

0:00

0 minutes

OK. So we've now hit 1:30. So I think this is our time to go forward. So welcome everybody. We've currently got, um, just short of 100 people joining us at the minute. So really cool to have everybody here, but we welcome everyone to another session of Outside In. So in case you don't know who I am, I'm Louise Lock, I am the customer service exec director, recently joined the ICO. I say that I've actually been here about six months now. So I don't know if I can go with that accolade for much longer, but in essence, because we're in customer service,

0:31

0 minutes 31 seconds

we have an awful lot of interaction with actually the topic of [REDACTED] going to talk today. So I'd like to introduce you to [REDACTED]. So [REDACTED], who's working on [REDACTED] at the National AIDS Trust and she's going to be talking to us today about engaging with in vulnerable customers and living with HIV. So it's a really good opportunity for us to hear the different perspective and to understand best practise of how they humanise customers, how to connect authentically with everybody and to really build trust

1:03

1 minute 3 seconds

and a genuine understanding of our customers who may be may be dealing with this. So this is a really important topic for customer service, but I know it is across the whole of the ICO to really make sure we are understanding how to support these vulnerabilities and to really make sure our services deliver to the expectation of our customers. So what we're going to do today, [REDACTED] is going to go through some material to understand for us to understand what she does and how to deal with the customer base. And at the end of the session,

1:33

1 minute 33 seconds

we will have opportunity for questions. So if you do have questions, please pop them into chat. Now [REDACTED] won't be able to see them. So we're not going to distract [REDACTED] from doing the presentation, but we will circle around at the back, back end of today to understand and try and cover as many questions as possible. So that's kind of the logistics for this afternoon. So without further ado, [REDACTED] the floor is all yours and welcome to the ICO. Thank you, Louise. Thank you for that amazing introduction.

2:04

2 minutes 4 seconds

I'm [REDACTED] As Louise mentioned, I'm gonna just have a presentation here. I'm going to try to present it from Teams. Let me just see if this. If someone can just confirm that you guys can see this.

2:17

2 minutes 17 seconds

Yeah, yeah. That works.

2:19

2 minutes 19 seconds

Fab and like, yeah,

2:22

2 minutes 22 seconds

cool. Thanks guys. So yeah, as mentioned, I'm [REDACTED] I'm the [REDACTED] [REDACTED] at uhm, National AIDS Trust. So by way of context, National AIDS Trust is a charity which supports people living with HIV in the UK. So we run a discrimination service which provides people with free legal advice on whether they've been discriminated against and support people to hold organisations accountable. So that's by directly advocating for people or encouraging people to make complaints or signposting them to regulators, which is where you guys come in

2:53

2 minutes 53 seconds

So as part of the work that I do, I signpost a lot of people to the ICO. In my experience, data breaches are the most common issue for people living with HIV, and they often kind of lend themselves to discrimination that happens after, which is something we're going to kind of go into today to give you guys a bit of an insight. So, yeah, thank you so much for showing up today and for showing interest in this area. I'm really hoping that I can add some value to the work that you guys are already doing and kind of paint a picture of how data breaches work from my perspective that you guys can kind of keep in mind as you

3:24

3 minutes 24 seconds

as we go through your work and cool. So what are we going to cover today? This is kind of all fluff at the beginning. I will be focusing on 2 areas. So the first bit will be to explore the impact data breach breaches can happen people's lives. So looking beyond just the just the breach itself, but everything around it too, that you guys don't always see when a breach is referred to you. And I'm obviously doing that through the lens of my own work. So I'll be looking at cases of discrimination that I've supported people with UM and as I kind of mentioned that oftentimes the data

3:55

3 minutes 55 seconds

breach is kind of the precursor to discrimination. And so that be kind of the first half and then we'll be looking generally at how to kind of have sensitive conversations. Obviously some of you run the advice line or communicate with individuals who report breaches or you know just dealing dealing with people on a day-to-day basis,

you know generally. So just want to kind of identify what to keep and identify what to keep in mind when you're speaking to people who are dealing with a breach or who may be vulnerable.

