

## Complaint by Ms K about *Sickness and Lies*

Type of case	Fairness and Privacy
Outcome	Not Upheld
Service	BBC iPlayer
Date & time	Accessed by the complainant on or around 5 August 2021
Category	Fairness
Summary	Ofcom has not upheld this complaint about unjust or unfair treatment in the programme.

### Case summary

The programme reported on the chronic illness community and “*chronic illness influencers*” on social media, and the groups targeting some of these influencers and accusing them of faking their illnesses. The programme included an interview with the complainant, Ms K. Ms K complained that she was treated unfairly in the programme because the nature of the programme and her expected contribution to it had been misrepresented to her by the programme makers. She said that had she known, she would not have given her informed consent to take part in the programme. Ms K also complained that the interview was edited unfairly in the programme.

Ofcom found that the programme makers had obtained Ms K’s informed consent to contribute to the programme, and that the programme did not change substantially so as to invalidate her informed consent. We also considered that the interview was not edited in such a way so as to cause unfairness to Ms K.

### Programme summary

The documentary programme *Sickness and Lies* was made available on the BBC’s On Demand Programme Service (“ODPS”), BBC iPlayer, on 5 August 2021 and was accessed through this service by the complainant on or around the same date. The programme focused on “*chronic illness influencers*” on social media and the groups accusing some influencers of faking their illnesses.

The presenter, Ms Octavia Woodward, introduced the programme:

*“A new kind of influencer has been born, the chronic illness influencer, and some are attracting huge followings...Celebrities have started to open up about their own chronic illnesses...But, with success has come suspicion. Huge online communities have formed of people determined to prove that some chronic illness influencers are faking it for money, fame and attention, and it can get extreme”.*

The programme included screenshots of comments posted on ‘Reddit’, an online forum, by people accusing influencers of faking illness on social media. Accompanying this, Ms K, in voiceover, said:

*“They [the forum users] shared my address, I started to become really hypervigilant that people would just be outside my flat and [footage of Ms K speaking to camera was then shown as she continued] kept my blind shut and my window shut”.*

The presenter continued: *“How far are the doubters prepared to go for proof, and how far are the influencers prepared to go to provide it?”*, before going on to say:

*“Back in February last year a friend sent me a link to a Reddit group. ‘People are accusing chronically ill people of faking it’, he said. I’ve spent most of last year investigating the chronically ill community. When I first entered this world, I got it. It can be hostile out there if you’re disabled or have a chronic illness that disables you. It often feels like you have to fit in with other people’s idea of disability. [Ms K] knows the feeling”.*

A photograph of Ms K taken from her Instagram account was shown. The programme went on to include footage of her as she was interviewed by the presenter, via video call:

Presenter: *“Would you call yourself an influencer?”*

Ms K: *I guess it’s the only way that I can really work and, sort of, network and generate people to have dialogues with, so, yeah”.*

The presenter then explained that *“millions around the world live with chronic illness, and that figure is growing fast, especially among young women...getting a diagnosis can take years”*. The footage of the interview with Ms K continued, during which a number of posts taken from her social media accounts, including photographs of her, were also shown:

Ms K: *“From the age of about ten or eleven, I started to experience chronic pain in my back and my legs, it sort of just spiralled as I got older. I was originally training to be a nurse, I ended up having to stop doing that course, so I ended up, kind of, finding a community online of other chronically ill people. That was really, really comforting and helpful”.*

The presenter explained that in *“just a few years”* the chronic illness community had *“swelled”*, and that *“people from all walks of life have found solidarity as they shine a light on invisible illnesses”*. The programme then focussed on *“Alex”*, who spoke about how she had received support and advice from

the chronic illness community. Further footage of the interview with Ms K was shown together with examples of the social media posts she referenced shown on screen:

Ms K: *"But, as I started to get answers, there was this really weird culture of people who would try and list off, kind of, how much worse they were, and you get people who list every single diagnosis or sometimes even their medications, or like, people who compete with 'look how high my heart rate got today' or 'how low my blood pressure got'. Which I used to do, annoyingly".*

The presenter said that she had had some of the procedures that some influencers posted about, and that *"some things just don't add up...I found other people were sharing similar doubts"*. She added that there was a Reddit group called *"illness fakers"* where *"nearly eighty thousand people act as judge and jury on who is really ill, and who is not...they create timelines, scouring influencer's social media for inconsistencies"*. An image of Ms K's Instagram account was shown before the programme included further footage of Ms K's interview. As Ms K spoke, images of posts accusing her of faking her illness that had been posted on the forums were also shown.

Ms K: *"I remember one of my friends saying that they have some group chats and my name had come up, and I remember going on to try and find whatever had been said and seeing the absolute torrent of information they were sharing and the thousands of people on there, mapping my family tree and looking way beyond just the things that they're claiming to seek out, which is illness faking, and you begin to question every single thing you've said.*

*I remember actually being prescribed a medication that could really improve my day-to-day life, and I put off taking that medication for about three or four months. I looked at everything that had been said, and I really, really believed maybe this condition isn't the case, maybe they are right, maybe there is nothing wrong".*

The programme went on to discuss the online forums and the people who had set them up, including an interview with a woman, "Amy", introduced as one of the *"original members"*, who was asked whether she regretted starting the group and whether she felt that the *"illness fakers"* forum had contributed to *"quite a big problem in the disability community of people not being understood"*. Amy said:

*"I don't know if I'd call it a failed experiment or...I think sometimes we forgot we were dealing with human beings...When it comes down to it, I feel like people were posted who I don't believe were faking. We're not saying women lie, because most of us ourselves were women with chronic illnesses".*

The interview ended and the presenter said: *"Things are getting so personal because for people like Amy, it is personal. As I investigated, I realised many of the accusers are chronically ill themselves. They're furious at the idea that people are faking illnesses, their illnesses, for fame, attention and*

money". The programme then briefly discussed the case of Ms Belle Gibson, a "wellness influencer" who was "outed as a faker" who had claimed to have terminal brain cancer, before moving on to focus on the concept of "Munchausen's by Internet" (i.e. a pattern of behaviour in which a person seeks attention and sympathy by feigning or exaggerating symptoms of illness in online venues)<sup>1</sup>.

