



## Review Paper

# A systematic review of the factors - barriers and enablers - affecting the implementation of clinical commissioning policy to reduce health inequalities in the National Health Service (NHS), UK

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## ABSTRACT

**Objective:** The aim of the present study is two-fold. First, it attempts to identify the barriers and enablers of implementing clinical commissioning policy. Second, it synthesises how these barriers and enablers affect the success of National Health Service (NHS) efforts to reduce health inequalities in the UK.

**Methods:** A systematic review was conducted. We searched large biomedical bibliographic databases, namely MEDLINE, EMBASE, CINAHL, Allied & Complementary Medicine, DH-DATA, Global Health and CINAHL for primary studies, conducted in the UK, that assessed the factors - barriers and enablers related to health inequalities, published from 2010 onwards and in English, and reported in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. We used Joanna Briggs Institute (JBI) Critical Appraisal and Mixed Methods Appraisal tools to assess the methodological qualities, and synthesised by performing thematic analysis. Two reviewers independently screened the articles and extracted data.

**Results:** We included six primary studies (including a total of 1155 participants) in the final review. The studies reported two broad categories, under four separate themes: (1) the agenda of health inequalities has not been given priority; (2) there was very little evidence for reducing health inequalities through the clinical commissioning (CC) process; (3) CC was positively associated with the restructuring of NHS; and (4) CC brings better collaboration and engagement, which led to some improvements in health services access, utilisation and delivery at the local level.

**Conclusion:** This study provides useful factors – barriers and enablers – to implement and deliver clinical commissioning policy in improving health and well-being. These factors could be assessed in future to develop objective measures and interventions to establish the link between commissioning and health inequalities.

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## Introduction

The National Health Service (NHS) refers to the government-funded medical and healthcare services that everyone living in the UK can use without being asked to pay the full cost of the

service. People often refer to these service as ‘free at the point of use or delivery’. Most of its health services are publicly funded and most of the money is collected through UK residents paying tax. Everyone counts, working together for patients, improving lives; respect and dignity, compassion and commitment to quality of care are the core values of the NHS.<sup>1</sup>

Since the establishment of the NHS in 1948, several organisational changes have been made, equally influenced by the components of commissioning and health inequalities.<sup>2</sup> The meaning and interpretation of the term ‘commissioning’ is extensively contested, as people often equate this term with contracting,

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assigning, authorising, hiring, and purchasing. Commissioning refers to many actions ranging from the health needs assessment for a population, through the clinically based design of patient pathways, to service specification and contract negotiation or procurement, with continuous quality assessment. Department of Health (UK)<sup>3</sup> defined commissioning as ‘The process of translating aspirations and need, by specifying and procuring services for the local population, into services for users which:

- deliver the best possible health and well-being outcomes, including promoting equality;
- provide the best possible health and social care provision;
- achieve this with the best use of available resources’ (p.11).

The term commissioning in the context of NHS refers to a ‘proactive and strategic process for the planning, purchasing and contracting of health services’<sup>4</sup> to be able to achieve high quality care that is effective and responsive to local people’s and patients’ needs, and ensures value for money (efficiency) for the well-being of communities and securing the best outcomes for local communities by making use of all available resources.<sup>3</sup>

Several authors argue that such action would help moving healthcare services from hospital to community settings, to avoid potential cases of emergency admissions as admissions trends have been observed in an inexorable increase,<sup>5–7</sup> as well as reduced health inequalities that may impact positively on the social determinants of health.<sup>8,9</sup>

Health inequality has been a global public health challenge and is now a key policy priority for every nation, as inequality damages the health of the poor people as compared to the health of the rich.<sup>10</sup> Avoidable health inequalities, therefore, are – by definition – unfair and unjust. The World Health Organization (WHO) defines health inequalities as ‘systematic differences in health status between different socio-economic groups. These inequities are socially produced (and therefore modifiable) and unfair.’<sup>11</sup> Similarly, in Graham’s<sup>12</sup> view, ‘Health inequalities ... are the systematic differences between more and less advantaged groups’.

Over the past 30 years, different strategies, for example, education, housing, the built environment, employment and income, have been implemented to tackle health inequalities, mainly focusing on ‘improving the health of the most deprived groups, and narrowing the gap or universal health improvements’,<sup>13,14</sup> but these issues have not been successfully and appropriately addressed. Still, the impact of health inequalities is very alarming. In England based on those individuals born in 2010, The Marmot Review appraised the existing published literature and reported that people who are currently dying prematurely each year as a result of health inequalities would otherwise have enjoyed, in total, between 1.3 and 2.5 million extra years of life.<sup>15–17</sup> Marmot et al.’s work on health inequalities further concludes that, despite general improvements in health, still a clear gradient appeared, such that people living in the poorest neighbourhoods, will, on average, die 7 years earlier than people living in the richest neighbourhoods.<sup>17(p.10)</sup>

Recently, the most extensive NHS reform has taken place in England with the implementation of the Health and Social Care Act 2012. This Act abolishes primary care trusts (i.e. local statutory organisations, created in 2002, responsible for improving public health and also considered as powerful local purchasing agencies, rooted in primary care),<sup>18</sup> and decentralises the decision-making process, including public health functions and resources to newly formed clinical commissioning groups (CCGs), also called CC.<sup>19</sup> This act includes: (1) a move to clinically led commissioning bringing clinicians closer into decision-making; (2) an increase in public involvement by establishing independent consumer

champion organisations; (3) create Public Health England, an executive agency of the Department of Health, to protect and improve health and to address health inequalities; (4) develop guidance and set quality standards for social care (National Institute for Health and Care Excellence [NICE]); and (5) allow fair competition for NHS funding to independent, charity and third-sector healthcare providers, in order to give greater choice and control to patients in choosing their care.<sup>1</sup> For the first time ever, this act has introduced specific legal duties of the NHS in reducing health inequalities between patients in access to health services and the outcomes achieved by creating the provision of healthcare for all.<sup>20,21</sup>

There is only one main local equity indicator for clinical commissioning groups (CCGs), which is inequality in potentially avoidable emergency admissions and the performance of commissioning against this varies. For example, despite serving the most deprived communities, Liverpool, City and Hackney in London, Fareham and Gosport, East Surrey, Crawley and the Isle of Wight CCGs appeared as the worst performers in most of these indicators, whereas Tower Hamlets and Portsmouth CCGs appeared on the best performers list. Similarly, South Cheshire, Manchester, Blackburn, Darwen and Islington performed badly on inequalities, while East Surrey CCG did well while serving wealthy communities, using emergency admissions as an indicator, i.e. how well the NHS is succeeding in delivering out-of-hospital services to deprived patients with complex long-term conditions.<sup>22</sup> There are local indicators for Improving Access to Psychological Therapies (IAPT) services and plenty of other national inequality indicators so we refer readers or practitioners to see these resources for official NHS equity indicators.<sup>23–26</sup>

A preliminary scan of the work (book, chapter, report or article) using a quick Google Scholar search and PubMed using variations on the ultimate search terms, e.g. clinical commissioning and health inequalities, shows some empirical research on health inequalities in UK settings,<sup>16,17</sup> but the literature has never been systematically reviewed or synthesised focusing on the role of healthcare in reducing health inequalities.<sup>27–30</sup> Second, some related reviews have reported benefits<sup>7,27,31–33</sup> as well as challenges, of commissioning.<sup>32,34–40</sup> Third, health inequalities are an important component of population health and addressing health inequalities is one of the top priorities for clinical commissioning because it is a moral imperative concerning social justice. It is now a legal requirement, and burdens of ill health and disability are more prevalent amongst the most deprived populations, who are least equipped and resourced to make the best and most appropriate use of services.<sup>41</sup> In addition, no systematic reviews have been published looking at these effects.

### Research question

This systematic review aims to answer the question: ‘what the barriers and enablers of implementing clinical commissioning policy are to reduce health inequalities in the English NHS (UK)?’

### Aims and objectives

The aim of the proposed research is to find out the factors – barriers and enablers – of implementing clinical commissioning policy that reduce health inequalities in the English NHS (UK). The objectives to achieve this are two-fold. First, it attempts to identify the barriers and enablers of implementing clinical commissioning policy. Second, it synthesises how these barriers and enablers affect the success of English NHS efforts to reduce health inequalities.

## Methods

This study utilised a systemic review design which involves 'collating all empirical evidence that fits prespecified eligibility criteria in order to answer a specific research question.'<sup>42,43</sup>

### Criteria for considering studies for review

#### Inclusion criteria:

1. Type of studies: To be included, articles had to report specifically on the healthcare commissioning and health inequalities reported in the NHS UK, published between 2010 and 2020;
2. Published articles using quantitative (e.g. cross-sectional, randomised controlled trials, cohort, case–control) or qualitative (ethnography, grounded theory, phenomenological studies); and
3. Article published in English in peer-reviewed journals, with retrieval full texts.

#### Exclusion criteria:

1. Articles not related to commissioning and health inequalities;
2. Articles related to commissioning and health inequalities but not reported or published in the NHS UK;
3. Commentaries, editorials, letters as well as other reviewers, e.g. narrative reviews, scoping reviews; and
4. Studies deemed to have overall poor quality.

### Search strategy

A broad search strategy has been designed to maximise the level of *sensitivity* and *specificity* in searching,<sup>44</sup> and improve both *recall ratio* and *precision ratio*.<sup>45</sup> We searched seven large biomedical bibliographic databases: MEDLINE, EMBASE, Allied & Complementary Medicine, DH-DATA, Global Health, CINAHL and PsycINFO. The literature search used the following terms: "Clinical commissioning"[All Fields], "Clinical commissioning groups"[All Fields]", "GP lead commissioning", "Healthcare disparities"[MeSH Terms], "healthcare disparities"[All Fields], "inequalities in health"[All Fields], "health inequalities"[All Fields], "health inequalit\*" [All Fields], "health inequit\*" [All Fields], using both medical subject heading (MeSH) and free terms to focus and broaden our search results appropriately for commissioning and health inequalities were used in the main search combined with the UK filter developed by Ayiku et al.<sup>46</sup> We utilised the 'Related Articles' including the best match and most recent features in PubMed. Searches were also supplemented by reviewing the reference lists ('references of references') of selected articles to find any other relevant articles. We contacted subject experts/information specialists from authors' universities to verify the research strategy, ensuring its comprehensiveness. We also contacted some study authors to identify additional studies. The literature search was conducted during May–June 2020 and the last search was conducted on 10 June 2020 in order to contemplate the recent studies. The searchers were not limited by study design. A detailed SR protocol with specific search terms has been developed by authors and provided in Additional file 1.

### Study selection strategy

All studies retrieved from the large biomedical bibliographic databases have been screened twice: first, screening of titles and abstracts based on meeting all inclusion criteria. Second, review of

full text of the studies. Both reviewers (KR and OM) were equally involved in both screening stages. For the first level of screening, i.e. screening for the titles and abstracts, we developed and used an abstract template suggested by Polanin et al.<sup>47</sup> to make the process more clear and transparent (Additional file 2). Any discrepancies were discussed and resolved by consensus. The standard Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram was used to provide the process of study selection<sup>48</sup> (Fig. 1). We also completed a PRISMA checklist for this manuscript (Additional file 3).

### Quality appraisal of included studies

We used Joanna Briggs Institute (JBI) Critical Appraisal tools<sup>49,50</sup> and Mixed Methods Appraisal Tool [MMAT]<sup>51</sup> to assess the methodological qualities. These tools have established content validity and have been piloted across all methodologies.<sup>52–54</sup> All six retrieved articles were reviewed by two reviewers (KR and OM), independently, using the standardised 10-item, 9-item and 5-item critical appraisal checklists for qualitative assessment, quantitative and mixed methods studies, respectively. To facilitate comparison of appraisal processes, both reviewers recorded the rationale for inclusion or exclusion, and discrepancies were resolved by consensus. Table 1 presents the results from the critical appraisal.

### Data extraction

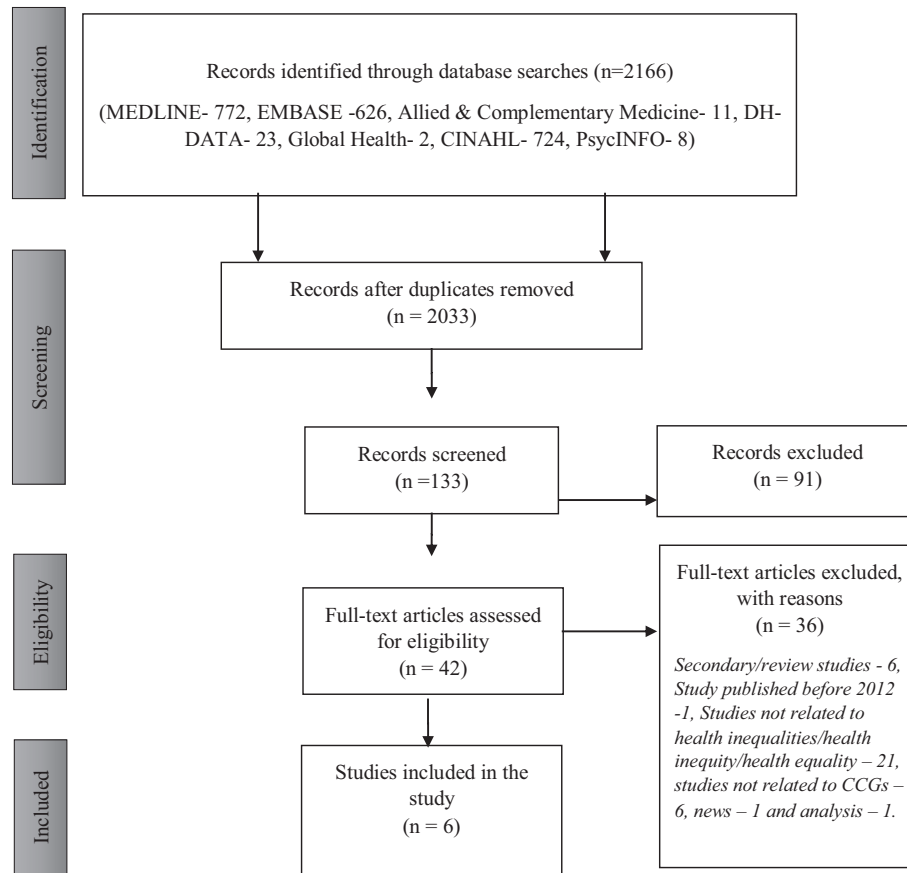
In our review, based on the guidelines produced by the Cochrane Group<sup>55</sup>, we developed a Microsoft Word sheet to extract data. We extracted data on author, aim of the study, theoretical framework/approach, study design, sample size, timeframe, as well as findings reported including the ethical approval (Table 2). When specific data were missing from the retrieved articles, we made attempts to contact the study corresponding authors via LinkedIn, ResearchGate and email. As Rodgers and colleagues note, this would not only improve the process of transparency by better understanding what sorts of data were extracted from which studies, but also recognising the contribution made by each study to the overall synthesis.<sup>56</sup>

### Data analysis and synthesis

Studies in this review were not sufficiently homogenous to analyse using meta-analysis.

We, therefore, analysed primary data combining the findings from both study methods using a convergent integrated approach, i.e. evidence from both qualitative and quantitative studies synthesised simultaneously (i.e. convergent).<sup>57</sup> As this review included more qualitative studies (4) compared to quantitative (1) or mixed methods (1), we adopted The Joanna Briggs Institute's approach of 'qualitising' for analysing data. According to the Joanna Briggs Institute, 'qualitising involves extracting data from quantitative studies and translating or converting it into "textual descriptions" to allow integration with qualitative data.'<sup>58</sup>

We used thematic analysis/synthesis as a method of integration or synthesis where assembled data were categorised and pooled together based on similar meanings or interpretations in themes and subthemes. In thematic synthesis, 'extracted data are coded, followed by grouping of codes which then make up a specific theme'.<sup>59</sup> We presented the results according to themes and then described quantitative and qualitative results in the same section. As Joff<sup>60</sup> suggested, we examined these themes and subthemes on 'their similarities, differences and contradictions', to be able to address the research question about potential barriers and enablers of clinical commissioning on reducing health



**Fig. 1.** PRISMA Flow diagram to show results of searches.

**Table 1**  
Results from the critical appraisal of methodological quality.

Results from critical appraisal of four qualitative studies - JBI Critical Appraisal Checklist for Qualitative Research <sup>49</sup>											
Studies no/Question no	1	2	3	4	5	6	7	8	9	10	
McDermott et al. <sup>62</sup>	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	
Turner et al. <sup>63</sup>	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	
Cheetham et al. <sup>64</sup>	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	
Salway et al. <sup>65</sup>	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	
In total	4/4	4/4	4/4	4/4	4/4	0	1/4	4/4	4/4	4/4	
Results from critical appraisal one quantitative study - JBI Critical Appraisal Checklist for Studies Reporting Prevalence Data <sup>50</sup>											
Study no/question no	1	2	3	4	5	6	7	8	9		
Al-Haboubi et al. <sup>66</sup>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes		
In total	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1	1/1		
Results from critical appraisal one mixed methods study -Mixed Methods Appraisal Tool (MMAT) <sup>51</sup>											
Study no/question no											
Gadsby et al. <sup>67</sup>											
<i>Qualitative components</i>	1.1	1.2	1.3	1.4	1.5						
	Yes	Yes	Yes	Yes	Yes						
<i>Quantitative components</i>	4.1	4.2	4.3	4.4	4.5						
	Yes	No	Yes	No	Yes						
<i>Mixed methods</i>	5.1	5.2	5.3	5.4	5.5						
In total	Yes	Yes	Yes	No	No (due to Low quality)						

inequalities. To generate themes, we followed Braun and Clarke's<sup>61</sup> key steps, e.g. (i) immersion and familiarisation – getting to know more about the data through in-depth reading and re-reading and comparing data across the dataset, (ii) coding – fixing the meaning for a segment of data (a word, phrase, sentence or

passage), (iii) developing and refining themes – involving some constant comparison with the aspects of the whole data, and (iv) organising themes and write-up. The relative contribution of each study to the synthesis is in Table 3. The coding process and the

**Table 2**  
Summary of reviewed studies.

Author	Aim and purpose of study	Theoretical framework/ approach	Study design	Sample size	Time-frame	Key findings	Ethical approval
McDermott et al. <sup>62</sup>	To analyse how CCGs have responded to the new responsibility and to identify challenges and factors that facilitated or inhibited achievement of integrated care systems	• Not provided	• Qualitative – exploratory approach • Data were collected using interviews and national telephone surveys	112	2015–2017	Integration of budgets and commissioning responsibilities; CCGs understood the roles of primary and local needs, new models of care	The study received ethical approval from the University of Manchester's Research Ethics Committee.
Turner et al. <sup>63</sup>	To inform current debates by reporting findings from a series of in-depth interviews conducted with a range of experienced professionals working in varied roles within the health and social care commissioning arena	• Not provided	• Qualitative methods • Data were collected using semi-structured and in-depth interviews	42	2012	Community did not feel any progress on the issue of health inequalities but reported better management due to partnership, commitment and strategic programme approach	Ethical approval was obtained from NRES East Midlands
Cheetham et al. <sup>64</sup>	To examine the factors affecting the design, commissioning and delivery of integrated health and well-being services (IHWs), which seek to address multiple health-related behaviours, improve well-being and tackle health inequalities using holistic approaches	• Not provided	• Qualitative methods • Semi-structured interviews and evaluation were conducted to collect data	16	2015–2016	Challenging organisational context but realised long-term benefits to population health and well-being	Ethical approval was obtained from research ethics subcommittees at Teesside, Durham Universities and NHS R&D approval
Salway et al. <sup>65</sup>	To what extent and in what ways are ethnic diversity and inequity considered within healthcare commissioning? What factors influence this commissioning practice?	• Not provided	• Qualitative method • Data were collected by semi-structured interviews	89	2010–2013	Tackling health inequalities not considered as part and parcel of commissioning	Ethical approval was obtained from the National Research Ethics Service (Nottingham Committee 2, and governance approval
Al-Haboubi et al. <sup>66</sup>	To explore: (i) whether there are inequalities in the use of dental services among adults residing in a socially deprived, ethnically diverse metropolitan area; (ii) satisfaction with services provided; and (iii) public perceptions on possible areas for improvement of local services	• Not provided	• Cross-sectional quantitative • Data were collected using interviews using a structured questionnaire	695	not provided	Community felt positively in terms of service improvement, affordability and accommodation	Ethical approval was obtained from the King's College London Research Ethics Committee
Gadsby et al. <sup>67</sup>	To examine key changes to the public health system following the reforms and explores the broad function of commissioning for health improvement within the new system	• Integrated theoretical framework	• Mixed methods • Data were collected employing multimethods – web-based questionnaire survey and in-depth case studies	201	2014–2015	Raised issues of time, costs and relationship between commissioners and local authorities but positively influenced the prioritisation and decision-making process	Ethical approval was granted by the University ethics committee and research governance approval

development of themes throughout the analysis were discussed among authors.

## Results

We identified 2166 references, scanned 133 titles and abstracts and retrieved 42 publications for full texts. From these, we included six studies that reported data on clinical commissioning and health inequalities<sup>62–67</sup> and excluded 36 studies (Additional file 4). A full report of the study selection process can be found in the Preferred

Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram in Fig. 1.

## Study characteristics

Table 2 shows a summary of the six included studies in the analysis. Of the six, four were qualitative,<sup>62–65</sup> and one article presented cross-sectional quantitative and another mixed methods analysis. Data were collected using semi-structured and in-depth interviews for qualitative studies, whereas both structured

**Table 3**  
The contribution of each study in a thematic synthesis.

Theme	McDermott et al. <sup>62</sup>	Turner et al. <sup>63</sup>	Cheetham et al. <sup>64</sup>	Salway et al. <sup>65</sup>	Al-Haboubi et al. <sup>66</sup>	Gadsby et al. <sup>67</sup>
Roles and performance	●		●			○
Tool/data		○				
Ethnicity				●	●	
Satisfaction					○	
Social grade					●	
Joint strategic needs assessments	○	○				
Priority setting		○				
Context	○		○			○
Organisation and structure	○		●			○
Wider determinants of health			○			
Fragmented and split			●			●
Financial costs and public health budgets	●		●	●	●	●
Change management			○			
Complexity	●					●
Dialogue between commissioners and providers	○		○			
Commitment	●	●	○			
Sharing and engagement	○	●				○
Collaborative, partnership and engagement		○	○			
Prevention and early intervention			○			
Decision-making						●
Health equity and inequality	●	○	●	●	●	
Pessimistic approach		●				
Prioritisation						○
Improve services	○			○	○	○
Contracts and retendering	●		●			●
Politicised			●			
Uncertainty and delays			●			
Relationships and responsibilities between councils and CCGs	○		○			●
Impact at a local level	●		●		○	
Alignment with the strategic priorities of prevention and early intervention	○		○	○	○	

○ facilitator; ● barrier; ● facilitator and barrier.

questionnaire surveys and in-depth interviews were used for quantitative and mixed methods studies. A total of 1155 participants (range: 16–695) participated in the included studies. All studies were conducted between 2010 and 2020 and focused on the NHS in England, UK. Quality assessments have been used for those six included studies. Out of standardised 10-item critical appraisal checklists for four qualitative studies, one article scored nine items<sup>63</sup> and three articles scored eight items.<sup>62,64,65</sup> Nine out of nine scored nine-item critical appraisal checklists for quantitative assessment for one article,<sup>66</sup> and the final article scored five out of five (for the qualitative component) and three out of five (for the quantitative component) from five-item critical appraisal checklist mixed methods studies.<sup>67</sup>

All studies clearly stated some theoretical premises as well as methodological approaches on which their studies were based. Similarly chosen methodological data collection methods and analysis techniques were reported appropriately. However, in four studies,<sup>62–65</sup> researchers' cultural and theoretical orientation and

their relationships between the researchers and the study participants were not described in detail. Similarly, in the quantitative component of the mixed methods study, researchers did not sufficiently discuss the integration of the findings from the qualitative and quantitative components. As Pluye et al.<sup>53</sup> suggested, different strategies such as reconciliation, initiation, bracketing, exclusion or triangulation would help to minimise these errors. Further details of the critical appraisal can be found in Table 1.

