

# Evaluating interventions targeting groups at risk



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December 2023

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**How to cite:**

Ardizzone, Gaia. 2023. *Evaluating interventions targeting groups at risk*. The Diversity of Student Experience Research Project. The Centre for Teaching and Learning. University of Oxford.

## About

I am a DPhil student in Medical Anthropology at the University of Oxford. I am interested in personal and subjective experiences of medicines, and in connecting these to broader patterns of inequality in healthcare. In my MPhil and DPhil research on hospital and home birth respectively, I have explored how risk is woven into discourses around birth, and how it is negotiated in practice by birthing people to ensure autonomy and safety in birth.

As I joined the Diversity of Student Experience project as a literature reporter on the medical anthropological side, I was keen to explore risk with a similar critical approach. I began researching literature at a time when the Office for Students had recently published a Risk Register (Equality of Opportunity Risk Register - Office for Students), which identifies 12 risk categories that are likely to affect success in higher education. This led me to focus on whether categories that describe disadvantage can inform appropriate interventions in education, and whether they adequately address institutional barriers faced by students.

For the report, I applied an anthropological lens to understand how individuals and groups considered vulnerable/disadvantaged/at risk experience interventions, shining a light on what might (not) work for them. I have centred the report on the idea that risk groups and categorisations make risk measurable, quantifiable and something that can be acted and intervened upon. Although the report focuses on health interventions, discourses and strategies, it gives a broader understanding of what recipients of research and interventions understand as valuable, and ultimately, of what has the potential to make initiatives un/successful. This stands to expand understandings of identity and risk that can be transferred from the field of anthropology and applied to that of education. The findings of this report further align with the broader project's aims and objectives, as they put recipients of interventions at centre stage in the development and evaluation of strategies to improve success and wellbeing.

# Highlights

The literature review combined deductive and inductive approaches, prioritising social science sources from databases like JSTOR, Scopus, and PubMed. Snowball searching, inclusion criteria favoring marginalised authors, and a focus on UK contexts guided selection. The analysis evaluates interventions based on both outcomes and processes, considering recipients' perspectives and identities shaped by interventions alongside measurable results.

The report is divided into three sections, all connected by examining risk narratives and risk groups in public health.

Section 1 looks at how neoliberal approaches to health promotion can further stigmatise groups considered "at risk," through use of fear, guilt, and overly individualistic framings of health issues.

- Promote portrayals of target groups and their issues that are based on real-life and on lived experiences, and avoid generalising or dramatising the experiences of target groups.
- Once respectful and unbiased communication repertoire(s) to use/avoid are identified, these need to trickle down to all levels of project design and implementation. Progress reviews can prove particularly useful to review and readapt language as the project progresses.

Section 2 considers the experiences of being designated to a risk group and how this can foster "biosociality" under certain circumstances, but also how it can generate or provoke exclusion.

- Categories of risk and vulnerability (hence target populations) need to emerge organically from the research — the piloting process here is crucial to identify how target groups and individuals define themselves (and act accordingly) in ways that might contradict their assumed vulnerability, or that might point to compounding factors in how they identify themselves in relation to their 'at risk' or vulnerable status and in relation to their role as recipients of interventions or as subjects of research.

Section 3 focuses on interventions that succeed through community collaboration, cultural competence, participatory methods that foreground recipients' voices and experiences.

- Training, or close collaboration with, "insiders" is key to designing and promoting initiatives that are sophisticated and adapted to the workings of particular communities and groups. This allows to break down institutional barriers to participation, and to design research that limits exclusion, hence preventing bias and inequality.

# Contents

<b>About</b>	<b>2</b>
<b>Highlights</b>	<b>3</b>
<b>Introduction: outlining purpose, focus, methods and process of reporting</b>	<b>5</b>
<b>Section 1: Neoliberal approaches to public health in the UK and implications of the individualisation of risk</b>	<b>12</b>
Neoliberalism in political economy and in health	13
‘Chains of risk’ of obesity and diabetes: exploiting fear with campaign imagery and media discourse	14
Youth health: ‘subversive’ teenage motherhood swept under the carpet	15
Sexual health, HIV prevention, and moralising discourse about and within gay communities	17
Conclusion	18
<b>Section 2: Considering ‘biosociality’ along with heterogeneous and intersectional identities in health strategies and research</b>	<b>19</b>
Biosociality and target groups’ heterogeneity in breast and ovarian cancer awareness interventions	20
Biosociality and intersectional identities in experiences of HIV prevention and treatment	23
Conclusion	25
<b>Section 3: Interventions and research that work: communitarian, collaborative and participatory methods and approaches</b>	<b>26</b>
Working from within communities to shape effective interventions: the case of cancer screening and ‘hard to reach’ groups (part 1)	27
Interlude: problematising the term ‘hard to reach’	27
Working from within communities to shape effective interventions: the case of cancer screening and <i>underserved</i> groups (part 2)	28
Interventions to improve mental health and well-being: cultural competence, narrative and patient-centred approaches	29
Blanket policies and participatory methods: the case of obesity and cardiovascular health among youth	31
Conclusion	33
<b>Bibliography</b>	<b>33</b>
Introduction	33
Section 1 (neoliberalism)	33
Section 2 (biosociality, heterogeneity, intersectionality)	34
Section 3 (interventions and research that work)	36

# Introduction: outlining purpose, focus, methods and process of reporting

This literature report aims to tackle the broader question of what evidence and experiences can contribute to the project's methodology — regarding the inclusion of participants and the use of language — by taking a closer look at discrimination and marginalisation through the lens of public health and medicine. In particular, this report gathers and evaluates the strengths and weaknesses of strategies aimed at ameliorating health for vulnerable groups, or for groups that suffer disproportionately from health conditions and afflictions. Ultimately, this report seeks to answer the core question of what risk narratives, rationales and categorisations in health and medicine achieve or fail to achieve for their individuals and communities of interest. Pinpointing the mechanisms that make interventions and policies successful for their target populations is essential to building an evidence base and to developing a methodology that can orient the project's practices towards building a new approach to understanding, studying and tackling inequality and discrimination.

Risk narratives and risk groups are the thread that connects the three sections into which this report is divided. A focus on risk narratives and categorisations helps us to explore and understand the different ways in which individuals who are part of a risk group value their identity in relation to health interventions and policy. The approach taken here is particularly concerned with the ways in which “the discourse, strategies, practices and institutions around [...] risk serve to bring it into being, to construct it as a phenomenon”, with a variety of related implications for individuals' and communities' experiences of their own bodies, health and illness, and broader social relationships (Lupton, 2013: 114). For this reason, following and amplifying the voices and experiences of groups at risk can make a substantial difference to the success of a health policy or intervention.

The first section explores what the use of risk groups and risk narratives in public health policy can achieve when policies and interventions are developed and implemented in advanced capitalist systems and in the current neoliberal era. This section reflects on how the neoliberal ideals of self-help and self-improvement have been woven into public health discourse across nearly three decades of service, discussing the implications of focusing health policy and discourse on individual responsibility and personal accountability. The section specifically explores language and imagery that are used in health policies and interventions and that are amplified by the media in wide-spread portrayals of vulnerable and at risk-groups, with the potential of further stigmatising such groups for their (ill)health.

The second section considers the effect of risk narratives and grouping in fostering 'biosociality' —a shared sense of belonging to a risk category for people with shared characteristics related to (e.g.) race, ethnicity, sexuality,



gender, socio-economic status. In particular, this section focuses on problematising homogenising approaches to grouping vulnerable people in ways that might not reflect the heterogeneous and intersectional nature of risk groups, in turn potentially hindering the effectiveness of interventions. This section also briefly reflects on the stigmatising implications of configuring particular groups and/or bodies as inherently disadvantaged or diseased, in turn furthering discrimination and inequality.

The third section turns to strategies and instances of interventions that work, focusing on the strengths of collaborative, communitarian, culturally sensitive, participatory and patient-centred approaches to designing and implementing strategies and interventions that target underserved and vulnerable groups.

The analysis and review of anthropological literature is central to this report, as the discipline of Anthropology — and, in this case, its medical branch — is particularly suited to document the real-life impacts, effects and experiences that stem from the implementation of health interventions, along with the implications for the identity of the groups targeted. Although this report relies on literature that is mostly qualitative, it occasionally draws from public health, scientific and (bio)medical databases for background and technical information about particular health interventions or strategies, and to add statistical and quantitative backing to the evaluation of such interventions and strategies. A detailed list of all the databases consulted is contained in Table 1 below. Each database is marked with a number — 1, 2 and/or 3 — indicating the section of the report to which the database is relevant.

