



This is a repository copy of Research fatigue in COVID-19 pandemic and post-disaster research: Causes, consequences and recommendations.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/161545/

Version: Accepted Version

#### Article:

Patel, S., Webster, R. orcid.org/0000-0002-5136-1098, Greenberg, N. et al. (2 more authors) (2020) Research fatigue in COVID-19 pandemic and post-disaster research: Causes, consequences and recommendations. Disaster Prevention and Management. ISSN 0965-3562

https://doi.org/10.1108/DPM-05-2020-0164

© 2020 Emerald Group Publishing. This is an author-produced version of a paper subsequently published in JOURNAL. This version is distributed under the terms of the Creative Commons Attribution-NonCommercial Licence (http://creativecommons.org/licenses/by-nc/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. You may not use the material for commercial purposes.

### Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial (CC BY-NC) licence. This licence allows you to remix, tweak, and build upon this work non-commercially, and any new works must also acknowledge the authors and be non-commercial. You don't have to license any derivative works on the same terms. More information and the full terms of the licence here: https://creativecommons.org/licenses/

#### **Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



l	Research fatigue in COVID-19 pandemic and post-disaster research: Causes, consequences and
2	recommendations
3	Sonny S. Patel <sup>1</sup> , Rebecca K. Webster <sup>2</sup> , Neil Greenberg <sup>3</sup> , Dale Weston <sup>4</sup> , Samantha K. Brooks <sup>3</sup>
4	<sup>1</sup> Fellow, NIH Global Health Scholar, Department of Global Health and Population, Harvard
5	Humanitarian Initiative, Harvard T.H. Chan School of Public Health, Boston, Massachusetts, USA.
6	Email: spatel@hsph.harvard.edu
7	<sup>2</sup> Department of Psychology, University of Sheffield, Sheffield, S1 2LT, UK. Email:
8	r.k.webster@sheffield.ac.uk
9	<sup>3</sup> Department of Psychological Medicine, King's College London, Weston Education Centre and
10	NIHR Health Protection Research Unit in Emergency Preparedness and Response at King's College
11	London, London SE5 9RJ, UK. Emails: neil.greenberg@kcl.ac.uk & samantha.k.brooks@kcl.ac.uk
12	<sup>4</sup> Behavioural Science Team, Emergency Response Department Science & Technology, Public Health
13	England, Porton Down, Salisbury, SP4 0JG, UK. Email: dale.weston@phe.gov.uk.
14	
15	Acknowledgements
16	Sonny Patel (NIH Global Health Scholar and Fellow) is supported by the Fogarty International Center
17	and National Institute of Mental Health, of the National Institutes of Health (NIH) under Award
18	Number D43 TW010543 at Harvard University. Dr Rebecca Webster is lecturer at University of
19	Sheffield. Dr Neil Greenberg (Professor), Dr Dale Weston (Research Fellow), and Dr Samantha
20	Brooks (Senior Research Associate) are affiliated to the National Institute for Health Research Health
21	Protection Research Unit (NIHR HPRU) in Emergency Preparedness and Response, a partnership
22	between Public Health England, King's College London and the University of East Anglia. Dr Dale
23	Weston is also a member of the NIHR Health Protection Research Unit in Behavioural Science and
24	Evaluation at University of Bristol. The authors would like to thank Dr Timothy B. Erickson, Dr
25	Simon Wessely, Dr John Simpson, and Dr James Rubin. The views expressed are those of the authors
26	and not necessarily those of the NIH, NHS, NIHR, Public Health England or the Department of
27	Health and Social Care. All authors read and approved the final manuscript.
28	

29	Abstract
30	<b>Purpose:</b> Research fatigue occurs when an individual or population of interest tires of engaging with
31	research, consequently avoiding further participation. This paper considers research fatigue in the
32	context of the current COVID-19 pandemic, to identify contributory factors and possible solutions for
33	future post-disaster research.
34	Methodology: We draw on examples from the literature and our own observations from the
35	recruitment and data collection phases of qualitative and quantitative studies, to provide an overview
36	of possible research fatigue in the current COVID-19 pandemic, with implications for future post-
37	disaster research.
38	Findings: People affected by disasters sometimes receive multiple requests for study participation by
39	separate teams who may not necessarily be coordinating their work. Not keeping participants
40	informed of the research process or outcomes can lead to disillusionment. Being overburdened with
41	too many research requests and failing to see any subsequent changes following participation may
42	cause individuals to experience research fatigue.
43	Originality: Guidelines for researchers wishing to reduce the occurrence of research fatigue include
44	ensuring greater transparency within research; sharing of results; and using oversight or gatekeeper
45	bodies to aid coordination. Failure to restrict the number of times that people are asked to participate
46	in studies risks poor participation rates. This can subsequently affect the quality of information with
47	which to inform policy-makers and protect the health of the public during the COVID-19 pandemic or
48	other public health disasters/emergencies.
49	Keywords: Research fatigue, Disaster research, COVID-19, research methods, Pandemic, Flooding,
50	disaster policy, Willingness to participate
51	
52	
53	
54	
55	

