

University of Oxford

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Facilitator: Hello everyone and thank you again for helping with this focus group. It is part of the European Horizon 2020 project ALLINTERACT on widening and diversifying citizens participation in science. All of you have already completed the consent form and agreed to recording. Thank you.

Today's focus group will take approximately between 1 or 1.5 hours depending on how quickly we can go through all the questions. Our focus group will be based on the egalitarian dialogue. The objective is that everyone should have an opportunity to answer every questions because your individual opinions and experience are important.

Facilitator: Let's now begin with questions about the Workshop on Equality, Diversity and Inclusion in Research that you participated earlier in July. **What are your general impressions of the workshop? And if it was beneficial, in what ways in particular it has benefited you?**

Speaker3: Yes. I don't mind starting. Yeah. I think it was beneficial, but I think we had too many of us. And I think that's why you had that. To get people's opinion and what's going on. Then this would be a follow up. But I think we didn't have enough time. I think it was two scores. We could have spent more time to get quality time and then emphasize. Not in a bad way. But I think the results we talk about today would influence your answers, I think. It was beneficial to start the conversation going forward. Like this.

Speaker4: Thank you. Yes. First of all, the venue was a bit strange for us to. To be for a workshop. It was that. No natural light. Very dark. So you felt a bit. Well, I felt a bit claustrophobic in that. That with all those heavy. Because it was the theatre, wasn't it. And we weren't told it was going to be a theatre. So it would have been helpful to because it just said it was the Old Fire Station or something. And anyway, so I think perhaps a few assumptions were made about for most people seem if you were not from Oxford, you wouldn't have known it was what it was. If you know what I mean, To call it just the old fire station was strange and a lot of us quite it was lovely to have the opportunity to see people you haven't seen for a long time, like Karen, for example. And that was really good. The food was fantastic, really excellent. And these environmental things do matter if you know it. I mean, the actual content was very well structured. I felt you and I and I know that Della said it was probably a bit too much, too many people, but actually I thought the structure worked for the number of people. I don't know enough about the subject and it was really useful to find out.

Speaker3: I think I actually respectfully disagree with what Mary said about the venue. I thought because I do know Oxford very well. I did know it was a theatre. I thought it was a great size for the number of people that we actually did had. I do agree that there was a bit of an echo in this because it's a theatre space, but it is really difficult to find venues for groups that big. But I did think for people that weren't from Oxford, it was a really good central place to get to. I know people in my group were going off to get the buses and the trains afterwards and it was very close to that rather than like if it had been in one of the hospitals or some somewhere else, it might be a bit more difficult to get to. So I did think it was a good central place to host it. In terms of the size, I did think it was good to see so many people and hear so many opinions. I thought it was really a good idea to split off into smaller groups, So I thought that worked very well because then we could have some more sort of well thought out conversations in smaller groups where we could all have time to say what we wanted to say and then feed back to the bigger group. So I thought that structure worked really well for the size of the group that we had.

Speaker5: I don't come from Oxford, and I'm always getting lost everywhere. But I find it quite easy to get to. But I spend a lot of time making sure that I did. So I was okay with the venue, but I think the acoustics were a bit poor. I'm don't have hearing problems, but I find it a bit difficult to hear what people were saying. I thought the food was good, but there was a shortage of pudding. There was supposed to be oranges and baklava or something, and they ran out very quickly and then they had to flit around later on. And I didn't think that was good, but I thought generally the food was very good. I agree with Shannon about the small groups and everything I know because I know a lot of people there that is very, very diverse and that that is good.

Speaker5: However, I would say that the facilitator on my table didn't really control things well enough, so there was a slight bit of friction. We had somebody there who's a friend of Boris Johnson, and we had somebody who had worked for Keir Starmer. And actually, the friction wasn't between those two. There was a young girl, sort of very militant woman, and she took issue with the woman who said she knew Boris Johnson. And I really think that the person facilitating should have, when we did the introduction, should have cut it off, took taken control and not allowed these kind of political infractions and stuff. So I'm not saying the facilitator was bad. I'm saying that she should have had a more controlling influence. I didn't realize she was the facilitator for quite a while, actually, but that's just my comment. But overall, I mean, I thought it was very stimulating. And the thing about people on the spectrum working in computers and how valuable they were, and I thought that I learnt a lot from that. That's what I have to say.

Speaker2: I enjoyed the session, but I think I'm with Della that if you are going to have that many people, you need more time. So either less people or more time because it felt a bit rushed. The acoustics were dreadful because if you've got loads of groups working in the

same room and their chairs are practically back to back, it's very difficult to hear. Even for those of us that actually wear their hearing aids. Most people over 60 have got hearing loss and I wasn't me, but don't wear hearing aids again. We had a bit of a facilitator problem because there was somebody on my table who I've worked with before and whatever the subject is, he always talks about, I shouldn't have said he. They always talk about the same thing and the facilitator needed to keep it on the right subject because we wasted quite a lot of time listening to that person's monologues that I've heard a lot of times before, and it was nothing to do with the subject. So I think facilitators actually recognising that they're in charge and they've got to make it work and get the project done in the time available, I think. But it isn't easy, especially when a lot of them are quite young and most of us aren't and are quite vociferous. Maybe actually a training session for how to facilitate might be useful if it hasn't been done before.

Speaker6: Excellent. Thank you very much. I agree with Mary entirely. I really enjoyed the food, the venue, the closeness of where it was. I agree a little bit with Georgina because I was on the same table as her. So I think in the future we may want to think about who knows who, because when we were there were four or five people who knew each other quite well. And so that became difficult for me because I didn't know anybody on that table. So it was a bunch of people who knew each other. I think what might have helped would have been having the paperwork beforehand. So although we were given bits of the what we had to discuss, if we had been given the paperwork, it would have been really good so that we would have known what what to expect. And I have already used what we did in the workshop, so I learned quite a lot from the workshop and have been able to apply it. Thank you.

Facilitator: What did you value the most about the workshop and what did you learn in particular?

Speaker4: I thought I knew quite a lot about discrimination and things like that and equality for my particular mental health perspective. And I've had done lots of disability awareness training and that sort of thing, but I wasn't aware of the current thinking of EDI. I'd never heard of it. To be honest, I heard about equality. I know about diversity and I know about inclusion. But I didn't know they were all in an acronym, which is now common way, Common descriptors descriptors. So I learnt that.

Speaker3: I think I really valued listening to the other people in the groups. This was the first time I'd done one of these in person, so it was a new experience to me. I've done a few of them online before, but it was an experience for me just meeting so many people and hearing their thoughts and having an actual conversation face to face, basically. I really did value listening to the feedback at the end as well from each of the different groups. Obviously we would have had our conversation in our group, which I did find really useful

and especially in our niche that we were talking about. But to hear from the other groups as well and to hear how the discussion had gone, I thought I really valued that.

Speaker5: Yes. As I said, I really learnt about the value of autistic people in certain kinds of industry. Although, of course, people should be valued for themselves. That research, I thought, was very good on our table. We had the thing about styles of leadership, whether men or women have different leadership styles. The stereotype is that women are touchy feely. How are you today? And let's all talk about it. And men are getting you get you get you dress and do all numbers. And I think it kind of suggested that there was a smidgen of truth in that, and I doubt it. I just from life experience, I think that there men who are touchy feely and women are authoritarian and all that. And that was kind of what we thought on our table. And the research wasn't really that strong, but that was it was very interesting. I really enjoyed schmoozing with other people. I was sitting with Mary originally and there was somebody on our table who I spoke to later. I learnt an awful lot from the research handouts. So I scooped up all the research handouts and read them later. So I found that very, very useful. And I do have a background in equalities and I do a lot in equalities now, but I think I still learnt a lot. You know, you can fall into the trap of thinking, Well, I know everything about this and you don't. So I think that was very useful.

Speaker2: I found it quite different to a lot of the workshops I'd been to because it's very much about getting people to challenge their own assumptions, which I thought was fabulous. But again, the facilitators really needed to make sure what people were doing and discussing. So I got a lot out of it because there are a lot of things that you, you just assume and actually happen to say, Well, why do you assume that? Do you actually know or are you just, you know, using what is really a bit of bias that you haven't recognised? And so I found it really valuable because of the different approach. And again, I learned a lot. So thank you.

Speaker6: Thank you very much. I really enjoyed the table. Having said that, you know, people knew each other, but the experience and the expertise around the table was fantastic. They knew quite a lot of what was going on and I hadn't taken that on board. Like everybody, I know quite a lot about EDI, but not he she bit and the male female bit. So I did learn a lot and I appreciated the experience and the expertise that was around the table. So yeah, absolutely. I did learn a lot. Thank you.

Facilitator: The next question is about the learnings from the workshop and how might the learnings from the workshop help you improve your work as public contributors?

Speaker4: Associate hospital manager under the Mental Health Act, which is as you know, a job. It's an occasional job, but we're having a training. Funnily enough, we're having a training session today and they've on the agenda is equality, diversity and inclusion, but in the wrong way round. And this is the workshop that we had and this, this refresher is really useful to me to try and influence policy, if you like. This came just at the right time really. I do a lot of conferences around research and they've got PPI quite well within research, but they haven't got equality, diversity and inclusion. And so I have been able to point out in these two conferences I went to this week and last week, not I haven't said you should do this, you should do that. You know, it's just informed how I'm listening to what they say. They all know that they could do better and they all feel it's difficult to do. And I think that's our next stage really is to. And that's what I was going to ask you. At the end of this research, are you going to do a tool kit or something?

Facilitator: Well, we're trying to, first of all, evaluate the effectiveness of this workshop, if it's useful at all, and also ways to improve it. And if it proves to be effective and useful to people, then yes, we'll make it available in open access and before doing this, hopefully will improve it further.

Speaker4: I think it's so good to do the three bits equality, diversity and inclusion together, because people do. They're very into black and minority ethnic, which is and so on, but they don't think to link them together, in my opinion.

Speaker3: Next week, we're doing interviews for a charity that I volunteer with. So I've actually found myself referring back to what we've been talking about in that session, but I haven't actually done them yet. But yeah, I do think this is going to be really helpful as I look to discuss topics with these new people, to see who to recruit and what to challenge myself about things. I might be thinking about them during those interviews.

Speaker5: Yes. As I say, I'm involved in a lot of things as we all are. And what you tend to get is there's a certain demographic of people who get involved in PPI and then has talked about a lot. And in my experience, people just think about minoritized ethnic communities, by the way, by me, and we have to say minoritized ethnic communities.

If you look at the NIHR research roadmap, they've done a thing on kind of BME what used to be. And the roadmap is very inclusive. So they include things like class, geography. So the issues facing people who live in rural areas are different to those in urban areas, and they'd look at maybe single parent families, all sorts of socio economic status carers.

Speaker4: Can you just say what you just said at the beginning? I'm going to write it down.

Speaker5: So BME out and you say minoritized ethnic communities. Right. Or minoritized communities. And that covers a lot of things. And in terms of it used to be, you know, seldom heard. And then it was, well, it's because you don't ask people. So then it's seldom asked or this underserved is the phrase now underserved. But in my experience, what happens then is it starts being discussed and people think of it in terms totally in terms of ethnicity. So then a group of largely, well, totally white, largely retired people then grabbed somebody who's. Visibly from an ethnic minority. And I think job done, they don't think holistically. So you don't get like we talked about the autism thing. You don't get people with learning disabilities or anything or sexual orientation isn't even discussed. Never mind anything else. And the thing is that diversity inclusion includes a lot of things, including intersectionality. So, you know, you have people who are black and gay and people who are single parent carers who are disabled, that kind of thing. So what I think about this workshop, first of all, what I remember now that it is very good that you or somebody got up and defined what equality, diversity and inclusion were, because a lot of people don't realize the difference. I think that was good. And I think you covered it in the round and separately, which I think is very good to keep people off the idea that, you know, you just grab somebody who's from the same background as you who's black or Asian and sit there. You're the token get on with it. I'm speaking very frankly because I've seen it so many times.

Speaker2: I do quite a lot of work looking at research grant applications for the really big grants. And I think the workshop is really sharpened up my ability to look at the PPI plans, because if you only involve two people, how on earth are you going to touch on anything to do with equality and diversity? And so I've started challenging the totally unambitious PPI plans and raising the issue of what attention have you given to equality and diversity? So it's been really useful for that. I was in a group last, I think it was last week or fairly recently when they were talking about health and care and we were talking about how budgets were spent. And I said, you know, there ought to be somebody with learning disability on any group because 70% of the under 65 budget goes on learning disability. And there was this sort of stony silence. So it's given me the courage to speak up for things that everyone forgets about. And just Karen was just saying that Minoritized is the latest buzzword. Equality is now being challenged by people saying it isn't equality we're looking for, it's equity. And equity, I think implies a bit of levelling up or possibly even positive discrimination, whereas equality doesn't. So just I think it's watch the space for whatever word we have to use next. Thank you.

Speaker6: I agree that there are lots of words that we really do need to think about. So I don't talk minoritized. I talk about diverse, diverse community groups and how we are like, you know, somebody was saying you put somebody black in a group with consisting mainly of white people, and they said, We work done, good job. And in fact we really do need to think about it. But also we also need to think about I was in a group recently with only learning disability group and I was the only one and they were really treated badly. So when I talked about it, I said, Why are you doing this to this group that really has got no voice in a

way, although they were trying to bring their voice on board, the next thing I knew I was chucked out of the group because I had raised the issue that they were not being treated properly. So I think we really do need to think how we bring people on board, how we look after them and how we can jointly do things together.

Speaker6: I think we really do need to think about that. And you see at the moment people are saying it is a one condition. For example, pathway. And I'm saying, no, don't do that. Bring everybody in together so that we all work together. Otherwise, some people, you know, sometimes you you as a black person are treated very badly. And if there is a group of people that are very aggressive, you will kind of hide away and think, you know, let me put my scarf on very quickly and just go under the table. So we also need to think about how we treat different people. And that's where equity, equality, diversity, inclusion, it all comes into into being how we treat each other. So the workshops are very good, so that it brings out quite a lot of interesting things, things that really are very deep in our hearts, but in a safe way we can talk about it. So there was safety in the group as well. So yes, I personally did appreciate the workshop. So thank you, everybody.

Speaker5: Can I just come back on something? Originally, it was all about equality. So sixties, seventies, equality. And then it became. Well, if, if you treat everybody the same, then you're not really you're not really ensuring equality because people are different, they have different needs. So then it became diversity and inclusion. I think inclusion covers the whole kind of gamut of what people are, including intersectionality and in terms you can't have positive discrimination, you can have specialized training in certain circumstances and you can have targets, but you can't have positive discrimination in employment. But they do have, because I'm involved in the British Psychological Society and interviewing, recruiting psychologists, they they came from a very, very narrow back to the point where there are clones and some organisations now have what they call contextual interviewing. So they take into account somebodies background. So if you get good A-level scores and you went to Cheltenham Ladies College, that doesn't really it's not really good as a predictor if you get good A-level scores and you went to Tower Hamlets Community College, that that says something else and they did a survey and they're asking about contextual interviewing. And a lot of organisations, universities that trained clinical psychologists have psychologists, psychology trainees who were the first in their family to go to university, who received free school meals, which are very good indicators of poor socio economic status and the fact you've got inclusion, the problem is that it's self-selecting. People don't have to answer these surveys. So if you looked at them, you think that everybody who's a clinical psychologist went to, you know, had a came from poor background. But it is moving on. And you can have contextual interviewing, which I think they have in America they have had for years. So I'm just saying that to flesh out the complexities of this area, which are complex and involve legal issues as well.

Speaker4: Is it me next? It's just I wanted to say we've forgotten about statutory requirements until Karen just immediately went about the Equalities Act and the protected

characteristics. And which is what? You're meant to be working towards. But unfortunately, as with a lot of legislation, they are. It's this is what you should do. And there's not much monitoring as to whether you do it properly or not. And also because the Equalities Act came from what was it, there was another act before that.

Speaker5: Disability Discrimination Act in 1995. That's right. And there was the first one was the Race Relations Act in 1965 and then 1968 and the Sex Discrimination Act in 1975. I work for the Commission for Racial Equality and Equality and Human Rights Commission for years. That that's how I know these things.

Speaker4: But what I'm trying to say is that you need to be up to date with the current legislation. And it's interesting historically to know what it's based on, but things progress all the time.

Speaker5: And and you get caselaw as well. So you can look at an act like the Equalities Act, which is consolidated, but it's moving on because of case law and that things that go to tribunals and that kind of thing. So you're right. Mary Totally.

Speaker4: Yeah. So you need to know the legal context, otherwise you get yourself into trouble as well.

Speaker5: I'm the Human Rights Act and we're now out of Europe. But we still signed up, I think, to the Human Rights Act, which has implications. Sorry.

Speaker4: Yeah. And then Parliament decides, Well, let's not think about Parliament just at the moment, shall we?

Speaker5: It's hard not to.

Speaker4: Exactly. And it just shows how it muddies the waters all the time. You know, you think, Right, we've got this. We're going to do it this way. It's good. And then other things happen. Right wing. Left wing, Whichever wing you care to mention.

Facilitator: If you spoke about the workshop with your friends or colleagues, what was their reaction? What did they tell you about it?

Speaker4: Okay, I shall start again, partly because I'm not quite completely diplomatic, I suppose. And to just bear that in mind. Yeah, because. I think Karen has already made this point, or one of the others may have already made this point about the same faces all the time. Yeah. And that was the case with your workshop as well. And it was very interesting to see people you've seen on Zoom who were there face to face and. It was it was a very nice, very stimulating. But it was also quite complicated because you thought I've heard this guy, the guy from Manchester who is a carer and but he's not. And what I'm trying to say is in this issue, the labelling of people, it's are you labelled as somebody who is a victim of your illness or are you look an unpaid carer for an informal carer or whatever the terminology currently is for this. And part of me and as I say, not being terribly diplomatic is I feel that if you are a carer you should bring the person you're caring for with you if you can. And I know there's all sorts of circumstances why you can't, but you are speaking on behalf of somebody and I don't think and it's but you also need to be clear that you are also speaking of your own needs rather than the needs of your family member or friend or neighbour or whatever.

Speaker4: And I think we get a bit confused as well. About the difference between people speaking for themselves. Nothing about us without us and people speaking in our behalf with very good reasons and whatever. Very good. I mean, for example, this is a long time ago, but my mother was obviously looking after me in inverted commas as far as the system goes. And she I took her to a meeting because I wanted her to know what I was doing, and she suddenly became herself. In this meeting, she said, I'm not. They were talking about older people and this time I was quite young. And she said, I'm not an old person, I'm me. And I thought that was fantastic, really good. But it was it was clear that she was speaking for herself. And I think we need to be aware of that all the time. Both sides, if you like.

Speaker5: I totally agree. And I was a long time carer for my father and I'm still sort of carer for my brother in law psychosis. And I'm totally aware that if you spoke to those people, they'd have a different perspective than I do. And you, you can bring for logistical reasons, you can bring the carers and the cared for together to sit to an event, but you have to separate them because you won't speak. I couldn't speak freely in front of my father and he wouldn't be able to speak freely in front of me. But what you're saying, Mary, I was going to make this point earlier on about people learning difficulties and disabilities. I've had this argument where I was a member of a PPI group to do with a trust. And they had somebody from a learning disability organization representing people with learning disabilities. And I complained about this and people were telling me to shut up. They weren't interested. And I said, you wouldn't have a white person representing black people. So why don't you get somebody with learning disability? And if you look at people Down syndrome, it's a spectrum. Some people very high functioning. And this went on and now was being fobbed off by the court and it just went on. And eventually they did have from this this charity, this

one worked for, they had the people who made a very good presentation and then they weren't interested in joining our group, which just as well is very boring.

Speaker5: But at least they had the opportunity and people learnt there that they could stand up and speak for themselves. You know, this idea that, well, I don't know what the idea was, and it's the same with people with dementia. They are carers and people with dementia have intimate and dementia, so they're lucid a lot of the time. But of course logistically you have to catch them in the moment when they're lucid. But there are ways around that. You know, as I say, you wouldn't ask why people what people felt. So ask people directly in regard to power force direct question. I haven't spoken to other people about the workshop because I don't because I consider it confidential. So I'm always worried about breaching confidentiality. So I haven't discussed it with anyone and I knew a few people there, but not money. I knew Mary and maybe one or two other people and I think you're going to get that. But there were plenty of people there I didn't know, so I thought it was quite mixed. Of course, the more PPI work you do, the more likely you are to see the usual suspects. But I thought it was quite, quite well mixed, actually.

Speaker2: And I haven't particularly talked about it because I'm afraid most of the people I know aren't actually signed up to. Equality, diversity, etc. being an important issue. So there are times that I try and chew away at them gently, but it's one of those things. Oh, it's like, you know, if somebody wants to say, I've always voted for X party, you have awful trouble getting them to change their mind. And I think people who would like a big brick wall built all around Britain, you're not going to change their minds either. So I knock on doors that are slightly ajar rather than the ones that are locked and bolted. That's a very honest comment.

Speaker6: I agree with quite a lot of points being made here because like Mary said, you have meeting the same suspects all the time. And I was I was looking at it and thinking, yes, there are probably about 70 of us nationally that we go to all the PPI meetings and workshops and everything. So it is but it is very difficult to try and find people that will come on these groups, because we have tried very hard to to mix people up. The other thing is the importance of training here is is really very important because you cannot have 1000 people represented on the steering group. So you got the learning disability team, you got the minor minority groups, you you got all sorts of people, people with mental health, people with disabilities. So the important is that we learn about the "I". We can challenge things when they are not being put right. And sometimes you do get into trouble because you are challenged it. But how do you then cope with those if people are very aggressive or against you challenging? I mean, I challenge the the NHS England at the moment because they want one issue workshops and I am saying you can't do that because there are some issues that are taboo issues that you cannot talk about.

Speaker6: There are some people with domestic violence, homeless people who don't want to give you their data or dates or dates of birth or postcodes or whatever. How do you bring everybody in? So there are lots of ways we can be working. And the way I have been thinking about is you have the carers, whichever carer it may be, you can have the staff as well. So if Pavel is one of the people who wants to do the workshop, why can't he be part of the workshop as well? Rather than facilitating, he can be part of the workshop. So we can have staff, we can have carers, we can have people with one condition and people from some minority groups so we can mix, mix and match things up. So that's where I am going with my thinking at the moment. So I don't agree with one issue workshops now.

Facilitator: What do you think about the potential for extending the workshop to other groups?

Speaker4: You need to have a database of all these initiatives throughout England, Wales, Scotland, Northern Ireland, Republic of Ireland and the rest of Europe. And that will be do your head in. So there aren't very many groups, but you could ask us as individuals whether we can think of for example, there is. I was involved in a project a long time ago with the European Patients Forum, which was called. It was a European funded project, a bit like the one you're talking about here, and it was called Value Plus, and it was about how people with disabilities can mix together. That's not the proper terminology, but and it's trying to see what each type of labelled group. So the conditions specific group, I suppose I'm talking about. It was fascinating to find out, you know, people deaf and hard of hearing groups, mental health groups, obviously, and then disability groups. And this is not the patient group. This is people like O, not Mencap or Scope who look after people with disabilities and may be working towards doing PPI correctly. But you know, it's depends what you want to happen from these groups. Really.

Speaker2: I think from reading a lot of research grant applications, I think researchers have got the hang of pity. They haven't actually got the hang of being of equality, diversity and inclusion. And I think this sort of workshop would be really good both for early career researchers and later career researchers, because some of the worst ones are the ones applying for professorship grants that they think if they've got the same two white ladies who've been working with them for ten years as their PPI, you know, they tick the box. And I always say, Well, why don't you refresh your PPI? Because you just hang on to the same people forever. They turn into semi-professional. And I suppose in my case, it's a bit like being a turkey who votes for Christmas because I'm actually saying use less of me and more of other people. But I do think researchers could benefit enormously because it's yeah, they're on a learning curve to get beyond PPI. You've got to do something about EDI as well.

Speaker5: Yeah. I'm not sure that all researchers have got the hang of PPI. Never mind either. Yeah, Yeah. The thing is that they. The NIHR is really getting strict about these things

now because they've been pushing and prodding for years and haven't got anywhere. So researchers I'm I'm quite shocked when people say, oh, people don't know about EDI. I found it really odd in this day and age. And the fact of the matter is they're going to they are going to have to get their heads around it, because then NIHR is pushing these things. And so therefore, I think it's in people's interest to have access to these workshops. But the thing is, you see, people are terrified. They're terrified of saying the wrong thing. So the terminology. So in a certain. If people round in the sixties, the polite term was coloured, not black. Constantly black was extremely rude. So there are people who say coloured. Benedict Cumberbatch got into trouble because he was talking about the lack of Black American black actors or the lack of opportunities for them. So he was he was advocating for black actors and he got involved in some storm because he said colored colored actors and then used pants done because it used the wrong word. And I thought that his his motivation was correct. And you get all this colored people of color, ethnic minority. Bme You can't say that anymore. People being having their pronouns, misgendered and all that. And I think there has to be a kind of acceptance that sometimes people use the wrong terminology. And I'm not talking about N-words or P words tonight stuff. I'm talking about the fact that people in different from different demographics use different terms and that that stops people from learning that, stopping people from discussing because they're terrified.

Speaker6: Yeah. Yeah, I agree with Karen, actually. So it is if, if these workshops were ongoing, I wouldn't be thinking just of research people. I would be thinking about everybody because research in the end does have an impact on people on the ground. So I was thinking of all the health organizations and the social care organizations. So it would be for everybody and for us it is. How do you talk about all this? Like we are talking quite openly here and confidentially here. So it will be in those workshops, people will be able to raise issues, concerns. What is that they have about whether it is words, whether it is how we take care of each other. The other thing that we need to also think about is faith, because I remember and that was again very recently I raised the question about faith and oh my gosh, people were really angry about that, that why did I talk about faith in a group? People faith is a is a protected characteristic, actually. But we don't want to talk about faith. I don't know why because we all think that somebody will come and be a terrorist or whatever, because I'm a Muslim and people think, oh, Muslim, you know, must be a terrorist. So it is you know, it is thinking about all those things in a very practical way. How do we support each other? The words we use, the the things we bring up is as well. So, yeah, I think I think they'll be very welcome. It will be but doing more So it is not just talking about certain things with the eye but covering everything. So yeah, that would be good.

Speaker4: Yes. I was going to say, I think we are in danger of trying to change the world. And it and that that's not a bad aspiration. But whether workshops can do it is another is another thing. So you need I feel you need to put boundaries on what you're doing because what we've talked about is fantastic and wonderful and it'd be really good to see. But I think we're all so used to lots of talk and no action, and there's a danger that this could be the same if we were not careful. So we need to have action points How how you can do it. And I don't know whether you want to focus on research only and somebody or whether that's just

a starting point because I'm fortunate. Well, I was going to mention the UK standards for involvement in research are a good starting point and should be looked. All researchers should be aware of them and look to see how they're not perfect. Of course they're not perfect, but so we don't I suppose I'm trying to say we shouldn't reinvent the wheel necessarily. We need to be. I mean, it's been a fantastic conversation, but how you actually put it into practice, this is a good job for you.

Speaker5: I think we've had a game changer, and that is COVID, because that exposed socioeconomic differences and also linked to ethnicity and. Minoritized ethnic communities traditionally don't take part in research. They're very, very skeptical about it. There's also areas where they don't get involved. But. What I remember now from the workshop is that the Yentl syndrome treating women like men, and the fact that car seat belts don't really work for pregnant women, but they don't work for women anyway, because women tend to be smaller and they carry the fat differently. It doesn't take into account breast tissue and the fact that men are run get osteoporosis underdiagnosed because people think it's a female thing. And then this thing happens with ethnic minorities or minority ethnic communities where, you know, they they have illnesses that white people don't tend to do, and then they have illnesses that white people have, but they're more prone to it, like prostate cancer in men from black African background. And their research does not include them and they're kind of left out. So I think COVID was a game changer for everybody. So I think people will be more amenable to it now to I and including people as participants and on trial steering committees in terms of production, what have you.

Facilitator: Has the workshop made you more involved in things related to science and research in general, has it had any effect on your interest and involvement in science and research?

Speaker5: No, because I was heavily involved anyway, so that may apply to other people, I think.

Speaker4: Okay. I was just going to say I agree with Karen, and we weren't. I wasn't clear where everybody was coming from for the for the workshop, the big workshop that we were talking about. Because whether you had people who didn't know, I don't think you have anybody who didn't know much about research at all because I think you'd gone to the Oxford. Network to get your people. So I don't think you had the the aim of the workshop was not to bring on awareness of PPI in new people or EDI in people who were not already accustomed to research. I believe so, yeah. So that's why I think. But it was it was great to do it. I mean, I'm not trying to say you shouldn't have done it. It was really good. And you've learnt a lot from us talking at that workshop and talking here, so I don't think it was a waste of time at all to invite people who weren't, who were. I don't think there was anybody who was naive to research. We were talking about one person who says the same thing all the

time now is that, you know, they need particular training, maybe a quiet word or something. I've had an example for myself recently of somebody who goes along to things and just only takes part in the bits he wants to take part in as and still gets paid and everything else. So I think we need to be aware of in a supportive way of where people are coming from, if you know what I mean, And not just say because you're a P person, you are wonderful. Perhaps. I mean, I am wonderful, of course, but.

Speaker5: Yeah, Well, following on from what Mary said, I think maybe the answer is to embrace strict, strict ground rules. And I'm not aware that on our table we had ground rules. Maybe we did, but they weren't enforced. In mental health, what you get is this. If you don't say we're here to discuss blah blah, what you get is so-and-so's history of psychiatric attention. So you get, oh, you know, the first time I'm not talking about me know, I remember going to this thing and it was. It was seen by, I think, C.R.N. that Nigel and we were there all day and the rest of us and two people never spoke at all because they never got a word in. That's a call to the people. And it was hijacked by somebodies journey through the psychiatric system. And I thought, you will you kind of bring it back on track. And after 3 hours I got word in and she said, Oh, well, we need to move on. I thought, you've just listened to somebody going on about the psychiatric problems for 3 hours. And I know that from working in the kind of mental health arena. So you'd say, you know, people have a right like this guy whose care people have a right to their opinion, they have a right to their story and their problems with it, particularly in mental health, which are going on. But you have to kind of say, we're here to talk about outcomes. I was facilitator with expert patient program, and we always had to say that at the beginning. And you really were not you were supposed to stop people if they ever talked about their own personal experience. And that is ridiculous. I used that. People took it because it's not really stick to just say, Right, we're going to talk about this or not. But I think there is a space for having ground rules and saying what we're here to do. And then if somebody talks about the psychiatric journey or the hobbyhorse, you can say, thank you.