Table 1 - list of databases used for reporting

Discipline	Database
Interdisciplinary databases for social sciences and humanities	(1) (2) (3) JSTOR - various scholarly journals. In particular branch on Life Sciences Project Muse - journals in the humanities and social sciences, with some scientific and medical titles (1) (2) (3) SCOPUS - multidisciplinary database containing papers, along with conference proceedings web resources, book series (1) (1) (2) Web of Science - abstracts, conference proceedings, papers in medical and scientific discipline
Biomedicine, life sciences and public health databases	MEDLINE - articles from National Library of Medicine, covering medicine, nursing, dentistry, veterinary medicine, the health care system, and preclinical sciences (3) PsycINFO - psychology and psychological aspects of related disciplines PubMed (also PubMed Central and Europe PubMed Central) - index of biomedical literature
Other	(1) (2) (3) SOLO (Search Oxford Libraries Online)

The selection process involves four stages adapted to each one of the three sections of report, and using different databases and keywords used for each section, due to the variation in focus across the three sections of the report (see Table 2). The process of researching literature for the first section of this report, including the exclusion/inclusion criteria that are relevant to Section 1 are detailed in Figure 1. Figures 2 and 3, detailing the process of sourcing material for Section 2 and 3 of the report, are included in the Appendix at the end of the report.

The target number of papers to pool and draw from for each section is approximately 20, with about 10-15 to draw for intervention/policy recommendations and to include in the final draft of each section. This is largely dependent on the fact that selection criteria for papers are not tied to keywords alone, but are also based on giving priority of inclusion to qualitative papers that: 1) report real-life experiences and include ethnographic vignettes and/or direct quotes of participants; 2) are written by queer and/or female and/or 'ethnic minority' and/or disabled authors; 3) report on UK-based health interventions/policies, or on countries that have a similar political, economic, social, healthcare setup to the UK. Although not all papers included in the report will simultaneously present all the features listed above, even the singular application of the inclusion criteria above (along with the keywords listed below) significantly reduces the pool of papers available for reporting.

Although neatly represented in the table below, the process of sourcing literature often implicated trial and error, especially when it came to inputting keywords into databases that returned thousands of results. Narrowing down the results based on relevance required refining searches by tweaking keywords, or changing the field in which specific keywords were to be contained (e.g. in all fields vs. only in titles/abstracts). This proved challenging as settings for advanced, multi-field searches are not equivalent across databases. For instance, only 10% of all articles on JSTOR have abstracts; Project Muse only allows to search in 'Content' or 'Title' (along with 'Publisher' and 'Author'); Web of Science allows for 'Topic' searches that simultaneously scan title, abstract and keywords. Furthermore, keywords (in particular 'health', 'intervention' and 'risk') had to be combined slightly differently for different section searches, as, for instance, using a particular combination that returned several results for Section 1 yielded no results for Section 2 searches. For transparency, all of these slight changes are reflected and documented in Figures 1, 2 and 3 below.

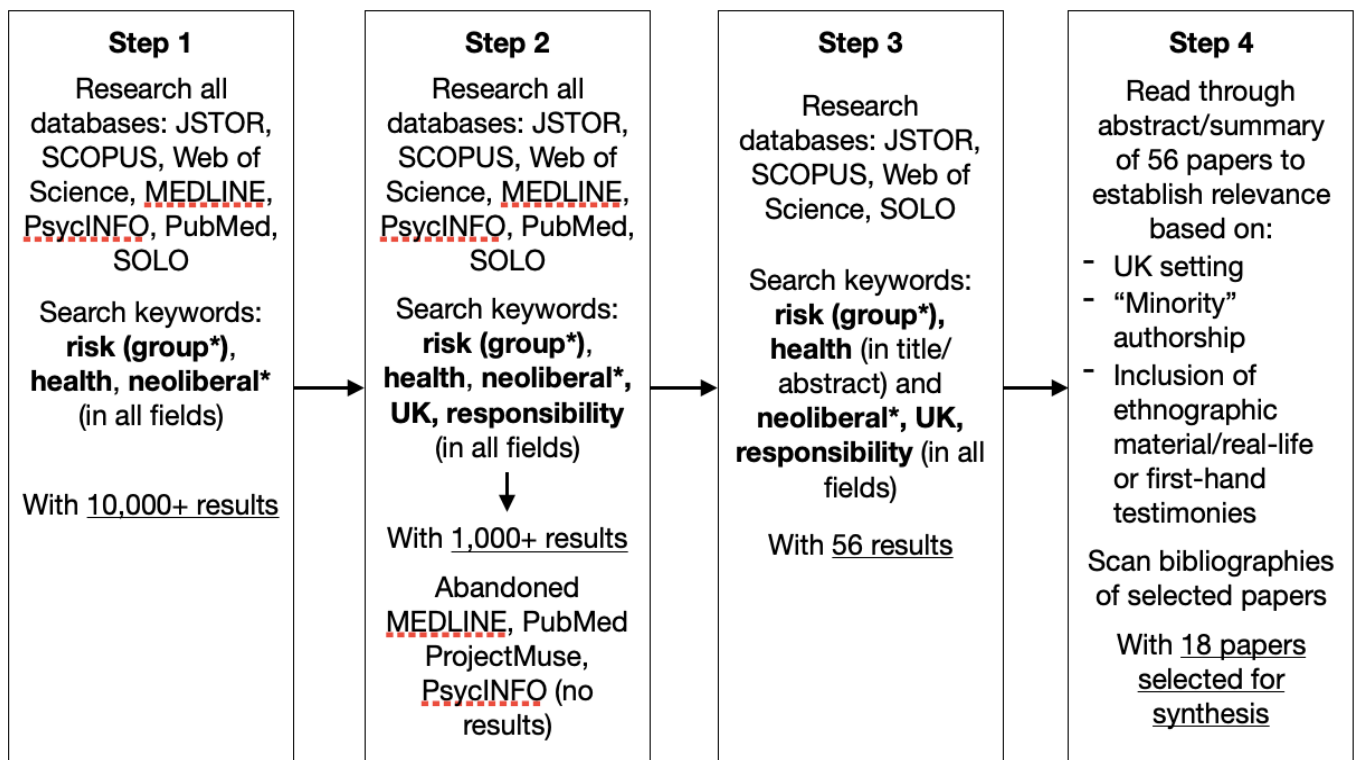


Figure 2 - four stages of literature research for synthesis for Section 2 of review

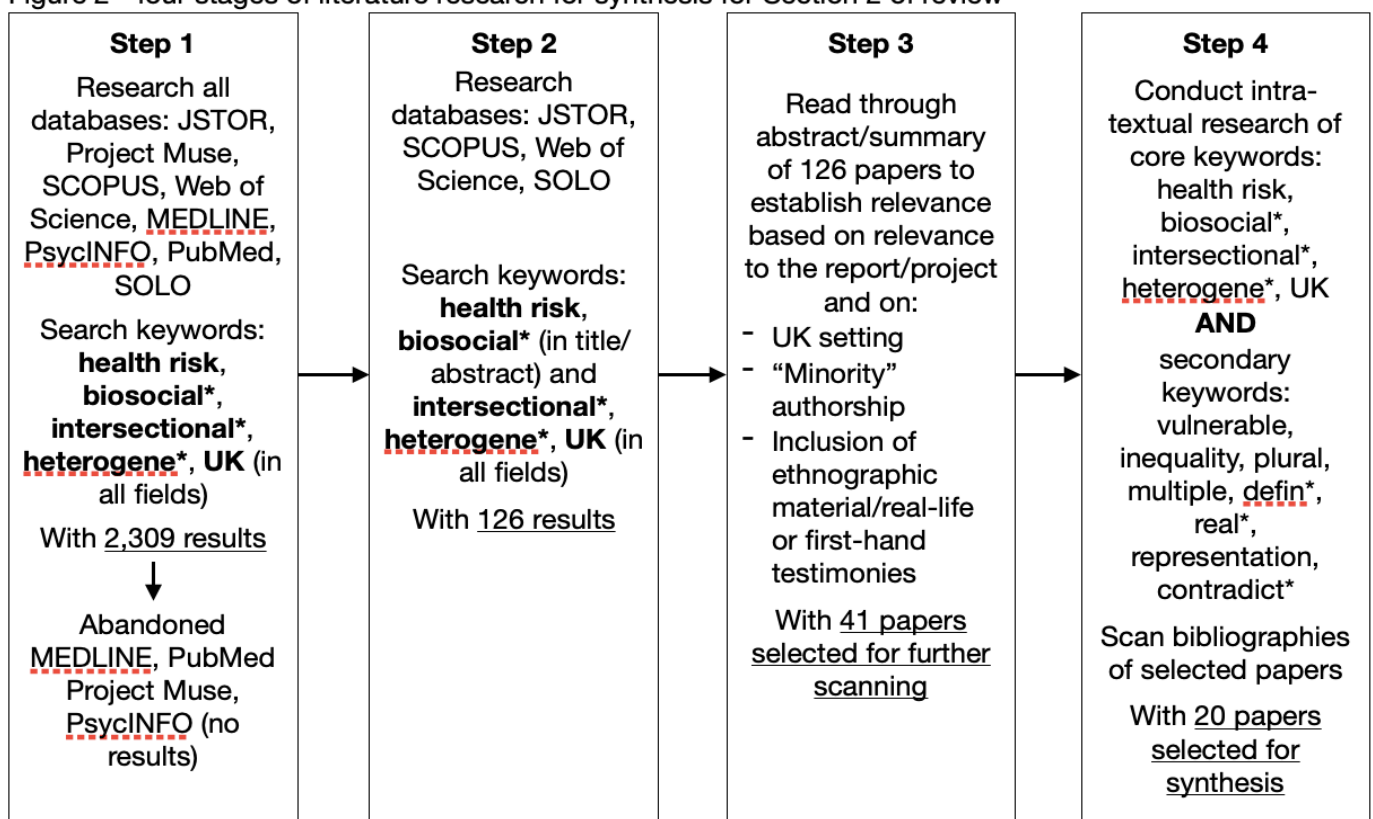




Figure 3 - four stages of literature research for synthesis for Section 3 of review

