

# BMJ Open Experiences and practices of people categorised as being 'at risk' based on age during the COVID-19 pandemic: a qualitative study in the UK and Germany

Katharina Wabnitz <sup>1</sup>, Stephanie Drössler,<sup>2</sup> Susannah Mayhew <sup>3</sup>

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For numbered affiliations see end of article.

## Correspondence to

Katharina Wabnitz;  
kathy.wabnitz@ibe.med.uni-muenchen.de

## ABSTRACT

**Objectives** The aim of this study was to comparatively explore the social representations of risk in individuals categorised 'at risk' based on age during the COVID-19 pandemic. What characterised their sense-making of being at risk and what effects did this have on their lives, behaviour and identities?

**Design** Interview-based qualitative study.

**Setting** UK and Germany, July–August 2020.

**Participants** 11 individuals from Germany and eight from the UK were recruited purposively. Inclusion criteria: to be at risk for a severe course of COVID-19 due to age  $\geq 50$  years (Germany) and  $\geq 70$  years (UK) based on official communication by the respective national public health authority.

Exclusion criteria: any form of dementia, pre-existing mental health issues, congenital physical or mental disabilities, being resident in a care home, having a personal relationship to the principal investigator.

**Methods** Semistructured in-depth interviews were conducted remotely. Reflexive thematic analysis was carried out to inductively develop themes illustrative of shared patterns of meaning across the whole data set.

**Results** Three main themes are reported. 'Establishing safe spaces' (perceiving safety and risk in relation to others and implementing prevention measures to maintain safe spaces); 'Assessing and responding to risk' (risk as danger relative to others and risk management as a responsibility of the individual) and 'Considerations on the value of a life' (in relation to quality of life, length of life and capacity to contribute to society). Cross cutting all of these, is the notion of relational assessment.

**Conclusions** The experience of risk and related behaviour is contingent on the individuals' mindset, body and the setting (geographical, political and sociocultural) one is positioned in. Negotiating identities is an inevitable process accompanying sense-making of (new) risks. Public health practice and communication could benefit from at least being informed by and at best being based on the meanings and representations of those whose health and well-being we want to ensure.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Our choice of remote interview technologies allowed for participation regardless of technological literacy.
- ⇒ Our study yielded rich exploratory data and we were able to reach theme saturation in the analysis.
- ⇒ A limitation of our study is that the small sample size and purposive sampling was not designed to ensure a representative sample.
- ⇒ This also led to limited geographical diversity across the 16 German federal states and the 4 UK countries.

## INTRODUCTION

### Pandemic context

On 30 January 2020, the outbreak of COVID-19 was declared a 'Public Health Emergency of International Concern' by the WHO.<sup>1</sup> Increasing age was identified early as a risk factor for a severe course of COVID-19, including death.<sup>2,3</sup> Notwithstanding the limitations in interpreting early evidence, national public health agencies had to assess the situation and give recommendations. There has been considerable variation between the age thresholds for categorising individuals as being 'at risk' communicated by national (public) health agencies:  $\geq 70$  years in the UK by the *National Health Service*,<sup>4</sup> and the range  $\geq 50$ – $60$  years in Germany by the *Robert-Koch-Institut*.<sup>5</sup> Based on these thresholds and more risk factors as they became evident, recommendations for protective behaviour have been issued in both countries.

In Germany, responsibility for enforcement of the national infection protection law lies with the 16 federal state governments. Therefore, decisions regarding restrictions in public life and containment measures in federal states were made by their respective governments. In the UK, decision power lies centrally with the four national governments.



An adjustment to this approach happened only a couple of months into the pandemic, when a framework for containing outbreaks locally was introduced.<sup>6</sup> Overall, the UK suffered a considerably higher death toll than Germany at the time of this research.<sup>7</sup> Decision-making about allocation of resources and preparing for potential situations of triage sparked public debates around proportionality and the value of individual lives.

Communicating chronological age with clear cut-offs as a risk factor may have resulted in driving internal divisions of societies, with ageism and age discrimination surging.<sup>8</sup> The UK government promoted self-isolation for all  $\geq 70$  years, thereby treating elderly people as a homogeneous group that can (or need to) be separated. With disinformation spreading, communicating with and about scientific uncertainty became a challenging exercise for political leaders and experts alike.<sup>9</sup> This was particularly evident in the discourse around risk for suffering a severe course of COVID-19 and the related restrictions of physical contact and mobility.

This study was exploratory with data eliciting in-depth perspectives from those that are targeted by measures undertaken to protect vulnerable groups in two countries. Its results can inform further research in the areas of risk conceptualisation and effective public health practice during infectious disease outbreaks.

### Effects of 'risk labelling'

Risk perception and related behaviour have been subject to extensive research in the fields of psychology and social sciences. Risk perception is recognised as being key to the management of acute health threats. For example, compliance with ad-hoc restrictions such as quarantine during outbreaks is associated with perceived risk for either contraction or transmission as could be shown in the context of the 2003 SARS outbreak.<sup>10</sup> To be 'at risk' becoming part of an individual's identity was shown to be an effect of increasing 'biomedicalisation', a term coined by Clarke *et al* in the context of technoscience.<sup>11</sup> One of five key components of biomedicalisation is an increased focus on surveillance in Western biomedicine, that is, early detection of illness and 'not-yet' illness to determine individual health risks.<sup>12</sup> The experience of being labelled 'at risk' for something can mark a transformative point in an individual's life. As the experience of 'being diagnosed with a risk' can be similar to receiving a diagnosis of disease, a new risk-label can contribute to marked changes in self-perception.<sup>13</sup> Being filed into a certain medical category does not regularly coincide with one's self-appraisal of personal health. Common ramifications include resistance, complacency or even changes in behaviour that perpetuate the categorisation in the sense of a self-fulfilling prophecy. This was shown in a qualitative study on self-perception versus medical assessment of frailty in elderly people.<sup>14</sup> Translating population-level relative health risks into something meaningful for the individual is challenging and can evoke feelings of vulnerability, awareness of mortality and

