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# Encouraging planting in urban front gardens: a focus group study

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## Abstract

**Aims:** Encouraging planting in front gardens offers mental and physical health benefits, as well as positive local environmental impacts such as reducing flood risk and improving air quality. However, urban front garden greenery has reduced in recent years. We aimed to explore adults' views regarding planting greenery in front gardens, barriers and facilitators, and their understanding of health and environmental impacts, to identify appropriate intervention mechanisms for behaviour change.

**Methods:** We carried out five online focus groups with 20 participants aged 20–64 in England, purposively sampled for variation according to age, gender, home ownership, income, ethnicity and residing in an urban or suburban area. We audio recorded each focus group, transcribed it verbatim and analysed transcripts using thematic analysis.

**Results:** Front gardening was a relaxing activity that provided benefits including increased wellbeing, fresh air and vitamin D. Planting in front gardens depended heavily on available time and space, garden orientation, local security and the weather. Front gardens could be a place for social interaction. Participants tended to prioritise neatness and tidiness over greenery. Lack of knowledge and low self-efficacy were key barriers. There was little awareness of the environmental benefits of front garden greenery; however, reducing flood risk and encouraging biodiversity were viewed positively.

**Conclusion:** Initiatives to encourage front garden planting should focus on plants that require little knowledge to acquire and care for, are suitable to the local environmental conditions and with a visual impact of neatness and bright colour. Campaigns should draw attention to local flood risk reduction and increasing biodiversity, in addition to personal health benefits.

## INTRODUCTION

Green spaces are an important asset for supporting physical and mental health, particularly in urban environments. They offer opportunities for physical activity and socialising and provide a healthier environment<sup>1</sup> by improving air quality.<sup>2</sup> This in turn reduces risk factors for poorer health such as higher body mass index (BMI) and inflammation levels.<sup>3</sup> Green spaces are also positively associated with long-term mental health benefits,<sup>1,4</sup> by triggering restorative undirected attention.<sup>5</sup>

Due to these benefits, within the United Kingdom, there has been a recent policy focus on creating and preserving green space. A 2020 Public Health England<sup>6</sup> review recommended that green and blue spaces be considered critical health assets, with local strategies to develop and maintain these spaces. In conjunction with other interventions, green spaces also contribute to the

national strategies for physical activity,<sup>7</sup> by creating more attractive areas to exercise, and for clean air, by reducing pollution from local roads.<sup>8</sup> NHS England put forward its own set of health-based recommendations in 2019 from its healthy new towns programme, including a focus on encouraging green spaces including private gardens and street greenery to be included in development.<sup>9</sup> This is particularly vital for deprived areas, which generally have less access to green space.<sup>6</sup>

Vegetated private garden space is a key part of local green infrastructure in the United Kingdom – 88% of British homes have access to private garden space.<sup>10</sup> The People and Nature representative survey of 24,994 adults across England found that 79% spent time in private gardens at least once a week, a much higher figure than 49% who had visited a community green space within the last month.<sup>11</sup> Increased

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time spent gardening is associated with greater vegetation in front gardens,<sup>12</sup> and gardening activity is linked to improved health outcomes,<sup>13</sup> reduced risk of vitamin D deficiency,<sup>14</sup> increased fruit and vegetable intake and lower BMI.<sup>15</sup>

However, there has been little focus in previous studies on front gardens, with many studies focusing on food production with assumptions of adequate space, security and privacy. Urban front gardens, the space in a residential dwelling between the front of the house and the street, are a particularly under-utilised and often small space. Although considered private, front garden spaces are seen by and may impact upon passers-by as well as those dwelling in the home. This contrasts to back gardens, which as they are placed at the rear of the house, are usually hidden from view, except for immediate neighbours. Higher-quality street greenery is associated with better perceived health, better mental health, and reduced acute health-related complaints, while higher quality and quantity of street greenery are associated with reduced stress and increased social cohesion.<sup>16</sup>

Front garden greenery offers additional indirect health benefits through environmental services, including reducing local flood risk,<sup>17</sup> cooling the home in hot weather and reducing air pollution from the street.<sup>18</sup> There are further benefits from vegetation and soil to carbon sequestration and to supporting biodiversity. It is therefore important to encourage the activity of gardening specifically in front gardens, to increase the level and quality of street greenery as well as ecosystem service co-benefits. Simple interventions such as introducing a small number of potted plants to front gardens in deprived areas show reduced stress, improvements in salivary cortisol parameters and increased sense of pride and care in the street.<sup>19</sup> While funding arrangements are needed to preserve local green space,<sup>6</sup> private garden spaces do not require local authority maintenance in the same way as other community green spaces. This further aligns with an asset-based public health approach of mobilising community assets and maximising

people's ability utilise these, in order to support individual and community health and wellbeing.<sup>20</sup>

However, private garden spaces (particularly front gardens) are more vulnerable to loss after development, from the changes and preferences of individual owners. In recent decades front garden greenery has reduced, with more hard standing and car parking space being introduced. A London study estimated that impermeable surfaces comprised almost two-thirds of front gardens, with a 40% loss of lawns in the previous 9 years.<sup>21</sup> This reflects a global change, with countries such as Germany and India also reporting loss of urban garden space.<sup>22,23</sup> Given the consequent health and environmental impact, it is vital to understand what affects individuals' choices about greenery in their front garden, and how to encourage gardening and planting of greenery. It is particularly timely to focus on private garden space, as during the COVID-19 lockdowns citizens in many countries were confined to their own homes, with limited outdoor time except within their own private garden. This highlighted the importance of private green space for fresh air, activity and limited social interaction with neighbours.

Urban gardening interventions have typically focussed on green social prescribing in community gardens,<sup>24</sup> community gardens and health outcomes,<sup>25</sup> or fruit and vegetable growth for improved nutrition.<sup>26,27</sup> Few interventions have been developed to increase home gardening and planting behaviour. This study was informed by an established model of behaviour change (COM-B), widely used in health psychology.<sup>25</sup> COM-B (Capability, Opportunity, Motivation, Behaviour) sets out the three types of factor necessary for behaviour to occur: the physical and psychological capabilities to undertake a behaviour, the social and physical opportunities and the automatic and conscious motivations.<sup>28</sup> COM-B forms part of a theoretical framework, the Behaviour Change Wheel, which maps intervention functions on to these components to overcome specific barriers and enable behaviour change.<sup>28</sup> The framework offers a rigorous and

systematic way to understand the range of factors affecting front gardening behaviour and subsequently to identify appropriate intervention types to target the behavioural determinants.

Surveys from a range of countries indicate that motivations for gardening are varied, such as aesthetics/sensory reasons, spending time outdoors, shading the house, observing nature and relaxation, pleasure or hobby, as a source of food, health, and seeing plants grow.<sup>12,29,30</sup> However, these studies surveyed wholly or predominantly gardeners, with samples skewed on gender and potentially on age and income. With the exception of one recent UK research programme,<sup>12</sup> these studies do not differentiate between front and back gardens. As quantitative surveys, they were unable to capture nuance and depth of experience or context. A gap remains on understanding the motivations of the broader population relating to why they choose, or do not choose, to garden in their front garden space.

We therefore carried out a qualitative research study to explore adults' views about planting greenery in front gardens, barriers and facilitators, and perceived associations between front gardens, health and wellbeing.

## METHODS

Focus groups use group interaction to understand what and how participants think, including shared understanding and norms.<sup>31</sup> We carried out five online focus groups, each with four participants, in February and March 2021 in the United Kingdom using commonly available videoconferencing software. At the time, the United Kingdom was under a third national lockdown due to the COVID-19 pandemic, with the public advised to stay at home and closure of non-essential businesses. We recruited adults aged 20–65 years, resident in England in urban or suburban areas, with a ground-floor front garden space between their door and the street at least the size of three large waste bins. Participants were purposively sampled for gardening/not gardening in their front garden, as well as potentially relevant demographic characteristics: renting/home ownership, ethnicity, income,

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gender and age. Participants were recruited and consented through a market research company and were paid £40 each for participating in a focus group, in order to encourage non-gardeners and underserved groups to participate. The study received ethical approval from University College London Bartlett School of Construction and Project Management Ethics Committee (ref 2020-StF-NM-002).

We developed the topic guide based on the research question, previous literature and the COM-B model.<sup>28</sup> Topics covered included the use and function of front gardens; and motivations, opportunities and capabilities required for planting greenery at the front and barriers to this.

We planned focus groups for gardeners (n=1), non-gardeners (n=1) and mixed (n=3), with slightly adapted topic guides. As we were particularly interested in physical health and environmental factors and these were not usually spontaneously raised, we also introduced information and questions on this in a neutral way such as 'Planting in front gardens can reduce your local flood risk. Is that something you've ever thought about when deciding to plant greenery in your front garden?'. Focus groups were led by RF (a health sciences researcher) and co-facilitated by NM (an environmental psychologist), both with expertise in qualitative research. They lasted 64–84 min.

Focus groups were audio recorded and transcribed verbatim. We carried out codebook thematic analysis.<sup>32</sup> All transcripts were read, and both authors independently generated an initial coding framework, which was amalgamated through discussion into a single framework and applied in a second round of more detailed coding. Although our coding framework was organised around the COM-B model,<sup>28</sup> to understand the behaviour of planting greenery in front gardens, we developed themes inductively, rereading data under each code and re-organising them into health-related themes, refined iteratively through writing.

## RESULTS

Our 20 participants were varied with regards to gender, geographic region, home ownership, location and

Table 1		
Demographics of study sample (n=20).		
Focus group type	Gardening status	Demographics
Gardeners	4 gardeners	2 male, 2 female 2 × 50–64 years, 2 × 35–49 years 2 suburban, 2 urban 2 owners, 2 renters 4 White British Income 2 × <£30k, 1 × £31–50k, 1 × £50k+
Non-gardeners	4 non-gardeners	2 male, 2 female 2 × 50–64 years, 2 × 35–49 years 2 urban, 2 suburban 2 owners, 2 renters 4 White British Income 2 × <£30k, 2 × £31–50k
Mixed 1	2 gardeners 2 non-gardeners	2 male, 2 female 2 × 35–49 years, 2 × 50–64 years 2 suburban, 2 urban 4 owners 4 White British Income 1 × <£30k, 3 × £31–50k
Mixed 2	2 gardeners 2 non-gardeners	3 male, 1 female 3 × 35–49yrs, 1 × 20–34yrs 3 suburban, 1 urban 3 owners, 1 renter 2 Asian/Asian British, 2 White British Income 1 × <£10k, 2 × £10k–31k, 1 × £31–50k
Mixed 3	2 gardeners 2 non-gardeners	1 male, 3 female 1 × 20–34 years, 2 × 35–49 years, 1 × 50–64 years 2 suburban, 2 urban 3 owners, 1 renter 1 Asian/Asian British, 1 Black African/Black British, 1 White British Income 3 × £10–31k, 1 × £31–50k

characteristics of front garden spaces, with some variation in ethnicity and age and limited variation in income (see

Table 1 and Box 1). Dichotomising participants into gardeners and non-gardeners was more difficult than

## Box 1. Characteristics of front garden spaces.

We sampled participants with a diverse range of front garden spaces. Sizes varied from a “very small little patch” (Mixed 2) to “quite a large front garden really. . .we’ve got a corner plot on a detached house at the end of a cul de sac.” (Mixed 1). The content of front gardens also varied highly. A few had fronts with no greenery:

*just tarmac. It’s literally a car park (Mixed 3)*

Many described a combination of paving and greenery, with space for parking one or two cars, but with additional greenery such as bushes or trees.

*it’s mostly lawn with a driveway and I’ve got a border under the front window. Massive Leylandii hedge. Another big kind of what looks like a rocket Leylandii bush, and a birch tree (Mixed 1)*

Some participants had lawns, of varying sizes. A few reported hanging baskets, herbs or garden ornaments. Pots of plants were commonly discussed in front gardens:

*what we have planted in the front are the two plants that were dug out but now in pots, and an olive tree in a pot. (Mixed 3)*

anticipated as participants described varied levels of gardening participation: the range of these experiences is reported throughout the results.

We identified four main themes in relation to the impact of front gardens on health: (1) effort and reward, (2) connecting with outdoor spaces, (3) the social nature of front garden spaces, and (4) gardening knowledge and self-efficacy.

### EFFORT AND REWARD

The most salient benefits of front garden greenery related to mental wellbeing and occupational activity, with gardens described as ‘therapeutic’ and ‘a sanctuary’. Part of this related to being outdoors in pleasant surroundings, but more often people related this to activity, with the idea of ‘pottering’ raised in most groups.

*I love like mowing the lawn and doing things like that. . .some days I’ll just potter and prune things back. (Gardeners)*

This was particularly the case for those who expressed greater enthusiasm for gardening, for both front and back gardens. Gardening was viewed as an absorbing distraction from stressors that led people to focus on the immediate present and ‘forget about the world’ (Mixed 1). This led to increased wellbeing.