#### Findings of the review

This study is organised under four major themes/findings which emerged.

**Finding 1: An overwhelming majority of the articles (five of six articles, 83%) indicated the agenda of health inequalities has not been given priority by clinical commissioning.**

The primary and overriding finding of this study is that clinical commissioning (CC) has not given health inequalities a priority agenda of the commissioning process. 69% ( $N = 480$ ) of study

participants who visited health services in the last two years reported that there were inequalities in the use of health services.<sup>66</sup> The study further reported that inequalities exist more among adult females (73%, adjusted prevalence ratio (PR) 1.14, 95% confidence interval [CI]: 1.03–1.27), among Asian ethnicity (85% Adjusted Prevalence Ratio (PR) 1.21, 95% CI: 1.03–1.43) followed by Black (65% adjusted prevalence ratio (PR) 0.94, 95% CI: 0.82–1.08) mostly among the age group of 45–55 years (79%, adjusted prevalence ratio (PR) 1.13, 95% CI: 0.92–1.38).<sup>66</sup>

Some evidence indicated that CC was more considered a public health activity to determine health needs of individuals or populations by identifying, assessing and prioritising their needs and actions as general public health functions rather than a commitment to reducing health inequalities.<sup>62</sup> One article, however, reported that CC has been used as a tool to improve service improvements to address inequalities.<sup>63</sup> Participants expressed these aspects thus:

Commissioning was considered one of the broad aspects of public health activity [...] identifying needs, reviewing service provision, deciding priorities, procuring services, and managing performance.<sup>67</sup>

Responsibility for the health inequalities agenda was seen primarily as a function of public health roles rather than part and parcel of core healthcare commissioning work, even where PCTs had adopted explicit strategic priorities relating to inequalities.<sup>63</sup>

CCGs understand primary care and local needs. Allowing CCGs to commission primary care alongside other services would support the development and implementation of local strategies for service improvement, support innovation in primary care and allow investment in primary care (by allowing resource shifting).<sup>62</sup>

**Finding 2: More than half of the articles (four of six, 67%) reported reform through restructuring and organisations, and strategic approaches in collaboration, commitments and engagement as benefits of commissioning in healthcare.**

The benefits of clinical commissioning have been reported across different studies. The commonest factors associated with the benefits of clinical commissioning are collaborative, partnership and engagement,<sup>62,64,67</sup> alignment with the strategic priorities of prevention and early intervention,<sup>62,64,66</sup> dialogue between commissioners and providers,<sup>62,64</sup> joint strategic needs assessments,<sup>62,63</sup> and planning and prioritisation.<sup>63,67</sup> Based on further analysis of the articles, three major benefits emerged:

a) *Context and restructure of services*: Since the Health and Social Care Act (HSCA2012), the commissioning process has been much better in terms of understanding the wider social-political context of local healthcare, recognising wider consultation on decision-making to plan and deliver health services involving local elected people and organisations. Similarly, this reform has relocated public health from NHS to local government, and prepared staff for transition to deliver integrated approaches.<sup>66(p.4)</sup> The following extracts illustrate issues relating to service context and restructure:

The relocation of public health from the NHS to local government provided important context for the introduction of integrated health and well-being services. Participants in both sites felt there were new opportunities to work across local authority directorates to address the wider determinants of health and health inequalities.<sup>64</sup>

There is wider consultation on decisions in the local council setting than in the NHS, and elected members now have a strong influence on public health prioritisation. There is more (and different) scrutiny being applied to public health contracts, and most councils have embarked on wide-ranging changes to the health improvement services they commission. Public health money is being used in different ways as councils are adapting to increasing financial constraint.<sup>67</sup>

b) *Strategic approaches - service integration and commitment*: CC offers greater knowledge and understanding of integrating local health services reflecting data to local health plans. McDermott et al.<sup>62(p.7)</sup> further add that “Integrated care [in the context of CC] requires detailed local work to build trust and develop context-specific mechanisms to work across boundaries.” Similarly, a great commitment through investment has been given within council services to improve public health to meet needs and expectations. Included articles reported these aspects as follows:

Potential for greater integration of knowledge and data on local communities, stronger Joint Strategic Needs Assessments (JSNAs) and better understanding of needs, was noted with the move of public health to Local Authorities. In addition, new structures, particularly the health and well-being board, created the possibility of new opportunities for representation.<sup>63</sup>

Greater recognition of public health objectives and expected outcomes in a wider range of council services as a result of public health investment. And we saw public health staff working hard to influence the wider workforce.<sup>67</sup>

Both local authorities had a long-term strategic commitment to community development and asset-based approaches, which was seen as beneficial by public health commissioners.<sup>64</sup>

c) *Partnership and engagement*: The association between CC and wider healthcare partnership and engagement has been reported positively in terms of meeting healthcare needs by reducing duplication costs/resources and sharing knowledge and expertise. These studies conveyed this view:

Expressed concerns that CCGs would have to start a lot of community engagement work from scratch and develop meaningful relationships with key communities. Engagement was seen by many participants to be important not just for understanding population needs, but also in commissioning services that effectively meet those needs.<sup>63</sup>

... recognised and articulated the potential added value of collaborative working between NHS and local authority partners, plus the third sector in WFL. Anticipated benefits included reducing duplication, extending the reach of existing services and programmes, sharing expertise and capacity and maximising opportunities for innovation. The idea of offering a more streamlined accessible approach, which seeks to knit together a number of different functions was broadly welcomed.<sup>64</sup>

GPC endorsement of the social model of health underpinning LWG and WFL, there was also broad acceptance of prevention and early intervention, recognised as being more cost-effective than long-term treatment.<sup>64</sup>

**Finding 3: All six articles (100%) indicated that there was some poor evidence for reducing health inequalities through the clinical commissioning process.** The commonest associated factors were:

(i) lack of commitment or focus on health equity and inequalities,<sup>62–66</sup> (ii) uncertainty and delays in resource allocation,<sup>62,64–67</sup> (iii) lack of trust and clarity in terms of the roles and performance<sup>62,64</sup> and poor relationship between the councils and CCs in planning and decision-making.<sup>62,64,67</sup> These barriers have been broadly categorised into two levels:

a) *Structural impediments*: All articles reported that in commissioning, the decision-making process was a challenge as it demanded wider consultation with a range of policy-planners, politicians, and decision-makers at local levels. Since the implementation of CCs, the positioning of public health teams at the local level varied mostly due to the unprecedented cuts to their budgets. One survey found<sup>67</sup> that 26% ( $N = 73$ ) of the public health teams were distinct public health directorates; 52% were sections of another directorate; and 22% had other arrangements, including merged, distributed and mixed models. Directors of public health (DsPH) also had different levels of access to key council decision-making bodies (53% of DsPH respondents were members of the council's most senior corporate management team), and different line-management structures (47% said that they were managerially responsible to the council's chief executive; 53% were managed by a range of other directorate heads). Because of such changes, DsPH therefore were not always in the best place for strategic influence in the council. Similarly, studies reported commissioning responsibilities have been fragmented between different organisations (NHS England, Public Health England (PHE), local councils and CCGs), and co-ordination was slow, difficult and bureaucratic.<sup>64,67</sup> Therefore, there was serious concern raised not only about diluting local authorities' action on health inequalities, but also failing to recognise and reduce health inequalities because of poor direction from central government and poor commissioner engagement in health services commissioning.<sup>63,67</sup> The extracts below illustrate this:

Decision-making within councils was found to be very different to that within PCTs. Decision-making across the local system following the reforms was intended to be more co-ordinated. However, with commissioning responsibilities now fragmented between NHS England, Public Health England (PHE), local councils and Clinical Commissioning Groups (CCGs), our research found that co-ordination was proving to be difficult.<sup>67</sup>

Poor track record of shifting resources out of secondary care and into the types of primary care and public health interventions felt to be capable of achieving a significant impact on health inequalities.<sup>63</sup>

b) *Personal impediments*: More than half of the articles reported personal impediments (three of six, 50%) to reducing health inequalities in the CC process. Commissioners' inadequate level of knowledge and expertise, poor trust/relationships between local authorities and staff involved in the commissioning process, poor partnership, working in different geographical locations and engagement, and a largely pessimistic approach have been reported as major challenges.<sup>63</sup> Some extracts below illustrate this:

Most commissioners did not view identifying and tackling ethnic inequalities in healthcare access, experience or outcomes as part-and-parcel of their job due to lack of clarity about their responsibilities.<sup>67</sup>

Pressures to get both services 'off the ground' quickly, coupled with different organisational cultures, a history of competing for contracts and mistrust arising from short-term contracts and

reducing budgets, may have destabilised early efforts to build relationships among staff and with communities.<sup>64</sup>

While asking about commissioners' influence and contributions, 92% of elected members responding to our survey ( $N = 38$ ) said they felt always able (45%) or quite often able (47%) to influence the priorities of the public health team.<sup>67</sup> In addition, there is now a greater disconnect between public health officers and NHS commissioners. In response to this survey, 48% of DsPH ( $N = 69$ ) said they felt 'less able' to influence local CCGs than before the reforms. This study found that evidence of meaningful engagement between public health teams and CCGs was limited.<sup>67</sup>

**Finding 4: Most articles (four of six articles, 67%) indicated improving health services, appropriate policy and approaches should be in practice.**

These studies reported service improvement associated with availability, affordability, and accommodation or flexibility of services.<sup>66</sup> Similarly, organisational contexts and appropriate translating of evidence into practice were factors reported that influence health services locally improving. Though health and well-being boards were meant to be the mechanism for coordinating commissioning across NHS, social care and public health at the strategic level, our survey found that amongst DsPH ( $N = 65$ ), 48% felt the Health and Well-being Board (HWB) was 'definitely' instrumental in identifying the main health and well-being priorities, and 45% felt it had 'definitely' strengthened relationships between commissioning organisations.<sup>67</sup> However, less than 5% felt that the Health and Well-being Board was 'definitely' making difficult decisions, and only 28% felt that it had 'definitely' begun to address the wider determinants of health, including health inequalities.

The extracts below highlight some relevant issues:

Greater accountability of healthcare commissioners to the public and more influential needs assessments via emergent Health and Well-being Boards.<sup>63</sup>

Investment and opportunities contained in national and local initiatives were seen as major contributors to enabling CCGs achieving a people-centred, locally driven, integrated primary care service with general practice.<sup>62</sup>

## Discussion

The main finding of this study is that there is very little evidence in the peer-reviewed literature of clinical commissioning policy having any noteworthy impact on reducing health inequalities. In this review, only six studies met our inclusion criteria from over 2166 citations in the major biomedical bibliographic databases. This study has clearly highlighted factors related to both benefits and challenges. Better collaborative partnership engagement and alignment with the strategic priorities, dialogue between commissioners and providers and joint strategic needs assessments and planning and prioritisation are revealed as the key enablers for the success of CCs and health inequalities.<sup>62–64,66</sup> The study, however, reported clear gaps due to different commissioning structures, different roles, financial pressures, accountabilities, trust and relationship between the councils and CCs in planning and decision-making, GP skills and competencies, organisation experience and local contextual conditions, to address inequalities in policy and practice.<sup>62–66,68</sup>

These identified different barriers and enablers (Table 3), are appropriately aligned with the Marmot health inequalities review, stating that health inequalities are determined by a complex mixture of factors, despite the fact that Marmot review was



conducted before implementation of the Health and Social Care Act 2012.<sup>1,20</sup> In 2008, Marmot was asked by the then UK Secretary of State for Health to conduct a review of health inequalities to assemble the evidence appraising the existing published evidences, and advise on the development of a health inequalities strategy in England from 2010. The review was published as 'The Marmot Review' in 2010.<sup>69</sup> The key themes reported from this review were: reducing health inequalities is a matter of fairness and social justice, action is needed to tackle the social gradient in health through proportionate universalism (providing universal services with added intensive support for those in greatest need), action on health inequalities requires action across all the social determinants of health, reducing health inequalities is vital for the economy, and effective local delivery requires particularly effective decision-making at the local level.<sup>17</sup> Marmot<sup>17</sup> also argued that 'addressing health inequalities at earlier stages of life was the surest way to reduce the long-term incidence of health inequalities'. NHS also reported that 'reducing health inequalities improves life expectancy and reduces disability across the social gradient. Tackling health inequalities is therefore core to improve access to services, health outcomes, improving the quality of services and the experiences of people.'<sup>70(p.11)</sup>

Due to implementation of CC, this study has found targeted and integrated approaches which would be beneficial to improve health and reduce health inequalities. It is because the remit of commissioning involves assessment of local needs, as well as deciding priorities and strategies and purchasing services for local populations, which is called *strategic purchasing*.<sup>62,71</sup> CC has been viewed as a new and integrated model of care, holding promise for addressing inequalities largely at the provider:patient interface.<sup>72,73</sup> We also argue that through CC, it is not just about having enough GPs, but also whether they listen to the whole community.<sup>73</sup>

Our study also found that power and decisions have been shared with communities and service providers, but still there are some gaps or challenges in terms of transformation of funds and availability of funds to run community services, and their priorities are structured differently.<sup>74</sup> Therefore, changing the culture of communities from passive consumers to active partners would be one of many options to make wider access to healthcare possible.<sup>73</sup> Atkins et al.'s finding in this context might be useful, because they suggest that we: "should work more clearly with local government public health team to define research questions [issues] through the lenses of local government and their proprieties and imperatives, taking into account the context of the significant loss of resources local government are dealing with."<sup>75(p.15)</sup>

Similarly, in CCs, changing responsibilities mean these two partners (health services and local government) have to think afresh about the way they address these issues and of course, things like devolution, e.g. CC gives us a new opportunity to look at this.<sup>76</sup> This also aligns with the findings of Baroness Thornton and colleagues, showing that the NHS can do things to help tackle inequality, addressing the social determinants of health and the wider factors.<sup>73</sup> Moran et al.'s<sup>74</sup> survey of over 2600 GPs claimed that though approximately 30% of the GPs agreed that commissioning was part of their role and responsibilities, most of them also agreed that their involvement would add value to the commissioning process in terms of influencing and addressing the local healthcare needs. The NHS Commissioning Board complements existing research, claiming that 'clinical leadership would significantly improve their performance in their practices' in the NHS.<sup>20</sup> Clinical leadership is, therefore, considered 'central to all models of primary care-led commissioning', involving both the components of service improvement and service redesign.<sup>39,62</sup> In fact, such interpretations are supported by earlier work,<sup>20,70</sup> i.e. effective

GP engagement to take on a greater level of responsibility in the commissioning of primary care services would be an important role, as reported by our own study.

Williamson<sup>77</sup> supports this view, stating that through better understanding of health needs and gaps, we can create some effective service models and care pathways. Similarly, this study also supports Smith et al. emphasising that: 'competent commissioning may help ensure appropriate monitoring and review of current services, the design and planning of necessary changes, and setting of priorities for funding.'<sup>8(p.12)</sup> Another study conducted by Atkins et al.<sup>75</sup> among public health directors and healthcare practitioners acknowledged that they need to develop service commissioning skills.

This study has further highlighted that one of the challenges GPs faced was due to poorly defining their roles in clinical commissioning, as well as the size of population they should cover.<sup>78</sup> Similarly, frustration at work among GPs, mainly due to increased volume of work and lack of resources, has been reported as a major barrier since the implementation of Health and Social Care Act, 2012, which has also been reported in Humphery and Claver's findings.<sup>79</sup> Working in collaboration with a wide range of stakeholders would help develop appropriate local healthcare strategies and evidence-inform policy in practice.<sup>75,80</sup> Unequal distribution of funds between primary and secondary care, resulting in inefficiencies and poor performance, have also been reported as other barriers. As reported in the previous study, we also found some limited attention to ethnic diversity and inequality within healthcare commissioning.<sup>81</sup> From the users' perspective, our study has reported that users' demand and expectations, in line with the demographic changes, would certainly influence GPs' ability in terms of (re)designing and (re)shaping primary healthcare services at the local level, as highlighted in other similar studies.<sup>69,79,82–84</sup> Therefore, as Checkland et al.<sup>78</sup> suggested, it is important to support the development of new models of service provision and work more closely with LAs, other providers (e.g. voluntary sector) and other local bodies (e.g. health and well-being boards) for commissioning of primary care services.

#### *Strengths and limitations of the review*

To our knowledge, this is the first systematic review to examine the factors – barriers and enablers – since the implementation of CC for improving health quality and reducing health inequalities in the English NHS. This review was conducted using a comprehensive search strategy, developing a systematic review research protocol and also attempting to address a particular review question, i.e. 'what are the barriers and enablers of implementing clinical commissioning policy to reduce health inequalities in the English NHS (UK)?' using both qualitative and quantitative evidences. DH<sup>3</sup> and NHS Improvement<sup>85</sup> proposed some commissioning cycles, but how a commissioning model would be meaningful in addressing health inequalities has not been reported before. CC is a continuous strategic assessment process. To make an effective link between CC and reducing health inequalities, it is important to make a stronger link between public health and broader work on the social determinants of health; putting people at the centre of the framework ensures their needs are appropriately met by providing best-quality care in primary care services. The process would also give more immediate results in improving public health, making it part of the local political landscape.<sup>86</sup> It is, therefore, important to routinely monitor the inequalities in access and health outcomes, acknowledging the skills and capacities of GPs and other healthcare providers in leadership and governance and ensure they can fulfil their operational and strategic roles effectively, efficiently and equitably.<sup>68,87</sup>

It is important to highlight that there is only one main local equity indicator for CCGs, which is inequality in potentially avoidable emergency admissions (called CCG improvement and assessment framework indicator)<sup>88</sup> but there are local indicators for improvement access to psychological therapy services (see more – the NHS equity right care packs<sup>24</sup>), and there are plenty of other national inequality indicators. CCGs were supposed to set their own quantitative local equity indicators and ambitions as part of the five-year plan, but most have failed to do so. National health inequality monitoring is better, but national monitoring does not help with local quality improvement and accountability – no individual CCG, hospital, GP practice or clinician is responsible for the national inequality picture, and so they can all safely ignore the national picture, which we consider a missed opportunity.<sup>89</sup> Therefore, the big policy issue is how to get CCGs to take this seriously – not just talk about it, but actually set quantitative equity indicators for their own local equity performance compared with similar CCG areas that can be monitored over time. An important analytical issue is how to monitor ethnic inequalities as well as deprivation-related inequalities – this is very difficult as ethnicity coding is weak. We argue that the identified factors from this study perhaps could be helpful for formulating appropriate indicators to monitor inequalities related to health at the NHS hospitals and GP practices.

Similarly, we need to get NHS equity performance indicators developed for hospitals and GP practices that benchmark their equity performance against the populations served by similar organisations. Provider organisations are the ones with power and influence so in a way equity monitoring for them would be more important than equity monitoring for CCGs which are rather feeble organisations lacking clout.<sup>89</sup>

This review has, however, some limitations. First, a potential limitation of this study is that as the study is internally funded, and therefore time and resource were constrained, we were unable to include and review grey literatures, thus studies could have been missed which may present another potential source of bias. However, efforts were undertaken to identify all relevant studies associated with clinical commissioning and health inequalities, using seven well-known major bibliographic databases. Second, there is a small number of studies conducted on the topic that meet the inclusion criteria, which brings a relatively small pool of research. This was unavoidable as we have clearly set out the timeframe as well as the country of publication. Third, studies are variable in sample size, quality and population which are open to bias, besides which the heterogeneity of data precludes a meaningful meta-analysis to measure the impact of specific enablers or barriers, therefore the findings warrant generalisation. Fourth, despite overall good methodological quality of the included articles, some studies provided inadequate descriptions of study methods and procedures.<sup>62,63,67</sup> We, however, added a detailed description of study methods and procedures. This review has been reported in accordance with the PRISMA statement for systematic reviews.<sup>48</sup> In addition, we also completed a 27-item PRISMA checklist (Additional file 3). Fifth, as Maden<sup>90</sup> reported while considering health inequalities in systematic review, 'there was no validated search filter for health inequalities'; therefore it was difficult to search the databases using the exact terms. However, we used these terms based on those used in a Cochrane methodological review, exploring how effects of health inequalities are assessed in SRs.<sup>91</sup>

## Conclusion

The current systematic review highlighted that effective CCGs are essential to promote equality, improve health outcomes and reduce health inequalities. This review recognises that improving social condition is important to improve people's health, as both

social and economic inequalities are bad for health inequalities. This study provides useful factors – barriers and enablers – to implement and deliver CC policy in improving health and reducing health inequalities. These factors could be assessed in future monitoring/evaluation of local primary care services. Further research is needed to find the best methods and approaches in terms of developing objective measures and interventions to establish the link between clinical commissioning and health inequalities improving equitable access, health outcomes and effective partnerships.

## Author statements

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### Competing interests

None declared.

### Authors contributions

KR conceived and designed the study with the advice from OM; KR and OM reviewed, analysed and interpreted the data and contributed to drafting, revising and finalising the manuscript. All authors read and approved the final version of this manuscript.

## Appendix A. Supplementary data

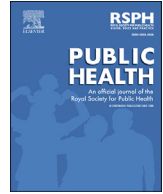
Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2020.07.027>.

## References

1. NHS England. *Understanding the new NHS*. 2014. Available at: [www.england.nhs.uk/nhsguide/](http://www.england.nhs.uk/nhsguide/). accessed 17 July 2020.
2. World Health Organization. *Regional office for Europe, European observatory on health systems and policies & boyle S. United kingdom (England): health system review*. World Health Organization. Regional Office for Europe; 2011.
3. Department of Health (DH). *Commissioning framework for health and well-being*. London: DH; 2007.
4. Smith J, Woodin J. Purchasing healthcare. In: Walshe K, Smith J, editors. *Healthcare management*. Maidenhead: Open University Press; 2011.
5. Institute of Public Health. *Commissioning for health and social care*. London: Sage; 2014.
6. Smith JA, Curry N, Mays N, Dixon J. *Where next for commissioning in the English NHS? Nuffield Trust*. King's Fund; 2010.
7. Smith JA, Mays N. GP led commissioning: time for a cool appraisal. *BMJ* 2012;**344**(Feb 16 2). e980–e980.
8. Heginbotham C, Newbigging K. *Commissioning health and wellbeing*. London: Sage; 2014.
9. Smith J, Wistow G, Holder H, Gaskins M. Evaluating the design and implementation of the whole systems integrated care programme in North West London: why commissioning proved (again) to be the weakest link. *BMC Health Serv Res* 2019;**19**(1):228.