4:23

4 minutes 23 seconds

And we'll go into kind of some wording to use for people living with HIV and kind of look more broadly at disabilities in a wider context.

4:34

4 minutes 34 seconds

Um, so why is this important for the ICO? um obviously, you guys determine if there's been a data breach or not. And that determination, you know, isn't going to change just because of all the other things in people's lives. But in the context of how these breaches happen and the impact and consequences, um can support you to manage complaints in a way that's empathetic and that will improve satisfaction with you guys as a regulator. And then another reason I have here, I've put, I've kind of pasted the

5:05

5 minutes 5 seconds

that wording here on the slide, but um, the public sector equality duty would apply to to the ICO and that's in the Equality Act, which is kind of the law that surrounds discrimination in the UK. And so there's a duty on public bodies to promote equal opportunities to end discrimination and to foster good relations with people with protected characteristics. So protected characteristics could be disability, or there's a whole kind of other group of them like race, sex, uh, age.

5:36

5 minutes 36 seconds

We'll come onto them a bit later, but um, essentially this duty is to ensure that public bodies are taken specific steps to meet to meet the needs of people with specific characteristics and remove disadvantages.

5:50

5 minutes 50 seconds

And the last thing is like it's really important for other people and people really care about what the ICO has to say. UM individuals who approach the ICO, from my perspective with the data breach likely have been, you know, personally affected by

the breach and this might be their only mechanism for holding organisations accountable. So you know, there are a lot of issues trying to access legal funding for cases. A lot of people can't afford to bring a legal case on data breaches or they may have passed the deadline to make a claim through another route if the data breach is connected to something else.

6 minutes 22 seconds

Or they may not want to go to court kind of in the HIV context because, um, justice is kind of done in public. So your HIV status would be made public by bringing something to court, which is kind of a weird catch 22. So you know, for other people that are approaching the ICO, they really care what you guys have to say. So yeah, I guess there's there's, there's lots of importance in that. Um,

6:46

6 minutes 46 seconds

OK. So getting on, we're going to kind of talk more about the HIV context and then, uh, open it up a little bit more widely to disability as a whole. So I've got a quote here, um, on the board from my colleague Adam Freedman. And he kind of explains why data breaches tend to be so frequent in HIV status settings. And this is because of the stigma attached to HIV. You know, it's oftentimes seen, it's like gossip, it's social currency to kind of share with other people, which drives people to share it. And there's still a lot of misinformation

7:18

7 minutes 18 seconds

about how HIV works. Um. And people feel they're entitled to share that information to safeguard others. You know, sometimes it's from a totally innocent standpoint, Um. But yeah, can have a really devastating impact on on other people. So I guess HIV as a whole, it's not something you can see. Like it's not a visible disability. So the only way that you know if someone is living with HIV is because either they tell you themselves or someone else tells them, tells you or something, shows them. Other cases where people find medication or that

7:50

7 minutes 50 seconds

kind of thing,

7:51

7 minutes 51 seconds

So at its core it relates to the sharing of information. You can't treat someone differently if you don't if you're not privy to that information. So that's why they're so connected to these cases and why discrimination is so linked to to the management of information.

8:08 Um so I thought I'd just before kind of going into to case studies, I wanted to just dispel some of the myths around HIV and the like a lot of the things on this often play a role in people sharing information. Like I mentioned, it's kind of safeguard others, um, or because they think that HIV works in a particular way. So I've put a few kind of the main things to kind of be conscious of, uh, from an HIV standpoint. I'm sure that some of you may have a really good understanding of HIV and some some of you may not. So yeah, it's worth going through

8:40

8 minutes 40 seconds

um it's useful obviously for you. But keep in mind as we go through case studies, uh, might give you an indication of maybe why things have been shared. So the first one there, HIV and AIDS are not the same thing. Um. So HIV is a virus. That's the kind of virus itself. AIDS is a collection of illnesses caused when HIV weakens the immune system.