The COVID-19 pandemic has seen members of the scientific community conducting research to improve our understanding of the virus and its wider impacts, providing insights into how to bring the virus under control. The overarching goal, as with all research, is to contribute high-quality scientific insight which improves knowledge, and this often utilises the strengths and expertise of individuals to form collective teams. However, COVID-19 related research is under pressure to be conducted as rapidly as possible in order to provide the evidence-base for decision makers. From rapid reviews on the psychological impact of quarantine (Brooks et al., 2020) to short letters on public health response for vulnerable population (Patel and Clark-Ginsberg, 2020), and understanding the antibody response in patients (Zhao et al., 2020), there have been 6,659 papers on COVID-19 published between 1st January and 3rd April 2020, of which 83% were in peer reviewed journals, and 17% came out as unreviewed pre-prints (Baker, 2020); only a small percentage of these papers do not containing primary data (COVID-19 Primer, 2020). As such, not only does the speed and amount of research have the potential to lead to a huge amount of waste from poor-quality research (Glasziou et al., 2020), they can also contribute to 'research fatigue,' as seen in post-disaster research (Clark, 2008, Neal et al., 2015, Pagano-Therrien, 2013) negatively impacting participants and potentially confounding the results of future COVID-19-related papers.

### What is research fatigue?

Low response rates in research are well-documented. Between 1975 and 1999 the average response rate to questionnaire-based studies fell from 64.4% to 48.4% (Baruch, 1999), and response rates have continued to decline over the last 30 years (Council, 2013). Whilst response rates have declined, the global scientific output of research studies roughly doubles every nine years (Bornmann and Mutz, 2015). Researchers are thus chasing a dwindling pool of willing participants. Unsurprisingly there are numerous publications exploring methodologies to increase response rates (Bower et al., 2009, Edwards et al., 2002, Mapstone et al., 2007, Millar and Dillman, 2011). However, the cumulative impact of participants being approached for multiple studies on response rates is often overlooked. Multiple participation requests can lead to people feeling exploited (Goodman et al., 2018, Koen et al., 2017): in other fields, for example, cases of people feeling pursued for help by multiple organisations (Morris, 2016) have drawn media scrutiny and the imposition of official guidelines (UK

Cabinet Office, 2015). Furthermore, poor research quality (including poorly designed, small-scale studies) can impair efforts to mount an effective, evidence-based response to a public health emergency such as the COVID-19 pandemic (Glasziou et al., 2020). Although research ethics certification exists to ensure that individual researchers treat potential participants with respect and protect them from harm (British Psychological Society, 2018), such procedures do not mitigate against multiple requests to participate in research within a short time period.

This issue has been referred to as 'research fatigue' also known as participation fatigue, which occurs when an individual or population of interest tires of engaging with research (Clark, 2008). This may manifest through reluctance to continue with an existing project, or refusal to engage with further research regardless of its importance. Clark (2008) suggests three main factors driving research fatigue among highly researched populations: perceived lack of positive change following previous research participation; disinterest in some or all elements of the research project; and practical barriers such as financial cost, time, and lack of organisation on behalf of the researchers.

Over-research is reportedly most prevalent in poorer communities and those with high proportions of people from ethnic minority groups or who are otherwise marginalised (Sukarieh and Tannock, 2013). Several groups, including refugees (Sukarieh and Tannock, 2013), individuals with HIV (Pagano-Therrien, 2013) and individuals with a disability (Kitchin, 2000) have complained about being over-researched. Even entire towns have been subject to over-research after becoming a 'symbolic location' for researchers studying socially differentiated populations (Neal et al., 2015).

# Why is research fatigue an issue for disaster researchers?

Globally, communities are increasingly affected by traumatic events, from disasters to terrorist attacks (CRED, 2015, Kitchin, 2000). Although each event is unique, well thought-out studies can identify needs or evaluate interventions that may be beneficial for the community in question or for future, disaster-affected communities. The current pandemic is no exception to this with numerous studies currently underway to evaluate the impact of COVID-19 on the mental health of the UK general

population and specific groups such as healthcare workers or people who are of a Black, Asian, or minority ethnicity background (Health Europa, 2020, NIHR Policy Research Programme Reviews Facility, 2020). Indeed, research fatigue may even be more of an issue for COVID-19 given the proliferation of potentially repetitive research investigating how people are coping. Furthermore, as COVID-19 is a universal disaster, its far-reaching impact may have led more researchers to refocus on COVID than would usually be the case with single disaster events.