10. Marmot M. *The health gap: the challenges of an unequal world*. London: Bloomsbury Publishing; 2015.
11. Whitehead M. The concepts and principles of equity and health. *Int J Health Serv* 1992;**22**(3):429–45.
12. Graham H. *Understanding health inequalities*. Maidenhead: Open University Press; 2009.
13. Bambra C, Gibson M, Sowden A, Wright K, Whitehead M, Petticrew M. Tackling the wider social determinants of health and health inequalities: evidence from systematic reviews. *J Epidemiol Community Health* 2010;**64**(4):284–91.
14. Asaria M, Ali S, Doran T, Ferguson B, Fleetcroft R, Goldblatt P, et al. How a universal health system reduces inequalities: lessons from England. *J Epidemiol Community Health* 2016;**70**(7):637–43.
15. Mazzucco S, Meggiolaro S, Suhrcke M. *The economic benefits of reducing health inequalities in England*. 2009. Available at: <http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-themarmot-review/fair-society-healthy-lives-full-report-pdf.pdf>. accessed 10 July 2020.
16. Frontier Economics. *Overall costs of health inequalities. Submission to the Marmot Review*. 2009. Available at: <http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review/fair-society-healthy-lives-full-report-pdf.pdf>. accessed 10 July 2020.
17. Marmot M. Fair society, healthy lives: the Marmot Review – strategic review of health inequalities in England post-2010. London: *The Marmot Review* 2010.
18. Smith J, Mays N. Primary care trusts: do they have a future? *BMJ* 2005;**331**(7526):1156–7.
19. Department of Health (DH). *The NHS constitution*. London: DH; 2009.
20. UK Government. *Health and social care act-2012*. London: DH; 2012.
21. Great Britain. *Department of Health. Equity and excellence: liberating the NHS*. London: Stationery Office; 2010.
22. Health SB. NHS success in tackling health inequality varies hugely across England. Available at: <https://www.theguardian.com/society/2016/aug/20/poor-healthcare-leading-to-hospital-admissions-shows-no-social-divide>. [Accessed 14 July 2020].
23. National Health Service. *Reducing health inequalities resources (NHS England)*. London: NHS; 2020. Accessed at: <https://www.england.nhs.uk/about/equality/equality-hub/resources/>. accessed 9 July 2020.
24. National Health Service. *Health inequality NHS right care packs (NHS England)*. 2020. Accessed at: <https://www.england.nhs.uk/rightcare/products/ccg-data-packs/equality-and-health-inequality-nhs-rightcare-packs/>. accessed 9 July 2020.
25. University of York. *Local health equity indicators for the NHS in England*. York: University of York; 2020. Accessed at: [https://www.york.ac.uk/che/research/equity/monitoring/Local equity indicator data packs for England](https://www.york.ac.uk/che/research/equity/monitoring/Local%20equity%20indicator%20data%20packs%20for%20England). accessed 9 July 2020.
26. University of York. *Local equity indicator data packs for England*. York: University of York; 2020. Available at: <https://www.york.ac.uk/che/research/equity/monitoring/packs/>. accessed 9 July 2020.
27. Balkham A, Alderson S. 'The biggest car crash in NHS history': the media portrayal of GP pay before and after the introduction of the Health and Social Care Bill 2011. *Prim Health Care Res Dev* 2017;**18**(1):84–91.
28. Exworthy M, Blane D, Marmot M. Tackling health inequalities in the United Kingdom: the progress and pitfalls of policy. *Health Serv Res* 2003;**38**(6p2):1905–22.
29. Exworthy M, Bindman A, Davies H, Washington AE. Evidence into policy and practice? Measuring the progress of U.S. And U.K. Policies to tackle disparities and inequalities in U.S. And U.K. Health and health care. *Milbank Q* 2006;**84**(1):75–109.
30. Stewart J. *The Government of uncertainty*. London: Institute for public policy and research; 1990.
31. Mannion R. General practitioner commissioning in the English National Health Service: continuity, change, and future challenges. *Int J Health Serv* 2008;**38**(4):717–30.
32. Takundwa R, Jowett S, McLeod H, Peñaloza-Ramos MC. The effects of environmental factors on the efficiency of clinical commissioning groups in England: a data envelopment analysis. *J Med Syst* 2017;**41**(6):97.
33. Wenzl M, McCusker S, Mossialos E. Commissioning for equity in the NHS: rhetoric and practice. *Br Med Bull* 2015;**115**(1):5–17.
34. Porter A. *David Cameron's NHS reforms are now a 'car crash', says Alan Milburn*. *Telegraph*. 2011. Available at: <https://www.telegraph.co.uk/news/politics/8578022/David-Camersons-NHS-reforms-are-now-a-car-crash-says-Alan-Milburn.html>. accessed: 14 July 2020.
35. Oliver AME. Equity of access to health care: outlining the foundations for action. *J Epidemiol Community Health* 2004;**58**(8):655–8.
36. Fleurbaey M, Schokkaert E. Equity in health and health care. In: Pauly MV, McGuire TG, Barros PP, editors. *Handbook of health economics*. New York: Elsevier; 2012.
37. Timmins N. *Healthcare model set for radical shake-up*. Financial Times; 2010. Available at: <https://www.ft.com/content/6e0d14e6-a88c-11df-86dd-00144feabdc0>. accessed: 14 July 2020.
38. Allin S, Grignon M, Le Grand J. Subjective unmet need and utilization of health care services in Canada: what are the equity implications? *Soc Sci Med* 2010;**70**(3):465–72.
39. Marshall M, Holti R, Hartley J, Matharu T, Storey J. GP leadership in clinical commissioning groups: a qualitative multi-case study approach across England. *Br J Gen Pract* 2018;**68**(671):e427–32.
40. Dixon M. Clinically led commissioning – joyous liberation or here we go again? *J R Soc Med* 2012;**105**(5):217–20.
41. National Health Service Crawley CCG. *Equality and health inequalities pack*. NHS Crawley CCG; 2018.
42. Antman EM, Lau J, Kupelnick B, Mosteller F, Chalmers TC. A comparison of results of meta-analyses of randomized control trials and recommendations of clinical experts. Treatments for myocardial infarction. *J Am Med Assoc* 1992;**268**(2):240–8.
43. Oxman AD, Guyatt GH. The Science of reviewing research. *Ann N Y Acad Sci* 1993;**703**(1 Doing More Go):125–34.
44. Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, et al. *Cochrane handbook for systematic reviews of interventions*. Chichester: Wiley; 2019.
45. Katcher BS. *Medline: a guide to effective searching in PubMED & other interfaces*. San Francisco: The Ashbury Press; 2006.
46. Ayiku L, Levay P, Hudson T, Craven J, Barrett E, Finnegan A, et al. The medline UK filter: development and validation of a geographic search filter to retrieve research about the UK from OVID medline. *Health Inf Libr J* 2017;**34**(3):200–16.
47. Polanin JR, Pigott TD, Espelage DL, Grotperter JK. Best practice guidelines for abstract screening large-evidence systematic reviews and meta-analyses. *Res Synth Methods* 2019;**10**(3):330–42.
48. Moher D, Liberati A, Tetzlaff J, Altman D. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009;**6**(7):e1000097.
49. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evidence-Based Healthc* 2015;**13**(3):179–87.
50. Munn Z, Moola S, Lisy K, Riitano D, Tufanaru C. Methodological guidance for systematic reviews of observational epidemiological studies reporting prevalence and cumulative incidence data. *Int J Evid Base Healthc* 2015;**13**(3):147–53.
51. Hong QN, Pluye P, Fabregues S, Bartlett G, Boardman F, Cargo M, et al. *Mixed methods appraisal tool (MMAT), version 2018. Registration of copyright (#1148552)*. Canada: Canadian Intellectual Property Office; 2018.
52. Souto R, Khanassov V, Hong Q, Bush P, Vedel I, Pluye P. Systematic mixed studies reviews: updating results on the reliability and efficiency of the mixed methods appraisal tool. *Int J Nurs Stud* 2015;**52**(1):500–1.
53. Pluye P. Mixed kinds of evidence: synthesis designs and critical appraisal for systematic mixed studies reviews including qualitative, quantitative and mixed methods studies. *Evid Base Med* 2015;**20**(2). 79–79.
54. Kerins C, McSharry J, Hayes C, Perry I, Geaney F, Kelly C. Barriers and facilitators to implementation of menu labelling interventions to support healthy food choices: a mixed methods systematic review protocol. *Syst Rev* 2018;**7**(1):88. <https://ph.cochrane.org/review-authors>.
55. Rodgers M, Sowden A, Petticrew M, Arai L, Roberts H, Britten N, et al. Testing methodological guidance on the conduct of narrative synthesis in systematic reviews. *Evaluation* 2009;**15**(1):49–73.
56. Hong QN, Pluye P, Bujold M, Wassef M. Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Syst Rev* 2017;**6**(1):61.
57. Lizarondo L, Stern C, Carrier J, Godfrey C, Rieger K, Salmund S, et al. *Chapter 8: mixed methods systematic reviews. JBI manual for evidence synthesis*. 2020. <https://doi.org/10.46658/JBIMES-20-09>.
58. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;**8**:45.
59. Joffe H. Thematic analysis. In: Harper D, Thompson A, editors. *Qualitative methods in mental health and psychotherapy: a guide for students and practitioners*. Chichester: Wiley; 2012.
60. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**(2):77–101.
61. McDermott I, Checkland K, Moran V, Warwick-Giles L. Achieving integrated care through commissioning of primary care services in the English NHS: a qualitative analysis. *BMJ Open* 2019;**9**(4):e027622.
62. Turner D, Salway S, Mir G, Ellison G, Skinner J, Carter L, et al. Prospects for progress on health inequalities in England in the post-primary care trust era: professional views on challenges, risks and opportunities. *BMC Publ Health* 2013;**13**(1):274.
63. Cheetham M, Visram S, Rushmer R, Greig G, Gibson E, Khazaeli B, et al. 'It is not a quick fix' structural and contextual issues that affect implementation of integrated health and well-being services: a qualitative study from North East England. *Publ Health* 2017;**152**:99–107.
64. Salway S, Mir G, Turner D, Ellison GTH, Carter L, Gerrish K. Obstacles to "race equality" in the English National Health Service: insights from the healthcare commissioning arena. *Soc Sci Med* 2016;**152**:102–10.
65. Al-Haboubi M, Klass C, Jones K, Bernabé E, Gallagher JE. Inequalities in the use of dental services among adults in inner South East London. *Eur J Oral Sci* 2013;**121**(3pt1):176–81.
66. Gadsby EW, Peckham S, Coleman A, Bramwell D, Perkins N, Jenkins LM. Commissioning for health improvement following the 2012 health and social care reforms in England: what has changed? *BMC Publ Health* 2017;**17**(1):211.
67. Hammond J, Mason T, Sutton M, Hall A, Mays N, Coleman A, et al. Exploring the impacts of the 2012 Health and Social Care Act reforms to commissioning on clinical activity in the English NHS: a mixed methods study of cervical screening. *BMJ Open* 2019;**9**(4):e024156.
68. Marmot M, Allen J, Boyce T, Goldblatt P, Morrison J. *Health equity in England: the Marmot review 10 Years on*. London: Institute of Health Equity; 2020.
69. NHS England/Commissioning Strategy/Equality and Health Inequalities Unit. *Guidance for NHS commissioners on equality and health inequalities legal duties*. London: NHS; 2015.

71. Klasa K, Greer SL, van Ginneken E. Strategic purchasing in practice: comparing ten European Countries. *Health Pol* 2018;**122**(5):457–72.
72. Henry H. *New Models of care and integrating services: commissioning, partnering and improving community wellbeing. Tackling health inequalities – devolution, integration and new models of care.* London: Westminster Social Policy Forum Keynote Seminar; 2016.
73. Westminster Social Policy Forum. *Tackling health inequalities – devolution, integration and new models of care.* London: Westminster Social Policy Forum Keynote Seminar; 2016.
74. Moran V, Checkland K, Coleman A, Spooner S, Gibson J, Sutton M. General practitioners' views of clinically led commissioning: cross-sectional survey in England. *BMJ Open* 2017;**7**(6):e015464.
75. Atkins L, Kelly MP, Littleford C, Leng G, Michie S. From the National Health Service to local government: perceptions of public health transition in England. *Publ Health* 2019;**174**:11–7.
76. Earwicker R. The impact of devolution on health inequalities – localising commissioning, service design and regional variation. In: *Tackling health inequalities – devolution, integration and new models of care.* London: Westminster Social Policy Forum Keynote Seminar; 2016.
77. Williamson D. New models of care and integrating services: commissioning, partnering and improving community wellbeing. In: *Tackling health inequalities – devolution, integration and new models of care.* London: Westminster Social Policy Forum Keynote Seminar; 2016.
78. Checkland K, McDermott I, Coleman A, Perkins N. Complexity in the new NHS: longitudinal case studies of CCGs in England. *BMJ Open* 2016;**6**(1):e010199.
79. Humphrey T, Cleaver K. General practitioners' perceptions on their role in light of the NHS five year forward view: a qualitative study. *Lond J Prim Care* 2018;**10**(3):54–8.
80. Marks L, Cave S, Hunter DJ, Mason J, Peckham S, Wallace A, et al. *Public health governance and primary care delivery: a triangulated study. Project Report.* London: National Institute for Health Research; 2011.
81. Blaxter M. *Key concepts: health.* Cambridge: Cambridge Polity Press; 2010.
82. Iqbal Z, Chambers R. Is it time to take primary care seriously in redressing health inequalities? *Qual Prim Care* 2009;**17**(4):243–5.
83. Warwick-Giles L. *An exploration of how clinical commissioning groups are tackling health inequalities.* Dissertation. Manchester: University of Manchester; 2014.
84. McDermott I, Checkland K, Coleman A, Osipović D, Petsoulas C, Perkins N. Engaging GPs in commissioning: realist evaluation of the early experiences of Clinical Commissioning Groups in the English NHS. *J Health Serv Res Pol* 2017;**22**(1):4–11.
85. National Health Service Improvement. *An introduction to the NHS change model.* London: NHS; 2016.
86. Bull C. *Localism plays to your strengths.* Public Heal Today; 2012. p. 4–5. Published online.
87. Limb M. Patients will be involved in assessing CCGs, NHS England decides. *BMJ* 2013;**347**(nov29 2). f7165-f7165.
88. NHS England, Analytical Team. *CCG improvement and assessment framework 2016/17.* London: NHS; 2017.
89. Cookson R. *Professor at the centre for health economics, and Co-director of the equity in health policy (equipol) research group.* Personal communication; 5 July 2020. 2020.
90. Maden M. Consideration of health inequalities in systematic reviews: a mapping review of guidance. *Syst Rev* 2016;**5**(1):202.
91. Welch V, Tugwell P, Petticrew M, de Montigny J, Ueffing E, Kristjansson B, et al. How effects on health equity are assessed in systematic reviews of interventions. *Cochrane Database Syst Rev. Published online December 2010*; **8**. <https://doi.org/10.1002/14651858.MR000028.pub2>.



## Original Research

# Changes in health among Syrian refugees along their migration trajectories from Lebanon to Norway: a prospective cohort study

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## ABSTRACT

**Objectives:** Conflict-driven displacement is an indisputable social determinant of health. Yet, data on changes in health along the migration trajectories of refugees are scarce. This study aims to assess the longitudinal changes in somatic and mental health and use of medication among Syrian refugees relocating from a conflict-near transit setting in the Middle East to a resettlement setting in Europe. Further, we examine different health status trajectories and factors that predict health in the early postmigration period.

**Study design:** This is a prospective cohort study.

**Methods:** Survey data were collected during 2017–2018 among adult Syrian refugees in Lebanon selected for quota resettlement and at follow-up approximately one year after resettlement in Norway. Our primary outcomes were non-communicable disease (NCD), chronic impairment, chronic pain, anxiety/depression, post-traumatic stress symptoms, and daily use of drugs. We estimated longitudinal changes in prevalence proportions using generalized estimating equations and evaluated effect modification of health outcomes.

**Results:** Altogether, 353 Syrians participated. NCDs declined (12%–9%), while the prevalence of chronic impairment, chronic pain, and use of drugs remained nearly unchanged (29%–28%, 30%–28%, and 20%–18%) between baseline and follow-up. Conversely, mental health outcomes improved (anxiety/depression 33%–11%, post-traumatic stress disorder 5%–2%). Effect modifiers for improvement over time included younger age, short length of stay, and non-legal status in the transit country before resettlement in Europe.

**Conclusions:** We find that mental health outcomes improve from a conflict-near transit setting in Lebanon to an early resettlement setting in Norway, while somatic health outcomes remain stable. Temporal changes in health among moving populations warrant attention, and long-term changes need further scrutiny.

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## Introduction

The world has never seen as many forcibly displaced individuals as now, with over 70 million people currently on the move due to

persecution and violent conflict.<sup>1</sup> Along with the high numbers of refugees and asylum seekers worldwide over the last years, there have been profound concerns among receiving countries as to how national welfare systems, including the healthcare systems, should accommodate the influx of large groups of individuals.

Forced migration is an indisputable predictor of health, and the health of refugees will affect their possibility to integrate in a new country.<sup>2</sup> Along their migration trajectories, refugees strive to mitigate the effects of war and atrocities, the challenges of the transit period, such as deprivation and uncertainty, as well as the difficulties in the postmigration phase, frequently including

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language barriers and financial constraints. In joint, these factors have a powerful potential to harm the health and well-being of people forced to flee.<sup>3</sup> On the other side, protective factors accompanying the migration journey may include social support, renewed hope for the future, recaptured experience of safety, and improved socio-economic standard upon resettlement.

The empirical health advantage of migrants compared with natives has been explained by the ‘healthy migrant hypothesis’ suggesting a selection into migration favouring overall healthy individuals in the countries of origin.<sup>4</sup> Importantly, it is uncertain whether this is true for forcibly displaced migrants, such as refugees. Various studies have found increasing burden of disease among refugees by length of stay.<sup>5,6</sup> The ‘exhausted migrant theory’ provides support for expecting deteriorating health outcomes among migrants over time.<sup>7</sup> This ‘exhaustion’ is considered multifaceted based on stressors related to adaptation as well as socio-economic factors and discrimination.

Less is known about the health in the early postmigration phase, which could be referred to as the ‘honeymoon phase’ due to the initial euphoria seen after resettlement in a new country.<sup>8</sup> It remains unsettled whether this theory of migrant health applies to forced migration. Few studies hitherto, if any, have traced health outcomes among refugees as they cross borders and shift from the transit phase to the early postmigration phase, and to our knowledge none have included somatic health outcomes. To shed light on the relationship between the honeymoon phase and the exhausted migrant theory, there is a need to address the temporal changes in both somatic and mental health in unselected samples of refugees also incorporating the transit phase.

The objective of this study is to assess changes in somatic and mental health and use of medication among Syrian refugees from the transit phase to one year into the postmigration period. Furthermore, we will investigate different health status trajectories and effect modifiers of changes in health along the migration path.

## Methods

### *Study design, setting, and data collection*

This is a prospective cohort study of Syrian refugees under protection by the United Nations High Commissioner for Refugees in Lebanon, with follow-up after resettlement in Norway. The study is a part of the CHART study, collecting survey data in Lebanon during the period August 2017 to April 2018 and at follow-up approximately one year after the participants had arrived as resettlement refugees in Norway.

At baseline we invited all Syrian refugees aged 16 and above participating in the mandatory pretravel course offered by the International Organization for Migration to self-complete a questionnaire in Arabic. Project staff assisted those with low literacy level, and healthcare workers were available to respond to potential signs of retraumatization.

For the follow-up survey, contact details of participants were obtained from The Norwegian Directorate of Integration and Diversity and public refugee offices in the municipalities of resettlement after consent from the participants. Arabic-speaking study staff contacted the participants by phone, and the study questionnaire was completed as a structured phone interview. The most common reasons for loss-to-follow-up included not wishing to participate further and not reachable after a minimum of three phone calls (Supplementary Fig. 1).

The study was approved by the Regional Committee for Medical and Health Research Ethics of South East Norway (ref. no. 2017/377) and by the International Organization for Migration. Informed written consent was obtained from all respondents prior to study

enrolment and repeated orally at follow-up. All data were stored de-identified on a safe server.

### *Measures*

The primary outcomes in this study are changes in somatic health, mental health, and use of medication between the transit phase and the early postmigration phase.

Demographic variables recorded included age, gender, country of birth, mother tongue, ethnicity, marital status, children, and education. To identify the exposures related to the migration process, our research team sought to map various aspects of the respondent’s migration journey: length of stay in Lebanon, stay in other transit countries, time in transit countries, solo-migration, and residence permit in transit country. The Single General Trauma Item was used to measure the exposure to traumatic events relating to the experience of forced migration.<sup>9</sup>

Questions on health conditions and chronic impairment were obtained from The Nord-Trøndelag Health Study (HUNT).<sup>10</sup> These questions enquire whether respondents suffer or have suffered from a range of health conditions including non-communicable diseases (NCDs), asking: Have you had or do you have any of the following (conditions), with possible replies ‘yes’, ‘no’, or ‘unfamiliar term’. Our NCD variable encompasses cardiovascular diseases, chronic respiratory diseases, diabetes, and cancer. Chronic impairment was defined as mental or somatic health problems or injury impairing daily life and lasting at least one year. Chronic pain was defined as experiencing physical pain for at least six months, and this single item has been validated as a standardized measure of chronic pain in population studies.<sup>11</sup>

Anxiety/depression and post-traumatic stress symptoms were assessed by the validated instruments Hopkins Symptom Checklist (HSCL-10)<sup>12</sup> and the Harvard Trauma Questionnaire (HTQ).<sup>13</sup> These instruments have frequently been used in surveys among refugees and have exhibited satisfactory psychometric properties among Arabic-speakers. The HSCL-10 item asks 10 questions to rate the extent to which specific symptoms of anxiety and depression have distressed the respondent during the last week on a four-point Likert scale, and we report mean item scores (range 1–4). Similarly, the HTQ asks 16 questions to examine post-traumatic stress symptoms using the same time frame and response scale with total score calculated as mean item score (range 1–4). The literature suggests a mean HSCL-10 score of 1.85 as threshold for predicting a clinically relevant anxiety or depression and a mean HTQ score of 2.5 as threshold for post-traumatic stress disorder (PTSD). In this study, we adhere to these cut-offs.

Use of medication was assessed by questions from the Oslo Health Study.<sup>14</sup> From a list of commonly used drugs, including drugs for chronic conditions, painkillers, and psychotropic drugs, respondents self-reported the frequency of their use (daily, weekly, less than weekly, or not at all) during the last 4 weeks.

The questionnaire was translated and culturally adapted after standardized procedures,<sup>15</sup> before piloting among a group of six Syrian refugees in a Norwegian asylum centre with subsequent minor adjustments.

### *Statistical analyses*

We described the data using crude prevalence proportions and medians with interquartile range (IQR). Differences in demographic variables between responders and non-responders were evaluated by X<sup>2</sup>-tests and Mann–Whitney U-tests to identify selection bias in the follow-up data.

The changes in prevalence between baseline and follow-up were evaluated using generalized estimating equations (GEE). This

method accounts for dependency between repeated measures in the same individuals. Data in long format with two observations per individual were analysed with logit-link and binomial distribution specified, and timepoint as a binary covariate with baseline data as the reference. Results are presented as odds ratios (OR) with confidence intervals (CI) obtained using robust standard errors. The HSCL-10 item, the HTQ-item, and the number of drugs taken daily were additionally analysed as continuous outcomes in GEE models with identity link function and Gaussian distribution specified. Missing values were handled with listwise deletion in all regression models.

Further, we constructed trajectory variables and calculated the proportions experiencing positive, negative, or no change in outcomes. These results are presented graphically as a Sankey-diagram.

Effect modifications by age, gender, and various migration experiences on change over time for the outcomes were investigated by stratification of effect measures and through introducing interaction terms in the GEE regression models.

