Orangedog interview

KA: So I'm gonna start recording now so we have all of this

Orangedog: Yep

KA: on tape. The reason I do that is so that I can type up basically what you've said into a transcript (.) You'll then get sent back the transcript (.) you can either just be like hundred percent happy with this but it might be there's some stuff you said that you're like ahh actually I kind of don't want that in the transcript

Orangedog: OK

KA: Or I wanna change that so you have the chance to make any edits you wanna make

Orangedog: OK yeah

KA: Um it will be fully anonymised so any mention made of your name or like the city you live in or school names they'll all just be removed

Orangedog: Yep

KA: So when I send you the transcript you'll see removed. Um (.) don't worry about it at all because I know it's so easy sometimes for names and stuff like that to slip out but if they do at all in the interview, then it it will all just be removed

Orangedog: Mm

KA: So just talk as freely and as naturally as possible (.) Um ((pause)) Yeah um (.) and then once we've done (.) a few interviews we're you're I think you're interviewee number 10

Orangedog: OK

KA: I think we're looking for another sort of seven eight more participants so around the midway point

Orangedog: Yep

KA: Um

Orangedog: You're not too exhausted at this yet then?

KA: No I like it I like it it beats just looking at Excel spreadsheets all day which is what I was doing before ((laughs))

Orangedog: OK

KA: I like the human side. Um but yeah once I've finished off with the interviews then we look at the transcripts for all of them identify key themes and ideas and do a bit of analysis and we'll send you back what our sort of initial findings are before we write it up as a paper

Orangedog: OK

KA: Um and you'll also have a chance to kind of reflect on what our themes are just the important thing to notice is you might not find that you kind of agree with everything identified as a theme because it's like the (.) you know the mixing

Orangedog: Yep

KA: of lots of people's information

Orangedog: And not just that you're only speaking to me for an hour

KA: Yeah

Orangedog: So it's not as though you're going to know everything about me or stuff like that so

KA: Well I think if I did I would maybe one of the best psychologists in the world I unfortunately I'm not one of the best psychologists in the world ((laughs))

Orangedog: Yet

KA: Yeah yeah gimme twenty years

Orangedog: Exactly

KA: Um (.) so yeah um (.) would you like to see the information PowerPoint again or?

Orangedog: Um go on then better safe than sorry

KA: Cool yep I will just get this loaded up um ((pause)) here we go ((pause)) My laptop is on its dying days

Orangedog: ((laughs))

KA: so every time I open it it's a -

Orangedog: How long has that been around?

KA: Um (.) since (.) 2018. I got it from a job and in theory it should be good but yeah. Feel free to skip through at your own pace

Orangedog: So remind me again about interoception we talked about this

KA: ((overlaps)) mm

Orangedog: on the call but unsurprisingly that slipped my mind mostly so

KA: Yeah it was a while ago no worries at all. So interoception is like our ability to detect and understand signals coming from inside of our body

Orangedog: Mmhm

KA: so that can be like our heart rate it can be how fast we're breathing or how hard we're breathing how badly we need to use the bathroom how hungry we are how thirsty we are. Um and there are different sort of levels of interoception so we can have sort of how much attention we pay to these signals

Orangedog: Mm

KA: how good we are actually noticing these signals. Like are we accurate when we notice them? Um and also how are we evaluating those signals? So for some people when they notice these signals they find it a bit stressful

Orangedog: Mmhm

KA: or they find it unpleasant and that can relate a lot to mental health. Um so yeah we can we'll chat about it a bit more as we go along so I don't have to like dump all this

Orangedog: Yeah

KA: info on you at the start and expect you to remember it cause yeah if there's one thing this interview is not going to be it is not going to be like

Orangedog: Yeah

KA: A test for you um but yeah please let me know if you have any more questions as and when they come

((pause))

Orangedog: Alright

KA: Cool cool. So I'm just gonna confirm that you are all happy to participate

Orangedog: Yeah

KA: OK amazing cool well thank you once again. You again you'll have seen it in the PowerPoint but you have the right to withdraw at any time or stop the study at any time we can take breaks skip questions and come back to questions later (.) um there are no right or wrong answers

Orangedog: Yep

KA: because what I'm interested in is your experiences and the joy of this kind of research is because I'm interviewing rather than just getting questionnaire responses um you know (.) getting a rich understanding of a smaller ((overlaps)) number of people

Orangedog: ((overlaps)) There's an opportunity to uh for a freeform conversation

KA: Yeah

Orangedog: in those places it can extrapolate extra information

KA: Yeah yeah exactly exactly. You've got all the psychology knowledge already. (.) Um and then yeah if there's any you know there's pens here papers here anything (.) um yeah feel free to just use whatever (.) um we'll start with just a very general question um which is can you please tell me a little bit about yourself? Now feel free to interpret this however you want to I'm also aware this is the most (.) deliberately open-ended question ever

Orangedog: Yes let's see what direction I take this (.) Um (.) I'm [REMOVED] I'm seventeen eighteen in two days um (.)((blows raspberry)) I (.) I'm at school I'm not in work (.) um ((pause)) I used to attend [REMOVED] grammar school ((exhales)) where else do I go with that?

KA: ((laughs))

Orangedog: What else will I tell someone about him?

((pause))

KA: Maybe do you have any hobbies or?

Orangedog: Ohh yeah I play football twice a week (.) uh

KA: So it's the playing as well as watching?

Orangedog: Oh yeah yeah yeah I play football with my brother twice a week. Um I go down on Tuesdays in the evenings and on Saturday afternoons they would lots of Polish people on Saturday afternoons (.) and they just shout expletives over and over again ((laughs)) and I won't repeat the particular word (.) um ((pause)) I game quite a bit

KA: Yeah?