unsettled self-perception.<sup>15</sup> SARS-CoV-2 poses differential health risks to people. This new risk coincides with the embodied risk of ageing, a 'corporeal risk'<sup>15</sup>—and can be contained through behaviour changes, similar to other lifestyle-related risks. This unusual convergence is situated in the wider context of Western societies in which both the process of ageing and individual health are part of the wider 'politics of life' in which the individual is expected to assume responsibility for both.<sup>16 17</sup>

### Social representation theory

Research into risk and its perception has long been dominated by a focus on cognitive processes triggered in an individual upon being confronted with risks and their consequences, expressed in probabilities of responsive behaviours.<sup>18 19</sup> This cognitivist view of human beings 'obscures not only the symbolic, meaning-making and emotive realms, but also the inter-subjective qualities of (the) human experience'.<sup>18</sup> Despite the recognition of affect and experience-informed judgement being a key mechanism in responses to risks,<sup>20</sup> there remains an understanding of the 'public perception of risk [...] as if it were an aggregated response of many private individuals'.<sup>18</sup> This also reflects the assumptions underpinning policies targeted at changing human behaviours.

Contrary to this, social representation theory (SRT) suggests that human thought and action is shaped and driven by the social, emotive and symbolic aspects of a phenomenon such as risk.<sup>21 22</sup> Thereby, it explicitly focusses on the 'sociocultural, historical and group-specific forces' that mould an individual's thinking,<sup>18</sup> on 'the 'we' contained in the thinking of the 'I'.<sup>18</sup> Social representations are an expression of the meaning attributed to phenomena such as (health) risks. The process of new representations being created entails three aspects: turning information (expert knowledge) into lay thinking, usually via media communication; making sense of new phenomena by comparing them to past events and interpreting them in light of current values and worldviews pertinent in society.<sup>23</sup>

Two interlinked processes are suggested to underpin the sense-making of a new risk: anchoring and objectification.<sup>24</sup> Through these, individuals come to terms with the unfamiliar and integrate what is a potential threat into prevailing group or societal orders and norms, into existing thought and organisational structures. Through anchoring in past events or experiences, new phenomena become represented in a familiar way, that is, manageable. This shifts the focus from intrapersonal to socio-historical processes in the human experience of risk. Objectification as a mechanism 'involves drawing on the current experiential world'<sup>18</sup> of a human being situated in a specific social context, to grasp a new phenomenon. Identity protection of the group and the self is a core function of social representations that emerge in light of a threat.<sup>21</sup> They serve to maintain the status of certain groups in society who distance themselves from others. SRT claims that 'human thought is relational at its root'<sup>18</sup>

and that what is being seen as rational by humans situated in one specific sociohistorical context diverges from those in a different context.

The aim of this study was to comparatively explore the social representations of risk in individuals categorised ‘at risk’ based on age during the COVID-19 pandemic in the UK and in Germany. We were interested in their sense-making of being at risk (ie, the anchoring and objectification of social representations of risk) as well as potential effects this labelling might have had on their lives, behaviour and self-identity. This included exploration of their attitudes towards containment and protective measures and how they experienced related behaviour in themselves and others.

## METHODS

This study was conducted in fulfilment of a postgraduate degree in Public Health. It was conducted from a critical realist perspective, acknowledging that (natural) phenomena exist independently from the human experience. This applies to the virus that emerged independently from human perception. Unpacking the sense-making processes, that is, individuals’ conceptualisation of the risk associated with SARS-CoV-2 and related behaviour, was the goal of this study. We conducted semistructured in-depth interviews via Zoom or telephone to enable wide participation. The physical distancing measures due to COVID-19 and feasibility in terms of time and geographical access justified this approach.

### Recruitment

To identify individuals categorised ‘at risk’ based on their age, participants over 70 years in the UK and over 50 years in Germany were purposively recruited between July and August 2020 through convenience and snowball-sampling, using KW’s network of professional and personal contacts as gatekeepers. They identified individuals and suggested participation to them.<sup>25 26</sup> Participants were contacted by email and informed about the purpose of the study and the credentials and experience of KW. Exclusion criteria were as follows: any form of dementia, pre-existing mental health issues, congenital physical or mental disabilities, being resident in a care home and having a personal relationship to KW.

### Data creation

KW developed a topic guide, which SM reviewed, including diverse questions to prompt conversations in relation to the study objectives. This was tested in a pilot interview and refined. KW carried out all interviews (see English version in online supplemental annex A). All participants were provided with study information sheets and consent forms in their language prior to the study. KW offered participants an informal phone call prior to the interview to answer any outstanding questions. Depending on participants’ capacities, either verbal consent was recorded as a separate file or signed consent

statements as scanned pdfs were provided. Each interview lasted between 30 min and 1 hour. The interviews were recorded using either Zoom or QuickTime-Player. All data were securely stored on an encrypted device, anonymised and treated strictly confidentially. All audio files were destroyed prior to submission of the thesis which preceded this paper.