Quite frequently there is a short-lived rush to identify and understand the immediate effects after high profile disasters; this has been termed a 'research gold rush' (Gaillard and Gomez, 2015, Gomez and Hart, 2013, O'Mathúna, 2012). Unfortunately, coordination between research teams is often lacking. Any community, or specific occupational grouping, affected by a traumatic event or situation may be approached by multiple researchers simultaneously; survivors, their relatives, and responders may therefore potentially receive multiple requests to participate. For example, in Shatila, a Palestinian Refugee camp, researchers were a constant presence in the lives of the residents, many of whom reported they had lost count of the number of interviews undertaken; over 223 academic articles and 128 books have been published about the camp (Sukarieh and Tannock, 2013). It is quite possible that the overabundance of rapidly and potentially poorly designed research (e.g., researchers with no prior background or track record in designed research topic and/or research lacks novelty and replicates what is already known) may not only reduce the impact of high quality research (Glasziou et al., 2020), but may even negatively affect willingness to participate. This could limit the possibility of conducting the high-quality research needed to properly understand the impacts of the disaster in the first place. Thus whilst the 'research gold rush' is understandable, it can be highly counterproductive.

## Factors affecting research fatigue

In considering research fatigue, it can help to divide contributory factors into those relating to individual studies and those related to the coordination of multiple studies. These factors are based on a combination of existing research and our own experiences in conducting such studies (Figure 1).

### Factors relating to individual research studies

- 1. **Limited participant pool.** Post-disaster, there is usually a finite number of participants who are able to participate in a given study (Collogan et al., 2004). This is typically defined by a combination of geography (e.g. distance from the disaster centre, city, or region) and exposure (e.g. direct victim, first responder or resident of affected city). Limited numbers increases the potential for individuals to be invited participate in multiple or repetitive studies (Newman and Kaloupek, 2004). During the current pandemic this is less problematic for members of a general population but still relevant for potential participants whose numbers are limited (e.g. those who have lost a close relative to COVID-19).
- 2. Individual reticence to participate. Communities responding to the disaster, or recovery activities, may be especially reticent to participate in research (Huizink et al., 2006, Logue et al., 1981) such as may be the case for current studies of essential workers. Low response rates may also be a consequence of individuals' reluctance to 'relive' the traumatic event (Galea et al., 2005). Individual reticence can thus require researchers to approach substantial numbers of affected people to achieve their desired sample size, which can be costly. This can, therefore, result in smaller, underpowered studies.
- 3. Perceived need for rapid research. Researchers often perceive that post-disaster research needs to be carried out whilst disaster response operations are ongoing (as in the COVID-19 pandemic) or as soon as possible after the incident, in order to investigate the immediate effects and what this means for the community (Council, 2006). This rapid-response tradition in disaster research developed for two main reasons. The first (illegitimate) reason is the desire to be among the first to publish on the event, which represents an unhealthy predilection for novelty over substance. The other (legitimate) reason is the recognition that data on the aftermath of disasters are perishable and information collected after a delay may be distorted and incomplete (Quarantelli, 1987). Furthermore, delayed information acquisition prevents it from being useful to alter the outcome of an ongoing disaster. The desire for speed (whether through good intentions or not) may lead to disaster studies being fast-tracked

through funding bodies and ethical review boards, or avoiding formal ethical review processes altogether. This sort of response can lead to oversights or mistakes, including insufficient piloting questionnaires or a lack of community feedback on recruitment approaches. Both can result in mistakes that appear at best unprofessional or at worst insulting to those affected, as well as being detrimental to the ultimate quality of the research.