*You could genuinely switch off because you [are] just digging mud. (Mixed 1)*

Others enjoyed gardens as a source of projects and creativity. The act of planning and seeing results generated pleasure, satisfaction and ongoing motivation.

However, the reward aspect was less salient for front gardens than back. Those who preferred spending more time in the back garden took a utilitarian approach, calculating a low benefit to themselves of a pleasant front garden versus the effort, time and money required:

*Why would you spend loads of money making my frontage look really pukka [excellent] when I’m not the one sat looking at it (Mixed 1)*

Front gardens were also considered more vulnerable to security risks than back garden spaces, leading to less time and investment. Theft was a particular concern:

*Last summer we had people stealing hanging baskets, like [participant] said earlier. . .you put a lot of effort into growing them and making them look nice and then people stealing them for their own pleasure or whatever, it’s not really nice (Mixed 2)*

No participants who rented discussed constraints in planting greenery from landlords. However, planting was considered a financial risk, particularly given the large array of possible plants and the need for knowledge regarding what would flourish best in their particular front garden.

*I could spend 200 quid [pounds sterling], and then a month later be looking at a big brown mess. (Non-gardeners)*

In addition, for those less interested in gardening or with little free time, gardening represented a non-essential investment of time they did not have, mainly due to work and childcare. The ideal compromise for those with little time was greenery requiring little effort to maintain. Here it was advantageous if front garden plants were left by previous owners, as most were retained out of ease:

*I’m just not particularly green fingered, and it was some quite nice shrubs that I inherited. So I’ve just kind of left them to do whatever they do (Non-gardeners)*

### Gardens as outdoor spaces

The physical health benefits of gardening were chiefly related to being outdoors in the ‘fresh air’ and getting vitamin D and sunshine, with exercise benefits only acknowledged in relation to heavy lifting. Appreciation of time spent outdoors had increased during lockdowns, and for some, the front garden became another space to use, almost an outdoor room. The sensory impact of being outdoors and of plants were consistently raised. The visual impact of the front garden was a particularly strong element, with ‘colour’ from flowering plants and ornaments valued highly as a key

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element of front gardens, both for one's own and others' benefit:

*If you've got it looking nice and tidy and full of different colours and plants and stuff, it's inviting (Mixed 2)*

Those without front garden greenery regretted having a less visually appealing garden, but rarely discussed other sensory aspects. Scents, such as freshly cut grass or lavender, were mentioned mainly by gardeners. However, the outdoors was not always experienced as pleasant – there was strong consensus in one focus group that litter (deliberately deposited or blown in by wind) was an issue, while insects, cat mess and hayfever were mentioned by a small number of participants as particular front garden issues. Poor weather was also a key barrier both to gardening and front garden greenery.

Front garden use depended heavily on orientation and position. Sunshine available in the front garden influenced time spent there and the plants that could be grown, while size influenced both what could be planted and whether a larger back garden space was more often used. Those near a main road felt it would be less pleasant to sit or garden at the front. Space for parking was a common issue, where need for off-street parking took precedence over greenery:

*It was never an option to turf it or grass it or garden it purely because the girls were getting older and driving and we needed the space for cars (Mixed 3)*

Despite appreciating outdoor time, planting greenery in front gardens for environmental reasons was not spontaneously raised in focus groups. Both gardeners and non-gardeners treated the idea with surprise and thoughtfulness, demonstrating a disconnect between front gardens and local environmental impacts:

*I've never really considered [reducing flood risk], but it actually makes sense (Non-gardeners)*

Enthusiasm was however expressed for learning more and raising awareness of ways in which front garden planting could have a tangible local impact, with particular emphasis on reducing flood risk locally and promoting biodiversity.

*if someone says if you plant this, it would help the bees then, or encourage the bees, I would say 'yeah ok' because I like the idea (Non-gardeners)*

### The social nature of front garden spaces

Front gardens had clear social benefits. There was a strong consensus within and across focus groups that spending time on activities in the front garden was an open invitation for neighbours and passers-by to chat, which many welcomed:

*In the front garden, you chat to people (Gardeners)*

Plants could be an important connection with friends and family, particularly for those more interested in gardening. A few mentioned that plants given to them by someone who had since passed away acted as visible reminders of the person. In all focus groups, some of the participants reported others starting conversations about plants or exchanging plants between family, friends and neighbours.

Lockdowns during the COVID-19 pandemic had increased the salience of front gardens as social spaces that developed a stronger sense of local community, offering incidental socialising opportunities for those spending the majority of their day at home, or as outdoor visiting spaces. Victory in Europe (VE) Day street parties (where people celebrated in their front gardens at a social distance) were spontaneously recalled as a key example of this. Increased socialising did depend highly on relationships with individual neighbours. Furthermore, there was a perceived need to be active in the front garden space, with the idea of sitting and relaxing out the front holding a stigma for some:

*I think sitting out the front people would say either this person's got too much time or he's looking at the neighbourhood gossip (Mixed 3)*

Relaxation was seen as something to mainly do in more private spaces, such as the back garden, partly as relief from socialising. Due to the high visibility of front garden spaces, participants considered how they represented their own social identity in the neighbourhood, and made positive and negative judgements about neighbours based on their front gardens:

*us and my two neighbours fortunately do tend to put a lot of time and effort into their garden, but then others are. . . There's a washing machine, a sofa and a mattress sitting in the front. . . They're obviously going to have no pride in anything. (Mixed 2)*

Being 'neat and tidy' was therefore prioritised as the ideal front garden, which could sometimes contrast with the idea of having lots of plants and greenery.

*A nice, neat, neat lawn and a nice driveway, I think it looks good. But it's not necessarily about loads of plants. I think it's just tidiness (Mixed 1)*

Few participants discussed wilding approaches to gardening, but where they did, they themselves considered it untidy or believed their neighbours would. Simple garden features with easy maintenance were valued, such as a lawn or pots. People also felt there was more pressure on front gardens to fit in with the rest of the street, suggesting that street-level initiatives could be useful.

### Knowledge and self-efficacy for planting

Those who gardened had typically accumulated knowledge over many years and were strongly interested in gardening. They often used more specific language, discussing 'perennials', 'bedding plants' and

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specific species, terminology that was off-putting for non-gardeners:

*if you say bedding plant, I don't really understand what that means. . . I just want plants that stay green all year round and don't drop their leaves (Non-gardeners)*

Jargon was particularly intimidating when visiting a garden centre, with some participants reporting embarrassment about their lack of knowledge and finding signage difficult to navigate. In contrast, more confident gardeners spoke about their local garden centres as a very helpful source of information. Gardening knowledge was seen as something primarily gained from experience and trial and error. Less confident gardeners typically relied on knowledge and advice, or gardening itself, from more expert partners or parents. There was a strong intergenerational quality to gardening – most participants (whether non-gardeners or gardeners) had learnt about gardening through family members, often parents or grandparents:

*I'd never known and never needed Alan Titchmarsh or Charlie Dimmock [UK TV gardening show presenters] to show me to tap and pull the roots out to encourage it. I've learned that from my grandparents. (Gardeners)*

People were therefore the most important gardening resource, with ongoing exchanges of ideas, plant cuttings and advice. On this basis, most focus groups favoured school-based interventions to engage young people in lifelong gardening and to teach basic principles. TV shows were potentially useful but criticised for concentrating on large-scale complex landscaping projects rather than simple basics achievable in limited spaces. Books were used by some, while websites were seen as an easy way of getting answers to specific questions and ideas for ways to change gardens.

## DISCUSSION

Front gardens were valued as spaces that improved wellbeing through relaxing

activity, visual benefits, socialising and through being outdoors in the fresh air. However, participants were only willing to invest time, money and effort on the space if, first, they spent a lot of time in it, which depended heavily on their time commitments, garden orientation, weather and local environmental factors such as litter; and second, if they felt sufficiently confident that they would see good results. Front gardens presented a social image to others, but were rarely connected with local or global environmental benefits. Basic knowledge and self-efficacy for planting were key factors affecting whether people planted greenery. Participants mainly learnt gardening through parents and grandparents, reinforced by trial and error, others' advice and the Internet.

However, there are few initiatives focusing on front gardens as a key area for change and how we can encourage individual behaviour change on this topic, despite their value as an individual and community health asset. Table 2 maps barriers and facilitators discussed in each subtheme to the capability, opportunity and motivation dimensions of the COM-B framework. We have mapped these to the intervention functions from Michie *et al.*<sup>28</sup> and to interventions reflecting these functions that were suggested by our participants. The range of barriers identified in Table 2 provide a starting point for local intervention – organisations can identify which are most relevant barriers for a particular population or area, what can be changed and at what level. When planning interventions, a multi-pronged approach addressing barriers across capability, opportunity and motivation are necessary to succeed in initiating behaviour change, particularly when interventions are co-designed. Implementing interventions at different levels (e.g. mass communication, local policy, and local initiatives) will facilitate these processes.

Gardening in general has received previous attention and study – positive personal effects on physical and mental health have been extensively demonstrated.<sup>13–15</sup> However, our study showed that mental health benefits and personal enjoyment are more strongly

prioritised than gardening as physical activity, aligning with an earlier large-scale quantitative study,<sup>12</sup> and so these should be communicated more widely.

Our research showed that the broader value of front garden spaces needs to be promoted at both national and local levels. Given the opportunity barriers to change identified in our study, local initiatives are needed to encourage green front gardens when planning new housing or to encourage change through incentives or neighbourhood projects. Schemes such as Britain in Bloom, an annual national competition which encourages planting and tidying in local areas,<sup>33</sup> shows positive community, health, economic and environmental impacts.<sup>34</sup> At present, this focuses mainly on community spaces rather than private gardens, but this could provide a useful template for further national or local strategies, for example, greenest street competitions. The current campaign of the Royal Horticultural Society (the United Kingdom's major gardening charity),<sup>35</sup> Greening Great Britain, includes a focus on front gardens from a national perspective; however, there is a need to ensure this is disseminated more widely and translated into local campaigns, projects and strategies. These will benefit from further qualitative research or co-design approaches with residents to ensure they respond to the local context, as well as applying the insights on motivations and barriers outlined above.

These campaigns could also raise awareness of wider social benefits, as contributing to a nicer street or creating a pleasant space for active travel were rarely discussed, with participants placing greater focus on how their front garden reflected themselves, rather than the local community. Likewise, a national UK survey found neighbours and community were mentioned as a reason for gardening by <5% respondents.<sup>12</sup> Social benefits were seen as important in this study but more about creating connections between neighbours and generations than providing a green community environment or local or global environmental benefits, so campaigns could encourage providing plants as gifts. Neatness was prioritised in a UK

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Table 2

**COM-B breakdown of factors affecting front gardening, associated intervention functions and how this could be implemented.**

<b>Factors identified from qualitative analysis</b>	<b>Intervention functions from Michie et al.<sup>28</sup></b>	<b>Examples of how this could be applied based on focus group data</b>
<p>Capability</p> <p>Psychological</p> <ul style="list-style-type: none"> <li>• Knowledge (from experience, learning from previous generations)</li> <li>• Self-efficacy and confidence</li> </ul> <p>Physical</p> <ul style="list-style-type: none"> <li>• Physical barriers were not mentioned by participants.</li> </ul>	<p>Training</p> <p>Enablement</p>	<p>Providing information on gardening in front gardens and simple basics through websites, TV and books.</p> <p>Maximise information available in garden centres, with clear directions to match garden conditions to plants available.</p> <p>Provide different levels of information targeted to different audiences (e.g. novice gardeners)</p> <p>Imparting skills through events and programmes such as local fairs or gardening clubs</p> <p>Encouraging learning from a young age between parents or grandparents and children, or school-based interventions</p> <p>Encouraging people to start with small changes and build up</p>
<p>Opportunity</p> <p>Physical</p> <ul style="list-style-type: none"> <li>• Time available</li> <li>• Resources (financial risk)</li> <li>• Inherited plants</li> <li>• Weather/climate</li> <li>• Requirement for other use of space (mainly parking)</li> <li>• Characteristics of garden (orientation, position etc)</li> <li>• Location of front garden (e.g. near main road)</li> </ul> <p>Social</p> <ul style="list-style-type: none"> <li>• Social norms of family</li> <li>• Social norms of street</li> <li>• Front gardens as reflection of social identity</li> </ul>	<p>Restriction</p> <p>Environmental restructuring</p> <p>Enablement</p>	<p>Change planning regulations to ensure new homes are built with greenery in the front garden</p> <p>Encourage large landscaping companies to consider environmental impact of changes</p> <p>Providing plants</p> <p>Provide advice on low-cost gardening and planting in different garden conditions and locations</p> <p>Provide advice on or supply plants that require little effort to maintain</p> <p>Encourage local in person and social media networks on gardening tips and exchanges of plants</p> <p>Encouraging spending time gardening between parents or grandparents and children</p> <p>Promoting pride in local neighbourhood</p>
<p>Motivation</p> <p>Reflective</p> <ul style="list-style-type: none"> <li>• Improving biodiversity</li> <li>• Reducing flood risk</li> <li>• Look nice and tidy for others</li> <li>• Security and litter</li> <li>• Frequency of use</li> </ul> <p>Automatic</p> <ul style="list-style-type: none"> <li>• Sensory benefits</li> <li>• Mental wellbeing</li> <li>• Fresh air and vitamin D</li> <li>• Socialising</li> <li>• Features/plants with emotional connections</li> </ul>	<p>Education</p> <p>Persuasion</p> <p>Incentivisation</p> <p>Coercion</p> <p>Persuasion</p> <p>Incentivisation</p> <p>Coercion</p> <p>Environmental restructuring</p> <p>Modelling</p> <p>Enablement</p>	<p>Promote the health, wellbeing, environmental and social benefits to both gardening activity and the end results of planting in front gardens</p> <p>Link to wildlife (e.g. supporting bees) and clear benefits to the local environment</p> <p>Provide an emotional reason to plant something (e.g. encouraging plants as gifts, planting as a memorial)</p> <p>Council grants, vouchers or other incentives</p> <p>Local competitions for front gardens or streets</p> <p>Provide examples of similar front gardens that have been transformed to be more green and visually appealing</p>