Speaker2: For me, it hasn't made me more involved. I hope it's made me better involved. And I think every time you learn something, it helps you to be better involved.

Speaker6: Yeah, I, I think I agree with Georgina, actually. It does make you want to get more involved. You get more information, you get more knowledge. So, yes, and I also because I'm involved in different things. So I also try and bring EDI into everything, every all the discussions. So have you thought about people who are blind? Have you thought about people with learning disability? Have you thought about all sorts of things? So we don't all need to be on the same workshops or same groups, but we all if the training is there, we can bring these issues in. So I think training is very important. I don't mind having any sort of training because it does increase your knowledge and your assumption says, Well, you think you know all of these things, but when you are in a workshop, Oh, I didn't know that. So yes, I personally appreciate any training you give us. I appreciate it. Thank you.

Facilitator: Yeah. Thank you. And did you receive a certificate?

Speaker6: Uh, I don't think I need certificates. I've got so many now. I have the paper. I've got piles and piles of certificates. So I'm finished with certificates. I'm happy to give my voice.

Facilitator: How could we improve the next workshop if we are to have another workshop?

Speaker6: Yeah, great. Thank you very much. I think it would be really nice when you need to it would be nice to have the papers beforehand so we can read the papers. Second is, is there any papers that say how things went wrong? What happened and things went wrong. So. And then how do we work around it to make things right again. So, so to bring it in in a different way. I personally wouldn't like to do two people talking to each other because some of them will get on like a house on fire and some of them we can't get on. So there may be personality clashes here. So but it could be a small group. I think we were seven in a group, but I think three might be quite nice with a good facilitator. It might work better. Yeah. Yeah, that's my contribution. Thank you.

Speaker2: Pairs aren't a good idea because they tend to self-select. People are sitting next to each other because they know each other. And I think it stops you being exposed to different ideas. I like small groups. Something like five actually, I think works quite well because then there's always plenty of time for people to talk. But I do think groups better spread out so that you're not picking up on what's going on at the next table. I think that's actually quite important, even if it means you have to scatter some groups off to a different room.

Speaker5: Thank you. Referring to what we said earlier, I didn't know anybody on my table. I'm sure I never met any of them before. And yet I think Mary knew everybody that maybe I don't I don't know how this how people were selected in groups, but maybe if you put people who wanted to who knew each other and then people who didn't know each other, maybe that would be better. People from different groups, if you see what I mean. But I was quite happy with the number. As I said, I just think you need the facilitators need to be. Have a firmer hand.

Speaker4: Yes? As somebody who travels because I live in Worcester and to get to Oxford is usually very good. But in this current climate, it's of rail strikes and stuff. It's a bit

uncomfortable to think a face to face meeting in Oxford. I'd loved it. I think it's a really good idea. But there was a train strike the next day and I had to leave, you know, as soon as I could in order to be sure to get a train back, which and all that stress is not good. So this comes to my point. Can you have hybrid meetings? So by which I mean that people who are able easily to get to Oxford and you can find out on a questionnaire as to how far they're travelling and all that sort of thing, and would they prefer a hybrid meeting or a and I'm, it's just I'd hate to miss out on more workshops, but if it's going to be this current winter and strikes and everything, it's, it's travelling for face to face is quite stressful I would say. And there were people at the workshop who had come a long way, a lot further than me. So and I do know a lot of people because I've been doing this for over 30 years. So it's it's not surprising, but I don't know everybody. I may give that impression, but I don't. So there were people there I'd never met, didn't know. And that's really good to have a mixture. As Karen says, it's really good to have a mixture. So that's what that's my main point was going to be could you look at doing a hybrid meeting? And that theatre obviously wouldn't be suitable for a hybrid meeting. Or maybe it is. I mean I people very mixed up about hybrid meetings.

Facilitator: Yeah. We looked at the doing it hybrid because actually quite a substantial number of people said that they would rather do it online or they can't attend at all, but they want to do it online. But technically it's very difficult to, to ensure equal experiences for people in person and online. So because there are requests were looking at the possibility of doing a purely online workshop, do you think it might work? Do you think you would benefit equally?

Speaker4: Well, I would. I really feel that a lot of people really like the opportunity to for face to face if they can. Yeah. And if you make it clear, like, for example, that the old fire station people from Oxford knew about it, knew where it was, but in the directions or the information, it didn't say, Well, I've said this before, It was, it didn't say it was a theatre, and I didn't know you could walk from the station because there were no walking directions given. Sometimes you have to spoon feed people and the more spoon feeding you do the better really about it's going to. And also when you talk about walking, you've got to bear in mind the mobility issues and that sort of thing. So it's just as you're talking about equality, EDI, then it's important to make sure that the venue suits, There are lots of steps and stuff like that. It wasn't a very good accessibility. Then I didn't think. The. So I know you can't be perfect, except most of the time you can try. You're trying to be perfect, which is really good. But it's some. Yeah.

Speaker5: I understand what they were saying, but I was just glad to get out. I hadn't been out of the house, really, for two and a half years. And I think there's always that tension between going to a community venue, which it was, and encouraging community projects, and the food was obviously provided by them. But they often have these problems, steps and what have you and poor acoustics. So I think it's a trade off. In my experience, hybrid meetings don't work very well, but I do attend them, but I often can't see who's in the room when I'm online and people don't identify themselves. So you just see a kind of lump and

group of people in a corner shouting out. But I remember now that I hurried to the station. I met Hamid. You know, Hamid, you don't Mary?

Speaker4: I certainly do.

Speaker5: He said the train's been cancelled because we catch the same trains one every hour. So we he went back to the fire station, I think, and I keep my heels for an hour because there's only one train an hour. So there are problems with, as Mary said, rail strikes and there wasn't a rail strike. I don't know why it was cancelled, but you do get these things. So it's like everything. There's pros and cons to everything.

Facilitator: How do you think citizens benefit from scientific research?

Speaker4: Yeah. I think it's using the word scientific is a real problem. It makes people worry, concerned. Are we going to be experimented on? Are we going to be part of a clinical trial and that side of. So that's my own view. I just feel because research is science, but if you're trying to look, there are some very I'm sure Carol's got good ideas about the. There's mental health, which is a very good. Have you heard of that? It's a science thing which explains science in a lazy way. And I think that's the approach to adopt.

Facilitator: Is the word scientific off putting for you?

Speaker4: Yes. It's only my prejudice. We're talking about EDI and my prejudice about being done to rather than being part of.

Speaker5: Yes. I promote research, but I don't use the word research. I was talking about a project or initiative or an opportunity. I don't use the word science or research until I'm coming out the door. Um, I think it's people, it's based on people's lack of understanding of research and how rigorous it is and how research is waylaid by ethics committees and all this kind of things. They knew how rigorous it was. They wouldn't be so worried. But in terms of your question, how do citizens benefit from scientific research? We've just had a very good example. Covid and vaccinations. If it weren't for scientific research, we'd still be sitting at home in our bedrooms, scared to go out. And I think that has changed people's perceptions. People who knew nothing about research. We're talking about the the R

number and the something curve and all that. They're talking ordinary people in the street were talking about quite scientific matters because they were Googling it and listening to those professors doom and gloom every night on the television flanking Boris Johnson.

Speaker5: So I think that, you know, I always find that people don't want to get involved in research. I think if he went to the doctor and they prescribe something and you said, Oh, what's this? They said, Well, I don't really know. But, you know, we tried. And few people liked it. We. We don't really know whether it works or not, but try it. And you'd be horrified. So why do they think these things come from? They come from the fact that people try them out. And I know people who have survived stage four ovarian cancer for maybe seven years, which is almost unheard of because they put themselves forward for clinical trials. And, you know, people have got better treatment, even people in control groups do better than they're involved in scientific research than people who aren't. So, you know, people do benefit. I don't know. It's from a lack of understanding. I think people are taught science at school, but they're not taught about research, scientific research. And it'd be helpful if they were really if they understood how rigorous it was.

Facilitator: Yeah. Thank you.

Speaker2: I think there's a lot of misinformation and misunderstanding still out there that and it's so difficult to change people's attitudes because some people will be obsessed about research is about making money for drug companies, and other people see themselves as, Oh, I can't volunteer, you know, I'll be a guinea pig, I might die. And actually trying to get the concept of research into some sort of science module at school so that people grow up understanding, you know, why there's a vaccination program, why you go to the doctor and why you shouldn't take too many antibiotics and all the other things that would be fairly easy to explain. And ideally, when youngsters are at a receptive age rather than when people have got, you know, I'm not going to learn anything else, I have my opinions on everything which seems to happen to a lot of people. So, you know, early introduction will, I think, change attitudes. But it's so difficult to change adults attitudes.

Speaker6: I agree with everything that is said just now. So I think what we should be doing, I am surprised that following COVID, we haven't taken that on board. That research is part of everything that is happening in the world at the moment. Excuse me. So we do need to give training. We do need to have educational programs. We can't expect people just to volunteer for something they don't have a clue about. And something that happened at Northwick Park. You know, everybody knows about it, but we don't know all the other good things that are happening. So bad news makes news. That is good news doesn't make news. So it is for us to think about how do you train? How do you give information? How do you like you know, somebody said about telling the young children who will then go and tell their parents and the grandparents what screening is all about, what research is all about, what medicine's all

about. So I think there needs to be quite a lot of communication about research. And I agree with Karen. Don't talk about science, science and research. Talk about something else. So we need to find words that we are not frightened of.

Facilitator: Are you aware of any initiatives that help to encourage and engage citizens in science?

Speaker6: So I know I know that the science museum puts a lot of things about science, and having been through to couple of them, it is really lovely to see what and what people do in the science museum here in our community. We got somebody who was a scientist, and so she she does with the children. She will bring different things for the children to take part in and and scientific experiments. So yeah, there are there are things going on.

Speaker2: I know that Women's Institute has science and discovery days, so but precisely what they're on on each occasion, you know, it wouldn't necessarily be scientific research or medical but an awful you know, they, they do try and encourage that sort of interest in people.

Speaker4: It's interesting that the the why should be mentioned because they were very good for me for training as a member of the WI. I learned how to chair meetings and take notes and stuff, which is a very good skill to have. And it stood me in good stead. And I'm no longer a member of the Women's Institute because I don't live in a village anymore. But apparently they are in towns and I have met people. But it's somehow you've got to be sure aware of the demographic of of the women's Institute, which is for me, it was really good. They were very helpful to me in my village. But it's because it's a community building thing. And so there are lots of groups. I mean, I'm now in Rotary, which again has a particular demographic, and I'm in an E club, which is with lots of people from Europe, which is fantastic. But it's again, they've got all sorts of things like the WI that you could get people involved in if you wanted to.

Speaker5: I know of quite a few things. So there's this thing called I think it's called the Annual Science Festival. And I went to it about just before COVID. So maybe three or four years ago when I was at Warwick University, because I live in Coventry and I got to hear about it and it was like three days of events and it's in September or this was in September. I think it generally is because the weather was lovely and it was free. And you heard talks by an expert from Warwick who's a psychologist, who's an expert on happiness. He said, If you want to be happy, get a dog and don't have kids. I remember that. And then there's all sorts of there was somebody there talking about microbe biotic resistance, which was terrifying. And then. That it was it was a brilliant three days I really enjoyed. I couldn't make it to every

day. And they they had dance classes because dance improves your cognitive ability more than anything else. So then you could take part in some kind of exercise beforehand. And after the dance, it was absolutely brilliant. Now I think that they have these in different places every year, but that was one of them. I don't know whether some things are accessible online. Then at our local general hospital, the University Hospital. Coventry. Warwickshire. They have a sort of open event every year in May for clinical trials day around May the 20th.

Speaker5: But to be honest with you, first of all, it's in the hospital. People don't want to go to hospital. There's the parking issue. It's horrendous apart there and expensive and it's very badly disseminated. Nobody ever hears about it. Even I get an email if I'm lucky. So I don't think anybody even turns up to it. It's very bad. But also Coventry and Warwickshire Partnership Trust, they have. Up until a few years ago we had an AGM and this was well attended by service users and carers. It wasn't just members of staff and they'd have somebody from they'd have a stall in the aisle or an eye department there. But everything seems to have gone online now. Everything. They just have a virtual event and they are another. Our department, if they come to my acupuncturist, has an annual research day and service users and carers are invited to it and they have sometimes they have like a workshop for people who are interested in that kind of thing. So that there are things going on. I don't know how widely advertised they are and I would say there's not that much interest, to be honest with you. And again, it's the usual suspects. It's me and three other people.

Speaker4: Yes. The two things. The first thing is there's a lot of science festivals which aren't free. Like Cheltenham Science Festival is quite expensive, quite interesting, but way out of the reach of most individuals. And there are other. So you have to be careful that the event you're promoting is affordable for people. Best free, of course. The other thing is what was I going to say? Oh dear. I've missed the other thing. That was the thing I was going to say in the beginning. Oh, yeah. It was to do with. Yes. Dissemination to agree with Karen that the a lot of these things aren't very clearly because it's talking to the converted, if you like. So and the other thing is I was going to mention was students, the universities, a lot of research seminars and stuff they put on. If you're on the university mailing list, you can get you can go online or well, it's now more online than it was before to very interesting topics that students come up with, some of which are a bit off field, if you like. There's a man at Worcester University who. University of Worcester, I should say, who has an interest in the devil. And he a research interest in medieval stuff and the devil. Fascinating. But you know, not exactly what you're trying to talk about here. So you need to be, again, aware of the different things that are available.

Facilitator: Are you aware of any initiatives to recruit new talent into sciences or public engagement activities, especially from underrepresented minorities?

Speaker6: So so one of the things so although it might not be totally scientific, one of the things we have found will bring a lot of diverse groups in is open spaces and environmental work and recycling. So we've got lots of things going on in our borough that are connected with open spaces, recycling, doing, doing things upcycling, you know, So we will get and the university is involved in it as well. And the council is involved and the NHS is, is, is in the periphery. So bringing everybody in together to support the community and the community supporting the organisations as well. So it's a two way process which I think is really fantastic. I, I will try and go to one of the days, but it is, it is an ongoing thing. We also got a lot of environmental work going on within the Council. So, you know, I think we if we don't talk about science and talk about environment now, we can bring science into it.

Speaker4: All I can say is very many of the groups that I am involved in are very are not representative in inverted commas. And everybody's aware that they should be, etc.. And they beat themselves up about how can they make it. And it's it's it seems to be a big struggle. And if you can help at all with saying this is the way you go about including people from ethnic groups I'm sorry, minoritized groups, but also seldom hurt. That's the word I like best. So it people struggle. Even those the PPI coordinators, the ones whose job it is to do, which are many, which is lovely to see. But they first of all, they expect you to volunteer if you're local. They don't expect you to be paid for your time, even if it's a small amount. Reward and recognition and valuing time is something my trust, the trust I work with. I'm paid. But the voluntary activity you don't get paid for at all. They can say, talk to us about this, that and the other. Oh, we can't. We will not. We can't pay, but we will pay travel and that sort of thing, which is and it's completely wrong and they can't and I keep mentioning it and they don't invite me anymore because I keep mentioning it.

Speaker5: I was just going to agree with Mary that that nobody's mentioned payment. And yeah, I mean, those people get paid. And I think there's still an exploitative element. I mean, we've been well paid by Powerball. And I avoided saying that. We were talking about the good parts about it. I do appreciate the money, but I mean, you know, this thing, we pay your travel expenses. Well, yes, because you wouldn't be there otherwise. And, you know, even if it's just a small thing, even if they offered you lunch or something, you know, I think it's. I mean, somebody I know asked me to be involved in this citizen thing. Citizen, I don't even know because I've done a lot of p work and I was told it's virtual and I wouldn't be paid for it. And I thought, Well, fair enough. And then she got some jealous involved at the last minute, and I was kind of being hustled to do this interview, although I agreed to do it. And it went on for an hour. And this other person was was dialing in from Switzerland. And she asked one question, and then they're off to Denmark. They're off to Denmark to present from. And I thought, well, what do I get out of it? You know, they didn't even pay towards the wi fi. You know, in previous times you'd meet face to face and you get your travel paid and you could go use your day saver. And these these kind of things. And now I've been asked to do more work with them. And I said, Why? So you can be your passport. Passport to go to Italy or somewhere. Sorry, I digress. But there are exploitation things going on. And also people should say up front, if they're paying you, because I've taken part in things where I was led to believe I'd get paid and that nothing was said about it. And I said, Well, where's my

where's the form to fill in? I've just been blunt. So I agree with Mary, and I think people don't like saying these things. People don't like mentioning it.

Speaker2: Actually, along that line, I've been at things where everybody except the people had their parking and travelling paid as well as their time because all of the staff did and not even parking spaces were offered to the, the lay people involved. And I think you've got to be fair and up front about things, you know, which is exactly what Karen said. But you know, when you know that somebody is there on an enormous salary plus mileage, plus parking space and they want to pick your brains for nothing, I won't do that any more, because my own theory is that the NHS doesn't value things unless it costs them money. And I think a lot of people are like that. And even if it's a token gesture like lunch or a free parking space or something, I think that's actually important and is even more important if you're going to go to people who don't have a tradition of volunteering because volunteering is not a norm in a lot of cultures. I mean, you see it in all sorts of places like the Sikh culture of feeding people and having, you know, open kitchens and helping on soup runs and all that sort of thing. But an awful lot of volunteering is a bit white, middle class. And if we're going to get away from that, there's got to be some sort of reward, I think, to encourage people to give up their time.

Speaker4: Thank you. Can I just say we are not grateful for the treatment we've had necessarily, and we don't want to give it, but altruistic is the word and give it give back. Because we can do that in other ways.

Speaker5: Yes. Regarding payment as well, I think it should be as early bureaucratic as possible. I'll give a very quick example. I was asked to be involved in something last year. I think it was. This was quite well paid and we were told it would do something for an afternoon, whatever it was. And then they said, well, you have to go to a pre meeting online and an after meeting, otherwise you won't get paid. Well that wasn't.

Speaker5: Forms. Yeah. That wasn't but and I can make the payment I couldn't make and I thought well you should have got your act together in the beginning. And then we had all these forms to fill in and then they lost mine. And then the people who were supposed to pick it up only work one day a week because of COVID or something. And the post room wasn't working because of COVID and all this. And it was confidential stuff. So then I had to send another form. Then they found the first form, and then there was the issue of which form they were going to keep and what they're going to do with it. Then the payment kept being deferred. So I think I did it last October, November, January, February. They're still deferring it. Then they paid us. And then they had they said we had to take tax out of it. So they took the tax out of it. Then they realized they hadn't paid us enough. And then they sent us another thing with some more money and then more tax. And then we. Oh, that's right. We had to become an employee for for the purpose of this was their nature. But because

they're based at certain university, we had to become employees. So then I got a pay 45 and a load of stuff about tax and how much I earned that year, which was like a couple of hours. And I thought, you know, the work is easy, filling in the forms and messing about with who comes in when they're only in once a week because of COVID. The person who should have picked it up wasn't there. They've got COVID, they're working and you lose the will to live. You really do you think, Oh, why bother? So you should make it easy. You should make it easy for people.

Facilitator: Are you aware of any policies that promote citizens engagement in science?

Speaker4: There is many, many policies. Every single organization has a policy and they are the same or slightly different. And if you're working for a charity, that's a different policy. So if you're talking about government policies, as we talked about before, it changes all the time. The statutory stuff we've already mentioned. And for example, the Mental Health Act is being consulted at the moment. It's not going to be implemented until 2005, something like that, because it's still going through parliament. And the thing is, it's an amendment to an existing act. It's not a new act. So and it's awful in lots of ways. So. It. And then there's going to be a code of practice which I'll have to rewrite in the same with deprivation of liberty safeguards under the Mental Capacity Act that is being changed to what's it called, Karen You probably know.

Speaker5: I can't remember, but I still refer to it as Dole's and Mental Capacity Act. But they are I know they've been changing it for ages.

Speaker4: And they haven't got any code of practice to enable this. Usually social services we're talking about here because it's used to ration. No, to not to share care around. And capacity is another complete thing in scientific research where you can exclude people with fluctuating capacity because it upsets your data. So there's that's another many policies procedures, but they don't necessarily all link together sorry.

Speaker2: I suspect there's a lot of policies out there that have never actually seen the light of day, because a lot of people think the work has finished when they've got their policy on the shelf. Unless you actually do something to market the policy. Nobody will ever know anything about it. And most of the things that I find out about, it's because I'm signed up for various people's newsletters. But if you don't know things exist, how on earth can you join in?

Speaker5: As I said, the NHS Constitution says that people have a right to take part in research, particularly in their geographical area. I'm not. I suppose that would be a policy. The NIH all has policies coming out of its orifices about involving people in research and SDI and all this, but I don't know how much influence you would think then I actually would have a lot of influence. But unless they put it on the. On the. Forms that people fill it. I mean, what what made them take take PPI seriously is because they had to say how they involved the public when they were doing the research grant applications. So unless you have a question about that on the grant applications, I don't I don't know what you do about that.

Speaker4: And also, if you're talking about nature, I. And they had a service user carer group called involved which has been merged into something called the Center for Evidence Dissemination. Therefore nobody knows what it means.

Speaker5: Yeah, I was just about to mention that because the old involved was very good. They had lots of guidance in booklets and case studies and examples of good practice, and they used to have a conference, maybe not every year, which lots of people went to. But that seems to have been subsumed into this centre for whatever you said. I can never remember the name of it, but a lot of the evolved guidance and policies and all that were were ignored. You get the NRA and all and they have all these bodies in groups and machines that produce policies and guidance. And then you have people who do the research who you've never heard of these things. Which suggests a problem.

Facilitator: Okay. I think that concludes all our questions. Unless you have any other comments, suggestions, observations.

Speaker6: I would I would like to say thank you to Pavel because it has been really nice to have a kind of a feedback and briefing or debriefing of of the session that we had. So yes, thank you very much. I think that was very useful to kind of express our. Concerns and other things in a way. So, yeah, thank you very much for doing this For us. Yeah. And for you, of course.

Speaker4: Thank you. Thank you very much. And if you're doing it in groups in Oxford, remember places like Blackbird Lees and things like that. That Oxford isn't just all Dreaming spires.

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Facilitator: Hello everyone and thank you again for helping with this focus group. It is part of the European Horizon 2020 project ALLINTERACT on widening and diversifying citizens participation in science. All of you have already completed the consent form and agreed to recording. Thank you.

Today's focus group will take approximately between 1 or 1.5 hours depending on how quickly we can go through all the questions. Our focus group will be based on the egalitarian dialogue. The objective is that everyone should have an opportunity to answer every questions because your individual opinions and experience are important.

Facilitator: Let's now begin with question 1: How do you think citizens benefit from scientific research?

Speaker1: Okay. Thank you. It could be as general, presumably as COVID was. The research in COVID helped all the citizens.

Speaker1: Certainly when I was involved in commissioning NHS, commissioning, a lot of the things we talked about, all the new innovations in medicine and practice that the NHS was current at the time involved in. I think all the suggestions that were made by the group and at times myself did shape the research and the process and the services they were delivering in the end. Some there were some cases where somebody's comment or opinion changed the way the NHS was thinking about that particular. Issue. Does that.

Speaker3: I think sort of aside from the science thing, there's something useful socially. If you're a participant, it's good for your general sort of self-esteem, I suppose. I was a very early participant in the Biobank project and still am, and I feel really annoyed to have got an email from them last week saying, Please don't participate in this new big research project because it'll just muddy the water effectively. And I feel a bit deprived that I could not do it because I was looking forward to volunteering and my husband's still working with Zoe. He's still dutifully contacting them every day. And I think that gives him a sort of just every morning he's got a chance to feel good about himself.

Speaker4: Yeah, I can think of a few examples. So for me, taking part as a PE member has been quite beneficial because I'm a student at university at the moment and it can I'll get sort

of if I'm doing a few peer involvement things a week, then it's I'm then earning enough to be able to spend a bit more at university. So it's for in terms of financial side of it, being a peer member is quite beneficial for me. And then in terms of actually taking part in research, I took part in, I think it was the cheer study which is looking at the effects of hearing the effects of COVID on hearing and whether it has an impact on hearing loss after getting COVID and taking part. And that was quite useful because they ran like a lot of hearing tests and it was just useful to have those tests run not in a kind of diagnostic way, but in a, oh, you know, you're healthy and that's all fine. There's nothing to be concerned about. So that's quite useful in terms of getting some medical sort of medical work back as part of the study. And then the third way that I found it to be really useful is as part of my degree, I do a lot of coding. And so I had a very specific question, which was I was wondering whether it would be easier to write code where you capitalize all the letters or whether you put an underscore in between the words. And I was wondering which way was more readable. So I looked it up and found a paper that had studied that and then an experiment to see which type was more readable. And it said that the type where you just capitalize the letters but don't include any underscores is more readable. So that then kind of impacted how I wrote code in the future. So that was quite beneficial for me. Just in that kind of particular instance when I wanted a like a specific answer to a question.

Facilitator: And do you think that all citizens benefit equally from scientific research or certain groups may be disadvantaged, for example, depending on gender, race, ethnicity, socioeconomic status, proximity to two major hospitals or major research centres?

Speaker4: I think one big factor is just awareness, because I think if you don't know that the research exists or you don't know that some scientific research has probably already been conducted on this and you don't know to look it up or where to look it up or how to find it, you're not really going to benefit from it. And I don't know how kind of awareness of research would vary by different kind of characteristics like race and gender and socioeconomic status. But I think just awareness itself is a huge factor. And if you've done academic research in the past or if you've been involved in science or if you're aware of the the role of PI in kind of studies, you're much more aware that this kind of research will exist. Whereas if you don't, it's very hard to benefit from something that you don't know, is there?

Speaker3: Um, well, I immediately thought of the problem of negative results not being published from what Emily was saying, and I think probably. We all suffer from that because. Well, there are various things keep coming up, don't they? So the researchers knew about this, but it never got published or the manufacturers knew about it. Possible actual harms, but it must waste an awful lot of money as well that could be better spent on other things. If people don't know that this works already been done and proved negative. So I think we probably all suffer from that. I know you're looking for benefits from and talking about socio economical things. Well, that's obviously been a trouble with COVID vaccine takeup, hasn't it? That's the sort of Michael Gove we've all had enough of experts. We don't trust them.

Approach seems to be stronger in some socioeconomic and racial contexts from what I've read. That says the woman who's just had her fourth injection.

Speaker1: It's the flip side, I think, to. To what Emily was saying, that, you know, the the that people don't know about the research. But I think we should also think about the researchers not going out of their way to go to the the small pockets of of people homeless, for instance, that you know, however hard they they try they will never know because they don't have access to anything. So it's also the other side of all this that the researchers have to know as well and be aware that when they say we have surveyed the whole population, they should also be thinking about the small groups that need to know and should be consulted and should should be asked or take part. And it's not just the homeless. There are all sorts of ethnic minorities who most of you know do not want to participate sometimes because they don't speak English. They don't have access to ways of of of of translations and things like that. I'm just thinking off the top of my head, trying to think of good examples of where perhaps, you know, it should come from the other side as well.

Facilitator: How do citizens, including you personally, your family, colleagues, friends and community around you become aware of the impact of scientific research?

Speaker1: I would think the first thing that that is most important. One of the things that is more most important is his media, is social media.

Facilitator: Are you on social media?

Speaker1: No. I used to be ages ago, but no, but I have other ways I can. I always digging around, you know, finding things. But I think for most of the sort of younger people, they Facebook and Twitter and all these sort of areas are the ones where they get most of the information, I think.

Speaker5: The people in my circle. They don't. I think it's really strange they don't. Apart from a couple of people that live with chronic health conditions who are very much part of it, and the rest of them just they're not interested. They just I find it quite puzzling because the. The enjoy the benefits that come from research but don't participate or are aware of it or are even that interested in participating. So I'm involved in a few different things and I'll mention it to people and they're just like, you can see they're just like, Nah, it's not for me. That's things other people do. So I don't, you know, and I've got there's like Elizabeth was saying there, you know, my my nieces, they're quite young. They're just in their early thirties. And

then I've got the likes of my mother and father in law. They're in their seventies. And just right across the spectrum there just just don't seem interested.

Speaker1: And yet, actually in many ways we are all interested because when COVID vaccinations were first out, there was so much. Media. Every bit of media was talking about the benefits and the conspiracy theories and all these sorts of things. So actually, whether we liked it or not, we were involved.

Speaker5: It's funny you say that actually, because I just heard from one of my great nieces yesterday. She's 15 and I had mentioned that I just on Monday got my flu and COVID booster and she said, Oh, mum, never, never let any of us, my nieces got five kids and let any of us have it because there's no enough research as to the, you know, any complications that there might be. So I suppose, yeah, in that respect it is on the radar. But, but generally research in general, not so much.

Speaker1: Yeah. Yeah. I think at the moment AI is so hot with the NHS and medical organisations and it's not, it's not public yet. You know, medical, your medical reports can be shared with research organisations if you want it to be. This is going to come out more and more. We are going to have a lot more discussions and I wouldn't be surprised if it ends up like the vaccination problems, you know, the conspiracy theories flying around.

Speaker5: Well, again, I just recently saw there was a call. I wasn't there for about 3 million UK residents to sign up for this project where they were going to. What was it to? I can't remember. It was just specific. It wasn't just specifically dementia. It was to track people across. So when you register for the rest of your life, regardless of your age, and then if you get X, Y, Z disease, at some point they can go look back at your test results and records. And when it was posted on social media as a news article, you never see people going in there and going, This is a fantastic idea. This is good for medical research. As I oh, you know, they just want to control us. They want to be in our lives every, you know, And yeah, so a lot of a lot of misunderstanding and misinformation I think just generally on.