Orangedog: I'm a particular fan of RPG games

KA: Ahh

Orangedog: All those types I've played a lot of them

KA: Is it mostly on like PC or?

Orangedog: No like X-Box mainly um (.) I used to play The Sims a lot when I was a kid I still play it from time to time

KA: I love The Sims

Orangedog: Yeah

KA: but actually I only really like designing the characters and then I got

Orangedog: ((laughs))

KA: I got bored

Orangedog: It is a bit- the problem I have is I play The Sims and I play it constantly for like a week and then I'd already have done everything I would want to do with the sim (.) and now I'm done that's it

KA: Yeah

Orangedog: I've achieved the career path I wanted I've got all the (.) the skills I wanted

KA: ((laughs))

Orangedog: The lineage is done that's it

KA: But then you can make really creative ways for them to die right?

Orangedog: ((laughs))

KA: Isn't that the logical next step? I remember my sister

Orangedog: Yeah

KA: like putting them in pools and taking ((overlaps))

Orangedog: Yeah you take away the ladder or you put a little box and just seal them in there that's slow though cause they just have to starve that took three days

KA: Aww no ((laughs))

Orangedog: ((laughs)) Um you could repeatedly try and start fires there was that too and just hope that one kills them

KA: ((laughs))

Orangedog: And yeah

KA: What a great game ((laughs)) Cool and in terms of your I'm going to use like a cliché now but your autism journey

Orangedog: Yep

KA: When were you diagnosed and

Orangedog: OK so I uh my mum would be better for this um (.) I think we started exploring the possibility (.) about five or four years ago they say my parents say that they had inklings of such when I was much younger

KA: Mm

Orangedog: But they never explored it (.) um but about five or four years ago I had some initial conversations at school (.) where I think the answer that pains so many people (.) came out which was ohh well you have some traits of I think Aspergers they decided that day

KA: Yeah

Orangedog: I think you have traits of Asperger's but not enough for a diagnosis I think that's what they said that day and that was quite a long time ago. And we ended up going through CAHMS

KA: Mm

Orangedog: And I think maybe two years ago maybe a little longer than that three years ago I ended up with a diagnosis

KA: OK yeah and do you think getting the diagnosis was kind of a positive experience for you or

Orangedog: ((sighs))

KA: Didn't change much or?

Orangedog: The thing is that's it depends on a lot because for some things it's going to have changed a lot um despite what you can try and convince people people will change the way they see you despite the fact that you had autism the day before you got the diagnosis and you're still the same person the next day (.) people will change the way they act for you. It's not necessarily in a bad way (.) they might show more compensation or support for (.) for or patience for what you're going through but for the most part you had autism the day before and you still have it the next day and the challenges are still the same. There's a few ways that people may change how they react to them but for the most part (.) it's the same

KA: Mm yeah I (.) I think that's something we tend to hear quite a lot from our from our participants actually. Um and what about your experiences with anxiety now you know is anxiety something you've kind of always felt throughout your life or?

Orangedog: ((Exhales)) see I can't put my finger on it because for me it I often question my own anxiety in a sense and I wonder whether cause I got the diagnosis I have so ((pause)) but yet I still

find myself questioning (.) to what extent I have it because I don't get an immense amount of anxiety attacks I've had a couple in my lifespan (.) um but (.) it's just something that if I am thinking about some of the ways I feel and whether or not they're normal or natural um (.) it's something that I've always always been with. I don't really remember times where I didn't ((sighs)) over think about different things and (.) potentially plot ways they could fail and they have to try and concoct ways to deal with that or subvert it

KA: Mm ((pause)) Yeah I guess it's difficult for me to ask you know when were you aware of your anxiety if it's just something that you've always you know

Orangedog: Mm

KA: your brains always worked that way um. And yeah was it mainly sort of the anxiety that led to um (.) leaving (.) leaving school seven months ago?

Orangecat: Um (.) there's a mix of things so the ((sighs)) I'm surprised it never happened earlier I got through GCSE without it ever happening um (.) but eventually coming to the start at a level I just ((exhales)) I don't know what it was I had a reasonably stressful summer I was in a slightly difficult situation (.) and I couldn't handle the uh a level situation. I think there was some friends left the school so I didn't have much to depend on anymore

KA: Mm

Orangecat: And (.) I (.) just couldn't handle the situation every day was so stressful

KA: Mm

Orangecat: and I ended up (.) they concluded it was best that I take a break after I had a um (.) a breakdown in my (.) care what're they called my care no what they were my care person at school I can't remember I can't think of the name for them

KA: Yeah

Orangecat: But they I had a breakdown in there and they decided that was the uh the best course of action and if you want to talk about the second time around which was reasonably similar it started in a similar way but it lasted longer and I actually thought that I was I was going to continue but then (.) there was a personal life event that I do not wish to discuss

KA: That's absolutely fine

Orangecat: Um which caused me to want to (.) yeah to have to step out of school

KA: Yeah OK it sounds there then it's almost a bit like a mixture of the anxiety (.) if you want to define it as like such like a its own thing but also some other things there like just the stress of dealing with (.) exams and things like that which can

Orangecat: I think

KA: and life events

Orangecat: I think the stress that I find in school is often concocted by social environments

KA: OK

Orangecat: I find social environments to be very performative like I am conducting a display for whatever suits best for what's in front of me