The programme included an interview with Dr Mark Feldman, who was introduced as a "leading expert...who defined a new category of Munchausen Syndrome". Dr Feldman stated that Munchausen's by Internet was "when a person goes online and either feigns or exaggerates symptoms of illness", and explained that "some of them, the posers, are genuinely ill or at least have health concerns...they go online and find this immensely supportive and caring group of people...so even when the [illness] is ruled out, they don't want to lose touch with all of these supportive people". The interview with Dr Feldman ended and the presenter said she was "still struggling with the idea that people posting about chronic illness should ever be disbelieved". The programme then focussed on the experiences of a woman, "Kaitlyn", who had contacted Dr Feldman because she "became convinced" her sister was faking an illness.

The programme continued, and the presenter said: "A small number of people do fake illnesses, but accusers are going to extreme lengths trying to extract confessions from them. And what about the many people who are wrongly targeted?". Further footage from Ms K's interview, as well as images of her Instagram account, was included. She said:

*"They moved it over to a forum that is completely unregulated, and they shared my address, and it was so terrifying. My biggest fear was someone could just show up. I know that in the past other people have had real life engagement with the people harassing them. I kept my blind shut and my window shut. I was just on edge the whole time that someone was going to be there, and someone was going to come, to the point of paranoia where I ended up getting incredibly mentally unwell and eventually hospitalised for it for quite a significant amount of time".*

The programme then included a brief interview with Alex in which she spoke about her experiences of being targeted by the Illness Fakers forum, and then went on to focus on the story of Ms Jaquie Beckwith, an influencer who "became a favourite subject of the Illness Fakers investigators", and who the programme reported had later "died from a complication with her feeding tube". This was followed by an interview with the Illness Fakers forum "moderator", who the presenter said had "experienced the betrayal of seeing her own illness mimicked in real life by a friend", the moderator said:

*"We had high profile influencers and the copycats, their entourage of people who buy the same things, same wheelchair...the same hospital bed...they want the same service dog. They claim the same illness, it's like seeing clones".*

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<sup>1</sup> [Munchausen By Internet](#), Dr. Marc Feldman.

The presenter asked the moderator: *“But do you not see how these kinds of conversations might be doing more damage than good?”*, to which the moderator responded:

*“There will always be people who come to the [forum] for less-than-ideal reasons, and for us it is a constant effort to mitigate the impact of those toxic people...Jaquie’s death became a seminal shift...some degree of dark humour can be therapeutic for people, but there is a line, and needs to not be crossed, and it’s got to the point as the sub [i.e. the forum] has grown so much, we need help”.*

The programme then included an interview with a Ms Anoushka Anderson, a *“forensic psychology researcher specialising in medical deception”*, who explained that *“at the end of the day...you cannot [be sure that someone is faking]”* and spoke about how, regardless of whether people are faking it or not, online harassment had become *“more aggressive”* and that this had driven influencers to take increasingly extreme methods to prove they’re ill. The presenter stated that she had been following some of the young women referred to by Ms Anderson, and went on to say:

*“Sometimes they contradict themselves, others have even admitted they’ve been exaggerating. But without access to their private medical records, there’s no way of knowing what’s really going on with them...While I was making this film, another chronic illness YouTuber dies...she had two feeding tubes, and the way she used them seemed strange. Does that mean she was faking her illness? Of course, it doesn’t. The truth is far more complicated”.*

Later in the programme, the presenter said:

*“[Ms K] is still in the process of recovery for her mental health, but she’s gained a new perspective on chronic illness influencing”.*

Footage of Ms K’s interview was then included, she said:

*“I think most people I know who have first got diagnosed with conditions that they’ve been trying to find answers to for years, they go through this period of really throwing themselves into the, sort of, advocacy, but what happens is they get so far down the rabbit hole that their identity sort of dissolves into only being unwell. I’ve seen with so many people I would have called friends, or people who I’ve got to know online, where they kind of got sucked into that and haven’t come out the other side. I can hide away from the internet and I can not have social media and disappear, but, at the end of the day, I’ve just shifted the way I use my account to be a lot more rounded and not just fixated on health”.*

The presenter concluded the programme:

*“The truth is nobody, not even experts, can really know what’s going on with someone just by looking at their social media, and nobody*

*should be putting their life at risk trying to prove themselves to others.  
Alex put it perfectly when they told me: 'If you don't like someone,  
instead of attacking their person, their entire being, just scroll away'.*

The programme ended without further footage of or reference to Ms K.

## **Summary of the complaint and BBC's response**

### **Complaint**

Ms K complained that she was treated unjustly or unfairly in the programme because:

- a) The programme makers had misrepresented the nature of the programme and her expected contribution to it. Ms K said that she would not have participated in a documentary that “focused on fakers”.

Ms K explained that she was told that the programme would focus on the harms of the forums which claimed people were faking their chronic illnesses. However, she said that the balance of the programme “fell towards illness fakers and disbelieving those with disabilities”. Ms K said that up until the release of the programme, she was assured by the programme makers that her “concerns were not justified” as the programme would focus “solely on the dangers of the forums and those who are falsely harassed and accused [of faking illness]”. However, she said that instead, the programme had “focused on cases of people ‘faking’ and painted the forums in a light of sympathy to the point of justification”.

Ms K also said that the working title of the programme was “You Don’t Look Ill”, which was “totally opposite to the final title [i.e. *Sickness and Lies*]” which she said she had only discovered on its release. She added that she was not made aware of any significant changes in the programme, such as the fact that the entire premise [of the programme] had been flipped”. Ms K said that all dealings with the programme makers were verbal or over “Instagram chat”, and that when she was given a release form to sign, she was given it when she was “leaving in a taxi” without it being explained to her. She said that she had felt “pressured [into signing] something that I had no time to go through”. Ms K said that the BBC did not take “the steps and precautions it was meant to with regards to working with a vulnerable person [Ms K]”.