Speaker1: To tell the whole story, put it in black and white so there can be no question. And then let's see if there will be any big fuss about, you know, microchips being injected in us and things like that. I don't know. It's very difficult to say what will be best, but I just think it's always there, always on the back foot, you know, the criticism lays into them and then they come out with this, you know, this is how it is. It's not like that.

Speaker5: There's a section of the population, I think, truly believe that there are government agencies collecting their data and then somehow going to use it against them in some way. And I don't know, maybe because I'm involved in research, I just think. But that's just ridiculous. Of course it's not. There's a lot of effort to go into for that. I mean, this is going to benefit future generations. But then, you know, with COVID, you had those that were for vaccines and for wearing face masks and for local lockdowns, and then you had folk that were totally against it. And I think it's kind of the same with research as well. You've got people that do it because it benefits others and people are like, Well, I'm not getting involved in that, you know, And they're just it's a bit selfish, can I say, you know, But maybe it's just lack of information. They don't really understand, you know, and they don't and they're maybe not interested enough to find out more.

Speaker3: I don't think it's always the researchers problem. One of the PPE groups I'm involved with, first of all, they have difficulty getting the information out into the various media. When they do, they find it so often distorted by journalists who either haven't understood the point or a sensationalizing it that in a way it's almost counterproductive to publicize their research.

Speaker4: Um, yeah. I think often people just don't become aware of the research or it's filtered through headlines and media. So I think one way that I've seen is BBC News, if they'll reference a study has shown that this increases life span and they might include a link to the study. And so that's one way I think that people can get exposed. But I think in terms of just someone searching up a paper or an article or something, I think that's quite rare for that to happen in terms of the general population. And I think one thought I had from before in terms of the factors that might influence whether someone engages with research more, I think one big factor is going to be education level and whether you can understand the kind of the academic style and that really kind of dense scientific paragraphs, you know, and p values and statistics and sort of very dense tables of information and whether you've got the kind of the education that will allow you to understand that or in most cases, whether it would just look too jargony and just, you know, if you get to the point of looking at a paper, you just ignore it completely because you can't understand what it's saying or even the title sort of impenetrable in terms of meaning. So I think that will be one big factor. And then also interest in the scientific field that if you're not interested in sort of research, you're not really going to want to look at any kind of outcomes or studies or scientific research because you don't think that it will impact you.

Speaker4: Um, and I think as Carolyn was saying, you know, it does impact people and people aren't always as engaged as they should be. But I think on the other side, everyone's sort of they've got lives to live almost. And unless you're kind of really invested in trying to understand a specific bit of research or the research cycle on the whole, you know, people will have jobs or studying or work or sort of hobbies or a family to deal with. So you need to have because it's not particularly easy to understand what's being said or what the conclusions are or what a paper means or what the statistics are talking about. I think unless

you've got a real sort of motivation to find it out, I think a lot of people aren't going to be directly engaged with scientific research and only sort of a step away from it when it's been filtered through media or they've been told about it by someone or they've been recommended a different treatment through the NHS because the NHS has seen this study and they've changed their kind of policies. But I think people engage less directly with research than they do, kind of indirectly.

Facilitator: Yeah. Thank you. And there is an interesting contribution from Joanne via the chat box. Citizens who are affected by a certain condition may well be more likely to look into research and findings.

Speaker1: So that's blindingly obvious. But as it were, as we have it in there. Thanks.

Speaker3: That's one of the things. Sorry. One of the things that actually a very good means of communication are the little leaflets you get handed out in hospitals. Um, which are usually, I think, well written and link up. If you've got a condition, you can find out an awful lot more simply by receiving one of these leaflets. And I would imagine that's a major conduit for communication to those who aren't particularly engaged, as we all are with following research or with what's going on internationally and nationally.

Facilitator: Oh, thank you. And so the clarification question about how citizens become aware of the impact of scientific research is about potential or possible barriers for citizens to become aware of the impact of scientific research. And some of you have already spoken about it. So, Emily, you mentioned the level of education and the ability to understand the statistics and the P values. Are there any other examples of the barriers to benefiting from scientific research?

Speaker1: Access. To media, To a computer, to a telephone. All this sort of way of finding information. Um. I the barrier of. Of the language.

Speaker5: I suppose for some people there might be accessibility issues as well. And I'm just trying to think. I think awareness is a big thing. I mean, I only I mean, I've always been aware of research, but I only kind of became involved in research during lockdown because I actively went looking for it. So I think unless you see an article pop up in your social media and when I think of I mean, I specifically thinking of the young people in my family, they don't read newspapers, they don't watch TV, they watch Netflix, so they don't see the news. And on their social media, they probably don't follow news outlets. It's going to be more than just their friends and family and, you know, kind of pop culture type things. So I don't really.

Speaker5: What the solution to that would be, but I think awareness is a really big part of it, just not knowing that it's out there and how you could participate, you know, that you don't have to be a patient to participate either. You know, there's different ways to to to participate or be aware of it.

Speaker3: Yeah, I think that's a very good point. Just knowing that it's possible to find things out if you're not growing up in an environment where finding things out is important, you just say, I don't know anything about that. So it just doesn't occur to you. Yeah. I think with a lot of people and as you say, if particularly if you don't follow the news.

Speaker5: And they live in a deprived area. They've had, I suppose, what would technically be called a, you know, socially disadvantaged upbringing. So there's just not really. I mean, I try and share what I can, but generally growing up, they've just not been exposed to that kind of thing. And I think that ties in with what you know, I can't remember if it was Emily or Joanna had said about, you know, being young and having, you know, someone who was a nurse in the family and getting you interested in it and, you know.

Facilitator: And Joan says via the chat box, Pirates can include time if people are too busy to take steps to look into and read about scientific knowledge, which is true. Thank you, John. And do you think open access facilitates access? Facilitate access? I'm sorry. I'm not trying to to make it to say it on purpose. Do open access article articles help you access scientific research and outcomes, and by open access I mean the open access publishing model. So traditional scientific journals ask people to either subscribe to their journal or ask libraries to subscribe, or if you are an individual, you can buy access to a certain article. And Emily, you mentioned an example about capital letters and done this course that you were able to find the the research paper that actually addressed this issue. Was it an open access or how did you manage to find it and how important open access for citizens to to access scientific research.

Speaker4: Yeah. For me, it's really important because, you know, I've not really got the money to be subscribing to 17 different journals if I want access to a single paper that they've got. And I'm quite lucky at the moment that I get some access through my university so I can use that to log in and access these journals. But that's for me is sort of like a second line of defence. And you know, often on the first try I want to be able to just access the journal if I'm searching it in Google. What's the is this better or is this better? And there's a paper that's got the right title and I click on it and I can't access it, I'll often just sort of click away from it almost immediately because I can't pay for it and I don't have to create an account and log in and get hundreds of emails a month from them sending me their newsletter because I want to sort of view their paper one time. So for me it's really, really

important because it just creates a bigger divide between people who've got access through an institution or, you know, the place that they're doing research at who are then already going to be interested in research and people who aren't interested who if they become slightly interested, they're immediately hit with a barrier of a paywall or so you need to be already a researcher to access this. So it's really important for me to have it freely available and public and as a PDF online and just immediately accessible.

Speaker5: Yeah, I totally agree with Emily. That's happened to be so many times. There's you maybe get a bit of the summary or maybe even all of the short summary, and then the rest is behind a paywall and you do you just click away from it because exactly like Emily, you don't want to sign up just to read that one article. And it's frustrating as well as you know, because if it's something that's important to you and you're trying to access this information and you can't get to it. Um, so open access is really, I think, really important.

Speaker3: I would agree. I read quite a lot of open access papers, not necessarily scientific ones, though. I think it's a great shame that. The free libraries. The county libraries aren't good at publicizing the fact that you can get onto a whole load of otherwise paid for research areas. Through them you can get on to things like J Store and other big collections of. I've journals and I've never yet met anybody who knew this. I'm always telling people, Oh, go to you. It's. It's worth so much.

Facilitator: Yes, exactly. Yeah. And John, that makes an interesting contribution. She says that the idea of reading a whole research article could feel quite daunting timewise. So even though even though she has a scientific background, it it's quite a significant time commitment and she has lost touch with the best ways to to search for scientific articles, which is also quite an important issue.

Speaker5: I would agree with that. I must admit I, I usually read the summary at the start and then the conclusions, and I skip the bit in the middle because, you know, I do find it quite you know, there's a lot of the bits. I don't really understand what they mean. And so I just skip that middle bit out and just get to the conclusions of the article and but yeah.

Facilitator: Are you aware of any initiatives to recruit new talent into science, especially from women, underrepresented groups, ethnic minorities and so on?

Speaker5: I have seen something like I have a vague. I couldn't tell you what it was called, but I'm sure there are the Scottish Government have have got something in place to try and recruit more women specifically into science, but I couldn't tell you the details or what the scheme was called or anything like that. So maybe not that, probably because I am not involved and I'm not of the age, the target age group that they would be appealing to. So

maybe it's more aimed at high schools and universities or something like that, I'm not sure, but I'm pretty sure that the Scottish Government have some have some sort of initiative in place.

Speaker3: Yeah, I know there's a lot going on in schools, particularly getting girls to do STEM subjects. And then, well, Cambridge has been boasting about the number of people from disadvantaged backgrounds that it's taken in for this present academic year, hasn't it? And Oxford is under pressure. And yes, just about everybody, I think, and I think the white males are going to be considered hard done by soon in the younger people. But a point that Joanna made about time is, I think, a very important for the PI getting other people involved. Only the only older people here are people who have enough control over their own timetables to be able to be present in a midweek afternoon. One pie group I was involved with was actually, I think, quite remarkable because it had four or five different ethnic groups represented, but still it met. Weekday afternoon. So only people who already had a certain status that they could not be at work at that time could be participants. Most of them, in fact, were already involved in other kinds of activity, active work involving research or supporting people and that sort of thing.

Speaker5: I think that's a good point, Julia, because I'm currently not working for health reasons, so I do this as in the PPI is so I can still keep my brain ticking over and contribute. And it has already crossed my mind that what's going to happen when I go back to work, you know, because a lot of these PPI groups, it's not just for a one off or a year and it's like a three year to four year project. So you're thinking, I'm available now, but when I go back to work and I still going to be available and I don't think I've done a single PPI project that has ever met outside of kind of classic 9 to 5 working hours, There's never any weekends or even meetings. Like you say, they're always weekday mornings or afternoons. And I think that does exclude a huge amount of people.

Speaker1: I've seen well, and just kind of person is the only one that can attend, you know, the either retired or not working or have have no sort.

Speaker1: Real place where they have to be at on that day. It's it's not really the groups never seem to be a good cross-section of the population. There's always a certain type.

Speaker3: It's not just if you're sort of on a factory assembly line that you can't do it, but it affects stay at home mothers. Yeah, nearly always. The meetings are in the afternoon. You could go and collect your child from school. Yes, this sort of thing. So it excludes an enormous section of the population.

Facilitator: Yeah. Yeah. And there is a great contribution from Joanna via the chat box. I do PPI with a university and they are now starting to use weightings to help those join who might be otherwise disadvantaged.

Speaker1: Well, of course lots of PPI does actively want does does use ratings. Well I meant for the courses, but in my particular case, yeah, that's not true actually, because the PPI group has also tried to recruit people, very various different types of people as well. So in both senses it is true. Sorry.

Speaker4: Yeah. So a few sort of thoughts I've got on that is I agree with I think everything that's been said in the it's often during the day or Yeah. Basically normally in working hours and the few exceptions that I've had to that are so there's a P group was called the PIN Foundation and it's one branch of that is specifically aimed at young people. And so they've really kind of understood that, you know, the need to not have it within school hours or within university hours. So they will often do like 5 to 7 p.m., often on a weekday. I've not seen any on a weekend, but I think that might just be out of choice of the P participants. But I've seen sort of a few groups that are taking that into account. But a lot of other people that I've been involved in has just been in the day and I've had to try and fit other things around it to be able to take part. And then one specific example I've got of a P um, recruitment that's trying to actively recruit under, um, underrepresented groups. I'll send the link in the chat. And so they've got a line in there that says we're recruiting people to join our P Senate that are, um, we particularly welcome applications from black, Asian and ethnic minority, LGBTQ+, younger people, disability groups and other underrepresented groups.

Speaker4: So they've explicitly said they're, you know, we're trying to recruit underrepresented people. From what I can see, that's kind of as far as they've gone, they're not sort of actively going out to these groups of people. They're not changing the application form. And I think I've looked at the application form and there's nowhere in there that you actually declare any of that. So I think they're just hoping that people from those groups will apply, but that's not actually taken into account in the application process. And I think they won't necessarily know if you know, I think unless you declare at some point they won't know if you've got, say, like a disability. But I think they're just so it's sort of it feels almost like an empty sort of promise of, you know, we want to recruit you, but we're not going to sort of take any steps to make that happen because, you know, you'd have to find that page to begin with. But I have seen a few groups that are taking steps towards trying to diversify their groups and say, you know, we welcome applications, but that's as far as it's kind of gone rather than actually actively reaching out to people. But it's sort of a step in the right direction.

Facilitator: Are you aware of any policies that promote citizens engagement in science and in PI in particular?

Speaker1: I think the NHS has that, doesn't it? Under the Health Act, the 2012 one, where it actually says there must be patient and public participation in policy decisions.

Speaker5: I was involved in an eight hour training camp over the summer, and I was the only Scottish representative for BP. I was there as a PI mentor for these early career researchers, and I was speaking to the two PPI experts they had there for the students. And they were saying that while in England the nature has this really like you were just saying, this robust PPI has to you have to show us in Scotland. They've not really got that fully in place yet. I mean, I've not been able to find out whether anything's changed that because that was in July, June or July. I was down there and but yeah, I think we're just lagging behind a little bit and having a really good I think the word I'm trying to say structure to it. And although I am involved in Scottish research projects and they do have obviously good PPI, but I just don't think it's as official as as with in nature.

Speaker3: The problem is where do you recruit the people from? Isn't it? I'm trying to remember I got involved with one because a support worker said, Look, they're looking for people. Would you do it? And others. I've sort of got through the local NHS newsletter that comes out and I think it's always been really just by chance that I've been somewhere and there's either been a notice on the notice board in a clinical context or something. And I mean, it's the same as you have to have the people who have the time, you have to have the people who find out about it. And it doesn't seem to me it's terribly good. There was something actually in the Oxford Mail actually had an advertisement recently advertising for people. I think there's been several. They've started advertising for both volunteers in research and getting involved carers. Oxford, I think is an organisation, a local council organisation and they sometimes publicize opportunities to get involved. But it must, it must be terribly difficult to find people.

Speaker5: That's nice. That's my experience as well, Julia. I actually all the projects I'm involved with, unless it's come through the nature kind of email, you know, you get the emails. The other ones I found because I have went looking for them. I'm just like, What's going on in Scotland? What, what, what do am I passionate about? And then I go looking for it and it's really hard to find. So I don't know where they're where they're recruiting because some of these projects are actually things that I have lived experience of. And it doesn't even come into my kind of, you know, through GP's or medical profession. I'm not, you know, I'm not seeing it or hearing about it or I don't know, apart from that one. I mentioned the start by that bit call out for the 3 million people for the cohort that they want because that did hit the media. I think that was on the news. That's the only one that I've kind of heard from that way.

Speaker3: But you've got to get on the email list to start with to hear about it. Yeah.

Speaker5: But in Scotland they have this kind of share register and I joined it years ago and I went on it the other day there and even though my email address hasn't changed in the time since I last joined it, it let me join it again. So it's kind of like and there are projects on there, but it's not emailing, I'm not receiving any emails from it. I think share is a Scottish. I think it's like the be part of research thing, but it's the Scottish one and it's just it's just so, just so hard to find things. That nature thing is the only thing that emails me regularly with opportunities. I think Joanne just met Joanne and just mentioned it there. They'd be part of research.

Speaker1: Which works in a similar way. You sign an email every week with things that might relate to you and for opportunities from that. Sorry, I've got a bit of flu. That's why my voice is going. Thank you.

Facilitator: In what ways do you think PPI benefits you personally?

Speaker5: It's a way to be heard, because quite often and for especially when it's a medical condition that you have or have had quite often, you don't get really listened to on the NHS, whether the consultants don't really have the time or whatever it happens to be. And these projects, you know, you give your experience for whatever it is, and they really listen and they weave into their project and you know that you may not benefit from whatever it is, but someone in the future or a group of people in the future will benefit from that. So I think there's just that. I think for me, it's very important to have that voice heard. So I find it very that's the part that I really and, and you're doing good for other people at the same time. So that's that's what it is for me, doing good for others and being listened to and and actively making change.

Facilitator: Yeah. Fantastic. And Carolyn, you also mentioned in the beginning that you've got involved into PPI and you found it useful because it kept your brain ticking. Yes. Yeah. Can you elaborate on this, please?

Speaker5: Well, it's just because the projects are so diverse. So you've got things where you have a lived experience of. So as a health condition that you directly have or something that you're passionate about. So one of the projects I'm involved with is, funnily enough, making research more accessible to people from socio economically disadvantaged and disadvantaged backgrounds. So I and how that can be a fluid thing. So you know, you were saying about getting more people included and making them aware and also helping researchers to make sure that they're thinking of certain things so that they're not leaving vital groups of people out of their research studies. So things like that. And just thinking up

ways as to, you know, how you could, you know, what barriers might be and how to resolve them and things like that. And it's really it's important work. I mean, my day job when I'm working, you know, I'm an administrator. I just type things into Excel and answer phone calls and all this. And I really feel that PPI work, you're really making a difference. You know, you're not just working for something corporation, just like soulless job. You're actually making a difference to people's lives. I love.

Speaker1: I think that that is the main sort of important thing for for me as well. The sort of idea that I'm gaining a lot of new information for myself, but I'm also able to give information which helps others. And and that's a lovely feeling when what you do in a very small way compared to all the the group that they're working as a group, but in a small way can can make such a huge difference. For example, some time ago I wrote. I am not a journalist, but I felt as if I was acting like a journalist. I interviewed the people that worked in the receptionist staff in some of the Buckinghamshire surgeries because there had been a lot of bad behaviour in surgeries. Patients were calling receptionists names and it even got into the newspapers, the local papers. So for Healthwatch, I was asked to, you know, I volunteered to go and, and, and look into it and ask them what it was all about, how's the reception is, etcetera. And I wrote an article which was published, sent round to all the surgeries, and they put it in their newsletter. And it was lovely to hear that. I don't know. A month later, you know, when I asked how did it make any difference? And I think nearly every single surgery emailed back to me saying, yes, they have stopped and people are actually coming to us and apologising for any of the patients that might have upset the receptionists. And I only asked a few weeks ago, you know, one of the surgeries again, you know, how is it and this is some time ago now. So it's worked. It's worked. People are much nicer to us. So I know it's a small, small thing. I mean, it's not big scientific research, but it's the same principle. You know, we can really gain so much from doing something like that. And I agree. And I think that's the main thing for for being a patient participation.

Speaker1: It's fun. It's good fun.

Speaker5: And also, if you've had a struggle and something's maybe not went right for you, and you can use that for a good. So it wasn't in vain, so, you know. So, yeah, there's a lot of that for me as well. Can I turn in it? Range from a negative into positive.

Speaker3: Well, I agree absolutely that it's. It's nice to feel useful more directly. Um. Some were. One of the groups I've worked with actually involves an area that is a source of some distress to me, let me say. And it's very useful to know you're not alone. It's very useful to know what. The experts are actually trying to do and. To feel that you're at least trying to do something to help solve the problem.

Speaker4: So for me, I think one benefit. So I've been asked to review some bits of papers and check that it's accessible to the public, check that if I'm sort of doing it in the role of a younger person, that it's meets the needs of young people specifically. And I've not found that it's particularly beneficial in terms of, I think, what a lot of other people have said about like I'm helping research because I don't see any outcome from that. But one thing, one way that it does benefit me is that I get a better understanding of the research process and sort of the academic style of voice. And so it's sort of a benefit to me to kind of be being exposed to lots of different types of academic research and papers and writing, but less so in terms of the final outcome, because I often don't see that or I can't always connect my input at the very initial stages to the outcomes at the very end.

Speaker3: I've I've done a little bit of what Emily's talking about in reviewing research questionnaires, and it's actually quite nice to feel my own ignorance is useful, because if I say I don't think this is clear or I don't understand what this word actually means, I think that's a very useful contribution, actually.

Facilitator: Can you think and suggest ways of equipping PPI contributors with knowledge and skills on the importance of equality and diversity in research? For example, maybe videos are more accessible and more time efficient. Or maybe leaflets or a website. What would be the most accessible way? The most accessible and enjoyable way with which you would like to be engaged?

Speaker4: I think one way is one big issue about trust. And do people trust the researchers? Do they trust that their data is going to be used in a way that they're happy with? Do they trust that they'll be properly reimbursed for their time? Do they trust the people behind all the research that it's being used for good, not bad reasons. And I think if a lot of the time sort of call outs for partner research is coming directly from researchers or is coming from a group that someone doesn't trust, they're not going to look into it anymore because they go to either this isn't for me or I don't trust what they're going to do or it's not clear enough about who's running this and what it's going to be used for. And I think one way to kind of improve that will be to have the information disseminated by people that they do trust. So like local community leaders or youth workers or your GP or your doctor or someone who you can who you trust can make a choice about, you know, is this research being done in a trustworthy way? And you know that it's then coming from someone that you do trust to say, oh, you know, say for example, someone at a local church who runs a small youth workshop has been contacted by some researchers to say, we want to do some research with the parents of young children. Could you talk to the parents? And I think coming it from someone that I know, someone that I have personally spoken to would be I'd be a lot more inclined to kind of get engaged.

Speaker4: And also, I think it's about whether you feel like research is for you. So if you don't think that you're the target demographic or you don't think that your opinions are that useful, you're not going to be particularly inclined to take part. And so one thing is having very clear inclusion criteria, You know, are you looking for someone like me? Because if I can't or if someone can't tell immediately whether or not they're the person that it's being aimed at, they're not going to try and take part. So I think hearing it from someone that they trust and knowing that they're the person that's being looked for, I think if you've got very specific requirements as well and you fit those and you're being told upfront, oh, we need a person from this racial background and this gender and this certain economic status, I think you might feel a lot more inclined to take part because you think, Oh, they're looking for someone specifically like me, rather than just saying, Oh, we want all views and we know that diversity is important. So if you if you feel that you're from a diverse background, please apply or something very vague. You could feel less sort of like you're being personally asked and it's going to feel a lot more impersonal so that you feel less likely to want to take part.

Speaker3: Well, I think it is getting out into the general public because there was that big row about blood oxygen monitors for people with COVID not working properly on black skin because they hadn't been calibrated. But in a specifically PPI context, which I think is what you want. Something I found very engaging was one group we used to get people who. Would come and talk about their research at the point when they're putting together their proposal. So one of the things they raised because it had to go into their proposal was how to get this cross section and how to communicate with the public. And I think that really helped the PI people because they were seeing a what people were doing and B, the problems they were having. So also, it's just very interesting to hear What about post docs are off. Desperately keen to get on to the great.

Speaker1: A combination of all these things are also good to think about. When to to. To get to involve more people. I'm thinking of something I'm involved with at the moment. It's called Optima, too. You probably are aware of it. No, it's to do with the the use of medical. As as I was saying earlier, your medical records being shared with research and their P part of the research project is having what Julia said they they will go out and they will have groups of people that they will be speaking to. They will have the doctor, the GP, talking to the volunteer patient. Then the researchers will go back to the patient and go through the the, the reasons for whatever they want from them. So there's a combination of a lot of things for that one project to get to all the different minority groups that they want involved in the project as well.

Speaker5: You just clarify the question for me just again, because I'm getting a bit confused because the answer I had in my head doesn't match what other people have been saying. So to if I've misunderstood the intent of the question, if you could just repeat it, please.

Facilitator: All right. Yes. It's about the best means to deliver training or information on the importance of equality and diversity in research. To public contributors, what's the best way to engage our public contributors so that they could help researchers to improve their research design or publish results in a way that would maximise equality and diversity?

Speaker5: I thought that's what you asked. I did have it right. I quite like the videos, the short videos that are animated and that use infographics because I find that you get you rather than having to digest a lot of information, whether you're if you're reading something, if you get the infographics, is a good way to convey why diversity is important and to begin with, because it's not I don't think it really matters what the project is. I think just in general why diversity is important and maybe I mean, probably a lot of people, when they think of diversity, they're thinking of maybe gender or gender identity or, you know, racial background and things like that. But there's all sorts of other forms of diversity as well. So maybe it would be easier to. Oops, sorry. My cats want attention at the moment and it would be quite good to see, you know, it to be colorful and and information or even like a kind of I was going to say a PowerPoint there. But then really you would have to have somebody presenting it. So I suppose I suppose within the PPE Group itself, you could have somebody come and present and that way you could ask questions as well. So it'd be like an interactive thing rather than just, you know, just sit and receiving lots of information that can be quite overwhelming. So but that's just I mean, I suppose it's just interpersonal preference and how you learn and and retain information. And you we're all a bit different. So maybe having different options available. So for somebody like me, the visual aspect works quite well. But you know, for somebody like Elizabeth, maybe sitting with people works better for her and just different options.

Speaker1: Yeah. So I think the point is I'm happy to go back and study the PowerPoint presentation.

Speaker5: I find the videos a little bit better. I was a bit, but but yeah, I think it's good to have options so that, you know, because we're all different. I mean, we're well, we are all diverse, aren't we? So we are. We are all. Different.

Speaker1: And that's why I was suggesting that they, the researchers should think about lots of different ways. Yeah. Yeah.

Speaker5: Rather than and just one.

Speaker1: Just going to go and do this. That's it. Or we'll give out leaflets and that's it. Yeah. They've got to think of different things because learning styles are so different.

Speaker5: Yeah. It's not a one size fits all is it. Really. Just generally across research, it's not.

Facilitator: Yeah. And Joan made a great contribution through the chat box for me, I think here indirectly from people. Who have been affected in this way could be quite meaningful them hearing it from a third party. And the very, very last question that. Requires a very simple answer, either in person or online. So if we're talking about. At workshop, at talk or interaction of some sort or idea, which is any sort of media that conveys information that takes about an hour and an hour and a half to to to get and to reflect on. Would you prefer an in-person event or online event? Where do you learn and reflect more online or through in-person interaction and presence?

Speaker1: Neither. I got used to it now. I always wanted to be in a meeting room with people. But since COVID, I've got used to having online meetings, so I don't mind personally.

Speaker1: Sorry, I. Where do we? Then and. More online or in person. But I missed the beginning of the question.

Facilitator: Yes. So if we were to design an intervention, a training session or of some sort, would you rather do it online or in person, depending on your personal preferences? For example, instead of having a series of talks or several people coming and talking or you work in in a small group with colleagues like you, instead we can have a video that that explains all the key points. So which format do you prefer for, for, for this type of learning activity in person or online? Hello, Johanna.

Speaker1: Thank you. I'll answer the chat. Thank you very.

Facilitator: Much. Yeah, okay.

Speaker5: I personally, if it's preference, my preference is to in person for that sort of thing. However, as Elizabeth rightly said, we're so used to this technology now, you know, and

doing all our PPE and whatnot that, you know, that we also depend on the location, timing and things like that. So really, either way is fine by me. But but if I had to prioritize them, I would put the in person first.

Speaker4: Yeah, it's tricky, I think, because COVID has changed how we do a lot of things. And I think if you'd asked me, you know, three years ago, my answer would have been 100% in person. The idea of doing something online would have been just out of the question. But I think now I've kind of realized that it's opened up the opportunities to take part in studies all over the country. I think there's one in Scotland that I've asked if I can take part in virtual, and they've said, yes, you know, three years ago I wouldn't have even considered having travelling that kind of distance to take part. But I think in terms of engagement, I find that when it's in person it's so much easier to engage with people. You can see their body language, their facial expressions, tone of voice. It's much easier to kind of communicate and get connect with people when it's in person. And I think sometimes I'm because if it's quite time limited, if it's online, then I only need to set aside that length of time. But if it's where I need to travel to, it's often half a day that I'll need to set aside to travel. But I think one time that I do prefer having it in person is if it's in a location either really nearby that I can walk to or get to very easily, or if it's in a location that I would like to travel to because I can then get the travel expenses reimbursed. So I've got friends in London, so I've occasionally had meetings in London where I've accepted so that I can get expenses paid to go to London, to travel to the meeting. I can then also see my friends while I'm there and then travel back. And that's a nice kind of added bonus for me as well as being able to contribute to the study. But I think in terms of practicality, online is much more practical and feasible and I can reach a wider sort of range of studies. But if I were to click my fingers and be transported somewhere, I think I definitely prefer in-person.

Facilitator: Great. Thank you. And John, what's your preference online or in person?

Speaker1: I'm just typing the answer in the chat box.

Facilitator: Thank you. This concludes our focus group.

ISCSP-ULisboa

ALLINTERACT

Transcript Focus Group – Experimental Group – Post Test

23rd of July, 2022 – 10h30

Online

F1_Facilitator 1

F2_Facilitator 2

P1_Participant 1

P2_Participant 2

P3_Participant 3

P4_Participant 4

P5_Participant 5

P6_Participant 6

P7_Participant 7

F2: Let's start with the first one. So, the first one says: "There are examples on Instagram of how citizens benefit from research to promote social campaigns or activism. For example, the use of the hashtag #StopBullying is related to social protests against racism and school violence and also makes visible the need to break the silence and become active bystanders against violence."

F2: If you like, the big question that we could ask to start the conversation is whether you, in your day-to-day life, face situations of this type. Or, if we want, if in your travel through social networks, be it Instagram or others, if you come across, if you face examples similar to this one, and in what way this, basically, also affects your life, your perception of the world, and if you realize that these campaigns may have some relation with scientific knowledge or may be rooted in scientific knowledge, or if, on the contrary, what you confront on social media, in different forms of activism, lacks this foundation. Maybe this could be the first question that we could ask around this topic. I don't know who wants to be first, there is no order. As you think... think about your daily experience traveling through the different social media, if you

are confronted with, let's say, posts or messages that you perceive to be, in a certain sense, rooted in scientific knowledge and that help promote this type of activism, if you will, or if, on the contrary, the messages that you confront, even related to forms of activism, are, let's say, scarce, from the point of view of their substantiation, in more in-depth knowledge, let's say.