### Analysis

An active process of reflecting about KW’s own positionality accompanied data creation and analysis, including through memo-writing (see online supplemental annex B). KW verbatim transcribed the interviews using [transcribe.wreally.com](https://www.wreally.com) and fully anonymised them. Therefore, the names included in online supplemental annex C (participant characteristics) and used in the main manuscript are pseudonyms. This allowed for deep immersion and extensive familiarisation with the data. KW analysed both data sets and developed initial codes in English and German, respectively, using NVivo. These were reviewed and discussed with SM. For theme development and write-up, KW translated the German codes, and cited quotes, into English. Data analysis was undertaken inductively, using reflexive thematic analysis according to Braun and Clarke.<sup>27 28</sup> This approach aims to provide an account of the thematic patterns within and across individual accounts. NVivo (V.12) was used for coding and theme development. KW first coded interviews from both countries separately to recognise any relevant differences and merged them later for theme development. SM reviewed and checked coding for a small subsample of interviews. Candidate themes were inductively developed based on the merged code-frame. These were reviewed and organised further into themes and subthemes.

### Ethics approval

Ethics approval was sought from the MSc Research Ethics Committee at the London School of Hygiene and Tropical Medicine, UK (LSHTM MSc Ethics Ref: 21843) and the Ethikkommission an der TU Dresden, Germany (Ref: BO-EK-233062020).

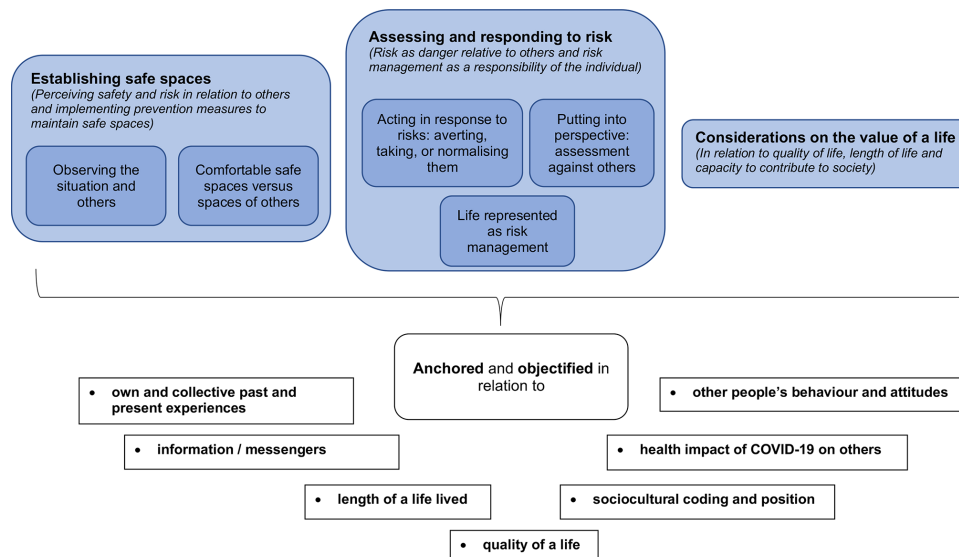
### Patient and public involvement

No patient or public involvement.

## RESULTS

In total, 7 interviews in the UK (one with a couple) and 11 interviews in Germany were conducted.<sup>29</sup> Participants’ ages ranged from 57 to 82 years and pre-existing health conditions were reported by 11 participants. Although this was not elicited explicitly, all participants were presumably from higher socioeconomic backgrounds and relatively highly educated based on the sampling in KW’s personal and professional networks (see online supplemental annex C for participant characteristics). After coding both country data sets separately, it was obvious that the code-frames were similar enough to





**Figure 1** Three themes that share the notion of relational assessment through objectification and anchoring as posited by social representation theory.

merge them and develop themes across the whole data set. Three main themes were identified (two of which had subthemes) and each is discussed in turn (see [figure 1](#)).

### Establishing safe spaces

COVID-19 as a new health risk warranted self-protective measures. Respondents talked about the spaces they felt safe in (typically their homes) and how they extended personal safety when outside their safe spaces (through distancing and mask-wearing).

### Comfortable safe spaces versus spaces of others

The extent of feeling ‘at risk’ is contingent on feeling safe in the position—both societal and geographical—one occupies. It was pertinent throughout the data set that the degree of personal risk people experienced was contingent on their physical distance to the virus. In the early stages of the outbreak, they were feeling safe in their countries as ‘China is far away’ (Tina) and only became really aware of it when it came closer to Europe as Susanne describes: ‘and then, peu à peu, the circles became narrower’. Upon the virus approaching, participants’ perceived safety zone shrank. Tina describes how they became more worried the closer the virus came:

then, as the first things happened in Munich [...] I was a bit concerned, but I didn’t know yet or nobody, no one knew what, what is COVID-19 anyway [...] When the thing started in Ischgl [ski resort in Austria] and then the first here close by in H. [which] is not far from here, that’s about one hundred kilometres from here. When it started there and the first death cases in this context happened, I was really concerned

When the virus was active in their proximity, people’s homes and their immediate personal contacts became their safe haven. Respondents mostly described themselves

as being privileged compared with others they imagined as having much more cramped, higher risk living circumstances. Timo said: ‘I’m incredibly privileged, I, um, have a small house in the countryside, live, um, have a garden around it’. For some, like Jamie, who kept themselves isolated, the only moments of contact with strangers were appointments at the hospital:

We were in a bubble in our house. [...] so the hospital became my one point of contact with the outside world