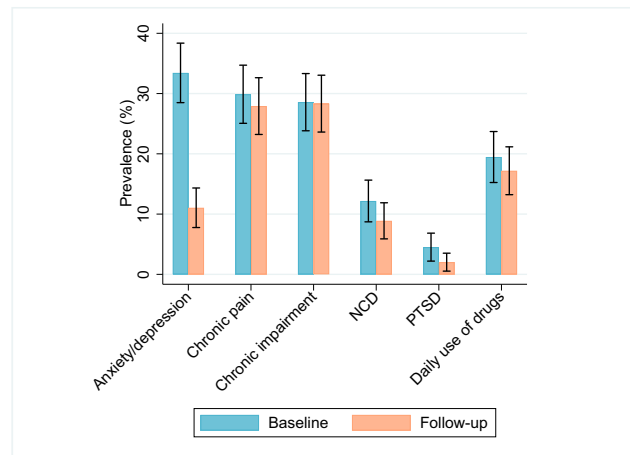
All tests were two sided with the level of statistical significance set to 0.05. Analyses were conducted in STATA IC 16.0 (StataCorp LLC, Texas, USA). We adhere to the STROBE statements for cohort studies when reporting this study.

## Results

At baseline, 506 individuals were recruited. Overall, 464 (92% of respondents) were confirmed settled in Norway, and 353 of them (76%) participated in the follow-up (Supplementary Fig. 1).

Our cohort of 353 individuals had a balanced gender ratio and a median age of 34 (IQR 27–41) years at baseline (Table 1). The proportion reporting exposure to trauma was 40%. Bivariate association analyses between the cohort and the loss-to-follow-up group did not reveal substantial differences indicative of selection bias (Supplementary Table 1).

The prevalence of NCDs declined from the transit to the early resettlement phase (12%–9%, OR 0.68 [0.46–1.00]) (Fig. 1, Table 2). The reduction was greatest for asthma, reported by 15 individuals at baseline, but only by 6 individuals at follow-up. Other somatic health outcomes, including chronic pain and chronic impairment, remained at the same level (29%–28%, OR 0.97 [0.73–1.29] and 30%–28%, OR



**Fig. 1.** Change in prevalence of somatic and mental health outcomes between baseline and follow-up. NCD = Non-communicable diseases, PTSD = Post-traumatic stress disorder.

0.92 [0.68–1.23], respectively). Conversely, mental health outcomes showed significant improvement from the transit to the resettlement situation, with a marked drop in the prevalence of anxiety/depression (33%–11%, OR 0.24 [0.17–0.35]) and PTSD (5%–2%, OR 0.44 [0.21–0.95]). There were no clear changes in use of drugs (20%–18%, OR 0.88 [0.65–1.20]). Comparison between analysing the HSCL-10 item, the HTQ-item, and the number of drugs taken daily as categorical or continuous outcomes did not reveal divergences.

Trajectories of prevalence of main outcomes are shown in Fig. 2. Most of the refugees did not report NCDs, chronic pain, chronic impairment, or mental health problems neither at baseline nor at follow-up. There were 12 (4%) new reports of NCD at follow-up, while 25 (7%) reported NCDs at baseline but not later. A similar pattern was seen for chronic impairment and chronic pain, where up to 15–17% of respondents were new reporters of this complaint at follow-up or conversely reported this complaint in baseline data only. For anxiety/depression only 16 (5%) acquired these health problems, while 96 (27%) improved from them, and for PTSD three times as many had an ameliorating trajectory compared with a deteriorating trajectory. Among respondents, 71% did not use drugs daily neither at baseline nor at follow-up.

As shown in Table 3, participants aged <40 had a larger improvement in anxiety/depression in the early postmigration period compared with older participants. Further, few years of stay in Lebanon was associated with stronger improvement in mental health compared to six years stay or more. Lastly, those lacking residence permit in Lebanon showed a greater reduction in PTSD symptoms after resettlement in Norway compared with those who had a residence permit while in Lebanon. Change in the main outcomes did not differ by gender or other migration-related experiences.

## Discussion

Our study provides new insight into the temporal changes in health among forcibly displaced individuals as they cross borders. Overall, we find that most Syrian refugees in both transit settings and early resettlement settings do not report health complaints. We observe a slight decline in the prevalence of NCDs, while the prevalence proportions of chronic impairment and chronic pain remain high along the migration trajectories of respondents. Noticeably, mental health parameters improve significantly among Syrian refugees between a transit phase and an early resettlement phase. Hence, this study provides partial support for the term ‘honeymoon phase’ as a description of the early resettlement phase.

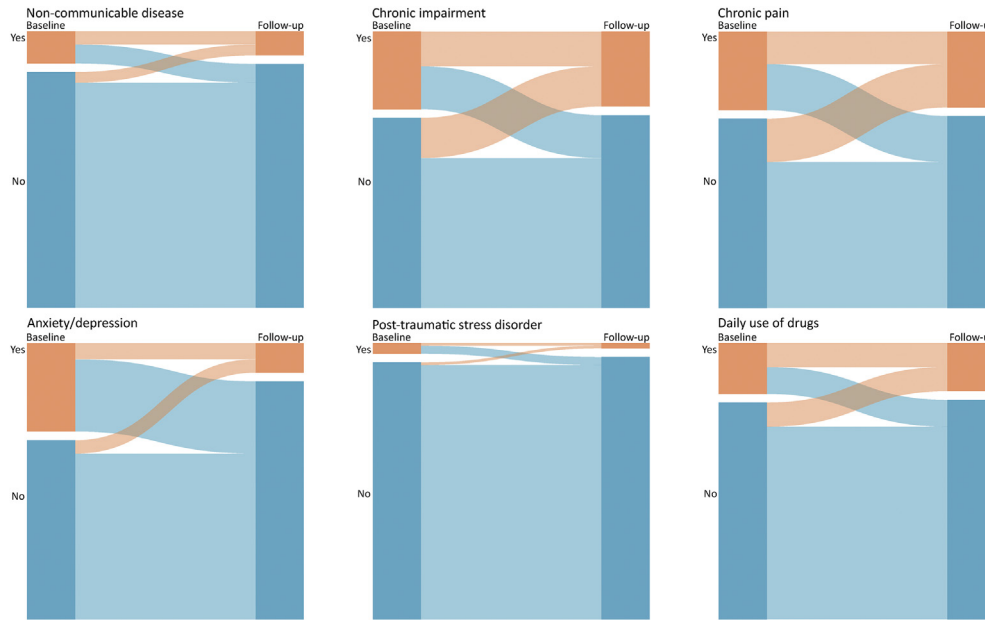
**Table 1**  
Sociodemographic and migration-related factors at baseline, n=353.

		n/median	%/IQR
<b>Sociodemographic factors</b>			
Gender	Women	181	51
	Men	171	49
Age (years)		34	27–41
Mother tongue	Arabic	335	95
	Kurmanji	15	4
Marital status	Married	265	75
	Cohabiting with partner	260	98
Number of children		3	2–4
Education (years)		8	6–10
<b>Migration and trauma-related factors</b>			
Time since flight from Syria at baseline (years)		5	4–6
Time since arrival in Lebanon at baseline (years)		5	4–5
Been in other transit country before Lebanon		20	6
Time in transit countries	Up to 2 years	8	38
	>2 years	13	62
No residence permit in Lebanon at baseline		242	69
Migrating alone to Lebanon		55	16
Exposed to potentially traumatic event(s)		135	40

**Table 2**  
Change in dichotomous outcomes from baseline to follow-up, n = 353.

	Baseline		Follow-up		Change	
	n	%	n	%	OR	95% CI
Non-communicable disease	42	12	30	9	0.68	0.46, 1.00
Chronic impairment	100	29	99	28	0.97	0.73, 1.29
Chronic pain	104	30	98	28	0.92	0.68, 1.23
Anxiety/depression (HSCL-10 cut-off 1.85)	118	33	38	11	0.24	0.17, 0.35
PTSD (HTQ cut-off 2.5)	14	5	7	2	0.44	0.21, 0.95
Daily use of drugs	66	20	60	18	0.88	0.65, 1.20

Changes in prevalence between baseline and follow-up using generalized estimating equations. OR = odds ratio; CI = confidence interval; HSCL-10 = Hopkins Symptoms Checklist 10; PTSD = post-traumatic stress disorder; HTQ = Harvard Trauma Questionnaire.



**Fig. 2.** Trajectories of prevalence proportions of somatic and mental health outcomes from baseline to follow-up.

While some claim that the ‘honeymoon phase’ only lasts the first few months,<sup>8</sup> the health of refugees in this migration stage is poorly examined. The existing literature is almost exclusively centred on mental health, show varying courses of outcomes, and there is broad variation in terms of time frames examined.<sup>16–21</sup>

The prevalence of NCDs showed an unexpected modest decrease from baseline to follow-up, and the decrease was most profound for asthma. We believe this finding may have several explanations ranging from response bias, self-diagnosing under difficult circumstances, or different diagnostic traditions. Others

**Table 3**  
Effect modifiers of change in dichotomous outcomes from baseline (T1) to follow-up (T2), n = 353.

	Non-communicable disease			Chronic impairment			Chronic pain			Anxiety/depression			PTSD		
	OR	95% CI	p	OR	95% CI	P	OR	95% CI	p	OR	95% CI	p	OR	95% CI	p
<b>By age</b>															
<40 years	0.32	(0.15, 0.72)		1.20	(0.84, 1.73)		0.94	(0.65, 1.37)		0.17	(0.10, 0.27)		0.32	(0.11, 0.90)	
≥40 years	1.07	(0.66, 1.72)		0.62	(0.37, 1.05)		0.85	(0.49, 1.47)		0.50	(0.27, 0.91)		0.89	(0.26, 3.01)	
Interaction test			0.01			0.04			0.76			0.01			0.21
<b>By time since arrival</b>															
0–5 years	0.67	(0.41, 1.10)		1.02	(0.73, 1.43)		0.90	(0.63, 1.30)		0.16	(0.09, 0.26)		0.23	(0.08, 0.67)	
≥6 years	0.89	(0.46, 1.71)		0.84	(0.44, 1.60)		0.88	(0.46, 1.67)		0.39	(0.19, 0.83)		1.48	(0.33, 6.60)	
Interaction test			0.51			0.59			0.95			0.05			0.05
<b>By residence permit in Lebanon, n (%)</b>															
No	0.72	(0.46, 1.13)		1.01	(0.72, 1.42)		0.90	(0.64, 1.27)		0.38	(0.20, 0.71)		0.33	(0.14, 0.81)	
Yes	0.50	(0.23, 1.10)		0.89	(0.51, 1.55)		0.93	(0.51, 1.70)		0.19	(0.12, 0.30)		2.09	(0.39, 11.16)	
Interaction test			0.43			0.69			0.88			0.09			0.05

Effect modification of changes in prevalence between baseline (T1) and follow-up (T2) using generalized estimating equations with interaction terms. OR = odds ratio; CI = confidence interval; PTSD = post-traumatic stress disorder.



have described a decrease in NCDs during migration and an increase after arrival in Europe but evidence of longitudinal changes relied upon cross-sectional data,<sup>22</sup> and dynamics of NCDs during migration deserve further scrutiny.

We find that almost one-third report chronic pain or long-term chronic impairments, and these levels remain stable between baseline and follow-up. Studies concerning chronic pain in refugees are usually confined to selected groups such as torture survivors,<sup>23,24</sup> and we have not been able to identify any peer-reviewed literature reporting prevalence of chronic impairments in unselected refugee populations, although some include impairment in their NCD definitions. Findings from Australia indicate stabilisation of poor self-rated general health across the first three years of resettlement,<sup>21</sup> and it might not be plausible to expect alterations in physical health until many years of exposure to migration-related stressors in line with the 'exhausted migrant' theory.

Mental health outcomes, both anxiety/depression and PTSD, drop markedly between our two measure points. We believe our finding is connected to the relief of resettlement and renewed optimism for the future. Only few studies have investigated temporal changes in mental health morbidity in cohorts of forcibly displaced individuals. While some found persisting or increasing levels of mental health problems over the first one to two years after resettlement,<sup>16,18,19</sup> others found decrease in mental ill health at one year.<sup>17,20</sup> For all these studies, the baseline data were collected after arrival to host country; thus, none compare the early postmigration phase with the transit phase.

In our cohort, one in five uses drugs for NCDs, psychotropics, or painkillers daily. While some studies refer self-reported unmet needs of medication among Syrian refugees,<sup>25</sup> few have looked at the prevalence of use of drugs. The number reporting daily drug use among our respondents did not change significantly between initial assessment and follow-up. However, the investigation into trajectories revealed that around 1 in 10 used drugs at baseline but not at follow-up and conversely, another tenth did not use drugs at baseline but used drugs at follow-up. Thus, the reasons for taking medication as well as the barriers to access medicines should be scrutinised further.

Stratified analyses pointed out three factors predicting increased improvement in mental health outcomes after resettlement. Firstly, younger age was associated with increased improvement in mental health in the early postmigration period. This finding is in line with findings among refugees elsewhere.<sup>17,21</sup> While the young might be more adaptive to fluctuating circumstances, those with higher age may suffer a more pervasive loss of beloved ones, belongings, status, and culture. Secondly, few years of stay in Lebanon was associated with increased improvement in anxiety, depression, and PTSD symptoms compared with many years of stay in transit settings. We believe that the length of time under temporary and uncertain conditions will represent an extra burden affecting life also after resettlement in a European country. Lastly, those lacking residence permit in Lebanon showed more progress in PTSD symptoms after resettlement with legal residency in Norway compared with those who also had a residence permit while in Lebanon. Thus, it is plausible to think that the relief of legal permission to stay in a country reinforces the trajectory of improving mental health.<sup>26</sup>

#### Limitations of study

Some important limitations of this study should be noted. Firstly, the effects of migration-related stressors may manifest many years after the initial exposure. A more comprehensive understanding of the associations between forced displacement and health requires follow-up for decades. However, these aspirations were beyond the purpose of this study.

Secondly, the demographic pattern of our cohort reflects the Norwegian authorities' official resettlement policy that explicitly gives priority to families. Females might therefore be over-represented in our sample compared with the gender distribution of Syrian immigrants in Norway in general. The frequency of exposure to traumatic events reported by the Syrians in this study seems to be below levels among Syrian refugees elsewhere.<sup>27</sup> We have no full explanation for this finding, but most of our respondents seem to have fled the ongoing atrocities in first stages of the war.

Lastly, this study relies on self-reported symptoms and complaints, which are not verified by clinical data or diagnostic interviews. Additionally, we deliberately chose to change the mode of data collection between baseline and follow-up. The shift from assisted self-completion of questionnaires to completion by telephone was a trade-off considered beneficial to optimize response rates and thereby limit selection bias. Similar studies among Syrian migrants have proved it extremely difficult to recruit by mail, and others have also changed the mode of data collection in follow-up of refugees.<sup>21</sup>

Despite these methodological concerns, we believe our study provides an important contribution to the knowledge gap regarding the health of forcibly displaced. Using a prospective design to trace health as refugees cross borders, our study enables direct comparison of findings in transit and the early postmigration phase.

We find that most of the Syrian refugees in our study do not report health complaints. Concerns among politicians and stewards of the healthcare systems in receiving countries, albeit not baseless, might be exaggerated in terms of needs for and cost of healthcare services to the newcomers.

In the transition from a perimigration to a postmigration period, there seems to be reason to expect an initial improvement in mental health parameters.

In the early postmigration phase, the focus should be directed toward detecting particularly vulnerable subgroups. Our study has identified older age and length of stay in transit as risk factors of less progress in mental health from the transit to the early resettlement phase.

While our data seem to support the notion 'honeymoon phase', at least for mental health, many studies demonstrate development of the 'exhausted migrant' over time. Thus, there might be reason to expect deteriorating health outcomes in the later postmigration period. Healthcare systems should be designed to identify and accommodate those who develop mental ill health after the initial period of resettlement.

#### Conclusion

We found that mental health outcomes improved among Syrian refugees along their migration trajectories from a transit phase in Lebanon to an early resettlement phase in Norway, while somatic health outcomes remained nearly unchanged. Public healthcare planners and practitioners should acknowledge longitudinal changes in health among forcibly displaced individuals and incorporate this concern into the planning of healthcare services for newly arrived refugees and asylum seekers.

#### Author statements

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this study. The views expressed in this publication are those of the authors and not necessarily those of our collaborators.

### Ethical approval

The study was approved by the Regional Committee for Medical and Health Research Ethics of South East Norway (ref. no. 2017/377) and by the International Organization for Migration.

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### Competing interests

The authors declare no competing interests.

### Appendix A. Supplementary data

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### References

1. UNHCR. *Global trends forced displacement in 2018*. 2019. Geneva, Switzerland.
2. UNHCR. *A new beginning. Refugee integration in Europe*. 2013. Geneva, Switzerland.
3. Abubakar I, Aldridge RW, Devakumar D, Orcutt M, Burns R, Barreto ML, et al. The UCL-Lancet Commission on Migration and Health: the health of a world on the move. *Lancet* 2018;**392**(10164):2606–54.
4. Aldridge RW, Nellums LB, Bartlett S, Barr AL, Patel P, Burns R, et al. Global patterns of mortality in international migrants: a systematic review and meta-analysis. *Lancet* 2018;**392**(10164):2553–66.
5. Diaz E, Kumar BN, Gimeno-Feliu LA, Calderon-Larranaga A, Poblador-Pou B, Prados-Torres A. Multimorbidity among registered immigrants in Norway: the role of reason for migration and length of stay. *Trop Med Int Health* 2015;**20**(12):1805–14.
6. Norredam M, Agyemang C, Hoejbjerg Hansen OK, Petersen JH, Byberg S, Krasnik A, et al. Duration of residence and disease occurrence among refugees and family reunited immigrants: test of the 'healthy migrant effect' hypothesis. *Trop Med Int Health* 2014;**19**(8):958–67.
7. Bollini P, Siem H. No real progress towards equity: health of migrants and ethnic minorities on the eve of the year 2000. *Soc Sci Med* 1995;**41**(6):819–28.
8. Oberg K. Cultural shock: adjustment to new cultural environments. *Practical Anthropol* 1960;**7**(4):177–82. os-.
9. Sigvardsdotter E, Nilsson H, Malm A, Tinghog P, Gottvall M, Vaez M, et al. Development and preliminary validation of refugee trauma history checklist (RTHC)-A brief checklist for survey studies. *Int J Environ Res Publ Health* 2017;**14**(10).
10. Norwegian University of Science and Technology. Helseundersøkelsen i nord-trøndelag (HUNT). Trondheim, Norway. [Available from: <https://www.ntnu.no/hunt>].
11. Landmark T, Romundstad P, Dale O, Borchgrevink PC, Kaasa S. Estimating the prevalence of chronic pain: validation of recall against longitudinal reporting (the HUNT pain study). *Pain* 2012;**153**(7):1368–73.
12. Strand BH, Dalgard OS, Tambs K, Rognerud M. Measuring the mental health status of the Norwegian population: a comparison of the instruments SCL-25, SCL-10, SCL-5 and MHI-5 (SF-36). *Nord J Psychiatr* 2003;**57**(2):113–8.
13. Mollica RF, Caspi-Yavin Y, Bollini P, Truong T, Tor S, Lavelle J. The Harvard Trauma Questionnaire. Validating a cross-cultural instrument for measuring torture, trauma, and posttraumatic stress disorder in Indochinese refugees. *J Nerv Ment Dis* 1992;**180**(2):111–6.
14. Norwegian Institute of Public Health. The Oslo health study (HUBRO). Oslo, Norway. [Available from: <https://www.fhi.no/en/studies/regional-health-studies/helseundersokelser/the-oslo-health-study-hubro/>].
15. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of good practice for the translation and cultural adaptation process for patient-reported outcomes (PRO) measures: report of the ISPOR task force for translation and cultural adaptation. *Value Health* 2005;**8**(2):94–104.
16. LeMaster JW, Broadbridge CL, Lumley MA, Arnetz JE, Arfken C, Fetters MD, et al. Acculturation and post-migration psychological symptoms among Iraqi refugees: a path analysis. *Am J Orthopsychiatry* 2018;**88**(1):38–47.
17. Cooper S, Enticott JC, Shawyer F, Meadows G. Determinants of mental illness among humanitarian migrants: longitudinal analysis of findings from the first three waves of a large cohort study. *Front Psychiatr* 2019;**10**:545.
18. Lie B. A 3-year follow-up study of psychosocial functioning and general symptoms in settled refugees. *Acta Psychiatr Scand* 2002;**106**(6):415–25.
19. Roth G, Ekblad S. A longitudinal perspective on depression and sense of coherence in a sample of mass-evacuated adults from Kosovo. *J Nerv Ment Dis* 2006;**194**(5):378–81.
20. Muller LRF, Gossmann K, Hartmann F, Buter KP, Rosner R, Unterhitzbenberger J. 1-year follow-up of the mental health and stress factors in asylum-seeking children and adolescents resettled in Germany. *BMC Publ Health* 2019;**19**(1):908.
21. Dowling A, Enticott J, Kunin M, Russell G. The association of migration experiences on the self-rated health status among adult humanitarian refugees to Australia: an analysis of a longitudinal cohort study. *Int J Equity Health* 2019;**18**(1):130.
22. Jervelund SS, Nordheim O, Stathopoulou T, Eikemo TA. Non-communicable diseases among refugee claimants in Greek refugee camps: are their health-care needs met? *J Refug Stud* 2019;**32**(Special\_Issue\_1):i36–51.
23. Harlacher U, Nordin L, Polatin P. Torture survivors' symptom load compared to chronic pain and psychiatric in-patients. *Torture* 2016;**26**(2):74–84.
24. Buhmann C, Mortensen EL, Lundstrom S, Ryberg J, Nordentoft M, Ekstrom M. Symptoms, quality of life and level of functioning of traumatized refugees at psychiatric trauma clinic in Copenhagen. *Torture* 2014;**24**(1):25–39.
25. Dator W, Abunab H, Dao-Ayen N. Health challenges and access to health care among Syrian refugees in Jordan: a review. *East Mediterr Health J* 2018;**24**(7):680–6.
26. Kleinert E, Muller F, Furajit G, Hillermann N, Jablonka A, Happel C, et al. Does refugee status matter? Medical needs of newly arrived asylum seekers and resettlement refugees - a retrospective observational study of diagnoses in a primary care setting. *Conflict Health* 2019;**13**:39.
27. Tinghog P, Malm A, Arwidson C, Sigvardsdotter E, Lundin A, Saboonchi F. Prevalence of mental ill health, traumas and postmigration stress among refugees from Syria resettled in Sweden after 2011: a population-based survey. *BMJ Open* 2017;**7**(12). e018899.



## Letter to the Editor

## Complexities to consider when communicating risk of COVID-19



The response to the spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) around the world has so far been characterised by governments issuing instructions about the action to take. However, as governments begin to ease restrictions, the potential for coronavirus disease 2019 (COVID-19) to spread is increased. We argue that correct understanding of individuals' risks of becoming infected and dying is a prerequisite for people and communities to take responsibility and engage in prevention practices, both for self and others, and also to reduce unnecessary anxieties and other unintended negative outcomes. At the same time, effective communication of these risks is fraught with difficulty and there are important complexities and social constraints that must be recognised and addressed. In our view, there has been little scientific discussion on the complexities, social determinants and impacts of COVID-19 risk communication. Here, we highlight seven major complexities in communicating risk and suggest directions for addressing these (Table 1). They serve as a framework for governments, researchers, policy and public health workers to critically appraise COVID-19 risk messaging efforts. As we are trying to highlight complexities that are widely applicable (rather than specific to certain countries or regions), their relevance will differ from context to context.