9:01

9 minutes 1 second

So you don't test for AIDS, you don't have AIDS. Um, if you want to kind of say that someone's got

9:06

9 minutes 6 seconds

and believe with HIV and have those extra complications, you could say that they have kind of advanced stage or late stage HIV instead of AIDS. So AIDS as a whole as a word has has been cancelled essentially. I I'll come back to that a little bit later, but it's just good to keep in mind for yeah, as we kind of go through things.

9:23

9 minutes 23 seconds

Um,

9:25

9 minutes 25 seconds

I have some other kind of, you know, pretty obvious things here. HIV can affect anyone. You know, there's kind of a stereotype of who HIV impacts. UH. Obviously, historically, there's a lot of significance in that and it's important to remember that. But yeah, as it stands at the moment, um, HIV can affect anyone. Uh, most people know their HIV status because they've been diagnosed. So, um,

9:49

9 minutes 49 seconds

that's also important to know. And 98% of people who are receiving treatment have an undetectable viral load. And if you have an undetectable viral load, you cannot pass on HIV. So when you're looking at these cases or when you're thinking of, you know, data breaches relating to HIV, it's it's very likely. I mean, the majority of people that are living with HIV in the UK are undetectable.

10:14

10 minutes 14 seconds

And, you know, a lot of those transmission risks that you might see, um, don't play a part. So,

10:21

10 minutes 21 seconds

yeah, it's good to keep that in mind. And I've got, I've got something here at the bottom. HIV cannot be passed on by kissing, hugging, biting, sharing cutlery. This is stuff that also comes up like quite, quite a bit, um, some misconceptions around that. So HIV is passed on through bodily fluids um blood, breast milk, semen, vaginal fluids. That's how HIV is passed on. So yeah, hogging, kissing, biting

10:45

10 minutes 45 seconds

um aren't kind of risks of transmission. And then the final point I have are there's a pill to take you can take to protect, protect against HIV. There's one you can take regularly. If you're um, feel that you might be at risk of of, um, getting HIV, you can take it. Uh,

11:04

11 minutes 4 seconds

either um, consistently or you can take There's new kind of injections or you can take a pill after, um, you think you might have been exposed to the virus, then you uh, can take pills. That's important to know. So the the kind of main point that a lot of HIV organisations are making at the moment is the the slogan undetectable is untransmittable. And um, it's just important to keep in mind and share that information or be aware of that information. Because uh,

11:35

11 minutes 35 seconds

yeah, it can lead to

11:38

11 minutes 38 seconds

can lead to some discrimination in some cases. And then we have here, I've just put this on the board, um briefly, I've just PrEp and PEP. So I mentioned that there was pills that can protect you. Prep is the um pill that you would take

11:50

11 minutes 50 seconds

kind of consistently, um, PEP is something if you've been exposed that you can take kind of an emergency works similar to an emergency contraception um type thing.

12:00

12 minutes

Cool. So come on back to the stigma stuff. I'm just gonna, um, I'm just going to share a video with you guys. Uh, we

12:11

12 minutes 11 seconds

did a I don't know if you can see this now. It should be on Safari.

12:16

12 minutes 16 seconds

Yeah, hang on. I'm actually gonna share it with, uh, sound. So a little while ago we did um, a

12:24

12 minutes 24 seconds

kind of interviews about Stigma with some of our service users, and I just wanted to share this one UM with you guys.

12:32

12 minutes 32 seconds

It's this lady Tresca who speaks about her experience with Stigma and HIV. Now it might be a little bit quiet, but I'm going to pop on subtitles so hopefully you guys can hear it. But yeah, let me know if you have any issues. Let me just put on subtitles here

12:52

12 minutes 52 seconds

and I got diagnosed in 2015. My oldest child at the time was 23. He started talking about getting separate plates and cutlery.