KA: Mm

Orangecat: And (.) one of the ways I think about social situations is (.) I usually when I say something I have an idea of what the person is going to say in response (.) I've already thought about what they say in response (.) and I hate it when they don't say what I expect them to say and it makes social situations exceptionally draining (.) cause I'm always thinking about whether I'm saying the right thing or if they're gonna say the right thing and if what I'm saying is the right thing based on what they're saying (.) and that means that going through a what eight nine hour day of school can be exceptionally exhausting because I've got so many little social interactions that I have to manage in which many of them I don't know the people that well and cannot predict their responses

KA: Mm (.) that sounds like it would be exhausting certainly

Orangedog: And I'd often find that I'd get home and I just wouldn't wanna talk to anyone

KA: Mm

Orangedog: I'm done with having conversations that day

KA: Yeah bit like your battery is drained (.) yeah um well I'm especially grateful then, for you taking the time out to chat with me today um

Orangedog: Um I'm far more capable in a one-on-one situation than a group situation

KA: OK that's good to know that's good to know. Um great now we're going to move on to a couple of sort of deeper questions about your anxiety and again if at any point you'd like a break or to move on feel free to just let me know. Um but if you were to describe anxiety to someone that's never felt it before just based on the way it feels for you how would you describe it?

((pause))

Orangedog: Trying to think of an analogy ((pause)) Perhaps I would describe it like if (.) you had a ghost and that ghost was you and they knew all your life experiences and knew everything you'd ever done or everything that's happened and how you felt about everything. It was you just as a ghost and it would follow you around and it whispers things in your ear just to make you doubt yourself just a little bit more than you ever need to and tries to concoct things based on the past like ((pause)) like it doesn't want you to do anything (.) Like it decides that it would be easier if (.) you just sat there all day because that would be the safest option (.) based on past experiences cause this ghost remembers every bad thing that happened (.) every single one (.) and it remembers how it made you feel and it can replay that it's a powerful ghost ((pause)) and it can make you feel those emotions again make you fear them again ((pause)) and it can even subvert the reality of the emotion and make you feel it in a more empowered way than before (.) to make an emotion that wasn't that scary at the time feel a hundred times more scary when you look back on it (.) and when you think about doing it again

((pause))

KA: Yeah that sounds I mean (.) off topic or a second but your way of describing things is absolutely wonderful it sounded like I was reading a passage from a from a book or something that was amazing thank you so much for sharing that. Um but on the flip side I'm so sorry because that sounds like something that is so intense to be experiencing and to have as you say that ghost following you around and (.) and amplifying things (.) um (.) So sometimes in CBT which I'm not sure whether you've had experience

Orangedog: I do have regular therapy sessions I believe it's psychotherapy

KA: Psycho- right cool yeah yeah yeah. Um so the two er they borrow things from each other all the time. Um in CBT there's this thing called the Hot Cross bun model which just sounds a lot more fun than it actually is. What it actually is is that we try to split things like anxiety and depression into different parts and so the thoughts the emotions the bodily sensations and the behaviour (.) um (.) and I guess um (.) with the kind of the ghost analogy you made there there's a lot there about the thoughts the kind of rumination um ((overlap)) and also

Orangedog: I wanna make it clear as well that ghost technically has no control over what you can or can't do. You are still within your own free will

KA: OK yeah

Orangedog: But the influence is palpable to things you do

KA: Yeah yeah (.) um (.) but yeah thinking for a second I guess about some of these some of these other aspects of the of the whole cross band model um in terms of the bodily sensations you experience with anxiety are there certain things you tend to feel or would you say that sort of the thoughts and the emotions are more salient?

Orangedog: In my personal experience and I don't know I don't know if this is me in particular as an individual but I find that my physical responses are far weaker than my mental responses

KA: Mm

Orangedog: Often it all feels as though it's in my head. I've had a few times where I've entered anxiety attacks. That's where it's felt physical

KA: Right

Orangedog: There's been occasions where I've had true anxiety attacks which have felt so whole body experience that you know my heart I could feel it being out my chest and my hand was sweating like crazy and there’s been occasions like that but the majority of the time it's all bouncing around my head

KA: Mm

Orangedog: It's like if you you know that game like Pong where you do that yeah

KA: Yeah

Orangedog: Imagine you sped that up thousand times (.) and then you kept playing (.)

KA: Mm

Orangedog: And that's what it feels like in my head. But physically (.) and people often talk about physical responses of anxiety and they say as I mentioned you know having your heart beat really fast and having sweaty palms or (.) sometimes have derealization with the situations that are going on around them. But (.) it never really has felt like that to me. I ((stutters)) I find that my physical symptoms are far less powerful than what goes on inside my head

KA: OK yeah that's interesting (.) um (.) we really like hear a range of of things on this. It's obviously anxiety that's is something that's so different in different people. Um and in terms of your behaviour are there like certain ways that you uh find yourself behaving when you're especially anxious or?

Orangedog: Um should we go absolute worst or slightly beyond ah slightly behind

KA: Mm whatever you're comfortable talking about

Orangedog: Cause absolute worst well I'll hit non-functional point where that's when I'm having a true anxiety attack and at that point all I can do is basically is curl up in a ball and shake that's when it hits its worst point. But that happens exceptionally rarely. Um the majority of the time (.) I will simply be on edge (.) ey (.) and I feel like I shouldn't try and downplay it and I'm trying I don't know if I am or not but the way I always envision it is the majority of the time (.) is (.) I can typically present to be OK (.) and that I am still a functional person in day-to-day life despite how anxious I may be feeling or despite what my brain is telling me and I can still do things and I still go out and I still take (.) sometimes I still take on challenges that I think maybe nerve wracking ((pause)) but it's still always there

KA: Yeah (.) yeah and I guess it's almost like that little bit of extra effort to do the things perhaps on top of on top of the anxiety (.) um

Orangedog: I'm not sure I've answered the question appropriately there but

KA: No I think I think that (.) that's certainly addressed (.) addressed exactly what I was I was looking for. And again there's no (.) it's all about your interpretation of the questions as well so

Orangedog: Well yeah but you have to ah you have your questions that you wanna ask and you wanna get answers

KA: ((laughs)) no but no I that definitely gave me the info I needed. Um and in terms of (.) your autism again how do you feel like that affects or interacts with your anxiety?