- b) The programme misrepresented Ms K’s view and the “facts from [her] lived experience”. In particular, Ms K said that:
  - i) The programme referred to her as a “*chronic illness influencer*”. Ms K said that she did not refer to herself as being chronically ill, however, her saying the word “disabled” was “cut out from the documentary”. Ms K said that this “felt very us versus them, with [the presenter] being ‘real’ disabled and the other people in the documentary being ‘fake’ disabled. Ms K said that the programme used her as a “poster girl whilst they spoke about fakers”.
  - ii) The way Ms K’s contribution was edited removed “huge amounts of context” and made it appear that she was “perpetuating ableism”. Ms K said that when she spoke about “people going down the rabbit hole, and illness becoming their identity” she had gone on to say, “how

could that not be the case as being ill is all consuming”. She said that “her counter and/or balancing statements had been removed”.

### BBC’s response

- a) The BBC said that it did not accept that the nature of the programme was misrepresented to Ms K, or that the way in which her participation was managed resulted in any unfairness to her. It said that the programme was described accurately and in sufficient detail to allow Ms K to make an informed decision as to whether she wished to take part.

### *Nature of the programme and consent*

The BBC said that Ms K had initially contacted the programme makers having heard about the programme. The BBC provided Ofcom with screenshots of correspondence between Ms K and the programme makers, conducted via Instagram, which it said showed that Ms K’s concerns had been addressed. The BBC said that Ms K was also told that:

- contributors were not permitted to control the editing process.
- the perspective of the “Illness Fakers” forums would be included for balance, but it would be made clear they were harmful.
- forum users would be expressing their view.
- the programme would look at why a small number of people exaggerated/faked illness.

The BBC said that this was an accurate account of the programme and that Ms K had responded to the message with a “heart emoji”.

The BBC said that, in line with best practice on dealing with vulnerable contributors, on 1 July 2020 the programme makers conducted a phone call with Ms K. It said that the programme makers recalled discussing what was in the programme, including the interview with a woman whose sister had faked illnesses, and that Ms K was broadly supportive of the idea the programme would deal compassionately with the small number of people who do fake illnesses. The BBC said that it believed Ms K understood that, in addition to looking at the harms connected with the “Illness Fakers” forums, the programme would cover some unhealthy dynamics within the chronic illness community, and that her contribution to the programme considered this. It said that this was also reflected in the unaired sections of Ms K’s interview, the transcript of which it said showed Ms K discussed how her experience of online communities of chronically ill people had become “*sort of toxic and a bit competitive*” and how as a result she had stepped away. It said that Ms K spoke about how her approach to social media and illness had become unhealthy and about how and why people tended to exaggerate symptoms on social media. The BBC said that the nature of the programme was also discussed during the filming. It said that the programme makers recalled that they had a conversation with Ms K about the programme which included sharing the details of the contributors involved at that point. It said that Ms K was made aware that an expert in Munchausen’s by Internet and moderators of the “Illness Fakers” board would be in the programme, as well as discussion of the case of Ms Beckwith.

The BBC said that it was regrettable that Ms K now felt disappointed by the programme and regretted her involvement, and that her response to it was initially more positive. The BBC provided Ofcom with screenshots of an Instagram post by Ms K, which it said showed that



although she appeared to be unhappy with the way it had been covered in BBC News social media output, she believed “the documentary itself is fine” and expressed the hope it would have a positive effect [on the dangers and harms of the online forums]. The BBC also referred to screenshots it provided of correspondence between Ms K and the programme’s presenter, Ms Woodward, the initial messages of which it said showed Ms K expressing thanks for having her on the programme and that she was “really grateful”. It said that Ms K had also asked to be tagged in any BBC social media output around the programme. The BBC said, however, that in the early hours of the following morning Ms K had said a “witch hunt” had started following the presenter’s appearance on BBC News and expressed a desire to withdraw her consent.

The BBC said that, in her complaint to Ofcom, Ms K said that the programme had focused on cases of people faking and painted the forums “in a light of sympathy to the point of justification”. It said that it did not accept this characterisation of the programme, which made the negative consequences of the forums and harms caused by individuals choosing to harass others entirely clear. It said that the programme sought to explore why some communities were “*determined to prove that some chronic illness influencers are faking it*” and how this had led to extreme actions which left chronically ill people afraid for their safety and required them to prove their illness, making their conditions worse in the process. The BBC said that the programme described communities of people who considered themselves “*judge and jury on who is really ill, and who is not*”, and that interviews with forum moderators challenged them on the group and its impact and held them accountable for the consequences. It added that Ms K had given her own account of her experience of being harassed in this manner, and that viewers would have been in no doubt as to the negative consequences of these forums. The BBC said that the programme acknowledged that a small number of people fake illnesses, but was not unduly condemnatory, acknowledging many had experienced genuine illness but had grown to need the support they received. It said that the presenter also noted that she struggled with the idea that people posting about chronic illness should ever be disbelieved.

The BBC said that it was unfortunate that Ms K felt she was not allowed to consider the release form she signed, but that those involved were adamant that no pressure whatsoever was put on her to sign and that there was no rush. It said that Ms K was told at the beginning of the interview that she would need to sign a consent form and that this gave the BBC the right to use the interview as it saw fit. It said that the programme makers recalled that, following the interview, Ms K had sufficient time to review the consent form, and that it was not clear what within the form would have caused Ms K to take a different view of her participation, had she taken more time to review it. The BBC said that, given Ms K had been interviewed at some length and had not raised any objections to any part of the discussion, it believed that the consent Ms K gave was properly informed and that she understood what her contribution involved.

#### *Programme title*

The BBC said that it did not accept that the title of the programme demonstrated that the premise of it was “flipped”, and that programmes frequently use working titles. It said that it did not agree that the current title had the meaning that Ms K assigned to it in her complaint, and that the “Lies” in “*Sickness and Lies*” referred to those told by people who claim others are faking illness as well as lies about health conditions.