13:02

13 minutes 2 seconds

And I

13:04

13 minutes 4 seconds

obviously I just felt like really like upset because that's my children and I thought they support me. At the time, my youngest daughter was 11 and my older children told her

13:15

13 minutes 15 seconds

that she's gonna do anything for me. She had to wear gloves. And they won't let my grandchildren come around me

13:21

13 minutes 21 seconds

in front of my face twice during arguments with my children

13:25

13 minutes 25 seconds

I would say that either you can let the stigma eat you up and kill you, or you can show it if somebody doesn't have to be friends, family. But I think people should talk about and just let it free you.

13:39

13 minutes 39 seconds

um.

13:41

13 minutes 41 seconds

Cool. I'm sorry. I'm just gonna go back to Um

13:45

13 minutes 45 seconds

presentation. So yeah, we actually, on that YouTube channel, there's a few um people that we've interviewed. So, um, if you're interested, definitely have a look,

uh, yourselves. And you can, yeah, hear from people's kind of first hand experience of what stigma looks like.

14:02

14 minutes 2 seconds

um so I just wanted to zoom out a little bit, Um, looking more generally at kind of disabilities on stigma. So

14:10

14 minutes 10 seconds

in the UK, living with HIV, you'll be classes as living with a disability in the Equality Act. That's kind of the way that they categorise it. Um. So that's why I'm kind of coming from a disability perspective. Um. So there's 16 million people that are disabled in the UK. Three out of four people have experienced negative attitudes or behaviour in the past five years. And 9 out of 10 people who have experienced negative attitudes said that it has a negative effect on their daily lives. And I've got this really interesting point at the bottom. It's estimated that 70 to 80% of disabilities are invisible.

14:43

14 minutes 43 seconds

So for you guys, that's really, um, interesting I think because a lot of those, uh, disabilities will need to be shared with someone or they'll need to be an information sharing of some sort for other people to be aware of things. So that's something definitely to keep in mind when you're talking to your own customers and to kind of be conscious of um and zooming out. Again, these are kind of just a list of other protected characteristics. I mentioned that a bit earlier in the Equality Act, which are worth kind of keeping in mind while we look at the case studies.

15:14

15 minutes 14 seconds

Um, they're identified in the Equality Act, which is the, uh, discrimination kind of framework that I would work with, uh, quite a lot.

15:24

15 minutes 24 seconds

Cool. So we're going to go into some case studies. And before I get going, I just want to flag that I will be talking about cases that come through to this service and I won't be sharing personal information, obviously. Um. Or given specifics about

cases, Um. And I've adapted the case studies a little bit to to kind of make sure it's most relevant for you guys and to remove any identifiers. Um,

15:49

15 minutes 49 seconds

But yeah, as I kind of mentioned, the purpose is to kind of show you the context for data breaches, UM, and kind of help you help you see that. So some of the things I'm going to be talking about are

16:00

16 minutes

can't be quite distressing or triggering. Um. So something to be conscious of as we go through it. And if anyone feels they need to hop off the call or take a breathe, absolutely feel free to do so. um yeah, we're going to be talking a little bit about harassment, discrimination, obviously, homophobia, violence, uh, people in the criminal justice system. So yeah, if you need a breather or if you want to hop off the call, that's that's totally fine. But just to kind of let you know, So the word scramble that I've, I've made on this slide, um, it's a mix of words

16:31

16 minutes 31 seconds

picked out from quotes from our service users. um so we kind of asked people who'd experienced data breaches how this had impacted them.

16:40

16 minutes 40 seconds

And I thought it was just a really powerful way of illustrating the consequences of some of these breaches.

16:47

16 minutes 47 seconds

Um,

16:49

16 minutes 49 seconds

cool. OK, so this is our first case study. This is in, uh, unemployment context, so I'm going to read through the slide, even though that might be annoying for some of, um,

17:01

17 minutes 1 second

just so that yeah, we're all kind of in the same place. So Gemma was diagnosed with HIV last year. She's on effective treatment and is undetectable. She's still coming to terms with her diagnosis and hasn't shared her HIV status with anyone yet. Gemma starts working in office. She needs some time off for medical appointments and requires some flexibility with hours as her medication can make her tired. She decides to share her HIV status with her line manager to make these requests and ask that it be kept confidential.