Orangedog: Whereas my ((sighs)) ((pause)) gimme a moment

KA: Of course yeah

Orangedog: Gonna concoct it in my head

KA: Yeah take all the time you need gonna grab some water

((pause))

Orangedog: I think one of the significant things is the way that (.) I've learnt to (.) handle my autism to protect myself from the anxiety (.) and how I conduct myself in social situations to protect myself from anxiety or making a mistake in the social situation that could cause me stress or

anxiety about future social situations is I've used my brain and my ability to think logically about a situation to (.) think what the best course of action are and to break what my anxiety is saying that is ((inaudible)) They interact in an interesting way because they seem to try and combat each other sometimes I find that my autism will follow a very logical path to (.) to get wherever it wants to go or follow (.) what makes the most sense (.) whereas my anxiety doesn't care about sense it cares about problems (.) and wants to find the problems whether they make sense or not (.) but those two things clash directly because the anxiety doesn't follow the logic that my autism follows ((pause)) so I'd actually argue that in some ways my autism helps me deal with my anxiety because it gives me a combative way of thinking that directly clashes with what my anxiety wants to make me think

KA: Mm (.) that's really interesting and actually it's (.) really nice in a way to hear that because what I've what I've heard from a lot of my participants so far is that for them their autism and their anxiety really go hand in hand and they kind of in their head can't separate the two because sometimes the things they're anxious about are for example how they might act in a social situation things like that um so it's very refreshing and nice to hear as well that autism can also be uh a mechanism to

Orangedog: I feel in their sense they're blaming themselves for things they may do differently

KA: Mm

Orangedog: Because the way I'm looking at what you just said about that them going hand in hand in that regard is because they're not tying autism as something that causes something they just or commands any control of their thoughts they're thinking of it as in a sense of this is some kind of attachment to them that they can't control

KA: Mm

Orangedog: So when they think about their personality they'll think about autism and that's how they that's what they'll connect it to. Whereas for me I don't think about my personality and connect it to autism I have my personality and then I have autism that coincides with that but the two things are not one and the same which I think a lot of people think when they have autism they think the two things directly crossover and that's who they are but it has nothing to do with that. The two things relate and can impact how (.) you behave in situations but they don't undermine your personality and take control

KA: Yeah that's a really interesting perspective and (.) yeah it's definitely interesting for me to think about it that way. Um (.) the next few questions are a little bit different now um and this is on something called alexithymia

Orangedog: OK

KA: And I'm just gonna refresh a little bit we might have talked about it briefly ((overlaps)) on the call

Orangedog: Don't recall it

KA: I also may not have yeah. So alexithymia is something that is quite tightly bound to interception and that's why we end up kind of always talking about one when we talk about the other um (.) and the interesting thing about alexithymia is we see it overlap a lot with different mental health conditions so like anxiety that we're looking at. But we also see it

occur a lot in autistic individuals um and what alexithymia is is a difficulty interpreting or describing your own emotions. Um and a lot of the time even researchers would just completely confuse the two and they would say that you know all autistic people can't talk about their emotions or all autistic people can't identify their emotions

Orangedog: Well I would I would disagree with that entirely on a whole

KA: Yeah well I'm glad you say that because that is kind of kind of how Geoff does research and he was saying well this is it's a bit silly isn't it? This doesn't seem like it's the case at all um (.) because whilst as I say there are (.) uh you know certainly some autistic people who do struggle with identifying and describing their emotions I- autism is by no means characterised by that and you could say exactly the same thing about neurotypical people. Um but yeah the reason I'm bringing it up now is again we ((stutters)) quite like to in our research treat alexithymia as something that is um (.) very distinct from autism and something that may or may not occur with it. Um so just personally um what's your experience like with this you know do you find it quite simple to identify and describe emotions or?

Orangedog: I feel ((pause)) ((sigh)) ((pause)) most emotions I can understand. I sometimes seem to try and explain things in a complicated way or try and (.) I'm gonna glam it up a bit

KA: ((laughs))

Orangedog: But I find that well I find that I can express my emotions with reasonable consistency

KA: Yeah yeah (.) and I guess sort of what we would use as the typical example of alexithymia might be um (.) if

Orangedog: Actually

KA: Oh?

Orangedog: Sorry to interrupt

KA: No problem

Orangedog: Um (.) I do have an issue with (.) say I got a gift for Christmas

KA: Mmhm

Orangedog: How expressing thankfulness for that gift can often be quite difficult

KA: Ahh ok in terms of sort of like your facial expressions ((overlaps)) and

Orangedog: Yeah so sometimes it can be that or even just how I how I act um (.) so with some big gifts that's quite easy cause your reaction is (.) is much more difficult to control but if it was I don't know something small let’s try and not sound really let’s go with the socks with the they’re the classic

KA: ((laughs))

Orangedog: Let's say it's some socks I'm not not thankful for the socks

KA: Mm

Orangedog: Socks are nice. But it can be difficult to express the smaller level of thankfulness and not sound disingenuous

KA: Mmhm ((pause)) Yeah definitely I've there were videos with me as a child being given presents and just looking completely stony faced which my family loved to bring up every now and again because I think I was similar I didn't quite in my head I would be like I'm happy but there would be no reason for me to think maybe I should express that happiness. Um (.) but yeah kind of related to that and ((stutters)) we'll stick with the metaphor of like a gift um say for some people who are alexithymic they'll be like handed a big present and they'll feel an emotion as they're handed that present which is a really intense emotion and they can feel that it's (.) they can feel that they're feeling something big but actually in the moment they can't quite tell if they're happy-excited or they're nervous and scared they (.) they can just feel something and that can lead to even what's meant to be like a (.) a positive eh situation it can sometimes feel negative because it's (.) it's just quite overwhelming. Um so have you ever had experience with anything like that?