Respondents’ personal safety zone was complemented by physical distancing and use of personal protective equipment. One participant, Anna, recalled how their comfort zone in which they felt safe among strangers shrank and expanded over time, contingent on the number of new infections in their town:

I remember exactly the feeling when I first took the tram and thought, now you find it horrible that someone sits down next to you and, and I also stood up then because I felt this was too close, um, in May. Now [at the time of interview in July 2020 when cases were falling], I did a train ride where—for hours, I was sitting next to somebody and wasn’t bothered

Hannah describes how they first isolated in their home and then decided to go outside again, using masks as a shield they trusted enough to pursue their work-related activities. Günther described how being physically not in immediate proximity to sick people, added to them not feeling very threatened:

we also didn’t experience it SO directly [referring to media images of sick people in Italian hospitals]. And since we didn’t experience anything SO closely, it wasn’t so, um [...], threatening

Many participants described themselves as being in a safe financial position due to their status as retirees who receive regular pensions as opposed to other (younger, working) people whose livelihoods were threatened by the pandemic response measures. Worries about financial hardship can compound the negative (mental) health impacts of the pandemic and related response measures. Their pre-existing identity as retired people thus became reinforced as a source of feeling safe (particularly from loss of livelihood) during the pandemic:

Those who are not earning the old age pensions, they're the ones who are really suffering anyway (Robert)

Being constrained to their homes and having reduced social contacts, participants mentioned how they valued having enough physical space and particularly access to the outdoors in order to cope well. Silke described how they even enjoyed the situation as it gave them the opportunity to spend more time gardening. Along with that, physical activity and other stimulating change, including interacting with friends and family (either at a good distance or over phone and e-mail) were recalled as being very important for participants, particularly during strict lockdown in both countries.

and I was also busy, so I always [...] phoned or wrote letters or [...] did something for other people and so I haven't yet missed anything really, you know (Hilde)

I was visited by friends occasionally [...] In fact, all the things that I had to do in the flat where rather time consuming. [...] And I must say since I've been going to the cottage [his own holiday cottage], I haven't woken up feeling so depressed in the mornings (Andrew)

Participants often compared their own living conditions and opportunities to cope with those of two particular population subgroups: families in small flats and old people in care homes. Günther, Jamie and Hannah mentioned families who were stuck with children in very small flats as being in more difficult circumstances compared with themselves:

I can't imagine what it's like if you're trapped in a small flat, um, in a high-rise with children (Jamie)

Care homes and their inhabitants, disadvantaged by physical or mental incapacity, were regarded as symbolic of high risk, vulnerability and suffering. Illustrated by Silke and Robert's quotes who talked very compassionately about those being 'shut away' in care homes as being deprived of family contacts, mobility and agency:

I think that various older people, who, I'm assuming, rather those in the care homes and not those who, who lived at home [...] Those who were shut away in care homes, I really felt sorry for the people who, who couldn't see their family (Silke)

I can understand that people in care homes and so on, where they have no control over their lives, and depend on other people, they must be very anxious (Robert)

Participants throughout distanced themselves from this specific population subgroup who they saw as *actually* being the ones who were vulnerable and in need of protection. Rose, a participant who emphasised their rage about the 'at risk' categorisation, described the hypothetical moment of entering a care home as turning into a vulnerable person:

the extremely elderly in the population who are in care homes, there is no doubt that they are vulnerable [...] they have to be given all the possible ways we can, of making sure that they're safe. Um, and I think, then, it's appropriate. [...] And if I get to the point where I have to go into a care home, you know, you have to accept that, that you are then vulnerable, um, and you're no longer able to contribute to society because you are either intellectually challenged or physically challenged

This quote is also illustrative of participants labelling of others 'at (more) risk' than themselves. Rainer evoked the idea of crowded care homes, with nurses being the ones who spread pathogens. Care homes were symbolic for what participants considered the opposite of a safe space. Furthermore, when talking about people in care homes, the ambiguities in determining the value of individual lives, became obvious which is taken up in the 'Life worth living' analysis below.

#### Observing the situation and others

Some participants talked about making observations to judge the situation in relation to safety. Seeing unsettling pictures in the media (watching the TV from their homes at a safe distance), notably from Bergamo in Italy, became a turning point in perception especially for Germans, whereas the notion that the UK Prime Minister contracted the virus was an example recalled by British participants that enhanced their feeling of being threatened—their safety zones had become infiltrated or were about to be. Günther said that people would start putting each other's behaviours under scrutiny:

and if someone came closer, it developed a little bit like, No, you are coming too close, can you not maintain the distance and it was also a certain—yes, everyone observed whether the other one did it correctly

Hannah equally observed other peoples' behaviours and was shocked by instances of behaviour where people did not comply with protective measures, especially among people in their age group:

I'm rather quite prudent and a little bit shocked, um, about the behaviour of other people. Once I entered a house [...], the 80-year-old janitor approaches me, without a mask, I said: Stay back two

metres—[imitating the janitor]: Oh, I'm healthy, nothing will happen to me. [...] elderly, I think they're simply still not informed enough, they're foolish

Susanne, Silke and Andrew described how learning about the situation in other countries influenced their feeling safe in Germany.

when you then saw, how elsewhere—everybody knows it—it was either downplayed or exaggerated or people died like flies, one was, one was then quite grateful about the way it is organised here (Susanne)

we currently see in America that infecting each other leads to an explosion [of cases] (Silke)

What constitutes a safe space is represented by participants with regard to their own position which is characterised by their physical distance to the virus, their compliance with the infection prevention procedures and in relation to others who are being perceived as worse off. This applies to the financially less secure, the people situated in poor living conditions and people of their own age group but who live in care homes. Participants' relational thinking here is posited by SRT: individual attitudes towards new risks are being developed through exposure to the immediate social context and information about the wider sociopolitical realm.