- 4. Participants feeling undervalued. Failing to communicate study results to a community, or even to say thank you to participants, can lead to feelings of dissatisfaction (Clark, 2008). Unfortunately, this situation is not uncommon. One participant in our own research reported that she did not receive any 'thank you' messages from researchers and that she also had to search online for the final reports, despite being told she would receive them once they were published (Patel, 2015). Seemingly small gestures such as these can make a big difference to participants, one study of participants during a pandemic found that they wanted to receive feedback about research but felt this was a neglected aspect which reduced the chance of them taking part in future (Gobat et al., 2018). Feeling undervalued may lead to mistrust in researchers in general, and reluctance to participate in other studies.
- 5. Seeing no change. Participants are often informed as to the general benefits that could be derived from their participation but often see no change nor improvement in their lives afterwards. Seeing no change can lead over-researched participants to not being able to trust researchers on the benefits and scope of their studies (Omata, 2019). Participants from our previous research have indicated that this may be a contributing factor to any decision to refuse to participate in future research. For example, one participant in our flooding study reported feeling that the outputs from three research studies she took part in were the same: published reports with nothing directly helping her and her community. She stated that "if no impact or change for the best will happen to us locally, then there is no point to join even if there's a financial incentive" (Patel, 2015). Another participant told us that "I can't be bothered to join a study because I know that no change will happen" (Patel, 2015). Even though participants often understood the need for research, there was a sense of a "lack of trust" or a "break in trust" in how their information would actually aid their community

- (Patel, 2015). It may be too soon to know if this is occurring with ongoing COVID-19 research but it is important for researchers to be aware of, plan accordingly, and further capture such information if it occurs.
- 6. **Media representation**. Incidents of considerable media interest are also likely to draw attention from researchers. For example, research on terrorism and terrorism-related issues has increased dramatically since the 9/11 attacks (Young and Findley, 2011). The media coverage of 9/11 has been labelled as the "largest, most compelling global media event in human history" (Grusin, 2010). In 2008, Silke (2008) noted that by 2010 over 90% of the entire terrorism literature will have been written since 9/11. Given the media coverage of the COVID-19 pandemic, it is likely that a similar bump in publications of pandemic literature will occur afterwards; along with, new found research interests in this area prompted by the media interests adding to the studies in circulation.

### **Factors related to study coordination**

- 1. Overwhelmed stakeholders / gatekeepers. Following a disaster, a 'gatekeeper' (e.g., local councils, human resources departments) is often available to facilitate researchers in accessing those affected. Understandably, such organisations can find themselves overwhelmed by the necessity of dealing with the aftermath of the disaster itself and it is possible that the relevant staff may themselves have been personally affected. Understandably, gatekeepers may have insufficient time, experience or inclination to assess quality or differentiate between multiple research proposals. Additionally, recruitment could bypass gatekeepers or committees completely through online requests on websites and social media outlets.
  - 2. Lack of monitoring of research requests. There are two usual points of monitoring research: the gatekeeper and the ethics committee. However, despite disasters often leading governments creating registries of affected people, the confidential nature of research means it is not always easy for gatekeepers to monitor how many recruitment requests these individuals receive. Similarly, post-disaster researchers are likely to have different ethical

procedures or requirements in place. For example, ethics approval may differ depending on an researcher's employer (e.g. universities or non-government organisations (NGOs)) or particularities of the research question or population of interest (e.g. the need to apply to a specific ethical board for some occupational groups such as the military). This lack of consistency in how ethical approval is obtained makes study coordination difficult as individual review boards will not be aware of other similar studies being put forward for review at other institutions. In addition, current ethical approval boards assess the ethics of individual studies in isolation and do not usually consider the ethical issues of potential competing research programmes.

3. Lack of communication. Researchers may be unwilling to communicate with each other for various reasons such as to time constraints, not knowing who to contact, or fears of losing control over their research. One participant in our studies after the UK 2013-2014 floods informed us that she had participated in discussions organised by local officials, local nongovernment organisations, and academic research groups and although all three groups, as a whole, asked similar questions, none of the groups were aware of each other (Patel, 2015). She gave her contact information to each lead contact of the group to help them connect with each other, but little came of it, as she recalls: "none can bother to talk to each other" (Patel, 2015).

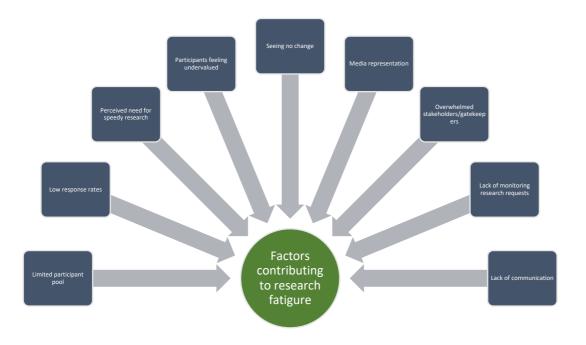


Figure 1. Summary of factors contributing to research fatigue in post-disaster research

# Recommendations to limit research fatigue

Based on the above factors, we next provide recommendations to help researchers limit research fatigue in post-disaster studies.