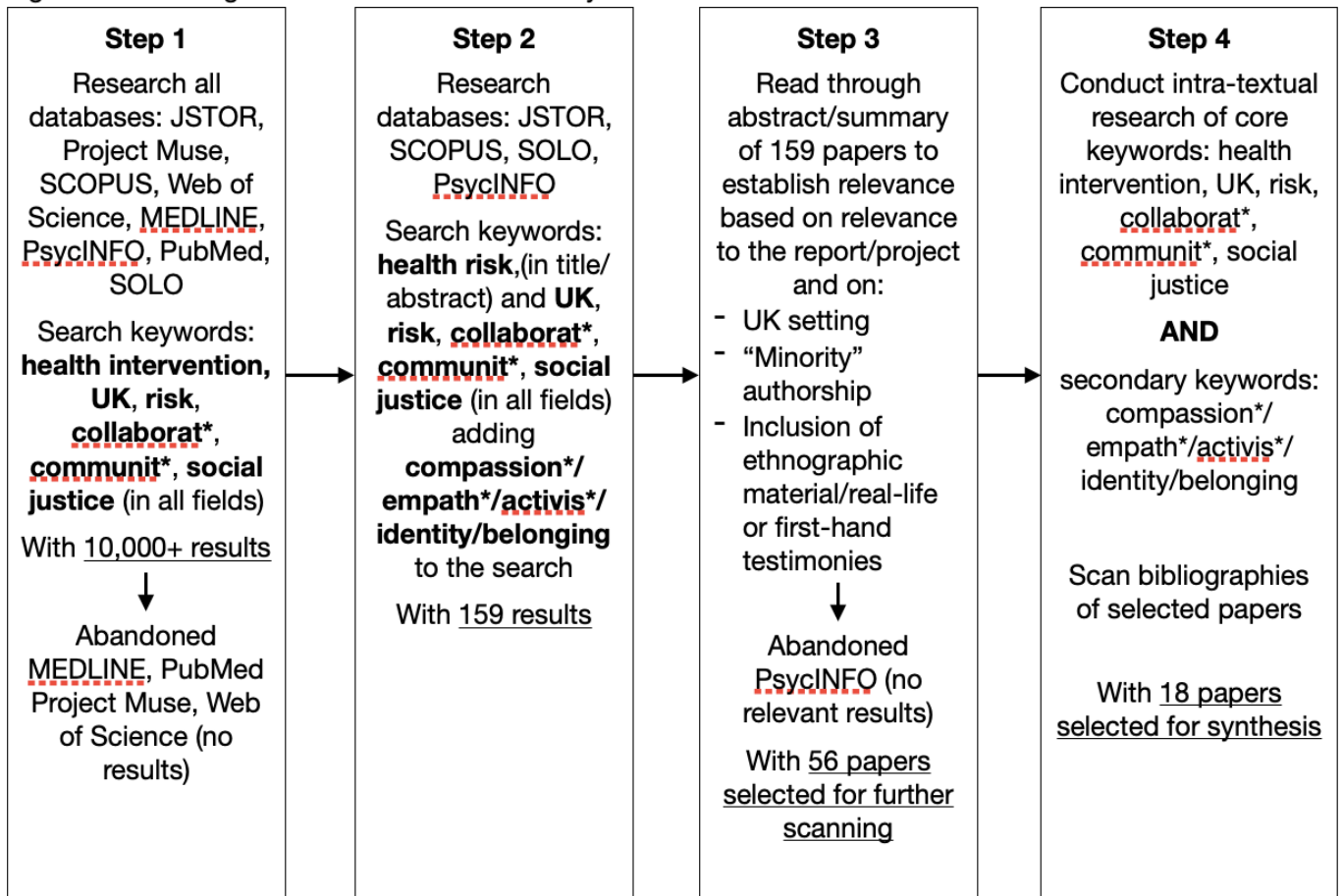


Table 2 - lists of keywords in relation to sections of report

	Keywords
General (applicable to all sections)	<b>Core: risk (group), health (intervention),</b> Additional: vulnerable, race, ethnicity, disability, gender, sexuality, SES, UK, inequality
Section 1	<b>Core: neoliberalism</b> Additional: blame, stigma, individual, responsibility, accountability
Section 2	<b>Core: biosociality, intersectionality, heterogeneity</b> Additional: plural, multiple, defin*, real*, representation, contradict
Section 3	<b>Core: collaborative, community, social justice</b> Additional: compassion, empathy, activism, identity, belonging

Table 3 - readapted from Leeman et al's (2016) table of guiding questions for the evaluation of complex health interventions through mixed methods literature reviews (MMLRs).

Contribution to understanding	Review questions
Intervention and implementation activities	What are the key features of X intervention or implementation process?
Perspectives of intervention recipients	<p>How do recipients experience an intervention?</p> <p>What problems do intervention recipients view as high-priority? And are these represented in intervention X?</p> <p>What types of approaches to intervention do participants embrace? And why?</p> <p>How do recipients problematise intervention X?</p> <p>What strategies do recipients put in place to influence or foster new/adapted interventions?</p>
Identification of promising interventions	<p>What interventions have demonstrated potential for broad reach and implementation in practice?</p> <p>What is essential to potential recipients in the evaluation of existing interventions and in the implementation of new ones?</p>
Broader implications of interventions ( <i>mediating factors?</i> )	<p>What aspects of daily life outside of the direct target of intervention X are also impacted?</p> <p>What other social actors/institutions outside of the direct scope of intervention X are also indirectly implicated in intervention X? And how do these play into the impact of intervention X?</p>

The process of reporting follows a combination of deductive and inductive approaches to researching and evaluating the literature —structured on the use of a mix of pre-formulated questions/keywords, and questions/keywords that might emerge during research, respectively (Leeman et al, 2016). At the core of these approaches is the evaluation of health interventions and policies, and, in particular, a closer inspection and examination of the strengths and weaknesses of interventions as they are incorporated and translated into real-

life, every day experiences for the individuals and groups they target. For the purpose of this report, the evaluation of health policies and interventions rests on considering both outcomes and processes of implementation, aiming to understand and assess both the effectiveness (or lack thereof) of particular strategies and approaches to health challenges and barriers, and the experiences and identities that those generate for the recipients in the process of achieving a particular outcome (or attempting to do so). This bi-fold focus is reflected in the initial questions guiding the process of reporting, exemplified below (Table 3).

In summary, this report will be divided into three sections, with the common thread of risk narratives and groups as points of reflection and departure for the study of discrimination and marginalisation in medicine and healthcare. The literature included in what follows is mostly drawn from (medical) anthropology and the social sciences, and seldom pulled from biomedicine, public health and life sciences databases. The approach to reporting is both deductive (insofar as it relies on pre-determined keywords for literature searches and questions for the analysis of existing literature) and inductive (as it is open to individuating new keywords and formulating new questions as the report progresses). The report ultimately takes a critical stance towards health promotion approaches, to evaluate the key features of strategies and discourse that are and are not effective at improving health and wellbeing of their target groups.

# Section 1: Neoliberal approaches to public health in the UK and implications of the individualisation of risk

Table 4 - key points explored in Section 1 of the report

Key points explored
Individuals at risk are placed within ‘chains’ of risk and are presented as both ‘risk-prone’ individuals who engage in irresponsible behaviour and choices, and as ‘at risk’ of burdening health systems and other individuals in their milieus, if not broader society altogether.
Interventions and attitudes that influence policies to target risk groups have the potential to further stigmatise and marginalise groups and communities that are already disproportionately afflicted by health issues and/or discriminated.
Interventions and policy also play a key role in shaping the language used to discuss risk, health, and particular groups, in turn playing a key role in everyday experiences of health and illness for groups considered vulnerable or at risk.

Table 5 - recommendations for project’s methods that emerge from Section 1

Recommendations for project methods
Avoid using language that promotes or exploits fear and guilt, as this can foster cultures of stigma and can create a fracture between target groups and research/outreach teams.
Promote portrayals of target groups and their issues that are based on real-life and on lived experiences, and avoid generalising or dramatising the experiences of target groups.
Once respectful and unbiased communication repertoire(s) to use/avoid are identified, these need to trickle down to all levels of project design and implementation. Progress reviews can prove particularly useful to review and readapt language as the project progresses.