### Assessing and responding to 'risk'

#### Life represented as risk management

When reflecting about what 'risk' or 'being at risk' means to them in the context of COVID-19, the notion of risk itself was negative throughout. Risk was conceptualised as a threat, a danger to physical, mental and economic integrity with death as the worst outcome imaginable. It is present as a matter of being alive and therefore needs to be managed continuously. Rainer's quote is illustrative of participants' thoughts on what role risk plays in their lives:

Risk is always, how should I say, a danger. A danger for, yes, risk for everything, right, so there are money risks, there are, um, health risks, right and um, everywhere where dangers lurk, um, there is risk. That means, I can do something and have to weigh up—a risk which I take, whether I master it and um, what the chances are that I get away with it

Participants all saw themselves as the principal agents, responsible for being aware of personal risks and taking action to avoid or reduce them. The following quote by Rose reflects the pertinent notion that risk management is also about accepting and dealing with uncertainty both regarding the degree of risk and the effectiveness of risk-reducing actions:

So I'm sensible and I will have a flu jab to mitigate that risk. But I'm aware that I still might get flu [...] the risk data will never tell you what happens to you. It tells you the likelihood of, you know, the chances

of something bad happen to you [...] And that's ever so true with the COVID data

One can only ever reach a certain degree of certainty, contingent on effectiveness of counteractions, one's own priorities and values and implications of other people or circumstances. Maggie and John put it as follows:

I mean, if you are crossing the road you are at risk [...] you are at risk when you do extreme sports, or—like skiing or, or like bike riding (John)—so you weigh up [...] is it worth the risk and often it is (Maggie)

#### Putting into perspective: assessment against others

Participants described how they reached conclusions about their personal COVID-19 risk by taking into account their own health (both perceived level of good health and fitness and diagnosed underlying conditions if present) to weigh and judge risk. For example, Anna said: 'and I'm actually pretty fit, I feel like a fit elderly' which made them feel confident enough to do shopping for people older than themselves. Taking in pictures, official numbers and information as knowledge evolved over time were also described as being important aspects of judging their personal risks. Hannah described a TV show as being their key moment for understanding of how much 'at risk' they actually were as opposed to a letter by their cardiologist:

I first became afraid when there were reports on television that people with cardiac insufficiency actually don't have any chance of survival [...] when the cardiologist wrote: Take care, you are a high risk patient, I didn't take it seriously

Participants also positioned themselves relative to other people in the 'at risk' category, to other people with underlying health conditions and to younger people. Compared with young, obese people, Heath claimed to feel much less 'at risk':

I'm appalled by levels of obesity in our population and in Scotland it's worse than England. And in young people. And I mean, I consider myself, um, a damn site more healthy than people I see around in their thirties and forties who are walking dead

Similarly, Susanne could relativise being in the 'at risk' category with knowing about a younger person on a ventilator and not knowing about any old person affected. Having had second-hand experiences of COVID-19, through acquaintances or friends who contracted it, was important in changing perceptions of being aware, feeling threatened and making a judgement about participants' own risk:

we did have several cases of COVID in the village. [...] so people did understand and one lady, she was, she must be late fifties and maybe even just about sixty, she's a nurse and she was on a ventilator for



three weeks. So we did understand that this is very serious (Lily)

Prior life experiences including experiences of other diseases they recalled either personally or as a witness were also used by participants to put the overall situation, its ramifications and the risk, into perspective. Some participants explicitly reflected on the subjectivity of their risk perception with Lily and Rose talking about their own attitudes to risk and Susanne and Silke referring to other people they knew and how they decided to handle the risk. Regarding the specific aspect of being 'at risk' because of their age, none of the participants made their risk assessment solely based on having passed the threshold that had been officially communicated. Rose's quote reflects that:

of course, age increases it [the risk] but [...] it increases it massively by the time you get over eighty [...] obesity, we now know increases it, diabetes increases it, ethnicity increases it [...] it's a complicated picture. And so I don't think as somebody who's fit and active and doesn't have underlying health conditions, I still don't think I need to shut myself away from society

It is rather *perceived* age and more importantly, *perceived* personal health and fitness, in conjunction with all the other aforementioned aspects which together inform the judgement of how much one is 'at risk'. Being positioned in a safety zone as described, further informs that judgement. This in turn had consequences on adopting behaviour changes and maintaining them. Participants did not follow official guidance when it did not match their personal risk assessment. Anna found 'that in North-Rhine Westphalia [their federal state] in my view they were too quick in easing the restrictions again and I then told myself, you don't have to do everything you're allowed to do'.

