessible based

on users' needs. There is no one-size-fits-all whatever you're doing, you need to work with your user group to find out what their needs are and then deliver the information in the way that it's appropriate for them. So that's what PIF does in a nutshell, but it's a great organisation to work for because we do hands on practical projects and we also work at a policy level contributing to guidelines development and that sort of stuff too.

Roger

Thank you, Sophie. Could you tell us what is the PIF Tick Trust Mark?

Sophie

Well, the Tick Trust Mark is a quality mark for health information. Again, it's a membership scheme. So people apply for the Quality Mark and they have to go through quite a robust assessment of their information production process to get it. And then we have ten criteria with lots of sub-criteria that people have to demonstrate that they're meeting.

As I mentioned, there are ten criteria and they range from evidence-based, which is obviously really crucial as the first point, but also back to those issues around having trained staff, having a written process in place so that you are actually meeting what you say you do involving users in the production of health information moving into some kind of co-production, thinking about how you deliver and your dissemination methods for health information, making sure that you are meeting those needs for different people in the audience and also looking at issues around health literacy, digital literacy, and accessibility. So it's a very broad standard. The final part of our standard is that we really ask people to have a continual cycle of improvement and that they're actually looking at and evaluating whether their information is making a difference to people because if it's not, you've got to question why you're doing it, and if it's actually meeting people's needs. So people who apply for the Trust Mark, if they have gone through our assessment and action planning process, they can then put the PIF tick on their health information.

I think seventy-six organisations have already been certified and we're now up to over one-hundred in total, working towards accreditation, if not already certified.

The reason we introduce this scheme was that because there's obviously a huge amount of misinformation and disinformation, and we've seen this loads in COVID, so it's trying to find a way that both patients and healthcare professionals can identify trusted sources to sign post people. It's early days. We only launched in March 2020, but it's beginning to have quite a big impact for us now and hopefully people will start to hear about and see the logo a little bit more. We started it because NHS England had a standard for health information called the Information Standard, which they decided to get rid of in 2019, and our Members just felt this was a really bad idea. So they asked us to step into that gap, and so we worked with our Members to co-create the standard. We did public consultation and then we piloted for six months before launching in March 2020, so it's come quite a long way. As with many things in the pandemic, things have had to develop quickly and we've had to do things differently but we also have a website which is

https://pifonline.org.uk/pif-tick
where you can access that information and a list of the organisations accredited under the scheme.

Roger

Excellent. Obviously, a lot of work.

Sophie

It has.

Roger

In bringing anything like that to fruition, there is a lot of behind-the-scenes work and I wish you well with the continuing success of it.

Sophie

It's one of our key things. We want people to be able to access this in those organisations that are Quality Marked now so that they can have reliable sources. So what we're trying to do is make sure that the Quality Mark is being used as access to other platforms. There's something called the “trip” database (a clinical search engine) that healthcare professionals use to provide print health information which will have Pif Tick information, health and care video which provides a lot of stuff as well as nhs.net with content E-health prescriptions data, prescriptions at some GP surgeries are starting to use so that people are getting sign posted straight away, particularly if they have digital health records which more of us are beginning to get now. So again it’s thinking all the way, not just about providing this service, but how we're going to get this trusted information into people's hands so that they can use it, or onto their devices.

Roger

Sophie, I believe you represent PIF in various ways. Can you tell us about that aspect of your work?

Sophie

Yes, I suppose that's really where we get much closer to this sort of policy arena. So I represent PIF on the NICE shared decision making collaborative, and as part of the group that developed the.

shared decision making framework for decision support tools that NICE released last year, shared decision making guidance. That was a really interesting piece of work and there does seem to be a big focus on shared decision making at the moment.

The Professional Record Standards Body, we've just been on the project group to develop their shared decision making standards. I don't know if you are familiar or unfamiliar with the Professional Record Standards Body? It is the body that is setting standards for health and care records. So what goes into your health and care record and what comes out of it in terms of letters that come to you or anything else should be following

certain standards, not always adopted by local NHS bodies. But that's what the PRSB does. So to try and make shared decision making a bit more of a reality, there's a standard process now that healthcare professionals should record when someone is making a major treatment decision and part of that will be the provision of information so that people are really looking at making informed decisions about their treatment. A lot of that is not just about content, it's also about how numbers and data are communicated to people because we know that UK literacy and numeracy rates are quite low and often these decisions are really complicated. I think it's something like 40% of people struggle to use health information just based on their literacy level, but actually it goes up to 60% of people who struggle when there is numeracy involved and there is a lot of numeracy involved when you're looking at data for treatment. So we've been working with other partners to try and make sense of that and to make it easier for people to understand those numbers when they're making a decision. Because I think what we've seen from a lot of the research is people will quite often sit in a consultation and they won't necessarily ask questions if they don't understand something, because most of us don't want to appear stupid. It's overcoming that issue so that people can make informed choices and to make an informed choice, you have to have had information that you can understand to make that decision, otherwise, how do you come to a decision? It's not an informed choice, so that's been our kind of key element in that area.