This section of the report retraces the ways in which neoliberal ideals of self-help and self-improvement have been woven into public health discourse across nearly three decades, discussing the implications of focusing health policy and discourse on individual responsibility and personal accountability. The section specifically explores language and imagery that are used in health policies and interventions and that are amplified by the media in wide-spread portrayals of vulnerable and at risk-groups, with the potential of further stigmatising such groups for their (ill)health.

This section discusses various papers that have critically approached neoliberal ideology as it is woven into discourses around health risks and health promotion, pointing in particular to the pitfalls of health strategies and discourses that shift the focus from state failure to individual failure in maintaining people’s health and wellbeing. The section presents papers and case studies that explore what impact the individualisation of risk has in practice, and in particular in the wording of policy and news presented by the media around the topics of sexual health, youth health and obesity in the UK

across the past three decades. The main focus here is the role of discourse and day-to-day communication in fostering stigma for groups that are vulnerable and potentially already marginalised, what Ayo (2012: 140) aptly synthesises as:

the consequences for those who fail to conform to the prescribed mandate as to what constitutes a healthy lifestyle are real. Such include among other things, public disdain and reproach for being a part of societal problems rather than a part of the solution, gazes of repulsion due to one's failure to manifest the symbolic metaphors of neoliberal citizenship, such as the self-governing individual or the capitalists hard work ethic, embodied in the taut, refined and fit body, and admonitions from both health experts and loved ones alike.

At the core of this section is the idea that at the intersection of neoliberalism and risk in health, individuals placed within risk categories might be portrayed as irresponsible for attracting and not acting on issues that put their health at risk, exacerbating the burdens of ill-health and pre-existing discrimination. The section presents three key findings, summarised in Table 4 below. Table 5 at the end of the section contains a recommendation for the project's methods that emerges from the literature discussed below.

## **Neoliberalism in political economy and in health**

Although there is considerable debate around the nuances of its definition, neoliberalism is commonly recognised as political and economic ideology that supports the deregulation of markets and the free-flow of commodities and capital as well as a reduction of state or government intervention in social and economic affairs (Ayo, 2012). As neoliberalism proposes a laissez-faire approach to economic and social regulation, citizens and institutions are invited to self-regulate. Ayo explains (2012: 101):

we can think of the political machinery of neoliberalism as a system of thoughts and beliefs about the effective rule of state, society and the market. These beliefs are pervasive in that the corresponding discourses directly shape the ways in which society is governed and expected to conduct itself, right from the privacy of one's own home to the administration of public institutions and across all demographics.

While neoliberalism is primarily recognised as an economic and political rationale, its moralising effects have pervaded discourses around health and lifestyle across the West in particular. Propelled by the WHO in the 1980s, public health approaches in the Global North have increasingly moved towards a focus on individual responsibility and accountability in the design and promotion of health strategies, spotlighting the role of prevention and individual behaviour (Ayo, 2012). Within the public health landscape of interventions and policies, neoliberal ideology has come to be the dominant



framework for the development and implementation of strategies to improve health, wellbeing and, more broadly, quality of life for groups that are recognised as at higher risk of being afflicted by various health issues. Neoliberal ideology applied to health promotion policies facilitates the making of the self-governed 'good' and 'healthy' citizen, by shifting responsibility for health on individuals and promoting —largely through consumerism— self-care, self-help and self-improvement practices.

## **'Chains of risk' of obesity and diabetes: exploiting fear with campaign imagery and media discourse**

The common threads of risk individualisation and of responsabilisation are identifiable across several areas of public health intervention and related media discourse in the UK. Much of the discourse around health improvement in the UK has focused on obesity and diabetes, with the latter being a key area of focus for public health intervention in what has been named the age of 'globesity' (Berlant, 2007). Obese individuals are placed on a risk continuum, not only because obesity is, in common understandings, caused by 'risky' behaviour and choices, but also because those affected are at increased risk of developing additional health conditions such as cardiovascular disease and diabetes (Brookes & Baker, 2022). Despite extensive research that foregrounds the role of 'obesogenic' factors and environments in the incidence of obesity, this condition remains intensely stigmatised in light of healthist and neoliberal approaches that shape health policy and lay discourse on obesity (Brookes & Harvey, 2015).

As Brookes and Harvey (2015) point out, governments of market-driven societies have been slow in understanding the role of 'obesogenic' environments, and in incorporating this rationale in the development of strategies and interventions to mitigate the incidence of obesity, prioritising, as in the case of the UK, self-regulatory codes of practice. In particular, Brookes and Harvey take a multimodal discourse approach to the analysis of images and annexed captions used in a campaign aimed at raising awareness around Type 2 diabetes and promoted by the partnership of Tesco with the charity Diabetes UK. The images presented in billboards and leaflets exploit fear and grief to construct diabetes as an 'invisible killer', portraying grief-stricken members of families embracing one another and showcasing captions that repeat "Check your risk of Type 2 diabetes. So you and your family don't suffer/Before it hits you and your family/Or risk stroke and amputation" (ibidem: 64, 65, 67). Fear and anxiety inducing images and text, that make viewers connect emotively and affectively to the subjects represented, also portray diabetes as a silent attacker, speaking to the idea that "no one is safe, everyone is at risk" (ibidem: 70). The visceral appeal of the campaign has the serious potential to burden with blame those afflicted by a condition that is largely set off by environmental factors and genetic predisposition, rather than 'bad choices' and inadequate lifestyle.

The role of media in creating fear and stigma is further evident in discourses around obesity and risk in the UK press. Brookes and Baker (2022) analysed risk references in a 36-million-word corpus of articles from the British press about obesity, published between 2008 and 2017, and found a substantial increase in the language of fear (with a peak in 2017), expressed in the use of dramatised formulations (e.g. *deadly* risk) and in the personalisation of risk (e.g. *your* risk). A similar task was carried out by De Brún et al. (2013) who examined representations of obesity in Irish media by conducting a thematic analysis on newspaper articles published in 2005, 2007 and 2009. They highlighted the concomitant role of public health policy and media outlets in the stigmatisation and further marginalisation of obese individuals.

Ireland is one of the European countries with the highest incidence of obesity (24%) and with the highest proportion of overweight individuals (37%). In light of this data, the Irish government set up the Irish National Task Force on Obesity, which, in 2005, made recommendations about dieting and exercising as mitigators of obesity. Of note is that — “the recommendations made by the Task Force may have influenced trends in Irish media reporting on obesity” (ibidem: 17). In common tabloid representations, obese or overweight people were commonly portrayed “as failing to act and as bringing physical disease, psychological illness, and social disapproval on themselves” (ibidem: 18). Responsibility was also represented as running along the roles of parenthood, and was put on parents who failed to act as guardians, indulging their children with fatty and sugary foods, contributing to exacerbate the obesity ‘epidemic’. Caricatural, visceral and exaggerated representations of obesity and diabetes not only contribute to fuel discourses that put the weight of responsibility on the shoulders of individuals who are already stigmatised, but also obfuscate the role of external factors in the incidence of particular conditions.

## **Youth health: ‘subversive’ teenage motherhood swept under the carpet**

Youth have also increasingly been the target of health and behavioural intervention, under the (neoliberal) tenet that individuals are responsible for making positive choices and avoiding certain behaviours, “instilling the notions that [they] are personally responsible for a safe and successful transition into adulthood” (Tinner et al, 2020: 529). Tackling teen pregnancy has been a core concern in public health policies in the UK, where young mothers have been portrayed as both ‘at risk’ — where teens from lower socioeconomic backgrounds are identified as more vulnerable to early pregnancy and to further, long-term, life adversities — and as ‘a risk’ to themselves, their children and, more broadly, society and the health system (McDermott & Graham, 2005).

The discourse around teen pregnancy in mainstream media has been polarised into two opposites; on one hand, young mothers are presented as vulnerable individuals and passive victims, and on the other they are accused

of making the conscious choice of getting pregnant in order to be granted financial support and benefits from the government (Brown et al., 2013; ibidem). Young mothers have nevertheless resisted demonisation and stigmatisation, and have pushed for the reframing of teenage motherhood in positive terms. One particular study by McDermott and Graham highlights that “what is striking about the focus on teenage pregnancy and early parenthood in policy debates is the absence of perspectives from young mothers themselves” (2005: 60).

In a systematic review of qualitative studies of the experiences of UK mothers under the age of 20, McDermott and Graham found experiences of motherhood in teens that reflect what they call ‘resilient young mothering’, exploring everyday practices, identities and ‘life-narratives’ of young working-class mothers in contemporary Britain. What emerges are not only overwhelmingly positive and fulfilling experiences and practices structured around the maternal role for teenage mothers, but also narratives that explicitly contradict public policy and mainstream media portrayals of young mothers as inadequate, incapable or irresponsible; young women often affirmed that they achieved maturity and established themselves in the role of responsible adults through motherhood. Positive examples of young mothering have been widely dismissed and systematically ignored by policy makers and the media alike — with the latter preferring dramatised and stigmatising renderings of the current state of youth health — even though the reality of young mothering contradicts accounts that paint young mothers as either actively irresponsible or as passive victims (Brown et al, 2013).