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context in our study, with participants generally preferring a low-effort garden unless they were interested in improving their garden as an ongoing project. Previous work has found that greenery quality (variation, maintenance, orderly arrangement, absence of litter, and general impression) better predicted health, stress and social cohesion than quantity,<sup>16</sup> suggesting even small changes to promote greenery that maintain a neat and tidy front may be beneficial. Policymakers should be aware that encouraging changes in front gardens may have long-lasting effects, as people often kept plants from the previous homeowner, and may trigger further changes in the community as people feel a social pressure to fit in with the rest of the street.

Perception of self-efficacy for gardening needs to be addressed – it was clear from some non-gardeners in our study that ‘mistakes’ and feeling unable to understand gardening jargon could significantly affect confidence. Initiatives to encourage planting in front gardens should focus on simple, cost-effective methods to increase planting that have a visual impact of neatness and bright colour. Clear instructions or recommended plants that are suitable for the terrain may help to overcome initial self-efficacy and environmental barriers and build positive reinforcement. Although there is existing information and resources – for example, the Royal Horticultural Society website allows someone to find plants based on garden conditions and has space for planning your own garden,<sup>35</sup> wider awareness and promotion of these kind of resources is needed. Social media may also play a role in this.

While many of the suggested behaviour change interventions from our COM-B analysis rely on education and advice, important opportunity barriers were also detected such as garden orientation, position and factors such as resources, security and litter. These may require more active local strategies, such as providing low cost or free access to suitable plants, implementing planning regulations regarding green space in front gardens and ensuring streets are well-maintained. These interventions and initiatives to encourage planting in front gardens need to be evaluated to build up an evidence base, particularly with regards to long-term effects. This approach is likely to apply across countries and contexts, with specific consideration given to likely variations in cultural norms, climate for growing plants, available housing stock and planning regulations.

Limitations of this study include a lack of patient and public involvement, although representatives were included in other aspects of this project. This article provides a starting point for exploring this topic in the UK context, and future studies are needed to explore subgroups in more depth (e.g. other countries within the United Kingdom, certain types of residence, those on low incomes). This was carried out in England, and while the findings align well with international survey studies,<sup>29,30</sup> more qualitative work is needed in different cultures and climatic zones. This was also carried out within the context of a national pandemic where people had been instructed to stay at home. Further work is needed to explore whether there have been shifts in front gardening behaviour or motivations

ascribable to or since pandemic lockdowns. As this is a qualitative study, the study was not intended to quantify or determine the relative importance of each of the barriers and facilitators to the wider UK public, which remains an area for further research using different methodologies.

## CONCLUSION

In conclusion, initiatives to encourage planting in front gardens are likely to be most successful if they focus on plants that are easy to access, simple to care for, do not take up too much space, are suitable to the environment and have a visual impact of neatness and bright colour. Campaigns to encourage planting greenery in front gardens should highlight the specific benefits of front gardening, particularly to reducing local flood risk and increasing biodiversity, in addition to local community and health benefits.

## CONFLICT OF INTEREST

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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# Outcomes of a residential respite service for homeless people with tuberculosis in London, UK: a cross-sectional study

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## Keywords

tuberculosis; homeless; residential respite; elimination; inclusion health; social exclusion; treatment completion; vulnerable populations

## Abstract

**Background:** Many countries are seeking to eliminate tuberculosis (TB), but incidence remains high in socially excluded groups such as people experiencing homelessness. There is limited research into the effectiveness of residential respite services (RRS), which provide accommodation and social and clinical support for homeless people with active TB.

**Methods:** We used a register of all cases of TB diagnosed in London between 1 January 2010 and 3 October 2019 to compare characteristics and outcomes of patients treated in an RRS with patients receiving standard care. The primary outcome was successful treatment completion. We used logistic regression to compare likelihood of completing treatment, and simulation to estimate the absolute change in treatment completion resulting from this service.

**Results:** A total of 78 homeless patients finished an episode of TB treatment at the RRS. Patients treated in the RRS were more likely than patients treated in standard care to have clinical and social risk factors including drug resistance, history of homelessness, drug or alcohol use, and need for directly observed therapy. After adjusting for these factors, patients treated in the RRS had 2.97 times the odds of completing treatment (95% CI = 1.44–6.96). Treatment ended in failure for 8/78 patients treated in the RRS (10%, 95% CI = 5%–20%). We estimated that in the absence of the RRS, treatment would have ended in failure for 17/78 patients (95% CI = 11–25).

**Conclusion:** The residential respite service for homeless TB patients with complex social needs was associated with better treatment outcomes.

## WHAT IS THE KEY QUESTION?

How does a residential respite service (RRS) affect the likelihood of TB treatment completion for homeless TB patients in London?

## WHAT IS THE BOTTOM LINE?

Patients treated in the RRS had higher prevalence of clinical and social risk factors for TB treatment failure than patients treated in standard care. The crude risk of TB treatment failure was similar in the two settings. After adjusting for clinical and social risk factors, patients treated in the RRS were almost three times more likely to complete TB treatment.

## WHY READ ON?

Improving TB outcomes among socially excluded groups including people experiencing homelessness is challenging and is central to elimination of TB in low incidence countries. These results show that an RRS is associated with improved TB treatment outcomes among these groups.

## INTRODUCTION

Tuberculosis (TB) remains a major global health problem despite substantial reductions in incidence,<sup>1</sup> with an estimated 10 million new cases in 2018.<sup>2</sup> While antibiotic treatment is

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effective, the toxicity and duration are obstacles to treatment completion. Non-adherence is common and in 2017 an estimated 15% of patients who began TB treatment did not complete.<sup>2</sup> This leads to further transmission, preventable deaths, and the development of antibiotic resistance.

TB is associated with poor and overcrowded living conditions.<sup>3,4</sup> In low incidence countries, TB is increasingly concentrated among groups with social risk factors including those with experience of homelessness, prison, alcohol dependence, and illicit drug use.<sup>5,6</sup> Global,<sup>7</sup> regional,<sup>8,9</sup> and national strategies<sup>10</sup> highlight these socially excluded groups as priorities for TB elimination. Homelessness is one of the most important risk factors for TB infection and transmission.<sup>11</sup> Homeless people may have increased exposure, delayed diagnosis, prolonged infectivity due to late diagnosis, lower adherence to treatment, and higher risk of complex and drug resistant disease.<sup>12</sup> Together, these factors can lead to increased risk of treatment failure and multiple episodes of TB.<sup>13–17</sup> In addition, some homeless people in the UK have 'no recourse to public funds' due to their migration status, meaning they cannot access welfare benefits or assistance with housing.

Clinical guidance in the UK recommends that people with active TB – including those with no recourse to public funds – should be provided with state-funded accommodation.<sup>18</sup> However, the lack of an agreed national pathway means such patients are at risk of being discharged to the street following hospitalisation for TB treatment.<sup>19</sup> Where accommodation is provided it is often in 'bed and breakfast' style lodging, lacking social and clinical support. Some services were previously established to provide integrated accommodation and social support to homeless people but have long since been closed.<sup>20</sup> Today, models for supporting TB patients with complex social needs include 'ad hoc' social support provided separately from accommodation, or service-level agreements between discharging hospitals and local housing teams to

provide rapid access to accommodation, without in-house social support.<sup>5</sup>

Most research into approaches to improving outcomes for homeless TB patients focuses on patient behaviour, including educational interventions, psychological support, incentives, and directly/video observed therapy (DOT/VOT).<sup>15,16,21</sup> Limited research has investigated the effectiveness of interventions that aim to improve housing and other material and social factors. We are aware of two previous studies of the outcomes of housing interventions for homeless TB patients in South Korea<sup>22</sup> and the US,<sup>23</sup> which both suggested improved treatment outcomes but were limited by their ability to account for differences in patients' clinical characteristics. One observational study found that homeless people in South Korea who received an enhanced housing package (including food and social support) had improved treatment completion, relative to treatment as usual.<sup>22</sup> Another study found that homeless people in California placed in residential treatment programmes had improved treatment completion rates compared with historical and neighbouring locations.<sup>23</sup>

### Olallo House: a residential respite service in London, UK

TB patients in London are usually managed in the community at outpatient clinics. Patients are assessed regularly and clinicians record risk factors including homelessness, drug and alcohol use, comorbidities such as HIV, and mental health problems. Directly Observed Treatment or Video Observed Treatment is sometimes provided for patients who have a high risk of treatment failure.<sup>21</sup> However, treatment failure is common in groups with these risk factors, particularly those with no recourse to public funds.

In response to these problems, a partnership of NHS and charitable organisations set up a residential respite service (RRS) in central London, UK, in 2010. The RRS is located in Olallo House, a 'safe house' for vulnerable migrants run by the charity Saint John of God Hospitaller Services. It aims to

support homeless TB patients with no recourse to public funds; facilitate safe and timely discharge from hospital; support TB treatment; provide accommodation; and provide comprehensive support including psychological help and support for drug and alcohol dependency. The staff team provides support for a range of social needs, seeking to enable long-term recovery, access to housing and employment, and independent living. To our knowledge this is the only contemporary UK example of a dedicated residential intervention providing comprehensive health and social support to TB patients with no recourse to public funds and complex social needs.

We aimed to compare the characteristics and treatment outcomes of patients treated at the RRS with patients treated in standard care, and to estimate the association between treatment at the RRS and treatment outcomes.

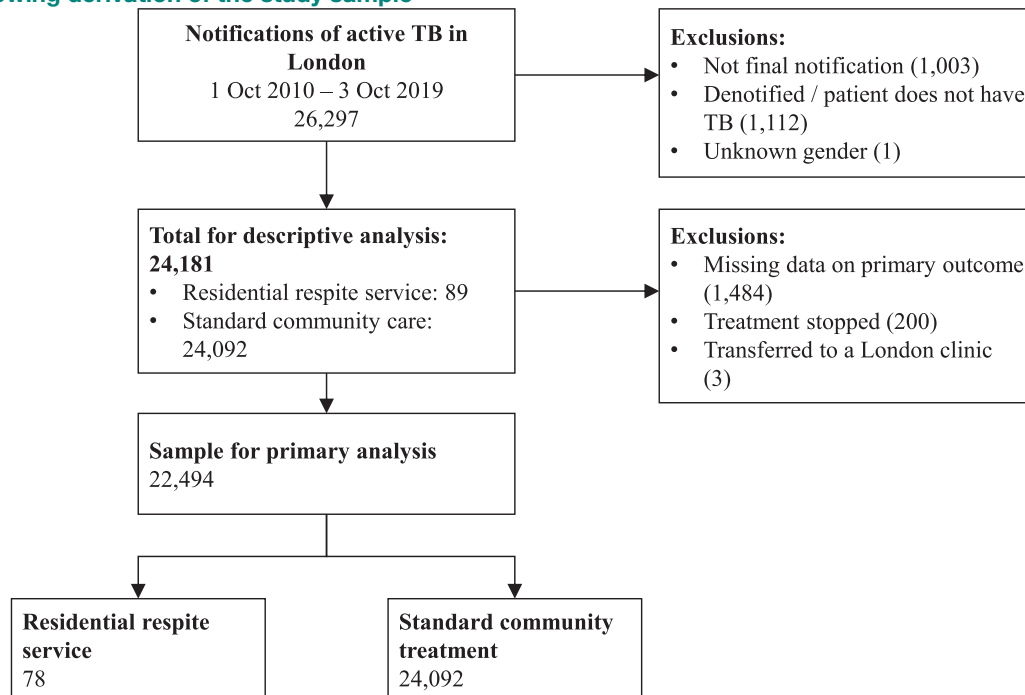
### METHOD

We did a cross-sectional analysis using linked routine surveillance data from Public Health England (now known as the UK Health Security Agency) and from the RRS. We compared cases treated in the RRS with all other cases of TB notified in London. Descriptive analysis compared the demographic, clinical and social characteristics of the two groups. We used logistic regression to estimate the association between support at the RRS and treatment outcomes.