#### Acting in response to risks: averting, taking or normalising them

The notion of individual freedoms in risk-taking and risk-averting and the idea of boundaries within which people (are allowed to) engage in individual sense-making are sometimes in tension. Putting risk in perspective and then acting accordingly is akin to a delicate staking-out of individual freedoms as these quotes illustrate:

there has never been freedom without considering the other, freedom always means that it doesn't harm the others (Hannah)

all the while [...] people were sort of recognizing the rules, but kind of making out their own version, as it suited them. And I don't think that's an unreasonable thing, within certain bounds (Andrew)

Participants explained how their lives constantly hold risks which they take, such as crossing busy roads or travelling at high speeds, because, as Hans says: 'without participating in the traffic, mobility is not ensured [...] but you

accept that because you want to take part in this mobile society [...] and it has many advantages'. Therefore, acting in response to risks in general and specifically in relation to COVID-19 involves consciously taking certain risks because there is enough to gain and not enough to lose, as Susanne says:

if I knew that I would certainly drop dead if I leave the house—then the risk would be too big. But since I, probably, won't drop dead [...] and even if I get COVID, still have a chance of getting better again [...] I would say it's worth the fun of leaving the house. So you have to make a judgement about risk, how that links to your own values and priorities

One learns to deal with risks and certain risks such as being part of (high-speed) traffic become a normal part of daily life. Similarly, adopting protection measures such as hand hygiene and wearing a face mask became a habit over time as Sebastian admits: 'as I said, washing your hands and wearing this mask, is not a problem for me'. However, not putting others 'at risk' as a matter of moral obligations also informed participants' behaviours although they did not necessarily see themselves at great risk. Silke vehemently made the point that they would not want to be responsible for spreading the disease:

assuming I had the disease and I would spread it, that would be irresponsible [...] no way. [...] so I would, for a very long time, be as reasonable as possible

They and other participants were most inclined to adopt measures when they seemed sensible and comprehensible to them, that is, when they were in line with their own personal risk assessment:

one of the things we make sure we do is that if and when we go out, we always wear gloves and always wear a mask, no matter what Boris Johnson may say or not say (Robert)

The role of the state in providing guidance which supports the individual's assessment was acknowledged, even desired by some participants and individuals who did not comply were regarded as irresponsible. The notion that the measures put in place needed to reflect proportionality, that is, to be fair and sensible, was underscored by Rose:

my attitude now would be, that if the population as a whole in an area were advised to take measures, I would do them for the good of society as a whole. I would not be happy about being told that because I'm over seventy, I effectively can't go out when everybody else is going out

Participants mentioned 'being good', that is, following rules set in place by the state as being sensible and reasonable vis-à-vis a threat such as COVID-19. The underpinning predicament here is trust which determines whether individuals can even consider new measures as being reasonable. The following quote by Silke illustrates this:



and it's also because there's credibility. Assuming I came from Syria and I didn't trust my government if they said something like, You have to wear masks and you have to separate, I wouldn't take it for real because the government has always betrayed me

Nevertheless, participants in both countries were also very aware of the fact that politicians might not be free from personal or other vested interests as they mentioned lobbying and political play when giving reasons for making their own judgements. The notion that the risk categorisation based on age had been too broad-brush underscored some participants' reluctance to accept it. Therefore, rather than simply internalising this categorisation, participants relativised it on a range of aspects and made a judgement based on their lived experience, their degree of perceived threat and their values and priorities.

Participants' general perception of risk as danger and risk management as a responsibility of the individual is in line with prevailing narratives and worldviews in Western societies: health is an integral part of individuals' identities and maintaining good health is a virtue. Relational thinking in an assessment against others as well as anchoring in past personal and collective experiences, are the mechanisms that allow for a representation of one's personal risk for the new disease. Values and priorities which are a result of one's sociocultural coding also feed into this. The emerging representation then contributes to individual behaviour.

### Considerations on the value of a life

Against the backdrop of the economic consequences of the pandemic response and the threat that health system resources could be insufficient, participants reflected on the value of individual lives. First, participants acknowledged that saving individual lives should not be a drain on the collective well-being of society. This was mostly reflected in the idea that the economy needed sustenance even at the cost of individual lives and restrictions for some.

another part of society is, to say it drastically, being shut away. I believe one has to accept that. Because [...] the life chances of the younger generation, um, you have to give them these chances and the elderly [...] don't contribute to economic output or anything else (Hans)

Second, the idea was pertinent that young people, who are yet to live their life, should be given this chance as opposed to older people, who have already had theirs:

if I had to choose between myself or my daughter—or my granddaughter, [...] it's a total tragedy if a twelve-year-old becomes terminally ill. [...] it's not a total tragedy if somebody at eighty-five becomes terminally ill, 'cause they've had a very good life. [...] you know, they've had a life that, that has been lived (Rose)

Third, participants questioned the value of a life in relation to its quality. While acknowledging that quality of life is a subjective and fluid judgement, participants associated being dependant on others (eg, residing in a care home, suffering from dementia or being bed-bound) with a reduced quality of life. Some participants were not entirely against the idea of sacrificing a few for the greater good or at least accepting the idea of restricting certain groups for the benefit of the majority. They also reflected on the idea of letting nature take its course, evolving from the public discourse around establishing herd immunity. Attitudes were ambiguous with some participants being repelled by both the term and the concept as such which evokes the idea of a herd of animals in which the individual does not count. Others were mentioning the burden of changing demographics and that the virus would potentially contribute to easing strains on society (notably the pension system) by 'killing off' the older generations and those who would have died soon anyway. John highlighted that

it's perfectly obvious that the economic price would have been much lower [had herd immunity been established] whether [...] the population would have stood for it or not, that I don't know. I think everybody would have stood for it, provided it wasn't their aunt, uncle, grandmother, son who died

hereby pointing towards an underlying and almost unavoidable hypocrisy that accompanies any utilitarian argument. Overall, participants' accounts reflected an awareness of moral attitudes which inform judgements about the value of a life. Rose, Hans and Heath reflected on the implicit general attitude that with retirement, people's lives lose value—at least in Western market economies as opposed to 'Asian communities who lead a more age-integrated lifestyle [...] the elderly are getting really revered and valued' (Heath).