The UK’s ten-year teenager pregnancy strategy implemented by the government between 1999 and 2010 is a positive example of what interventions can achieve when they approach their target groups in ways that avoid moralising and stigmatising them further. In a move to foster learning and open communication around sexual health and reproduction, the intervention partly hinged on a media campaign aimed at broadcasting conversations about contraception and chlamydia between young people and parents or professionals on TV, radio and in cinemas at specific times to reach the widest possible audience (Hadley et al., 2016). Leaflets were also distributed to parents through pharmacies, instructing on how to foster conversations with teenagers around safe sex and pregnancy. One of the strengths of the intervention was further identified in the regular reviewing of progress, which helped to progressively tailor strategies to findings and make adjustments where needed. Though the target of a 50% reduction in under-18 conception rates across a decade was not met through the initiative, the latter is still defined as a ‘the success story of our time’ (Toynbee, 2013, in Hadley et al., 2016), as it contributed to significant reductions in teenager pregnancy across various regions of the UK.

## Sexual health, HIV prevention, and moralising discourse about and within gay communities

The area of sexual health is one that comes under great amounts of scrutiny, as sexual behaviour is a frequent site of responsabilisation (Hildebrandt et al, 2020). In particular, those who are deemed most at risk of contracting sexually transmitted diseases are often portrayed as being at fault for their own condition as they engage in 'risky' or 'irresponsible' behaviour. In countries such as the UK, where the burden of HIV infection falls disproportionately on gay, bisexual and men who have sex with men, the discourse around prevention and transmission can be particularly stigmatising, and can further damage groups that are already marginalised (Williamson et al., 2019).

Williamson et al. (2019) have conducted focus groups in Leicester, England, with a mix of HIV+ and HIV- negative men, to explore the impact of stigmatising discourses on perception of pre-exposure prophylaxis (PrEP) among gay, bisexual and men who have sex with men. Tabloids, or what one of the participants (identified as P2) refers to as 'red-top papers' have fostered the idea that PrEP "is an expensive means of the NHS for allowing gay men to have reckless, unprotected sex without protecting themselves [without using condoms], that it's by all means, it's nothing like one-hundred percent successful actually it's just a means of financing people's promiscuousness", despite the effectiveness of reducing HIV transmission. This mainstream media view is so pervasive and determining in shaping perceptions of gay men, that it is echoed by another participant in the study as they discuss distancing themselves from an acquaintance after seeing he was holding the drug Truvada between his teeth in his Facebook profile picture: "I think that's disrespectful personally. Run away with anything... Reckless, flaunt things in people's faces. When I saw all of this I took a step back from the person. I don't know how to be with this person... I find it hard to get my head around people like that".

Other participants not only associated PrEP with promiscuity, fetishism and 'esoteric' sexual practices, but also with the use of recreational drugs which may affect the efficacy of PrEP. Tabloids are explicitly identified as complicit in the labelling of men who have sex with men as 'lazy' and 'irresponsible', and in the calling for a diversion of valuable NHS resources towards health causes 'more deserving' of government funds (Williamson et al., 2019). In this context, the choice of language and the association between homosexuality and irresponsibility have several and obvious ramifications for the consolidation of homophobic stereotypes, and for the potential to create fractures within and further marginalise a community that already faces constant attacks and discrimination.

## Conclusion

In the arena of health management, neoliberalism has had considerable moralising effects on the way health and illness are understood and, consequently, are tackled with policies and interventions. The concept of risk has become central to self-governing and self-improvement practices, that have been promoted with a variety of strategies. Studies conducted across the UK in relation to health policy matters such as diabetes, obesity, along with youth and sexual health have demonstrated the detrimental effects of inducing guilt and remorse, or exploiting a language of fear to prompt individuals and groups at risk to improve their health. This often leads individuals who are already affected by particular conditions or are otherwise vulnerable to carry the additional burdens of shame and social stigma. Appropriate, non-stigmatising language, and open communication that fosters learning and understanding are key elements to the success of interventions and policies that aim to reduce barriers to health and wellbeing without creating additional obstacles.



## Section 2: Considering ‘biosociality’ along with heterogeneous and intersectional identities in health strategies and research

Table 6 - key points explored in Section 2 of the report

Key points explored
Vulnerability or being identified as medically at risk fosters a shared sense of belonging and creates networks of cooperation and mutual understanding between members of vulnerable/at risk groups above and beyond quotidian forms of ethnic, gender or behavioural solidarities.
Individuals that make up risk groups —though sharing ‘biosocial’ understandings of their ‘at risk’ status— might contest and challenge their status as a result of their own understandings of their identity and of personal histories, experiences, trajectories.
Overlapping experiences of identity and risk are often tied to sensitive nodes and experiences, and embracing intersectionality in research allows to tap into dimensions of experience that might be otherwise obfuscated by neat and clear-cut categorisations.
Being at risk creates the opportunity for individuals and communities to confront biological and social understandings of their status, and generates new forms of aggregation and advocacy around issues of self-definition, identity and belonging.

Table 7 - recommendations for project’s methods that emerge from Section 2

Recommendations for project methods
Categories of risk and vulnerability (hence target populations) need to emerge organically from the research —the piloting process here is crucial to identify how target groups and individuals define themselves (and act accordingly) in ways that might contradict their assumed vulnerability, or that might point to compounding factors in how they identify themselves in relation to their ‘at risk’ or vulnerable status and in relation to their role as recipients of interventions or as subjects of research.
Effective interventions and tailored research need to be moulded on the experiences of recipients/subjects, as all parties stand to benefit from extended collaboration and from a reworking of the notion of expertise as a bi-lateral endeavour. Creating a research environment that fosters understanding and sharing between all of the parties involved in research is essential to shaping interventions that can be welcome and can have a real impact in the lives of their recipients.

A wealth of literature in anthropology deals with Paul Rabinow’s seminal concept of ‘biosociality’, coined in 1992 in an endeavour to capture the criteria around which groups form, and “the fact that many groups of people can be characterised in both biological and social ways” (Hacking, 2006: 81). The link between biosociality and matters of health, and in particular matters that relate to vulnerability and risk understood in the (bio)medical sense, is not only immediate, but also analytically fruitful, as it allows to understand the ways in which shared identities create new forms of social aggregation and gregariousness.

“We define “biosocial” as a broad concept referencing the dynamic, bidirectional interactions between biological phenomena and social relationships and contexts, which constitute processes of human development over the life course” (The Biosocial Approach to Human Development, Behaviour, and Health Across the Life Course, PMC, [nih.gov](https://pubmed.ncbi.nlm.nih.gov/))

Herrick (2023), for instance, uses the concept of biosociality to illustrate the forms of co-operation borne out of creating a ‘Clinically Extremely Vulnerable’ (CEV) group of people across the three UK lockdowns during the unfolding of the Covid-19 pandemic. In particular, she points to forms of biosociality that emerge as the CEV sought to collectively make sense of shifting (and at times unclear) guidelines across the imposition and lifting of lockdowns, and to offer support to one another amid crisis.

Membership to CEV — broadly established for the immunocompromised, elderly and pregnant people, though ever-changing slightly — prompted people to create groups on social media to exchange experiences and ask questions by fostering a sense of belonging to the CEV community, or to create and contribute to threads on online forums clarifying or questioning the meanings and implications of government guidelines in relation to shielding at home for often prolonged periods of time. Membership to the CEV group also had substantial political, social and material implications, as it granted access to social support networks, government support, and priority vaccination.

In this case, grouping people together under the shared threat of infection and further serious complications, allowed the government to invite an estimated 25% of the UK population to shield and to create various (social, financial and material) forms of support, while fostering new forms of sociality, collaboration and support around the shared understandings of protection from infection. Although only in passing, Herrick also discusses the idea that the CEV was “a single category which belied significant internal heterogeneity” (2023: 220).

The sections that follow highlight the importance of considering both biosociality and heterogeneous/intersectional identities in health interventions and discourses.

## **Biosociality and target groups’ heterogeneity in breast and ovarian cancer awareness interventions**

Following the voices of target populations that are defined as particularly vulnerable or at risk of developing certain conditions is essential to understanding the complex interplay between identifying and ‘disidentifying’ with a designated group at risk: “while the delineation of ‘at risk’ groups often draws on scientific expertise, biosocial communities may then turn to challenge the expertise and knowledge which first defined them as being ‘at

risk” (Brown et al, 2019: 511). This questions the validity of ‘expert’ definitions that might be contested in practice, and points to the need to make expertise a collaborative and participatory endeavour that involves experts, researchers, participants and members of target groups alike.

A case in point is Brown et al.’s evaluation of a breast cancer awareness DVD distributed in the London borough of Hackney, targeting Black women in particular, due to the concern that Black women aged 25-50 are at increased risk of developing more severe forms of breast cancer at a younger age. The intervention was designed to target 14 GP practices, where women between the age of 25 and 50 whom had defined themselves as ‘Black’ upon registration at such practices were sent the DVD in the post. The DVD juxtaposed images of White, Black and Asian women, inviting viewers to challenge the idea that breast cancer is a disease that primarily affects white women, and promoting the practice of self-examination along with attendance to health screenings. The contents of the DVD, along with the targeting of a particular audience, contributed to the representation of black women as a distinct biosocial community. Brown et al conducted focus groups to evaluate the efficacy of the DVD in promoting breast awareness. Their attention was called to the ways in which the black women who participated in the study collectively questioned and contended the idea that they were a population “at risk”. They articulated complex understandings of themselves — based on shared political identities and struggles, at once claiming and contesting their association with a shared African heritage due to different lifestyle choices, or cultural and community lives. In particular, they sat uncomfortably with “what they perceived as an unproblematised notion of ‘blackness’ that underpinned the message of the DVD and the wider project” (ibidem: 513).