P1: I can start. I think that yes, for those of us who use social media normally, or regularly, yes, these messages are enough, but I don't think it's enough with just a hashtag or a short message. I think it's enough if it's linked to images, to some text that's a little bit simpler, but explains the situation. I think it's important that... I think people don't connect with a very short message. I think we need a little bit more context and, in this case, I think images are very, very important. Especially, since you put the example of Instagram, Instagram is basically just images, and so it's very important to also link a short story with images or with a context: a news story or anything that explains what's happening or why this message is posted.

F1: Anyone else? We have the issue of images here as well.

P2: Me, do you hear me?

F1: Yes, yes.

P2: For me, specifically, the use of hashtags is still not very well used. I recently discovered that if a person puts in a hashtag "stop bullying" on Twitter, like in the example, there appears a list of publications that have that hashtag. But I don't know if it works the same on other social media to do that investigation of publications related to a specific term. I think education in this kind of thing, so that people also start to use well, to put it that way, this kind of system to, like in the example of "stop bullying" or racism in general, or homophobia, how do some explain to others how is the use of this. I don't know, I think I also have a kind of generational barrier...also these kinds of tools in social media. And also... I don't know... Also, personally, if this also came out of a social response or research that says that such and such topic has to do with, whether it's bullying or homophobia, etc. That. I don't know if it was a little bit clear.

P3: Yes. I think in the analogy that he was talking about, like, I thought it was important, like Instagram and stuff, are ways that you can encourage, I think, some kinds of social discussions, but it's also and very easy to manipulate which discussions are going to gain the most relevance, right? Like, what are the hashtags that are going to gain the most relevance, people are going to get into it and they're going to be able to talk about it. So, I think that, although it is important, because it is a language that is closer to the people and they can have more access, go after the things that are easier with the hashtags, it is easier to... like, you don't know who is choosing, which information is really going to appear. So, I guess that's it: it has its good side, to be able to gain a lot of visibility and talk about things that maybe wouldn't be talked about in other ways, and to have this possibility, for people to know a little bit more because even though it is quick information, it is a lot of information. So, a little bit of fast information here, a little bit of fast information there... if you put it all together... maybe. But at the same time what information is that going to appear, like... I guess that's my question.

F1: More.

P4: So, I guess I agree with what has been said here now. I feel that the use of hashtags, at least in my perception, is more useful when it stimulates people to expose a situation of violence, for example. I think it was like the hashtag "Me too", that people were exposing situations of violence and I think that it starts to pull from invisibility. But, at the same time, I know that many hashtags end up staying in a shallow area, you know? and maybe that's why they distance themselves from part of the academic research. Maybe it's a little... a little disassociated. I also kept thinking about hashtags in a more right-wing or conservative field. I think we talked during the program about gender ideology and there are hashtags against gender ideology. And it's something that maybe is completely separate from what academia understands, right? People continue to replicate... for example in Brazil, gender ideology outside of school, you know... I really can't imagine what that would be in the practical fields or in the academic field. So, I think it can also be, hashtags can spread a lot of misinformation. That's it.

F1: That is, the dangers, right? We had already talked about this in some of the other sessions. The risks that we face when we are exposed to information that is being disseminated through social networks. Maybe I would add another point that has to do with this, which is: I don't know if you, in your browsing through social media, if this is perceptible, when the contents have this substance, if you will, and this foundation, or when they don't. Whether that is perceptible or not. If the existence of that foundation... if immediately, when you see an image, as you were saying earlier... sometimes the images, the memes, the hashtags, if it's immediately visible that it's something... I don't know, based on fake news or fake science, or if, in fact, it's based on something with feet and head, isn't it? Is that immediately noticeable or not at all?

P4: I think I can talk about that. I think it depends a lot...I'm going to talk...it's very personal, it depends a lot on your virtual bubble. I think I also ended up following a lot of people from academia, so I end up reading more posts with some rationale. But I also see many other posts that want to expose a theme, but lack substance. I do see a lot of activism that doesn't... I don't know, it's almost to mark the territory, but they don't bother to pass on a deeper understanding to people or substantiated or with sources or with references. I see very few references. I think now it's started... I've noticed that people have started to ask for more references on Instagram posts, which I use more, people who were using each other's information and not giving proper credit. So, people are a little bit more conscious to put some reference. I think this is super interesting to be able to differentiate what kind of information is also substantiated or not. But, that's it... I think it will depend a lot on the virtual bubble in the end.

F1: It depends on our own bubble, doesn't it? So, does this conditioning or, if you will, access, how shall I put it, direct or indirect access, or a direct or indirect relationship with science, depend more on our own bubble than the way this knowledge is disseminated on the networks? Are they independent things? I don't know, I'm thinking about myself... it's not a question for the debate.

P4: I don't want to monopolize the conversation here either, but on this issue, you talked about... our own... the way we set up the bubble and the way it's disseminated. But I would put maybe a third factor, which is how the virtual platform was designed. I stopped using Facebook some time ago now and I just use there more Instagram as a social media. And it

has a lot of comments about Instagram because it changed the logic, the algorithm changed recently to follow the TikTok's wave. So, it... when it has images and text, especially long text, Instagram starts not displaying more and starts putting more videos. I really struggle with how... of cravings or content-pointing videos is going to inform better than text, personally. So, I think it's getting a little further away from a deep access to information, because the platform just doesn't show it. And people need to follow this, right? in order to have some relevance within the media. So, I think it is a combination of all of this. Which platform is being used, how we set up our virtual bubble and then how this content is going to be disseminated.

P5: I also think that it will depend a lot on which social media is focused on people, right? How information is disseminated will also depend a lot on which one. For example, on Facebook, many say how information is focused like on Instagram or Twitter. On Twitter it is relevant to use hashtags where the information moves in that direction. Instagram is much more visual, so... P4 also said that videos are much more important to people today. That's also because the ways of informing, how to deliver the information, are changing. On Facebook they also have a lot of movement of potential investigations or things of relevance, because Facebook today is also focused on an older person. That's what I see. So, it's information with a lot more text so people can read and get informed. So, I think that nowadays if we do combine all this, and I think it is necessary to always have, as P1 also says, of a text or an information that can be also, that leads or that invites to keep investigating.

F1: Thank you. Let me see... well, I don't know if anybody else wants to add anything. I had another... another comment that was coming to me here, which is... for example, when you are confronted with these images or with certain hashtags, even if they have some kind of scientific basis, is that immediately perceptible or not at all? That is, when you are confronted, I don't know, with a meme, with a photo, with an image, with a video, with a hashtag in the message, that is... and for example with campaigns or with forms of activism... it is perceptible that these messages, whether they are visual or in text, have this... they may have this basis. That's immediately perceptible, or to find that basis you have to do research.

P3: I would say not always, right? Like, it depends on your trust or distrust. Like, at first, you're going to distrust everything, nothing is trustworthy at first glance. Now, if you already trust that information vehicle, it's going to be trustworthy, right? Like, if I have a person that I follow and I trust what they say, anything that comes from them, I can say that I trust. Or not. You don't have to be suspicious of everything that comes from anywhere, I will confirm it first... I think it is very relative, like... it is not in itself the format, but rather like the relationship you have with it, isn't it? I think that at first it is not... things are not reliable, for me. I'm super suspicious, so any information that comes my way I'll try to find out first. I wouldn't share something without kind of researching if it makes sense, if it has some kind of bias, etc. Even if I know and I have seen that vehicle being reliable before. But that's just me, right? Like, it doesn't matter so much about the face, the thing can be super nice and look reliable and say it has a link underneath that says such and such, but I go to the link and after the link I go... you know? I go into a spiral of confirming information. Anyways, that's it.

P1: I think it depends a lot on the format of the information. Why? I think it's someone who's talking seriously, with a lot of background on any given topic, you can tell it's like that. When it is a video or when it is a longer text... because, for example, a photograph, an image, can be manipulated to deliver, for example, fake news, it is easier. But when it's to deliver more serious information, it's usually other formats. But it also depends a lot on who is the person delivering the information. If it's a person, someone who is working on the topic, is known to work on the science topic... For example, I enjoy TikTok a lot, a lot. And I learn a lot there, I learn a lot... for me it's great, in a minute, to learn anything. I think it's fantastic. And I learn a lot. For example, I really like astronomy and I follow lots of working scientists, astronomers, and so I'm not going to question the information that they're delivering because they're people who work in the field, right? And so on. But when it's a topic that I work on as well, obviously I'm going to go to primary information sources. But it depends a lot on the format in which the information is delivered. So... I guess that's it: it depends a lot on the format, it depends on who it is, it depends on the target audience. If I want to... for example, in Chile now we are in a very complex political situation, a lot is happening. And there is a lot of information that is false, a lot, a lot. And it's very easy for somebody to hand out false information. There are a lot of people who are not going to... look, we're going to vote for a new constitution, and, look, and it's a constitution that, for people who don't usually read it, it's very long, it's a lot. So, nobody's going to read the constitution, or a lot of people aren't going to. And, so, it's very easy to tell people, 'Look, the constitution says you're going to be homeless, you're going to be I don't know... something.' And, of course, it's easy. So, it depends a lot on who's participating or who's delivering the message, the format of the message, and also the target audience, I think it goes a little bit that way.

F1: Thank you very much, P1. Anyone else?

P4: I identified myself very much with P3, because I am absolutely suspicious of everything I read, be it someone in a forum... I think that when there are references, nowadays, even if it doesn't fit into the social media format, references, it gets a little strange, but I think I value it more when I see the bibliographic reference in a post or something like that. About the format, I also remembered something that happens in Brazil, that there is an organization called "Brasil paralelo" (Parallel Brazil). It is an extreme right-wing, neo-liberal organization and they have, they get very high funding to make videos and talk... and in a documentary format, right?, to educate the right-wing population, let's say, about the history of Brazil, about political history, about the history of education. It's just that in the videos it's always people from the right-wing spectrum, and they are people who may have some renown, but that information is always distorted, it's always, I don't know, it creates a climate... it's a very fine line, because sometimes they are based on facts, historical facts, but they create a narrative that distorts everything. And the production is spectacular, the production is... you just watch it and it looks like it was a documentary made by people with high... So, that's it... I see, I imagine that people who watch it or something, and don't have that criticality, will easily, when the person's name appears and "doctor in", think that they will be in good hands. So, I think that being suspicious of everything for me is fundamental.

F1: Anyone else? Just before we move on to the next topic...I don't know if anybody else wanted to say anything now? Before we move on to the next topic, one question I'd like to ask is this: in what way what we've been doing over the last few weeks may help you... or in what way has it impacted the way that you sort through the information and the messages

that you're confronted with. If it had any impact. It may have had no impact at all, and it may have brought nothing new to your way of doing things, but we would like to hear either because it brought something new or because it brought nothing new. Both things are absolutely valid and it is not an evaluation from us. We really want to understand if it worked, how it worked, and what didn't work. So, in this sense, the question is this: if what we have been doing these weeks could help, in what way did it help, or not, or was it indifferent regarding this filtering exercise.

P5: For me, I have not done research since I left the university in the year 2013, but until now I had not searched or looked again for studies or things that might be more research-related. So, for me it was very interesting to search again and also see what is a certain research as well. I am also very grateful of that for again refreshing this information.

P2: For me, personally I am... I really like paper, the physical book. So, when I want to read something that is of interest to me, I always go to some person I know, either who has studied or has read some book regarding some topic. Specifically, I'm reading a lot of masculinity, so I've asked F2 and some other person which books are more suitable to read. But with this focus and with these sessions that we've been having, finding or knowing that there are pages for specific things, for specific topics, is going to make the topic of reading on the computer much easier and also more friendly for me. Because I also find it very hard to have on my phone or on my computer to read. A book I can take to a square, I can read, I don't know, on the train, on the bus... So, it's more convenient than carrying the computer or always having the phone too. So it helps me to have more reliable research pages, but always, in my case, I will prefer a physical book for my research or readings.

F1: Anyone else who wants to speak up... Okay. So, F2, we can move on to...~

F2: Let's move on to the next one... okay. Can you see? Yes? Ok. Today's second topic is as follows: "In many languages, the use of masculine forms has traditionally been used to refer to both women and men, although feminine forms are available, too. A cross-linguistic (Italian and German) study shows that word pairs help to avoid a male bias in the gender-typing of professions and increase women's visibility; at the same time, they decrease the estimated salaries of typically feminine professions. This potential payoff has implications for language policies aiming at gender-fairness."

P2: What does "the word pairs" mean?

F1: It is when the masculine and feminine are used. For example: "Portuguese men and women". Basically it has to do with the so-called inclusive language, which is now gaining other nuances, isn't it?, and other forms of non-binary identities, for example.

F2: That pair of words that is very present in speeches now.

P2: P2: My experience with language... many years ago I had to learn to use the feminine with me also in speeches, in readings. As I mentioned a few sessions ago, I always worked with feminist movements. So, they always, whether they were many men or few men, they always tended to speak more in the feminine way. For me, obviously because of education, because of social pressure, it was always a little uncomfortable at first. But as time went by, I understood that it's not always... whether it's one man there or a hundred, why it always has

to be the masculine way of speaking. That to begin with. And then, as years went by, I've made the transition easier according to the scope that I'm talking about or developing. And once, talking to a friend from Spain, it was very... interesting what she said: that her boss decided, in her work agency, to always speak in feminine. She said that this experience was very positive because we also started to feel a little better, women also felt more... I don't know, recognized, things like that. So, it was also changing the way the staff started to interact with each other. It was very funny to hear that, because, of course, it has to do a lot with how one talks or how one expresses one's ideas to also, either to convince another or to substantiate an idea. And... that's it, from my side, for the moment.

P1: This topic, for me, is a little bit exhausting. Not because of this issue, but because I can't understand why so many people have a problem with having, with using a more inclusive language. And especially in the area that I'm studying, it's very important to use inclusive language. It's not enough with using pairs, I also have to use a more inclusive language of all the gender varieties that exist. And why is it, for me... today we have many experts, linguistic experts, especially in the Spanish language there are many... and for me it's not a linguistic issue, it's a political issue of making different realities visible. But for me the main basis, and when I'm speaking - I work at a university in Chile - therefore I also have to teach, and when I use an inclusive language, I do in my daily life, I use an inclusive language, it's just out of respect for others, respect to be treated as they want to be treated. I want to be treated with respect for how I am, who I choose to be, and therefore I have to be respectful to other people. So, for me it is a main foundation, respect. But from there it is a political issue of making realities visible. In my experience, I studied a profession in Chile where there are usually only women and I was the only man sometimes in the classroom and the rest were only women. Now, I never had a problem. They didn't use this question of "look, only one man, so let's speak in masculine", no. They spoke in the feminine and that was it. I had no problems with that. So, for me it is very much incorporated in my day-to-day life, to have a respectful language. But it is a political question of making realities visible. And today, for me, who am studying this issue of gender identities, it's very important because there are people who don't identify with the masculine or the feminine or both or whatever. So, we have to be respectful of those identities. But it's tiring when someone starts saying: "No, because the Spanish language is bla, bla, bla", because for me... the truth is that I don't have patience for this anymore, because, look, the language changes a lot, it has changed a lot, we don't speak the same Spanish or Castilian as we did in the 15th century. It will change, in the future it will change. But that's not the problem, that's not the situation of why we are using an inclusive language. It's a question of respect for people. So, it's a struggle that we have to face, isn't it?

P5: I also think that talking with inclusive language is still a change, isn't it? For example, I work for the mining company and many men work there. So, when I say in my reports, in my documents "men and women", they also get a little... strange. But I don't know, I interviewed a woman for a mining job a month ago and she was very happy because it was the first time that she would be able to work there. But, okay, going back to the theme, I think that while it is very important today to speak in an inclusive way, I also think that it is very little, it still has to be more inclusive, because we also remain in the binarism, don't we? "Men and women" and where are also the people who don't think, feel or want to be "men and women". For example, I speak a lot in inclusive language, but people also get like tired because I always

speaking with two or three genders to include the people I can speak to. I, in writing, also write with inclusive language, I make use of the... how do you call in Portuguese the "x"?

F2: "X".

P5: Thank you. So, I continue to make use of this letter that is more neutral and people get very upset, because I don't use a masculine language for example to talk about other things. So, I think there is still a lot of lack of understanding and comprehension of this, and people being open to speak in a more inclusive language as well.

P3: I think it lacks, actually, yes, openness and everything, but also something more constant. Like, I feel that it changes a lot, you never know what the next form is... like this, it gives you the feeling like "ah, ok, before I used the 'x', now I'll use the 'u' and then I'll use I don't know what". For example, my mother is a designer and from time to time she has to do some communication and she wants to use inclusive language, so she calls me and says: "P3, how do I write this? How is it being used now?"... And she is always asking me, like, she has asked me this a few times, because there is no... like this confusion. Like, I've told her once and she's always going to use it that way. No. I told her once and now it may not be that way anymore, and I think it is normal, like... until it spreads or whatever... language is not like that, it doesn't change overnight and it is defined, people get used to it, they progress and so on, but I think that is where people have a hard time, because they can't be sure of anything, like... it may be that, but it may not be that, it may be that... The fear of making a mistake I think is very big. So, like, sometimes it is better for me to speak in the masculine because I know it already is, than to have to try to understand. I think it's more because of this constant change and you can't keep up with this change, it's not easy to keep up with this change, I can't google what the best pronoun is and it's there, like, ready, given, right? there must be a research behind it, you have to know someone or like some people prefer it this way, some another way... in short, like, I think that, doing a little bit of devil's advocate, is the difficulty. Anyways, that's it.

P2: I also think that with inclusive language, as has already been mentioned, it has to do with the change of language, which is a living thing. But also, in Spanish we still... I don't know much in Portuguese, but in Spanish - Castilian, there are many neutral words that we can also use when we write, when we speak. But, of course, since we don't use them much for the moment, we have to use them, it is not easy to remember those words. But there has always been a permanent language, so we have to see how we incorporate this, as P1 said, due to a thing of respect for the other person more than anything else. That's it.

P4: I agree with what has been said. Language is already political, isn't it? So, I think it needs to change in order to change society. I personally, I don't know, I've been learning how to use it, but I still don't feel that I've been able to incorporate it well, and I think it's normal, as P3 said, there are many changes, and P2 said, we sometimes forget... I feel that I haven't always been able to remember it, but I think that... I totally agree. I think that for everyone it was strange when they first heard a change of... for example, to use the "e" in "todes" [translation for "everyone" in Spanish or Portuguese], for example, it gives that strangeness and nowadays it is not so strange, so, I think that with time it will be incorporated, I think it will be better.

P1: Look, I was thinking... for those who are concerned that, effectively, language... is changing, every day we have new ways of referring to other people and it can be a little bit... we can get confused. But I think the most important thing, more than the words, is the tone or the respect that there is in our ways of speaking to other people. There are people who, for example, don't identify with the binary categories... look, no one is going to guess that someone doesn't identify... someone who looks like a woman doesn't identify as a woman, since they haven't said they identify as a man, for example. But that person is not going to have a problem if someone gets it wrong and treats her or him as a woman, but she or he can say, "No, I'm not a woman, I'm a man, I use man pronouns or neutral pronouns," or whatever. There. So, from then on, we go on to talk about how that person wants to be treated. But the problem is when there are people who resist that situation. There are many people who resist and say: "Oh, no, you are not going to say how I have to speak. I speak and I have my way of speaking because the Portuguese language or the Spanish language is like that" and so on. That's when the problem starts, but we can get it wrong. We can do it, but if it is in a context of respect... look, if I don't know that in a group there are non-binary people, for example, I can make a mistake. But if I'm speaking in a context of respect and if there's a person who says "I'm a non-binary person," then from then on let's speak very respectfully to that person. So that's it: the problem is resistance, the resistance of people to change, to have the will to speak according to what people identify with, and so it's that more than the correct use of words. And also, what P2 is talking about is very important. I, just now I was in a seminar, an online lecture on inclusive language use in research. And it was very interesting because they talked a lot about that, the professor talked a lot about that, how we talk and, for example... For example, I'm writing a thesis and maybe the university won't allow me to use "x" or "@" or anything. So, I have to be very careful in using words: words that are neutral, words that... speaking about "people" and not about "men" or "women"... speaking about "people" or things like that, is very important. We have ways of speaking even in contexts where the correct use of language is very respected. So, we have ways to speak also in research. But also, if it is possible to include these new concepts of inclusive language, we also have to empower ourselves in those spaces and try to incorporate more inclusive language... The use of the "and" in Spanish is very informally used, but if we have the option to include it, then let's include it to also give visibility to people that don't identify with the gender binarism. I found P2's contribution very interesting.

F2: Yes, this is also very interesting because, in the end, this leads us to reflect, for example, who it is that defines the rules of language. That is, who is the person or the institution that defines how people should speak or what is correct speech. There are people who think that while... for example, it happens with migrant people, like me or the people who are here, we are migrants, for example, except F1, but what happens when we are in the process of learning a language, a different language, and we make a lot of mistakes, because it's also part of the process. But you have a group of people who think that as long as the message gets through... like, if the message gets through and produces the effect, the communication is correct, let's put it that way, regardless of the use of the words. Other people, on the other hand, think that... or they may have more resistance to a "less correct", let's say, less academic communication, for example. And so, maybe briefly, what is the challenge that you see in your areas, in your day-to-day life, in the areas where you develop, interact, in the use of inclusive language and this idea... why behind it is this idea or the goal to end the false neutral, the false neutral that comes to be the universal masculine, in essence. In what ways does this represent a challenge for you.

P2: I, personally always speak "the people" or "staff" or more colloquially "the guys" and that kind of thing, because also, as I don't have much knowledge of the more specific Portuguese vocabulary, I try to arrange those words within the vocabulary that I know to be able to refer to people and also, I don't know, for example I've heard the word "gajo" (Portuguese slang for "guy") a lot and once I was talking to my boss about a client "that gajo" ("that guy") and he looked at me and said, "No, he's a client. So, it's "the guy" or "the person" or "the client", but not gajo," because one assumes that "gajo"... it's not very nice to say it like that to someone. Of course, there I, with these mistakes, will enrich the vocabulary. But of course, I don't know... it always has to do with... I think, with the environment or with the people with whom one is developing, whether at work, in the studios... one always accommodates... using or taking the tools one already has, even if they are minimal within a new vocabulary, a new language.

P4: F2 asked about our area of expertise or work, I remembered the... in my work, I work at Teleperformance and I do a lot of email contact with clients and I think it was at the end of last year, actually, Teleperformance launched a campaign of the kind that we could use our social name if it's different from our registered name. And that started to... I work on a project where men are the biggest part of the group. There we have a more informal chat that also includes our supervisors, but the conversation is also more informal, it is not for official communications, and every time this point comes up at work, whether it is with Teleperformance's own report or when they changed the templates from "Dear Sir" or "Dear Madam" to "Hello, the person's name", or even when once a client sent an email and in parentheses was "he/his", someone cut it out and put it in that chat and there are always jokes, there is always a diminishment in that. People who say that this complicates more than it helps, that being too inclusive ends up being exclusive, excluding... I don't really understand what this can mean, but people laughing, people saying to each other: "Look, now you can use your social name," as if being trans were a joke or... so, many... even supervisors made jokes of this kind and I am shocked, without believing it. I also feel... a little bit censored when even superiors make the joke. To what extent can they do harm within the work by bumping into each other or at the end. So, I try to speak out in a somewhat restrained way, but I think there is still a huge resistance. And it is interesting that when I entered Teleperformance, on the first day of the presentation of the company, it was very like: "we are inclusive and we are... in short, we respect everyone and... here we have several nationalities... it is important to be inclusive". Then, on the second day, I was faced with the total opposite of that: with sexist jokes, xenophobic jokes. It was really a shock. Nowadays I have no contact... in the end, I work from home and that contact with the staff has minimized a little bit, but I think it is still a huge challenge and still in the workplace to have, like this, a respect, an inclusion.

F1: I have one last thing here: I have been listening to you and there are two or three points here that seem crucial to me from what you have been saying, regarding this issue of language, right?, and the way we refer to people, and the way we refer to them and we can include them in that way we refer to them, we can include them or even let them... exclude them by a misuse of language. And I think that these points are based on the following ideas: first, it will be the difficulty of others understanding the need for this inclusive language and the different forms that this language can take. In other words, others don't understand that there is this persistent resistance to this inclusive language. Another issue is: the difficulty we ourselves have in using inclusive language correctly, in reformulating inclusive

language... well, I think these are the two major points. And my questioning is this, and that has to do with that quote that was projected, right? In what ways do you feel that, I don't know, science, gender studies, language studies, can or might help in a better understanding about the need for inclusive language, or might help in a better use of inclusive language by those who want to use it. So how... if you think there is a virtuality, in essence, of closer communication between gender studies, language studies and, if you will, the general public, in creating greater acceptance and, if you will, tools for the use of inclusive language.

P4: I don't know, I feel that we have to really think about strategies on how I can incorporate these languages, but I also think that there is a lack of information. I think that if the strategy came with more information about what non-binary people are, like... it is shocking how many people still have no idea what they are. So, that they are non-binary people, that they are... and even disseminate these studies, right? There are societies or languages that are more inclusive, that have an "x" or "y" effect on inclusion in jobs or in the end. I think that incorporating the... like education, the usefulness of this, I think would be interesting. And at the same time, I don't know if it would work, because those who want to keep their place of power will do anything not to give it up. So, I think it ends up being a bit of a war too, a bit of a lock, and sometimes it has to be opened, right?

P3: I was thinking here... do you want to talk P2? I was thinking here about what P4 was talking about before and up until now, like... the fact that, ok, you change the way you talk in a company, but if that doesn't go along with an information, the change is not going to happen, people are not going to understand. And I think that's really what science proves, like... you produce this information, so that people can change the way they talk, that they can understand what they are doing. So, like, if you just change the middle name and don't, I don't know, talk to your employees about why this is important, it's no use. They're going to continue it, they're not going to understand what that change works for, what it's for. The change is not going to work, there will be no change at all. It's just a thing there. So, I think that's why science has to, that's why I'm aware of it, needs to keep producing and keep up, so that people can have information and the change actually happens. If one thing doesn't keep up with the other, it doesn't make sense. And that's where the difficulty is, because I don't think science is distant from people in general, but I think it has that... it doesn't have that space. Like... the space could be used, could be given to people, like... and I think most people would feel... openness and a possibility to talk, but there is no space for that. Social media sometimes is a space, but it's not the best space to communicate science. So, I think what's missing is kind of that: finding a space, a medium where you can talk about science without being, like, a big deal. For example, in the company you could have a day to talk about gender and invite a social scientist to talk about it. Like... in the end, they shouldn't be so hard, right? That's it.

P2: Yes, I agree with P3. I will also bring up again what P1 said, that it has to do with a political thing and also an age barrier, people's ages. And also, I think that's where social development is happening. A person who is also very comfortable in his house, who doesn't read much, who is not interested in scientific articles, etc., will always stay on the same path and their change... will not want to have a change or it is going to be slower. But also, people, as F2 said earlier, who protect the vocabulary who are they... those who don't want the vocabulary to have an evolution... as P3 said or P4's comment also: how do we incorporate certain gender policies, vocabulary policies, I don't know, of... any topic, but

there's also no basis that goes with that. It's just... I don't know if it's for fashion, I don't know... but I think... I don't know P4 if I'm wrong, but if the company or the person who instituted the act of changing to the social name gave some reference of that, so that people wouldn't have so much room for jokes and that kind of stuff. So, of course, if we want to have some kind of approach with... if we want the staff or the guys, I don't know, to have an approach to scientific topics, that are more friendly to the society that is not inserted in that group of people, just use a simpler vocabulary, for example, I don't know... so that everything is also easier to understand.

F2: Thank you very much for your responses. Let's move on to the following topic which is...I'll share it now. So, we have the following topic here which is "It is commonly believed that the academic sector does not generate enough value for society. However, others maintain that academic research generates benefits in many ways. Applying a new version of the 'technological innovation system' framework to nanotechnology in Sweden, researchers found a rich pattern of impact, including substantial 'commercialisation'. However, the effect of academic activities is constrained by factors exogenous to academia: a lack of knowledge about environmental and health risks, institutional and market uncertainties, poorly coordinated policies and insufficient access to innovation-related capital."

P3: I don't know if I understood it very well, but... what I remembered now from that... like, a lot of times people don't know that that's science. Or like... that something has changed because of science, somehow. I saw a tweet or something the other day that was like, "oh, ten years ago people kept talking about the ozone layer, and now nobody talks about it anymore, see?" Like, it's nothing. And then it was someone else saying, "No," like, "we don't talk about it anymore because scientists have discovered such and such a thing and now it's not like one of our big problems anymore." But that's it, like... this link of... there was a lot of talk about it in the media, and now we just don't talk about it anymore, it doesn't exist. Why is that? Right? It just doesn't stay. So, I think that's the question. Many times, we don't know that it is science, if science has solved some problem or why it is important.

P2: In my personal case it has to see also that for me science has always been like... just cells and I don't know... But, of course, it had to do with language research or I don't know, anything else, for me it's hard... that it's united, but it has to do with this: science covers many things, not only cells, for me, in this case. How also the education that we have had has an approach to us to get closer to science, to research in general.

P1: I think the example we have of how science, research impacts people's lives, the example of vaccines, now for Covid... because... and this is very connected to what we already talked about, for example language. P4 said before that there are people who won't... there is a lot of resistance to change. It's the same with science. There are people who even today don't believe in vaccines, and vaccines are the greatest proof of the impact that science has on our lives. But... and the good news for me is that there is a higher percentage of people who believe in science and don't need, the ordinary people, from the streets, someone to explain the scientific method of how we came to get this result. People believe, they believe that the people behind research are serious people who are prepared for that and will give this result that will obtain. It's important and... somehow that is it. I think the importance and... how we break down some barriers between science and the general

population is by democratizing knowledge. That people have more access to knowledge, for example to the publications that we can have... that's it. To me, the best thing is that people believe, they believe. If I come, for example, and I... I have... my field is human sexuality and I'm going to talk about sexuality and people don't question what I'm talking about when I go to talk in a school, with students or with their fathers and mothers... I'll talk and they believe what I'm saying, they don't question what I'm talking about. So, I think it's important... There's resistance, we're always going to have resistance, but usually there are people who show resistance to anything. And... science is enough. But it has to be democratized, so that knowledge reaches people and does not stay in the academy, does not stay in the laboratories. This new knowledge has to reach people somehow. That's it.