((pause))

Orangedog: I think if I was (.) to give something (.) similar to that because I don't think I experience that directly

KA: Mm

Orangedog: But something similar to that that I sometimes do experience is that (.) say for example recently I'm getting what's called PIP payment I don't know if you've heard of PIP payment before?

KA: Yep yeah

Orangedog: So I've recently found out that I'm going to receive payment

KA: Mm

Orangedog: Some time in the next two weeks. And that's very good that's brilliant (.) but (.) instead of just having the instant happiness which I did I was happy (.) I begin to consider the potential negatives very quickly so I start to start to think well I can't let this money go to waste what am I gonna need to spend it on? Is there bad ways I can spend it on wherefore the money just disappears straight away? Is this gonna be enough money for what I wanna do stuff like that

KA: Hm

Orangedog: That's the only example I can give more that I would rather than just accept the positive

KA: Yeah

Orangedog: And if something is positive accept it I would begin to consider how many different negatives there could be alongside that

KA: Yeah that sounds a bit like as well the (.) the overthinking that you mentioned earlier on um (.) but yeah that must be quite exhausting sometimes I can imagine. Um (.) This is a bit abstract ish but again linking back to this like how we interpret emotions if you were feeling really really happy how might that feel to you? What kind of things do you pick up on?

Orangedog: I don't recall all that many occasions where I've had an overwhelming feeling of happiness you know this sort of (.) whole body experience of happiness where that's the overriding feeling (.) cause usually I'm considering a lot of things at once um ((exhales)) ((pause)) Do you want me to describe an image of what I think it should feel like in my head or like what the image what it should feel like is. Or do you want what I think it (.) regularly would feel like for me?

KA: Yeah maybe what it regularly does feel like [overlaps]

Orangedog: [overlaps]

KA: Rather than what it should um ((pause)) But it doesn't have to be super regularly it could also be if there are I don't know perhaps if there's a notable occasion that you remember feeling especially very happy and that might be a bit easier

((pause))

Orangedog: I'm not sure to answer the question directly but I feel as though pure happiness in my in my brain is quite difficult to stumble across

KA: Mm

Orangedog: because typically (.) the emotion to be mixed is usually a cocktail

KA: Right yeah

Orangedog: Things will mix all the time there will be a lot more of that or a lot more of this but I feel as though and I would've argued that this is quite common for everyone that would surprise me if it wasn't is that ((pause)) human beings emotions mix and match and they aren't just one simple OK now I feel happy and now I feel sad and I feel this and I feel that (.) you might feel quite happy but also considering this (.) or quite sad also feeling a little bit alright about this. So for me I find that a lot of my personal experiences are emotions that are mixed and a lot of my experiences if I look back on them will convey mixed feelings in me and I can think of very few times if any where I can look back and think the only emotion that I was feeling there was just happiness

KA: Mm

Orangedog: And I'd be surprised if if that wasn't the case for other people

KA: Yeah it's interesting isn't it? I think maybe for me there have been times but very very short periods of time where I've felt you know pure happiness for a bit or pure anger for a bit but it's very rare and then as you say day-to-day it's more of a mix but if something big happens it kind of (.) I guess I'm still feeling all of those other things but they're just temporarily eclipsed by some of the-

Orangedog: You want the Sims analogy?

KA: ((laughs)) yeah? ((overlaps)) Of course

Orangedog: ((overlaps)) you know when on the Sims ((end of overlap)) if you have a negative emotion

KA: Mm

Orangedog: But you've let's say recently got married

KA: Yeah

Orangedog: All of your happiness motions will go up to the top

KA: Mmhm

Orangedog: And if you've got a long stack of them let's say you're I dunno um uncomfortable cause you need the toilet that's gonna go way to the back and you won't even notice it

KA: Yeah

Orangedog: It's behind that it's stuck behind things

KA: Yeah

Orangedog: It's still there but it's stuck just behind those things and I think about that all the time. You know at school when people say well why didn't you go at breaktime?

KA: Yeah

Orangedog: Because that emotion of being uncomfortable cause you need the toilet was subverted by the happiness of being outside and playing with your friends so you didn't notice at the at break because you were distracted

KA: Yeah yeah (.) that's interesting and we'll get back on to that in a second cause I think especially that example of needing to go to the toilet that links a lot with what we're gonna talk about with interoception. Um just a bit of a heads up we're probably just a little bit over the halfway point now

Orangedog: Yeah

KA: So we can take a bit of a break if you'd like one or

Orangedog: I'm alright

KA: Right

Orangedog: How do you feel about it? What's going on- how do you feel about so far?

KA: Oh I love this I feel like I feel like the tables have been turned yeah I mean I think you're giving me loads of really really amazing information and I really like that you take the time to (.) to think about what your answers are going to be because for me that feels like then I'm getting you know (.) I'm getting a genuine answer from you and yeah I'm super

Orangedog: Have you had many difficult interviews up to this point?