### Dataset and sample

We used data from the London TB Register (LTBR), a routine surveillance database maintained by Public Health England, which includes information on all cases of TB notified by medical practitioners in London. In the UK, TB is a statutorily notifiable disease and LTBR collects data on patient demographics, disease factors such as site, drug sensitivities and previous TB treatment history, and social risk factors for all cases diagnosed or managed by TB clinics in London.<sup>24,25</sup> Data are entered to LTBR by clinic staff. Data on drug resistance is added directly from reference laboratory reports. We

Figure 1

**Flow-chart showing derivation of the study sample**

extracted demographic, clinical, and social information from LTBR for all cases aged 18 or older notified between 1 January 2010 and 3 October 2019 (26,297 cases). Each record represented a unique 'treatment notification period', which begins upon notification and ends when a final outcome (treatment completion, death, loss to follow-up, or transfer to another clinic) is recorded.

We extracted data from the RRS including a unique individual identifier that was common with LTBR, the dates of residence at the RRS, and details of social risk factors such as homelessness. We linked this data to the LTBR data using the unique identifier and flagged cases that were resident at the RRS during their notification period (89 cases). Five patients treated in the RRS had multiple episodes, but each had only one episode of treatment at the RRS (i.e. the other episodes were in standard community services), and in all such instances the episode in the RRS was the most recent episode.

For descriptive analysis, we excluded cases where the patient had a later episode of TB (1003 cases); cases that

were 'de-notified' due to misdiagnosis of TB (1112 cases); and one case with unknown gender (see Figure 1). Further exclusions were made for logistic regression analyses, due to missing variables specific to each outcome (see below, and Figure 1).

### Outcomes

Our primary outcome variable was a binary flag indicating treatment completion. Those who died, were lost to follow-up, or were flagged as 'transferred out' to non-London clinics without further information were considered to have not completed treatment. Those with missing outcome data (1484 cases), whose TB treatment was stopped (200 cases) or who were transferred to a clinic outside of London (three cases) were excluded from primary regression analysis. Following these exclusions, 22,494 individuals (of which 78 treated in the RRS) were included in regression analysis.

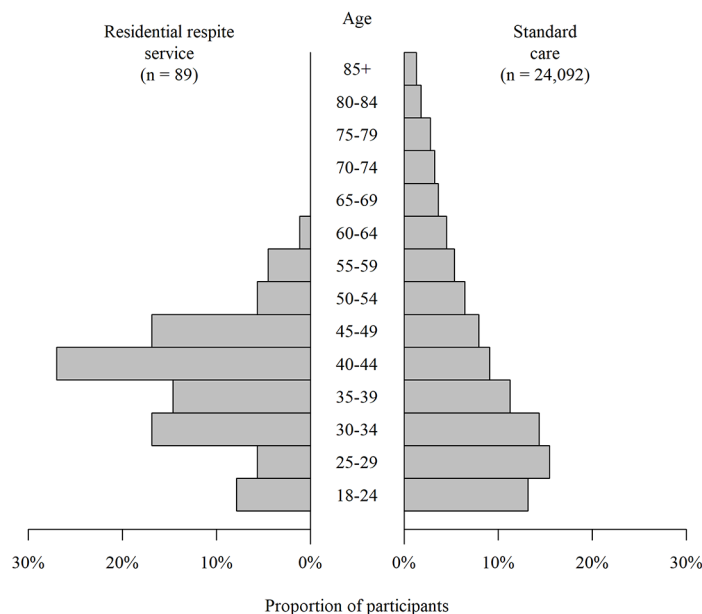
Our secondary outcome was death during the notification period; cases where death was flagged in LTBR (TB as direct, contributing or incidental cause) were assigned this outcome. We exclude

cases that were lost to follow-up, had no outcome information, or who were transferred out (2992 cases).

### Covariates

We selected potential confounders based on an a-priori logic model (see Supplementary information). Demographic covariates were (1) age, (2) sex, and (3) ethnic group (Asian, White, Black, other, or unknown). Clinical covariates were (1) the patient's sputum smear status; (2) the site of disease, coded as two non-exclusive binary variables showing (a) whether the patient had pulmonary disease, and (b) whether the patient had disease at a 'complex site' including miliary, central nervous system, or disseminated TB; (3) drug resistance, from clinician input and verified by reference laboratory tests, coded into three levels based on the maximum resistance indicated in either source: (a) fully sensitive or unknown, (b) isoniazid mono-resistant, (c) rifampicin resistant or multidrug resistant (MDR). Social covariates were (1) history of homelessness, (2) history of drug use, (3) history of prison, (4) alcohol dependence

Figure 2

**Age distribution of study participants**

(recorded as concerns about the patient's ability to self-administer treatment affected by alcohol), and (5) whether a need for DOT was recorded. DOT may be recommended for different reasons but often relates to social barriers to care and we therefore used it as a marker of social exclusion.

**Statistical analysis**

We compared patients treated in the RRS with patients treated in standard care in terms of demographic, clinical, and social variables. We then used logistic regression to estimate the association between the outcomes and the location of treatment (the RRS or standard community care), adjusting for demographic, clinical, and social covariates. We then conducted a simulation to estimate how many treatment completions would be experienced among patients treated in the RRS if they were treated in standard community services. In this simulation, we fit a logistic regression model on the whole sample with treatment completion (primary outcome) as the dependent variable and the same independent variables as above but excluding the location of treatment. We then used this

model to generate 1000 simulations of the primary outcome (i.e. treatment success/failure) for the 78 RRS patients with data on treatment completion; interpretable as scenarios in which these patients were treated in standard community care. We reported the .025, .5 and .975 quantiles of the number of treatment completions.

**Missing data**

Some patients did not have outcome data (e.g. due to ongoing treatment) and we excluded these patients from analysis. Where information on social risk factors (history of homelessness, drug use, prison, or alcohol dependence) was missing, we coded the variable as 'missing'. We conducted a sensitivity analysis to assess the possible extent of bias resulting from this missing data. We created two scenarios: (1) imputing data for missing social risk factors for patients treated in the RRS as the presence of risk factors, and for patients treated in standard community care as the absence of risk factors and (2) the reverse scenario, imputing missing social risk factors for patients treated in the RRS as the absence of risk factors, and for patients treated in standard community care as the

presence of risk factors. We reported the primary outcome in these scenarios. Data were complete for other variables, apart from sex, which was missing for one patient (who we excluded from analysis).

Analysis was performed in R version 3.5.2.

**RESULTS**

A total of 24,181 patients meeting the inclusion criteria were notified to LTBR between 1 January 2010 and 3 October 2019, of which 89 were treated at the RRS.

Patients treated in the RRS were more likely to be male, of White ethnicity, and born outside of the UK. Although the median ages were similar, the age distribution was different. Those treated in the RRS had a narrower distribution with an older modal age (Figure 2). Patients treated in the RRS were more likely to be sputum-smear positive, have pulmonary TB, to have been a hospital inpatient during their TB episode, to have isoniazid mono-resistant, rifampicin resistant or MDR, and more likely to require management via DOT. RRS residents were much more likely to have experienced homelessness, imprisonment, drug use, or to currently use alcohol to an extent that it affects their ability to self-administer treatment (Table 1).

**Primary outcome**

A total of 22,494 patients had a valid primary outcome measure at the end of the notification period, of whom 78 were treated in the RRS. A similar proportion of patients treated in the RRS and in standard community care completed treatment (approximately 90% in each setting) and the crude odds ratio was 1.03 (95% CI = 0.53–2.34). After adjusting for demographic, social, and clinical variables, the odds ratio was 2.97 (95% CI = 1.44–6.96). The results are shown in Table 2. Detailed results of the regression model, including coefficients for covariates, are shown in Supplementary information. In sensitivity analysis of missing data, the fully adjusted odds ratio was 2.87 (95% CI = 1.40–7.03) in the first scenario and 3.00 (95% CI = 1.48–6.97) in the second scenario, suggesting limited potential

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Table 1			
Demographic, clinical, and social characteristics of patients with diagnosed TB in London, 2010–2019			
Variable		Residential respite service	Standard community care
Total		89 (100%)	24,092 (100%)
Demographic characteristics			
Age	Median (IQR)	40 (34–45)	37 (28–51)
Female sex		3 (3.37%)	9845 (40.86%)
Ethnicity	Asian	5 (5.62%)	10,977 (45.56%)
	Black	12 (13.48%)	6055 (25.13%)
	White	49 (55.06%)	3,107 (12.9%)
	Other	23 (25.84%)	3722 (15.45%)
	Unknown	0 (0%)	231 (0.96%)
Clinical characteristics			
Sputum smear positive		46 (51.69%)	2545 (10.56%)
Pulmonary TB		82 (92.13%)	11,007 (45.69%)
Miliary, CNS or disseminated TB		3 (3.37%)	1078 (4.47%)
Hospitalised		69 (77.53%)	7586 (31.49%)
Drug sensitivity	Fully sensitive	73 (82.02%)	22,756 (94.45%)
	Isoniazid mono-resistant	8 (8.99%)	927 (3.85%)
	Rifampicin resistant or MDR	8 (8.99%)	409 (1.7%)
Social characteristics			
History of drug use	No	62 (69.66%)	22,327 (92.67%)
	Yes	23 (25.84%)	886 (3.68%)
	Missing	4 (4.49%)	879 (3.65%)
History of homelessness	No	13 (14.61%)	22,521 (93.48%)
	Yes	76 (85.39%)	844 (3.5%)
	Missing	0 (0%)	727 (3.02%)
History of prison	No	71 (79.78%)	22,626 (93.91%)
	Yes	13 (14.61%)	664 (2.76%)
	Missing	5 (5.62%)	802 (3.33%)

(Continued)

## Outcomes of a residential respite service for homeless people with tuberculosis in London, UK: a cross-sectional study

Table 1 (Continued)

<b>Demographic, clinical, and social characteristics of patients with diagnosed TB in London, 2010–2019</b>			
<b>Variable</b>		<b>Residential respite service</b>	<b>Standard community care</b>
Alcohol	No	47 (52.81%)	21,599 (89.65%)
	Yes	40 (44.94%)	901 (3.74%)
	Missing	2 (2.25%)	1592 (6.61%)
Need for DOT		79 (88.76%)	2838 (11.78%)
Outcomes			
Treatment completion	Yes	70 (78.65%)	20,046 (83.21%)
	No	8 (8.99%)	2370 (9.84%)
	Incomplete	11 (12.36%)	1676 (6.96%)
Death	Yes	2 (2.25%)	871 (3.62%)
	No	71 (79.78%)	20,245 (84.03%)
	Incomplete	16 (17.98%)	2976 (12.35%)

TB: tuberculosis; MDR: multidrug resistant; DOT: directly observed treatment; IQR: interquartile range; CNS: central nervous system.

Table 2

<b>Association between treatment in a residential respite services and outcomes (treatment completion and death)</b>	
<b>Odds ratio (95% confidence interval)</b>	
Primary outcome: treatment completion	
Unadjusted	1.03 (0.53–2.34)
Adjusted for demographic variables	1.29 (0.65–2.92)
Adjusted for demographic and clinical variables	1.67 (0.84–3.80)
Fully adjusted (demographic, clinical, and social variables)	2.97 (1.44–6.96)
Secondary outcome: death	
Unadjusted	0.65 (0.11–2.09)
Fully adjusted	0.37 (0.06–1.31)

bias from missing data in social risk factors. We also observed strong associations between missing data and treatment failure (see Supplementary information), which may suggest a process in which covariate data is less likely to be recorded for patients who do not complete treatment.

### Secondary outcome

We were able to ascertain whether death occurred for 21,189 patients, of whom 73 were treated in the RRS. Of those treated in standard care, 871/21,116 (4.1%) died, while for those treated in the RRS 2/73 died (2.7%). The fully adjusted odds ratio for death during treatment comparing

patients treated in the RRS with patients treated in standard community care was .37 (95% CI = 0.06–1.31).

### Simulation

Among patients treated in the RRS, 8/78 episodes ended in treatment failure. Based on simulation we estimate that in



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the absence of the RRS, 17/78 episodes (95% CI = 11–25) would have ended in failure. This suggests that the RRS was associated with a halving of the number of treatment failures.