#### Seven challenges and recommendations for communicating risk

One: The risks of acquiring SARS-CoV-2 infection and of dying from COVID-19 disease once infected vary considerably by epidemic context and between individuals.<sup>1</sup> Nevertheless, it is apparent that the risk of infection varies with the stage of the epidemic, which varies by microregion, and an individual's exposure, which is often much higher for healthcare workers and carers and elevated for those with jobs that cannot be carried out from home, amongst whom ethnic minority groups and people living in greater deprivation may be overrepresented.<sup>2</sup> The risk of death from COVID-19, given infection, varies substantially according to age, male sex, obesity and other factors.<sup>3</sup> Thus, there is no 'one number' to quote to people for their risk; but, at the same time, everyone should know the range in which their risk is likely to fall. Finding ways to provide clear and targeted information about who is at increased risk whilst also recognising the intersectionality of these factors is essential.

Two: Unintended outcomes – such as anxiety, avoiding going to work and limited healthcare seeking – can result for some people. Thus, overestimating one's own risk could be as unhelpful to economic well-being and health overall as understating one's own risk. Moreover, some people aware of their individual risk may (un)willingly take risks, for instance, by making a trade-off between risk and maintaining a livelihood. Communicating risk of

SARS-CoV-2 infection must be considered in the broader context of a group of risks as great or greater than that from COVID-19.<sup>4</sup> Therefore, developing strategies to mitigate these risks is important too.<sup>4</sup>

Three: How we communicate risks can have negative wider social consequences. Messages about the 'new risk' may reproduce constructions of COVID-19 as a 'foreign invader', facilitating stigma and xenophobia.<sup>5</sup> Risk communication may also construct new social norms about how to act and behave in public, which, inadvertently, contribute to blaming and shaming those who are unable to comply – disproportionately affecting already stigmatised groups.

Four: In our view, there has been little communication of actual risk to the individual about the risk involved, and into this vacuum, misinformation and misunderstanding have proliferated. When risks of acquiring SARS-CoV-2 infection and of dying from COVID-19 then are communicated, it takes place in an arena with a lot of background noise, including misinformation that is sometimes deliberate,<sup>6</sup> and distrust of medical information. Communication about risk needs to cut through this noise by working with the different channels of communication (social media, community groups, local leadership structures, public campaigns) that people listen to and creating community knowledge and trust in public bodies that act to prevent amplification of misinformation.

Five: Self-perception of risk is not static but evolves constantly with the epidemic for the right reason (risk of infection is genuinely dynamic in the course of an epidemic) and the wrong reason (persons can acclimatize to a risk and risk compensation can set in). When an epidemic starts, risk communication messaging arguably needs to be harder hitting than later when people already feel 'at-risk' and taking preventative steps has become the 'new normal'. Over time and as evidence and messaging gets updated, fear of infection, which can be a key predictor of risk-reducing behaviour change, may be replaced by ambiguities, individualistic perspectives on the response, personal experiences and values as key determinants.<sup>7</sup> Adapting risk messaging to the epidemiology of COVID-19 will be critical to maintain positive behaviour change.

Six: Risk involves both risk to self and risk to the community, and prevention measures may protect the individual (e.g. hand washing), close contacts and the wider community (e.g. face covering), or both (social distancing). Improving people's accurate risk perception – and an understanding of how their own behaviour affects the risks of others – is essential to strengthen their resolve in reducing transmission and their capacity to creatively find ways to shield themselves and others from infection. Even when substantial pharmaceutical interventions become available, their uptake may be affected by similar considerations, with computation of one's own risk being further complicated by factors including the effectiveness and local coverage of vaccines.

**Table 1**

Considerations and recommendations to communicate risk in the COVID-19 response.

**Communicate variation in risk**

- Avoid oversimplified 'one-size-fits-all' risk messages
- Distinguish between risk of SARS-CoV-2 infection and risk of severe COVID-19 disease
- Target risk messages to people according to their levels of risk and capacity to adopt alternative prevention methods
- Communicate the uncertainty of risk estimates and that new data may lead to changes

**Protect against unintended outcomes of COVID-19 prevention measures**

- Develop risk messaging that reflects the broader socio-economic and health context and is actionable by local people.
- Include messaging to mitigate other forms of risk (e.g. young women should still adhere to government advice but not put off trips to hospital for breast cancer screening)

**Avoid negative social consequences of risk messaging**

- Avoid using unhelpful metaphors (e.g. war, enemy) in risk messaging.
- Avoid using language that can cast shame or blame to people

**Tackle misinformation**

- Monitor the emergence and spread of myths and misinformation on social media and within the community
- Use locally trusted institutions and individuals to address misinformation and channels that are widely used by the relevant population
- Promote trust in official sources by ensuring that messaging from all such sources is consistent

**Reflect changes in the nature of risk and risk perception as the epidemic evolves**

- Review, revise and explain changes in risk messages as the epidemic evolves
- Develop risk messages that counteract innate tendencies for message 'fatigue'

**Promote motivation and creative capacity**

- Use data on risk to stimulate and strengthen motivation to follow government guidance
- Encourage people to think creatively and tailor prevention methods to their own circumstances (e.g. to find effective ways to shield vulnerable family members)
- Foster a sense of collective responsibility (e.g. risk messaging that emphasises that your actions benefit others)

**Consider the broader social determinants of risk**

- Recognise and address social and health inequities, social norms, discrimination and political agendas, which put some people at greater risk or prevent them from engaging with risk-reducing practices.
- Make freely available health services and equipment to assist risk-reducing practices

Finally, Seven: Improving risk perception in isolation from broader social determinants and impacts of risk are unlikely to result in an effective communication strategy. COVID-19 is affecting disproportionately certain strata of society, with some population groups at a disadvantage with regards to access to services, housing, employment and so on. Risk communication cannot ignore these determinants. Individuals may have sound understandings of risks of becoming infected and dying and are yet unable to engage or comply with public health messages (e.g. wear a mask if you do not have any; get tested if you have no access; access treatment if you will have to bear the cost of treatment; stay home if you are asymptomatic SARS-CoV-2-positive; respect distancing if you live in a crowded household and so on).

**Going forward**

Theory and prior experience strongly suggest that individuals' understanding of their own risk of infection and death from COVID-19 is crucial for adopting new behaviours that are tailored for their own risk, in addition to helping motivate adoption of generalised public health messaging.<sup>8</sup> This is not easy – the risk varies over time and between persons in ways that most societies are only beginning to understand – and messaging must be considered in the context of many complexities, which are often rooted in social and health inequities, social norms and discrimination, political agendas and other features of our society. Nevertheless, this is a crucial endeavour – every bit as useful as the construction of the generalised policy directives – and attention must be increasingly devoted to it.

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The authors declare no potential conflict of interest in the commentary.

**References**

1. Verity R, Okell LC, Dorigatti I, et al. Estimates of the severity of COVID-19 disease. *medRxiv* 2020. <https://doi.org/10.1101/2020.03.09.20033357>.
2. Williamson E, Walker AJ, Bhaskaran KJ, et al. OpenSAFELY: factors associated with COVID-19-related hospital death in the linked electronic health records of 17 million adult NHS patients. *medRxiv* 2020. <https://doi.org/10.1101/2020.05.06.20092999>.
3. Banerjee A, Pasa L, Harris S, et al. Estimating excess 1-year mortality associated with the COVID-19 pandemic according to underlying conditions and age: a population-based cohort study. *Lancet* 2020. [https://doi.org/10.1016/S0140-6736\(20\)30854-0](https://doi.org/10.1016/S0140-6736(20)30854-0). Online First.
4. Hogan Alexandra B, Jewell Britta L, Sherrard-Smith Ellie, et al. Potential impact of the COVID-19 pandemic on HIV, tuberculosis, and malaria in low-income and middle-income countries: a modelling study. *Lancet Global Health* 2020. [https://doi.org/10.1016/S2214-109X\(20\)30288-6](https://doi.org/10.1016/S2214-109X(20)30288-6).
5. Logie CH, Turan JM. How do we balance tensions between COVID-19 public health responses and stigma mitigation? Learning from HIV research. *AIDS Behav* 2020:1–4. <https://doi.org/10.1007/s10461-020-02856-8>.
6. Mian A, Khan S. Coronavirus: the spread of misinformation. *BMC Med* 2020;18(1):89. <https://doi.org/10.1186/s12916-020-01556-3>.
7. Dryhurst S, Schneider CR, Kerr J, et al. Risk perceptions of COVID-19 around the world. *J Risk Res* 2020:1–13. <https://doi.org/10.1080/13669877.2020.1758193>.
8. Schaefer R, Thomas R, Maswera R, et al. Relationships between changes in HIV risk perception and condom use in east Zimbabwe 2003–2013: population-based longitudinal analyses. *BMC Publ Health* 2020;20:756.

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## Editorial

## Coronavirus disease 2019: emerging lessons from the pandemic



And so, four months into the global pandemic, there are now more than 3.5 million reported cases and more than 250,000 deaths worldwide.<sup>1</sup> The figures are likely to be an underestimate in view of under-reporting and underdiagnosis. Several countries that were hard hit early on such as Italy, France and Spain appear to have past the peak of the first wave of the pandemic, whereas others including Russia, Brazil and India remain on the ascendency. Casualty numbers will continue to rise in the coming months and years as a consequence of infection and disruption of health services, disease screening and immunisation programmes, and management of chronic diseases. There will also be wider socio-economic impacts on health owing to lost income, poverty and hunger.

So, what have we learned so far? First, rapid response is the key. As Dr. Michael Ryan, Executive Director of the World Health Organization's Health Emergencies Program, said at a briefing on the coronavirus disease 2019 (COVID-19) outbreak in March, "Speed trumps perfection ... Be fast and have no regrets". This is a highly infectious virus wherein its transmissibility appears to be greatest before and around the time of symptom onset.<sup>2</sup> Unfortunately, the speed of its exponential spread has exceeded the response times of most health systems, and several countries were caught flat-footed. Both the US and UK governments, for example, have been criticised for their suboptimal response to COVID-19. They were slow to react to the threat, to implement wide-scale testing, to source sufficient ventilators and personal protective equipment for healthcare staff and to recognise the vulnerabilities of nursing and residential care homes. Where speed is of the essence, top-down bureaucracy can be a major hindrance. Lower level agencies end up being reactive, awaiting national instruction, rather than being proactive in anticipating local needs and responding quickly to local issues. Decentralisation of response may help speed up reaction times and enable adapted responses.

Second, there is no single magic bullet for this pandemic, be it contact tracing apps, point-of-care tests or antivirals. A combination of measures is clearly required. Physical distancing and hygiene measures are paramount. Also essential is the ability of local systems to identify possible cases early, to trace their contacts and to isolate both cases and contacts to break chains of transmission. Although testing is essential to confirm cases, the infrastructure and processes for testing introduce delay that could allow spread to take place before effective measures are implemented. Moreover, there are limitations with all the existing types of tests, including concerns of their sensitivity and specificity.<sup>3,4</sup> Support and monitoring of persons who are in quarantine are essential, to

monitor for possible deterioration, adherence with quarantine, as well as for psychosocial and welfare support.

Transparency is also the key. The value of transparency of information, plans and strategies is about the 'Why?'—Why are we taking a particular course of action? In liberal democracies, this transparency is the key to public trust. Public trust in government will undoubtedly influence people's compliance and support of national directives to 'shelter-in-place' or 'lockdown'. Transparency also requires sharing of information. In the absence of this, where there is a void, there is a risk that people fill the void with ideas that may not be well founded or could even be counterproductive. There is the very real risk of further pandemic waves or localised outbreaks that may require the reimposition of lockdown measures. The continued support of the public will be the key as personal hygiene and physical distancing measures as well as increased public vigilance for illness will be required for many months to come. The public health benefits of such measures must be made clear.<sup>5</sup>

Experience from around the world highlights the importance of community engagement.<sup>6</sup> We have to be careful not to adopt a veterinary approach, treating the population as helpless victims, but consider them as a potential community asset. This does not sit comfortably in the UK as it is not usual practice to meaningfully engage with communities, and we are more comfortable with the familiar top-down bureaucracy. The latter may be accepted in peacetime, but as time passes, it is likely there will be greater clamour for decentralisation of disease control efforts and greater empowerment of local communities and authorities. Moreover, national decreed responses tend to be 'one size fits all'; this does not always meet local needs or fit local contexts. Local agencies know their local situation, communities and partners, and are likely to be best placed to deliver a tailored response.

COVID-19 also demonstrates how once again the distribution of infectious diseases follows a social gradient. Like tuberculosis, HIV and measles, COVID-19 affects many marginalised and socio-economically disadvantaged population subgroups more than others. These trends happen both within and between countries. In the UK, a social gradient is evident, with greater infection prevalence and severity in deprived areas.<sup>7</sup> COVID-19 has also disproportionately affected people from black and ethnic minority groups. This will to a large extent reflect endemic issues of marginalisation, poverty, socio-economic disadvantage, poor housing and insecure jobs. Elsewhere, migrant workers in Thailand, Singapore and the Gulf states who work and live in poor conditions are at high risk of outbreaks, and many will lack access to health services.<sup>8</sup>

Similarly, rural populations in low- and middle-income countries are likely to be at high risk owing to the inadequacies in disease surveillance and rural health care.

Public health threats are deadly. As a speciality, public health is seen by some as a backwater for failed doctors. Public health is not sexy. Cardiology is sexy. Neurosurgery is sexy. No surprises then that public health struggles for influence over the specialities or resourcing. But, if COVID-19 has shown us anything, it is that populations die from public health threats. If intensive care units, hospitals and clinics are full, it is because public health measures have failed. Medicine treats the effects of diseases, but public health addresses the root causes. It is harder to put out a fire once it has started.

Public health investment is value for money. In the UK, public health has been grossly underfunded and under-resourced for years, and more cuts in public health funding are in the pipeline. Deprioritized. This has consequences. Although the UK has a decent health protection system, it could have been stronger had the government invested in it more. Communicable disease control teams kept COVID-19 at bay for a month, delaying the epidemic. The economic costs of a month of lockdown far exceed the miniscule investments in public health. Because of COVID-19, public health is suddenly in the spotlight. When this is all over, there is a risk it will be quickly forgotten again. There is also the frightening possibility that science and public health will be made a scapegoat for political failings during the COVID-19 crisis. This is despite the best efforts of public health professionals and scientists, having done as much as they can with the available resources.

Finally, COVID-19 is a global health security issue. It has direct impacts on the world's economies and dire consequences socio-economically. David Beasley, Executive Director for the UN World Food Programme, has warned of a hunger pandemic in low- and middle-income countries, with more than 265 million people at risk.<sup>9</sup> This pandemic disaster is also likely to have a long tail of consequences including those already seen, and the mental health effects could be profound.<sup>10</sup> As we warned previously, this threat cannot be dealt with by nations in isolation as the virus respects no borders. Global concerted action is required if we are to effectively eliminate this existential threat.<sup>11</sup>

### Conflict of interest

A Lee and J Morling are co-editors of this journal and declare no other conflict of interest.

### References

1. WHO. *Novel coronavirus (2019-nCoV) situation Report - 108 (website)*. WHO: 7 May 2020. Available at: [https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200507covid-19-sitrep-108.pdf?sfvrsn=44cc8ed8\\_2](https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200507covid-19-sitrep-108.pdf?sfvrsn=44cc8ed8_2), 2020. [Accessed 8 May 2020].
2. Cheng HY, Jian SW, Liu DP, Ng TC, Huang WT, Lin HH. Contact tracing assessment of COVID-19 transmission dynamics in Taiwan and risk at different exposure periods before and after symptom onset. *JAMA Intern Med* 2020 May 1.
3. Döhla M, Boesecke C, Schulte B, Diegmann C, Sib E, Richter E, Eschbach-Bludau M, Aldabbagh S, Marx B, Eis-Hübinger AM, Schmithausen RM. Rapid point-of-care testing for SARS-CoV-2 in a community screening setting shows low sensitivity. *Publ Health* 2020 Apr 18.
4. Mallapaty S. Will antibody tests for the coronavirus really change everything? *Nature* 2020 Apr 18.
5. Webster RK, Brooks SK, Smith LE, Woodland L, Wessely S, Rubin GJ. How to improve adherence with quarantine: rapid review of the evidence. *Publ Health* 2020 Mar 30.
6. San Lau L, Samari G, Moresky RT, Casey SE, Kachur SP, Roberts LF, Zard M. COVID-19 in humanitarian settings and lessons learned from past epidemics. *Nat Med* 2020 Apr 8:1–2.
7. Bowyer R, Varsavsky T, Sudre CH, et al. Geo-social gradients in predicted COVID-19 prevalence and severity in Great Britain: results from 2,266,235 users of the COVID-19 Symptoms Tracker app. *medRxiv* 2020. <https://doi.org/10.1101/2020.04.23.20076521>.
8. Bhopal RS. COVID-19: immense necessity and challenges in meeting the needs of minorities, especially asylum seekers and undocumented migrants. *Publ Health* 2020;182:161–2.
9. Anthem P. *Risk of hunger pandemic as COVID-19 set to almost double acute hunger by end of 2020*. World Food Programme Insight; Apr 16 2020. Available at: <https://insight.wfp.org/covid-19-will-almost-double-people-in-acute-hunger-by-end-of-2020-59df0c4a8072?gi=95cf6dd88677>. [Accessed 3 May 2020].
10. Gunnell D, Appleby L, Arensman E, Hawton K, John A, Kapur N, Khan M, O'Connor RC, Pirkis J, Caine ED, Chan LF. Suicide risk and prevention during the COVID-19 pandemic. *The Lancet Psychiatr* 2020 Apr 21.
11. Lee A. Wuhan novel coronavirus (COVID-19): why global control is challenging? *Publ Health* 2020 Feb;179:A1.

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## Original Research

# Negative impacts of COVID-19 lockdown on mental health service access and follow-up adherence for immigrants and individuals in socio-economic difficulties



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Homeless

## ABSTRACT

**Objectives:** Lockdown measures in response to the coronavirus disease 2019 (COVID-19) pandemic can have serious mental health effects on the population, especially in vulnerable groups, such as those living in poor socio-economic conditions, those who are homeless, migrant workers and asylum seekers/refugees. In addition, these vulnerable groups frequently have greater difficulty accessing health services and in treatment adherence. The aim of this study is to estimate the impact of the COVID-19–related lockdown on service utilisation and follow-up adherence in an Italian mental health outpatient service for migrants and individuals in socio-economic difficulties.

**Study design:** The design of this study is a retrospective cross-sectional study.

**Methods:** All patients who visited the mental health outpatient service in the months of February and March in the years 2017–2020 were included in the study. To compare service utilisation before and after the lockdown, the number of patients who visited the mental health outpatient service for psychiatric interview were recorded. Follow-up adherence was calculated as the percentage of patients who visited in February and subsequently attended a follow-up visit in March of the same year.

**Results:** The number of patients who visited the outpatient service between February 2017 and February 2020 was continuously increasing. In March 2020, fewer patients visited the service for psychiatric interview, in line with the introduction of lockdown measures. In addition, the number of the patients who visited in February 2020 and returned for their follow-up visits in March 2020 declined from approximately 30% over the same months in 2017–2019 to 17.53% in March 2020.

**Conclusions:** The lockdown-related reduction in numbers of patients accessing the mental health service makes it difficult to help vulnerable populations during a period of time in which their mental health needs are expected to increase. Moreover, the reduction seen in follow-up compliance increases the risk of treatment discontinuation and possible relapse. Proactive alternative strategies need to be developed to reach these vulnerable populations.

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## Introduction

The coronavirus disease 2019 (COVID-19) pandemic, as a result of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection, has led to a public health emergency, thousands of deaths, generalised economic depression, unemployment and worldwide quarantines. Italy was the first European country to be severely impacted by the disease, with the total number of cases

currently being 238,499, with 34,634 deaths.<sup>1</sup> On 8 March 2020, in response to the growing pandemic of COVID-19 in the country, the Italian government imposed a national restriction of movements of the population, with the exceptions of buying food and other necessary items (e.g. drugs, disinfectants), essential work and health emergencies.<sup>2</sup> The national lockdown ended in June 2020 and proved to be useful in reducing the spread of SARS-CoV-2 infection.

However, such restrictive measures will likely have serious mental health effects on the population.<sup>3–6</sup> In particular, there are certain subgroups of the population that are particularly at risk in this situation due to their precrisis vulnerability. Among them,

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there are those who live in poor socio-economic conditions,<sup>7,8</sup> those who are homeless,<sup>9</sup> migrant workers,<sup>10,11</sup> asylum seekers and refugees<sup>12,13</sup> and patients with existing mental health disorders.<sup>14,15</sup> In addition, some individuals will fall into several of these subgroups, thus increasing their risk.<sup>16</sup> For example, asylum seekers whose request of international protection has been rejected are often homeless, without documents, without jobs, live in poverty and also have symptoms of post-traumatic stress disorder (PTSD) due to their migratory experience, as well as depressive and adjustment disorders related to their present poor living conditions. This is not an unusual problem in Italy, and it has actually worsened over the last year due to a law removing the ‘humanitarian’ forms of permission of stay in the country and consequently the right for those people to be hosted in reception centres and get a job.<sup>17</sup>

Previous research has shown that migrants in poor sociocultural conditions have an increased risk of mental health problems, including the worsening of PTSD,<sup>18</sup> higher rates of psychoses<sup>19</sup> and difficulty in access and/or inadequate treatment in some mental health services of the Italian National Health Service.<sup>20,21</sup>

There is evidence that the COVID-19 crisis has had a negative impact on the mental health of vulnerable populations through different mechanisms.<sup>22,23</sup> Unfortunately, no data are currently available in specific populations, such as those investigated in this study; however, the authors recently performed a phone-based data collection survey (personal data, article in preparation) showing that there are several pathways leading to mental distress. For example, participants reported intrinsic effects related to anxieties of being infected; consequences of the quarantine, both on living experience (e.g. sense of imprisonment reminding traumatic experiences, intolerance to inactivity, boredom, depression) and interpersonal relationships (e.g. forced and conflictual cohabitation in reception centres); fears for the health of relatives living in their home countries; increased social marginalisation (e.g. homeless remained without food, clothing, furniture, laundry and washing facilities or without acceptance in public dormitories); job loss and additional economic difficulties; reduction of the activities in the mental health outpatient services, with increased difficulty in accessing them; increased fears of being taken by the police in the cases of undocumented migrants (the reduction of people around the city made them more visible in the streets) and inability to obtain necessary medications.

The aim of this study is to evaluate the impact of the COVID-19–related lockdown on two specific problems possibly faced by mental health patients with a history of immigration and/or socio-economic difficulties: that is, difficulties in mental health service utilisation and follow-up adherence. In particular, the study was conducted in an Italian public health outpatient service that was specifically dedicated to migrants and individuals with socio-economic difficulties. The authors believe that this study is necessary because problems at this level have been predicted on the basis of theoretical considerations but, to the authors’ knowledge, no evidence measuring this effect is currently available. Moreover, centres dedicated to migrants are frequently based on volunteers, and their reports often remain in the grey literature, thus remain difficult to access by the scientific community.

## Methods

This retrospective study was conducted by the Mental Health Unit of the Italian National Institute for Health, Migration and Poverty (INMP), based in Rome. To facilitate access of migrants and homeless people, the INMP uses a low-threshold setting with a transcultural approach model. Information routinely and

systematically collected in medical records was used, and all patients signed an informed consent form to use their data for study and research purposes.

The study included all patients who received at least one psychiatric interview in February (286 patients) and March (269 patients) in the years 2017–2020. Patients who visited the service in February were considered as the baseline population. Their socio-demographic data and diagnoses were considered in the sample description. Psychiatric disorders were categorised into eleven groups, reflecting the frequency of International Classification of Diseases (ICD)-9 disorders diagnosed in the healthcare unit (the ICD-9 diagnostic system is currently for official statistical recording used in Italy).