KA: Um I think it's always you know I wouldn't ever like to say especially that an individual was like difficult to interview but as I'm sure you can imagine um with autism there is a huge range of like communication patterns

Orangedog: Yes

KA: Um

Orangedog: And some people may have been signed up more by their parents than themselves

KA: ((laughs)) yeah I don't think I've had so much of that so far so I mean everyone I've I think every interview I've had I've definitely gone away thinking wow like I've learned something from that. They've given me (.) um (.) you know and it might be that (.) there are differences in exactly how that's communicated but I've ((stutters)) definitely been ((stutters)) happy with all of the interviews um but I will say um (.) there is there have been I guess uh some interviews where participants have um found it easier to engage or I guess it just you know it's very difficult regardless of your background to sit in a room with a stranger and open up about your mental health to them um (.) I think I was I was in therapy a lot as a teenager so it doesn't faze me so much ((laughs))

Orangedog: Really?

KA: But I totally understand

Orangedog: I've been in therapy for about a year now so

KA: Yeah yeah do you find it useful?

Orangedog: Um I do but I would like to say that by this point in the therapeutic process he acts more as a life coach than necessarily a therapist most weeks

KA: Ahh

Orangedog: Sort of come to him with what's going on in my life at the moment and get an opinion on how it's going

KA: Yeah

Orangedog: And what I should be doing

KA: Yeah

Orangedog: Which is beneficial

KA: I think that's quite yeah uh that sounds like it's it's a practically quite useful thing

Orangedog: Well as he's someone who knows a significant amount of about me

KA: Mm

Orangedog: He can make better judgement decisions for and approach the way he expresses things in a slightly better way

KA: Yeah yeah I think my um therapist that I had most recently didn't take that approach with me because I think he knew that he would give me advice and that I would not follow that advice and then next week we would be like why ((laughs)) why didn't you do that?

Orangedog: Uh yeah

KA: So he was more just like

Orangedog: That happens still anyway

KA: Yeah

Orangedog: But that's on me if that happens

KA: I think that's a very natural part of life right is um (.) being given advice and then

Orangedog: So you need to have it at the back of your mind so you feel slightly more guilty when you proceed not to follow it

KA: ((laughs)) exactly exactly (.) um ((pause)) but (.) but yeah as I was saying so some of my participants are just more or less comfortable talking about the mental health side of things um but I think I've been I've been yeah really happy with how they've gone so far. At the beginning I was so nervous I'm still quite nervous doing the interviews I don't know if you can tell

Orangedog: Umm you're quiet but I wouldn't I wouldn't have described you as being nervous

KA: ((laughs)) My first interview I was so ((overlaps)) nervous

Orangedog: more allowing me to ((end of overlap)) to speak I'd say

KA: Ah Ok well good that sounds like a favourable review (.) um but yeah I was like shaking like that the first one I did uh but then er then they were also quite nervous too and we just had a bit of a laugh about why were we both nervous why were we both scared of each other and it got a bit easier after than um. But I've had good training on dealing with nerves because believe it or not you've seen Geoff and he you've seen him and he's very nice

Orangedog: Yep

KA: Geoff can be very very scary and we have lab meetings with him sometimes and he gives his brutally honest feedback and I think if I can deal with Geoff's brutally honest feedback I can deal with interviews cause ((laughs)) that's the real scary thing

Orangedog: How bad can it be?

KA: I mean the thing is it's always-

Orangedog: I won't tell!

KA: ((laughs)) he's so nice and like whenever he gives you feedback it's because

Orangedog: He wants to help

KA: He thinks yeah and the feedback he gives you will be fantastic and if you change it according to what he says you'll have a way better paper than you had before but he's a very blunt person. Um (.) cool (.) So we'll move on now to the last section but it's a bit longer than the other sections um and that is on interoception which is which is my lovely PhD topic

Orangedog: Yes

KA: Um and yeah just to recap again it's our ability to feel and interpret and understand any signals that come from inside our body um (.) so I'm going to talk about heartbeat first of all because that's one that we tend to look at a lot. Um so for some people just like sitting here now they'd be able to feel their heart beating like without taking their pulse without anything or you know feel it some people describe it as feeling it beating in their chest some people say that they can feel it in their like fingers or their neck um some people say they can actually hear it in their ears

Orangedog: I ((stutters)) There's been times I think when I was a little bit younger I could actually recognise it more I don't recognise it all that often now

KA: Mm

Orangedog: Um from time to time if I for example let's say got sweaty I was doing a run

KA: Yeah

Orangedog: I can often here in my ears

KA: Mmhm

Orangedog: But I'd say that's about it in terms of what I can hear of my heart. Find out that a lot of other people can hear my heart

KA: Ooh

Orangedog: Which is interesting (.) but

KA: Yeah that's so interesting. I I've become that annoying person because this is my PhD topic and it's therefore all that I think about at the moment if I'm giving someone a hug I'll be like I can hear your heartbeat

Orangedog: Yeah yeah yeah

KA: And your heartbeat it's really fast right now and no one ever wants to be told that I feel. Um but I I'm rubbish at feeling my own heartbeat unless I'm really really anxious about something

Orangedog: People can even hear my heartbeat through a phonecall

KA: Wow you must have like a really strong heart

Orangedog: ((laughs)) yeah but I can't hear it

KA: ((laughs)) yeah um and (.) yeah I guess talking specifically about anxiety and times when you're anxious I know you said before that it wasn't so much it unless it's in an extreme scenario that you feel

Orangedog: In the potent situations I can feel absolutely everything in my body all at once

KA: Wow OK (.) And do you think that makes you more anxious when you feel it all?