We've been working with the Centre for Perioperative Care, looking at getting People fitter and understanding risk in surgery, and patient involvement looking at self-care. We've also been talking to organisations like Healthwatch about how we can influence the accessibility review of the accessible information standard, which I think has now been delayed yet again, but it is very much about trying to influence all of these areas of policy to make sure that people do have access to health information.

Roger

I know you've already alluded to this, but obviously this has an enormous impact in terms of the general public and the reality of all our lives, it shows really just how much there is to do, doesn't it?

Sophie

There's a huge amount to do and I think the problem is traditionally with health information and with the best will in the world, it tends to be written by people with degrees and it comes with a lot of complexity and so it's hard to use, language that you do or don't understand. It's just difficult, and so it's hard for people to unlearn what they spent years learning and that goes for doctors as well. But I think the problem is most people who've been involved in user engagement in health information have also come from those backgrounds. It's the people who are more likely to be ill, they're going to be the people who perhaps don't come from certain backgrounds. They're suffering some kind of other generalised inequality associated with poverty, who are then locked out of health information. There could be other reasons why it's difficult for them to access health information because it's not provided in the format they can use, for example. So it's actually really thinking when we're producing information, who is this information for? Where is it going to make the biggest difference? Where is it going to have the biggest impact in helping and impowering people to manage their health and so that's where we come down to user engagement all the time and I've just been working on a demonstration project in Nottinghamshire where people are looking at surgery for MSK conditions (that affect the bones, joints, muscles, and spine) and you know the healthcare professionals have this not very nice term. They think we've all become de-conditioned during the pandemic, probably because we're all sitting on Zoom and Teams calls, schools are not getting out and doing as much as we used to. So most of us have put on a bit of weight or just maybe not as fit as we were before. So now they're trying to tackle these backlogs of waiting lists having these very difficult conversations with people about their general health and what they're trying to do is say you're going to probably have to wait eighteen months for this surgery, so in the meantime, we need to try and get you fitter. But these are very difficult conversations to have. People can very, very quickly feel judged if you're overweight, if you don't exercise. So we've just had this whole co-production panel with a group of people in Nottinghamshire, all of whom

have lived experience. Some of them are quite physically disabled, which makes it much more difficult for them to do some of the exercise that perhaps might be required, and we've been trying to look at how we can get these messages across in a way that's going to resonate with people. The first point people have come back with is don't make this sound like a school report about my health, because it's going to switch me off, and talk to me in a way that is not going to make me feel judged but is going to make me feel supported and recognise this whole area, particularly around weight, is something that is very complex, it's very emotional. So we've started off with get your mind in place first, and we've worked with this and it's really changed the tone. It has also highlighted areas of misinformation. Nobody on this panel thought the BMI measurement was something that was valid or evidence-based and all thought it was complete rubbish. So we've had to think about, OK, so where doctors are using these tools and there is a bit of misinformation. Then we need to find a way that is going to resonate with people, actually this is something that is evidence-based,

and it is used for a certain reason. So doing that user engagement has completely turned around this project and I think this is by working with these community groups. You're then going to get the tone right for health information as well, and I think that's so important. So I think the real challenge for the sector is to embed this user involvement and people think it's difficult to do. We don't think it's actually that difficult to do fundamentally, you can dress it up in a lot of academic jargon about and around co-production and all of these issues. But it's fundamentally about talking to people and actually listening to them. There's no point talking to people if you think well, that doesn't fit with what we want to do. You actually need to listen to them and implement the changes, and you need to do it early enough in the process so that you're not sitting with a complete app or web solution, and that's ready to go, and then thinking oh, this isn't going to work at all. I reviewed some decision aids recently that have been done for maternity care and they were almost at that point. There were lots of issues there that we felt needed unpicking. So get those users involved, work out what the accessibility issues are. There's a big push for digital at the moment in the NHS, particularly I think as we go through the ICS structures, there's going to be a bigger push to have everything recorded digitally to have digital health records. But again these have to be accessible to everybody. I think that's really complex. When we ran our webinar recently on accessible formats, it

was the other speaker Roger that showed the CAPTCHA thing that you have to use for people who are blind or have sight difficulties or sight loss so that you can't see the traffic lights or the thing, and everybody interpreted the number code that was sent instead in a different way. But it was so appalling. So that's totally inaccessible. And I think some of the things around the NHS app, I think those have been proved now, but initially some of those things around like recording video and stuff like that was quite difficult. And I think some of that has been improving, but we've really got to think about everyone when we're making things.

Accessible for people, and I think we need to think around particularly some of the digital projects as well about people who are deaf or have hearing loss. There's an assumption they can read, but that's not always the case. They might use sign language, but they might never have learned to read phonetically. I think it's about challenging the assumptions that we have by actually going and working out what it is that people need so that they can get involved, otherwise people are excluded from having the information they need to make these decisions and make the choices that are best for them fundamentally.