The number of patients who visited in February was also compared with those who visited in March for each particular year group. For 2020, the number of patients who visited in February and March was divided into three time periods of about ten days for each month (1–10th, 11–20th and 21–end of the month) to highlight the fact that the change started after the lockdown was established. Furthermore, to assess follow-up compliance, we used, as proxy, the number of patients who visited the service in February and then attended at least one follow-up visit the following month.

## Data analysis

The sociodemographic characteristics and psychiatric categories of the study population are reported, and trends in the number of patients attending interviews are shown graphically. Continuous variables were computed as means  $\pm$  standard deviations (SDs), and categorical variables were calculated as frequencies. Trend differences were reported as absolute numbers or percentage change when appropriate. In addition, the 95% confidence interval (CI) of percentage change was calculated and significance reported.

## Results

Table 1 summarises the characteristics of the 286 patients who visited the mental health outpatient service in February. Participants were mainly men (75.17%) and had a mean age ( $\pm$ SD) of 37.37 ( $\pm$ 13.43) years. Patient age and gender did not differ significantly between the study years. Geopolitical areas of provenance and diagnostic groups changed each year depending on unpredictable pathways of access related to the population dynamics, although the main provenance of Africa (above all Western/Central Africa) remained, and a prevalence for PTSD and depressive, adjustment and psychotic conditions was maintained. The proportion of Italians in poor socio-economic conditions who visited the outpatient service fluctuated between 5% and 10%.

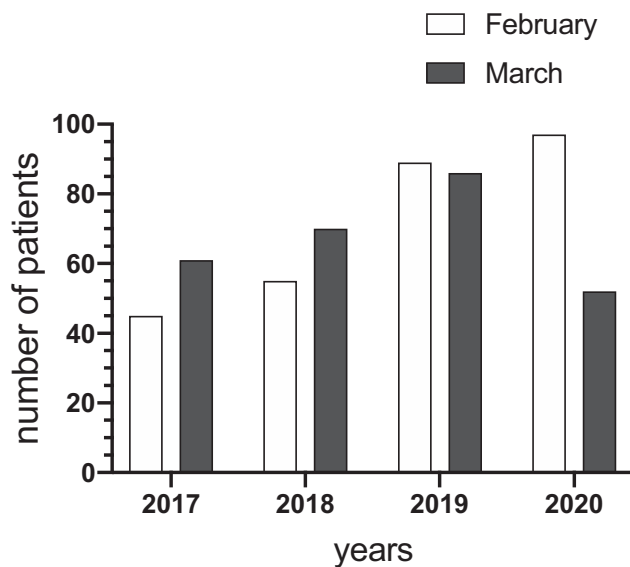
As shown in Fig. 1, there was a trend of increasing numbers of patients who visited the service between 2017 and 2020, until February 2020. Subsequently, a drop of the number of patients who visited in March was registered (Fig. 1) and, more specifically, a reduction in the number of psychiatric interviews after the 10th of March 2020, which corresponds with the period in which the lockdown was established in Italy (Fig. 2).

In addition, whereas in the period 2017–2019, at least 30% of the patients who visited in February attended a follow-up visit in March of the same year; only 17.53% of patients accessing the mental health outpatient service in February 2020 came back for the scheduled follow-up appointment in March 2020 (Fig. 3), showing a significant decrease of 46.57% (95% CI: 19.80 to 71.03;  $P < 0.001$ ).

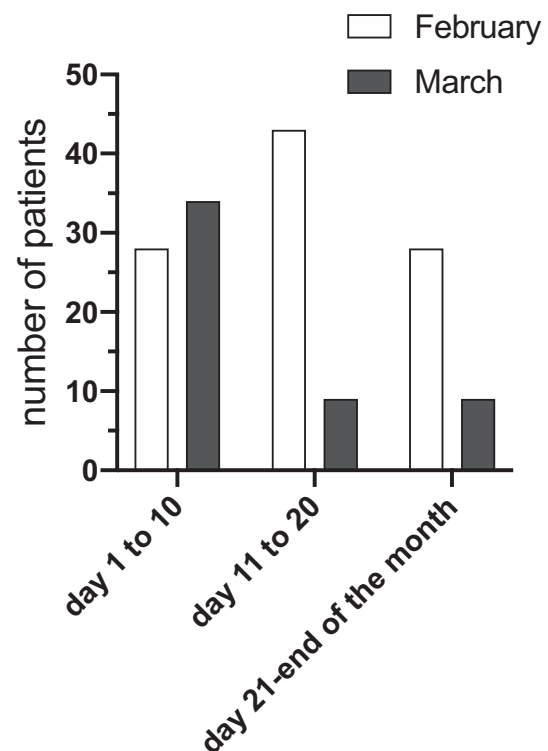
**Table 1**  
Characteristics of patients who visited the mental health outpatient service in February 2017–2020.

Characteristic	Year			
	2017	2018	2019	2020
No. of patient visits in February	45	55	89	97
Age in years (mean $\pm$ SD)	33.58 ( $\pm$ 10.57)	38.55 ( $\pm$ 14.94)	36.11 ( $\pm$ 13.24)	39.61 ( $\pm$ 13.57)
Women [n (%)]	14 (31.11%)	13 (23.64%)	17 (19.10%)	27 (27.84%)
Geopolitical area of provenance [n (%)]				
Western/Central Africa	21 (46.67%)	21 (38.18%)	47 (52.81%)	33 (34.02%)
South/Central Asia	6 (13.33%)	4 (7.27%)	1 (1.12%)	11 (11.34%)
East Africa	5 (11.11%)	2 (3.64%)	4 (4.49%)	6 (6.19%)
Europe	4 (8.89%)	13 (23.64%)	4 (4.49%)	18 (18.56%)
Italy	3 (6.67%)	4 (7.27%)	9 (10.11%)	5 (5.15%)
South/Central America	3 (6.67%)	2 (3.64%)	10 (11.24%)	11 (11.34%)
East Asia	2 (4.44%)	1 (1.82%)	1 (1.12%)	0 (0%)
Middle East	1 (2.22%)	1 (1.82%)	5 (5.62%)	7 (7.22%)
North Africa	0 (0%)	7 (12.73%)	8 (8.99%)	6 (6.19%)
Diagnosis [n (%)]				
PTSD	11 (24.44%)	12 (21.82%)	28 (31.46%)	29 (29.90%)
Psychosis	7 (15.56%)	8 (14.55%)	19 (21.35%)	9 (9.28%)
Depression	5 (11.11%)	13 (23.64%)	10 (11.24%)	20 (20.62%)
Anxiety	4 (8.89%)	2 (3.64%)	3 (3.37%)	2 (2.06%)
Adjustment disorder	3 (6.67%)	8 (14.55%)	3 (3.37%)	7 (7.22%)
Somatization	3 (6.67%)	4 (7.27%)	3 (3.37%)	5 (5.15%)
Personality disorder	2 (4.44%)	1 (1.82%)	10 (11.24%)	5 (5.15%)
Bipolar disorder	1 (2.22%)	1 (1.82%)	1 (1.12%)	3 (3.09%)
Alcoholism	0 (0%)	3 (5.45%)	1 (1.12%)	6 (6.19%)
Other mental disorder	4 (8.89%)	3 (5.45%)	9 (10.11%)	10 (10.31%)
No mental disorder	5 (11.11%)	0 (0%)	2 (2.25%)	1 (1.03%)

PTSD, post-traumatic stress disorder; SD, standard deviation.



**Fig. 1.** The total number of patients who visited in February compared with those who visited in March (2017–2020).



**Fig. 2.** The number of patient visits in February and March 2020 (10-day periods compared).

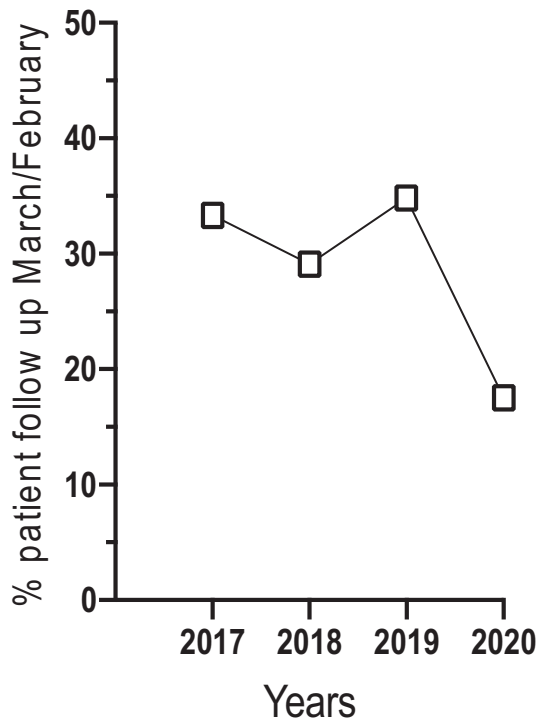
## Discussion

As a result of the COVID-19 pandemic and consequent lockdown, migrants and, more generally, individuals in poor socio-economic conditions can experience a greater negative impact than the general population.

The first key factor is the psychopathological reaction to the situation (i.e. the COVID-19 pandemic). Indeed, in these subgroups of the population, difficult living conditions, together with previous experience of severe traumas and mental distress, are expected to increase levels of anxiety and consequently negatively impact mental health.<sup>10,12,24</sup> To the authors' knowledge, this feared effect

on the mental health of migrants, refugees and homeless people has not yet been quantified, so further research on this issue is needed.

The second key factor is the difficulty in access to treatment if mental conditions are deteriorating, as expected. Theoretically,



**Fig. 3.** Percentage of patients who visited in February with at least one follow-up visit in March in the years 2017–2020.

lockdown measures should not hamper the ability of receiving medical care,<sup>2</sup> and the Italian National Mental Health Service has modified its organisation and procedures to enable treatment of emergent needs.<sup>25</sup> However, factors such as insufficient information,<sup>10</sup> total quarantine in reception centres that report COVID-19 cases among their asylum seekers and other barriers to the access to mental health services<sup>26</sup> can limit the possibility of receiving adequate psychiatric help. To the authors' knowledge, this study is the first evaluation of the effect of the COVID-19 lockdown measures on the accessibility and follow-up use of public mental health services for immigrants and individuals with poor socio-economic conditions. It should be noted that, in some outpatient services, after the start of lockdown measures, appointments for psychiatric interviews were not available or were restricted only to emergencies. However, even during this period, the psychiatric service in the present study continued regular interviews on a free-access model; accordingly, the effects registered here are not due to changes in the organisation of the outpatient service but due to possible external factors (e.g. information about available facilities, movement restrictions).

This study shows a relevant reduction in the total number of patients who visited the mental health outpatient service after the lockdown, with the risk that new mental health needs are neglected in a period when they are expected to increase. Moreover, a significant reduction in the number of follow-up visits has also been demonstrated, which has potential negative effects on therapeutic compliance and increases the risk of relapse.

This study is limited by that fact that it is a retrospective single-centre study, so the findings cannot be directly generalised to other services. However, it has been reported that mental health services such as the one in this study, specifically oriented to migrants and individuals in poor socio-economic conditions, usually perform better than general mental health services in terms of both accessibility and patient satisfaction.<sup>20,21</sup> Consequently, it is highly

probable that the situation described in this study can be an indication of a more general issue for the entire National Health Service.

Owing to the relevance of these problems of accessibility and continuity of treatment for the mental health of the most vulnerable individuals in the population, proactive strategies should be implemented to monitor emergent needs and provide territorial assistance, with online assistance where feasible.<sup>27,28</sup>

### Author statements

#### Ethical approval

This study has been performed in accordance with the Helsinki declaration. The research design and ethical considerations were reviewed and approved by the Italian National Institute for Health, Migration and Poverty Review Board.

#### Funding

None declared.

#### Competing interests

None declared.

### References

- Italian Ministry of Health. *Coronavirus: La situazione in Italia [coronavirus, the situation in Italy]*. 2020. <http://www.salute.gov.it/portale/nuovocoronavirus/dettaglioContenutiNuovoCoronavirus.jsp?area=nuovoCoronavirus&id=5351&lingua=italiano&menu=vuoto>. [Accessed 22 June 2020].
- Conte G. Ulteriori disposizioni attuative del decreto-legge 23 febbraio 2020, n. 6, recante misure urgenti in materia di contenimento e gestione dell'emergenza epidemiologica da COVID-19. [Further dispositions to put in act the law-decree 23 February 2020, n.6, with urgent measures to circumscribe and manage the COVID-19 epidemiological emergency]. *Gazzetta Ufficiale della Repubblica Italiana* 2020;59:1-6.
- Jakovljevic M, Bjedov S, Jaksic N, Jakovljevic I. Covid-19 pandemia and public and global mental health from the perspective of global health security. *Psychiatr Danub* 2020;32:6–14. <https://doi.org/10.24869/psyd.2020.6>.
- Sani G, Janiri D, Di Nicola M, Janiri L, Ferretti S, Chieffo D. Mental health during and after the COVID-19 emergency in Italy. *Psychiatr Clin Neurosci* 2020. <https://doi.org/10.1111/pcn.13004>. Apr 4.
- Tian F, Li H, Tian S, Yang J, Shao J, Tian C. Psychological symptoms of ordinary Chinese citizens based on SCL-90 during the level I emergency response to COVID-19. *Psychiatr Res* 2020;288:112992. <https://doi.org/10.1016/j.psychres.2020.112992>.
- Zhang J, Lu H, Zeng H, Zhang S, Du Q, Jiang T, Du B. The differential psychological distress of populations affected by the COVID-19 pandemic. *Brain Behav Immun* 2020. <https://doi.org/10.1016/j.bbi.2020.04.031>. Apr 15.
- Chung RY, Dong D, Li MM. Socioeconomic gradient in health and the covid-19 outbreak. *BMJ* 2020;369. <https://doi.org/10.1136/bmj.m1329>. m1329.
- Wang Z, Tang K. Combating COVID-19: health equity matters. *Nat Med* 2020;26:458. <https://doi.org/10.1038/s41591-020-0823-6>.
- Lima NNR, de Souza RI, Feitosa PWG, Moreira JLS, da Silva CGL, Neto MLR. People experiencing homelessness: their potential exposure to COVID-19. *Psychiatr Res* 2020;288:112945. <https://doi.org/10.1016/j.psychres.2020.112945>.
- Liem A, Wang C, Wariyanti Y, Latkin CA, Hall BJ. The neglected health of international migrant workers in the COVID-19 epidemic. *Lancet Psychiatr* 2020;7:e20. [https://doi.org/10.1016/S2215-0366\(20\)30076-6](https://doi.org/10.1016/S2215-0366(20)30076-6).
- Page KR, Venkataramani M, Beyrer C, Polk S. Undocumented U.S. Immigrants and covid-19. *N Engl J Med* 2020. <https://doi.org/10.1056/NEJMp2005953>. Mar 27.
- Kluge HHP, Jakab Z, Bartovic J, D'Anna V, Severoni S. Refugee and migrant health in the COVID-19 response. *Lancet* 2020;395:1237–9. [https://doi.org/10.1016/S0140-6736\(20\)30791-1](https://doi.org/10.1016/S0140-6736(20)30791-1).
- UNHCR. COVID-19 will not leave behind refugees and migrants. *Lancet* 2020;395:1090. [https://doi.org/10.1016/S0140-6736\(20\)30758-3](https://doi.org/10.1016/S0140-6736(20)30758-3).
- Chevance A, Gourion D, Hoertel N, Llorca PM, Thomas P, Bocher R, et al. Assurer les soins aux patients souffrant de troubles psychiques en France pendant l'épidémie à SARS-CoV-2. [Ensuring mental health care during the SARS-CoV-2 epidemic in France: a narrative review]. *Encephale* 2020. <https://doi.org/10.1016/j.encep.2020.03.001>. pii:S0013-7006(20)30064-30066.

15. Yao H, Chen JH, Xu YF. Patients with mental health disorders in the COVID-19 epidemic. *Lancet Psychiatr* 2020;7:e21. [https://doi.org/10.1016/S2215-0366\(20\)30090-0](https://doi.org/10.1016/S2215-0366(20)30090-0).
16. Bhopal RS. COVID-19: immense necessity and challenges in meeting the needs of minorities, especially asylum seekers and undocumented migrants. *Publ Health* 2020;182:161–2. <https://doi.org/10.1016/j.puhe.2020.04.010>.
17. Law n.132. Conversione in legge, con modificazioni, del decreto legge 4 ottobre 2018, n. 113, recante disposizioni urgenti in materia di protezione internazionale e immigrazione, sicurezza pubblica, (omissis). [Conversion in law, with changes, of the law decree 4 October 2018, n.113, with urgent measures regarding international protection and migration, public security (omissis)]. *Gazzetta Ufficiale della Repubblica Italiana* 2018;281:1–17.
18. Aragona M, Pucci D, Mazzetti M, Geraci S. Post-migration living difficulties as a significant risk factor for PTSD in immigrants: a primary care study. *Ital J Publ Health* 2012;9. <https://doi.org/10.2427/7525>. 67-4.
19. Jongsma HE, Gayer-Anderson C, Lasalvia A, Quattrone D, Mulè A, Szöke A, et al. Treated incidence of psychotic disorders in the multinational EU-GEL study. *JAMA Psychiatr* 2018;75:36–46. <https://doi.org/10.1001/jamapsychiatry.2017.3554>.
20. Griffiths G, Tarricone I, Study Group. The provision of mental health services to immigrants and refugees in Italy: the barriers and facilitating factors experienced by mental health workers. *J Psychopathol* 2017;23:79–86.
21. Petta AM. *Indagine sui bisogni sanitari e di salute mentale dei rifugiati e richiedenti asilo ospiti dei centri di accoglienza nel territorio di Roma. [Inquiry about the sanitary and mental health needs of refugees and asylum seekers hosted in the reception centers of the territory of Rome]*. Rome: Crossing Dialogues; 2019.
22. Júnior JG, de Sales JP, Moreira MM, Pinheiro WR, Lima CKT, Neto MLR. A crisis within the crisis: the mental health situation of refugees in the world during the 2019 coronavirus (2019-nCoV) outbreak. *Psychiatr Res* 2020;288:113000. <https://doi.org/10.1016/j.psychres.2020.113000>.
23. Huang Y, Zhao N. Generalized anxiety disorder, depressive symptoms and sleep quality during COVID-19 outbreak in China: a web-based cross-sectional survey. *Psychiatr Res* 2020;288:112954. <https://doi.org/10.1016/j.psychres.2020.112954>.
24. Kar SK, Arafat SMY, Marthoenis M, Kabir R. Homeless mentally ill people and COVID-19 pandemic: the two-way sword for LMICs. *Asian J Psychiatr* 2020;51:102067. <https://doi.org/10.1016/j.ajp.2020.102067>.
25. Percudani M, Corradin M, Moreno M, Indelicato A, Vita A. Mental health services in lombardy during COVID-19 outbreak. *Psychiatr Res* 2020;288:112980. <https://doi.org/10.1016/j.psychres.2020.112980>.
26. Bartolomei J, Baeriswyl-Cottin R, Framorando D, Kasina F, Premand N, Eytan A, et al. What are the barriers to access to mental healthcare and the primary needs of asylum seekers? A survey of mental health caregivers and primary care workers. *BMC Psychiatr* 2016;16:336. <https://doi.org/10.1186/s12888-016-1048-6>.
27. Kannarkat JT, Smith NN, McLeod-Bryant SA. Mobilization of telepsychiatry in response to COVID-19-moving toward 21st century access to care. *Adm Policy Ment Health* 2020. <https://doi.org/10.1007/s10488-020-01044-z>. Apr 24.
28. Liu S, Yang L, Zhang C, Xiang YT, Liu Z, Hu S, et al. Online mental health services in China during the COVID-19 outbreak. *Lancet Psychiatr* 2020;7:e17–8. [https://doi.org/10.1016/S2215-0366\(20\)30077-8](https://doi.org/10.1016/S2215-0366(20)30077-8).



## Short Communication

## Public health and political science: challenges and opportunities for a productive partnership

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## ABSTRACT

**Objectives:** We aim to advance productive collaborations between public health and political science by highlighting key challenges to an effective partnership between these fields and examining the opportunities that exist to overcome them.

**Study design:** This short communication takes a descriptive analytical approach.

**Methods:** We synthesize conceptual insights drawn from (1) a recent international workshop that brought together researchers at the intersection of public health and political science and (2) the emerging literature on 'public health political science.'

**Results:** Although public health and political science would appear to be natural partners, work typically occurs in parallel rather than in partnership, resulting in missed opportunities for productive collaboration. We identify three key challenges to an effective partnership between political science and public health. These include the need for a common language and shared understanding of key concepts; mutual recognition of the complexity and diversity within each field; and a deeper engagement with their conceptual and methodological complementarities and differences. We also identify the area of evidence-informed policymaking as particularly ripe for productive collaboration between public health and political science.

**Conclusions:** As the roles of politics and scientific evidence in public health policy grow ever more contentious, public health and political science need to move beyond their disciplinary comfort zones and engage productively with the different perspectives and contributions that each field has to offer.

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Public health is a critical policy challenge for governments around the world. The coronavirus disease 2019 (COVID-19) pandemic provided an extraordinary demonstration of this simple fact. But even in the regular course of public health, there are divisive debates over vaping as an alternative to combustible tobacco products, the looming global crisis of bacteria resistant to existing antibiotics, and the explosion in the abuse of opioids. Challenges similar to these require decisions by governments amid a lack of agreement (and in many cases, a lack of conclusive evidence) about whether, when, and how to act. Public health is thus inherently political – as public health actors have long understood.

Public health and political science would appear to be natural partners. Indeed, the past decade has seen increasing interaction

between them, with political scientists paying closer attention to public health issues and public health researchers drawing more on the contributions of political science and related disciplines, such as public administration and public policy. However, key disjunctures between public health and political science have led to something of a stalemate, and such work typically occurs in parallel rather than in partnership. As a result, the tools and insights of political science remain underutilized in public health research, and work in political science often fails to fully account for the complexity and heterogeneity of the public health enterprise and to benefit from its methodological and substantive insights. Although there is a rich tradition of work in political science on various aspects of health policy broadly defined, it is incomplete. Most of this work is focussed on the politics of health care and health services delivery, not public health policy or public health institutions (even if, in the United States for example, public health and health care are sometimes hard to separate). Moreover, much of this work is firmly rooted in, and oriented towards advancing, political science theory

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and methods. It is not typically interdisciplinary in the sense of also integrating knowledge and methods from health disciplines. Similarly, if we begin with public health scholarship that engages with political science, there are also significant gaps.<sup>1</sup> For example, these studies often deploy political science theories and concepts instrumentally, using them as ‘a reservoir of concepts that might fix a public health research problem’ but proceeding within a public health epistemological lens and for a public health audience.<sup>2</sup>

Although it is neither necessary nor desirable for all work on public health policy and politics to be intensely interdisciplinary, the lack of engaged partnership between public health and political science has resulted in a missed opportunity to integrate and advance the conceptual, theoretical, and methodological tools of both fields. In an attempt to overcome this stalemate, there has been a movement by scholars working at the intersection of these fields to create more robust, two-way bridges between public health and the social science disciplines that address politics, governance, and the policy process – perhaps most visibly in the quickly evolving body of scholarship on the role, use, and utility of scientific evidence in policymaking.<sup>3–6</sup> These efforts aim to address dual trends in existing research that arise from the lack of productive communication between public health and political science: public health studies that do not integrate relevant political science concepts or use them instrumentally, and work in political science that focuses on public health only as an illustrative case study or critiques the public health enterprise’s understanding of concepts such as politics and power without offering a constructive and engaged alternative.<sup>2</sup> Building on earlier contributions in this area, we propose terming this body of work ‘public health political science’ to highlight its focus on interdisciplinary partnership.<sup>4,5</sup>

This short communication highlights three key challenges to such a partnership between political science and public health, and examines the opportunities that exist to overcome them. It draws on insights that emerged from a recent international, interdisciplinary workshop that brought together a group of scholars working at the intersection of the two fields to examine what such a partnership might look like.