- 1. Increase transparency. Researchers should ensure that the potential benefits of study participation are clearly emphasised in all communication, verbal or written, with potential participants and the organisations they work for. These might include direct benefits to individuals (such as directly improving their wellbeing), organisations (in terms of improving disaster-related policies and procedures), or wider society. Researchers should also always be transparent about their motivations; organisations and individuals are otherwise less likely to participate in studies, especially if they are concerned that responses will be misconstrued to fit a certain agenda (Crowley, 2013, Horn et al., 2011). Being upfront about study aims can ease participants' potential fears by emphasising their ethical guidelines, reflexivity, and the importance of unbiased research.
- 2. **Sensitivity regarding past negative experiences.** Researchers should remain cognisant that disaster affected individuals, or organisations, may have previously had poor dealings with

researchers, or with journalists, the media or politicians who may have misrepresented their communities, or the attitudes of individuals within those communities (Crowley, 2013). As well as being transparent, it is important for researchers to acknowledge any past negative experiences potential participants may have had and explain why the proposed research will be different. Researchers should be very careful to only promise to deliver what they can deliver. For instance, they should not promise that someone will be able to access timely and effective care if they answer a survey in a particular way if the research team cannot arrange that.

- 3. Sharing results. Researchers can help build trust by involving participants in different stages of the research cycle (Involve, 2020a). At the very least, researchers should ensure that participants are kept informed about any publications or reports that arise, for example by maintaining a study website, updated at various stages of the project, for participants to look at as researchers studying the recent Zika virus outbreak have committed to do (Jorge and Albagli, 2020, Kmietowicz, 2016). Researchers may consider dissemination meetings at the end of the study where findings can be presented and recommendations discussed. Participants may even be given opportunities to help with revisions to manuscripts or the development of subsequent research or interventions. This can be part of ensuring public involvement in disaster research, whereby research is carried out 'with' or 'by' those that are affected rather than 'to', 'about' or 'for' them (Involve, 2020b).
- 4. Plan studies ahead of time. Carrying out 'speedy research' after disasters may be helped by researchers planning studies ahead of time and having approved study protocols/measures in place for different types of disasters. Planning ahead may help improve study quality since potential difficulties can be mitigated against ahead of time. One example of this is the programme of 'sleeper studies' commissioned by the National Institute for Health Research (NIHR) in preparation for the next influenza pandemic (NIHR, 2016). These involve preapproved study protocols, ready to be activated in the event of a pandemic. Additionally, these pre-approved study protocols lower the barrier of poorly designed research, which is

- generally determined in a late-stage adjudication if the research is written for a peer-review journal.
- 5. Communication. Finally, it is imperative that there is good communication between researchers and their potential participants and between different research groups to reduce the chance of multiple studies examining the same topic. This should avoid duplication, increase synergy, and help to prevent the same individuals receiving multiple research requests from different organisations. To facilitate this, some societies, journals and funding boards have put together repositories and data sharing for post-disasters such as for Zika outbreaks (BMC, 2020b, Jorge and Albagli, 2020, Kmietowicz, 2016, Lancet, 2020b) and COVID-19 related research (BMC, 2020a, Glasziou et al., 2020, Lancet, 2020a, NIHR, 2020). Researchers should consult these repositories and also discuss new studies with those who are likely to be aware of potential overlaps or synergies, such as professional organisations, research funders, and government agencies.

Future research

Notwithstanding this review, it remains that the research community still does not fully understand the precise consequences of research fatigue, although it is clear that they are negative. Future studies should therefore aim to highlight better methodologies to reduce the likelihood of research fatigue affecting study quality. Given the complexities inherent in recruiting participants to study research fatigue, a compromise may be to incorporate this into post-disaster research. For example, qualitative studies involving disaster-affected communities could consider asking all participants whether they have been aware of other community members being annoyed or tired with research requests, and asking for participants' suggestions for how the problem could be reduced. Research could also be conducted with academics to explore their attitudes towards research fatigue and recommendations for addressing this. Such research, considered alongside the factors and recommendations identified herein, may represent the building blocks of a framework of post-disaster recruitment and research coordination. Such a framework may help ensure that future studies can be proactive in reducing research fatigue.