### *Due care*

The BBC said that it strongly contested the complainant's assertion that it failed to exercise due care when working with a vulnerable contributor, and that the extensive correspondence between Ms K and the programme makers before and after the programme did not support this aspect of the complaint. The BBC provided Ofcom with a copy of its "Psychological Risk Assessment" of Ms K, which it said it had carried out to ensure Ms K was capable of participating and showed that the programme and potential consequences of it were discussed at length with the complainant, and that due thought was given to her involvement. It said that, throughout the production process and following broadcast, the programme makers had remained engaged with Ms K and answered her questions. It said that a senior editorial figure was involved in ensuring Ms K was offered the professional help recommended by industry specialists.

- b)i) The BBC said that Ms K was entitled to a view on how she would prefer to be described, but that it did not, however, agree that describing her in these terms was unfair to her. It said that both Ms K's Instagram and Twitter accounts were "The ChronicConic", which suggested that Ms K was not uncomfortable with identifying with the term "chronic". The BBC said that her unedited interview also showed that Ms K considered that, despite her reservations about the term, it was one she accepted. It said that, while the unedited interview included Ms K referring to her disability, it also included her discussing finding support from "*other chronically ill people*". The BBC said that there was no suggestion that she was not disabled, or that she was herself exaggerating or faking a health condition.
- b)ii) The BBC said that it was in the nature of documentaries that contributions were edited, and that it did not agree that the edits outlined in the complaint had the effect of changing the meaning of Ms K's comments. It said that it was a matter of fact that Ms K said the words assigned to her, including her observation on the point at which illness became someone's identity. The BBC said that the transcript of Ms K's unedited interview did not include the language described by Ms K in her complaint to Ofcom and that, in any case, a comment to the effect that she understood this dynamic (i.e. between illness and identity) did not show the comment as aired was misleadingly edited. The BBC said that it did not believe that fairness would require editing a contribution so as to include an interviewee's counter arguments against their own comments.

### **Preliminary View**

Ofcom prepared a Preliminary View that Ms K's complaint should not be upheld. Both parties were given the opportunity to make representations on the Preliminary View but only the complainant chose to do so. The representations, insofar as they are relevant to the complaint entertained and considered by Ofcom, are summarised below.

### **Complainant's representations**

In relation to head a), Ms K said that she did not agree with Ofcom's Preliminary View that she had given her informed consent to participate in the programme, or with the "version of events" put forward by the BBC in its response to her complaint. Ms K said that the programme as made available on iPlayer had taken "a different avenue" to that discussed prior to her participation, and that by misleading her about the nature of the programme the BBC had put Ms K in "direct harm".

### *Nature of the programme and consent*

Ms K said that the initial conversations about her participation in the programme took place while she was in hospital care. Ms K said that the material that surrounded her contribution to the programme was “a completely different direction to what was agreed”, and that she had understood from conversations with the programme maker that the programme would focus on herself and “Alex”, and that there would be “one person from the forum”. Ms K said that she did not know that there would be illness fakers participating in the programme, and that this was not something that she herself wanted to participate in.

Ms K said that, prior to filming, she had told the programme makers that she would not participate in anything that “draws people towards the forums that bully people”, and that the programme makers had reiterated to her that viewers would be “disgusted” by the forums and that there would be “no traffic driven to the forums by putting the information out there”. Ms K said that she had understood that, while there would be an element of neutrality, the programme would focus on the “toxic culture” of the online forums. She said that she had also understood that the nature and content of the online forums would be alluded to in the programme. Ms K said that she had “checked in” with the programme makers “continuously” to check that her understanding was correct and that the programme was “following the agreed path”. She said that the night before she was due to film her interview, she had expressed concerns about the “direction” of the programme and “requested a guarantee” from the programme makers, who subsequently reassured her that the programme would “show how dangerous the forums are”, and that it was on this basis that she agreed to carry on with her participation. Ms K said that the information about the forums included in the programme, however, was far more detailed and shown unredacted, and that the programme “put stalkers on a pedestal” and made them “seem like saviour internet warriors”. Ms K said that she would not have been comfortable participating in such a programme.

Ms K said that, shortly before the programme was made available, she had received a telephone call from the programme maker, who had informed her that “it [i.e., the programme] had all changed” but that it was no longer possible for Ms K to withdraw her consent as she had signed the release form. Ms K said that the BBC was aware that the way the programme had changed (i.e., by including detailed information about the online forums and featuring illness fakers) meant that Ms K would be “under the magnifying glass” and would be “harassed”, but that the programme makers had continued to assure her that it would not exacerbate anything more than was to be expected. Ms K said that, after the programme was released, she had been hospitalised as a result of “the sudden barrage of harassment”, and that this could have been avoided by the BBC not providing information for people to be able to seek out the forums.

Ms K also reiterated her complaint that she had been given the release form as she was “leaving in a taxi” after filming, without it being explained to her, and that she had not had enough time to consider the form properly.

### *Due Care*

Ms K did not agree with the BBC’s submissions regarding due care and the steps it had taken and said that the BBC had “back-dated and doctored what they had done”. Ms K said that the BBC did not offer for her to see a psychologist after the programme had been released, and that she had had to request this herself. Ms K said that, during a subsequent telephone call, she was told by the psychologist that

“he could not help her as it was not his field” and that he had been “grabbed” by someone and asked to call Ms K, and that “someone should have called prior [to the programme being released]”. Ms K said that the BBC had not done any of the things referred to in their submissions “off their own accord” and that she had not been offered any support and had “had to fight for the support [I] did eventually get”.

In relation to head b), Ms K reiterated her complaint that the programme had been edited in such a way that had misrepresented her view. Ms K said that the programme had cut any use of the word disabled and that this had the effect of presenting the presenter as the disabled person and Ms K as not. She added that the presenter had taken a “neutral stance” throughout the interview with her, which was “different to the tone taken in the rest of the programme”. She said that this subtle editing had decontextualised everything that she was saying to give a very different message. Ms K said that she had very clearly said that she worked in disability advocacy, not as an influencer, and that that opening statement changed what she was saying.