F2: The case that we brought to the focus group also opens up other lights... it shows other things as well. And that idea that science, to be effective or financed, has to have a commercial impact, for example, has to have some quantifiable effect on society, that it has to... that science has to be translated into something concrete, tangible, right? And it is very much, as P2 mentioned, this idea that medicine and cells are science, but also other areas of research or science, even if it follows the scientific method, etc., are sometimes not very well considered science, also because they remain, for example, in the area of thought, in the area... so I wanted to raise this concern here, about this view that the case... it speaks of a substantial commercialization, in the case of Sweden, right? However, until some scientific breakthrough... not proving that it will have this effect on society, they often remain in truncated investigations that do not advance... what do you think about this?

P6: Hi, can I take the bus while moving?

F1: Sure.

P6: Well, this is an expression in Brazil that we say... "pegar o bondi", which is like a tram, right? Where people go up while moving. Well, this is an expression in Brazil that we say... "pegar o bondi", which is like a streetcar, right? Where people go up like this and it is moving. I think I have a very important question here, okay? I think that we have to look very carefully at what we consider "ordinary" or "extraordinary" in people's lives. Because this has a judgment about those people. And I think that often the problem, for example, to take the example of culture, which I think applies to science too, is... culture is often considered extraordinary, it is considered as something... a luxury, something extra... and, well, I am of the opinion that culture is the most ordinary thing there is. Beans and rice is an essential good and so is scientific knowledge, science and all that. I think it's also an essential good for people. I mean, it is so essential that what is done at the university, in many ways, is applied in everyone's life, including those people who try to discredit the academic environment in some way, as is happening a lot in Brazil at the moment, because universities ended up becoming protection castles against the advance of fake news and the politics of lies, of scandal that is happening there. So, it was like a stronghold, you know? And it is obvious that our rulers observed this and started a very heavy propaganda to discredit the university. And it was the university that gave us the vaccine in Brazil, it was through the State of São Paulo, USP and Butantan that opened this door for the vaccine, which was being criminally neglected by the president at the expense of people's lives. So, as P1 said, because of university, academic, scientific research, millions of lives were saved there, right? And also... I was in USP at that time, at the University of São Paulo, and I was

doing an exchange program there. And I have this memory that one of the songs that we produced... I make music, you know, it was a song in response to this attack on the image of the universities by the government. We were responding that USP is part of everybody's life, our university. It is not the only one, you know, but all of them do it that way. But just to give an example, it evaluates the quality of the water that we drink, it evaluates the food safety of the things we eat, it is involved in the production of electricity that we consume every day, it is involved... the Federal University of Rio de Janeiro is involved in the oil that we consume every day, in oil research... And so... because when we say that it is something separate from people's lives, it is a lie. What is done in a university is directly... influences people's lives. So, I think that this is a fundamental process that you are doing here: bringing this awareness, which I think is already a reality. Sometimes we are really making the links like this to... but it is already real like this... the university and citizens are one thing. At least I... observe. That's it.

F1: Thank you, P6.

P5: I also think that it depends a lot on the target audience, doesn't it? I'm thinking, for example, about HIV research. It has been more than 30 years of research, it is in a progression that was very slow for a long time, because also the target audience was not... how to say... an accepted audience, you know? Also, for example, transsexuality. It has been out of mental illness for a few years now. I think that also truncates or holds back or doesn't advance research very much because they don't have the interest of people to give an answer, right? For example, I'm thinking also with the Covid vaccine. In a very short time, they already have a vaccine that is ready, it was helpful for everyone, but it wasn't so with other issues, with other diseases that need a much more directed (focused) vision. I think that also, at the cross-cutting level in the studios, also generates the advancement of research or not: which is the target audience that will finally receive or will have benefits from the research.

F1: Thank you.

P2: I think it has to do with that, with what P5 said: the HIV vaccine, the cancer vaccine, etc., are for such a "small" public, that it doesn't give an economic support to investigate it further or do research faster. Not like that Covid or a pandemic, which gives more... gets more money from us than for the ozone layer, as P3 also said, that already... protecting the ozone layer doesn't give money, but pesticides do, for example. So, there I think is the union, unfortunately, with research. Probably, the research that gives more money is the one that will give more money to the pharmacies, to the companies that make medicines or whatever, you know? Regrettably, that's what happens... in my opinion.

F2: Okay, thank you very much. If nobody has any more opinions on that topic, let's move on to the next one, because time is running fast and we still have some topics to talk about. I'll share the screen then so we can look at the following... One thing that has already been talked about, somewhat here, throughout the focus group... the following: "Practical activity in the classroom should provide a simplified version of science, making it easier to understand, and be seen as a communication rather than a discovery exercise. Some of these experiences are founding principles on which scientific public engagement activities are built, encouraging social involvement whilst enabling learning more overtly than the more

formal classroom setting. However, public engagement allows science to be presented in different ways to the conventional school science laboratory.”

P5: I think that today it is important that teachers have much more, get much closer to the students with a distinct teaching and learning process. It's also important to change the much more traditional ways of delivering theory. There has to be the possibility also that those who receive information can understand it much easier. So, I think yes, it's important to make that change as well. Plus, of course, attracting people to research, like... for example, I studied in a school, in different schools, so I never had an approach to science. Because I, just like with P2, for me science was cells and I don't know what a cell is. So, I was always far away, distant, and I feel that I lacked this possibility to know science in a different way, in a way closer to this, to the investigation itself.

P3: I think I disagree a little bit with what is written here. I don't think you have to give a simplified version of science in the classroom, because that's what already happens. Like, a lot of times what you give is misinformation about what science is. For example, I... when I first got here, I did two years of biology in college. It was the first degree that I did. And as soon as I got to the first class, it was like "forget everything you have learned about biology so far, because it was all wrong" and like... "let's learn it all over again". And I don't think that's what it has to be. Like... okay, it can be... it doesn't have to be so complex... what you are learning doesn't have to be complex, but... it's not simplifying to the point where it doesn't make sense, that it's not the information that you should be getting. And at the same time, I don't think it's just communicating information either. I think it is exactly the opposite: you teach people how to think, how to discover, how to investigate, and then from that, one can learn new things and the knowledge can be more complex or less complex if you teach the person how to learn how to think, how to... not like "how", but give them the tools to be able to do that kind of thing. So, I don't think it is like... you simplify the communication, simplifying what you are communicating, but giving the tools for the person to be able to go after the information. I think this is what is missing in schools and not just simplifying, because I think this is exactly what happens at the moment: we simplify, simplify, simplify, and don't give space to think differently. I don't know if this was exactly what the text meant, but at first this is what I thought.

P1: I'm not sure I understand what's written either, but what I understand about practical activities in the classroom has to do with the fact that what we do... in my case, that I teach... when we're teaching, we're teaching something with a basis. And when we're doing practical things, we already know that by doing anything practical, we're going to have an outcome. And we already know that future result, because somebody has investigated and already had those results. So, what we have to do with who we're working with, in the case of students in a classroom, is for them to be able to understand that what we're teaching or what we're doing, is something that's already been studied by somebody and somebody already had those results, that we already know now that we're going to get by doing things correctly or according to a model or a guide, as somebody already did. And that's it. I can understand that when we talk about simplified science, because it's impossible to do in a classroom everything that someone has done in years. And so, that's it: that anything that we are doing in practice and that is based in science, in scientific evidence, is because someone has already done it. So, we already know the results and this is the right way to get those results. I don't know if I understood it well, but it's a little bit my idea.

P2: I don't know, I think it has to do with the ages of the people who are being educated in science. In Chile, a few years ago, there was a movement of women who were doing science for girls, so... also... that the scientific world is mostly more towards the male side, etc. So, they made this movement. I don't know if it continues now, but of course, it didn't get much acceptance to generate money for the same thing, because it was "science for girls." And in the case of the classes, I think that to bring it closer to boys and girls, you have to simplify the vocabulary so that they can also integrate that knowledge. And this evolves according to age and academic level. Outside school, if you go to university... you already have another type of vocabulary, you already have another way of rationalizing certain topics... or after that, in the work environment, as P1 said, it is already more in practice, people who have already done a lot of things for many years, so they already have many advanced steps and have to think in another way to see how this can evolve into something different. So, of course, if we are going to think in a simplification, for me, it has to do with that: with the age and with the type of class that we are doing at a certain time of life.

P4: I'll just comment on that as well. I feel that it would need some simplification, but I think the challenge is also a little bit what P3 was talking about. The challenge is... when there is so much simplification, it ends up giving half an idea or even an untruth. So, I think that some simplifications are so important... especially in the more subjective area, when science is more connected to thinking or reflect, I think that trying to simplify so much sometimes doesn't really get the message across. So, this is a concern that I also have, but I think that in my area of study, which is criminology, I have seen that at least the main thinkers are concerned that all their articles or texts be easy to understand. It is a real purposeful concern so that there is a public debate, so that people can pick up a text and understand the idea. I think this makes all the difference. I think that sometimes we get into such a sophisticated world of words and concepts inside the academy that we have to force ourselves to try to convey a clear message. It can be a complex thought, but at least it should be clear, so that... when we talked about the language of politics, it is also a question of class, isn't it? People from the lower classes may not have access to a certain vocabulary, and this limits their access to knowledge. So, I think that we have to have this concern, yes, to be able to strengthen this relationship between science and citizens.

F1: If no one else has anything to add, I propose that we move on to the next topic, F2.

F2: Ok, I'll go on the next topic then. So, you guys are seeing there that the following topic says: "Groups such as women and ethnic minorities are under-represented in science, technology, engineering and mathematics. This under-representation becomes evident as the academic and professional scale progresses, making representation figures smaller at higher levels. This is due to the existence of stereotypes about the presence in the technological and scientific sector. The influence established by this decision and the school trajectory, the academic achievements, the recommendations and work of parents, the stereotyped ideas they have towards this sector, are variables of analysis. These variables may make it possible to detect the key point on which to influence the investigations and the proposals for intervention that derive from them."

F1: Basically, we are confronted with the under-representation of women and certain minorities in science, aren't we? What are their causes and how can this problem be overcome, if you will, this disparity can be overcome.

P4: About this, I... I don't know if this is totally related to the question, but I remembered... I think that this excerpt explains well the importance of affirmative policies. As this one... I think that the system was planned precisely to prevent these minority groups from reaching the technological space that, in one way or another, is a space of power. I think that professions that involve technology and engineering, usually are well paid or enjoy some prestige and therefore are spaces, so, of power. It can also have a great power to manage people's lives, especially and currently technology. So, I think the system is set up in a way that minority sectors don't get to these spaces and that's why affirmative policies are important, to kind of create a catapult - is it used here in Portugal?

F1: Yes.

P4: Okay, okay. A catapult to launch people from minority groups into those spaces. If we are going to wait for the world to be color-blind, that we don't see colors or we don't see genders, it is going to take a long time and science and technology are going to keep these people where they are. So I think you really need to think about shortcuts to start populating minorities in those positions and think about the costs, right? Talking about technology, I remember a lot about... I don't know if it was a comment from the meeting we had there in the past, about... nowadays the identification of people in the criminal process, for example, there are cameras that identify people to try to find the accused, a person who committed a certain crime, and the people who make these technologies and produce them, end up leaving biases, biases, for the technology to identify people of color, for example. So, I think that if you have more people of color producing these technologies, easier to prevent that from happening and... I don't know, that's why I think it's so urgent.

P1: Now, in... not only in those areas that are in the text, ethnic minorities, women and other minorities have been made invisible. In science as a whole they have been made invisible and this happens not only because... look, it happens because they have been, for example, in the case of women, they have been made invisible not only as objects of study, but also as those who produce knowledge. We, since we were children, have studied... the math books, the books on anything, the ones who did everything were men. In Chile, for example, we only talked about ethnic groups, indigenous groups, only as part of history, but now that I am an adult, I am aware that I had a classmate who was indigenous... completely invisible, for example. And... that's changing, very slowly, but it's changing. We already know that there are women who have done and are doing a lot of science, producing a lot in science. We have, also, indigenous women who are working in science. Not only in science: literature, in other areas. But it is important to go beyond that: we have to move forward in making visible what they have done. And that starts at a young age, when we are little. We have to work with children, we have to show children that there are women who have done many things, we have to show children that the indigenous people have done many things. In our case, as Latin Americans, before the arrival of the Europeans, the indigenous people did a lot of things. And, therefore, I think that there is a work to be done. Look, and also, for example, in the case of... women, indigenous people or ethnic minorities and other minorities, as I said, it is very important... already as an object of study, they have to be made visible. We talked about this in some session that we have to aim research at all populations. Some time ago, for example, in the area of pharmacology, pharmaceuticals, drug studies were only done on men. They were only done on women if they were products, for example, contraceptives. But, for example, the other drugs... and... although we know the

drugs or the amounts are different for men and women, things like that have now changed and there's a lot of change still to be done. And I think that's the way it is. I think we have to start working from a young age, with children, make the realities visible, make these groups visible, and as I say, in Chile, which is the experience I know, it is changing, but it's a very slow change. I think we still have to move faster in these changes.

F1: Yes, P2.

P2: To add a little bit more, I think it has to do with the economic difference in the delivery of education. If you pay for a more expensive school, you get a better education than in a public school or a school of less resources. In Chile, it's generally like that too. So, the approach to these subjects, to science, to mathematics, to engineering, etc., is seen diminished in schools that have less resources for educational materials compared to schools that have more economic resources for that. And also, as P1 said, every text or achievement made throughout history, there is always a man. At school, it's very difficult to teach that there are women who have done important things and... I don't know... so, to go with that change and with a general leveling up, I think, of education as well, that it's a right, not a privilege.

F2: I kept thinking here that this example now connects a lot with what we talked about a few minutes ago about language use. For example, these professions, these areas of people's development, are usually masculinized and are constructed from the masculine. For example, professions like... I don't know, lawyers or engineers, doctors... usually, in order to try to cover a broad group of people, one speaks in the masculine and, so, this example here, the last one we are talking about now, speaks precisely to how these stereotypes can condition, or not, the way other groups that have historically been excluded from science and research as disseminators, or as... people who do science dissemination or research, have been excluded from it. So, I think it's interesting to also look at that by connecting both points as well.

P5: I'm remembering... in Chile, there is the University of Chile, it's like two centuries old and it's the first time that there is a woman dean of the university. First time in the history of the university that it's possible a woman in that position. And, outside her office, she has the name. It says, "Rector" (male word in Spanish for "dean") But she was asked if she wanted to keep the name "Rector" or if she wanted to change the "Rectora" (female word in Spanish for "dean"). Obviously, she decided to change "Rectora", because there has to, also, be certainty that it is a woman who has that position and not remain unseen because it is, in general, "Rector". So, I think it is very important also to make this change and also to push for it to always exist, isn't it? I also remember that in Chile, the Chamber of Deputies used to be only "Chamber of Deputies" ("Diputados", in Spanish) and now it's also "Chamber of Deputies" (Diputados and Diputadas, in Spanish) because it's also necessary to highlight that it's not only men who stay there. That's it.

P3: I think that this issue of language, even the issue of social differences and so on, I think I'm going to go into something a little different maybe, but it even pervades what our desire is. Like... if I as a woman have all the conditions to be an engineer, I will have this desire to be an engineer (female form), while all my life I have heard that engineers (male form)... it is always spoken of in the masculine sense... I don't know... it doesn't even appear... it may not

even appear as a possibility for me because what I see is not that, like... it is not women engineers or women in leadership positions... it is like... remember that this also influences our own desire. Not only as an opportunity, but in what we want and see as a possibility for ourselves. While language is very much connected to that as well.

F2: Does anyone have any other opinions on this topic? We are almost done. It's only two more sections and we'll finish. So, I'll move on to the next one. One second... here. Can you guys see it?

P3: Yes.

F2: Do you? Well, the prior to last topic today says: "Governments require the universities to change their way of acting and to be more responsible with the requirements of social development. Thus, the policies which are based on Open Science have been developed, such as "A recommendation on Open Science"; "Open and inclusive collaboration in science: a framework"; "Open science by design". These policies require universities to be more transparent regarding the dissemination of scientific results so that the benefit of science could pass to the public"

P3: I think that besides being open with the results, it is important to be open about where it comes from. Like: Why is this research being done? Who is funding this research? Those kinds of things. Because sometimes... that question that we were talking about earlier of trusting or not trusting the information, a lot of times my distrust within academia is much more connected to that, like who is behind this research. Like... because that can often influence where they want to reach. So, I think more important than having clear results, without having... I don't know, clear backgrounds. I can't find a better word.

F1: Anyone else?

F2: P6 said he agrees completely. But if you want to open up your opinion a little more, P6, the microphone is available. Go.

P6: I was going to say that I agree, because there really are companies that have directly financed the construction of laboratories in the School of Medicine, to conduct certain studies and so on, to corroborate their own interests. And, ok, let them do that, but this transparency is very important... that they really are, because I think it is part of the ethics of science. It is a very frontal attitude, in relation to what... where it comes from... background as P3 said. I think this is very important. Maybe we could have more manuals and models that are accepted by everyone and that we could understand a little better where each thing comes from. And in relation to people reading, or not, or knowing or not the results, I think that we also need to create a bigger policy, there, an Education one, maybe from the school, of searching for this kind of things, like we did here: the databases and everything else. Maybe, you know? The schools could also subscribe to some databases of some articles that could be interesting and stimulate this research from an early age. Because we really don't know where to look and we get a little isolated, you know? What is produced seems to be an autophagy. That thing produces for its own consumption, you know? And I think this could really improve a bit, too.

F2: Thank you P6. Anyone else?

P1: Me. I've said before that I share the idea of democratizing science in ways that effectively, especially for those who are directed to research, who are the target of my research also have some direct benefit. And not... and, we already have alternatives for that today, but I think... I was thinking I'm going to say something that I don't do, but I think it's good to do it. And I can try to be more consistent with this. For example, if I'm doing a survey, showcasing the results of the survey, showcasing the results of this survey the people who participated in this. A lot of times we finish with, "Look, you have my e-mail and you can reach out to me if you want to know something," and I think we should be more active in giving the information back to the people who participated. Because we believe that the results of my research are going to improve lives, in the case of these researches that are more social, like mine, that they are going to improve the lives of these people and many times we don't do it. Although we are open to handing out information, if someone is requesting it, but it's a more active way of actually democratizing information. And I don't know, I think... when we talk about democratizing research, we are also thinking about publications, and sometimes it's not easy to access publications and you have to pay... but usually when we are in academic contexts it's easier, isn't it? Because universities pay for the licenses to access the journals, but it's not always like that. But now we have some less legal options. I think it's a great, democratic way for us to access information. I think it's very important. I don't know if we all researchers should pay in all journals so that the journals make the publications available to the whole population, although who are going to consult the journals are usually researchers, more than a regular person. But I don't know what the alternative is, but I think it's important. It also depends a lot on the... there are universities that are smaller, that maybe don't have the same resources and it's hard to pay for licenses for all the journals, and who is... the researchers at that institution have less access to information. But there are different ways. I think for one part is in returning the information of the results to the participants, somehow, little by little... for the target audience of my research, who are not necessarily the participants, also have access to this information. And then the researchers, who can access it somehow, without having to pay for every publication they need to read. I think that's a little bit of it.

P2: Of course, and then, maybe, I don't know, people who study singing or music or theater, they do... the university does a concert for us to show their talents or their career progress during their years of study. Of course, maybe do those kinds of things, seminars or scientific things. I don't know, that a group of students discovered such a thing. And also, more accessible. In Chile I knew some people from seminars also to show certain advances in science, but of course, they are for a certain elite, because it is very expensive to go to these kinds of things for a person who doesn't have so much money and who is interested in these topics as well. So there maybe think about that too: make knowledge more open also, imitating these other things, like concerts... make a science concert...

F2: So, in order to respect time, let's do the last section which is next. Just a second. Can you see?

F1: Not yet, but almost there.

F2: Okay.

F1: There it is.

F2: Well, and the last session of the focus has to do specifically with your opinion, regardless of how much you were able to participate in the program. Some people were able to participate throughout the entire program, some people were only able to participate for other reasons in one or two sessions. Regardless, we wanted to know your opinion in terms of are the challenges and opportunities that the initiative, the program "Citizenship, gender and science: topics for the future", may have to face. This is open. The slide is a guide, but the idea is to talk a little bit about challenges and opportunities of this program. How do you see the program, what did you feel, how valuable was it for you, etc.

F1: And I would also add how, looking at the program that you participated in, will it help, or could it possibly help in the future to solve or help solve some of the problems that we identified in today's conversation, which were several. If there is anything that... any potential that this program may have in solving or helping to overcome these challenges that we have been discussing today.

F2: Go ahead.

P1: I am, sadly, someone who did not participate in all the sessions, but from what I was able to participate and from what I give... the most important thing for me was the idea that since we are talking about science and gender, first recognize what the differences are, what the gaps are - I don't know if it's a word that exists in Portuguese...

F1: Yes, yes.

P1: ...between men and women, and within men and women, all dissent or sexual diversities that put us on the same level. And I speak especially in the case of women, for example. As researchers, for example, I work with women, colleagues, and there are many differences in the opportunities that they have and the opportunities that I have. I'm talking about them as women, often mothers, other times also wives and caregivers and sometimes they must be absent from work for these reasons and they are at a major disadvantage there. So, first we have that: to see what the differences are in order to achieve some equality or equity, I don't know, in the opportunities that we have as researchers, as actors, actors - I don't know which is the feminine form... in the production of science, of a recognition. And from there also the diversities, that there is a lot to do in terms of the opportunities that we have to be able to access, to have a place in science, not only as an object of study, but as someone who produces knowledge. And then we have the issue of research having this gender approach, incorporating this gender gaze into our research, although they are not researchers aimed to study gender differences in anything, but to include a gender variable always in the research. I think that's also... and in the different areas. We're from different areas here, and I think it's important to take this into consideration for any area. I was talking about the other areas of technology, which may be different from mine, but I think it is also important there where research has already been done, where this gap has already been identified, and therefore, there we already know that we have to produce research from this gender approach. So, I think that's what stays with me. And it is interesting to meet people who are in this line, from different areas, to try to have this more comprehensive look at social reality today, which is very important. That's it.

P2: For me it was very good. I think I couldn't attend just one session, and now, as always in the social field, I'm very... Maybe this program could be interesting to talk to the parish

councils to do these kinds of sessions or more massive education. Or also with schools, I don't know. I think it's a very good idea to bring people closer to science, to gender, to these topics, but of course, it's always staying for those, I don't know, who are always inserted in the work on gender, who are doing research work or who are, I don't know, with some associated title, etc. But people, in general, don't have that access. Maybe, of course, if we approached these kinds of programs to the parishes, to the schools, to the police, etc., we could make a greater globalization of these kinds of topics. And while the sessions, to me at least, follow up with more readings maybe. Provide some names or, as P1 said, encourage more of this: knowledge from women within the themes, or a link you send to read or to go deeper into what was talked about in a session, for example. That's it.

P5: I will take things from P1 and from P2. I feel it's very important to do research from the community to the community. For example, from the LGBT community, from within, for the community and for people who are not, because for a long time we were study subjects. So now it's important for us to be somewhere else, from doing research from actual living as well. And I think it is a good idea what P2 said about also opening the studies, the science, to the regular people. Portugal is a country where people are older and have preconceived ideas that can be wrong. So, it is also important to give the possibility to bring science closer to the people. So that it can be that possibility also to open or to invite other people. That's it.

P4: About this, about the opportunities, which is what has been talked about, at least I see an opportunity that can be very interesting for teenagers, in the case of people who are in school. I think that younger generation in Portugal is more curious and involved in gender issues, and people maybe who are in high school and that may be thinking about the careers they want to pursue, I think that a program like this could meet that curiosity. I think it would be very interesting. I think that's it for now.

P3: Yes, I think I agree with everything that's been talked about so far. And I think that this method, like, that you used, makes sense for this. Because it somehow gets you to think about certain topics, and I think that's what's interesting, isn't it? You not only bring up discussions, but you can, like, see a little bit of thinking about science. And that is what is important. Like, not only for those who already know a little bit, even if you are already in academia, to think... it is important to think this together, because sometimes I think that academic thinking becomes very individual, so it is important to bring this to a more collective space. And that's it, to expand, not to be so inside the academy, but to expand to people who don't know anything about this subject and see, like, how it is... and mix it up, not only having a group with people from the school. No, like... it's interesting to have a group where you have people who already study gender and you have people who have never studied gender in their lives and to be able to have that as an exchange. I think that's a way to... yes, to bring science closer to, like, people who wouldn't have access to that science as well. I think that's a good way. And then you have what they talked about: in addition to that, give options to access these topics that were discussed, so that this person really feels that there's a lot to read about this topic, but maybe they're going to forget to look for it later... like, "we did this work for you," like, "here's the link and you can go after it." I think it's important, I think it's a good way of promoting debate.

P6: P6: Look, I agree with what you said here. The only one missing is P4, right?

P4: I already talked.

P6: You've already spoken, so there you go. Sorry. People I agree. I will subscribe to what has been said.

F1: Thank you very much for your... for your participation, for your opinions. I don't know if F2 has anything you still want to ask or add.

F2: I'm just left here with one task to do. It's because I think that what P1, P3, in general everybody mentioned is also super interesting and important, which is how we can share the research processes when we invite people, for example, to be part of the processes. And the project has already done some dissemination of some things. So, I was thinking here that maybe on our part the commitment could be, after the focus group session, to see what has already been disseminated, available, and share it with the group. And also, the commitment that when the final results of the focus group and the project are ready, we will share those results with you as well. Because it's been very interesting to know your opinion. So, I was reflecting on how we could address that point as well: that people not only participate in the process, but also have access to the results of the process. I think that... it's also a way to keep people interested in participating in these kinds of projects as well. So, it's interesting feedback. And, no, I also think some really important ideas came up about, eventually, if we do this program next year or later, things that we can include to still make the program a more robust one. The idea of reaching other audiences seems very interesting to me and very important for the goals not of the project, because the project will end next year, but how can this program be sustainable over time or not. And I think that this can also be a great finding or a great result of the project here in Portugal, for example. I was reflecting on this. And now, I want to thank you sincerely for your willingness, your commitment, your time, which is so valuable, and your participation, which has been great, not only in the program, but also... with Laura and César we have been here for a year talking in the focus groups. So that's it. I am very grateful and very happy too.

F1: Well, I subscribe to almost everything F2 said. Now it is my turn to subscribe and sign below and add a few more things. To add, right away, the deepest thanks for your commitment, for not giving up. And so, it requires patience and willingness and to make time available here, especially during the weekend, and to say that F2 has just said: it is our task, if we want, our responsibility, to maintain this contact. Making the scientific process also a process of dialogue with people that don't participate becomes absolutely central after all this path that we have taken. And I should also add that this is a relatively common path, at least in my sociological research experience, but also in the CIEG's experience as a research center. That is, it's not using people, let's say, "exploiting" people as an object of study, but working with them, and therefore, also, we are responsible for showing them what is the end result of our project that depended on their participation. And, therefore, I think that this is the least we can do in science, especially in science that involves human beings, other people, right? So, this is a commitment that we have to assume and we will assume with you, and it is assumed with you, that in the phases in which it is opportune and possible, and as soon as it is possible to share both partial and final results of the project, this will be done with you. We will do this sharing. Obviously, we cannot do it when we feel like it, because we do not coordinate the project, but as soon as we get that green light from the central team, which is the University of Barcelona, this sharing will be done immediately. Because I think

it's absolutely crucial and it's fair for those who participate. And also, to emphasize something that was said in this last part and that has also been said in other ways in other sections of this focus group, which is the issue of age or social or socioeconomic differences, this is, in the relationship with science. And, therefore, this raises the need for programs of this nature to also be open to other publics, to other publics of other ages, younger, but also older. We always tend to think of the youngest, of those of school age, of the people called... the young-adults or... therefore, people of working age, but we forget about a very large part of the population, which are the elderly. And it's important for science to reach those people. So, age is absolutely crucial. As a matter of fact, as it is crucial in gender issues, gender acts differently throughout people's age and, therefore, science also necessarily relates in a different way to what it has to relate and the science produced in the gender area in a different way with different age publics. And then also the social differences, right, the inequalities also mark the access to science. Therefore, the programs have to start thinking about this diversity and this ability to include all people, so to speak, in the promotion of scientific culture. Everyone has the right, so to speak. There was an old saying: "everyone has the right to the city, everyone has the right to culture"... we could add "everyone has the right to culture, everyone has the right to science", right? And so, in this sense, your contributions mean that we have to rethink this program taking into consideration the great diversity of people who still remain alienated from science. And obviously think of different mechanisms: talking to people who are not very available, for example. This is also an incentive, so it's marked here. And thank you once again for your commitment, okay? Thank you very much.

University of Groningen (RUG)

Moderator- Recording started. So, after we discussed the introduction part, and we set the ground rules, let's move now to the topics. The first topic is how citizens benefit from scientific research. But as we said, before, we focus more on scientific research around education. I'm going to give you some scientific evidence that come from the research done by Allinteract project. The first comes from social media analytics, and this something that we found on a Facebook page. And the second is coming from systematic literature review and it's evidence from two scientific papers. In Facebook, we found many groups and many pages about teaching and about teaching science or teaching mathematics. And there was a lot of evidence that teachers share their resources in those pages, like tips of what they are doing in the class, such as memorizing techniques, finger counting and other strategies for mathematic learnings. And the second evidence I'm going to provide comes from two different papers, papers that they let us know that there has been a lot of research on how to engage minoritized students, like students who come from a non-dominant Western culture or Aboriginal students or in general students who are considered cultural minorities, racial minorities, etc. So going back to the topic that we have to discuss...if we would form this as a question: do you think citizens benefit from scientific research on education? And how? Do you have any experience any memories? Or any thoughts?