311	Conclusions
312	While the benefits of rapid publication of evidence during or after a disaster or emergency – such as
313	the current COVID-19 pandemic - cannot be disputed, researchers should remember that the speed
314	and quantity of research studies carried out may create research fatigue which could negatively impact
315	on both participation and research quality. This paper highlights the importance of transparency and
316	communication with both participants and other researchers, as well as demonstrating sensitivity
317	towards research participants, particularly given that many will have had traumatic experiences.
318	Research fatigue is rarely discussed in the literature but is particularly pertinent for researchers in
319	disaster preparedness and response. This review, which also draws on our own experience of disaster
320	research in the UK, aims to foster stronger research in disaster preparedness and response both during
321	the COVID-19 pandemic and beyond.
322	
323	References
324 325 326 327 328 329 330 331 332 333	Baker, S. (2020), "Huge Covid-19 output prompting 'sea change' in access to research", <i>Times Higher Education</i> , available at: https://www.timeshighereducation.com/news/huge-covid-19-output-prompting-sea-change-access-research (accessed 29 May 2020)  Baruch, Y. (1999), "Response Rate in Academic Studies-A Comparative Analysis", <i>Human Relations</i> , Vol. 52 No. 4, pp. 421-438.  BMC (2020a), "ISRCTN registy", Springer Nature, available at: https://www.isrctn.com/?gclid=EAIaIQobChMIIYu-lp7C6QIVQh0rCh0EZQWuEAAYASAAEgJMtPD_BwE (accessed 20 May 2020)  BMC (2020b), "Statement on Data Sharing in Public Health Emergencies", Springer Nature, available at: https://www.biomedcentral.com/about/press-centre/business-press-releases/11-02-16
334 335 336 337 338 339 340	<ul> <li>(accessed 20 May 2020)</li> <li>Bornmann, L. and Mutz, R. (2015), "Growth rates of modern science: A bibliometric analysis based on the number of publications and cited references", <i>Journal of the Association for Information Science and Technology</i>, Vol. 66 No. 11, pp. 2215-2222.</li> <li>Bower, P., Wallace, P., Ward, E., Graffy, J., Miller, J., Delaney, B. and Kinmonth, A. L. (2009), "Improving recruitment to health research in primary care", <i>Family Practice</i>, Vol. 26 No. 5, pp. 391-397.</li> </ul>
341 342 343 344 345 346 347 348 349 350	British Psychological Society (2018), "Code of human research ethics", Leicester, UK, The British Psychological Society, available at: https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20- %20Files/BPS%20Code%20of%20Ethics%20and%20Conduct%20%28Updated%20July%20 2018%29.pdf (accessed 25 May 2020)  Brooks, S. K., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenberg, N. and Rubin, G. J. (2020), "The psychological impact of quarantine and how to reduce it: rapid review of the evidence", <i>The Lancet</i> , Vol. 395 No. 10227, pp. 912-920.  Clark, T. (2008), "We're Over-Researched Here!": Exploring Accounts of Research Fatigue within Qualitative Research Engagements", <i>Sociology</i> , Vol. 42 No. 5, pp. 953-970.

- 351 Collogan, L. K., Tuma, F., Dolan-Sewell, R., Borja, S. and Fleischman, A. R. (2004), "Ethical Issues 352 Pertaining to Research in the Aftermath of Disaster", Journal of Traumatic Stress, Vol. 17 353 No. 5, pp. 363-372.
- 354 Council, N. R. (2006), "Research on Disaster Response and Recovery", Facing Hazards and 355 Disasters: Understanding Human Dimensions, National Academies Press. 356