### DISCUSSION

Our results suggest that a residential respite service with housing and care is associated with reduced risk of TB treatment failure for patients with social risk factors and clinically complex disease (including multidrug resistance).

Risk factors for treatment failure were common in the RRS cohort. Despite this, patients treated at the RRS service had similar crude probability of completing treatment to patients in the community. The regression modelling and simulation suggest that risk of treatment failure for these patients would have more than doubled in standard community care, increasing risk of mortality, hospital re-admission, onward transmission, and development of multidrug resistance. We did not find evidence of a difference in mortality risk but our analysis lacked power.

There are several possible reasons why treatment at the RRS was associated with better outcomes. First, the RRS provided accommodation during TB treatment. People with social risk factors such as homelessness are often discharged from hospital into inadequate living conditions, including rough sleeping.<sup>26</sup> Attending outpatient appointments and adhering to antibiotic regimens can be challenging in these conditions. Second, the RRS at Olallo House provides DOT for all residents and achieves high rates of treatment fidelity which may not be the case for patients treated under DOT in the community.<sup>21</sup> Third, the RRS aims to improve social outcomes including helping residents to find work, live independently, and reconcile with families and home communities, and this may improve treatment success.

Our findings are the first that we know of to estimate the effect of a housing or residential service package on TB treatment completion among people legally unable to access state housing support. Our results are similar to those

found by a study of patients in South Korea, which estimated that an intervention including housing, meals, DOT and case management was associated with an increased likelihood of treatment success (adjusted OR: 4.19, 95% CI = 1.63–10.80).<sup>22</sup> Our study also adds to an emerging body of literature that demonstrates the importance of intermediate or 'step-down' care upon discharge from hospital for improving health outcomes for people with social risk factors.<sup>27,28</sup> We used a comparison group of patients treated in standard services, something not undertaken in previous studies of similar populations.<sup>23</sup> A key strength of our study is the use of a routine dataset, which allowed access to a large, well-characterised sample, including demographic, clinical and social information. Previous evaluations have not been able to adjust for clinical and social characteristics of participants.<sup>22</sup>

The study also has several limitations. We focused on TB treatment outcomes and did not capture other potential benefits of the RRS, including reduced delays to hospital discharge, reduced risk of re-admission, reduced onward transmission, and broader social benefits. We identified some issues with data quality, and particularly in under-recording of social risk factors. For example, routine data in LTBR show that 85% of patients treated in the RRS had experienced homelessness, but all RRS residents are homeless on entry. Social risk factors may also be under-recorded for patients treated in standard community care. There may also be residual confounding where variables recorded in LTBR do not fully reflect differences between the groups. For example, patients treated in the RRS have usually experienced long periods of sleeping rough immediately prior to their episode of TB, while patients identified as homeless in standard community care may have a range of experiences, including shorter periods and less severe forms of homelessness such as sofa-surfing.

Achieving successful treatment outcomes for homeless people with no recourse to public funds can be challenging and expensive. The mean

length of stay at the RRS within our cohort was 230 days, which at a cost of £90 per day (the amount paid by commissioners of the service at the time of publication) equates to £20,700 per person. This is lower than the costs noted in other examples of individuals with TB and no recourse to public funds, which have shown that costs of hospital inpatient care with DOT and additional case support can be over £170,000.<sup>19</sup> Comparing the costs and outcomes of the dedicated RRS investigated here against other ad hoc forms of support – such as provision of social support outside of the residential setting, or service-level agreements between secondary care and local housing teams<sup>5</sup> – is beyond the scope of this article but would be a fruitful avenue for further research.

### CONCLUSION

Incidence of TB remains high in socially excluded groups, even while incidence of the disease in the general population has fallen over the past decade.<sup>6</sup> The findings reported here provide evidence that treatment in an RRS can improve treatment success for homeless people with no recourse to public funds. Patients treated in the RRS had higher prevalence of clinical and social risk factors for TB treatment failure than patients treated in standard care. The crude risk of TB treatment failure was similar in the two settings. After adjusting for clinical and social risk factors, patients treated in the RRS were more likely to complete TB treatment.

Improving TB outcomes among socially excluded groups including people experiencing homelessness is challenging and is central to elimination of TB in low incidence countries. These results show that an RRS is associated with improved TB treatment outcomes among these groups, which can inform national strategies to reduce and eliminate TB.

### AUTHOR CONTRIBUTIONS

Conception and design was done by L.C., D.L., Y.A., C.A., A.H., and A.S.; data collation by Y.A. and C.A.; data analysis by

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L.C. and D.L.; and manuscript preparation by L.C., D.L., Y.A., C.A., A.H., and A.S. Additional contributions in the form of information about the Residential Respite Service were made from Miguel Neves and Pawel Zabielski, both of whom are employed by St John of God Hospitalier Services, which runs the Residential Respite Service.

## CONFLICT OF INTEREST

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Y.A. and A.S. work for an NHS service ('Find & Treat' at University College London Hospitals NHS Foundation Trust) that provides clinical support to the Residential Respite Service described in this study.

## ETHICAL APPROVAL

This article presents the results of a service evaluation and ethical consideration was not required (as per UCL's Research Ethics Committee exemptions policy – see <https://ethics.grad.ucl.ac.uk/exemptions.php>).


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## DATA AVAILABILITY STATEMENT

The data used are maintained by Public Health England and further analyses may be possible with approvals from Public Health England.

## SUPPLEMENTAL MATERIAL

Supplemental material for this article is available online.

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The reach and benefits of a digital intervention to improve physical activity in people with a musculoskeletal condition delivered during the COVID-19 pandemic in the UK

# The reach and benefits of a digital intervention to improve physical activity in people with a musculoskeletal condition delivered during the COVID-19 pandemic in the UK

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## Keywords

COVID-19; physical activity;  
digital intervention;  
musculoskeletal condition;  
COM-B; behaviour change  
wheel

## Abstract

**Aim:** To evaluate a digital intervention to improve physical activity in people in the UK with a musculoskeletal condition delivered during movement restrictions brought about because of the COVID-19 pandemic.

**Method:** Service evaluation data collected from 26,041 participants over 5 months was assessed against national datasets to understand the reach and representativeness of the digital physical activity intervention. Measures to restrict the movement and interaction of people were in place during these 5 months. Cross-sectional data from 2752 participants across different stages of the 12-week programme assessed levels of physical activity and the components of behaviour as defined by the COM-B model (Capability, Opportunity, Motivation = Behaviour). Regression analysis investigated the relationship between programme stage and physical activity and the components of behaviour.

**Results:** In comparison to the UK population of people with a musculoskeletal condition, the intervention participants were over-represented by females, White, and inactive people. A cross-sectional analysis suggested that the number of participants regularly active increased by programme stage. Scores for the behavioural components of automatic and reflective motivation, physical and psychological capability, and physical opportunity were also improved by programme stage.

**Conclusion:** The service evaluation suggests that the digital intervention, designed to improve physical activity in people with a musculoskeletal condition, could be beneficial during measures to restrict movement to slow the spread of infectious disease in those who are already motivated to become or stay active.

## INTRODUCTION

The COVID-19 pandemic resulted in restrictions across many countries limiting the movement and interaction of people, including stay at home orders that altered how people undertook physical activity. On 20 March 2020, the Prime Minister of the UK announced the first of three

national lockdowns to slow the spread of SARS-CoV-2. The measures to restrict movement and interaction of people were entered into law on 26 March 2020. These measures began to ease from May 2020 but were again tightened as a second wave of infections hit; the UK Government announced a second lockdown in November

2020. After an initial lifting of some restrictions in December 2020, a third lockdown was announced in January 2021. Restrictions began to be lifted in March 2021.<sup>1</sup>

Social distancing and restrictions on movement impacted physical activity levels across populations. The lockdown restrictions closed leisure facilities and limited people to one outdoor activity a day with members of their own household meaning that many of the ways that people used to exercise were no longer available. Sport England report that adult activity levels reduced during the COVID-19 pandemic owing to diminishing opportunities due to restriction on permitted activity as well as diminished motivation and sense of capability.<sup>2</sup> As a result, the importance of digital platforms promoting physical activity increased, offering an alternative solution to becoming or staying active.<sup>3</sup>

Even prior to the COVID-19 pandemic, Public Health England (now the Office for Health Improvement and Disparities) advocated the use of digital interventions to influence healthy lifestyle behaviours.<sup>4</sup> Griffiths et al.<sup>5</sup> highlight the paucity of high-quality evidence evaluating the impact of digital interventions on physical activity in people with arthritis, who experience long-term challenges to staying active. To address this gap in the literature, this study evaluates Let's Move with Leon, developed by UK charity Versus Arthritis and designed to improve physical activity in people with a musculoskeletal condition.

### Development of Let's Move with Leon

Physical activity has many benefits for people with a musculoskeletal condition, such as pain reduction, improved physical function and mental wellbeing, and protection against other long-term conditions such as heart disease and diabetes.<sup>6</sup> However, even before the impact of the COVID-19 pandemic, many people with a musculoskeletal condition in the UK were not active to the required levels, with almost a third classified as completely inactive.<sup>7</sup>

Interventions with a theoretical grounding stand the best chance of

success.<sup>5</sup> Let's Move with Leon is an online intervention developed using the Behaviour Change Wheel (BCW).<sup>8</sup> The BCW has a behavioural model at its centre, the COM-B model (Capability, Opportunity, Motivation = Behaviour), which suggests that behaviour is made up of six components: psychological and physical capability, social and physical opportunity, and reflective and automatic motivation.<sup>8</sup> The BCW incorporates three stages to designing behaviour change interventions: (1) understanding the target behaviour, (2) designing the intervention, and (3) intervention delivery.<sup>8</sup> The intervention development process began in September 2019, prior to the then unforeseen COVID-19 pandemic. Once the pandemic hit and the resulting movement restrictions were enforced, the pace and intensity of intervention development increased so to launch the digital intervention as quickly as possible. Let's Move with Leon was launched on 16 September 2020.

To understand the target behaviour, informal face-to-face discussions took place in July 2019 with 100 people with a musculoskeletal condition through support groups from across the UK and from a Versus Arthritis Volunteering conference held in Wales. In addition, the Versus Arthritis Online Community was reviewed for mentions of exercise or physical activity<sup>9</sup> and 815 people with a musculoskeletal condition were surveyed<sup>10</sup> to capture data on the barriers and facilitators to being active. An ad hoc review of the literature was undertaken to understand the capability, opportunity, and motivational barriers and facilitators to physical activity for people with a musculoskeletal condition.

To further understand the target behaviour and possible intervention delivery options, conversations took place in late 2019 with 25 healthcare professionals involved in the design, development, and delivery of services and activities for people with musculoskeletal conditions. This was followed by three intervention development workshops held between November 2019 and February 2020 with members of the Versus Arthritis Digital, Partnerships, and Health Information teams, a person with arthritis, with

representation from Sport England, an arms-length body of government responsible for getting more people active.

The intervention development workshops were facilitated by R.H. and J.W., working through the BCW stages to design, develop, and plan delivery of the intervention. Finally, an advisory group of 41 stakeholders including healthcare professionals, physical activity professionals, academics, and patient representatives was established to check and challenge the intervention development process. Over the course of intervention development, the group met on three occasions.

### Intervention components

Let's Move with Leon is comprised of 12 pre-recorded YouTube exercise sessions, each lasting around 30 min in length, details of which are sent weekly over email, coupled with a 35-page Activity Tracker, which can be printed or completed digitally. In addition, intervention users have access to an online Activity Hub which provides introductory videos, videos on how to get started with the programme, and videos on how to get up and down from the floor safely. Users can access a frequently asked questions section, an online community and information about the benefits of physical activity. The use of intervention functions, behaviour change techniques, and policy categories as outlined in the BCW<sup>11</sup> are presented in Supplementary Tables 1 and 2.

### The aim of this article

This article aims to assess the reach and the representativeness of users of Let's Move with Leon during the UK COVID-19 restrictions. Furthermore, this article aims to examine differences in physical activity and the capability, opportunity, and motivation of its participants to be physically active at different stages of the programme.

### METHOD Study design

This is a service evaluation defined by the National Research Ethics Service<sup>12</sup> as an

evaluation to understand how well a service is achieving its intended aims and benefitting service users with the results informing future decision-making. This evaluation uses secondary data collected by Versus Arthritis as part of service delivery. Anonymised data was made available to researchers at London Metropolitan University for the purposes of this service evaluation.

### Service evaluation data

Service evaluation data was collected by Versus Arthritis from 26,041 users who signed up to Let's Move with Leon between 16 September 2020 and 25 February 2021. Data was collected at sign-up on gender, year of birth, ethnicity, musculoskeletal condition, levels of physical activity, and how they heard about the programme. In addition, participants answered questions regarding their self-efficacy for individual development, their confidence in maintaining lifestyle change, the impact of their condition on daily life, their ability to lessen this impact, and their beliefs on the benefits of lifestyle changes in relation to their condition and its management. The measures used are presented in Supplementary Table 3.