The first challenge to creating a partnership between political science and public health involves the lack of a common language and shared understanding of key concepts. A prime example involves their divergent understandings of ‘politics’ and ‘evidence’ and the relationship between the two. A large body of work in public health emphasizes the importance of bringing scientific evidence into policy decisions through increasingly more sophisticated processes of knowledge translation and exchange, with political forces and interests often represented as obstacles to be overcome by more policy-relevant knowledge and political will. Political scientists acknowledge the importance of scientific research but emphasize the contested nature of what constitutes evidence and the multiple other considerations that decision makers must balance in representative democracies.<sup>7,8</sup> Building a shared understanding requires sustained cross-disciplinary engagement and learning that goes beyond ‘dipping into’ each others’ concepts and cases, as sometimes occurs in both fields.

A second challenge involves recognizing the complexity and diversity within each field. Neither is unitary or homogeneous and embracing complexity is key to learning from each other and advancing in partnership. However, there is a tendency in both fields to view the other through a somewhat shallow or instrumental lens. Political science, public administration, and policy studies have a breadth of theories and insights to offer, but public health research often draws repeatedly on a limited set of models of the policy process or applies them in a simplified form that does not accurately reflect the ‘messy’ nature of policymaking in practice.<sup>4,5,9</sup>

Public health is also a complex field that encompasses different methodological traditions, substantive foci, and sets of actors, but work in political science sometimes conflates the perceptions of politics that exist across this range of perspectives. There are many ways of understanding politics, including by practitioners, and political scientists could stand to learn from public health actors’ frontline knowledge of policy implementation from both a clinical and community perspective. A comprehensive public health political science requires the views of colleagues in all walks of public health and politics, not just in research and academia.

Finally, there is both a challenge and an opportunity to build on the complementarities and differences between public health and political science. As an example of complementarity, most public health actors wish to influence public policy in one way or another; indeed, skills such as advocacy and policy development are identified as core public health competencies in several countries.<sup>10</sup> Successful policy influence requires a multilayered understanding of what motivates and influences policymakers to adopt public health promoting policies. Such analyses are at the core of political science. From the perspective of political science, a key complementarity involves public health’s advanced understanding of evaluation and implementation science, which can provide critical methodological tools to understand the distal impact of policies. Conversely, a key difference that is ripe for productive engagement involves the above-mentioned divergence in thinking about evidence. A productive engagement with this difference would keep sight of the critical importance of scientific evidence and technical expertise, while also leveraging political scientists’ understanding of democratic institutions and the politics of evidence. It would ask both how evidence can be produced and used in more democratic ways, and how institutions of representative democracy can incorporate valid scientific evidence into their decisions more effectively and systematically.

Several steps can be taken to address these challenges and leverage the opportunities for an interdisciplinary partnership, as others have begun to suggest.<sup>2,3,5,10</sup> First, such partnerships would benefit from more cross-disciplinary courses in schools of public health and departments of political science. This would introduce future public health professionals and scholars to the rich body of work in political science on governance and policymaking at an early stage and introduce political science students to public health as a multifaceted discipline in and of itself, rather than simply an object of study and critique. A second and related step would see the hiring of more faculty who work and teach at the intersection of these fields. Third, interdisciplinary work would benefit from more focused funding. This would help overcome the disciplinary silos that are reinforced when public health research is solely under the purview of health research funding bodies (and assessed in accordance with the traditional criteria of science-based disciplines), and political science research is under the sole purview of social science funders (and assessed by the traditional criteria of social science-based disciplines). Finally, advancing work at the intersection of these fields requires cross-publishing of joint efforts in their respective journals. Owing to the different criteria for articles in public health and political science publications, interdisciplinary researchers must orient their written work toward one particular audience, which reduces the prospect of reaching (and advancing) both fields. Journal editors could help address these obstacles by introducing more flexible article formats and organizing special issues to highlight research at the intersection of public health and political science.

As the roles of politics and scientific evidence in public health policy grow ever more contentious, we urgently need to move beyond our disciplinary comfort zones and engage productively with the different perspectives and contributions of public health

and political science. We therefore call on our colleagues across both fields to bring their experience, expertise, and vision to bear on the effort to build such a partnership.

### Author statements

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#### Ethical approval

This work did not require ethical approval.

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### Competing interests

The authors have no competing interests to declare.

### References

1. Greer SL, Bekker MPM, Azzopardi-Muscat N, McKee M. Political analysis in public health: middle-range concepts to make sense of the politics of health. *Eur J Publ Health* 2018;**28**:3–6.
2. Mykhalovskiy E, Frohlich KL, Poland B, Di Ruggiero E, Rock MJ, Comer L. Critical social science with public health: agonism, critique and engagement. *Crit Publ Health* 2018;**29**:522–33. <https://doi.org/10.1080/09581596.2018.1474174>.
3. Bernier NF, Clavier C. Public health policy research: making the case for a political science approach. *Health Promot Int* 2011;**26**:109–16.
4. de Leeuw E, Clavier C, Breton E. Health policy - why research it and how: health political science. *Health Res Pol Syst* 2014;**12**.
5. Greer SL, Bekker M, de Leeuw E, Wismar M, Helderma J-K, Ribeiro S, et al. Policy, politics and public health. *Eur J Publ Health* 2017;**27**:40–3.
6. Smith K. *Beyond evidence based policy in public health*. Palgrave Macmillan; 2013.
7. Parkhurst JO. *The politics of evidence: from evidence-based policy to the good governance of evidence*. Routledge; 2017.
8. Cairney P. *The politics of evidence-based policy making*. Springer; 2016.
9. Fafard P. Beyond the usual suspects: using political science to enhance public health policy making. *J Epidemiol Community Health* 2015;**69**:1129–32.
10. Jones DK, Atkeson P, Goodman A, Houston M. More public health leaders should run for office. *J Publ Health Manag Pract* 2020;**1**. <https://doi.org/10.1097/PHH.0000000000001131>.





## Original Research

# Self-reported access to health care, communicable diseases, violence and perception of legal status among online transgender identifying sex workers in the UK



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## ABSTRACT

**Objectives:** Transgender-identifying sex workers (TGISWs) are among the most vulnerable groups but are rarely the focus of health research. Here we evaluated perceived barriers to healthcare access, risky sexual behaviours and exposure to violence in the United Kingdom (UK), based on a survey of all workers on BirchPlace, the main transgender sex commerce website in the UK.

**Study design:** The study design used in the study is an opt-in text-message 12-item questionnaire.

**Methods:** Telephone contacts were harvested from BirchPlace's website (n = 592 unique and active numbers). The questionnaire was distributed with Qualtrics software, resulting in 53 responses.

**Results:** Our survey revealed significant reported barriers to healthcare access, exposure to risky sexual behaviours and to physical violence. Many transgender sex workers reportedly did not receive a sexual screening, and 28% engaged in condomless penetrative sex within the preceding six months, and 68% engaged in condomless oral sex. 17% responded that they felt unable to access health care they believed medically necessary. Half of the participants suggested their quality of life would be improved by law reform.

**Conclusions:** TGISWs report experiencing a high level of risky sexual behaviour, physical violence and inadequate healthcare access. Despite a National Health System, additional outreach may be needed to ensure access to services by this population.

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## Introduction

In the United Kingdom (UK), sex work is complexly regulated, and while for the most part it is legal in England, Wales and Scotland (although activities like running a brothel and street crawling remain criminalised), in Northern Ireland it is illegal to pay for sex.<sup>1</sup> In recent years, although, with the development of apps for mobile phones and websites, it is widely believed that the market for sex has expanded. Little research, however, is available to ascertain the

health and social risks experienced by sex workers<sup>h</sup> using these digital means, with the vast majority of public health studies of sex workers around the world drawing on samples from street-based sites or convenience samples at healthcare clinics.<sup>2–4</sup> However, researchers suggest these sampling frames are skewed and likely to

<sup>h</sup> We note the controversy surrounding language and sexual commerce. Throughout we acknowledge the subjectivity of those engaged in selling sex by referring to them as 'sex workers', whereas we refer to sexual commerce often as 'prostitution' to reflect the contention around exploitation and sex work. Herein we seek not to form direct opinions on these linguistic debates and so we use 'sexual commerce', 'prostitution' and 'sex workers' throughout, and in line with an author's own language preference.

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overlook the highest risk groups, marginalising some sex workers who do not operate in public spaces, including those working online, from both qualitative and quantitative research.<sup>5</sup> Weitzer<sup>6</sup> notes, for example, that whilst street-based prostitution comprises as little as 20% of the market in the US but comprises 80% of academic research. Although emerging research in the UK explores digital sex work, such research has itself also highlighted the general continued focus on female street sex workers.<sup>7</sup>

One especially high-risk group is transgender-identifying<sup>i</sup> sex workers (TGISWs). Although public health research into sexual commerce has recently begun to diversify whom it researches,<sup>8</sup> notably engaging with Lesbian, gay, bisexual, transgender, queer and intersex + (LGBTQI+) sex workers,<sup>9</sup> transgender and non-binary sex workers continue to receive far less attention.<sup>10–12</sup> Such a limited lens is concerning research from the Americas suggests that transgender women sex workers have higher rates of human immunodeficiency virus (HIV) than non-transgender sex workers and the general population.<sup>13</sup> Research suggest that these transgender women engage in sex work in greater numbers because of their experience of social stigma and employment discrimination which limit income generation options, whereas the cost of gender confirming surgeries may drive higher risk taking behaviours as clients generally pay more for condom-free sex and drug use.<sup>13–15</sup> This research also surmises that sex work may be taken up not just as a means of survival and surgery access but also as a way to access social support and acceptance of who they are from other members of the TGISWs community.<sup>13</sup> Indeed, the limited available research suggest TGISWs face many barriers to good health and well-being as a result of discrimination around their gender identity, and that sex work both reflects and magnifies these factors.

What literature exists on TGISWs is available, mostly from qualitative studies, has yet to address how the shift to using online spaces might impact on their exposure to risks.<sup>8</sup> Recent recommendations from the *Lancet* series on promoting health in sex workers was to make health care available for all,<sup>16</sup> which ostensibly is the case in the UK environment. Yet little is known whether, in fact, TGISWs who now operate in online spaces are receiving adequate healthcare access, without risk of stigma and are safe from exposure to violence.

To address these limitations, here we conduct a survey of all TGISWs actively operating on BirchPlace UK, which markets itself as '[t]he original home of transgender and bi-curious, happy people!' and has facilitated online sexual commerce since 1995. BirchPlace UK was selected not only because of its dominance in the market but also because of its representational diversity Terms of Use permitting data scraping (which most websites prohibit).

## Methods

### Survey design

We performed a structured SMS survey of TGISWs who advertised services on BirchPlace UK. We used a closed-question, structured survey method. Albeit critiques by feminist and queer scholars, who argue quantitative surveys and statistical data processing reflect a masculine, positivist tradition and cannot capture the complexity of social life,<sup>17–19</sup> we contend that this approach

does, with appropriate care, offer a means to collect large and diverse data sets able to inform public policy reforms, particularly considering debates in the UK over the legal status of sex work.<sup>20</sup>

### Participants

We collected respondents' contact details and information from the website using R software. Specific tags were used to retrieve information from the advertisements where available, including: sexual orientation; self-reported age and prices for different sexual services.

A twelve-item questionnaire was then administered using Qualtrics Ltd survey software to all scraped numbers through an SMS link (refer Web Appendix 1 for full survey). These messages were only sent to those identifying as transgender. The message contained a link to the online survey, which was mobile optimised and could also be answered on a conventional browser. Participants were provided information on the study and consent processes required to participate before receiving the questions. After completion of the survey and its closure, all text numbers were deleted from the software to protect participants. In addition, the responses remained deidentified from the number contacted.

### Analysis

All statistical analyses were performed using STATA, version 15.1. To describe and cross-tabulate the results of the survey, we used simple descriptive statistics. As the population represented the entire universe of BirchPlace online sex workers, there was no adjustment performed for clustering or sampling. Thus, survey means and standard deviations were calculation without weighting.

### Ethical review

Ethical approval for the study was obtained from the Institutional Review Board (IRB) at Bocconi University. It precluded direct contact with participants, thereby limiting potential to enhance sample response rates through offering prizes for participation.<sup>10</sup> It did, however, reduce the chance of fraudulent responses.<sup>20</sup> The survey questions related to participants' own sexual and recreational health practices, their opinions on sex work (il)legality, as well as their access to and experiences of health care providers. To proceed, participants had to actively 'click' in agreement to a standardised informed consent form, as approved by the IRB and in line with incoming General Data Protection Regulation (GDPR) requirements. To ensure data confidentiality, no identifying information was retained (including IP address). All researchers were fully blinded.

## Results

Our initial harvesting from BirchPlace identified 1703 advertisements, of which 1241 corresponded to unique telephone contacts. Among those, 592 numbers were active, yielding a final sample of 592 phone numbers corresponding to unique TGISWs listings.

In a successive wave of three SMS contacts, starting in June 2018, we received 69 responses to our SMS links, from which 53 participants completed the survey whole or in part. Where a participant failed to answer a question or selected an option that they did not wish to answer, we have included these in the denominator figure, but demarcated them as 'declined to answer'. Failure to answer a question may have indicated either an inability or unwillingness to respond.

<sup>i</sup> We use 'transgender-identifying' or 'trans-identifying' throughout to represent the self-identifying nature of those we scraped data from online. Because some individuals identify as pansexual and/or non-cisgender, but do not demarcate their gender identity in online advertisements, we may not have identified all participants. We note the diversity of identity terms preferred by individuals.

### Access to health care

Although health care, including sexual health care, is free-at-the-point-of-use across the UK from the National Health Services, nine respondents (21%) replied that in the last year they, for any reason, felt at one least once that they were unable to access any kind of health care that they believed to be medically necessary. Thirty three respondents (62%) identified they feel comfortable contacting general practitioners (doctors) if they needed help or treatment, whereas six (11%) reported not being comfortable doing so and fourteen respondents declined to answer the question.

Turning to sexual health screening, thirty five respondents (66%) reported having been tested for gonorrhoea, thirty one (59%) for chlamydia, thirty seven (70%) for HIV/AIDS and thirty four (64%) for syphilis, within the previous twelve months. For those who had been tested, they were then optionally asked if they had tested positive for any of these sexually transmitted diseases, of which nine reported having been treated in the last year for gonorrhoea, nine for chlamydia, one for HIV/AIDS and three for syphilis.

### Risky activities

We asked questions about high-risk activities including intravenous (IV) drug use and sexual activity without a condom. Two respondents (4%) reported that they currently inject IV drugs, whereas forty five respondents (85%) stated that they do not and six participants (11%) declined to answer. The two respondents who reported using IV drugs were then prompted with a further question about whether they use these drugs with clients, to which one responded that they do so 'very rarely' whereas the other responded 'at least once a week but not every day'.

Among high-risk sexual activities, we asked only about condom use, segregating vaginal/anal sex from oral sex. Fifteen respondents (28%) confirmed that they have engaged in vaginal or anal sex without a condom with a client in the preceding six months. Of these, ten identified that this was 'rarely', whereas four reported they do this 'regularly', and one declined to answer. Thirty six respondents (68%) confirmed that they have engaged in oral sex without a condom with clients during the preceding six months. Twenty seven identified that they do this 'regularly', whereas eight stated they do this 'rarely' and one declined to answer.

### Intimidation and accessing law enforcement

Twenty one respondents (40%) reported that they have been threatened by a client while working or felt physically intimidated to do something they did not want to do. Twenty three (43%) respondents reported that they would hesitate to contact law enforcement if they needed them.

### Perceptions of the law regarding sex work

Respondents were asked about their current understandings of the law, which form of regulating sex work they believe would improve their quality of life, and which legal arrangement would best improve their accessing of health care.

First, we asked about knowledge of institutional frameworks governing sex work. Of those reporting operating in England ( $n = 40$ ; 75%), three believed both the buying and selling of sex are currently illegal, twenty seven believed both the buying and selling of sex to be legal, six believed that buying of sex is illegal while sale is legal, and six individuals declined to answer. Of those identifying they operate in Wales ( $n = 4$ ; 7.5%), all believed the buying and selling of sex are legal. Of those reporting operating in Scotland ( $n = 7$ ; 13%), all believed that the buying and selling of sex are legal.

Of those who reported working elsewhere ( $n = 5$ ; 9.5%), three reported that, where they work, they believe both the buying and selling of sex to be legal, one that the buying of sex was illegal but the selling of sex legal, and one declined to answer.

We further asked which legal measures they perceived would most improve their quality of life. Twenty four identified sex work being made entirely legal, whereas seventeen believed it would be best if it were made legal, but some aspects restricted like owning a brothel. One believed that both the buying and selling should both be illegal, whereas eleven declined to answer the question.

Finally, we asked the TGISWs which legal provisions would be best to increase access to health care. Twelve respondents identified sex work being decriminalised, twelve if the law required obligatory health checks for those selling sex, even without their consent, thirteen identified buying and selling being legalised, and two identified making selling sex legal but buying illegal. Fourteen individuals declined to answer the question.

## Discussion

### Main findings

Our study revealed that, despite operating in an environment where health care is free at the point of use, a significant portion of TGISWs did not receive sexual health screenings and reported being unable to access medically necessary health care. Furthermore, our study found that many experience high levels of exposure to physical violence and engage in risky sexual activities, including condomless vaginal or anal sex.

### What is already known on this topic

Access to safe and effective sexual healthcare services for TGISWs widely recognised as a human right. Globally, TGISWs experience a higher prevalence of HIV and sexually transmitted infections than the general population or other sex workers, leading many studies to highlight the unique challenges faced by transgender and non-binary sex workers in accessing appropriate health care.<sup>21</sup> The literature presents a complex set of factors including stigma, social disadvantage and exclusion acting to produce and reinforce health disparities.<sup>21</sup> Little research has explored health access for TGISWs who use digital technology rather than street-based methods for procurement.<sup>10,11</sup>

### What the study adds

The study design has several important strengths. It is, to our knowledge, the first time a systematic and comprehensive sampling frame has been defined and tested for online operating TGISWs in the UK. This overcomes limitations of convenience samples at clinics, which select into the sample those accessing health care. It also overcomes the street-based selection bias of much of the research on sex workers in the UK. This enables our study to evaluate real and perceived barriers to healthcare access, which other quantitative analyses have not been able to do thus far in the UK comprehensively. Methodologically, our findings demonstrate the potential for using Internet contact methods to identify and evaluate the experiences of sex workers. TGISWs should be identified and considered in their own right in future research and proposed reform projects.

### Study limitations

Before turning to the implications of our study for research and policy, we must first acknowledge its many limitations. First, as

with all self-reported data, there is potential for misreporting, creating measurement error. Second, much prior public health research has identified sex workers at healthcare clinics, creating potential for sampling bias and also yielding low numbers of TGISWs. Although our sampling frame covers the main population of online TGISWs, their risks may not correspond to those who work on street-sites, brothels or other settings. Nonetheless, it is believed that Internet procurement creates an environment less risky for workers to operate in, as they can negotiate their own terms and sites with clients, as well as screen potential clients for risks. Third, our response rate was relatively low for a traditional SMS survey, although this is not to be unexpected given that we faced a difficult-to-reach population and the IRB did not give approval for response-rate boosting techniques, such as offering prizes or cash for participation. However, by not using incentive-based methods to increase response rates, it may also have prevented differing biases, such as agencies responding as if they were workers. Because the survey method involved an opt-in approach, we do not know what role the inclusion of advertisements managed by an agency, rather than specific individuals, will have had on the denominator, complicating the task of calculating a valid response rate.

### Conclusions

Taken together, our results show that despite access to publicly funded healthcare services, which offer free sexual health services and communicable disease treatment to all in the UK irrespective of immigration status, nine respondents reported feeling unable to access needed health care in the last year. All but one of these individuals identifies being a British or European Union (EU) citizen in their nationality, hence we can rule out the impact of overseas migrant charging on dissuading access to health care.<sup>22,23</sup> However, there are many other reasons why need is not met, including access to facilities where they are needed, and with convenient opening hours.

Only 62% of our respondents identified feeling comfortable accessing a doctor, and therefore it is critical for future qualitative research to explore why TGISWs in the UK might feel unable or unwilling to access health care. Past studies show apprehension with accessing care amongst the general population is hugely varied, and therefore it is critical to explore TGISW' feelings about access both quantitatively and qualitatively to inform interventions to improve access.<sup>24</sup> We note that access to health care is vital not only because the respondents identified experiencing sexual infections and high-levels of risky behaviour but also because 40% of respondents reported that they have been threatened by a client while working or felt physically intimidated to do something they did not want to do. These results corroborate a previous study of internet-based sex workers (n = 240) which found that about half had experienced crime in their work, including threatening and harassing texts/calls/emails, verbal abuse and removal of condom.<sup>25</sup> Forty three % of respondents reported that they would hesitate to contact law enforcement if needed.

For policy, our research is consistent with support for decriminalising sex work. Consistent with prior studies, criminalising many aspects of sex work may marginalise and lead sex workers into vulnerable positions.<sup>25,26</sup> Our survey found that vast majority of TGISWs strongly favoured decriminalisation. But this is not enough. In addition, the survey makes clear risk to health arise from exposure to physical violence and crime. TGISWs struggle to access police and legal representation when needed to safeguard their health.

### Author statements

#### Ethical approval

Approval was granted by the Institutional Review Board (IRB) at Bocconi University, Milan, Italy.

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#### Competing interests

There are no competing interests to declare amongst any of the authors.

#### Availability of data and material

The data sets used and/or analysed during the current study are available from the corresponding author on reasonable request.

#### Authors' contributions

J.S. initiated the study. D.S., S.S. and M.V. collected the data. V.T. and S.S. processed and interpreted the data, discussing findings regularly with all members of the team. All authors contributed to the drafting of the article, interpretation and revisions.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2020.05.066>.