Orangedog: Oh god yeah um the first time I had it the physical response is exceptionally scary cause as something you if I haven't felt before which I hadn't at that time it becomes this shock to your system like oh my god there's stuff I never usually feel. It feels like you're dying which sounds extremely dramatic to say

KA: No

Orangedog: But (.) it feels like you are going to pop you're going to explode

KA: Yeah

Orangedog: From the pressure build up inside your body

KA: We hear people all the time talk about how they think they're having a heart attack

Orangedog: Yeah

KA: Or (.) yeah it doesn't sound extreme at all and I'm just I'm sorry you have to experience it

Orangedog: It’s very rare (.) it’s (.)

KA: Yeah but with that kind of day-to-day anxiety you get it you don't doesn't

Orangedog: No it seems to be a massive jump like my day-to-day I usually I don’t feel much ((inaudible)) there's been a couple of occasions where maybe if there was something particular happening let's say let's say as well someone you didn’t like walking past

KA: Mm

Orangedog: I might be able to feel my heart rate go up in that situation

KA: Ah like the change and

Orangedog: Yeah

KA: Yeah

Orangedog: But it’ll be more the change than necessarily feeling my heart

KA: OK yeah (.) um (.) and

Orangedog: Potentially I’d feel a ((sighs)) a slight pressure in my heart

KA: Yeah yeah that’s interesting (.) and then moving on to a slightly different example now and that's how hungry you are or how full you are

Orangedog: I absolutely detest feeling full up. Hate it hate it hate it hate it hate it

KA: Ahh

Orangedog: Hate over-eating

KA: Yeah

Orangedog: I always I hate it so much (.) hate over-eating

KA: Yeah

Orangedog: I hate having a full stomach

KA: This is so so interesting because I as well as anxiety I also look at sort of eating behaviours and and eating disorders

Orangedog: I cannot stand it I hate having a full stomach

KA: Ahh (.) and do you find that that can sometimes affect the amount you eat like do you restrict?

Orangedog: I will often say to myself I will start to feel full that’s that. I eat quite slowly

KA: Mm

Orangedog: Mainly for the purpose of making sure my body knows when it's full

KA: Mm

Orangedog: Um (.) so (.) I no I never overeat

KA: Yeah

Orangedog: I never overeat. I hate the feeling of it just all full up and rammed and uncomfortable

KA: Yeah yeah (.) And what about when you're feeling hungry is that equally as kind of aversive or?

Orangedog: It's not equally I actually prefer to be on an empty stomach but it is very uncomfortable as well

KA: Mm

Orangedog: Like I hate that too

KA: Yeah

Orangedog: I would argue I'd rather be on an empty stomach than a full stomach though but preferably it's just somewhere in between

KA: Yeah. And do you find it quite (.) like noticeable to you when it's either so I guess I'll give you a bit of an example to make you so for some of our participants who I guess you would describe them as saying that they have low interceptive awareness of their hunger signals they can go an entire day without eating if they're not at school where they have sort of set meal times they just will never feel they don't feel the sensation of hunger they just eat by the clock. Would you say that you ((stutters)) do feel those sensations or?

Orangedog: Um (.) I would argue I'll only feel them in an extreme circumstance

KA: OK

Orangedog: Often (.) I would just get the impression that I need to eat and I don't know why because I don't think about my stomach very often and I often think that I don't feel that hungry

KA: Mm

Orangedog: But I would get the impression that I need to eat

KA: Gotcha yeah (.) yeah

Orangedog: But I also gah urgh I can't stand it

KA: ((laughs))

Orangedog: Really I don't I don't know what bothers me so much about it I cannot stand it

KA: Yeah yeah (.) um I'm actually going to focus a bit on some more eating questions cause again it's something that we see overlaps a lot with all of these different things we've discussed today. Um but have you ever had any sort of problems with beyond just the discomfort of fullness?

Orangedog: Um honestly, no I've always had very OK eating habits

KA: Yeah

Orangedog: I mean I eat pure junk my diet is not good

KA: ((laughs))

Orangedog: But (.) aside from that no I've always ate really a reasonably regular amount

KA: Yeah

Orangedog: I would argue I'm potentially slightly overweight if you argued if you want BMI style

KA: Mm

Orangedog: You would you would find that I was slightly overweight so

KA: I don't trust BMI

Orangedog: Yeah no one does. But I am in the 91st percentile of my age for weight (.) which seems extreme

KA: That doesn't hm (.) well yeah I feel it's really hard to draw anything meaningful from these statistics sometimes. Um ((pause)) But yeah and then with I guess sometimes we see um with uh autistic individuals that there are certain like sensory preferences or aversions to certain food

Orangedog: Oh god uh I think you'd have to ask my mum on that one (.) Um because they don't go near me anymore with that with food I don't like

KA: Ah

Orangedog: Um I was a very fussy eater as a kid

KA: Yep

Orangedog: Exceptionally fussy I had a very very small palate. I think there was a period of my life where I only liked butter (.) and yoghurts ((laughs)) stuff like that

KA: Yeah

Orangedog: Um ((pause)) but nowadays I'm a little bit more palatable I think you know ((pause)) get through a week and eat a whole different meal every day so

KA: Nice

Orangedog: Yeah

KA: Yeah

Orangedog: Um ((pause)) but it's not exactly the most broad ((pause)) um (.) palate

KA: Yeah yeah (.) I think that can be that can be quite common I certainly when I was younger I didn't I mean it was texture stuff for me (.) I couldn't

Orangedog: Yeah I find textures to be the problem more than more than anything

KA: Yeah

Orangedog: I hate broccoli on an extreme level

KA: ((gasp)) I love broccoli

Orangedog: Why?

KA: ((laughs))

Orangedog: It’s vile it’s so vile

KA: Oh Geoff just-

((opens door))

GB: Sorry guys [removed] asked if you could finish in about ten minutes because of the parking

KA: Oh yeah yeah yeah of course yeah

Orangedog: Is that OK?