Several participants pointed to their understanding of breast cancer as a disease that mostly affected white women, and to the fact that they felt ‘othered’ or alienated in the way they were indiscriminately grouped together and designated as a group at risk. One participant voiced her disapproval:

So what is it about our colour, you know, and genetics that makes us, considering we’re all different — my dad’s Jamaican and I’m mixed race, this lady’s Somalian, yeah, Africa, see, so — but we’ve all got the same high risk of having an aggressive cancer. (ibidem: 561)

This excerpt crystallises many participants’ questions around what it was exactly about being black that puts them at increased risk of developing breast cancer earlier and in more aggressive forms. Interventions such as this, which rely on creating a shared sense of epidemiological risk to sensitise a particular group to a pressing health issue, need to be sensitive to the heterogeneity within the communities they aim to target, or run the risk of not creating the changes they aim to effect among communities that risk struggling to identify with the category promoted for the intended target population. This issue further speaks to the need to use terminology and representation strategies in health research and interventions that are “precisely defined and acceptable to those being described” (Aspinall, 2002: 803). The analytical counterpoint to

essentialising categorisations in research must then come from collaborative efforts to reconcile scientific and medical understandings with subjective and personal definitions of identity and risk.

In a different paper that resulted from the same study by Brown et al. (2017), other factors that related to women's identities were identified as relevant for engagement with breast awareness initiatives and the uptake of related practices of self-monitoring and screening. Specifically, discussing the same breast awareness DVD, the black women who participated in focus groups prioritized connecting affectively and emotively to the contents of the DVD. They drew connections between their affective ties to their daughters as a powerful motivating force for embracing the practices presented in the DVD and becoming advocates and educators around the issue of breast cancer.

As BME women have been identified as a population at risk of developing breast cancer at a younger age and in more aggressive forms than their White counterparts, increased scientific knowledge of genetics may provide a solution to improve understandings of risk and, subsequently, to implement prevention strategies and practices. To this end, Machirori et al. (2021) investigated the ways genetic technologies for the detection of mutations in genes BRCA 1 and 2 — that can predict the incidence of breast and ovarian cancer — and the diagnoses and clinical discussions that resulted from testing, were received by 15 women residing in the UK and self-describing as being from Black, African, Black African, Black Caribbean or South Asian backgrounds. In participants' accounts, understandings of risk in relation to genetic testing and diagnoses were (unequivocally) the product of the evaluation of various sources of information, and of various personal and familial experiences and perspectives that not only changed according to the social spaces they occupied (as they moved across countries or continents and geographies of familial relationships) but also over time. Having a test result, for instance, meant that women had to fit medical knowledge around the possibility of developing cancer into their already constructed perspective around the heritability of cancer, a task that implied that testing positive without a history of cancer in the family, or a negative result with a history of cancer in the family, were particularly hard to make sense of. Sense making, managing expectations and personal understandings of risk in relation to family history are all elements that point to the need for collaboration between experts and the targets of research and interventions to create shared and accurate understandings of risk and of barriers to health.

These examples speak to the limits of approaches in health interventions or in clinical settings that assume the homogeneous nature of their target groups at risk — “biosociality is a fragile and heterogeneous accomplishment, with implications for the way we practice medical and social science research, design community-targeted public health interventions and conceptualise risk” (Brown et al, 2019: 509). Although a shared sense of belonging can be (and often is) established among those placed in risk categories, the personal life histories, perspectives, experiences, choices, and trajectories that are unique

to each individual that makes up a target group have to be considered and accounted for if an intervention is to be accepted, and effective, for its target population.

## **Biosociality and intersectional identities in experiences of HIV prevention and treatment**

For communities that have historically faced discrimination, sharing their experiences with and rallying around others facing similar circumstances has been key to both improving health conditions and in securing collective rights. For those who have contracted HIV or are at risk of this, Young (2016) explains the endeavour of creating a biosocial community is essential to finding safe spaces, but also to sensitising, educating and protecting gay and bisexual men.

While UK HIV rates are some of the highest in Europe, Young decided to focus on the case of the Northeast of England, where HIV rates remain relatively low in proportion to the population, but rather unexplored as HIV-positive status is usually studied in the more 'ordinary' urban gay spaces of London or Manchester. Conducting semi-structured interviews with 23 men, identifying as gay, bisexual and/or as men who have sex with men, Young found that biosocial communities are key to management of HIV risk, as the existence of such communities allows to establish collective understandings of self-management, and bodily and sexual practices. For instance, these communities shared understandings around the importance of bodily fluids (and around the use of protective barriers or protective measures), physical signs of illness (or lack thereof) and generated empathy, belonging and care through sharing stories of community loss.

Despite the collective sense of responsibility established among communities of HIV+ or at risk of contracting HIV, a subsequent study by Young et al (2019) focused on experiences of HIV in Scotland, "by looking at communities (epidemiologically determined, but socially imagined) and recognising the heterogeneity of these groups tied together through an enhanced risk and/or experiences of HIV" (ibidem: 3). In an endeavour to shape strategies for the impending implementation of TasP (treatment as prevention) and PrEP (pre-exposure prophylaxis) for HIV transmission in Scotland, Young et al set out to explore HIV citizenship to be a form of biological/therapeutically emplaced citizenship, "specific to the experiences of people living with the virus" (ibidem). They conducted interviews with members of the groups most affected by HIV, namely gay, bisexual men and men who have sex with men (20 participants in total), and African migrant men and women (14 participants).

Young et al. understood that HIV treatment and prevention strategies employed by various individuals are "deeply intersectional, influenced by individual medical biography, HIV generations, sexual cultures and beliefs in



biomarkers” (ibidem: 8). Although a ‘biosocial’ sense of responsibility towards others and towards oneself guides choices and management of HIV treatment and prevention measures, the uptake of such measures is primarily dependent on individual histories and understandings of the body, health and illness in relation to HIV. These understandings vary substantially not only between the different groups that make up the ‘HIV community’, but also within said groups. Some participants identified with ideas of ‘toxic’ bodies, both as they carry a viral load and as they are affected by drugs’ side-effects; others are concerned with wasting government and health services resources by either taking up treatment/prevention, or not doing so and causing a delayed but greater burden in terms of cost-effectiveness; others are preoccupied with taking action, ‘fighting’ or taking responsibility for their condition and acting upon this. The complexities of HIV citizenship and the understandings, choices and forms of action that result from being HIV+ or at risk of this all speak to the challenges of conducting research and designing policies and interventions with individuals, groups and communities that define themselves in multiple, overlapping and dynamic ways, eluding neat categorisations.

The strength of intersectional research is brought to the forefront in Doyle’s (2009) work, critical of how recent European research has monitored “the patterns of HIV among the diverse groups of people often confusingly labelled ‘migrants and ethnic minorities’” (ibidem: 175). Based on semi-structured interviews conducted with Black African migrants in London, she highlights the issues of quantitative methods and research that seeks to break complex variables down into separate and unitary items, or to combine apparently similar subjects into single categories for analytic purposes. Taking a qualitative approach, she sets out to explore life with HIV/AIDS for Black African migrants in London with an intersectional understanding that “individual lives and identities are shaped by diverse elements, which are themselves mutually constitutive” (Doyal, 2009: 177).

In the specific case of her research, she studies “the constitutive relationships between ‘being a Black African’, ‘being a migrant’, and ‘being HIV-positive’ as they are played out in London” (ibidem). Several core themes emerge from interviews, pointing to how participants are concerned about their HIV status in relation to their gender identity, their migrant and legal status, their sexual orientation, and understandings of their heritage and of the social/cultural obligations or burdens they would have face in the countries they left behind. Although they appeared relieved because of both the availability of treatment and more liberal (British) attitudes towards their sexual orientation, gay/bisexual men navigated an acutely complex and challenging social life, as their marginalized intersecting identities and HIV+ status compounded. They were often reluctant to disclose their status both as gay/bisexual men and as HIV+, as they found that “there were very few settings in which both these fundamental aspects of their identity could be expressed” (Doyal, 2009: 183). As Doyal concludes (2009: 184):

These brief examples illustrate the value of intersectional approaches in opening up a number of important issues that are too often left unexplored in the existing literature on living with HIV. They can be used to diagnose policy problems and also to prescribe solutions in the context of global, regional and local diversity.

Research that pays attention to intersectional and sensitive issues can thus become a platform for vulnerable groups to express their identities and to feel listened and validated. This offers the possibility to shape spaces of collaboration where researchers can gain significant insights and participants can in turn feel safe and empowered, hence encouraged to share their experiences and their vicissitudes alike.