## Decision

Ofcom’s statutory duties include the application, in the case of all television and radio services, of standards which provide adequate protection to members of the public and all other persons from unjust or unfair treatment in programmes in such services.

In carrying out its duties, Ofcom has regard to the need to secure that the application of these standards is in the manner that best guarantees an appropriate level of freedom of expression. Ofcom is also obliged to have regard, in all cases, to the principles under which regulatory activities should be transparent, accountable, proportionate and consistent and targeted only at cases in which action is needed.

In reaching its decision, Ofcom carefully considered all the relevant material provided by both parties. This included a recording of the programme and transcript of it, and both parties’ written submissions, including the complainant’s representations on the Preliminary View. After careful consideration, however, we considered that the points raised did not materially affect the outcome of Ofcom’s Preliminary View to not uphold this complaint.

When considering complaints of unjust or unfair treatment, Ofcom has regard to whether the broadcaster’s actions ensured that the programme avoided unjust or unfair treatment of individuals and organisations, as set out in Rule 7.1 of Ofcom’s Broadcasting Code (“the Code”)<sup>2</sup>. In addition to this rule, Section Seven (Fairness) of the Code contains “practices to be followed” by broadcasters when dealing with individuals or organisations participating in, or otherwise directly affected by, programmes, or in the making of programmes. Following these practices will not necessarily avoid a breach of Rule 7.1 and failure to follow these practices will only constitute a breach where it results in unfairness to an individual or organisation in the programme.

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<sup>2</sup> ([The Ofcom Broadcasting Code](#)) These include new provisions regarding the protection of participants that have recently been added to Section Seven of the Code. However, these provisions apply only to programmes made on or after 5 April 2021 and are not applicable in the complaint in this case as production began prior to this date.

- a) Ofcom considered Ms K's complaint that the programme makers had misrepresented the nature of the programme and her contribution to it, and that she would not have participated in a documentary that "focused on fakers". In doing so, we had particular regard to the following Code Practices:

Practice 7.2 states:

"Broadcasters and programme makers should normally be fair in their dealings with potential contributors to programmes unless, exceptionally, it is justified to do otherwise".

Practice 7.3 states:

"Where a person is invited to make a contribution to a programme...they should normally, at an appropriate stage:

- be told the nature and purpose of the programme, what the programme is about and be given a clear explanation of why they were asked to contribute...;
- be told what kind of contribution they are expected to make...;
- be informed about the areas of questioning and, wherever possible, the nature of other likely contributions;
- be made aware of any significant changes to the programme as it develops which might reasonably affect their original consent to participate, and which might cause material unfairness;
- be told the nature of their contractual rights and obligations and those of the programme maker and broadcaster in relation to their contribution;
- be given clear information, if offered an opportunity to preview the programme, about whether they will be able to effect any changes to it.

...

Taking these measures is likely to result in the consent that is given being 'informed consent'...".

We first examined the information that was made available to Ms K by the programme makers with regards to the nature and likely content of the programme, and Ms K's likely contribution, in advance of her agreeing to participate. In doing so, we took account of both parties' submissions (set out in detail in the "Summary of the complaint and BBC's response" section above), and the complainant's representations on Ofcom's Preliminary View. We also considered whether there were any significant changes to the nature and content of the programme prior to it being made available on BBC iPlayer which may have altered Ms K's willingness to be involved and may have invalidated the consent she had given earlier in the programme making process.

From the complaint, reiterated by the complainant in her representations on the Preliminary View, Ofcom understood that Ms K believed that she was not told that the focus of the programme would be on cases of people "faking [illness]" and/or that the programme would present the forums which claimed people were faking their chronic illnesses in a sympathetic light

“to the point of justification” and that, had she been aware of this, she would not have consented to taking part. Ms K said that she had understood from her correspondence with the programme makers that the programme would focus on the harms of the forums which claimed people were faking their chronic illnesses and “solely on the dangers of the forums and those who are falsely harassed and accused”.

Ofcom took into account that, in Instagram messages sent to the programme makers on 11 November 2020, Ms K expressed concern about the way the forums would be framed in the programme, in particular that “depending on how it’s framed it can become neutral”, which Ms K said that she had “no intention of being complicit in”. We considered that, in the Instagram messages sent to Ms K by the programme makers on 11 November 2020 by way of response, it said that, in relation to the forums, the programme had to be “balanced and give them (i.e., the forum moderators and users) their say”, but that there would be “no balance about how harmful the forums are”. It was also stated that the presenter’s “journey” was going to “get quite quickly to the view that a) they do no good, only harm and b) the idea a load of people online could determine if someone is ‘really’ ill is just not possible”. Ms K was also informed that the “aim” was that her contribution to the programme would “firmly set [Ms K] in the real world” as a “real rounded” individual, and the moderators and founders of the forums in a “hostile online world”. We further took into account the Instagram message sent by Ms K to the programme makers on 21 June 2021, in which she asked whether the programme conveyed her in a good light and the “Reddit people [the forums]” in a bad light. Ofcom considered that, in the programme makers’ response on the same date, it was said that the programme conveyed the forum users as “extremists” who were mostly chronically ill themselves and “looking for simplicity in a complex issue”, but also gave them the opportunity to “express concern about how bad it’s got”. It was also said that the programme would touch on the case of Ms Beckwith and explore “why a small number of people do exaggerate/fake illness” and “get to the point that the [forums] are creating a very harmful dynamic of people under pressure to ‘prove’ [illness]”.

We compared the Instagram messages exchanged between Ms K and the programme makers about the nature of the programme with the content of the programme as made available on BBC iPlayer. We took the view that the content broadly aligned with the information provided to Ms K in advance of her participation. In particular, we took into account that, while the programme did give members of the forums an opportunity to put forward their views, the potential harm caused by the forums was recognised, both by the presenter and the interviewees themselves, and it was made clear in the programme that, in reality, it was not possible to prove as fact whether or not someone was faking an illness.