17:27

17 minutes 27 seconds

Her manager is shocked, asking intrusive questions about how she acquired HIV and showing concern that Gemma may pose a risk to other members of staff.

17:36

17 minutes 36 seconds

Manager schedules a meeting for a week's time, putting it in her calendar as discussion with Gemma about managing her HIV.

17:43

17 minutes 43 seconds

One of Gemma's colleagues, Luke, sees the meeting because it can be accessed by anyone. It's a Teams calendar that, yeah, I'm sure you guys may have used as well

17:52

17 minutes 52 seconds

um Luke tells a colleague and where it spreads that Gemma is living with HIV and Gemma starts getting harassed at work. She's told that she's dirty and that women don't get HIV. Management are aware of this harassment, but don't do anything about it.

18:06

18 minutes 6 seconds

Gemma's line manager also starts treating her differently, avoiding talking to her and not giving her work, not putting her forward for promotion

18:14

18 minutes 14 seconds

so the situation becomes unbearable and Gemma is forced to leave the work as she is receiving no support.

18:21

18 minutes 21 seconds

She wants to do something about it, but she doesn't know what. It's hard for her to talk about and she can't reach out to friends or family as they don't know about her HIV status and she's afraid they will be judgmental.

18:31

18 minutes 31 seconds

So she contacts the discrimination service four months after leaving the job. Um, she's advised that she has discrimination claims with merit. Uh, yeah, being treated differently, having harassment at work um being kind of forced to leave her job. But she's out of time to bring a legal claim. So there's time limits to to bring an employment claim. It's three month time limit. So you know for a lot of people that are experiencing, I've had something quite traumatic happen or I've had something difficult happen or don't want to talk, you know, struggle to to vocalise things

19:03

19 minutes 3 seconds

takes some people a lot longer than three, you know, three months to before they kind of come forward and seek advice. So that leaves a lot of people outside of the

19:10

19 minutes 10 seconds

legal ability of bringing a claim on something that happened to them. So you know, at at this point for Gemma, her main

19:19

19 minutes 19 seconds

option is to report the situation to the ICO.

19:22

19 minutes 22 seconds

You know, it's not going to solve every single all of the issues, but it can at least identify has there been kind of an initial breach, Um. And that acknowledgement can mean quite a lot for for Gemma. It's worth kind of noting that issues in the workplace are the most common thing that are reported to the discrimination service and like oftentimes information is shared. It's not, you know, not put on a teams calendar, it's shared by coworkers or by managers or where medication is found. I mentioned that Um

19:51

19 minutes 51 seconds

previously that kind of, uh stuff has happened before and um, yeah, so I guess employment is probably one that that we see a lot of and you you guys probably see a lot of as well.

20:03

20 minutes 3 seconds

OK, turn into the next umm case study. This is Jordan Isaacs. Isaacs is living with HIV and diabetes and they had to go to A&E for an unrelated medical issue. When they arrived, they shared their medical conditions with the staff and they were immediately separated into an isolated room.

20:23

20 minutes 23 seconds

No one came to see them for 12 hours. They were in a lot of pain, were given no food and water, nearly went into hypoglycemic shock and had to remove their own cannula.

20:34

20 minutes 34 seconds

Um. Jordan asked why no one had come in and was told there was a sign on the door saying Jordan Isaacs HIV positive risk of infection upon entry.

20:44

20 minutes 44 seconds

Um. Jordan was upset, embarrassed, angry, exhausted. Um,

20 minutes 49 seconds

there's some of the words that people would often kind of express in these situations, Contacted the discrimination Service and they were advised to bring a legal claim and report the situation to the Care Quality Commission um and for Jordan.

21:02

21 minutes 2 seconds

Jordan might be most upset that anyone in the hospital could see their name and their HIV status and they've since disengaged from care, cancelling important appointments and missing checkups due to the trauma. Now this is quite a serious case of kind of discrimination and data protection being breached.