## **Conclusion**

Understanding biosociality can alert to the ways people define their identity in multiple, overlapping and shifting ways, as individuals or groups, in relation to social, biological and medical facts. The case studies on breast cancer awareness point to how individuals that might be grouped together problematise the very definition of what makes them at risk, and instead connect affectively to the contents of the DVD on breast cancer that they are presented with. Similarly, groups at risk make sense of their status by way of personal histories and geographies of familial relationships. In foregrounding personal histories and identity, individuals and groups can create new ways of advocacy, pointing to the importance of collaboration between recipients of interventions and experts involved in the design and implementation of such interventions.

This further constitutes an invaluable opportunity for researchers to create platforms for individuals and groups that are vulnerable or at a disadvantage, where sensitive issues and stigmatised nodes of experience can be safely shared and understood, as demonstrated in the case of intersectional research that highlights the issues faced by participants who struggle to share aspects of their identity due to stigma and marginalisation. This provides an opportunity for enriching research and creating interventions that are tailored and effective to the needs and struggles of their targets.

## Section 3: Interventions and research that work: communitarian, collaborative and participatory methods and approaches

Table 8 - key points explored in Section 3 of the report

Key points explored
Particular groups are underserved by institutions. Training to promote interventions is one of the keys to success, as involving trained ‘insiders’ contributes to designing and implementing interventions in ways that are flexible, sensitive and attuned to the needs of individuals within broader communities. It is important to engage a full range of methods and to consider the specific people and the place where engagement unfolds, building interventions that are tailored so as to avoid exclusionary methods and research practices.
Foregrounding the narratives of participants and establishing transparent and empathetic communication channels ensure that trust and collaboration are maintained between recipients and providers of interventions and initiatives.
Blanket policies are a double-edged tool. Well informed policies have the potential to benefit multiple groups both within and outside of the direct intervention target group as well as extending the scope and primary objectives of interventions. However, they also run the risk of inaccurately problematising the condition of already marginalised groups.

Table 9 - recommendations for project’s methods that emerge from Section 3

Recommendations for project’s methods
Training, or close collaboration with, “insiders” is key to designing and promoting initiatives that are sophisticated and adapted to the workings of particular communities and groups. This allows to break down institutional barriers to participation, and to design research that limits exclusion, hence preventing bias and inequality.
Transparent, collaborative methods grounded in intra-community co-operation and empathic understanding help to establish trust and shared narratives that foreground the experiences of the subjects of research/recipients. Learning circles are especially effective to create an environment where sharing, discussing and understanding are possible.
Using participatory methods that amplify the voices and experiences of recipients of interventions and of subjects of research is key to avoid essentializing, and to adjust the target of blanket policies. This can be done by reframing target groups and individuals as ‘subject matter experts’, relying on personal diaries and, more broadly, on the collection of first-hand, experiential material.

This section focuses on instances of interventions that work, and on positive mechanisms or factors within larger interventions, including successful strategies to enhance both their positive reception and efficacy. Focusing first on the instance of improving uptake of cancer screening in South Asian communities in the UK, the section discusses how training peers as community health champions can effectively break down cultural barriers to uptake of care, working with (rather than on or around) ‘hard to reach’ communities. The section then turns to interventions aimed at improving

mental health across various vulnerable populations, with a particular focus on the benefits of centring interventions on collaboration between practitioners/clinicians and participants, stressing the importance of bi-lateral communication, and narrative and patient-centred approaches for improving mental health and wellbeing more broadly. The last section discusses blanket policies and their positive impacts, with a focus on obesity and cardiovascular health, along with productive participatory methods that turn the subjects of research and interventions into active *researchers* that can directly contribute to shaping initiatives and their efficacy.

## **Working from within communities to shape effective interventions: the case of cancer screening and ‘hard to reach’ groups (part 1)**

Although the public is able to recognize early cancer symptoms and signs in the UK, attendance to cancer screenings has declined in recent years. One of the approaches taken to tackle this issue is the introduction of community-based health workers (CBHWs) who facilitate initial access of individuals to health care settings (Bellhouse et al., 2018). Conducting a systematic review of literature on the positive effects of CBHWs for early cancer diagnosis, Bellhouse et al (2018) found that CBHWs are associated with a statistically significant increase in cancer screening attendance in ethnic minority groups for three types of cancer: breast, cervical and colorectal.

In the context of cancer screening, ethnic minority groups are often referred to as ‘hard to reach groups’, as they are the groups with the lowest rates of uptake of screening, as well as those most affected by aggressive and advanced forms of cancer at the point of screening and diagnosis. In the UK, South Asian women constitute one of the groups with the lowest screening rates, and with a higher chance of attending visits when breast and cervical cancer are in their more advanced stages. Several barriers have been identified as preventing Pakistani, Indian and Bangladeshi South Asian women (combined, the largest BAME group in the UK according to the Office for National Statistics, 2011) from accessing cancer screening services, namely language barriers, lack of knowledge, gender expectations in particular in relation to family roles, and fears or resistance to receiving care from male professionals (Payne et al., 2022). Payne et al. (2017) note that in conducting a scoping search of the literature, they found no evidence that attempts had ever been made at tailoring cancer screening interventions to the underserved South Asian community.

### **Interlude: problematising the term ‘hard to reach’**

The use of the term ‘hard to reach’ in health research and intervention has been increasingly problematised by institutions and researchers, as it puts the burden of failure to be reached on the very groups that should be specifically targeted through interventions, rather than on the institutions and regulatory bodies that fail to target them. In this way, institutional barriers to health are

redressed as cultural barriers, feeding the cycle of health disparities and inequality.

Rai et al. (2022) address this paradox by exploring how the exclusion of particular groups (that inevitably become defined as 'hard to reach') is built into research practice, reflecting what they term 'methodological whiteness'. As they worked to optimise a home-based blood pressure monitoring intervention, they noticed that "improvements in stroke incidence seen in white populations have not been replicated in racially minoritised groups" (ibidem: 58). They further found that at all levels of intervention (from patient recruitment to data analysis and reporting), racially minoritised and otherwise disadvantaged groups systematically fell through the cracks of the study. Some participants from less privileged backgrounds struggled with reading the material that was provided to them as part of the intervention, but in the presence of researchers downplayed their difficulties, which meant that the intervention was assessed as adequate by the wider research group. This offered a stark contrast to more literate or native speaker participants who gave extensive feedback and often used medical terminology to do so.

Furthermore, since racially minoritised and socioeconomically disadvantaged groups have "more strokes, at younger ages, of greater severity, with worse outcomes and with increased risk of reoccurrence" some participants bore the triple burden of being disadvantaged, having been affected by a stroke, and being likely underrepresented in the intervention (Rai et al, 2022: 63). This is exemplified in the case of Ms A, a South Asian woman whose stroke had left her paralysed from the chest down. She was only able to complete a small part of the study, as she had young children and her husband worked long shifts at the factory; "her life did not 'fit' with the research timeline and requirements. Later, she was keen to re-engage, but it was too late: the study had moved on without her" (ibidem: 66). All of these instances speak to the issues of research that creates institutional barriers for groups that are already disadvantaged, and feeds the cycle of bias as it legitimises the use of the term 'hard to reach groups', shifting the focus from problematic research practices and institutional barriers, to individuals and communities that are systematically underserved.

## **Working from within communities to shape effective interventions: the case of cancer screening and underserved groups (part 2)**

The intervention 'Wise up to Cancer' is a community-based health intervention designed to improve uptake of cancer screening, and pivoting around the training of community members as health champions who would promote a health questionnaire and raise awareness around breast and cervical cancer screening. Payne et al. (2017) trialed the intervention in order to tailor the questionnaire to the South Asian community and conducted semi-structured interviews with 14 stakeholders: women who had received the intervention, health champions and community workers. They found that engaging



community members and peers was particularly effective in breaking down language and cultural barriers, and had a direct impact on participant engagement, revealing issues they would have otherwise not discussed. Speaking the same language and having first-hand experience of culturally grounded issues raised around the questionnaire facilitated understandings and fostered trust between health champions and participants. Furthermore, delivering the intervention in community settings such as schools and religious settings, and engaging women who were considered prominent in the community, had a positive impact on willingness to participate. The strength of the communitarian approach was further resonated in the finding that women often felt more comfortable when asked to fill out the questionnaire individually, but in the company of other women. In all of the instances above, insiders' understanding and sensitivity to the specific needs of community members, which translated into increased flexibility in the study design, allowed to tailor the intervention to the needs of South Asian females, in turn increasing participation in the study, awareness and willingness to get screened.