Mateo - I think that citizens until now, don't benefit from scientific research, but there is there like several things that we can do. For example, last month in Spain, there was like a very big day in which universities have to explain which research has been done and which benefits could the citizens could obtain from the so for example, in this day, I was in the center of my CTR, Maria explaining how my research in science education could benefit them and doing some exercises and this kind of thing. So this, this, these events, I think, then they are necessary for a foreign for this. So this my my opinion.

Moderator - So can I ask something? When you say benefit, do you mean that the research that is done is not useful for them? Or that they don't really have access to this research?

Mateo - that's exactly the second one.

Moderator - The second one?

Mateo - Yeah. Yeah. Yeah. Because, for example, in the school in, thanks to our research, in science, education, I think many schools can change their way of teaching. So they don't know that they are using the knowledge but of for research, but then they are using it. So it's the second option that you told me. Yeah.

Moderator - Okay. And if I was to form my question different, I would ask: how do citizens benefit from scientific research? So how, for example, the PhDs or the projects, the EU projects that we are doing in science education... How can the citizens benefit from that research? I'm researching on ways to engage minority students... Does this have any effect on citizens? Or do I just study some papers and write a thesis which will impact no one else in the world besides other researchers that might read the thesis? Can somehow students with minoritized identities benefit from my research? And how can they?

...

Maybe is it more helpful to speak about your research. For example, Eleni... Do you think that anyone will benefit from what you're doing on your PhD?

Eleni - If we think that I collect data from universities and the lectures in the university, the papers and what I'm developing can help the lectures of the university to address some issues they have understand better what they are doing, reflect on their teaching. And yeah, I chose to focus on the lectures because one lecture influenced 200 students saying one class, so a gives more impact related on that, that was my thinking regarding this. So

Mateo - sorry, in my case, I think regarding my PhD, I think it's I studied about concrete a topic in science. Okay, so how to teach it? How to transfer the this teaching in teaching learning sequences, and process precisely in my first paper, we discovered, we found out that there is not normally a gap between research and schools, besides our research, set up in research, because we don't agree in a lot of things. You know what I mean? For example, if you want to teach floating and sinking, researchers from the United States, consider that there is one way to teach it, and then in Europe and other way, so we don't agree in the essential things in order to teach. So how can how could we solve this problem? I think that we need to first we need to agree in research. And then we need to go to the to the schools and, and transfer this knowledge. In my opinion, this could be the way because if we don't agree in essential things, it's difficult to transfer this into the citizenship. The reality I mean.

Moderator

So Mateo, do you think that all this debate benefits the citizens, the future students for example? Or is it something that the scientific communities are doing for the sake of research, without thinking how to actually benefit the students?

Mateo - It's a difficult question. Well, I think if we do the way that I explained previously, it will benefit the steel and if not, it is difficult to for them to obtain benefits for the for this research or for this debate. If the debate is solely between researchers, it will it will not it will not help but if we include all the all the people, yes.

Moderator - Okay, okay. I hear you. Shall we continue to now...sorry, do you want to add something?

Mary

I want to say that research in any type of field always has benefits, even if it's not quantifying evidence of benefit upon people. If it does not have a positive and I don't know forthcoming outcome. At least now you know, that something does not work for something. So it's it always benefits the citizen into an extent, it we have to be more specific. If we if we had like A specific example. We could say yes or no. But since we are talking in general, I mean, that's that's how people evolve through exploring and in science and science education as well exploring is research.

Moderator

Thank you, Mary. So let's move on to the second topic. Are citizen aware of the impact of scientific research? It seems that we have established that there is an impact of scientific research. If no research has taken place, the education system would be [different]. Can you remember how education used to be some decades ago? If no research on education had taken place, totally different kinds of practices would still be acceptable in the schools, like hitting students for punishment. The learning theories and the pedagogies that followed them, they all came through research. They would have not been introduced if it wasn't for research, not inquiry, not culturally relevance etc. We still wouldn't know if active participation in groups is helpful for example, because we would only do lectures for all kinds of levels.

(participants nodding and agreeing)

So let's say now that we have recognized that there is an impact, but are citizens aware of this impact? For example, do the parents, the caregivers, the students, do they understand that the way the students are taught right now is a result of all the research that has taken place in education, the last decades? And to help a little bit discussion, we have again some evidence. This came from Reddit. There's a picture there, I'm not sure if you can read the whole text. As you can see, people in reddit share several debates about scientific articles,

and they discuss how important scientific research is in their lives. And we have, for example, one case, one case from Reddit, where the users, they debate about whether drugs and cannabis have a negative effect in pregnant women and their babies. You could see that users were exchanging arguments, but when they did not share their source, the other members of the discussion would ask about their source. Saying for example: "How do you know that? Where is your citation? What's your reference? What's your source? How did you find out that?" Yes, so this is, this is an example. Nowadays, many people, they have understood that scientific research is important. And that's why when they discuss about something and they exchange statements, they do ask for the for references, like Why do you say that? Where is the research done behind that? So you can claim that? What's your experience? Have you done similar discussions? Do you use references when you talk about when you give statements?

Mateo

I think it depends on the context. Because for example, if you if you're talking if we are debating speaking, I'm not going to tell you the reference. But but if you are using, for example, Reddit, I can understand that people, people want to know the source, the source of the of the statement, for example, the other day I saw in in Twitter, or the wait about politician politics here in Spain, and one of the people that were talking as stated that we need to be well informed and with and use the scientific evidence so I think this could be an example of this, what you're telling people now, and I would say that young, people are are looking for these kinds of things. References evidence on these kind of things.

Moderator

So Mateo, you say when you are just talking and discussing, you wouldn't use references. But let's say you were talking with someone who was trying to persuade you that boys are better in mathematics than in girls. How would you reply to that? If they were saying "Yeah, we all know that boys are better in mathematics" how would you reply?

Mateo

then I would try to explain him or her. Why, and what we know, thanks to research, but I'm not going to tell him or her according to X 2022.

Moderator

Because you, you will probably not have something on the top of your head, but would you question them, asking them for example "where do you know this information?" Do you have any research ton that or is that a myth?

Mateo

Exactly, exactly. Yeah. Yeah. Yeah, the thing is that I'm not going to use the reference Exactly. I'm going to explain the research, you know what I mean?

Moderator

Any other memories or experiences the topic?

Eleni

I don't, I will not go, like give a citation to something this is. But maybe I will do an overview of the layout showed, like, the key points is, you know, when this question was done with these measures, we did this and this and this, and later, and that is sold these days and days. But not with citation. Yeah, I know that this doesn't sound right. But you cannot go to someone and say a name and then persuaded them, then meet it. Exactly. So you try to give more of a overview of what is happening in the field, know the specific names on the field, something?

Moderator

And do you think that citizens in general are aware that scientific research is done and that it has an impact? Maybe it's easier, for example, to think the case of medicine. Maybe it's easier to say

Mateo

Yes..

Moderator

basic research is done. And that's why I now have the product paracetamol now, and I can take it or that's why we know that the surgery can be done, etc. Do you think this is the case with education as well? Do citizens they realize that there is research behind all these educational platforms that we were talking before the recording for example?

Mary

Yeah. I think citizens are not aware that there is research on education and many things on the on the way we were taught and people now are taught and our parents were taught is completely different. And it's based on on research and on beneficial stuff, actually. Mostly because it's it's not something you would ever see on the on the media. For a scientific discovery in any other field, you would hear it possibly on social media or on on the news or something like that. But scientific research on education is never is never published, they would never say, Oh, we found out that instead of people learning, the when, when they go to school, instead of learning, this is a this is B, this is C, you go and now you people are taught phonetically instead of just learning the letters, which is something I know because that's what my brother did. And we have 18 years we are 18 years apart. And personally I think it works better and they Do understand better how to speak how to phrase everything, but no one knows how it changed why and it's changed and how this you know, aim to become the way people are taught. So, I think this is not making the findings of scientific research public or say we have a breakthrough in a platform that all citizens can know does affect their belief of evolution in this field.

Moderator

Shall I move on or does anyone else have something to add? No? okay. The third topic we have to discuss is about initiatives that actually succeed, to engage citizens in scientific participation. So, you can think of sites, platforms events. For example, there is something that is called "edit athletes" that happened in Wikipedia, the free encyclopedia. We can even discuss the fact that Wikipedia is also free, and everyone has access to add information. This is also an initiating that calls the citizens to participate in science, because it's not yet another case of citizens receiving information without being able to contribute. Citizens can participate in the distribution of knowledge and add things. In the example we show, on March 2021, there were several initiation in which citizens would join together to translate, for example, content in different languages such as material related to equity, biographies of women scientists for example. Do you have in your mind any other initiatives that might help citizens participate in scientific research?

Mateo

The event that I explained at the beginning of the of the session, I think it could be very helpful for this for the for engaging citizens. So because organized by universities, or I don't know how to say I don't mean to in English, I the City Hall, the City Hall is the name. I think this kind of events in which all the people of the city can go are the best option.

Eleni

Other ideas, some, like events or competitions saying stem they have injuries like robotics and things like that so many people through this competition, get to know what is robotics and Okay, in Greece, they connect this wisdom, but it's not what it is. But yeah, it's a good

start for learning something so about engineering, many, many parents afterwards have subscribed their kids in this kind of courses and events. And I think it was quite helpful to have the European competitions that students will participate

Moderator

Do you have something in mind, or should I connect it the next topic? Because it's very similar.

Mary

Sorry, can you repeat the question?

Moderator

So Mary, do you have anything to add? Any other initiative that you have in your mind? Or should we continue to the next topic? I'm saying that because it's very relevant to what we are discussing

Mary

I think it's it's been said by everyone else. I cannot think maybe science fairs, in collaboration with schools instead of universities could also help

Moderator

What about the platform that we used in our previous meetings? Do you think this is a successful initiative to engage citizens in scientific?

Mateo

It takes time for the people on either side but I think people don't know platforms like it's, it's easier to go to something from the municipality or the university or the school, or a proposition that you find those kind words rather than somebody in your link. And specifically for this platform, I think if, if it's a part of a competition, or a part of its actively given to people, it would be beneficial, because there are many things discussed there. And you can even learn stuff. I was on the sides. And besides, I think we need we, we need to use the social media. I mean, if you are going to use a new platform, you know, you need to use with the social media existing. I mean, if for accept, for example, if you're in Twitter, and

Facebook, and you can explain, explain that you are using a new platform in order to do research on these kind of things. So we need to use the social media because the social media, people know social media and use social media. So we need to use it.

Moderator

So going back to events around STEM education, the next topic is, again about initiatives that they're focus on engaging, or better recruiting new talent in science. So bringing more children in STEM fields, or in science, or attracting maybe more minoritized students to follow a trajectory in STEM. Do you know any initiatives that are about recruiting new talent in science?

I'm will go back to what Eleni said before because it sounds very similar to me. When you do a STEM event or robotics events, and you introduce them for the first time to engineering, this is also a way to introduce to them a possible trajectory, "look at something that you could do, and maybe you could work on that when you grow up.

Mary

Yes

Mateo - This this kind of events are useful, but I am thinking that for example, if if I am thinking about research that explain that girls don't feel comfortable with science, also with math, but also because the teachers, some of the teachers, say some words, for example, 'you are not good for math, you are good for math'. So these kinds of small things, influence these choices. So apart of these events, we should as a teacher, we should think what we will tell to our students because it influence to the future.

Moderator

So what would be an initiative that would help maybe those students that they already have teachers who don't believe in them? What kind of initiatives would help those students? What would you organize as a researcher as a teacher? What could you organize, to maybe come into contact with those students in order to include them?

Mateo

For example, thanks to my PhD in science, education, I know I know a lot of woman that works work in, in in science, so I will try to show them my students that there are a lot of women that work in science and I would like them to the women scientists explain their experiences. The point is that the examples

Moderator

How would you share the experiences of these women with the students? Would it be like a video or an event where they present their experience with the women go to the schools, would you do an out of school club for these girls/ What would you do?

Mateo

I would go with my students to the university and because I know I want them to see the reality of this women I mean the school is is just a context but we can go out from the school and see the reality and I would try to do this frequently to go to the university to see women to see men and working in science in science education this

Moderator

So for you and the initiatives would be to bring into contact the students with real scientists so they can have real role models and

Mateo

yeah,

Moderator

[...] and let's see more representation of diverse identities in science.

Mateo

Yeah,

Moderator

Okay. You want to add something anyone else? Here as the scientific evidence I wanted to show you this slide. There are science fairs that take place as we also mentioned earlier, there are also scholarships to promote the inclusion of people from a specific origin or for a specific gender etc. And again, it is important to provide role models of women scientists, exactly what Mateo said.

And we continue with topic five now. So policies that promote awareness raising actions and citizen engagement in science. I know this must be more hard. But I was wondering if you have on your mind any policies that might be helping in engaging more citizens in science, or if you don't know existing policies, maybe if you can come up with something that maybe would help. And a scientific evidence that might help you think of more is the following: we already know that some governments require universities to be more transparent about the dissemination of scientific results in order to benefit citizens. So for example, I could be a researcher working on a university where the policy would require that whatever I am doing in my research, I should publish the data, maybe even the raw data of this research. So citizens can be able to read what I'm doing, they have access to my data, and then they can also evaluate whether they can trust my research. And, and use the results. Or maybe according to other policies, they would have the right to use my data to continue the research. Other policies are trying to promote open science, open science means more that the public citizens don't have to pay in order to participate in science, and they have access to read scientific articles for example, which so far, you usually can do only when you are able to pay a subscription in the journal that published the article.. Which means not all the citizens have access, but only the citizens that can pay the fee have access. Do you have any other policies in your mind that are helping citizens participate in science, or maybe they could help? I know the significant form.

Eleni

In the university that I am, we have the open days, so students with their parents can come and explore the university. And they have also the bass, the trailered from one group that goes around and they are doing some experiments with the kids. This is also nice and the open access publications. This is

Moderator

Do you want to explain what is the open access publication?

Eleni

And yeah, it's basically what you said before so the universities have the university have as the policy to when we publish in a journal, we can publish open access so everyone can

have access to our research and this is important and for the studies can go wherever fast and easy

Moderator

yes, thank you,

(...)

And the second scientific evidence I didn't share before is that EU asks scientists to promote, to engage in public communication through conferences, publications, policy statements. They are encouraged to communicate with citizens. Do you have anything else to add in policies or should we wrap up maybe?

Mateo

I do not.

Eleni

Okay, me neither.

Moderator.

Mateo, do you also have anything similar like open access publications in your university?

Mateo

Yeah, I was thinking about this open open access? Okay, yes, in my university, we have this but I was thinking, for example, I present my results in platform, okay in with my paper, do you really think that normal people aren't going to is going to read my research paper? I think this is not the way to disseminate and to to engage citizens would not be good for you. But for example, if you wear your teeth at Eton school, because you have all this background, you may go into the literature and then you can go back in your class when we found the studies. Yes, but this is, this is because of my background, because I have a PhD but normal teacher don't have a PhD.

Moderator

it might not be the solution for everything. But that is a different question. Imagining that someone, a citizen, not studying in a university because they don't have the money, not even being able to learn about research being done, because they don't have the money. Imagine the case of a person that does want to read a paper but has no access to scientific research, because they need to pay. How are we going to engage citizens in science if we do not even give them access to read what is happening? So in order to engage citizens, we need to do so many different things in different levels, different initiatives. But yeah, making sure that if anyone wants to read the paper, they can have it regardless of their economic status is also important.

Mateo

Yeah. So yeah, it helps, obviously, yeah, it helps.

Moderator

Yeah. So if you agree, I will stop the recording and then we can do a closing together. Okay.

University of Barcelona (CREA - UB)

1 [00:00:00.260] - Speaker 1

Está. Os saldrá la ventanita, supongo. Vale, pues un poco. Lo que quería introducir es al inicio de la sesión, o sea, de todas las sesiones. En octubre o así hicimos la primera, el primer acercamiento de cómo trabajáis las ciencias si conocéis algunos, algunas actividades que promovieron la ciencia, un poco así, y después hicimos las tertulias científicas. Si? hemos hecho diez sesiones, que hemos estado calculando diez tertulias y ahora hacemos como otra vez las preguntas que hacíamos al inicio. Un poco. Para ver más diferencias, aunque ya hemos cogido un poco lo que habéis ido interviniendo, no? Es un momento, un poco de reflexión de la actividad. Vale? Un poco es lo que queríamos saber, en qué os ha beneficiado, no? todo el tema de en tema científico, como impacto social, no? Porque a veces, la ciencia no llega. Habéis estado leyendo artículos científicos en educación y cómo os ha beneficiado?

6 [00:01:22.490] - Speaker 2

Bueno, yo creo que a no tener tanto miedo a la hora de leer cosas que al principio no entendíamos o que tenías que leer o releer, no? Pues como que las últimas lecturas se da, no es que fueran más fáciles, pero como que estábamos más acostumbradas al vocabulario. No sé, era más sencillo y a reflexionar más. Sobre el día a día, ya no es solamente a nivel de tertulias. En el día a día, me ha ayudado a ser mucho más reflexiva.

12 [00:01:57.400] - Speaker 3

Yo entendí diferentes puntos de vista de las personas que estaban allí, ya que éramos de diferentes edades, diferentes culturas.

15 [00:02:14.640] - Speaker 1

No sé si Speaker 4 está.

16 [00:02:16.200] - Speaker 4

Hola sí. Si que estoy. Sí, más que todo, puntos de vista de diferentes pensamientos, no?

17 [00:02:32.250] - Speaker 1

Por ejemplo, conceptos científicos sobre violencia género o educación así, habéis aprendido algo?

18 [00:02:38.870] - Speaker 5

Bueno, yo es lo que iba a hacer, a decir, que los primeros artículos suelen ser muy farragosos, o sea, no sé, suelen ser muy espesos, pues porque tienen unos lenguajes complicados y es la primera vez que lo oyes, como por ejemplo os acordáis de la violencia aisladora, no? de la violencia de género aisladora, bueno, cuando ya se lee más veces, cuando te lo vuelves a leer, cuando te dicen además aquello que habíamos hablado, no? la metodología de cómo seguir en un trabajo, bueno, pues empiezas a aprender qué es un trabajo científico, qué es un artículo científico y cuando no lo es. Porque nunca te habían caído tus manos y entonces ves pues cómo es el método científico. Entonces a mí eso me ha ayudado muchísimo a entenderlo y a saber que hay una, unos puntos de vista de aprendizaje que no habíamos tocado. Yo por lo menos no había tocado porque tú te lees manuales, te lees lo que te dicen otras personas, te lees algún artículo que te dice un experto. Pero bueno, yo no estaba acostumbrada a leer artículos científicos directamente de las personas que recogen esos datos y ya solamente eso. Y luego claro, bueno luego conocer, conocer a vosotros, porque creo que además de conocer nuestros puntos de vista, nos ha ayudado mucho, o por lo menos a mí, en crear un vínculo, un vínculo diferente al que teníamos. Sabes? Eso para mí ha sido muy positivo.

20 [00:04:05.600] - Speaker 1

Porque cuando hablaba Speaker 2 por ejemplo de de que ella pensaba, o sea le hacía reflexionar, no? Cuando hacía un artículo tú tu Speaker x o las demás, si eso crees que en las tertulias científicas llevan a que cojamos esa conciencia social de lo que nos está pasando al lado?

21 [00:04:32.300] - Speaker 2

Sí, yo creo que sí, porque a medida que vas leyendo vas viendo las diferentes opiniones, bueno, no solo opiniones, a nivel científico. Por ejemplo, cuando hemos hablado de diferentes escuelas, como que siempre te puedes quedar con algo bueno de cada sitio, sabes? es una manera de aprender de unos y de otros, que no siempre lo que hace uno es lo mejor. Y así al escuchar, bueno, a leer, a leer cosas que son beneficiosos para otros, como que te hace a ti replantearte cosas también, sabes?

24 [00:05:08.300] - Speaker 4

Pero también a mí lo más interesante es, me parece, los datos evidentes, no? los estudios de caso concretos, reales en que se basan, no? los estudios científicos. Y a partir de aquí

ver que no, no solo son historias comentados por ahí y que de verdad están en el punto de vista de de los científicos y de otros grupos que están estudiando, no? Estos comportamientos.

25 [00:05:58.240] - Speaker 1

Y qué lectura os ha gustado más o os ha llamado más, en las diez que hemos leído? las ocho y las nueve, no sé y cuál es la que más os ha llamado la atención? O más ha creado más impacto? la habéis hablado en casa, por ejemplo.

26 [00:06:15.870] - Speaker 5

Bueno, es la misma que la que he dicho antes. La violencia de género aisladora, en la que el que hablamos sobre ese tema es la que más me aportó, porque luego he oído hablar de ese término. Luego, claro, porque cuando sabes una cosa y la oyes, dices ostras, enlaza rápidamente el conocimiento. y luego, pues, estuve escuchando también en otra tertulia, claro, que ahí nos decía que Cataluña es el primer país del mundo que ha legislado sobre eso. Y sí, en otra formación también de comunidades que decían que el País Vasco es el segundo país. Y entonces me acordé. Digo, claro, que Cataluña es el primer país que ha legislado sobre eso y se hablaba de la importancia. O sea, claro, que esté legislado ese tema es haber avanzado mucho en la violencia de género y en definitiva, la violencia.

27 [00:07:09.020] - Speaker 4

Para mí creo que todos los temas han sido muy interesantes, todo.

28 [00:07:17.580] - Speaker 2

A mí el de la violencia aisladora y también el uso de las tecnologías. Me resultó muy llamativo que al final no todo es tan malo.

31 [00:07:30.090] - Speaker 1

Sí. Y por ejemplo, otra pregunta que que quería haceros es, por ejemplo, si consideráis que las tertulias científicas os ha hecho más involucraros en cosas de ciencia, yo sé que habéis hecho algunas, habéis ido a más formaciones, no sé, a ver que en qué os ha aportado más o qué os ha llevado más a ciencia, o a buscar cosas. No sé.

33 [00:08:06.360] - Speaker 5

Bueno, yo a raíz de las formaciones que hicimos en Cuenca, que hay unas páginas donde hablan de los bulos, pues entonces ya pones ahí el poquito de la vida. Es decir, vamos a buscar aquí artículos científicos, quiero decir, es que ha sido para mí como iniciarte en algo. A partir de ahí, ahora como pones mucho más interés, pero estamos iniciándonos. o sea yo me estoy iniciando, estoy pues eso, mirando en estas páginas, mirando el diario feminista. Cuando voy a formaciones pongo los oídos de otra manera, pero todavía no te podría decir que estoy leyendo ni un libro ni muchas más cosas, sino que estoy como pendiente, como en la formación esta, pues me apuntaré a tertulias científicas porque yo no sabía lo que era. Vale? Y eso que a nivel de de toda España se, me pasaban ya artículos, pero no sabía. Oye, tengo que diferenciar entre las lecturas literarias, tengo que aprender a diferenciar entre todas ellas para saber qué es lo que más me interesa en cada momento. Pero eso ya es mucho, saber lo que te falta, cuando a veces cuanto más sabes es porque te das cuenta que te falta más. A mí me falta mucho, pero eso ya es importante.

35 [00:09:28.670] - Speaker 1

Los demás? Bueno, tu Speaker 5 buscando los artículos. Los tenías tú más preparados que yo. Jeje

38 [00:09:37.130] - Speaker 4

Pues yo prácticamente estaba acostumbrada a este tipo de discusiones, de búsquedas, tuve una temporada en la facultad, cuando estudié en mi país, en Rumanía. Hicimos unas tertulias de este tipo con un gran académico de mi país y fue muy relevante para mí. A partir de este momento empecé a ver de otra manera los estudios científicos, y luego bueno, poco a poco yo por mi cuenta a ver algún libro, libros de psicología. Pero bueno, este encuentro con todas las chicas de estas tertulias han sido como un guau! Un soplo. Un soplo nuevo. Otra vez a disfrutar, no? a disfrutar, efectivamente, de las ideas, de la de como ve cada uno estos estudios.

39 [00:10:56.840] - Speaker 1

No sé, Speaker 2. No me acuerdo de tu nombre ahora.

42 [00:11:03.870] - Speaker 2

Speaker 3. Bueno, por mi profesión sí que estoy más acostumbrada a leer cosas científicas, pero más cosas destinadas, de cosas de salud. Es verdad que a veces me parecía muy farragoso todo eso de los métodos. Cuando, bueno, no sé. Y ahora digo como, ay mira, si es lo que hacemos en tertulias, no sé.

49 [00:11:30.250] - Speaker 1

No sé si tú, Speaker 2, ves una diferencia entre leer sola y leer en grupo, porque a veces...

50 [00:11:36.970] - Speaker 2

Claro, no tiene nada que ver.

52 [00:11:38.920] - Speaker 1

No sé si eso a veces no sé si pensáis que os da más facilidad, no? A mi pasa. No sé si, a entenderlo.

53 [00:11:45.160] - Speaker 2

Sí, sí. Así es más fácil. Sí, si. Y tu? (PREGUNTA A SPEAKER 3)

Speaker 3

Yo es que siempre me ha gustado la ciencia y he buscado libros, sobre todo de mujeres científicas y esas cosas. Y sí que es verdad que cuando lees sola es como que vas a tu ritmo, pero cuando lees con más personas estás como obligada a leerlo. Entonces, es como que tienes metas.

59 [00:12:18.480] - Speaker 1

Vale. Después había pensado. O sea, si por ejemplo o más también sobre todo para Speaker 3. si pensáis, por ejemplo, si estas tertulias dialógicas se llevaran más a cabo en la sociedad con los niños y las niñas, donde adolescentes, tendrían esto más interés por lo que es la ciencia. Provocaría esta motivación a conocer, a saber.

60 [00:12:53.180] - Speaker 3

Sí, yo creo que sí, que habría más gente que se interesaría, no tipo profesional, pero sí para saber más.

61 [00:13:02.580] - Speaker 1

Las demás. Que pensáis? No era solamente para Speaker 3 en la principal

62 [00:13:09.360] - Speaker 4

Yo creo que. Perdón. Perdón. Perdón, Speaker 5.

63 [00:13:13.950] - Speaker 5

No, no, continúa tu continua tu.

64 [00:13:17.100] - Speaker 4

Yo creo que todo lo que es leer es muy, muy bueno.

65 [00:13:26.070] - Speaker 5

Yo si no hubiera visto como el impacto que han tenido las tertulias en los alumnos, tendría una opinión diferente. Pero creo que ver a los clásicos son libros, a veces que no son fáciles de leer, pero según como se transmite puedes crear en los alumnos esas ganas de aprender. Y creo que con el resto de tertulias pasa lo mismo. Pero primero, la persona que dirige la tertulia se lo tiene que creer y tiene que creer que eso es una buena manera de aprender, de aprender juntos y aprender más fácilmente. Porque sí que es cierto que a veces a todos nos resulta difícil la comprensión lectora en los clásicos. Si escuchamos y hacemos una tertulia musical, pues dices yo nunca he oído eso, pero y las primeras veces serán difíciles, no nos entenderemos. Pero cuando escuchas a las otras personas lo que cada uno ha entendido, te vas animando. Y de eso se trata, de compartir ese aprendizaje. Que yo creo que sí. Creo que los alumnos y de hecho sé que en colegios lo han hecho las tertulias científicas con otros textos, pero los que llevamos esas tertulias los podemos organizar, tenemos que conocerlos porque hay que conocerlos antes y saber exactamente cómo motivarlos mejor para el aprendizaje.

66 [00:14:46.990] - Speaker 1

Otra de las preguntas, o sea, penséis, por ejemplo, que estas acciones, como las tertulias, sensibilizan o hacen que la gente se vuelva con más compromiso, hacia la ciencia o a buscar, o no sé. O cuando escucháis noticias en televisión, o a ver si esto existe o no, como decía la plataforma, esto existe o no, o es un bulo o no?

68 [00:15:20.150] - Speaker 2

Yo creo que te ayudan a tomar más conciencia sobre las realidades que hay, yo creo que sí.

70 [00:15:30.310] - Speaker 1

Y conocéis otras acciones o a partir de las tertulias habéis conocido más acciones que potencien esta conciencialización de la ciencia. O esta vocación por los temas científicos o el compromiso por la ciencia. No sé si habéis investigados más o lo que se hace en otras tertulias.

73 [00:15:58.690] - Speaker 5

Sí, yo más que nada en otras formaciones. Pero es que estoy motivada del tema porque veo que veo que aprendo y además hay impacto social y cuando uno más aprende es más consciente. Cuando más consciente eres, más te quieres implicar en la sociedad y por lo tanto, también te da mayor libertad el aprender, sabes? te hace ser más libre porque conoces más y entonces tienes más opciones de escoger. Yo creo que sí, que el impacto muchas veces es que y de hecho cuando nosotras estábamos hablando o cuando la tertulia de Sant Jordi fue bien porque había gente, todo el mundo lo que dice no solamente que bien, que también sino y podríamos hacer y el año que viene y podríamos y tal, y eso son iniciativas y son lo que decimos "taca d'oli", de tener ganas de hacer más.

74 [00:16:55.370] - Speaker 1

Como escuela, no? supongo?

75 [00:16:58.070] - Speaker 5

Bueno, yo lo valoro muy positivamente como escuela y como barrio, porque, bueno, también la gente que estábamos en este grupo son gente muy implicada en casi todas las cosas que pasan en el barrio, sabes? y eso va más allá de, yo creo que ese es el impacto que tenemos que y de hecho Speaker 2 este año abandona el colegio, pero decimos que las tertulias tienen que ser abiertas a la gente del barrio, bueno, a gente que quiera, sabes? Pero que podamos compartir, que yo creo que eso sería lo importante e interesante.

76 [00:17:30.170] - Speaker 1

Perfecto. Ahora ya os hago la última pregunta. Speaker 5, ya me ha hablado un poco, de qué esta actuación se ha llevado en otros lugares o en otras circunstancias, que no son escuelas o como San Boi. Y si tenéis alguna información sobre esto? Bueno, vosotras presentasteis en el Congreso de Comunidades. Fuisteis ahí para conocer no sé qué

feedback, por qué no sé qué feedback os dieron o si había gente que quería mejorar. O qué os dijeron.