### References

1. Crown Prosecution Service. *Prostitution and exploitation of prostitution*. 2018. <https://www.cps.gov.uk/legal-guidance/prostitution-and-exploitation-prostitution>. [Accessed 14 September 2018].
2. Drucker J, Nieri T. Female online sex workers' perceptions of exit from sex work. *Deviant Behav* 2018;**39**:1–19. <https://doi.org/10.1080/01639625.2016.1257890>.
3. Hubbard P, Whowell M. Revisiting the red light district: still neglected, immoral and marginal? *Geoforum* 2008;**39**:1743–55. <https://doi.org/10.1016/j.geoforum.2008.05.003>.
4. Uy J, Parsons J, Bimbi D, et al. Gay and bisexual male escorts who advertise on the internet: understanding reasons for and effects of involvement in commercial sex. *Int J Men's Health* 2004;**3**:11–26. <https://doi.org/10.3149/jmh.0301.11>.
5. Cunningham S, Kendall TD. Prostitution 2.0: the changing face of sex work. *J Urban Econ* 2011;**69**:273–87. <https://doi.org/10.1016/j.jue.2010.12.001>.
6. Weitzer R. New directions in research on prostitution. *Crime, Law Soc. Chang.* 2005;**43**:211–35. <https://doi.org/10.1007/s10611-005-1735-6>.
7. Sanders T, Connelly L, King LJ. On our own terms: the working conditions of internet-based sex workers in the UK. *Social Res Online* 2016;**21**. <https://doi.org/10.5153/sro.4152>.
8. Jones A. Sex work in a digital Era. *Social Compass* 2015;**9**:558–70. <https://doi.org/10.1111/soc4.12282>.
9. Smith NJ, Laing M. Introduction: working outside the (hetero)norm? Lesbian, gay, bisexual, transgender and queer (LGBTQ) sex work. *Sexualities* 2012;**15**:517–20. <https://doi.org/10.1177/1363460712446270>.
10. Rosser BRS, Oakes JM, Bocking WO, et al. Capturing the social demographics of hidden sexual minorities: an internet study of the transgender population in the United States. *Sex Res Soc Policy* 2007;**4**:50–64. <https://doi.org/10.1525/srsp.2007.4.2.50>.
11. Laing M, Campbell D, Jones M, et al. *Trans sex workers in the UK: Security, services and safety*. 2017. p. 39–52. <https://doi.org/10.4324/9781315196893-3>.
12. Browne K, Cull M, Hubbard P. The diverse Vulnerabilities of lesbian, gay, bisexual and trans sex workers in the UK. In: Hardy K, Kingston S, editors. *New sociologies of sex work*; 2016. [https://books.google.co.uk/books?hl=en&lr=&id=LiUfDAAAQBAJ&oi=fnd&pg=PP1&dq=LGBT+%22sex+work%22+UK&ots=FapM1Bog1N&sig=b2Tliv1\\_](https://books.google.co.uk/books?hl=en&lr=&id=LiUfDAAAQBAJ&oi=fnd&pg=PP1&dq=LGBT+%22sex+work%22+UK&ots=FapM1Bog1N&sig=b2Tliv1_)

- 3NLpuo7NjVcpqAPQIEo#v=onepage&q=LGBT %22sex work%22 UK&f=false. [Accessed 6 May 2020].
13. Sevelius JM, Keatley JA, Gutierrez-Mock L. HIV/AIDS programming in the United States: Considerations affecting transgender women and girls. *Women's Heal Issues* 2011;**21**:S278–82. <https://doi.org/10.1016/j.whi.2011.08.001>.
  14. Sausa L, Keatley J, Operario D. Perceived risks and Benefits of sex work among transgender women of color in san Francisco. *Arch Sex Behav* 2007;**36**:768–77. <https://oae.ovid.com/article/00000851-200736060-00002>. [Accessed 27 May 2020].
  15. Nemoto T, Sausa LA, Operario D, et al. Need for HIV/AIDS education and intervention for MTF transgenders: Responding to the challenge. *J Homosex* 2006;**51**:183–201. [https://doi.org/10.1300/J082v51n01\\_09](https://doi.org/10.1300/J082v51n01_09).
  16. Shannon K, Crago A-L, Baral SD, et al. The global response and unmet actions for HIV and sex workers. *Lancet (London, England)* 2018;**392**:698–710. [https://doi.org/10.1016/S0140-6736\(18\)31439-9](https://doi.org/10.1016/S0140-6736(18)31439-9).
  17. Farran D. Seeking Susan. Producing statistical information on young peoples leisure. In: Stanley L, editor. *Feminist Praxis: theory and epistemology in feminist sociology*. London: Routledge; 1990. p. 91–103.
  18. Graham H. *Do her answers fit his questions? Women and the survey method*. London: Heinemann; 1983.
  19. Stanley L, Wise S. Method, methodology, and epistemology in feminist research processes. In: *Feminist Praxis*. London: Routledge; 1990. p. 20–60.
  20. Miner MH, Bocking WO, Romine RS, et al. Conducting internet research with the transgender population: reaching broad samples and collecting valid data. *Soc Sci Comput Rev* 2012;**30**:202–11. <https://doi.org/10.1177/0894439311404795>.
  21. Brookfield S, Dean J, Forrest C, et al. *Barriers to accessing sexual health services for transgender and male sex workers: a systematic qualitative meta-summary*. *AIDS Behav*; 13 March 2019. <https://doi.org/10.1007/s10461-019-02453-4>.
  22. Hiam L, Mckee M. Making a fair contribution: is charging migrants for healthcare in line with NHS principles? *J R Soc Med* 2016;**109**:226–9. <https://doi.org/10.1177/0141076816638657>.
  23. Hiam L, Steele S, McKee M. *Creating a 'hostile environment for migrants': the British government's use of health service data to restrict immigration is a very bad idea*. *Health Econ Policy Law*; April 2018. <https://doi.org/10.1017/s1744133117000251>.
  24. Taber JM, Leyva B, Persoskie A. Why do people avoid medical care? A qualitative study using national data. *J Gen Intern Med* 2015;**30**:290–7. <https://doi.org/10.1007/s11606-014-3089-1>.
  25. National Police Chiefs' Council. *National policing sex work guidance*. 2017. <https://www.app.college.police.uk/app-content/major-investigation-and-public-protection/prostitution/>.
  26. Lindsay C. *Conference passes sex work motion unamended*. *LibDem Voice*; 2017. <https://www.libdemvoice.org/conference-passes-sex-work-motion-unamended-53676.html>. [Accessed 14 September 2018].



## Short Communication

## Who is lonely in lockdown? Cross-cohort analyses of predictors of loneliness before and during the COVID-19 pandemic



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## ABSTRACT

**Background:** There are concerns internationally that lockdown measures taken during the coronavirus disease 2019 (COVID-19) pandemic could lead to a rise in loneliness. As loneliness is recognised as a major public health concern, it is therefore vital that research considers the impact of the current COVID-19 pandemic on loneliness to provide necessary support. But it remains unclear, who is lonely in lockdown?

**Methods:** This study compared sociodemographic predictors of loneliness before and during the COVID-19 pandemic using cross-cohort analyses of data from UK adults captured before the pandemic (UK Household Longitudinal Study,  $n = 31,064$ ) and during the pandemic (UCL (University College London) COVID-19 Social Study,  $n = 60,341$ ).

**Results:** Risk factors for loneliness were near identical before and during the pandemic. Young adults, women, people with lower education or income, the economically inactive, people living alone and urban residents had a higher risk of being lonely. Some people who were already at risk of being lonely (e.g. young adults aged 18–30 years, people with low household income and adults living alone) experienced a heightened risk during the COVID-19 pandemic compared with people living before COVID-19 emerged. Furthermore, being a student emerged as a higher risk factor during lockdown than usual.

**Conclusions:** Findings suggest that interventions to reduce or prevent loneliness during COVID-19 should be targeted at those sociodemographic groups already identified as high risk in previous research. These groups are likely not just to experience loneliness during the pandemic but potentially to have an even higher risk than normal of experiencing loneliness relative to low-risk groups.

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## Introduction

Loneliness has been recognised as a major public health concern associated with heightened risk of mental and physical illness, cognitive decline, suicidal behaviour and all-cause mortality.<sup>1–3</sup> Loneliness itself has been referred to as an epidemic, and there have been heightened concerns about its effects during the global pandemic of coronavirus disease 2019 (COVID-19). Lockdowns and ‘stay-at-home’ orders announced internationally have led to physical and social distancing and reports of many individuals experiencing social isolation. Whilst social isolation (the absence of social interactions, contacts and relationships with others) is conceptually distinguished from loneliness (the feeling that one’s

social needs are not being met by the quantity or quality of one’s social relationships), the two are known to be interrelated, with isolation often being a risk factor for becoming lonely.<sup>4</sup> As a result, there have been calls to ascertain how the pandemic has affected loneliness to ensure that individuals at risk receive necessary support.<sup>5,6</sup>

In particular a key question is who is lonely in lockdown? On the one hand, individuals who already experience loneliness may be feeling even more isolated as a result of social distancing measures. Previous research has highlighted that particular groups at risk of loneliness include women, being either younger (e.g. aged younger than 25 years) or older (e.g. aged older than 65 years), living alone and having low socio-economic status, as well as poor mental and physical health.<sup>7,8</sup> Preliminary research within Europe has suggested that these groups may indeed be at risk during lockdown and heightened loneliness is also affecting distress levels.<sup>9</sup> However, it is also possible that enforced lockdowns are actually

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meaning that new groups are now at risk of loneliness.<sup>10</sup> The pandemic has forced millions globally to curtail face-to-face contact and social activities, cut jobs and employment opportunities, restrict travelling and limit outdoor activity. For many individuals, this will be a radical departure from their patterns of usual daily life, and they may find habitual coping mechanisms (such as meeting with others) disrupted, leading to a heightened risk of feeling that the emotional and social support available to them is insufficient to meet their needs. It is important to understand predictors of loneliness during the pandemic even as first lockdowns ease because countries are likely to move in and out of further lockdowns over the coming months. Moreover, for some individuals at heightened risk of illness ('shielding'), staying at home may be required until a vaccine is produced. Therefore, this study compared sociodemographic predictors of loneliness before and during the COVID-19 pandemic using cross-cohort analyses of data captured before and during the pandemic.

## Methods

### Participants

Data were drawn from two sources. For data collected before the pandemic, we used Understanding Society: the UK Household Longitudinal Study (UKHLS); a nationally representative household panel study of the UK population (2009–2019). Our analyses used the most recent wave of UKHLS (wave 9), where the loneliness measures were introduced. The wave nine data were collected between January 2017 and June 2019. To be consistent with the UCL COVID-19 Social Study, we restricted participants to those aged 18+, leaving us a total sample size of 34,976 participants. Furthermore, we excluded those who had missing value in loneliness or any of the covariates (11%). This provided a final sample size of 31,064.

For data during the COVID-19 pandemic, we used data from the UCL COVID-19 Social Study; a large panel study of the psychological and social experiences of more than 50,000 adults (aged 18+) in the UK. The study commenced on 21st March 2020 involving online weekly data collection from participants for the duration of the COVID-19 pandemic in the UK. Whilst not random, the study has a well-stratified sample that was recruited using three primary approaches. First, snowballing was used, including promoting the study through existing networks and mailing lists (including large databases of adults who had previously consented to be involved in health research across the UK), print and digital media coverage and social media. Second, more targeted recruitment was undertaken focusing on (i) individuals from a low-income background, (ii) individuals with no or few educational qualifications, and (iii) individuals who were unemployed. Third, the study was promoted via partnerships with third sector organisations to vulnerable groups, including adults with pre-existing mental illness, older adults and carers. The study was approved by the UCL Research Ethics Committee (12467/005), and all participants gave informed consent. In this study, we focused on participants who had a baseline response between 21st March and 10th May 2020. This provided us with data from 67,142 participants. Of these, 10% of participants withheld data on sociodemographic factors including gender and income and therefore were excluded, providing a final analytic sample size of 60,341.

### Measures

In both data sets, loneliness was measured using the three-item UCLA (University of California, Los Angeles) loneliness scale (UCLA-3). The questions are as follows: (1) how often do you feel a lack of

companionship? (2) how often do you feel isolated from others? (3) how often do you feel left out? Responses to each question were scored on a three-point Likert scale ranging from hardly ever/never, to some of the time and to often. Using the sum score provided a loneliness scale ranging from 3 to 9, with a higher score indicating higher levels of loneliness. In addition, we also examined the single-item direct measure of loneliness asking how often the respondent felt lonely, which was coded on the same scale as the UCLA-3 items.

Covariates included age groups (18–29, 30–45, 46–59 and 60+), gender (woman vs. man), ethnicity (non-white vs. white), education (low: GCSE or below, medium: A-levels or equivalent, high: degree or above), low income (household annual income <£30,000 vs higher household annual income), employment status (employed, unemployed, student and inactive other), living status (alone, with others but no children, with others including children) and area of living (rural vs. urban). All variables aforementioned were harmonised between the two data sets.

### Analysis

To compare risk factors for loneliness, we used Ordinary Least Square regression models fitted separately in the two data sets. Survey weights were applied to both samples throughout the analyses to yield national representative samples of UK adults. The analyses of UKHLS used cross-sectional adult self-completion interview weights, whereas analyses of the UCL COVID-19 Social study were weighted to the proportions of gender, age, ethnicity, education and country of living obtained from the Office for National Statistics.<sup>11</sup> The descriptive and regression analyses were implemented in Stata v15 (StataCorps, Texas).

## Results

Descriptive statistics for the two samples are shown in [Table 1](#). Loneliness levels were higher in the UCL COVID-19 Social Study than in UKHLS, with 32.5% of people feeling lonely sometimes (28.6% in UKHLS) and 18.3% often (8.5% in UKHLS).

Risk factors for loneliness were near identical before and during the pandemic. [Fig. 1](#) presents the estimated coefficients (coef) and 95% confidence intervals (CI) from the regression models. Adults aged 18–30 years were more likely to be lonely compared with adults aged 60+ before the pandemic (coef = 1.01, 95% CI: 0.89–1.12), and during the pandemic (coef = 1.58, 95% CI: 1.48–1.68). People living alone, similarly, were more at risk before and during the pandemic (coef = 0.61, 95% CI: 0.51–0.71 vs coef = 1.10, 95% CI: 1.02–1.18). Having a low household income and being unemployed were also persistent risk factors. Being a student was only a moderate risk factor before the pandemic (coef = 0.19, 95% CI: 0.02–0.35) but was a greater risk factor during the pandemic (coef = 0.43, 95% CI: 0.28–0.58). Other risk factors including non-white ethnicity, being a woman, having low educational attainment and living in urban areas were only small risk factors but were maintained before and during the pandemic.

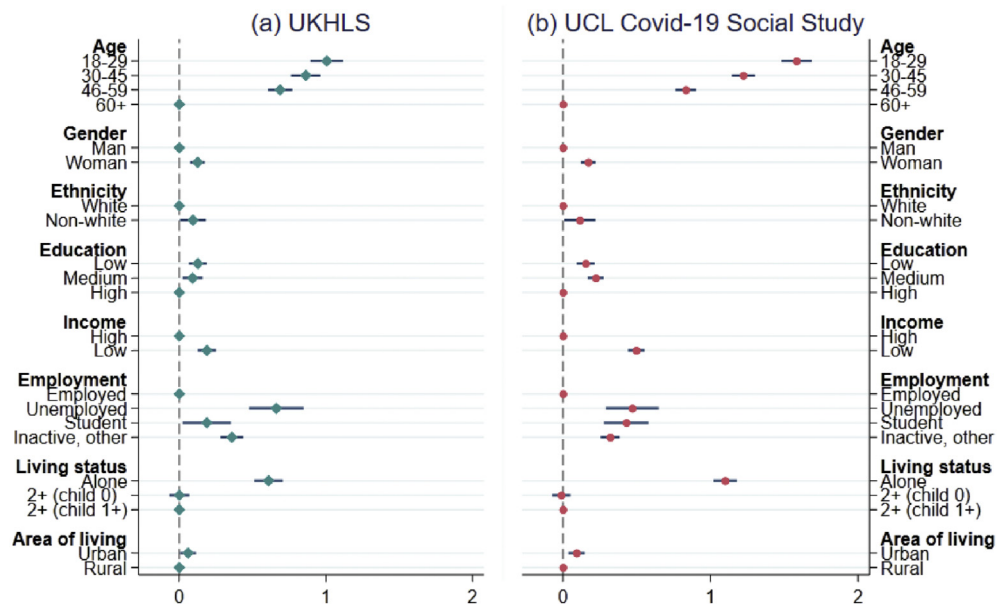
## Discussion

This study explored who was most at risk of loneliness during the UK lockdown due to the COVID-19 pandemic and compared whether risk factors were similar to risk factors for loneliness before the pandemic. Young adults, people living alone, people with lower education or income, the economically inactive, women, ethnic minority groups and urban residents had a higher risk of being lonely both before and during the pandemic. These results echo previous studies on risk factors for loneliness.<sup>7,8</sup> These

**Table 1**  
Descriptive statistic of the explanatory variables (weighted).

Variables	Categories	UKHLS (N = 31,064)	Covid-19 Social Study (N = 60,341)
Age	18–29	16.8%	18.5%
	30–45	23.1%	27.2%
	46–59	25.5%	24.4%
	60+	34.7%	29.9%
Gender	Women (vs. men)	51.8%	49.8%
Ethnicity	Non-white (vs. white)	7.2%	12.5%
Education	GCSE or below	50.6%	32.0%
	A-levels or equivalent	23.2%	33.5%
	Degree or above	26.2%	34.5%
Household income	Low (<30 k) (vs. high)	40.1%	48.6%
Employment status	Employed	56.6%	59.6%
	Unemployed	3.8%	3.3%
	Student	3.6%	6.5%
	Inactive other	36.0%	30.6%
Living status	Alone	18.9%	18.3%
	With others (not children)	49.9%	53.9%
	With others (including children)	31.2%	27.8%
Area of living	Rural (vs. urban)	24.5%	20.4%
UCLA loneliness scores	UCLA-3: score 3	48.4%	34.0%
	UCLA-3: score 4	13.9%	13.8%
	UCLA-3: score 5	11.8%	12.9%
	UCLA-3: score 6	15.7%	17.0%
	UCLA-3: score 7	4.0%	7.6%
	UCLA-3: score 8	2.6%	5.9%
How often do you feel lonely	UCLA-3: score 9	3.5%	8.8%
	Hardly ever/never	62.9%	49.2%
	Sometimes	28.6%	32.5%
	Often	8.5%	18.3%

UCLA, University of California, Los Angeles; UKHLS, UK Household Longitudinal Study.



**Fig. 1.** Coefficients and 95% confidence intervals from the regression model on loneliness.

findings in the UK are also echoed by some recent data from Spain during their lockdown, which highlighted similar risk factors.<sup>9</sup> However, these data show that some people who were already at risk for being lonely (e.g. young adults aged 18–30 years, people with low household income and adults living alone) experienced an even greater risk during the COVID-19 pandemic compared with usual (indicated by higher coefficients). Furthermore, being a student emerged as a higher risk factor during lockdown than usual, although this builds on wider research suggesting that loneliness can be a problem for students and has been rising over the past six years.<sup>12</sup>

This study has a number of strengths including its cross-cohort comparisons of two large samples with harmonised measures before and during the pandemic, as well as its consideration of a broad range of sociodemographic characteristics. However, the data compared are from different participants, hence it is not clear whether those individuals experiencing loneliness during lockdown had previous experience of loneliness. Furthermore, the COVID-19 Social Study is a nonrandom (albeit large, heterogeneous, well-stratified and weighted) sample. Hence the results presented here are not presented as accurate prevalence figures for loneliness during the pandemic. It is possible that the study inadvertently



attracted individuals who were feeling more lonely to participate. Finally, the study looked at broad risk categories. Future studies are encouraged to (i) consider whether the interaction between different risk categories (e.g. unemployed adults living alone) or accumulation of multiple risk factors affected loneliness levels during the pandemic, (ii) track the trajectories of loneliness across lockdown and (iii) explore the potential buffering role of protective social or behavioural factors.

Overall, these findings suggest that interventions to reduce or prevent loneliness during COVID-19 should be targeted at those sociodemographic groups already identified as high risk in previous research. These groups are likely not just to experience loneliness during the pandemic but to have an even higher risk than normal of experiencing loneliness relative to low-risk groups. Such efforts are particularly important, given rising concerns that loneliness could exacerbate mental illness and lead to non-adherence to government regulations.<sup>13,14</sup> As such, supporting individuals experiencing loneliness during and in the aftermath of the pandemic should be a public health priority.

### Author statements

#### Ethics approval

Ethical approval for the COVID-19 Social Study was granted by the UCL Ethics Committee. All participants provided fully informed consent. The study is GDPR compliant.

#### Competing interests

All authors declare no conflicts of interest.

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### Availability of data and materials

Anonymous data will be made available after the end of the pandemic. Full details of the COVID-19 Social Study including a the study protocol and user guide are provided at [www.COVIDSocialStudy.org](http://www.COVIDSocialStudy.org).

### Authors' contributions

F.B., A.S. and D.F. conceived and designed the study. F.B. analysed the data, and F.B. and D.F. wrote the first draft. All authors provided critical revisions. All authors read and approved the submitted manuscript.

### References

- Jeste DV, Lee EE, Cacioppo S. Battling the modern behavioral epidemic of loneliness: suggestions for research and interventions. *JAMA Psychiatry. Published online March 2020*;4. <https://doi.org/10.1001/jamapsychiatry.2020.0027>.
- Leigh-Hunt N, Bagguley D, Bash K, et al. An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Publ Health* 2017;**152**:157–71. <https://doi.org/10.1016/j.puhe.2017.07.035>.
- Stickley A, Koyanagi A. Loneliness, common mental disorders and suicidal behavior: findings from a general population survey. *J Affect Disord* 2016;**197**: 81–7. <https://doi.org/10.1016/j.jad.2016.02.054>.
- Hawkey LC, Cacioppo JT. Loneliness matters: a theoretical and empirical review of consequences and mechanisms. *Ann Behav Med* 2010;**40**(2):218–27. <https://doi.org/10.1007/s12160-010-9210-8>.
- Armitage R, Nellums LB. COVID-19 and the consequences of isolating the elderly. *The Lancet Public Health* 2020;**5**(5):e256. [https://doi.org/10.1016/S2468-2667\(20\)30061-X](https://doi.org/10.1016/S2468-2667(20)30061-X).
- Banerjee D, Rai M. Social isolation in Covid-19: the impact of loneliness. *Int J Soc Psychiatr* April 2020. <https://doi.org/10.1177/0020764020922269>.
- Pinquart M, Sörensen S. Risk factors for loneliness in adulthood and old age—a meta-analysis. In: *Advances in psychology research*. vol. 19. Nova Science Publishers; 2003. p. 111–43.
- Victor CR, Yang K. The prevalence of loneliness among adults: a case study of the United Kingdom. *J Psychol* 2012;**146**(1-2):85–104. <https://doi.org/10.1080/00223980.2011.613875>.
- Losada-Baltar A, Jiménez-Gonzalo L, Gallego-Alberto L, Pedrosa-Chaparro M del S, Fernandes-Pires J, Márquez-González M. “We are staying at home.” association of self-perceptions of aging, personal and family resources, and loneliness with psychological distress during the lock-down period of COVID-19. *J Gerontol B Psychol Sci Soc Sci* 2020. <https://doi.org/10.1093/geronb/gbaa048>.
- Fancourt D, Steptoe A. Is this social isolation?—we need to think broadly about the impact of social experiences during covid-19. *BMJ* 2020. <https://blogs.bmj.com/bmj/2020/05/22/jis-thissocial-isolation-we-need-to-think-broadly-about-the-impact-of-social-experiences-during-covid-19/>. [Accessed 12 June 2020].
- Overview of the UK population: november 2018. Office for National Statistics; 2018. <https://www.ons.gov.uk/releases/overviewoftheukpopulationnovember2018>. [Accessed 7 May 2020].
- Hysing M, Petrie KJ, Bøe T, Lønning KJ, Sivertsen B. Only the lonely: a study of loneliness among university students in Norway 2020;**2**(1):1–16. <https://doi.org/10.32872/cpe.v2i1.2781>.
- Okruszek L, Aniszewska-Stańczuk A, Piejka A, Wiśniewska M, Żurek K. Safe but lonely? Loneliness, mental health symptoms and COVID-19. *PsyArXiv* 2020. <https://doi.org/10.31234/osf.io/9njps>.
- Cerami C, Santi GC, Galandra C, et al. COVID-19 outbreak in Italy: are we ready for the psychosocial and economic crisis? Baseline findings from the longitudinal PsyCovid study. *Social Science Research Network*; 2020. <https://papers.ssrn.com/abstract=3569868>. [Accessed 5 May 2020].