Versus Arthritis collected cross-sectional data from 2752 participants across different stages of the programme in February 2021. The cross-sectional survey assessed levels of physical activity and the components of behaviour as defined by the COM-B model being physical and psychological capability, social and physical opportunity, and reflective and automatic motivation.<sup>8,13</sup> The cross-sectional data was matched to the programme sign-up data where available. The cross-sectional survey is available in Supplementary File 1.

### Data analysis

To assess intervention reach and representativeness, participant characteristics were compared to national datasets where available. The cross-sectional survey data was assessed for the relationship between programme stage, physical activity, and COM-B component using regression analysis. An adjusted model, using the

match cross-sectional and participant sign-up data, controlled for age, gender, ethnicity and sign-up scores for quality of life, the ability to achieve goals, impact of condition, ability to self-manage, perceived control over condition, understanding of healthy lifestyles, and the ability to maintain physical activity in times of stress. All variables were entered into the model; complete matched data was only available for 495 of the cross-sectional participants.

## RESULTS

### Reach and representativeness

It is estimated that in 2017 18.8 million people in the UK had a musculoskeletal condition. Between 16 September 2020 and 25 February 2021, 26,041 participants signed up to Let's Move with Leon, 0.14% of the eligible population. Most Let's Move with Leon participants (59.99%) heard about the programme through a Versus Arthritis communication channel (website, publication, email, or social media) and 36.34% heard about the programme through adverts communicated through Facebook. A full breakdown of how participants came to hear of Let's Move with Leon is presented in Supplementary Table 4. The reach of the Let's Move with Leon promotional activity is not known; however, it is reported that Versus Arthritis had 2.2 million interactions with people with a musculoskeletal condition in 2019.<sup>14</sup> Therefore, it is possible to calculate a crude reach figure of 1.18%. The representativeness of the Let's Move with Leon users is presented in Table 1.

The Let's Move with Leon users were over representative of females, White people, and older people with very little representation from those under the age of 35, just 1.20% of participants. The mean age of participants was 65 years with 72% of participants aged between 55 and 75 years. Let's Move with Leon users were more likely to be inactive than the population of people with a musculoskeletal condition (62% vs 44%) at programme initiation, which may be due to the measures to limit movement to slow the spread of SARS-CoV-2; it is noted that the measures used to assess physical activity differ and this may have

impacted upon this result.

Table 2 reports on participants' self-efficacy for individual development, confidence in maintaining lifestyle change, knowledge and perceived benefits of lifestyle changes in relation to their condition, and its management and their ability to lessen the impact of their condition.

Most Let's Move with Leon users at programme initiation had a good understanding of how to make lifestyle changes to support condition management (87.27%) with an understanding of what constitutes a healthy lifestyle (87.70%) but were less likely to be confident in their ability to be able to maintain lifestyle changes in times of stress (41.69%) and achieve the goals that they set themselves (19.36%).

### Analysis of the cross-sectional data

The characteristics of participants in the cross-sectional survey were broadly similar to the full Let's Move with Leon user population in terms of age, gender, and ethnicity. The cross-sectional survey participant characteristics are available in Supplementary Tables 5 through 7. Table 3 and Figure 1 present an analysis of the cross-sectional participant scores for the behavioural components of physical capability, psychological capability, social and physical opportunity, and reflective and automatic motivation.

An unadjusted regression analysis suggested small but significant improvements across all components of behaviour as programme stage increased. These significant findings remained unchanged in the adjusted model with the exception of social opportunity which did not see a significant increase. The regression analysis indicated that physical activity increased as programme stage increased in both the unadjusted and adjusted models (unadj odds ratio (OR): 1.164, 95% confidence interval (CI) (1.119 to 1.210),  $p < .001$ ; adj OR: 1.161, 95% CI (1.052 to 1.281),  $p < .01$ ) (Table 4).

## DISCUSSION

This article set out to evaluate a digital physical activity intervention delivered

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Table 1				
Characteristics of the Let's Move with Leon users compared to UK population estimates where available				
Characteristic	Let's Move (n)	Let's Move (%) <sup>a</sup>	UK population estimates (%)	Difference (%)
Gender <sup>b</sup>				
Male	2300	8.83	44.15	-35.32
Female	23,700	91.01	55.85	35.16
Other	41	0.16		
Age range <sup>b</sup>				
<35	308	1.20	16.32	-15.12
35-64	13,812	53.82	49.62	4.21
65+	11,541	44.97	34.06	10.91
Data not provided or spoiled	380			
Ethnicity <sup>c</sup>				
White	24,715	97.47	91.68	5.79
All other ethnic groups combined	642	2.53	8.32	-5.79
Data not provided	684			
Condition <sup>b</sup>				
Inflammatory arthritis or autoimmune disease	8892	37.41	-	-
Osteoarthritis	13,052	54.92	-	-
Chronic joint pain	17,471	73.51	-	-
Osteoporosis	2400	10.10	-	-
Other	321	13.51	-	-
Multiple conditions (included in the figures above)	13,821	58.15	-	-
Data not provided	2274			
Physical Activity status <sup>d</sup>				
Regularly active <sup>e</sup>	4970	24.26	29.00	-4.74
Fairly active	2888	14.10	27.00	-12.90
Inactive	12,627	61.64	44.00	17.64
Data not provided or spoiled	5556			
Quality of life				
Good or very good	8961	39.08	-	-

(Continued)

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Table 1 (Continued)

<b>Characteristics of the Let's Move with Leon users compared to UK population estimates where available</b>				
<b>Characteristic</b>	<b>Let's Move (n)</b>	<b>Let's Move (%)<sup>a</sup></b>	<b>UK population estimates (%)</b>	<b>Difference (%)</b>
Neither good nor poor	7800	34.02	–	–
Poor or very poor	6169	26.90	–	–
Data not provided	3111			
<b>Impact of musculoskeletal condition</b>				
None at all	224	0.96	–	–
Mild or very mild	3192	13.66	–	–
Moderate	11,288	48.28	–	–
Severe or very severe	8675	37.11	–	–
Data not provided	2662			

<sup>a</sup>Percentages are calculated from the data available excluding missing and spoiled data from the total.  
<sup>b</sup>Estimates taken from Versus Arthritis.<sup>7</sup>  
<sup>c</sup>Based on age-standardised population estimates from the Office of National Statistics.<sup>15</sup>  
<sup>d</sup>Estimates taken from a 2019 Versus Arthritis survey.<sup>10</sup>  
<sup>e</sup>Regular physical activity is defined as 150min of moderate intensity activity each week.<sup>16</sup>

Table 2

<b>Self-efficacy, knowledge and confidence of Let's Move with Leon users at programme initiation to make lifestyle changes</b>				
<b>Question</b>	<b>Agree</b>	<b>Neither agree nor disagree</b>	<b>Disagree</b>	<b>Data not provided or spoiled</b>
	<b>n (%)<sup>a</sup></b>	<b>n (%)<sup>a</sup></b>	<b>n (%)<sup>a</sup></b>	<b>n</b>
I can achieve most goals I set myself	4052 (19.36%)	7973 (38.09%)	8906 (42.55%)	5110
Making lifestyle changes could improve the management of my condition	18,871 (87.27%)	2488 (11.51%)	264 (1.22%)	4418
I often feel like I cannot do anything myself to lessen the impact of my condition	7707 (35.47%)	6752 (31.07%)	7270 (33.46%)	4312
I understand what contributes to a healthy lifestyle	19,979 (87.70%)	2389 (10.49%)	412 (1.81%)	3261
I am confident I can maintain lifestyle changes even during times of stress	9048 (41.69%)	6862 (31.61%)	5795 (26.70%)	4336

<sup>a</sup>Percentages are calculated from the data available excluding missing and spoiled data from the total.

during the COVID-19 pandemic in the UK. The digital intervention, Let's Move with Leon, was assessed for its reach, the representativeness of its participants

to the UK population of people with a musculoskeletal condition, and its potential benefits for physical activity and the components of this behaviour.

An evidence-based approach was taken to develop the Let's Move with Leon digital intervention, first understanding the behaviour of physical

Table 3

**Mean COM-B score (out of 10) by programme stage from a cross section of Let's Move with Leon users (n = 2752)**

Programme stage (n)	Physical opportunity	Social opportunity	Reflective motivation	Automatic motivation	Physical capability	Psychological capability
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Signed up but not started (n=367)	6.79 (2.34)	6.34 (2.67)	7.28 (2.32)	5.22 (2.36)	5.81 (2.40)	6.73 (2.31)
Week 1–2 (579)	6.82 (2.42)	6.30 (2.61)	7.04 (2.26)	5.06 (2.38)	5.86 (2.49)	6.68 (2.38)
Week 3–4 (n=624)	7.09 (2.15)	6.50 (2.48)	7.53 (1.98)	5.70 (2.30)	6.36 (2.33)	7.30 (2.05)
Week 5–6 (n=459)	7.27 (2.20)	6.74 (2.57)	7.70 (1.90)	5.87 (2.28)	6.51 (2.40)	7.45 (2.05)
Week 7–8 (n=300)	7.47 (2.09)	6.79 (2.56)	7.53 (2.10)	5.94 (2.36)	6.60 (2.36)	7.30 (2.11)
Week 9–10 (n=98)	7.56 (2.25)	6.62 (2.71)	7.64 (2.08)	6.17 (2.42)	6.59 (2.50)	7.42 (2.41)
Week 11–12 (n=104)	7.57 (2.03)	6.67 (2.52)	7.56 (2.26)	5.96 (2.50)	6.78 (2.24)	7.39 (2.12)
End of programme (221)	7.15 (2.33)	6.78 (2.63)	7.53 (2.18)	5.98 (2.50)	6.50 (2.39)	7.34 (2.32)

SD: standard deviation.

Table 4

**Regression analysis of the relationship between programme stage and physical activity and the COM-B components**

	Unadjusted (n = 2751)		Adjusted (n = 495) <sup>a</sup>	
	OR	95% CI	OR	95% CI
Regular physical activity <sup>b</sup>	1.164***	1.119–1.210	1.161**	1.052–1.281
Physical opportunity	0.098***	0.056–0.141	0.134**	0.034–0.234
Social opportunity	0.080***	0.032–0.129	0.067	-0.041–0.176
Reflective motivation	0.069***	0.029–0.109	0.147**	0.053–0.241
Automatic motivation	0.152***	0.108–0.196	0.198***	0.094–0.302
Physical capability	0.133***	0.088–0.178	0.174***	0.067–0.281
Psychological capability	0.113***	0.071–0.154	0.155**	0.058–0.252

OR: odd ratio; CI: confidence interval. N.B: Programme stage units were coded 1 to 8 with 1 being signed up but not started; 2, in week 1 or 2 of the programme; 3, in weeks 3 or 4 of the programme; 4, in weeks 5 or 6 of the programme; 5, in weeks 7 or 8 of the programme; 6, in weeks 9 or 10 of the programme; 7, in weeks 11 or 12 of the programme; and 8, at the end of the programme.

<sup>a</sup>Adjusted model controlled for age, gender, ethnicity, and programme sign-up scores for quality of life, the ability to achieve goals, impact of condition, ability to self-manage, perceived control over condition, understanding of healthy lifestyles and the ability to maintain physical activity in times of stress.