It is a matter for the programme makers and broadcaster to decide how best to ensure that they have obtained any necessary informed consent from contributors, and there are a number of potential ways in which this can be demonstrated. The existence of a signed release or consent form, for example, can provide useful evidence as to a contributor’s understanding of the nature and purpose of the programme and their contractual rights, as well as their willingness to participate in the programme on those bases. While it does not, in and of itself, mean that informed consent was given, obtaining a signed release or consent form may demonstrate that the broadcaster had a reasonable belief that informed consent had been obtained.

In this case, we carefully considered the content of the release form that Ms K had signed on 12 November 2020, the day that her interview was filmed. The release form stated that “the contributor acknowledges that the nature and purpose of their contribution has been explained to them”. We took into account that Ms K said in her complaint, and reiterated in her representations on the Preliminary View, that she had felt pressured into signing the release form, and that she had been asked to do so when “leaving in a taxi” and without it being explained to her. However, in Ofcom’s view, given the circumstances set out above, it was reasonable for the BBC and programme makers to have understood that they had sought and obtained Ms K’s informed consent because she:

- contacted the programme makers following their approach to her and had actively engaged with them in phone calls and correspondence;
- agreed to be interviewed and was provided with further information on how her contribution was likely to be presented and the general nature of the programme;
- did not raise any particular concerns with the programme makers at the time of the interview;
- signed a release form on the day of the interview; and
- in Instagram messages sent to the programme makers and the presenter on 5 August 2021 following the release of the programme on BBC iPlayer, requested to be credited in “anything that goes out”.

Ofcom then went on to consider Ms K’s complaint that the programme makers had misrepresented the nature of the programme and her expected contribution to it, and whether there was a failure by the BBC to make her aware of any significant changes to the programme that might reasonably affect her informed consent. In particular, we understood from the complainant’s representations on the Preliminary View that Ms K felt that she had received reassurance from the programme makers regarding the “direction” of the programme and that it was on this basis that she had agreed to proceed with her participation.

We took the view that the main focus of the programme was the concept of online forums that exist to “call out” influencers who users believe are faking illnesses, including the experiences of people targeted by the forums, such as Ms K, and those of the forum creators. We took into account that, in doing so, the programme also covered a number of other topics, such as Munchausen’s by Internet, and explored instances where illness may have been exaggerated or faked, for example the story of “Kaitlyn” and her sister, before going on to include the discussion with Ms Anderson about influencers going to extreme lengths to prove their diagnosis due to pressure online. In Ofcom’s view, when these topics were discussed, it was contextualised by the presenter’s journey through the chronic illness community online. We also took into account that the potential dangers of the forums and the difficulty of determining whether or not someone was faking an illness in reality was referred to and reiterated at various points in the programme by the presenter, Ms K and the forum creators themselves.

We acknowledged Ms K’s representations made in response to Ofcom’s Preliminary View that the complainant felt that the programme included more detailed and substantial information about the online forums than she had expected based on her conversations with the programme makers, and that it “put stalkers on a pedestal” and made them “seem like saviour internet

warriors”. We also noted Ms K’s submissions made in response to the Preliminary View that the programme makers had specifically reassured her that the programme would not drive traffic to the online forums, and that, shortly before the programme was made available, she had received a telephone call from the programme maker, who had informed her that “it [i.e. the programme] had all changed” but that it was no longer possible for Ms K to withdraw her consent as she had signed the release form. It was not possible for Ofcom to determine, from the available evidence, the extent to which any communication of this nature, as described by the complainant, took place. We understand that Ms K may have preferred that the programme had framed the online forums in a different way, or that it had focused solely on the potential harm posed by the forums and not “cases of people faking”, and we acknowledged that she said that she would not have agreed to contribute to the programme if she had known this. However, we considered that the content of the programme as made available on BBC iPlayer did broadly align with the information provided to Ms K in advance of her interview, in that it still included a substantial amount of information about the potential harm caused by the forums, including the personal accounts of Ms K and others targeted by the forums. In our view, the additional coverage of cases where people had either faked their illness, or been thought to have done so, and the inclusion of the perspective of the forum moderators (which we note that Ms K was informed about prior to contributing to the programme, in the Instagram message exchange on 11 November 2020) did not constitute a significant change to the programme. In our view, the fact that the BBC did not draw these points of focus to Ms K’s attention specifically, prior to the programme being made available on BBC iPlayer, was unlikely to result in material unfairness to Ms K in the particular circumstances of this case.

Ofcom also considered that there was nothing in the material provided to Ofcom by either party to this complaint, such as the contributor release form and correspondence between the parties, which suggested that the programme makers had deliberately set out to mislead Ms K into contributing to the programme. Ms K also said in her complaint that she had not been made aware that the title of the programme “*Sickness and Lies*”, had changed from the working title, “You Don’t Look Ill” however, such matters are an editorial decision for the broadcaster, and we did not consider that failure to inform Ms K of the change resulted in unfairness to her in the programme or invalidated her informed consent. Further, Ms K did not raise any concerns about the title of the programme in her correspondence with the programme makers shortly after its release on 5 August 2021.

Given all the factors above, we considered that the programme makers had taken steps to establish that the informed consent of Ms K had been obtained, and that, in the particular circumstances of this case, the programme’s inclusion of the perspectives of forum users and focus on instances where people may have faked or exaggerated illness did not amount to a significant change in the nature of the programme so as to invalidate Ms K’s informed consent.

- b) We then considered Ms K’s complaint, reiterated by the complainant in her representations on Ofcom’s Preliminary View, that she had been treated unfairly in the programme because it had misrepresented her view and the “facts from [her] lived experience”. In doing so, we had particular regard to the following Code Practices:

Practice 7.6, which states:



“When a programme is edited, contributions should be represented fairly”.