Overall, the morale of attributing the same right to life to all individuals was unquestioned unless a situation of triage is entered, either concerning two individuals or an individual and society. The criteria evoked by participants to then make choices between lives hinged on the three aspects of quality of life, length of life and capacity to contribute to society. This collective social representation of a valuable life can be understood as an outcome of the common sociohistorical and economical context of Germany and the UK. It can also serve the purpose of assessing the value of a life against others' through relational thinking.

## DISCUSSION

### Risk representations and negotiation of identity in liberal democracies

We explored risk conceptualisations and related behaviour in the context of the COVID-19 pandemic. In the following, we discuss our inductively developed findings in relation to the concepts of anchoring and objectification, drawn from



SRT. The common link between all themes and subthemes is ‘relational’, meaning that risk assessment happens relative to other risks and other peoples’ risk, safe spaces are perceived as such in relation or comparison to other spaces and the value of a life is relative to its length and richness of experiences.

Participants drew from diverse information sources and employed a range of comparative elements to come to terms with and define their risk in relation to COVID-19. By *putting themselves into perspective*, that is, in relation to others and other risks, akin to the processes of anchoring and objectification predicated by SRT,<sup>24</sup> they were able to conceptualise their personal risk. This explains the discrepancy between being ‘labelled’ at risk and ‘feeling’ at risk which was present to varying extents throughout the data set. Their individual risk assessments were based on past personal and collective experiences, their current position both geographically and within their social networks, their values, priorities and (new) information. Participants acknowledged the important role of expert knowledge which was evident through its absence at the beginning of the pandemic. Hence, they were dependent on their own knowledge systems to guide their (re)actions and incorporated evolving knowledge into their lived experiences. For example, participants described how judgement of their personal risk and related behaviour, including the establishment of safe spaces, changed over time, informed by personal and second-hand experiences of the pandemic and its impacts. This speaks to the existence of common anchoring and objectification processes and knowledge systems despite sociocultural differences. The first survey examining COVID-19 risk perception in 10 countries also found that peoples’ perception of risk was significantly associated with sociocultural and experiential factors.<sup>30</sup> Furthermore, the study found that risk perception was an important predictor of engaging in protective behaviour which our findings also support.

Dealing with a new phenomenon happens through a wide range of communication processes and channels which, as well as knowledge-sharing, may spread rumour and misinformation.<sup>31</sup> Communication thus facilitates the formation of knowledge systems, which drive behaviours. It has been argued that social representations are inherently dialogical, ‘as it is only through communication that a novel object can be said to have a social reality’.<sup>32</sup> Hélène Joffe wrote that ‘within SRT, the concept ‘representation’ is imputed with dynamism since it refers as much to the process through which representations are elaborated [...] as it does to the structures of knowledge that are established’.<sup>18</sup> Individuals are not just passive receivers of expert knowledge. They put experts and institutions under scrutiny, drawing from sociocultural processes in the past and present.<sup>33</sup> Participants made what one participant named an ‘informal assessment’ about how to (re)act to COVID-19. What experts could regard as ignorance is an expression of individual agency in judging expert knowledge for its relevance to lived experiences.<sup>33</sup> It was also within personal networks, above all including family and friends,

that participants’ risk representations evolved. These could stretch the globe, as some participants described how their thinking was informed by exchanges with friends and family members in other countries such as the USA or China. However, it is not only exchange of information that facilitates sense-making. Emotions such as trust and anxiety, which were explicitly mentioned by participants, also drove their risk representation. These were described as having pivotal potential in making sense of risks.<sup>18</sup> Furthermore, participants’ individual priorities and values which were in turn contingent on presumed lifetime left, quality and quantity of prior life experiences and attitudes to disease and death (in themselves representations that are fluid) underpinned their sense-making.

Responding to risks is a predicament of Western societies, in which control over disease and death (and hence also over risks) has become part of the collective identity and thus inevitable for the individual who is part of these societies. Identities in Western societies are increasingly infused by biomedicalisation, that is, diagnoses of disease and disease risks, are incorporated in people’s self-perception and acting on those, that is, engaging in health-risk averting behaviour, is expected.<sup>11</sup> Indeed, Robert Crawford even suggested that health and being healthy has become a defining social representation in Western societies for being a good and responsible citizen.<sup>17</sup> Being good and responsible, that is, acting within lines drawn by the state was expressed as informing participants’ risk-avoiding behaviour. It has been argued that a corporeal risk (which age is, too), is more easily accepted when symptoms of that risk are being felt by the individual.<sup>15</sup> This was a salient feature in participants’ accounts as their chronological age often did not match their self-identity: they did not *feel old*, and therefore did not feel ‘at risk’. Yet, being diagnosed with a risk can be akin to receiving a diagnosis of disease with the *potential* disease being translated in a present experience of disease.<sup>13 15</sup>

Serge Moscovici wrote that identity protection, both of the group and the self is entwined in constructing social representations.<sup>21</sup> In rejecting or only partly assimilating the ‘at risk’ label, particularly in relation to being old, participants (re)negotiated their health and age identities. Most participants resisted their own representation as ‘other’, that is, as old and ‘at risk’ but rather applied it to those in care homes who they saw as much more vulnerable and ‘at risk’. ‘Othering’ was also experienced by elderly in Turkey who experienced stigmatisation and loneliness due to mobility restrictions imposed on them.<sup>34</sup> The notion of ‘self’ versus ‘other’ is salient in many theories of risk conceptualisation.<sup>33</sup> The ‘other’ in the pandemic context for our participants often comprised those who behaved in an irresponsible way and hence constituted a potential source of infection, that is, risk. Interestingly, they employed the same way of blaming the irresponsible ‘others’, (hereby mostly referring to young people), as being the ones who presented a risk. However, they also engaged in reflections about the risk experience of those that they othered, for example, young peoples’ risk of losing their livelihoods.