Roger

There look to be huge areas still to be addressed in the sector and I think so much of what you've been saying just rings bells across other areas such as those using Easy Read information and messages putting the user at the centre of what one does, not talking at people, talking to people and so many of these things just resonate right across sectors and it's just so easy to use language that people just don't understand and the assumption as you say about being online is everybody's online, aren't they. Some may have no interest in being online and how do you reach those people? They're equally valid.

Sophie

Yes. And it's interesting because we've been working with a group of GPs recently and they were saying having the ability to access digital NHS services and information on health generally is probably as an important piece of knowledge as whether or not somebody's housebound because there is an assumption that we can all do virtual appointments, we can all do these things, but actually if you are not

digitally enabled, whether that's because you don't have the skills, you don't have the connection or you just don't have the devices or the broadband connection, these things are quite expensive, then actually you are being excluded and with this work we're doing in Nottingham, the panel has been really clear that it can't only be a digital solution. There has to be a paper-based solution. The thing that people often forget around digital tools is the why. Why is someone going to use it? Because fundamentally, unless it's going to make someone's life easier for somebody to use a digital tool, then they're probably not going to bother. So you have to find that motivation about what it is that might make that easier for somebody.

Roger

That is so true of the information itself.

Sophie

It is, yes, absolutely. And I think, one of the things we hear from people over and over again is that they hate having to repeat their stories within the health care sector. And when you move along a pathway, I think people are under a misconception that the NHS is one massive, large single organisation and that data flows from one part of it about your patient history, about your record, you know your general health, your GP record as accessible to the hospital. That's simply not the case, which is why people are asked to repeat their stories over and over again, and they find it really irritating. To me personally, that is also a massive patient safety issue, because you're just relying on somebody to report what's happened to them. I'm the first person to say my memory might not be what it was a couple of years ago So I think that I'm having that understanding that if you download one of these digital health records that you will have this information, you will have this. You can share it with whoever's involved in your care, and that's really empowering for people. It saves time as well because you're not having to repeat your history over and over and over again. I think it's trying to understand how these things work. And I think there's been a lot of misinformation about the data sharing in the NHS, partly because it was handled really badly and the way it was released by the government last

year was so complicated that people just couldn't get their heads around it.

I don't think they did a terrific job in the pandemic either. Some of the shielding letters that went out were incomprehensible. We used one of them in our training, how would you do this better? They were just incredibly difficult and incredibly complicated.

Roger

Clair, just wondering whether we have any questions.

Clair Woolrich

We do. In your view, where does the UK rank compared with other countries in this field?

Sophie

I think there are two things that we've got that are really strong. One is the NHS and people love the NHS and they really trust it. When we had the COVID pandemic, the hits on the NHS website went up enormously. People will come in from outside to look at the NHS website. So I think globally, it's a brand that people trust.

the other thing that we have in this country, which is perhaps not so well developed in some other countries, is a really active charity sector

by different therapy area and disease area and I think that they are increasingly user-led, not always, but I think they are very, very focused on their users. And I know that one of the things that really is driving organisation’s information production is really looking at what's coming through, where the questions are coming on their websites, what's coming through to their helplines, what's coming through from their, maybe their social media activity. So I think in this country we are quite good, actually at listening to people. It's hard to say exactly how we rank elsewhere.

The States have done a fantastic program for digital health records, which I think has worked really well for them. But it's hard to say, but I do think on the whole in this country there is quite an active health information sector and certainly it's quite a professionalised health information sector as well. It's wider than just healthcare professionals, which can be the case elsewhere.

Roger

Thank you Sophie.

Clair, anything else?

Clair

Yes. Looking at developments since you joined PIF, what are you most pleased about?

Sophie

Oh that's an interesting one. Actually I think one of the things that we really saw in COVID was that they really had to break down and simplify those messages and target them to individual communities. And I think that idea that one-size-fits-all just got blown apart in the pandemic and I think we've seen that really clearly that you have got to think about the accessibility needs of different types of communities. So to access things like COVID testing COVID vaccination, I think we've had to think about targeting communities based on cultural beliefs as well and using trusted voices from within communities. I think we've really had to think much more about how to engage people, how to motivate them to do things and to get to that much more granular level about individual need. I think that's one of the really positive things that's come out of the pandemic. I also think it has highlighted this whole issue of health inequality, that what we saw was that the people who were quite often most affected were those that already had quite poor health for a range of reasons, so I think that has bought a look at the wider social

determinants of health, which takes me right back to where I started about housing, about air quality. All of those things, we're not all born equal. And I think it's having that wider recognition of the sort of social determinants of health is really valuable. And I think what we also have seen is a much wider use of different types of health information, different formats. The more we can have the same message delivered in multiple formats in multiple ways, then the more likely it is that more people will be able to access those messages.

Roger

So true, Sophie, thank you so much for being our guests. This is a very important area to which I think we will return sometime in the not too distant future.

Thank you, also to Clair for assisting with the admin of this event.

Do join us in September, on the sixth, when Gwyn McCormack will join us from positive Eye Limited, and I know she's going to be a very interesting speaker, as indeed all our speakers are, they all have different messages. Very interesting and I'm loving this series. So thank you. And may I say on behalf of us all, goodbye from us all until next time.