Practice 7.9, which states:

“Before broadcasting a factual programme...broadcasters should take reasonable care to satisfy themselves that material facts have not been presented, disregarded or omitted in a way that is unfair to an individual or organisation...”.

- i) We considered Ms K’s specific complaint that she was treated unfairly in the programme because it referred to her as a “*chronic illness influencer*”. Ms K said that her saying the word “*disabled*” had been cut from the programme, and that this felt very “us versus them”, with [the presenter] being “real disabled” and the other people in the documentary being “fake disabled”. Ms K said that the programme used her as a “poster girl whilst they spoke about fakers”.

We also took into Ms K’s representation on Ofcom’s Preliminary View that she had clearly said that she worked in disability advocacy, not as an influencer, and that this opening statement had therefore changed what she was saying.

In assessing whether Ms K’s contribution to the programme had been edited unfairly, Ofcom carefully examined the full unedited footage of the interview with Ms K and compared it with what was included in the programme. It is important to understand from the outset that it is an editorial decision for the programme makers and broadcaster to make in selecting and editing material, including interview footage of a contributor, for inclusion in a programme. However, in editing such material, broadcasters must ensure that they do so in a manner that represents the contribution fairly. Practices 7.6 and 7.9 remain important even where, as with Ms K, a contributor has specifically acknowledged, in the context of the signed release form, that the broadcaster or programme maker is entitled to edit her contribution as they deemed fit.

We took into account that during the unedited interview with Ms K, the presenter asked Ms K whether she would refer to herself as an “influencer” and the following conversation took place (with the text included in the programme in bold and italics):

Presenter: “...*Would you call yourself an ‘influencer’?*”

Ms K: *I really don’t know why; I have a weird resentment to the term ‘influencer’. But I think that’s my own problem. I would say though that since coming away from nursing and having a much more home-based job, I guess as much as I hate to say it, I probably am going down the influencer path because **it’s the only way that I can really work and, sort of network, and generate people to have dialogues with, so, yeah, maybe**”.*

The conversation continued as the presenter went on to ask Ms K about the demographic of her online following, her experiences of being targeted by the Illness Fakers forum, her broader experience of her illness and her hopes for the chronic illness community in the future.

We also took into account that, in the unedited transcript, Ms K had made references to her “disability” and being a “disability advocate”. Towards the start of the interview, prior to asking Ms K about identifying as an influencer, the presenter asked Ms K whether she had experienced people “doubting [your] disability” and the following exchange took place, none of which was included in the programme:

Presenter: *“So, have you ever had in real life people doubting your disability?”*

Ms K: *Yeah, I definitely have, both from myself and people around me had doubts about my disability and my health. I think when I was first getting diagnosed and first trying to work out what was going on, because all of these things were so new and it, there was a lot of doubt and a lot of questioning of ‘were these symptoms just me having chronic pain, or were they actually a condition’, and there was a big question mark for a long time”.*

We recognised that Ms K’s reference to “my disability” was not included in the programme. We also noted that, while the unedited transcript of Ms K’s interview indicated that she had not explicitly said that she “worked in disability advocacy, not as an influencer”, the complainant had made a more general reference to being a “disability advocate” and some of her advocacy and, that this too was not included in the programme. However, as stated above, it is an editorial decision for the broadcaster to make as to what material to include in a programme, provided it does not result in unfairness.

We acknowledged that when asked by the presenter whether she would call herself an influencer, Ms K had stated that she had a “weird resentment to the term” and that the programme did not include the reference she made to having a disability, or to her work as a disability advocate. However, we did not consider that the omission of such information misrepresented her response to the question included in the programme about whether she would call herself an influencer specifically, to which she had said in the unedited footage: “since coming away from nursing and having a much more home-based job, I guess as much as I hate to say it, I probably am going down the influencer path...”. We therefore considered that the inclusion of her comment in the programme without providing the additional contextual information concerning her disability did not alter the meaning of her response and that it remained an accurate and fair reflection of what she had said in the unedited interview in response to a question about whether she would consider herself an influencer.

Ofcom understood that Ms K would have preferred the programme to have identified her as being disabled, and that she felt the editing of the programme was very “us versus them”, with [the presenter] being “real disabled” and the other people in the documentary being “fake disabled”. We took into account the BBC’s submission that there was no suggestion that Ms K was not disabled, or that she was herself exaggerating or faking a health condition. Ofcom also took into account that at no point in the programme was it suggested that Ms K was “fake disabled”, rather, in our view, the programme acknowledged that Ms K suffered from a chronic illness and/or disability as a result of her symptoms. In particular, we took into account the presenter’s statement that “It can be hostile out there if you’re disabled or have a chronic illness that disables

*you. It often feels like you have to fit in with other people's idea of disability...[Ms K] knows the feeling".* Further, later in the programme, when introducing a segment of Ms K's interview, the presenter said: *"A small number of people do fake illnesses, but accusers are going to extreme lengths trying to extract confessions from them, and what about the many people who are wrongly targeted?"*. Taking the factors above into account, in Ofcom's view, viewers were unlikely to have been left with the impression that Ms K was in any way faking illness or disability, or that her condition was lesser than that of the presenter of the programme.

Therefore, having carefully compared the unedited footage of Ms K's interview with the footage included in the programme, we considered that Ms K's comments included in the programme about her being an influencer were a fair reflection of what she had said and that the omission of a reference to her disability was unlikely to have resulted in unfairness to her.

- ii) We next considered Ms K's complaint that the way her contribution was edited removed "huge amounts of context" and made it appear that she was "perpetuating ableism". Ms K said that when she spoke about *"people going down the rabbit hole, and illness becoming their identity"* she had gone on to say, "how could that not be the case as being ill is all consuming". She said that "her counter and/or balancing statements had been removed".

As at head b) i) above, Ofcom carefully examined the full unedited footage of the interview with Ms K and compared it with what was included in the programme. We understood the complaint to be about the editing of the part of her interview featured at the end of the programme in which she spoke about her perspective on *"chronic illness influencing"* and people's illness *"becoming their identity"*. We therefore narrowed our focus to this specific issue.