21:21

21 minutes 21 seconds

You know, not all healthcare related kind of data breaches will look like that, but the impact is is huge. Like there are a lot of people that will access the service that

then say like look I just, I can't go back to the hospital, can't go back to my GP, I don't feel comfortable talking to healthcare staff. So it's really serious. You know, it can have obviously an HIV context. It can have a really big impact on

21:42

21 minutes 42 seconds

UM

21:44

21 minutes 44 seconds

people um and it's just worth, I've just popped this in here. Uh, this was guidance that I think you guys were in would have been involved in. This guidance that I've been sharing a lot with my service users on UM patient confidentiality and this kind of STI context. So that's good to keep in mind if you guys are if something that comes up,

22:05

22 minutes 5 seconds

yeah, it's been really useful guidance this. I'm hoping those kind of

22:08

22 minutes 8 seconds

change happening, but uh, yeah,

22:11

22 minutes 11 seconds

still, I guess an issue for for a lot of people.

22:15

22 minutes 15 seconds

OK. The next case study is Carl.

22:20

22 minutes 20 seconds

Um, Carl is in prison for a minor offence.

22:25

22 minutes 25 seconds

Prison officer sees him taking medication and ask what is it for and Carl doesn't wanna answer because he can be heard by other people in the prison.

22:34

22 minutes 34 seconds

He shares his HIV status on the prison officer calls him slag that you can see on the screen

22:42

22 minutes 42 seconds

um

22:43

22 minutes 43 seconds

the officer tells other people on the way and Carl becomes a target in the prison. He's subject subjected to harassment, abuse and violence. Eventually his transferred to another prison due to concerns for his safety.

22:57

22 minutes 57 seconds

Um yeah, there have been quite a few prison related cases that have come up. I think if you're kind of known to be living with HIV in prison context that puts you in quite a dangerous situation. So obviously data breaches of this type type can be,

23:09

23 minutes 9 seconds

um, very scary for those individuals.

23:16

23 minutes 16 seconds

And then the final uh final case study we have is Zeinab Um. Zeinab is living with HIV, lives in a small town. She's the victim of domestic abuse from an ex partner.

23:28

23 minutes 28 seconds

Her ex partner is threatening to share her HIV status with the local community, harassing her by text and leaving notes on her door.

23:36

23 minutes 36 seconds

Zeinab is terrified because she doesn't know how anyone. She doesn't know anyone else living with HIV and is afraid of how how people will react. Zeinab makes the decision to move to another town for her own safety.

23:47

23 minutes 47 seconds

So I guess, like I know from the ICO perspective or from a data protection perspective, it's can be difficult to do something on a personal breach like that or a personal kind of threat. But I think it's just important to have an understanding of how this information can be weaponized. Um. And I think these cases are, yeah, really good examples of of how it kind of works in practise.

24:13

24 minutes 13 seconds

Just gonna move on to having sensitive conversations. Um, if you guys do have questions on those case studies or uh yeah, on anything after this, you can obviously put them in the chat. And um, yeah, we can come to them after

24:25

24 minutes 25 seconds

Um.

24:27

24 minutes 27 seconds

So having sensitive conversations, good starting point from an HIV perspective is the People First charter. It was launched in 2021 and it promotes Person First HIV and sexual health language. So they recognise that language matters and people living with HIV or at risk of HIV experience,

24:46

24 minutes 46 seconds

excuse me, stigma and discrimination on the wrong language perpetuates this. So a person first language simply puts people before their condition, recognising that people are people and not defined by their condition. So in HIV care we avoid terms like HIV infected person and use people living with HIV. So as a general rule and

there's kind of extends beyond the HIV context, this is for other kind of disabilities or conditions where the condition is separate to the person

25:18

25 minutes 18 seconds

ourselves. It's better to have a person living with HIV. So like, you know, if you took away the HIV, they'd still be the same person. If you take away someone that's homeless, if you take away the homelessness, they'll still be the same person. So person experiencing homelessness, person living with HIV, person living with diabetes, things that are not intrinsic to the person themselves. And then when you look at something that's intrinsic. So autistic people, that might be an example where you know, that's a,