<sup>b</sup>Regular physical activity is defined as 150min of moderate intensity activity each week.<sup>16</sup> \*\* $p < .01$ ; \*\*\* $p < .001$ .

activity in people with a musculoskeletal condition, before using the BCW to design the intervention. The development of Let's Move with Leon directly involved

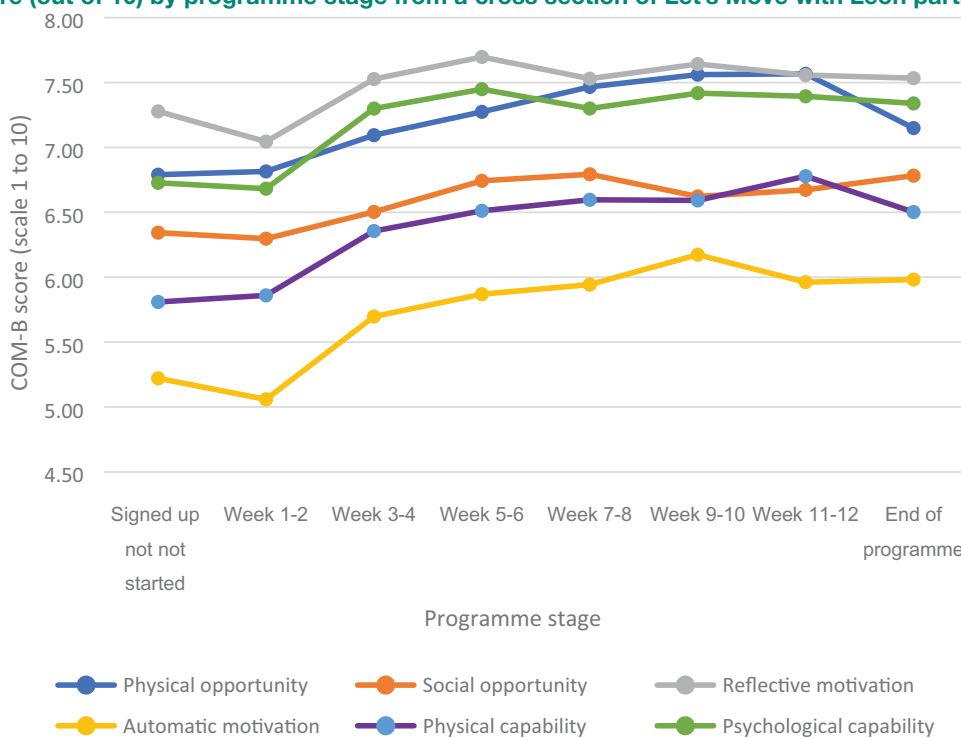
100 people with a musculoskeletal condition and 66 professionals. A large number of people with a musculoskeletal condition in the UK signed up to Let's

Move with Leon during the COVID-19 pandemic between the months of September 2020 and February 2021 (n = 26,041). However, there is a



Figure 1

Mean COM-B score (out of 10) by programme stage from a cross section of Let's Move with Leon participants (n=2752)



significant amount of missing service evaluation data at programme sign-up, up to 21.34% depending on the question. From the data available, it is suggested that users of Let's Move with Leon are most likely to be aged 55–75 years (72% of participants), female (91%), White (97%), with chronic joint pain (84%), with their condition having a moderate to severe impact on daily life (85%), and with a moderate to good quality of life (73%). At programme initiation users are most likely to be inactive (61%), with a good understanding of what contributes to a healthy lifestyle (88%) and with the knowledge that lifestyle changes could improve their condition (87%).

While the profile of those who signed up to Let's Move with Leon is not representative of the broader population of people with a musculoskeletal condition in the UK, this is not unexpected as behaviour change interventions are not one size fits all.<sup>17</sup> That said, action should be taken to investigate the

underrepresentation of users from ethnic groups other than White, males, and younger people. The participants may represent those that are more likely to engage with a digital intervention during a period where restrictions to movement are in place, but it is probable that they also represent those that are more likely to engage with Versus Arthritis, the charity that developed Let's Move with Leon. Advertising through Facebook seemed to be effective at engaging participants in this intervention with 36.34% of participants coming through this route.

The behavioural components of reflective and automatic motivation, physical and psychological capability, and physical opportunity increased with programme stage. Interventions which encourage engagement stand the best chance of success;<sup>5</sup> however, increasing social opportunities in an online setting is challenging. The Let's Move with Leon programme directs users to a Facebook group which has 7476 members, suggesting that only 28.71% of the Let's

Move with Leon participants made use of this group; this may explain why the scores for social opportunity did not increase by programme stage. It is noted that the reflective motivation scores reported from the cross-sectional participants yet to start the programme were high (7.28/10), suggesting that people drawn to this programme were already motivated to make a change despite the lockdown measures and social movement restrictions.

The chance of participants being regularly physically active increased by programme stage. This suggests that Let's Move with Leon improved physical activity in participants during a time of restricted social movement resulting from the COVID-19 pandemic. However, caution is advised in the interpretation of cross-sectional data as this only shows associations and group differences, not causation.

The data presented in this article was collected during the COVID-19 pandemic, including three UK national stay at home orders with varying degrees of movement

restrictions in between. This is a unique situation, with little evidence against which comparisons can be drawn. It has been suggested that engagement with online physical activity programmes increased during lockdown with numbers decreasing afterwards.<sup>18</sup> It may be that such digital programmes only reach particular population groups, for example, an over-representation of female users has also been reported in other studies.<sup>3,18</sup> The findings reported in this article should be considered in future digital programme evaluations to enhance understanding of the reach and impact of similar programmes; this is in the national interest as highlighted by the UK Parliament Committee to explore the impact of digital technology on physical activity.<sup>19</sup>

The available data would suggest that a digital intervention, such as Let's Move with Leon, designed to improve physical activity in people with a musculoskeletal condition, could be impactful during measures to restrict movement to slow the spread of infectious diseases in those who are already motivated to become or stay active. Now that measures to limit movement in the UK have eased, intervention analysis should

continue to identify those currently engaging (and those not engaging) with the programme, its use and its impact; a randomised control trial and process evaluation is currently underway to achieve this aim.<sup>20</sup>

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### AUTHOR CONTRIBUTIONS

J.W. prepared the manuscript. J.W., D.S. and S.H. completed the analysis of the service evaluation data. R.H. and K.B. lead the development of Let's Move with Leon. A.A. and A.H. managed intervention delivery and collection of the evaluation data.

### CONFLICT OF INTEREST

The author(s) declared the following potential conflicts of interest with respect

to the research, authorship, and/or publication of this article: The data presented in this paper were collected by Versus Arthritis. R.H., A.A., A.H., and K.B. are all members of staff at Versus Arthritis. No other conflicts of interest are declared.

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### ETHICAL APPROVAL

Ethical approval for this service evaluation was granted by the Ethics Committee for the School of Social Sciences and Professions at London Metropolitan University.

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### SUPPLEMENTAL MATERIAL

Supplemental material for this article is available online.

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**Title page**

**Article Title:**

**A systematic review of ethnic disparities in the uptake of colorectal cancer screening.**

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**Abstract:**

## **Background:**

Colorectal cancer (CRC) screening reduces mortality but variation exists in uptake. Ethnicity is suggested to play a role however there is no high-level evidence to support this. We aim to clarify the impact of Ethnicity on CRC screening uptake and our barriers to its understanding.

## **Methods:**

A Systematic Review to identify studies reporting on the participation of ethnic minorities in CRC screening worldwide was performed.

Compliance with screening according to ethnic groups and screening modality was evaluated compared to the 'White' control group.

## **Results:**

29 studies were included in the review reporting on 3 994 016 patients. Substantial variation in categorisation of ethnicities (40 sub-categories) and screening modality studied was observed. 12/19 studies for 'Blacks'; 12/16 for 'Hispanics', 4/4 for 'Asians', 3/5 for 'South Asians' and 6/7 for 'East Asians' suggest a less likely or significantly decreased compliance with screening for all screening modalities ( $p < 0.05$ ). Where screening modality was singular, minority groups like 'Blacks' and 'Hispanics' were more likely to take up flexible sigmoidoscopy compared to colonoscopy and faecal testing. Interestingly 'Japanese' and 'Vietnamese' groups consistently show no difference in the uptake of CRC screening compared to the 'White' majority.

## **Conclusion:**

This is the only systematic review on this topic. It highlights the persistently poor uptake of screening in ethnic minorities and identifies barriers like variation in ethnicity categorization, screening modality and study design utilised to understanding the intricacies of this relationship. Further collaboration and action needs to be undertaken internationally to improve inequity in the uptake of screening.

*What is already known:* Generally, ethnic minority groups may be at higher risk of poor outcomes due to potentially lower uptake of colorectal cancer screening based on observational studies.

*What this study adds:* This is the first systematic review of this vast topic and highlights 1) Varying relationships between screening uptake and ethnic minority, i.e. not all groups may be at risk; and 2) those at risk may prefer flexible sigmoidoscopy to colonoscopy or stool testing. An important barrier to definitive conclusions is a lack of consistent ethnicity census categorisation globally which needs to be addressed urgently.

## **MANUSCRIPT:**

### **INTRODUCTION:**

Colorectal cancer (CRC) is the 4<sup>th</sup> most common cancer and 2<sup>nd</sup> most common cause of cancer death worldwide with an incidence of 19.7 and 11.5 per 100,000 respectively.[1] In the UK it results in 16 000 deaths per year.[2]

CRC related mortality is complex but stage at diagnosis plays an important role. Early diagnosis and removal of precancerous polyps or early stage CRC is associated with longer-term survival.[3] In the UK, the Bowel Cancer Screening Programme (BCSP) was introduced for this purpose. It is effective in detecting a greater proportion of Dukes A cancers compared to unscreened populations (35% versus 11%) and

reducing mortality by about 15-33%. [4,5] A benefit in reduction of cancer incidence has also been observed with screening. [6]

The BCSP was formally introduced in the UK in 2006 to all 60-69 year olds and then extended to 60-75 year olds in 2010. Those individuals eligible for screening are invited biennially and sent a guaiac Faecal Occult Blood Test (gFOBT) kit. The purpose of the test is to detect traces of blood in the stool, which may indicate a pre-cancerous or cancerous lesion. More recently Faecal immunochemical Test (FIT) is replacing gFOBT because it is more sensitive for the detection of advanced neoplasia and CRC, and is associated with higher participation rates. [7] In addition a one-off flexible sigmoidoscopy is being offered to men and women at 55 years of age. [8]

Bowel cancer screening campaigns have also been initiated in countries like the USA, Netherlands, France, China, Japan, and South Korea but with significant variation in strategy and implementation. [7] For instance, in the USA screening is offered to 50-75 year olds with annual gFOBT or FIT and periodic flexible sigmoidoscopy (every 5 years) or colonoscopy (every 10 years). These are delivered via a combination of opportunistic screening and organised programmes. [9] In China, where screening is available, it is offered to 40-74 year olds with an initial gFOBT followed by a per rectal and colonoscopic examination. [7] The National screening programmes in Japan and South Korea offer an annual FIT test in the first instance. [7] Opportunistic screening compared to organised likely increases inequity in screening. [10]

In spite of screening, disparities in survival from CRC continue in certain ethnic groups worldwide. [11,12] This may in part be secondary to poor compliance with bowel cancer screening. Different ethnicities may have different cultural and health

beliefs, different levels of education, understanding and acculturation that negatively impacts upon their use of faecal testing and endoscopic procedures.

Increased migration globally and multicultural societies have led to increasingly diverse communities at a higher risk of delayed CRC diagnosis. It is important then to understand if ethnicity plays a significant role and which ethnicities are at particular risk to decrease the gap in health inequity and improve screening utilisation and cancer outcomes.

## **METHODS:**

### **1. Search strategy**

Our systematic review was performed in accordance with guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-analysis group.[13]

A literature search was performed using a combination of free-text terms and controlled vocabulary on the databases, MEDLINE and EMBASE. The following search terms were used in combination: “Colorectal cancer”, “Ethnicity”, “Minority” and “Screening”. A detailed search strategy is provided in Supplementary Table 1. There were no restrictions on location and date of publication or type of bowel screening investigation used.

### **2. Inclusion and exclusion criteria**

Only studies reporting on the odds/hazard/risk of participation of different ethnic groups in a colorectal cancer screening programme in comparison to a control were included. Studies were excluded if they:



- a) Evaluated the influence of socioeconomic status, sex, literacy rate, family history of colorectal cancer and region, without evaluating the effect of ethnicity.
- b) Were duplicates.
- c) Were abstracts without an accompanying published study.
- d) Did not report the odds/hazard/risk of uptake per ethnicity.
- e) Were confined to a high-risk population for bowel cancer rather than a general screening population e.g. previously diagnosed CRC, significant family history or inflammatory bowel disease patients.

### **3. Data extraction**

Three reviewers extracted data independently (NP, NL, HKSIS). The data extracted was as follows: first author, year of publication, time period evaluated, country, screening test performed, number of participants, participant characteristics (Age and Sex), ratio of uptake of all the ethnic groups reported, 95% confidence intervals and p values where provided (Appendix A). Broad and sub-group classifications are listed in Table 1.

Broad Group Classifications	Sub-Group Classifications
<b>Whites</b>	White
	Non-Hispanic White
	Dutch
	Non-latino White
<b>Blacks</b>	Black
	Non-Hispanic Black
	African American
	African
<b>Hispanic</b>	Hispanic
	Latino
	US born Latino
	Mexican born Latino
	Mexican
	Puerto Rican
	Cuban
	Dominican
	Central or South American
	Surnamese and Antillean
	Other Hispanic
<b>Asians</b>	Asian
	Asian or Pacific Islander
	South Asian or Asian Indian
	South East and East Asian
	Chinese
	Hong Kong Chinese
	Vietnamese
	Filipino
	Japanese
	Korean
	Other Asian
<b>Other</b>	Non-African American
	Native American
	American Indian or Alaskan Native
	Hawaiian
	Other Western
	Middle East and Central East
	Other
	Other: Non-White, multiracial and Hispanic
	Unknown
Multiple	

Table 1: Broad and Sub-group Ethnicity classifications.