As set out above, it is an editorial decision for the programme makers and broadcaster to make in selecting and editing material for inclusion in a programme. However, regardless of whether Ms K had signed a release form acknowledging that the BBC or programme makers were entitled to edit her contribution as they deemed fit, any editing of such material must be in a manner that represents the contribution fairly.

We took into account that during the unedited interview with Ms K, the presenter asked Ms K about how she planned to deal with any future contact with the Illness Fakers forum users and the following conversation took place (with the text in bold and italics included in the programme):

Presenter: *"Going forward, what's your plan to deal with this? Like, this is really difficult for you.*

Ms K: *I sort of had a sit down with myself in May when it all kicked off again and went through this thought process of, **I can hide away from the Internet and I can not share anything and not have social media and disappear. But at the end of the day,** I have to work from home, I have to work using the Internet and, also, I shouldn't censor myself regardless of if I'm online or if I'm not. It's still gonna happen. And I've sort of made an agreement that I don't check what's happening unless it's a genuine risk that I need to know*

*about, and I just tread really carefully with how I present on social media and what I share. And **I've just shifted the way that I use my account to be a lot more rounded and not just fixated on health**, because that's one of the main things that they target, and also, it's, I'm just not interested in it anymore. So, I've just, yeah, I've made the conscious choice that I'm still gonna be as vocal and present on social media, just making sure that I'm not just this disability advocate and that I'm very private about very personal information".*

The interview continued with Ms K being asked about what she had posted about on social media and what other advocacy she had undertaken, and what her hopes were for the chronic illness community online. The presenter then asked Ms K about perceived "competitiveness" in the chronic illness community online and the following exchange took place:

Presenter: *"Could you describe to me the one-upmanship and the competitiveness, because I'm disabled which, like you said is, it's the same but is different to chronic illness. [inaudible] before until I looked into the chronic illness space, so could you explain what happens and why you think it happens?"*

Ms K: *Yeah, I mean, I think a lot of people in the chronically ill community, probably everyone has experienced invalidation about their symptoms before diagnosis, and because of that I think there's this need to prove yourself and show 'oh look, I'm really sick, this is really happening', and I think this sort of competitive one-up culture comes from invalidation...there's just this need to show like 'I'm the sickest' and I think, to be honest, that's really tied into the Reddit culture and that's probably where it was born out of. But it's just that uninhibited need to share information to show how valid and how sick they are, and I've seen it, **I've seen it with so many people who I would have called friends, or people who I've got to know online where they've kind of got sucked into that and haven't come out the other side.** It kind of reinforces the sort of culture of people hunting down illness fakers because of this really dramatic need to show that you're the worst, or that you're really unwell. Yeah, it's a weird culture.*

Presenter: *What do you mean didn't come out the other side?*

Ms K: ***I think most people I know who have first got diagnosed with conditions that they've been trying to find answers to for years, they go through this period of really throwing themselves into the, sort of, advocacy, and showing what the condition does and doing all their monthly challenges and awareness weeks, but what happens is it can catalyse into this mentality of showing every single***

*day how that impacts you. Which, for some people is good awareness, but for some people it's to prove how bad it's got. A lot of people go through that phase, then they realise they're a multifaceted person, come out of it and like reintegrate their disability or health into their life in a way where it's just part of them. Whereas, **for some people, they get so far down the rabbit hole that their identity sort of dissolves into only being unwell, and they don't seem to be able to come back from that**".*

The interview continued after this with Ms K being asked about: whether she thought the online forums such as Illness Fakers were exacerbating the problem; whether she thought that some people ever do exaggerate their symptoms in an attempt to appease the forum users; if she thought that there was any justification for the forums and whether they had made her doubt her own symptoms; and, what would Ms K like to say to the forum users and moderators, some of which was included in the interview footage with Ms K featured in earlier parts of the programme.

The transcript of the unedited footage above indicated that Ms K had not gone on to clarify "how could that not be the case as being ill is all consuming" at any point. Therefore, Ofcom did not consider this element of the complaint further.

Ofcom considered that Ms K's specific comments about how she tried to conduct herself on social media and any perceived competitiveness in the chronic illness community online (including comments on illness becoming people's identity in some cases), despite being edited substantially, were an accurate and fair reflection of what she had said in the unedited interview and did not distort the meaning of what she had said or present her views in a way that was unfair. We took into account the BBC's submission that, in any case, a comment to the effect that Ms K understood this dynamic (i.e. between illness and identity) did not show the comment as aired was misleadingly edited. We acknowledged that Ms K also spoke in the unedited interview about people in the chronically ill community who had experienced "invalidation", and how this was likely to be a contributing factor to any culture of having to prove illness, and about how some people came through this "phase". While only a comparatively small part of Ms K's interview was included in the programme, it is an editorial decision for the broadcaster as to what material to include in a programme, provided it does not result in unfairness. In our view, the omission of these parts of her contribution did not alter or misrepresent her contribution to the programme in a way that made her appear "ableist".

We also carefully considered the context in which Ms K's contribution was presented in the programme. We took into account that Ms K was clearly identified as "disabled or have a chronic illness that disables you", and we considered that it would likely have been clear to viewers that Ms K's contribution was an account of her own personal experiences of finding support in the online community, but also being targeted by Illness Fakers and other forums. We considered that the interview with Ms K at the end of the programme was positioned as a summary of her online experience and the "new perspective" she had gained on "chronic illness influencing" as a result of her personal experiences. Within this context, we considered that Ms K's views on the chronic illness community online were presented in a way which was not unfair to her.

Having carefully compared the unedited footage of Ms K's interview with the footage included in the programme, we considered that Ms K's comments included in the programme about the way she had decided to conduct herself on social media, and her concerns about the wider community and culture of people feeling they are required to prove their illness were a fair reflection of what she had said, and that her comments were not edited or presented in a way that resulted in unfairness to her.

**Ofcom has not upheld Ms K's complaint of unjust or unfair treatment in the programme.**