## **Interventions to improve mental health and well-being: cultural competence, narrative and patient-centred approaches**

Across various qualitative, ethnographic studies and systematic scoping reviews, a few themes are recurrent in the context of evaluating mental health services and interventions from the perspective of users and providers alike. Among these are the relationship with their service providers. Cartwright et al. (2022) report in their scoping review of qualitative literature on the topic forensic mental health service users, that qualities such as empathy, active listening, being non-judgmental and speaking to people 'on their level' are conducive to a productive and positive relationship with their therapist. They also often mentioned that it was easier to establish a rapport based on trust with therapists of the same gender, and a relationship based on understanding with therapists from a similar background. These themes are salient to other investigations and studies around experiences of mental health care across different groups, speaking to the importance of effective communication, a component of the therapeutic relation that is understood as key by service users and providers. Assessing peer reviewed research relating to mental health of Black populations in the UK, Devonport et al. (2022) explored the determinants of health, and interventions intended to enhance experiences of mental health services by comparing mental health by racial and ethnic groups. They found that Black Caribbean and Black African patients, when compared to White groups, are twice more likely to be diagnosed with psychosis, are subject to more frequent and longer hospital stays, are more likely to have the police involved, and have worse recovery from psychosis at 10-year review. They are also less likely to engage with mental health services due to preoccupations around racism, stigma, exclusion, confidentiality, language barriers, and due to lack of knowledge around the services offered.

Devonport et al. further highlighted that a common focus in the literature available on this issue was on using a patient-centered communication style to “allow Black patients a voice in conveying their experiences” (ibidem: 8). This allows insights into experiences of racialised identities, and into rationales for help-seeking behaviours that impact mental health and wellbeing. An instance is that of CaFI (Culturally adapted Family Intervention), designed to assist African-Caribbean individuals diagnosed with Schizophrenia. Pivoting around psycho-educational collaboration between therapists, relatives and service users, CaFI is a culturally adapted intervention that has the double benefit of fostering conversations on addressing understandings of mental illness, offering explicative models, and laying the groundwork for behaviour change, while lessening the power imbalances “inherent in relationships between mental health practitioner and patient, and often magnified when White practitioners work with Black service users” (Devonport et al., 2022: 8). In the context of improving access to psychosocial interventions for depression and anxiety, Gask et al. (2012) similarly stress the importance of cultural competence, which can be seen as a specific form of patient-centeredness, where the clinician tries to enter the patient’s world and to see the illness with ‘the patient’s eyes’. They suggest that clinicians develop ‘shared narratives’ with patients, so as to develop a shared understanding of how the patient conceives the role of the professional, the role of the therapeutic encounter, and appropriate behaviour in responding to illness.

Communication emerges in Bhui et al.’s (2013) review of interventions to improve therapeutic communications between black and minority ethnic patients in contact with specialist mental health services and their staff, especially amongst refugees. They argue that although language barriers have been discussed as a fundamental precursor to the inefficacy of therapeutic interventions, “dissatisfaction and inequalities are also prominent among Anglophone migrants and other people from BME groups who speak English” (ibidem: 2). The causes of dissatisfaction with care, failure to engage with services or accept treatment, and fears about safety and stigma reflect different assumptions underlying causes of treatment for emotional and mental distress. Collaboration between patients and practitioners “to explore diagnostic issues and treatment”, “sets expectations about roles and responsibilities, and implements a core plan and ongoing evaluation” (ibidem). This process is supported by nurturing relationships that reframe the patient as an expert as they work to develop health care goals and strategies in collaboration with professionals.

Bhui reiterates the need to centre assessment of mental health care and treatment plans on “personal narratives and meaning-making, including attention to fractured moral frameworks, moral injury, social injustice and failures of state protections that are distressing, but not easily resolved through health systems” (2022: 1). Bhui thus argues that refugees fleeing conflict, famine, political violence and encountering mental health services should not receive care that is neglectful of their unique narratives and their

intersectional positions, and proposes a 'refugee rose' of approaches, methods and themes that are to be considered when providing mental healthcare to afflicted populations.

The framework for assessment and treatment developed as a result recommends the foregrounding of personal narratives of affliction that detail history, environment, ecology, social and structural determinants of (ill)health; an eco-social approach that stresses compounding factors. The intervention that results "includes learning circles to create connections, improve communication and linguistic skills, reduce social injustice, provide empowerment and agency, leading to less anxiety and depression among refugees" (Bhui, 2022: 3).

## **Blanket policies and participatory methods: the case of obesity and cardiovascular health among youth**

Youth health has been a focus of policy in recent years, especially in relation to the issue of epidemic obesity and being overweight. This is particularly fecund territory for policy; schools across the UK have adopted The Daily Mile as a scheme to increase physical activity within the school day (Hanckel et al., 2019). The Daily Mile (hereon TDM) originated in Stirling, Scotland, in 2012, and requires school teachers to take pupils out of their classroom to run for 15 minutes per day, a time period that allows them to cover the distance of approximately one mile. The initiative is flexible and adaptive, so "teachers can implement it at any time of the day, and in varied weather conditions, without any need for special equipment. It is therefore designed to be a simple, free (in principle) and sustainable intervention which is inclusive for all children" of various backgrounds, genders, physical ability (ibidem: 2).

Hanckel et al (2019) conducted fieldwork in the London borough of Lewisham as part of its Health & Wellbeing Strategy to assess the implementation, intended and unintended effects, and real-life impacts of TDM as the scheme was adopted by five primary schools for pupils aged 5 to 11. Through the use of mixed methods including interviews, focus groups, participant observation and the analysis of secondary data, Hanckel et al observed that the intervention produced several positive effects that were not strictly related to the improvement of cardiovascular health and the reduction of obesity. They observed that, although TDM targeted students who were overweight, it affected all children participating as it increased general physical literacy, along with improving and creating new peer-to-peer relations and teacher-to-peer relations. As a parent interviewed remarked: "I'll be honest there are some children that do have some weight issues, I'm not going to lie, as I said my son's not the slimmest, and he's not the fittest, but I think they all benefit from it, but some more than others" (ibidem: 7). Furthermore, TDM also brought benefits to children from deprived families (29.6% children of Lewisham live in income-deprived households) who would otherwise have no means to carry out physical activity indoors or outdoors.

Although blanket policies that target youth at increased risk of being obese or overweight can prove to be beneficial for a wider group of students, the work of Azzarito (2012) exposes the fallacies of categorising particular groups of youth as more at risk than others. The premise of her work lies in the idea that schools directly contribute to raising awareness around individual discipline, self-management and compliance with normative discourses of healthism and physical activity promotion. The discourse around physical activity and youth tends to centre around homogeneous concern groups, or 'bodies-at-risk', hence around dichotomous thinking through the categories of unhealthy/healthy, different/normal, fit/unfit, with the burden of prejudice falling disproportionately on kids from ethnic minorities. In her endeavour to document physical exercise routines in youth frequenting inner-city, state-run schools in the Midlands, Azzarito engaged 'student-researchers' to use digital cameras to create visual diaries around physical activities and practice. She unearthed the heterogeneity of meanings around moving bodies that can be captured through creative, self-determining visual means. As Azzarito further explains, visual research can reposition young people 'at risk' or 'at disadvantage' as 'experts in their own lives', where "young people's reflections might thus challenge stereotypes, beliefs and ongoing inequalities, by opening up transformative possibilities" (2012: 297). This proved a fruitful research method to explore understandings of health and bodily practices in communities deemed at higher risk of being 'unfit'.

In the case of her ethnographic work, Azzarito reported on the particular case of a young girl, Shreya, born in Mumbai, India, and considered at risk of being unfit and unhealthy in public policy understandings. Following the experiences reported by Shreya in her visual diary, however, it becomes clear that she is greatly invested in recreational, leisure and sports practices, going on walks, playing cricket in the garden with her brother, practicing yoga and Indian dancing every day, and helping with chores around the house. Shreya's instance challenges the stereotyped portrayals of South Asian girls in UK public health reports as 'anti-sport' and physically inactive, and offers a glimpse of what visual methodologies offer, as they allow to counteract narratives that homogenise bodies, struggles and disadvantages by encouraging research subjects to express their own ways of defining themselves.

Visual methodologies engage vulnerable groups and have the potential to reframe such vulnerability by turning the targets of policies and interventions into active *researchers* (not merely participants) in the process of shaping strategies to improve health, unearthing salient nodes of experience that might otherwise be glossed over by 'blanket' risk categorisations. More broadly, arts-based, collaborative research methods have been found particularly effective at bridging the gaps between data, the production of 'living knowledge' and interventions (Byrne et al., 2018). They are also being increasingly used across disciplines to enable and empower participants to make sense of the self, and to inform the development and implementation of policy.

## Conclusion

Several elements that relate to the participation of subjects in research have proved to strengthen accuracy of research and efficacy of intervention and policy. Engaging members of the community to liaise between researchers and participants can provide invaluable insights into community-specific dynamics, allowing to tailor interventions to the needs of individuals and communities. Increasing research flexibility to accommodate community and individual needs also allows to remove the barriers of institutional practices that, if unchecked, can hinder or bias research results, exacerbating the systematic exclusion of particularly vulnerable and already disadvantaged groups.

Reframing participants and target groups as 'subject matter experts' in issues that directly affect and concern them is also essential to prevent generalisation and to gain nuance and richness, and is supported by the establishment of open communication and trust, along with a range of participatory methods such as learning circles and (visual) diaries.

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