25:50

25 minutes 50 seconds

UH central part of who that person is or someone that maybe is deaf, you could have UH, they might prefer to be called deaf person or an autistic person. That's kind of the general rule of thumb. But obviously, yeah, it's not always, um, going to be really clear cut. And it's kind of about just figuring out the best thing for, UH, either something that's accepted or the way that the other person the person impacted

26:17

26 minutes 17 seconds

refers to themselves. Um, But yeah, from an HIV context, it's people living with HIV is kind of the the phrasing that I would use. I've got a few slides here just kind of

26:30

26 minutes 30 seconds

identifying what's things to kind of think about from the HIV context. So hopefully they'll be useful for your work if you are speaking to people living with HIV. So mentioned earlier on HIV is a virus, AIDS is a collection of illnesses. So you don't have AIDS, uh, you don't ask for AIDS and you kind of use late, late stage HIV instead of AIDS if you want to talk about someone that's got those kind of complications. And I have the same here over on the left side, HIV positive, HIV infected. Again, just putting the person first person living with HIV

27:01

27 minutes 1 second

kind of removes the UM,

27:04

27 minutes 4 seconds

the personal element of it.

27:07

27 minutes 7 seconds

Um,

27:10

27 minutes 10 seconds

similar here. Uh person living with HIV, spread HIV, catch HIV infects like those kind of wording of uh

27:20

27 minutes 20 seconds

kind of medical terms that kind of scare mongery a little bit like

27:25

27 minutes 25 seconds

transmit and acquire have slightly less kind of power behind them. So just trying to kind of be conscious of are the words that you're using, UM,

27:34

27 minutes 34 seconds

implying something,

27:36

27 minutes 36 seconds

And this one is an interesting one obviously for you guys. I don't know if it's something that you would kind of be able to take forward in your work, Um. But recently there's been a discussion about disclosing HIV status and that being there's a kind of insinuation that you're disclosing something bad, Um. So the preferred way to talk about it is share HIV status. And you know, that's not necessarily something that you guys would be expected to use. You know, some people will go to the ICO and they will want like an official record. They will want the official wording

28:07

28 minutes 7 seconds

them. It's more just to kind of think about, you know, the words that obviously holds a lot of power and there's a lot of different ways that we kind of

28:15

28 minutes 15 seconds

say things about people without directly saying things about people. And I guess disclose and share is kind of an interesting one to think about.

28:24

28 minutes 24 seconds

Um. So yeah, there are no fixed rules of what is correct and very over time between individuals. So it's critical to ask communities with a given condition how they prefer to be described and to revisit this. So you're not going to get it right all the time. And you might not always have an opportunity to ask people, you know, but it's just like putting yourself in a situation where you're open to that discussion. Um. And you know, if you don't want to ask, ask. You can always try to mirror as well. Like, that's something I do all the time in my work where someone uses a particular phrasing or use particular words, and I try to kind of copy the same

28:56

28 minutes 56 seconds

words that they use. And that's just an accessibility thing as well of just, um, you're showing like, I hear what you're saying and I'm levelling with you at the way that you communicate. It's kind of, uh, makes it much easier to have kind of a fruitful discussion. Um, So if you don't feel like you can ask, you can always just mirror instead.

29:20

29 minutes 20 seconds

Um,

29:22

29 minutes 22 seconds

so as kind of a general, uh, some general things to keep in mind. Um, as you go about your work, Um, the first one being I think the most important one really.