357

358

359

360

361

362 363

364

365

366

367

368

369

370

371

372

373

374

375

376

377

378

379

380

381

382 383

384

385

386

387

388

389

390

391

392

393

394

395

397

- Council, N. R. (2013), Nonresponse in Social Science Surveys: A Research Agenda, The National Academies Press, Washington, DC.
- COVID-19 Primer (2020), "COVID-19 Primer", available at: https://covid19primer.com/dashboard (accessed 20 May 2020)
  - CRED (2015), "The human cost of natural disasters 2015; a global perspective", available at: http://reliefweb.int/sites/reliefweb.int/files/resources/PAND report.pdf (accessed 20 May
- Crowley, J. (2013), "Stop Catastrophizing Relief Efforts in the Philippines", available at: http://ideas.time.com/2013/11/14/stop-catastrophizing-relief-efforts-in-the-philippines/ (accessed 20 May 2020)
- Edwards, P., Roberts, I., Clarke, M., DiGuiseppi, C., Pratap, S., Wentz, R. and Kwan, I. (2002), "Increasing response rates to postal questionnaires: systematic review", BMJ, Vol. 324, pp. 1183-1185.
- Gaillard, J. C. and Gomez, C. (2015), "Post-disaster research: Is there gold worth the rush?", Jàmbá: Journal of Disaster Risk Studies, Vol. 7 No. 1.
- Galea, S., Nandi, A. and Vlahov, D. (2005), "The Epidemiology of Post-Traumatic Stress Disorder after Disasters", Epidemiologic Reviews, Vol. 27 No. 1, pp. 78-91.
- Glasziou, P. P., Sanders, S. and Hoffmann, T. (2020), "Waste in covid-19 research", BMJ, Vol. 369, p. m1847.
- Gobat, N. H., Gal, M., Butler, C. C., Webb, S. A. R., Francis, N. A., Stanton, H., Anthierens, S., Bastiaens, H., Godycki-ćwirko, M. and Kowalczyk, A. (2018), "Talking to the people that really matter about their participation in pandemic clinical research: A qualitative study in four European countries", Health Expectations, Vol. 21 No. 1, pp. 387-395.
- Gomez, C. and Hart, D. E. (2013), "Disaster gold rushes, sophisms and academic neocolonialism: comments on 'Earthquake disasters and resilience in the global N orth'", The Geographical Journal, Vol. 179 No. 3, pp. 272-277.
- Goodman, A., Morgan, R., Kuehlke, R., Kastor, S., Fleming, K. and Boyd, J. (2018), ""We've Been Researched to Death": Exploring the Research Experiences of Urban Indigenous Peoples in Vancouver, Canada", International Indigenous Policy Journal, Vol. 9 No. 2.
- Grusin, R. (2010), Premediation: Affect and Mediality After 9/11, Palgrave Macmillan UK.
- Health Europa (2020), "COVID-19: mental health of 41% of British population at risk", Health Europa, Congleton, UK Pan European Networks Ltd, available at: https://www.healtheuropa.eu/covid-19-mental-health-of-42-of-british-population-atrisk/99959/ (accessed 20 May 2020)
- Horn, E., Edwards, K. and Terry, S. (2011), "Engaging Research Participants and Building Trust", Genetic testing and molecular biomarkers, Vol. 15, pp. 839-40.
- Huizink, A. C., Smidt, N., Twisk, J. W. R., Slottje, P. and Smid, T. (2006), "Epidemiological disaster research: the necessity to include representative samples of the involved disaster workers. Experience from the epidemiological study air disaster Amsterdam-ESADA", Journal of *Epidemiology and Community Health*, Vol. 60 No. 10, pp. 887-889. 396
  - Involve (2020a), "Briefing note eight: Ways that people can be involved in the research cycle", available at: https://www.invo.org.uk/posttyperesource/where-and-how-to-involve-in-theresearch-cycle/ (accessed 1 June 2020)
- 399 Involve (2020b), "What is public involvement in research?", available at: 400 https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/ (accessed 401 20 May 2020)
- 402 Jorge, V. d. A. and Albagli, S. (2020), "Research data sharing during the Zika virus public health 403 emergency", University of Borås, Sweden Quarterly, available at: 404 http://informationr.net/ir/25-1/paper846.html (accessed 20 May 2020)

- 405 Kitchin, R. (2000), "The Researched Opinions on Research: Disabled People and Disability 406 Research", Disability and Society, Vol. 15 No. 1, pp. 25-47.
- 407 Kmietowicz, Z. (2016), "Research bodies vow to share data on Zika", BMJ, Vol. 352.
- Koen, J., Wassenaar, D. and Mamotte, N. (2017), "The 'over-researched community': An ethics 408 409 analysis of stakeholder views at two South African HIV prevention research sites", Social 410 Science & Medicine, Vol. 194, pp. 1-9.
- 411 Lancet (2020a), "COVID-19 Resource Centre", available at: https://www.thelancet.com/coronavirus 412 (accessed 20 May 2020)
- 413 Lancet (2020b), "Zika virus resource centre", Elsevier, available at: 414 https://www.thelancet.com/campaigns/zika/statement (accessed 20 May 2020)