82 [00:18:12.490] - Speaker 5

Bueno, si este año en la de comunidades presentamos justamente esta, las científicas, la experiencia que hicimos este año, les pasé el PowerPoint que hicimos y se interesaron sobre todo gente, porque claro y bueno, hablamos del barrio de cómo y del impacto que eso tenía entre todos nosotros. Y hablé de las nacionales porque era donde yo realmente aprendía de los artículos. Entonces mucha gente vino a preguntarme por las nacionales porque también se querían conectar.

83 [00:18:40.480] - Speaker 1

Eran docentes, no? Supongo que se aislaron.

84 [00:18:43.840] - Speaker 5

Claro, casi todos los que estábamos ahí en Cuenca yo imagino que seríamos docentes, sabes? Y luego lo típico que hacen es felicitarte porque, o sea, comunidades entre comunidades como familias vienen más a felicitarte, a preguntarme que como las madres, como se habían apuntado, como las habíamos encantado, como habíamos montado el grupo. Sobre todo felicitaciones. Ahora, interesados estaban en participar en estas tertulias porque les dije que había varias maneras y una de ellas eran las nacionales, cosa que también me pareció muy interesante porque de eso se trata el impacto es de que vaya, de que nos vayamos concienciando todos, de que es una manera de aprender.

85 [00:19:27.480] - Speaker 1

Qué pensáis Speaker 2 o Speaker 3? Siempre que se va con familias o se habla con familias, sabéis que sois protagonistas, no? No sé porqué, es como muy rompedor. O sea que, no sé que yo creo que.

90 [00:19:46.690] - Speaker 2

Es chulo, no? es bonito esto, no?

Speaker 1

Y si.

90 [00:19:46.690] - Speaker 2

Y que podamos estar de una manera o de otra, en boca de otras personas. Pues si esto hace de que en cada comunidad de aprendizaje o en cada escuela se plantee hacer cosas parecidas. Pues eso que tenemos todos ganado, no? a nivel de sociedad y de todo. O sea que muy bien.

91 [00:20:10.240] - Speaker 1

Sí, yo creo que a veces es como que, Speaker 3, corrígeme si no me equivoco, pero que una parte de docentes piensa que es imposible que las familias estéis participando. Me explico? Que participéis en tertulias científicas. O sea, imagínate la mentalidad que tiene la gente, o sea, con cariño. Pero claro que las familias leen si están cosas motivadas. Me explico? Entonces es muy rompedor que que estéis vosotras en estas.

92 [00:20:40.990] - Speaker 5

Muchos profesores me han preguntado a lo largo de todo el curso que si podían estar, que se habían enterado o que les habían dicho. Pero claro, como es en el calendario escolar, pues no les podía, podía invitar si había alguno que tuvo que tiene exclusiva, que por ejemplo [profesora] había venido las dos últimas pero estaba hoy en el médico con sus padres. Y ya te digo que se han interesado mucho. Y luego allí en Cuenca, sí que me preguntó alguna comunidad. Pero cómo habéis empezado justamente por las científicas? Claro, lo lógico es habría empezado por un libro o un libro más cortito, a lo mejor de literarias y tal. Digo, pues mira, porque nos los plantearon. Y yo les dije "no creo ni que lo hubiéramos pensado". O sea, nos hemos lanzado. Y entonces es verdad que fue el mayor reto porque las científicas tira todo el mundo un poquito para atrás y sobre todo incluso el primer día que te lees el primer artículo. Pero bueno, la verdad es que en este, en este barrio y en este colegio, las madres que participan, que son muchas y que bueno, ya has visto que el grupo ha variado de 3, 4 ,8, íbamos cambiando. Bueno, es gente que se implican bastante y que no tienen miedo a nada a veces. Eso está muy bien.

95 [00:21:50.800] - Speaker 1

Por ultimo, no sé si queréis añadir alguna cosa más. Bueno, nos vemos el año que viene. Seguro. Si son científicas, otra cosa, pero no sé en lo que serán tertulias dialógicas, no se si alguna cosa que queráis añadir.

98 [00:22:15.650] - Speaker 2

Bueno, muchas gracias. Y además, el día que fuimos a la universidad también fue una experiencia súper chula. Con los niños del colegio y todo, súper bien.

99 [00:22:24.350] - Speaker 1

Cada vez que llevas alumnos y familias allí con el alumno y las alumnas, es rompedor porque tienen esta idea de que las familias no participan, que las familias no hacen nada, que las familias no sé que y como ya seas de otra cultura y tal, ya están los parches que puedas tener, no? Entonces claro, para ellos me dijeron que está flipando, o sea, está flipando de vosotras. Sabes que yo digo que cuando eso que llevas docentes y eso es rompedor, pero cuando llevas familias y niños y niñas eso ya es, se les desmonta todo lo que habían pensado.

100 [00:23:05.390] - Speaker 5

Sí sí. un poquito las comunidades, es así. O sea, lo que realmente impacta o a mí más me roba el corazón, es que todos tienen que participar, todos tienen que pasar para que eso realmente funcione. De hecho, el aprendizaje, de hecho, escolar, es para que mejoren las competencias, que por cierto sigue mejorando. Ya lo dijimos en el Consell escolar, han mejorado y tal. Es que tiene que participar todo el mundo, no puede... Y esto es lo que a mí me roba el corazón. Porque decir ostras si una cosa así funciona y podemos montar una pequeña sociedad que luego se transmita, pues eso, al barrio o a otros institutos, cuando Speaker 3 sea profesora de un instituto que lleve un instituto.... Claro, son realmente cosas muy esperanzadoras y que bueno y que te hacen sentirte más activa en tu profesión y como ciudadano. Creo que lo importante.

104 [00:24:05.960] - Speaker 1

Pues no sé si tenéis alguna cosita más, si no podemos, si podéis despidiendo a XXX y a mí y ya. si Speaker 4.

105 [00:24:15.860] - Speaker 4

Yo doy las gracias por todo porque así me estoy continuando en formarme y eso es un agradecimiento total. Para mí, es crecer cada vez más a vuestro lado.

106 [00:24:35.080] - Speaker 1

Qué bonito. Esto se acabó. Bueno, chicas, pues.

107 [00:24:40.180] - Speaker 5

Bueno, pues haremos un formulario o algo. No?

108 [00:24:43.220] - Speaker 1

Sí, si quieres vamos hablando y cuando yo, yo siempre hago lo que la primera tertulia o la primera reunión es organizar con las mamás o los papás. Un poco el año. Podemos organizar una sesión o con XXX y pensar como queremos las tertulias. Si queremos feministas y tenemos otro mas científicas o para un poco variar, ser una y una o cada 15 días una diferente, no? Pues hoy os toca este y con otro no? Y ni un poco así. si os parece bien y el centro de Isabel vale muy bien.

109 [00:25:27.670] - Speaker 5

Pues nada, que tengas un buen alumbramiento.

[00:25:31.120] - Speaker 1

Sí, espero que sí. Que sea fácil. Chicas. Gracias por contestar. Que vaya muy bien.

[00:25:39.030] - Speaker 3

Estamos en verano.

[00:25:40.600] - Speaker 2

Hasta luego. Adiós.

[00:25:42.700] - Speaker 5

Adiós, Speaker 4. Buenas vacaciones. Que estás de vacaciones?

[00:25:47.170] - Speaker 4

Sí, esta semana. Muy bien. Speaker 5. Te quedas un poquito?

[00:25:52.150] - Speaker 5

Vale. Sí, es verdad. Te dije que así te podría decir el curso escolar.

[00:26:00.630] - Speaker 4

Sí.

[00:26:01.320] - Speaker 5

Vale.

[00:26:02.900] - Speaker 4

Vale.

University of Helsinki (UH)

Does the topic you teach identify and explore any equality and diversity issues explicitly in the subject material?

- Mostly in that sense that for example everyone is able to design their own home and that any size and style is good. Accepting what you have and appreciating that and making the most out of it.
- Recycling is a good thing and money does not dictate how a home can be designed. We also talk about how a home can function better for a wider group of users, and how much space for example a person in a wheelchair needs.
- When we talk about colours we talk about that colours are seen differently in different cultures and the amount and angle of sunlight affects this as well.
- Course studies in a language should always take diversity into account. Some of the topics, such as colonialism and science need to be considered when teaching French. There are also differences in geography and the relationship between the centre and periphery.

Have you thought about how the learning outcomes you deliver may introduce unnecessary (or unintended) barriers?

- I have thought about it and I try not to show too many examples or say that things should be done in a certain way. For example, when students are designing a moodboard I don't show them any readymade moodboards because I think it is unnecessary.
- I often talk about the path rather than the outcome. In design the importance of the path in itself can be more valuable than the outcome.
- Thinking about family. Cannot make assumptions about what a family might mean when using it as a topic for language instruction. Some people also may not want to talk about their family.

Can you identify a 'hidden curriculum' that reflects certain values, dispositions, and social and behavioural expectations that may contribute to discrimination?

- There are certain stereotypes how a designer should be like and what kind of projects they should deliver. But I try to fight against these prejudices. The social media and the world we live in has made design and interior design easily accessible to everyone.
- I think being original and true to yourself are still the most important things. This is a tricky question.

- How do you discuss the French revolution? What does liberty and freedom and fraternity mean at the time? The translation of liberty is not freedom. There are cultural differences in terms of how we define freedom.

Does your teaching use the full range of learning styles and use a range of resources?

- I could be more versatile and use more new software especially designed for teaching.
- But still I think that drawing is a good way to understand for example measures and it is an important skill and means for how you document your thinking. So I encourage students to draw.
- Use multistategy approach. Need to consider all sociocultural views.
- How do you deal with fake news? How do you deal with non-binary distinctions when teaching.

Is your teaching material presented in formats that are easily accessible and are alternative formats available?

- All the material is available online in pdf files. All the lectures are easily accessible.
- Normally I give a paper copy of the timetable and the assignments but they are also available online depending on the different platforms that each school uses.

Does the class draw participants from the full range of students?

- I think my courses have been quite popular among students from different nationalities and different age groups.
- Prepare for life of class reflects society

What are the experiences of students of the topic and are there any differences between learner groups?

- I can say that generally oversea students work hard and take the assignments really seriously (this happens at the university).
- After the coronavirus I have noticed that students have been generally really active and enthusiastic about studying and meeting people now that there a fewer restrictions.
- Different voices must be heard.
- There is a need for critical thinking in all forms of knowledge including science. Encourage students to bring their own material

Are there any equality and diversity issues or challenges for, or faced by, you?

- The situation in the world right now can cause underlying tensions between students but I haven't seen any issues really in my courses.
- I view students as equal persons and their learning is the most important thing. I try to listen to them individually and also understand if they have problems in their personal life, which sometimes happens, and they might not be able to deliver the assignment on time.
- Always thinking about both content and way of delivery.
- How do we deal with difference in knowledge

Università degli Studi di Milano-Bicocca

UNIMIB

Focus Group group – gruppo di controllo

Data: 7 ottobre 2022

Ricercatrici presenti: Speaker 2, Speaker 1

Speaker 1: Grazie per essere qui. Come vi anticipavo via mail, l'obiettivo di questo FG è riprendere alcuni temi che avevamo già affrontato nel primo focus group e capire se ci siano delle riflessioni ulteriori. Ripercorreremo i temi che avevamo affrontato. L'obiettivo è comparare le risposte con le altre vostre risposte e con quello del gruppo sperimentale.

Speaker 2: Prima di cominciare vorrei comunicarvi che abbiamo predisposto un voucher "simbolico" per ringraziarvi.

Speaker 1: I benefici che i cittadini e le cittadine hanno usando i risultati della ricerca quando discutono o vengono usate delle campagne on line. Per es. quando vengono effettuate campagne sulla violenza di genere. Cosa pensate di questo aspetto?

Pausa (...)

Speaker 1: Pensate anche alla vostra vita quotidiana, per es. se anche voi lo fate o osservate che gli altri lo fanno. O se no vedete che discutono senza elaborare questa conoscenza.

Speaker 3: Se devo guardare in generale su quello che si vede e si sente, sia sui social media, ma anche dal panettiere, no, penso che la gente non abbia molto chiaro i dati di qualsiasi ricerca scientifica, scientifica ci metto dentro anche le scienze umanistiche. Poi ce ne sono alcune che sono ri-sottolineate, ripubblicate, mi viene in mente la violenza di genere, per es. "una donna uccisa ogni tre giorni", che poi si diffondono nella narrazione popolare, nei tg e che poi diventano conosciute. Il passaggio da conosciute a usate per una riflessione personale, anche lì io mi fermerei. Non è detto che sapere i dati, vuol dire anche rielaborare i dati, e generare un pensiero critico rispetto a quel dato. In generale, c'è poca predisposizione allo studio e alla ricerca. Andare a vedere fonti e andarsi a fare un'idea. Ci si fa un'idea e ci si fa un'opinione, prima di ricercare.

Speaker 2: Tu dove vivi?

Speaker 3: Parma.

Speaker 2: immagino che tu abbia avuto diverse occasioni per viaggiare in Europa. A tuo avviso ci sono delle specificità in negativo? O non hai avuto modo di osservare qualche differenza?

Speaker 3: Io non ho abbastanza esperienza per risponderti. Quando sono all'estero... io accompagno, faccio viaggi della memoria, di studio. Le persone con cui mi confronto sono ricercatori e ricercatrici, quindi già nelle nostre professioni... in quel caso il paragone funziona, ma in un'élite. Mi è capitato di confrontarmi con una ragazza in Polonia sull'aborto (pausa) e noto alcuni punti in comune.

Speaker 4: Mi è venuto in mente a proposito dell'estero... un viaggio con due amiche, un viaggio che avevo fatto ad Amburgo. Si dà per scontato la conoscenza anche da parte delle nostre nuove amiche tedesche di alcune situazioni italiane che avevano a che fare con la politica. Io sono rimasta meravigliata del fatto che noi crediamo molto nel fatto alcune cose che succedono nel nostro contesto, nel nostro ambiente abbiano un impatto anche per le persone che conosciamo all'estero. Abbiamo la sorpresa che la vedono totalmente diverso da noi. I punti di interesse potrebbero diventare per altri meno importanti che da noi. Per es. ci sono molti temi che vengono messi molto in risalto qua in Italia e che all'estero hanno un altro connotato. Adesso non vado sul tema dell'aborto... non lo so a proposito di alcuni temi... forse conta molto quanto viene gettonato quel tema, quanto è diventato importante per la comunità scientifica in quel paese. In quel caso riguardava la politica, ma riguardava anche altri temi. Noi viviamo in un contesto che viene manipolato e anche noi contribuiamo a questa manipolazione. Credo che sia... qual è il tema principale? Qual è il tema che si veicola di più? Ci sono dei temi che coinvolgono tutti... io vedo tonalità diverse in funzione di quanto viene detonato un tema.

Speaker 2: quali sono i punti di vista delle altre persone?

Speaker 5: Rispetto all'estero.... Il discorso dei dati... che non tutti si basano sui dati... varia... io ho fatto un periodo negli USA... c'era un'ignoranza nel posto dove vivevo io, cioè che credevano... ero nel sud dell'Illinois.. robe dell'altro mondo... io vivevo in un paesino in cui le donne pensavano di non poter abortire... però non avevano una cultura adeguata e credevano alle fake news... infatti negli USA il numero di gente che crede alle fake news è altissimo... cosa che nel nord Europa... io ho una mia carissima amica belga, loro hanno un modo di vivere completamente diverso... io credo che la cultura conti molto, ma anche... secondo me si citano i dati sbagliati perché noi viviamo nell'epoca della società, quindi andiamo sempre più veloce. Non abbiamo il tempo. Qui i social influiscono tantissimo. Io apro Instagram, seguo la pagina delle news, mi leggo quello che mi propina, però non vado ad approfondire. È sempre tutto più veloce.

Speaker 1: quindi non c'è il controllo delle fonti rispetto a tutto quello che arriva, quindi anche quando si citano non c'è tanta autoconsapevolezza.

Speaker 5: no. Finché la gente non capisce che i social sono un mezzo ma devono anche vivere al di fuori... no.

Speaker 5: io penso che le persone quando prendono dei dati personalmente, lo fanno, lo fanno anche spesso, ma poi se ne dimenticano, magari in una situazione diversa e quindi cambiano idea... per poi trovarsi in un altro posto rielaborarli e variarli ancora. Noi come casa della donna facciamo diversi eventi, la gente viene, riflette, poi ci parli e qualche tempo dopo è come se dicessi cose nuove. Ecco, quello che ho notato io.

Speaker 2: da parte mia ho messo al centro il tema dell'accelerazione e poi dell'alienazione che poi si vive. A tua volta ritiene che ci possa essere un nesso tra correre alla notizia successiva se vuoi stare dentro una comunità/eventi e consapevolezza sulla scienza.

Speaker 5: Penso che ci sia un nesso tra correre alla notizia successiva se vuoi stare dentro una comunità/eventi e consapevolezza sulla scienza il fatto che ci siano tutte queste notizie insieme, e che siano anche contrastanti...bisognerebbe mettersi lì e riflettere, ma credo che poche persone lo facciano. Un giorno dopo pensano a una cosa, un giorno il contrario. Oppure pensano "basta, non ne posso più", questo mi è capitato spesso, di sentire "io non seguo più il tg tanto dicono sempre le stesse cose"

Speaker 1: la consapevolezza degli impatti della ricerca sociale non è alta o secondo voi lo è ma non lo usano?

Speaker 5: l'impatto ci può essere, c'è, ma è solo riferito a una certa parte, a un'élite di persone. Nella vita di tutti i giorni le persone non stanno attente a quello che dice la scienza, sia che si guardi a dati scientifici o a quelli dei vaccini... ma... è proprio come se fosse un altro mondo.

Speaker 1: l'altro tema riguarda il tema delle iniziative e delle azioni. Il progetto ha lo scopo di capire in che modo queste azioni utili ad avvicinare scienza e società possano essere disegnate. Quelle che erano state disegnate o sono disegnate in passato avvicinavano sempre le stesse persone... un'élite piuttosto istruita che ha il capitale culturale, le conoscenze per partecipare. L'altra volta vi avevo fatto l'esempio del museo che aveva usato volti umani o aveva dato accesso ai laboratori degli scienziati... per capire il loro lavoro. In che modo le iniziative potrebbero essere disegnate per avvicinare scienza e società?

Speaker 4: mi viene sempre in mente un esempio. Quando c'è troppo, non facciamo altro che allontanarci... anche per cose che ritenevamo interessanti. Mi riferisco per esempio a questa cosa dei vaccini. Adesso io personalmente mi sto un po' allontanando... non mi interessa più il discorso scientifico del medico. Sento questo desiderio di allontanarmi dal dato scientifico... mettendo degli occhiali di diverse diottrie... sarebbe un non vedere, un non sentire... è diventato troppo. Poi quando abbiamo bisogno di fare una piccola ricerca, di conoscere, sapere... ciascuno che ha una sua modalità... noi troviamo quello che siamo fatti per cercare... non possiamo trovare qualcosa che non è già nel nostro essere. Per questo che la mia ricerca è diversa dalla tua, perché siamo condizionati da noi, dal significato nostro... di cercare e di trovare le cose. Rispetto alle azioni, io direi... basta, mollateci... ci dovette mollare, non bombardarci. Questo non è un discorso molto scientifico. Quando c'è di troppo, questo ha un effetto negativo sulla popolazione. Adesso voglio pensare con la mia mente.

Speaker 1: Da una parte bisogna aumentare la partecipazione... però dall'altra il cittadino/a non vuole partecipare... oppure il cittadino vorrebbe se si parlasse della vita quotidiana.

Speaker 4: può essere. In questo momento... non è il linguaggio troppo alto/troppo basso, ma alla quantità. Speaker 2 parlava delle notizie di guerra. In questa situazione è di troppo.

Speaker 2: Vorrei portarvi uno stimolo. Il rapporto tra individualizzazione dei saperi (l'individuo parte dalla sua visione del mondo) per costruire una relazione personale con il mondo/scienza. Io sono metà alto-atesina... e sono sempre rimasta colpita... le percentuali del Sudtirolo... è sempre stato fortemente no-vax, impegnato in una serie di mobilitazioni che avevano cifre sbalorditive, a tal punto che forze politiche che li rappresentano raggiungono livelli elevati. Questo accade nell'Alto Adige perché lì c'è una forte influenza calvinista... noi siamo un paese al contrario... noi abbiamo un approccio non calvinista, non è tanto la prospettiva individuale. Vi risuona?

Speaker 5: è una cosa su cui ragionavo... non so se ci sia il nesso.... Io sono per metà di Reggio C. passo un mese l'anno lì... nonostante RC sia una delle città più ignoranti d'Italia... la teoria scientifica, o la parte sui vaccini... non ci credono però nello stesso tempo la quantità di gente che decide di intraprendere le carriere scientifiche è altissima. Magari pensi che quello che ti dice il governo... no, ti vuole fregare, però poi mandi i tuoi figli al liceo... perché la stessa mentalità ignorante che ti dice "non devi vaccinarti" è la stessa che ti dice "non troverai lavoro se non ti iscrivi allo scientifico". Io quando dico che faccio cinema... mi guardano un po' male.

Speaker 2: Ho insegnato in Calabria e conosco questa ambivalenza della cultura locale. Le culture locali contano.

Speaker 3: certamente il sostrato dove nasci e l'aria che respiri è la tua cultura... ti forma la mente, l'idea di futuro, le relazioni... ritornando alle iniziative e ragionavo anche sul fatto delle professioni... sull'avvicinamento... la sociologa, il giornalista... anche lì manca una selezione di quello che troviamo. Se mi devo avvicinare a una professionalità con il mio senso critico mi posso trovare il giornalista che ritengo bravo, dal giornalista che non ritengo bravo. Tutto questo però mi può confondere perché non riconosco la professionalità all'intero mestiere... una selezione sarebbe anche un modo per riconoscere la qualità di una persona.

Speaker 1: Chi dovrebbe selezionare?

Speaker 3: per esempio, quando un direttore del giornale sceglie chi invitare e posso mettere sullo stesso piano due persone che hanno qualità diverse.

Speaker 1: Umberto Eco e la selezione delle fake news sui giornali. Quindi tu dice che se ci fosse questa selezione ci sarebbe più qualità.

Speaker 3: sì, sarebbe un buon filtro. Poi tu hai fatto quell'esempio del museo... certamente l'avvicinarsi semplificando cosa si fa alle persone è una buona strada. Lo scienziato che ti spiega quello che fa, te lo rende capibile, non banalizzandolo, ma semplificando... già toglie quella distanza tra la persona comune e il professionista. È un po' l'idea che l'accademico che deve uscire fuori dalle mura se lo vuole studiare ed interpretare. E questo si può fare anche molto con l'infanzia. Per es. i bambini vanno nel laboratorio, loro vanno in classe aperta, in un'ottica di genere aperta sarebbe una bella iniziativa.

Speaker 1: Altri commenti sulle azioni. Considerate che ci sono milioni di iniziative soprattutto sulle donne, però non sempre sono efficace. C'è tanto però poi non c'è tanta partecipazione. C'è qualcosa che non va nel setting che viene creato.

Speaker 5: io vivo a Pisa, una città piccola, universitaria... e l'Università c'è spesso in città... in tutta Italia abbiamo avuto la notte dei ricercatori e ho notato che la maggior parte sono uomini e anche le persone che si avvicinano sono uomini; le donne c'erano, ma giravano lontane. Adesso devo vedere... c'è un altro festival... la maggior parte delle iniziative sono gestite da uomini... malgrado abbiamo tante personalità femminili notevoli queste non ci sono in piazza, eccetto sempre le stesse che non possono far tutto. Le altre dovrebbero essere più vicine alla popolazione. Bisognerebbe far vedere che ci sono. Perché se l'offerta è solo maschile, è difficile vedere un avvicinamento.

Speaker 1: questo secondo te come mai?

Speaker 5: secondo me per tradizione. Nelle famiglie è così, è normale pensare che le donne si avvicinano meno alla scienza, sono spesso crocerossine, cioè infermiere, medico, ma non tecnici. Invece bisognerebbe a quei punti, prima nella scuola e poi far vedere le donne che abbiamo.

Speaker 1: i famosi modelli di ruolo.

Speaker 5: sì, sono molto importanti.

Speaker 2: la parola che mi viene in mente è stereotipi. I famosi stereotipi di genere. Le donne hanno certe piste di azione, gli uomini hanno certe piste di azione. Ormai sono decenni (dalla fine degli anni 60) che in Italia, come in altre parti, le donne hanno smentito questi stereotipi, ma come diceva, Speaker 5, ci sono queste tradizioni come dei solchi di pensiero... non stai a riflettere... se effettivamente un tipo di... rapporto con la scienza può portare tua figlia, tua sorella in una direzione lontana dalla tranquillità dei ruoli di genere più tradizionali, leggi la maternità, il prendersi cura e bla bla... non si fa neanche lo sforzo. Per esempio, secondo voi, come gruppo di donne di età diversa, storie diverse etc. quali potrebbero essere le azioni concrete per smantellare questi stereotipi per niente utili alla nostra auto-espressione... perché è vero che abbiamo le Cristoforetti, i vertici del CERN a Ginevra... sono figure... non ci ripagano del vuoto che proviamo quando apriamo qualsiasi tg e vediamo questa sfilata di maschi tutti uguali... pochissime donne... pensiamo a queste riunioni europee... voi cosa proporreste?

Speaker 3: Secondo me bisogna lavorare su due canali. Il primo è maturare la consapevolezza. Perché a consapevolezza che abbiamo noi, molte ragazze non ce l'hanno, e anzi molte donne mature non ce l'hanno. È lo svelamento, far vedere quello che hanno davanti agli occhi, ma che non riescono a vedere, ma non ne riescono a vedere gli effetti. Io sono in classe a parlare di queste cose per la mia professione e quello che vedo... se chiedo se ci sono giochi diversi tra bambini e bambine è chiaro a tutti che ci siano giochi diversi. Quando li fai ragionare sul motivo per cui la bambina ha la scopetta elettrica e il bambino ha il camioncino e le fai associare ai ruoli che avranno da grande... e fai fare loro il passaggio, allora ti dicono che non ci avevano mai pensato. Quindi il primo passo è far vedere le cose e creare consapevolezza tra le persone. E il secondo passo è la presa di parola. E questo è un altro step che è difficile fare e questo io in classe lo vedo, nelle classi miste, mi trovo molto spesso a parlare con i maschi, e non le femmine, anche se le femmine avrebbero molto da dire. Però il timore di alzare la mano, di dire la loro e di essere giudicate

è molto più alto. Quindi bisogna dire che si può parlare... e anche l'esempio chi sta in classe e ti dice 'io ti ascolto' e che mi dicesse cosa pensa, che non c'è niente di sbagliato, che è importante prendere parola, se no io sparisco... è importante, e si può ragionare. E poi io ahimè sono una storica, quindi raccontare il coraggio della forza delle donne prima di noi, come se salissimo sulle spalle di altre donne prima di noi. Allora lì è più facile prendere parola.

Speaker 2: Giusto. Personalmente approvo. Su questa lotta agli stereotipi e poi la trasformazione di questa lotta in azioni.

Speaker 5: Il ruolo principale dovrebbe svolgerlo la famiglia, ma siccome la famiglia a volte per tradizioni, per cultura, ha difficoltà a proporre questa visione... dovrebbe essere la scuola, dove i bambini passano tante ore, ed è lì che i ragazzi si rendono conto che è la stessa cosa, possono avere gli stessi obiettivi e arrivarci in una stessa maniera. Questo è molto importante.

Speaker 4: mi è piaciuta molto questa idea della presa di parola. Evidentemente ha un effetto su... sul farsi sentire... ma anche sul sentire... certo molte volte ci succede quando chiediamo alle donne (io lavoro molte volte con le donne straniere), dando voce alle donne... in qualche modo hai delle aspettative, per il modo in cui sei fatto tu, e molte volte rimani stupito delle risposte che molte volte sono simili... e ti chiedi quali sono le azioni perché vorresti cambiare a tutti i costi qualcosa, come volete fare voi... io credo, a proposito della parola e della consapevolezza... credo che ci sia qualcosa che abbia a che fare con la presa di responsabilità di ciascuno... ha a che fare con questo modo individuale o collettivo di pensare il mondo. Io mi allineo al gruppo e faccio quello che gli altri che fanno oppure io ho scoperto in me qualcosa che mi può portare a fare quello che (dice) il mio sé autentico. Questo è un lavoro difficilissimo. È vero che... noi tra donne rimaniamo sorprese quando stiamo con le donne e vediamo che la loro risposta è sempre quella. E tu dici: "Ma come? Non ti svegli?" E tu ti rendi conto che non puoi neanche intervenire. Chi sei tu? Quanto ci vuole? Quali sono i tempi di ciascuno? È un discorso difficile. Presa di parola, consapevolezza, la ricerca di quella parte autentica di ciascuno credo che sia la cosa migliore del mondo. Io uso una parola ogni tanto che è "stamistic" (minuto 52.36) perché ha anche fare con la statistica e con quello che ha a che fare con il misticismo, con una parte mistica di noi stessi... siamo tutti e due... e non sappiamo fare diversamente, e non c'è una scienza che ci può insegnare a cercare il sé autentico. Diamo la parola, certo! Accettiamo che sentiremo le stesse cose per anni. Però diamo la parola.

Speaker 5: Io sono d'accordo con quello che è stato detto. Per me è fondamentale perché una giovane bambina, ragazza che vede... che vuole fare un lavoro in un campo scientifico fa molto... in tutti campi.

Speaker 1: Quindi, ti faccio una provocazione, Speaker 5, una presidente donna, secondo te può in qualche modo aiutare la causa delle donne?

Speaker 5: Non quella che lo diventerà nel giro di una settimana! (ride). Però al di là delle idee... sicuramente non farà niente per le donne. Il messaggio che arriva è che una donna ci può arrivare. Al di là di tutto. Se sei donna ce la puoi fare... l'idea è che tu ce la faccia senza magari togliere l'aborto. Poi si entra in discorsi più complessi.