This could be interpreted as a way of anchoring young peoples' experiences to their own youth and perspective they would have had as a younger person. By *putting themselves in other people's shoes*, that is, mentally reversing their relationship with others, they added granularity to their risk representations. Commonly used as an idiom, this might not have been theorised in SRT and we suggest it as a mechanism in constructing social representations. Another example of the COVID-19 risk being objectified in a social representation that involves 'othering', was the representation of care homes being the opposite of a safe space, places of higher risk and vulnerability. It also served to reinforce participants' own representation of being independent, mobile and 'not a burden', neither for their social network, nor for society at large.

Early work on the COVID-19-response among the elderly in China has shown how infection-protective behaviour is influenced by the positive assessment of information received from government.<sup>35</sup> In liberal, democratic systems like Germany and the UK, the actions taken by governments to respond to the pandemic have challenged the relationship between citizens and the state. Despite close similarities between the data from the UK and Germany, we would cautiously claim that overall, participants from the UK expressed less trust in their government than participants from Germany. Open communication of scientific uncertainty was well regarded as participants asserted their governments were not to blame for uncertainty, rather for not being honest about it. In both groups, the notion of acting sensibly and being driven by reason was pertinent. Interpreting personal risks and behaving accordingly was seen as reasonable within certain bounds set by the state to guarantee individual freedoms without compromising those of others. Despite individual-level renegotiation of what was acceptable, the overall societal response to the pandemic in both countries has still been uniform enough to achieve a bending of the epidemiological curve (at the time of collecting these data). This suggests that some consensus on acceptable protective behaviour is possible while allowing for individual 'sense-making within certain bounds'.

### Methodological limitations and strengths

An inherent limitation to the recruiting method is selection bias. Therefore, the sample throughout both nationalities was likely rather homogeneous with a higher socioeconomic and educational background as snowballing took place within the networks of KW. Conversely, this meant they were able to engage in-depth with the abstract and moral-ethical concepts of interest to the research. Maximum geographical variation was not reached across the federal states in Germany and countries and regions of the UK. Acquiescence or desirability bias could have been present, but participants disclosed very honestly those behaviours and thoughts which were not in line with any expected attitudes or the rules. Recall bias might be present as participants were asked to recount their experiences. Positively, using either videocall-applications or telephone allowed for

participation regardless of technological literacy. During video-calls, it was easier to use non-verbal cues, but the telephone interviews were at least as rich. During transcription, KW sought to include prominent pauses and non-verbal utterances as far as possible. Researcher bias might have been present due to their background reading of the effects of risk-labelling by doctors, playing out in their choice of interview questions. The biggest limitation to this study is the fixed timeframe it was subject to. Being able to iterate between the different stages of analysis over a longer period and recruiting a more diverse sample might have added more aspects to the interpretation or consolidated it. Nevertheless, this was an exploratory study and critically for high-quality qualitative research, saturation within the sample was reached.

### CONCLUSIONS

Our data show that the experience of risk and related behaviour is contingent on the individual's mindset, the state of their physical body and the setting (geographical, political and sociocultural) one is positioned in. These three aspects are not static. Sense-making of risks happens through anchoring in past personal and collective experiences, including the shared experience of living in a liberal democracy, uptake of information and objectification by putting the three aforementioned aspects into perspective. To achieve consolidation and more understanding of these complex meaning systems and how they are created, triangulation with other methods and within other populations would be warranted.

Our participants were homogeneous in terms of their epidemiological 'at risk' categorisation, but they were heterogeneous in terms of their meaning and knowledge systems regarding their risk. As categorisation of people in (risk) groups will likely stay a mechanism for managing and interacting in human society, using categorisations based on *meaning and lived experiences*, rather than epidemiological risk-classification, would arguably be less resisted and more reflective of lived realities. SRT has enabled us a richer understanding of the issues shaping people's perceptions of and reactions to COVID-19 and how people strive to anchor and objectify their understandings and experiences in relation to others and their sociopolitical past and present context. Taking this into account, a more nuanced approach to risk-categorisations could enable a wider legitimate spectrum of risk-reduction actions that foster individual choice and agency, without compromising those of others. This would improve trust and compliance with response actions as well as benefiting the mental health and well-being of those affected by current rigid risk categorisations. Public health practice and communication could benefit from at least being informed by, and at best being based on, the meanings and representations of those whose health and well-being we want to ensure.

### Author affiliations

<sup>1</sup>Institute for Medical Information Processing, Biometry and Epidemiology (IBE), Chair of Public Health and Health Services Research, Ludwig-Maximilians-Universität München, München, Germany

<sup>2</sup>Medizinische Fakultät Carl Gustav Carus Institut und Poliklinik für Arbeits- und Sozialmedizin und Public Health, Technische Universität Dresden, Dresden, Sachsen, Germany

<sup>3</sup>Department of Global Health and Development, London School of Hygiene & Tropical Medicine, London, UK

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### ORCID iDs

Katharina Wabnitz <http://orcid.org/0000-0002-2394-101X>

Susannah Mayhew <http://orcid.org/0000-0002-2433-3809>

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