415

416

417

418

419

420

421

426

427

428

429

430

431

432

433

434

435

436

437

438

439

440

441

442

443

444

445

446

447

448

449

450

451

452

453

454

- Logue, J. N., Hansen, H. and Struening, E. (1981), "Some indications of the long-term health effects of a natural disaster", *Public Health Reports*, Vol. 96 No. 1, pp. 67-79.
  - Mapstone, J., Elbourne, D. and Roberts, I. G. (2007), "Strategies to improve recruitment to research studies", Cochrane Database of Systematic Reviews, No. 2.
  - Millar, M. M. and Dillman, D. A. (2011), "Improving Response To Web and Mixed-Mode Surveys", Public Opinion Quarterly, Vol. 75 No. 2, pp. 249-269.
- Morris, S. (2016), "Poppy seller who killed herself got 3,000 charity requests for donations a year", 422 The Guardian, London, available at: 423 https://www.theguardian.com/society/2016/jan/20/poppy-seller-who-killed-herself-got-up-to-424 3000-charity-mailings-a-year (accessed 20 May 2020) 425
  - Neal, S., Mohan, G., Cochrane, A. and Bennett, K. (2015), "'You can't move in Hackney without bumping into an anthropologist': why certain places attract research attention", Qualitative Research.
  - Newman, E. and Kaloupek, D. (2004), "The Risks and Benefits of Participating in Trauma-Focused Research Studies", *Journal of Traumatic Stress*, Vol. 17 No. 5, pp. 383-394.
  - NIHR (2016), "What lessons were learned for future research in a pandemic?", available at: http://www.dc.nihr.ac.uk/highlights/pandemic-flu/what-lessons-were-learned-for-futureresearch-in-a-pandemic.htm (accessed 20 May 2020)
  - NIHR (2020), "COVID-19 and Mental Health Studies Register", available at: https://www.maudsleybrc.nihr.ac.uk/research/covid-19-studies/ (accessed 20 May 2020)
  - NIHR Policy Research Programme Reviews Facility (2020), "COVID-19: a living systematic map of the evidence", London, UK, Evidence for Policy and Practice Information and Co-ordinating Centre, available at:
    - http://eppi.ioe.ac.uk/cms/Projects/DepartmentofHealthandSocialCare/Publishedreviews/COV ID-19Livingsystematicmapoftheevidence/tabid/3765/Default.aspx (accessed 25 May 2020)
  - O'Mathúna, D. P. (2012), "Roles and Challenges for IRBs with Disaster Research", Disclosure of Unlabeled Use This educational activity may contain discussion of published and/or investigational uses of agents that are not indicated by the FDA. Postgraduate Institute for Medicine (PIM) and CenterWatch do not recommend the use of any agent outside of the *labeled indications.*, p. 167.
  - Omata, N. (2019), "'Over-researched'and'under-researched'refugees", Forced Migration Review, No. 61, pp. 15-18.
  - Pagano-Therrien, J. (2013), "Exploring Research Fatigue in HIV-Infected Youth", Journal of the Association of Nurses in AIDS Care, Vol. 24 No. 1, pp. 11-16.
  - Patel, S. S. (2015), "Defining community resilience as it applies to disasters [oral presentation], in Local knowledges of risk, hazard, and disaster: culture, power, and discourse [session]", in 75th Annual Meeting of Society for Applied Anthropology: Continuity and Change [conference], Pittsburgh, PA.
  - Patel, S. S. and Clark-Ginsberg, A. (2020), "Incorporating Issues of Elderly Loneliness into the Coronavirus Disease-2019 Public Health Response", Disaster Medicine and Public Health *Preparedness*, pp. 1-2.
- 456 Quarantelli, E. L. (1987), "Disaster Studies: An Analysis of the Social Historical Factors Affecting 457 the Development of Research in the Area", International Journal of Mass Emergencies and 458 Disasters, Vol. 5, pp. 285-310.

Silke, A. (2008), "Research on Terrorism: A Review of the Impact of 9/11 and the Global War on
 Terrorism", in Chen, H., Reid, E., Sinai, J., Silke, A. and Ganor, B. (Eds.) *Terrorism Informatics: Knowledge Management and Data Mining for Homeland Security*, Springer, pp.
 27-50.

- Sukarieh, M. and Tannock, S. (2013), "On the Problem of Over-researched Communities: The Case of the Shatila Palestinian Refugee Camp in Lebanon", *Sociology*, Vol. 47 No. 3, pp. 494-508.
- UK Cabinet Office (2015), "New law to protect vulnerable from rogue fundraisers", Cabinet Office, available at: https://www.gov.uk/government/news/new-law-to-protect-vulnerable-from-rogue-fundraisers (accessed 20 May 2020)
- 468 Young, J. K. and Findley, M. G. (2011), "Promise and pitfalls of terrorism research", *International Studies Review*, Vol. 13 No. 3, pp. 411-431.
  - Zhao, J., Yuan, Q., Wang, H., Liu, W., Liao, X., Su, Y., Wang, X., Yuan, J., Li, T., Li, J., Qian, S., Hong, C., Wang, F., Liu, Y., Wang, Z., He, Q., Li, Z., He, B., Zhang, T., Ge, S., Liu, L., Zhang, J., Xia, N. and Zhang, Z. (2020), "Antibody responses to SARS-CoV-2 in patients of novel coronavirus disease 2019", *medRxiv*, p. 2020.03.02.20030189.

Figure 1. Summary of factors contributing to research fatigue in post-disaster research