KA: Yeah don’t worry we’re close to close to the end anyway. Um (.) yeah (.) Broccoli I like broccoli but I think I'm a bit weird on that one. Certainly as a kid I-

Orangedog: It's an alien food I hate it

KA: ((laughs)) that’s why I like it I quite like the whole alien food thing (.) Um ((pause)) cool I’m just gonna. We've done the hungry one (.) oh yeah this one I dunno some people find it embarrassing to talk about I very much do not find it embarrassing to talk about but that's the needing to use the toilet one

Orangedog: OK

KA: Do you find you're quite OK at telling that kind of thing or?

Orangedog: Er when I was a kid I can name one instance of me just refusing to go to the toilet and just sitting there and pissing myself while playing FIFA I was like six

KA: Yeah

Orangedog: But that’s not that unsurprising. Although I do note that I feel like I go to the toilet too often nowadays like I get I get the start of the feeling and I'm like oh I'll go so

KA: Yeah

Orangedog: That's all I would really say about that I find that I want I need to go to the toilet reasonably often

KA: OK yeah I am really bad for it and that I I don't realise I need to pee until I like really need to pee

Orangedog: No the second I feel anything I know of

KA: You’ll go? It's see we're absolute opposite ends of the spectrum with this. Um cool and these signals in general you know we spoke about the heart beating the hungriness the needing the bathroom um when you feel these signals is it ever quite a negative experience? Like do you do you dislike being aware of these signals in your body?

Orangedog: I dislike feeling full

KA: Yeah yeah

Orangedog: But that's the only one that I can think of on the spot that I feel genuinely uncomfortable about

KA: Mm

Orangedog: The rest I sort of just think well they're feelings I mean they don't impact me greatly

KA: Yeah yeah (.) um (.) I think that's yeah kind of similar for me yeah. Um and then are there times when you feel more or less aware of these signals?

Orangedog: As we've established exceptionally more where during any form of anxiety attack

KA: Yeah yeah

Orangedog: Um ((pause)) potentially in social situations groups social situations I can find myself feeling a little bit more alert on how my body's feeling

KA: Interesting

Orangedog: And except and definitely more on how other people may be feeling

KA: Yeah. That's um (.) we've actually heard kind of that masking and the experience of masking can either make participants hyper aware of bodily signals or the opposite and they are almost thinking so much about masking that it completely detracts from their own experiences of bodily sensation. Um I don't know if either of those sort of ends resonates with you?

Orangedog: Now here's the thing with my masking I don't even think I do it intentionally anymore I

KA: OK

Orangedog: You know it's not like I go home and I sit down and I go oh I can finally stop all that you know it's not (.) it's just something I do (.) um

KA: Mm

Orangedog: ((blows raspberry)) I mask to match the impression and the expectations that other people want

KA: Yeah

Orangedog: That's what I seek to attain with masking

KA: Mm

Orangedog: My bodily functions (.) don't have an immense amount to do with that so

KA: Gotcha yeah

Orangedog: Maybe I'm a tiny bit more sensitive to it because I'm on sort of a higher twitch thinking

KA: Mm

Orangedog: And I'm thinking about um lots of things so they come into my mind and made my mind react quicker but that's the only reason I could explain why I might have a slightly more

responsive um (.) might be slightly more responsive to bodily signals when I'm if I'm masking in social situations

KA: OK well thank you so much that that is all of the questions and thank you-

Orangedog: We got blitzed through at the end

KA: Oh no I mean to be honest I think that was pretty much everything cause a lot of what I was gonna ask you about you already covered anyway because we're just yeah

Orangedog: Yeah

KA: Yeah um but no fantastic. I just wanted to check is there anything that you think I might have missed anything that you would like to finish up?

((pause))

Orangedog: Being hyper aware of other people's emotions and what they expect from me and maximising how I blend in socially via that is something that my autism has generated to try and protect myself in a social situation. What does that mean to you?

KA: Mm as in what does it mean to me?

Orangedog: Yeah what was what is your like in relation to autism and anxiety and stuff like that what's your first response to that?

KA: Oh on like a personal level or like a research level?

Orangedog: Um let's go for both

KA: Yeah. Um so I guess from a research level it's kind of ((pause)) So there's a lot in the literature about the overlap between autism and like social anxiety specifically and then adaptive and maladaptive practises as a kind of result of that interaction and I guess this (.) this idea that you might um (.) through it I think as you'd kind of mentioned before a certain like logical thought process pattern that one might associate with autism you seek to kind of find patterns in people's behaviours in ((stutters)) their emotions that might be adaptive in terms of um (.) imposing a sort of predictability to social interactions or at least you being able to understand it to a degree. Um so I guess it's in keeping with that. But I think unfortunately a lot of the literature on autism also takes a deficit approach and doesn't attempt to look much further than (.) um you know there's a real lack of research on how mindsets within autism can be used in an adaptive way if that makes sense

Orangedog: So basically I think what you're if we use uh more crude terminology most research things focuses on how autism is bad

KA: Yeah

Orangedog: Rather than how autism is good

KA: Which is why we're (.) we are I would say we as a lab we just try and view it as not ((stutters)) it's slightly strange to us that we would see just a style of thinking that someone has as an inherently good or bad thing

Orangedog: If you remember what I said at the start about it not being a personality in of itself is an attachment onto the personality that is adaptable

KA: Yeah

Orangedog: It changes (.) you as a person but it is not you as a person

KA: Mm

Orangedog: And it is not bad or good

KA: Exactly exactly and um and yeah so that's kind of I think I digressed a bit and we might need to wrap up