29:35

29 minutes 35 seconds

Disabled people are likely to have experienced stigma or discrimination. Bear this in mind when speaking about disability related breaches. So people that are reaching out to the ICO, um, you know, it's likely they've been let down by other organisations or they've experienced stigma from other people they speak to about these issues. And that's like, you know, beyond the HIV context. um we had the slide a little while ago about, UM, kind of being treated slightly differently and experiencing things that are stigmatised. And so,

30:05

30 minutes 5 seconds

you know, looking back at the example of Gemma, the employment example, she's only ever had negative experiences of sharing her HIV status. So when you're speaking to someone about this, like, bear that in mind, try to be patient with them and and give people like, obviously we don't have all the time in the world to be letting people get out what they need to get out. But try to give people the time and the space to articulate what they want to say. And sometimes, I don't know how many of you would kind of be having these conversations over the phone or um,

30:36

30 minutes 36 seconds

be having these kind of communications. But a trick that I use often, which I think is quite useful, is

30:42

30 minutes 42 seconds

if I'm kind of struggling to navigate a conversation and someone else has clearly struggling to say what they want to say or to explain a situation that's been quite traumatic to them. It's just to basically mirror the last sentence that they use when they kind of trail off. So they might say, like, ohh and then it was all really bad and work and then say, OK, it was all really bad and work. And you know, because we're humans, we want to fill that silence, say, well, yeah, it was really bad on work because my manager said that and say, oh, your manager said that. Yeah, they said that because I saw this. Sometimes it's just about like providing the

31:14

31 minutes 14 seconds

literally mirroring back someone what they've just said so that they can feel they can go kind of deeper into that, uh

31:23

31 minutes 23 seconds

topic. But umm, yeah, just I guess as a general rule, like

31:28

31 minutes 28 seconds

people are not gonna come on, uh, be talking to the ICO and necessarily expecting you to have you know all the tools to figure out what you're meant to be doing. But it's just about giving people space that they can feel comfortable sharing that. Um for some individuals the ICO is the only mechanism mechanism to hold organisations accountable to kind of mentioned about the issues with legal UM bringing legal claims and issues with that becoming quite public UM, you know, people do really care about the ICO and

31:59

31 minutes 59 seconds

and what the ICO has to say. So just kind of bearing that in mind, um, something really specific on that, but just

32:06

32 minutes 6 seconds

it's important. Uh, yeah, for other people then data breaches being part of a much larger story. So I'm hoping that I've kind of, yeah, touched on that a little bit. And I'm sure that if you were to look at other kind of spaces or other protected characteristics or disability more in general, you'd see that as well. I'm sure that you guys do see a lot of the bigger story or have an idea of that. But UM,

32:26

32 minutes 26 seconds

yeah, it's good to be to be aware of. And then everyone has their own preferences on how they want to be addressed. If you're unsure, ask or mirror their language. Um, So they're the kind of main things that I would encourage you to keep in mind when you are talking to vulnerable people.

32:40

32 minutes 40 seconds

Um, which brings us to the end of the presentation. Um. So I think there may be some questions that have come true. Um, in the chat, Louise, I don't know if you want to,

32:53

32 minutes 53 seconds

um go through them. no absolutely, [REDACTED] thank you ever so much. Gosh, I don't even know where to start with all of that frankly. And I'm pretty sure everybody else that's on this call probably thinks exactly the same in terms of content. So we do have a couple of questions actually. But just before that, I just wanted to summarise a couple of things that you've mentioned. I think it's amazing to hear and somebody actually [REDACTED] has mentioned it as well, how when we're back with HIV as a topic which is really

33:24

33 minutes 24 seconds

clear. So it's really good to get that definition to make sure we're all on exactly the same place because I'm pretty sure you know, not necessarily all of us understood that before. The other thing I thought was really interesting, which we really thrive on the in the ICO is understanding that people become before their condition. I think that's a really, really good point for everyone to take away. I obviously the examples given by people living with something versus around the other way, albeit not always the case, but the majority of the cases I think it's good.

33:55

33 minutes 55 seconds

And likewise the ask how people prefer to be described versus reflecting and mirroring as as as a really good tactic as well to make sure people feel comfortable. But the thing I think resounds mostly especially with our customer service teams is giving people the time to actually explain how we can help them knowing that the ICO could be one of the most valuable pieces of input for them, I think is a really, really good thing for you to share and to let us know. So thank you for doing that as well [REDACTED] I think that's really important.