Speaker 2: Lei perché ce l'ha fatta? Perché quel partito è il suo... l'ha creato lei, l'ha pensato lei... non. Ha avuto da scontrarsi con una... partitocrazia patriarcale maschile... com'è successo... mi è piaciuta l'osservazione di Speaker 3 a proposito del suo sguardo storico... nella sinistra, se andiamo a vedere l'ostracismo a cui è stata sottoposta Nilde Iotti, tutto quello che è stato detto sulla sua storia con Togliatti... penso se non vado errato che sia stata la prima presidente della Camera. Ma nondimeno noi non abbiamo mai avuto una Presidente della Rep donna... una presidente del Consiglio donna... tutto questo è in relazione a un'altra questione che si lega al tema della partecipazione e della cittadinanza che è il fascismo. Uno dei cavalli di battaglia quando discuto di violenza contro le donne, machismo, sessismo... è la nostra storia... certo, avendo studiato quello che c'è in Europa, non è che i cosiddetti paesi del democratico Nord siano privi di stereotipi, però le radici così potenti del virilismo, come lo chiama Bellassai, non le ho trovate; le ho trovate perché abbiamo avuto un ventennio fascista. A proposito della presa di consapevolezza, io penso che dovrebbe essere preso ad oggetto.

Speaker 3: Io ritengo molto importante quando si parla di stereotipi di genere quando si parla di mascolinità ai ragazzi. Fare tutta una serie di attività... noi abbiamo fatto due serate sulla mascolinità tra la fine dell'800 e l'inizio del 900 e i giorni nostri, perché anche gli uomini devono essere in discussione, guardarsi indietro e sapere che possono mettersi in discussione invece... certi periodi si sono rafforzati certi modelli non con la pistola, ma in modo più dolce... è comunque un'imposizione. Sulla Meloni, è vero quello che dice Speaker 5... vedere lì una donna sicuramente per una ragazzina o una ragazza di adesso, nel simbolico, nell'immaginario, è già, mi viene male a dirlo, è già un passo avanti, però che tipo di potere incarna? Una politica maschile e maschilista. Anche se si ritiene una donna, una madre... già così è maschilista. Lei incarna quel potere lì. Per me è molto lontana dal potere femminista. Simbolicamente potrebbe essere un passo avanti, ma potrebbe essere uno specchietto per le allodole: "Beh, adesso ce l'avete anche voi la Presidente del Consiglio". Questo non deve essere un contentino, ma deve essere un tema di discussione. Questo è un tema da affrontare, difficile per una classe delle scuole medie, ma d'altra parte potrebbe essere un tema da affrontare. È un po' come un pink-washing.

Speaker 5: una volta che decostruisci la mascolinità hai fatto tutto il lavoro. Adesso noi parliamo di Meloni, era il caso più eclatante. Oggi però le donne per arrivare ai posti più elevati devono parlare con uomo. Andrebbe decostruita la mascolinità per ogni campo.

Speaker 3: il buono è che adesso si può parlare anche di questo! Perché ci arrivate, con che linguaggio, con che parole d'ordine? Naturalmente quella riflessione lì la puoi fare in molti ambienti... quando Speaker 5 parlava di ricercatori uomini e invece di ricercatrici... è perché c'è un'idea del maschio che si deve far vedere che deve essere professionale, di successo, di carriera, che sta bene in quel ruolo e non si sente a disagio, mentre la donna deve essere spinta: non è lei che si propone, non è lei che prende parola. C'è sempre questa idea... sì, lo saprei fare, non lo so, non me la sento, mando avanti gli altri...

Speaker 5: l'errore alla donna viene perdonato molto meno rispetto ad un uomo. L'errore è sempre legato al fatto che si tratta di una donna. Quindi le donne stanno dietro le quinte.

Speaker 4: io ho pensato alla Meloni. Secondo me sarà sacrificata dagli uomini, perché chi ha lavorato con le donne sa che in questo mondo mascolinizzato, questi comportamenti producono... le donne possono auto-distruggersi... la scienza, gli studi ci dicono questo. Quando ho visto il risultato e ho visto quella sfilata di uomini, ho pensato... mizzica non avranno pietà, sono sicura e anche le donne saranno senza pietà. E questo mi fa pensare al fatto che noi non abbiamo fatto abbastanza. Avendo qui dei ragazzi che fanno gli educatori per i piccoli faccio la differenza tra l'educatore e il professore faccio la differenza nel modo in cui spiegano ai bambini... dicono le cose direttamente, senza fronzoli... forse è quello... che manca... in politica... questa possibilità di far vedere le prospettive. Io molte volte ho visto che le persone non riescono a sentire il discorso dell'altro se è diverso dal proprio, non ci stanno con la mente, non hanno la capacità. Io avevo un amico che vedeva Rai1 e non riusciva a guardare il canale di Emilio Fede... uno non può... però come fai a crearti una prospettiva diversa se guardi sempre la stessa cosa. Come fai? In Meloni c'è di più di quello che dici. Come fai a vedere la Meloni in un modo diverso se la inquadri sempre come maschilista, fascista? Sono senza pietà anche io, però credo che... l'azione della scienza potrebbe essere questo: dare alla gente la possibilità di vedere più prospettive.

Speaker 3 (deve andare via prima e saluta).

Speaker 1: volete fare delle aggiunte?

Speaker 5: con questa storia della Meloni... essere femministe vuol dire portare avanti delle idee, dare la possibilità di far andare avanti le donne... però, perché per forza? Questo è maschilista. Il fatto che lei sia riuscita in maniera difficile è un suo merito, per chi la pensa però in una certa maniera, il fatto che sia una donna non vuol dire niente, è un personaggio politico che deve adempiere dei doveri... allora se è donna va bene mi sembra tutt'altro che femminista.

Speaker 2: alla fine diventa più rassicurante avere una donna in questa posizione. Alla fine del tunnel pensi che una donna la controlli... se metti Renzi da una parte e Meloni dall'altra... Renzi per tenere sotto controllo... ci ha fatto morire per 10 anni... se dovessimo controllare la Meloni ce la mangiamo in un boccone perché è una femmina della specie. Vorrei portare all'attenzione il fatto che il nostro pianeta è in pericolo. Nell'arco di qualche di un decennio il pianeta sarà inabitabile (secondo le scienze esatte), quindi abbiamo bisogno di una rivoluzione copernicana. Chi la può fare? Io sono convinta che la possano fare solo le donne. Meloni o non Meloni, lei è la punta dell'iceberg, io penso che dovremmo unire le nostre forze per dare una spallata. Ci sono donne che non solo hanno figli, ma anche dei nipoti... le scienziate che li hanno ci dicono che il pensiero anche delle generazioni dei non ancora nati spinge sulle loro menti, diceva il grande Jonas. Facciamo. È un tema enorme, poi a quest'ora di notte diventa anche angosciante! Basta pensare alla bolla di metano: l'inquinamento prodotto anche se non ammazza la gente è dannosissima. Rispetto alla Co2 dalle 3 alle 5 volte più velenosa. Dobbiamo stare dalla parte del vivente non solo umano. Le donne dicono ci siamo. Ci siamo in Iran, in India, etc. per lottare contro questa sopraffazione.

Focus Group– gruppo sperimentale

Data: 27 ottobre 2022

Ricercatrici presenti: Speaker 1

Speaker 1: Lo scopo dell'incontro è quello di discutere dell'intervento che abbiamo fatto con la prof.ssa Zucco... è passato un po' di tempo, comunque, per sommi capi ha trattato del tema della medicina di genere e del rapporto donne e scienza. Che impressione avete avuto in relazione al tema trattato e all'intervento. Sappiamo che si è trattato di un intervento limitato, però volevo chiedervi l'impatto su di voi, se vi ha suscitato qualcosa e poi sul tipo di intervento.

Speaker 2: A me risuonavano le parole della professoressa, perché avevo letto... sì... c'è... poi anche nei libri di scuola è così, c'è sempre il maschio, solo quando si studia il corpo si studia il corpo femminile, allora c'è la figura della donna. I bambini cosa leggono? Il padre lavora, la mamma sta a casa. Secondo me tutte queste piccolezze influenzano tantissimo... ero stata ad un incontro della casa delle donne su come la pubblicità influenzi anche i gusti già dai 2 o 3 anni e infatti le pubblicità hanno come messaggio "fai la mamma", non è come quello dei bambini dove il suggerimento è "esplora", oppure "gioca". Per le femmine non ci sono questi giochi, c'è la cucina. Anche la medicina è maschilista perché gli studi sono sugli uomini, gli esperimenti sono sugli uomini. Non sono banalità!

Speaker 1: Quindi in parte ti ha stimolato una riflessione che in parte avevi già avviato.

Speaker 2: sì direi di sì.

Speaker 1: sul tipo di intervento, astruendo un po'. Nell'ultimo FG avevamo parlato di quali azioni potrebbero generare consapevolezza.

Speaker 2: andrebbe riformulato tutto: dalla pubblicità, ai libri di scuola, al fatto di fare esperimenti sempre sugli uomini. Queste cose andrebbe cambiate... in questo modo si cambierebbe il tipo di pensiero e si avrebbero più ragazze.

Speaker 1: L'intervento aveva l'obiettivo di avvicinare la scienza alle persone. Secondo te un tipo di intervento così riesce ad attivare la partecipazione?

Speaker 2: penso che un tipo di intervento come quello che abbiamo fatto attiverrebbe, potrebbe essere interessante, magari alcune cose si fanno però non le senti da qualcun altro magari non inizi un processo di riflessione o di voler cambiare le cose.

Speaker 3: secondo me è stato molto interessante. La schietta verità: sapevo tutto quello che è stato detto. Magari qualche esempio... forse sull'utero e sulla grandezza del bacino... avendo studiato molto quei temi sulla medicina di genere. L'intervento... quindi il mio giudizio non è quello di una persona che sente quelle cose per la prima volta... penso che fosse ben congegnato: gli esempi erano carini, molto attrattivi per presentare il concetto, di studi di medicina, quindi è stato molto carino sia sul passato, cosa facevano gli uomini nell'800 e cosa studiavano e fare un link con il presente, e quindi oggi... le donne muoiono d'infarto perché i sintomi sono diversi... la pillola alle donne perché quando hanno provato a

fare la sperimentazione sugli uomini nessuno sopportava il mal di testa... scusate! Poi le temperature degli uffici sono calibrate sugli uomini e non sulle donne... e da qui... ci sono dei libri carini che ti spiegano come la società sia antifemminista e guarda caso le uniche facilitazioni che ci vengono date sono sempre legate alla maternità: vuoi il parcheggio? Solo se sei incinta.

Speaker 1: Sui mezzi pubblici...

Speaker 3: solo se sei incinta! Se hai le mestruazioni, stai per svenire e hai i crampi no. Perché non sei fertile e non hai un bambino. Se fai la spesa da sola perché sei madre, l'uomo non ti aiuta... se sei incinta bene. Se no cazzi tuoi! Se no non sei rilevante. Magari hai la metà dei muscoli... ci sono delle cose che non vengono considerate. Secondo me è importante attivare una certa coscienza sociale in questo genere di interventi: i diritti negati attirano le tante belle parole accademiche. Si possono fare tanti bei discorsi però poi a seconda del pubblico che hai... ci sono delle cose che consideriamo normali perché noi ci siamo cresciuti dentro... una serie di diritti negati... penso che sia la leva giusta... il problema è che le persone non sanno che il femminismo è questo... non siamo donne che odiano gli uomini perché abbiamo le mestruazioni... siamo donne che rivendicano dei diritti che sembrano banalità, ma nella vita di tutti i giorni rendono la vita molto più difficile. Si può andare da cose più grosse... abbiamo salari più bassi... quella è una roba grossa, poi però c'è la vita di tutti i giorni.

Speaker 2: tutte le piccolezze della vita di tutti i giorni.

Speaker 3: tutte piccolezze a cui non fai caso...

Speaker 1: secondo voi una cosa del genere (un intervento del genere – quello che abbiamo fatto) può avere un impatto reale... perché io ho avuto l'impressione che malgrado abbia parlato tanti esempi etc. fosse un po' centrata su di sé.... Cercasse la vostra interazione, ma poi parlasse molto.

Speaker 3: è vero...

Speaker 1: Scusa volevo sentire prima un momento Speaker 4.

Speaker 4: l'incontro che c'è stato con la prof.ssa l'ho trovato molto stimolante, poiché avevo letto il libro di Caroline Perez su statistiche sulle donne... c'era anche la medicina di genere. Io ho trovato nei suoi dati tutto quello che aveva detto la prof., ne sono consapevole e mi ha fatto riflettere... adesso in confronto ad anni fa i cambiamenti ci sono stati... e l'attenzione alle problematiche delle donne è maggiore. Sicuramente c'è stato un progresso... bisogna vedere in confronto a prima, adesso se ne parla e prima non se ne parlava. E questo grazie al lavoro delle donne, al femminismo... anche se c'è tanto da fare. Bisogna lavorarci, non bisogna fermarci.

Io ho trovato l'intervento stimolante. Il progresso c'è stato. Prima nelle scuole non se ne parlava, ci sono tante associazioni, volendo si può partecipare, essere attivista. Di essere consapevoli dei nostri diritti e delle problematiche che ci sono. Questo grazie alle donne. Dobbiamo essere sempre propositive.

Speaker 1: volevo chiedervi un parere sulla scienziata, sullo stile. In parte vi ho influenzato dicendo che ho trovato che, sebbene volesse la vostra interazione, ha poi parlato molto. Siete dello stesso avviso?

Speaker 3: Sì, sono dello stesso avviso.

Speaker 3: dipende cosa si vuole ottenere. Il metodo dell'esperta coinvolta nell'intervento è stato più formale, accademico. Può essere. Puoi fare un intervento di quel genere, per appassionare. Però a quel punto non devi scegliere un target troppo esperto, perché gli argomenti che hai scelto non sono così nuovi, né troppo poco esperto perché non catturi le persone se non le fai partecipare. Io penso... nella formazione formale viene fatto... è carino il gioco... porta un esempio della tua vita personale come donna, poi fai un intervento, poi dopo che hai fatto questo intervento di consapevolizzazione, ti viene in mente qualcos'altro, per vedere il cambiamento. Magari uno porta un esempio grosso... abbiamo gli stipendi più bassi del 15%... oppure quando ero in ospedale... questo è un metodo carino per divulgare una cosa in maniera partecipata.

Speaker 1: Noi le avevamo detto di fare un intervento interattivo, mentre è stato più dall'alto verso il basso. Le altre? Come l'avete trovata?

Speaker 4: Sappiamo che... io avevo letto quel libro "Invisibili", perché ci sono le statistiche sulle donne... dal bagno allo stipendio...

Speaker 3: questa cosa del bagno non l'ho mai capita... perché abbiamo lo stesso numero di bagni quando loro vanno molto meno... incomprensibile... sì, lo conosco... la temperatura degli uffici...

Speaker 4: anche sulla medicina di genere, il tema del battito del cuore... l'ho trovato reale... l'ho associato a ciò che diceva la professoressa... come contenuto mi sembra stimolante.

Speaker 1: L'obiettivo è capire... suggerire se un intervento così può attivare le persone... per portare un po' di consapevolezza. Magari uno potrebbe commentare anche "No, interessante, ma nulla di che".

Speaker 4: è interessante questa azione intervento che avete fatto... per sensibilizzare le donne... non tutte le donne hanno voglia di conoscere e sensibilizzare magari che non hanno letto... non tutte hanno letto libri come questo, io perché faccio parte del gruppo intercultura della Casa delle donne e quindi su certe tematiche sono sensibile mi metto a leggere, ma non tutte hanno la possibilità e hanno la consapevolezza... ciò che fate è un buon stimolo, è da replicare e vi ringrazio.

Speaker 1: Prendere un articolo scientifico e analizzare come questa ricerca è stata fatta, quali risultati sono emersi, potrebbe essere un'azione fattibile, potrebbe essere troppo demotivante, perché c'è un linguaggio tecnico.

Speaker 2: secondo me dipende dal pubblico con cui si vuole usare questo approccio.

Speaker 1: un pubblico che non ha familiarità con il mondo della scienza, che non ha una base o un grado di istruzione elevato.

Speaker 2: potrebbe essere, però c'è anche il rischio che qualcuno si senta demotivato, e poi non riesce a seguire i tecnicismi... bisognerebbe provare, perché poi ogni persona reagisce in modo diverso, magari avendo le basi, c'è quello che partecipa attivamente. Mentre un'altra non avendo le basi non segue o non condivide.

Speaker 3: qual è l'obiettivo?

Speaker 1: mostrare come viene condotta la ricerca e come si arriva a quel risultato. Magari in una presentazione come quella della professoressa... ha raccontato degli aneddoti e magari qualche risultato di ricerca, però alla fine io non entro nel processo, per esempio per capire di più per entrare nei meandri... qualcuno potrebbe dire... magari fammi vedere come sei arrivato. Per esempio quando c'è stato tutto il dibattito sui vaccini... ci sono state tante discussioni... per esempio, perché ci vuole tanto tempo per arrivare al vaccino. Perché ci sono una serie di procedimenti e di regole che devono essere rispettate.

Speaker 3. Non è un intervento paragonabile con quello che abbiamo fatto con la professoressa. Se l'intervento è uno... a livello introduttivo meglio quello della professoressa, per chi proprio non ha idea che ci siano donne nel mondo scientifico, qualcuno può trovare interessante sapere che ci sono donne che hanno fatto una carriera scientifica, hanno fondato un'associazione... se non ne sai niente, scoprire che in realtà un mondo c'è, è già... può aprire dei mondi a tante persone. Non è vero che la scienza è degli uomini, perché ce la raccontano così. Questa è una donna, una donna normalissima, è ha fatto la scienziata. Infatti, quando la Zucco ha parlato di come ha fatto la carriera e ha fondato l'associazione era interessante... far vedere che le cose sono più accessibili... certo magari lei è il caso singolo che ha sfondato il soffitto di cristallo, e tante trovano delle limitazioni, quindi va contestualizzato. Poi, se uno fa più di un incontro, in una delle varie attività può far vedere come la scienza procede e può essere interessante... magari prendendo un argomento di rilievo come possono essere i vaccini, nel senso non andando in argomenti di nicchia. Se invece si va su qualcosa di socialmente molto sentito, molto dibattuto... allora... se lo cali... e le persone non lo sentono come particolarmente estranee. Nel caso della Zucco c'era anche una questione di tempo, quindi lei è andata un po' più a ruota libera...

Speaker 1: questo è anche un tema, cioè come lo scienziato avendo un pubblico davanti si rapporta. Speaker 4... sui benefici o sull'intervento.

Speaker 4: Sapere che ci sono le donne... la formazione è stata interessante... non saprei cosa dire... come impatto su di me... io ho usufruito della scienza, dei medici... ho usato la conoscenza scientifica per me, per la mia salute. (divaga).

Speaker 1: volevo portarla su di te, sull'impatto che ha avuto su di te l'intervento...

Speaker 4: Sì, ha avuto un impatto perché avevo già letto quel libro, sono una persona che legge tanto e che legge libri scritti dalle donne, perché sono una donna, però non escludo neanche gli uomini. A casa mi le cose si sono invertite, lui fa le cose che facevo io, mentre io

faccio il maschio della casa. Questo potere... sì, c'è il progresso... è la vita che va avanti... non vorrei anche il potere assoluto, il potere deve essere condiviso. Avevamo anche parlato del cognome da dare ai figli.

Speaker 1: Che tipo di suggerimenti possiamo dare? Pensate che vengono fatti milioni di interventi alla fine, però poi si vede che alla fine questi interventi non portano a nulla o partecipano sempre lo stesso. Non è un problema di quantità. Non sempre però arrivano. E chi partecipa ha sempre le stesse caratteristiche. Nell'ultimo FG avevamo parlato della vita quotidiana o anche vi avevo fatto l'esempio dei volti mani usati da un museo per avvicinare la scienza.

Speaker 3: perché una persona che non sa di scienza, non gliene importa nulla nella vita quotidiana, dovrebbe venire a sentire il vostro incontro? Questa è la vera domanda. A cosa può servirgli nella vita? La comunicazione deve basarsi su questo. Quindi bisogna capire quali sono gli interessi, i sub-interessi e le... finalità... perché accrescono la consapevolezza! Ma non gliene frega niente! Sì, perché ti do qualcosa per approfondire... è gente che non studia che non legge... cosa cavolo gliene frega... non fa parte del suo background, quindi è leva con cui è proposta che... purtroppo.... Se per esempio a uno interessa i soldi qual è il modo in cui io posso collegare l'intervento... a una parte di popolazione interessa il calcio... come le collego queste due cose? Come faccio a far vedere che questa area può avere una ricaduta... se continui a proporre un modello per un certo target che corrisponde agli interessi di un certo target non ci stupiamo... è lì è una questione di analisi di mercato... cosa vuole, cosa cerca, che bisogni ha? Perché potrebbe venirvi a sentire? È quasi una questione politica.

Speaker 1: Certo. Adesso non abbiamo tempo di parlarne però questa esigenza di avvicinare il pubblico e la scienza è nata in un momento storico politico particolare negli Stati Uniti dopo la II guerra mondiale perché siccome si investono tanti soldi... questi soldi sono dei cittadini allora l'obiettivo era quello di fare in modo che ci fosse una vicinanza per giustificare agli occhi dei cittadini l'importanza di investire...

Speaker 3: la stessa identica cosa andrebbe fatta per l'uso delle tasse, perché la gente non paga le tasse? Perché non comunicate come vengono spesi quei soldi e come vengono anche sprecati?

Speaker 1: le persone non collegano le tasse al fatto che possono andare alla Asl a usufruire di un servizio.

Speaker 3: e quelli che se ne rendono conto sono quelli che hanno un reddito talmente tanto alto che per loro andare dal pubblico o dal privato è uguale, vanno dal privato, vedono quanto pagano e pagano le tasse per quegli altri...

Speaker 1: tornando alla domanda che vi avevo fatto...

Speaker 2: Ci dovrei pensare!

Speaker 1: è una questione gigantesca. Se c'è qualche spunto in termini di azione ben venga. Per esempio, Speaker 4 tu parlavi dei medici...

Speaker 4: Io mi sono trovata ad essere seguita... io sono in follow-up... se non ci fosse stata la scienza non sarei viva. Ho usato i medici... sia pubblico che privato... ho sfruttato perché è di diritto... tuttora sono in vita grazie al loro lavoro... ho usato il pubblico e il privato...

Speaker 1: Ecco, ma in questa relazione medico-paziente come vedi il dialogo tra le due parti?

Speaker 4: La struttura sanitaria l'ho trovata eccellente in Italia, c'è una relazione gerarchica, perché io non ho la conoscenza che ha il medico... ciò che mi diceva... dalle visite successive... sono sempre stata ... ho... avuto anche io da parte mia... mi hanno curato e io mi sono fatta curare, ho fatto ciò che mi dicevano...

Speaker 1: ma in termini di comunicazione, il medico con te come si relazionava?

Speaker 4: dipende dal medico, ci sono medici umani, medici... la maggior parte... li ho trovati... ho delle esperienze positive nei confronti dei medici. Io vorrei che uscisse da questo incontro il positivo che ha fatto la scienza per me. Io sono viva grazie a questo.

Speaker 1: Questo è importante. Nel tuo caso avevi un problema specifico... qui ovviamente la discussione è quando uno non ha bisogno e vuole relazionarsi con la scienza come questo rapporto si declina.

Speaker 3: io ho un'opinione diversa.

Speaker 1: Sì, mi ricordavo dall'ultimo FG che tu eri stata più critica.

Speaker 3: Sì... io so molte cose di medicina... allora, non ho avuto una malattia complessa come quella di Speaker 4, ma ho delle sindromi e delle malattie fin dalla giovane età e sono convinta che se non avessi letto, chiesto più pareri etc. non fidandomi... quando mi pongo di fronte a un medico gli faccio capire che qualcosa so, perché mi sono resa conto che si ti poni come uno che non sa e vuole essere guidato il risultato è sempre molto pessimo. Ma io l'ho visto con il mio ragazzo che ha un problema in questo momento... è andato da solo a farsi la visita: gli hanno diagnosticato delle cisti quando ha delle fistole, quindi molto più gravi, per arrivare sul tavolo operatorio e sentirsi dire che non erano cisti erano fistole, perdendo 8 mesi, con svariate infezioni e sofferenze. Io gli dico: fammi venire con te alle visite. A me questo non succede più. Io non mollo. Se non mi torna, insisto. Se tutto quello che mi è stato detto... poi ci sono delle discordanze, perché io soffro e si sa che le cisti non fanno soffrire... vuol dire che qualcosa non torna. E una persona che ha un carattere diverso arriva sul tavolo e scopre che non sono cisti, ma sono fistole. Ho avuto anche io dei dottori...

Speaker 1: qui è competenza scientifica.

Speaker 3: è opinione, hanno tutti opinioni diverse, però non ti spiegano bene. Io non faccio niente se non faccio almeno due consulti. Però questi sono soldi. Chi non può andare da tre specialisti come fa? (divaga sul suo problema fisico).

Speaker 2: se lo può permettere chi ha soldi.

Speaker 5: eccomi, scusate. Ho avuto un problema tecnico.

Speaker 1: volevo chiederti un parere sull'intervento. Ha avuto qualche impatto? Che impressione hai avuto?

Speaker 5: l'intervento era molto interessante. Mi aveva coinvolta.

Speaker 1: ti è quindi ti è rimasta un'impressione...

Speaker 5: molto positiva.

Speaker 1: secondo te, in termini di coinvolgimento può portare qualcosa?

Speaker 5: perché venga ascoltato di più è importante che venga portato al concreto, agli esempi, a delle situazioni reali, quindi uno si sente più coinvolto. Bisogna coinvolgere su situazioni reali, stare sull'astratto... dipende da ognuno, dal tipo di esperienza, dal livello intellettuale.

Speaker 1: infatti è questo il tema. L'obiettivo è evitare che siano sempre le stesse persone. Bianco, uomo, il livello culturale alto... magari una persona con una base meno solida... si generano delle resistenze...

Speaker 5: anche perché gli accademici di solito usano terminologie e modalità di espressione che è più faticoso seguire... non è tanto la laurea, ma che tipo di contesto vivi, riesci a capire meglio, per cui... se la cosa se ci rivolgiamo a tutte bisogna approcciarsi alle cose in modo più semplice e meno accademico. Per quello lei mi era piaciuta, era molto chiara, non era lì statica.

Speaker 1: forse l'interazione non è stata molta. Immagina un pubblico che non è tanto avvezzo... voi siete anche persone interessate (la Casa delle donne etc.), però per delle persone che non hanno un bagaglio potrebbe inibire?

Speaker 5: non tantissimo, ma abbastanza. Bisogna sempre fare esempi perché così uno può capire bene. Non era distante dal pubblico. Chiaro che è una professionista.

Speaker 1: Da qui a usare i risultati della scienza, a usarli quando uno discute nei media...

Speaker 5: il passaggio è meno diretto, sì.

Speaker 1: L'obiettivo è suggerire azioni...

Speaker 5: ma come mai parlavate di medici?

Speaker 1: perché io ho chiesto ad Speaker 4 della comunicazione medico-paziente, visto che lei parlava dei problemi di salute.

Speaker 5: il medico si mette su un piedistallo, usa delle terminologie incomprensibili, però lui deve farti capire. Deve scendere dal piedistallo e questo in linea di massima non succede. Il medico si allontana sempre di più dal paziente, dalla sua anima e dalla sua psiche. Io avevo un problema di psoriasi e dopo vari tentativi sono andata da una dottoressa bravissima che ha avuto la capacità anche di creare un rapporto, di chiedermi com'era la mia vita etc. e mi ha subito diagnosticato psoriasi. Mi è passato tutto nel giro di due mesi. Mi ha dato un senso di sicurezza. Alcuni sono terrificanti. (divaga) Lei mi ha curato con l'omeopatia.

Speaker 1: devi avvicinarti alla vita delle persone.

Speaker 5: Il medico di base vogliamo parlarne? Non è vendere camicie. Significa lavorare sul corpo, sulla salute... è singolare, è il dio denaro.

Speaker 1: c'è questo scollamento... con i vaccini poteva essere un'occasione perché si parlasse, perché si usassero i dati per discutere, dall'altro il modo in cui è stato comunicato...

Speaker 5: ecco, parliamone, perché io sì mi sono vaccinata però ho dovuto avere l'amica medica che mi ha spiegato. Con i media non va bene...poi la gente ha paura... siccome vede il medico come uno che sa... lei mi spieghi bene! Parli come me! La gente ha paura, per cui se uno chiede troppo, magari il medico si innervosisce. Probabilmente la scienza si vede come irraggiungibile. L'avvicinamento è difficile...

Speaker 1: soprattutto chi non ha studiato tanto oppure...

Speaker 5: sì, ma è il popolo, ma c'è tanta gente che è così. Non è un caso che abbiamo votato come abbiamo votato. Questo è dovuto alla poca partecipazione e ignoranza.

Speaker 1: ultima domanda, tu che fai parte della Casa delle donne, sul tema delle azioni che si potrebbero fare.

Speaker 5: secondo me, bisognerebbe fare informazione. Tanti momenti di informazione. Noi stavamo pensando di fare come Casa delle donne... una cosa sulla menopausa, perché può iniziare a 40 anni, oppure può capitare a 50 anni e tutto quello che può capitare e a livello fisico, e a livello psichico è enorme. Noi pensavamo di parlare anche di questo. È venuto fuori questo dal direttivo. Può durare tanti anni. Quando è successo a me non capivo. E poi si pensava con le ragazze che fanno parte delle comunità lavorare sul tema dell'igiene. Informare con degli scambi.

Speaker 1: tu partiresti dal corpo...

Speaker 5: la colleghi alla psiche... anche perché ti fanno vedere tutte questi giovani o queste vecchie che non invecchiano mai, rifatte e poi è un disastro poi quando invecchiano! Invece c'è altro e puoi sentirti anche bene.

Speaker 1: questo riguarda tutte.

Speaker 5: ci passiamo tutte. E senza spaventare. E poi ci sono paure. È l'unica strada.