#### **4. Outcomes of interest**

Odds/Risk/Hazard ratio of an ethnic group participating in the CRC screening with respect to the reference group as reported in the studies included.

#### **5. Analysis**

Where p values were available and at least less than 0.05, a result of 'Significantly less likely' was given. Where no p value was available, if an odds/risk/hazard ratio was <1 and both upper and lower limits of the 95% confidence interval (95% C.I.) was <1, a result of 'less likely' was given. Simple proportion calculations were performed to analyse the trends in ethnicity classification and impact of ethnicity on compliance/uptake of CRC screening.

### **RESULTS:**

A search through EMBASE and MEDLINE identified 5 856 references. An additional 4 references were identified from an analysis of individual reference lists. 1 377 duplicates and 4 391 inappropriate abstracts were excluded. The remaining 92 full text papers were analysed (Figure 1).

Twenty-nine studies, reporting on 3 994 016 patients, were in keeping with our inclusion criteria and included in the review (Appendix A).[14-42] The majority of the studies were performed in the USA (25/29). Of the remaining studies, 2/29 are from the UK, 1/29 from the Netherlands and 1/29 from Hong Kong. 25/29 Studies were retrospective cohort studies.

The age range extended to as young as 40 years old and up to greater than 70 years (Appendix A).

The screening modalities varied greatly between studies and included Barium enema (3/29),[15,18,23] Colonography (1/29),[23] and Proctoscopy (3/29).[26,32,34] The screening modality utilised in one study was not specified.[41] The majority of studies (11/29) used the standard combination of stool (gFOBT/FIT) and Endoscopy (Flexible sigmoidoscopy/Colonoscopy) as their modality of screening (Table 2).

	<b>Screening modality: Single</b>	<b>Screening Modality: Multiple</b>
gFOBT	5	N/A
FIT	1	N/A
gFOBT + FIT	N/A	2
Colonoscopy	4	N/A
Flexible Sigmoidoscopy	2	N/A
Colonoscopy + Flexible Sigmoidoscopy	N/A	5
Other single (Proctoscopy, Barium Enema)	0	N/A
Stool + Scope	-	11
Other Multiple	-	6

Table 2: The modality of CRC screening used in the 29 studies. Screening modality was not specified in one study.[41]. N/A= Not applicable. Stool + Scope is any combination of gFOBT and/or FIT and Colonoscopy and/or Flexible Sigmoidoscopy only.

The classification of ethnic categories varied significantly: A total of 40 ethnic groups were described and reviewed. Due to the variation in descriptive terms for ‘White’, ‘Black’, ‘Hispanic’ and ‘Asian’ ethnicities, in this review we grouped them into broad then sub group ethnic categories to allow for an analysis of trends (Table 1): For instance, ‘Whites’ included categories described as ‘White’, ‘Non-Hispanic White’ and ‘Non-Latino White’ while ‘Blacks’ included ‘Black’, ‘Non-Hispanic Black’, ‘African American’ and ‘African’.

All but four of the studies reviewed were compared to ‘Whites’ as the reference group.[23,26,35,36]

**Blacks:**

The ‘Blacks’ category of ethnic minority was the most commonly studied (19/29). 6/19 studies demonstrated a significant negative association ( $p < 0.05$ ) while another 6/19 suggested a likely negative association between ‘Black’ ethnicity and uptake of screening (95% CI range  $< 1$ ) irrespective of analysis type, screening modality used or time period (Table 3).

Study Name[Ref] N=3,577,174	Analysis Type	Significantly less likely	Less likely	No difference	More likely
<b>Ata et al. 2006[14]</b>	Univariate	N/A	N/A	N/A	N/A
	Multivariate			1	
<b>Burgess et al. 2011[15]</b>	Univariate	1			
	Multivariate			1	
<b>Burnett-Hartman et al. 2016[16]</b>	Univariate	N/A	N/A	N/A	N/A
	Multivariate		1		
<b>Calo et al. 2015[17]</b>	Univariate		1		
	Multivariate	N/A	N/A	N/A	N/A
<b>Cooper and Doug Kou 2008[18]</b>	Univariate	N/A	N/A	N/A	N/A
	Multivariate	1			
<b>Crawford, Jones, and Richardson 2010[19]</b>	Univariate	N/A	N/A	N/A	N/A
	Multivariate			1	
<b>De Jesus et al. 2010[20]</b>	Univariate	N/A	N/A	N/A	N/A
	Multivariate			1	
<b>Doubeni et al. 2009[21]</b>	Univariate		1	1	
	Multivariate			1	
<b>Doubeni et al. 2010[22]</b>	Univariate		1	1	

	Multivariate			1	
<b>May et al. 2014[23]</b>	Univariate		1		
	Multivariate		1		
<b>Mehta et al. 2016[24]</b>	Univariate	N/A	N/A	N/A	N/A
	Multivariate		1		1
<b>Wallace et al. 2012[27]</b>	Univariate	N/A	N/A	N/A	N/A
	Multivariate	1			
<b>Wang et al. 2017[28]</b>	Univariate	1			
	Multivariate			1	
<b>White et al. 2011[29]</b>	Univariate	N/A	N/A	N/A	N/A
	Multivariate	1			
<b>Changoor et al. 2018[30]</b>	Univariate				1
	Multivariate				1
<b>Robb et al. 2008[33]</b>	Univariate			1	
	Multivariate			1	
<b>Deutekom et al. 2009[38]</b>	Univariate	1			
	Multivariate	1			
<b>Harmon et al. 2014[40]</b>	Univariate			1	
	Multivariate	N/A	N/A	N/A	N/A
<b>Rastogi et al. 2019[42]</b>	Univariate			1	
	Multivariate			1	

Table 3: Summary of the outcomes regarding uptake of CRC screening of the included studies reporting on ‘Black’ compared to ‘White’ categories. N= Total population size. 1 = the outcome found. N/A = Not applicable/ Not studied.

Importantly the largest study (N = 1 746 714),[16] with the strongest power to detect association, suggests less likely compliance (OR:0.93; 95%CI 0.92-0.95) for ‘Blacks’ compared to ‘Whites’ on multivariate analysis after adjusting for age, sex, healthcare system, income, insurance and co-morbidity score. This is relatable to the majority of screening programmes worldwide including the UK, as the population ranged from

50-75 years and utilised any of FIT/gFOBT/Flexi and colonoscopy modalities. This is true also for Mehta et al 2016[24] (N= 1 319 901) and Cooper and Kou 2008[18] (N=153 469) where multivariate analysis showed a less likely (RR:0.94; 95%CI 0.93-0.95 in 2007-2009; RR:0.97; 95%CI 0.96-0.97 in 2010-2013) and significantly less likely uptake (HR: 0.89, 95%CI 0.85-0.94, p<0.001) respectively. In addition, no difference over time after starting a screening programme was observed in Mehta et al. 2016.[24] Barium enema uptake as part of screening was included in Cooper and Kou 2008.[18] In comparison, the relatively smaller studies (N range: 2 155- 9 575) utilising a combination of screening investigations claim no difference between 'Blacks' and 'Whites'.[14,15,22]

Of note, we should mention that one study in the USA suggested 'Blacks' are more likely to take up screening if insurance was accounted for (Univariate: OR: 1.14, 95% CI: 1.06-1.23, p<0.01; Multivariate: OR: 1.20, 95% CI: 1.11-1.29, P<0.01).[30] The discrepancy of this result may be attributed to the population being largely men in the Armed Forces who overall have a better health behaviour; or the greater utilisation of endoscopic rather than stool screening which may be more acceptable to the Black ethnic population.[16] Although this result remains true on multivariate analysis, the study doesn't make clear what confounders are adjusted for.

A review of studies selective for their screening modality show lower uptake with FIT and gFOBT[24,38] but no difference in uptake with gFOBT[19,21] on multivariate analysis for Blacks compared to the majority population (White or Ethnic Dutch). Certainly, Mehta et al. 2016[24] with the largest population of 1 319 901 suggests the less likely uptake (RR: 0.82, 95% CI 0.81-0.83 in 2007-2009; RR: 0.92

95% CI 0.91-0.93 in 2010-2013).

Endoscopic uptake also varied: The uptake for colonoscopy has been described as less likely (RR: 0.87, 95% CI 0.85-0.89 in 2007-2009; RR: 0.93 95% CI 0.92-0.95 in 2010-2013)<sup>24</sup> or no difference (OR: 1.06 95% CI 0.79-1.44, P>0.05) for ‘Blacks’ compared to ‘Whites’.[42] This may be because of the small population number of only 4 190 in the latter study.[42] Interestingly, the uptake for flexible sigmoidoscopy was higher for Blacks which persisted over time in one study (RR: 1.11, 95% CI 1.09-1.13 in 2007-2009; RR: 1.22 95% CI 1.19-1.24 in 2010-2013)[24] but then showed no significant difference (OR 1.96, 95% CI 0.86-4.46) in another where the population was significantly smaller (N=4 303) with only 41 identifying as ‘Blacks’.[33] Where colonoscopy and flexible sigmoidoscopy have been grouped together, there appears to be no difference in uptake for ‘Blacks’ compared to ‘Whites’.[19,21] This may be explained by the trend in greater flexible sigmoidoscopy uptake simply due to the nature of the screening protocol in the USA where flexible sigmoidoscopy is more commonly offered.

**Hispanics:**

The second ethnic category most commonly studied were ‘Hispanics’ (16/29) of which 7/16 studies suggest a significant negative association (p<0.05) while another 5/16 suggested a likely negative association (95% CI range <1.00) between ‘Hispanic’ ethnicity and uptake of screening irrespective of analysis type, screening modality used or time period (Table 4).

<u>Hispanic' Vs Whites</u>					
Study Name[Ref]	Analysis Type	Significantly less	Less likely	No difference	More likely



N= 3,527,007		likely			
Ata et al. 2006[14]	Univariate	N/A	N/A	N/A	N/A
	Multivariate		1		
Burnett-Hartman et al. 2011[16]	Univariate	N/A	N/A	N/A	N/A
	Multivariate				1
Calo et al. 2015[17]	Univariate			1	
	Multivariate	N/A	N/A	N/A	N/A
Cooper and Doug Kou 2008[18]	Univariate	N/A	N/A	N/A	N/A
	Multivariate	1			
Crawford, Jones, and Richardson 2010[19]	Univariate	N/A	N/A	N/A	N/A
	Multivariate	1		1	
De Jesus et al. 2010[20]	Univariate	N/A	N/A	N/A	N/A
	Multivariate			1	
Doubeni et al. 2009[21]	Univariate		1	1	
	Multivariate			1	
Doubeni et al. 2010[22]	Univariate		1		
	Multivariate			1	
Mehta et al. 2016[24]	Univariate	N/A	N/A	N/A	N/A
	Multivariate		1		1
Nagelhout et al. 2018[25]	Univariate	1			
	Multivariate	1			
Ramai et al. 2018[26]	Univariate	N/A	N/A	N/A	N/A
	Multivariate		1		
Wang et al. 2017[28]	Univariate	1			
	Multivariate	1			
White et al. 2011[29]	Univariate	N/A	N/A	N/A	N/A
	Multivariate	1		1	
Deutekom et al. 2009[38]	Univariate	1			
	Multivariate	1			
Harmon et al. 2014[40]	Univariate	1			
	Multivariate	N/A	N/A	N/A	N/A
Rastogi et al. 2019[42]	Univariate			1	
	Multivariate			1	

<i>Asian' Vs Whites</i>					
Study Name N=197,664	Analysis Type	Significantly less likely	Less likely	No difference	More likely
Cooper and Doug Kou 2008[18]	Univariate	N/A	N/A	N/A	N/A
	Multivariate	1			
Ramai et al. 2018[26]	Univariate	N/A	N/A	N/A	N/A
	Multivariate		1		
Wang et al. 2017[28]	Univariate	1			
	Multivariate	1			
Robb et al. 2008[33]	Univariate	1			
	Multivariate	1			
<i>Asian-Pacific Islander' Vs' Whites</i>					
Study Name N=3,097,508	Analysis Type	Significantly less likely	Less likely	No difference	More likely
Burnett-Hartman et al. 2016[16]	Univariate	N/A	N/A	N/A	N/A
	Multivariate				1
Mehta et al. 2016[24]	Univariate	N/A	N/A	N/A	N/A
	Multivariate		1	1	1
White et al. 2011[29]	Univariate	N/A	N/A	N/A	N/A
	Multivariate			1	
Changoor et al. 2018[30]	Univariate			1	
	Multivariate			1	
Lee et al. 2011[32]	Univariate	N/A	N/A	N/A	N/A
	Multivariate			1	
Rastogi. et al 2019[42]	Univariate	1			
	Multivariate			1	

Table 4: Summary of the outcomes regarding uptake of CRC screening of the included studies reporting on ‘Hispanics’, ‘Asians’ and ‘Asian-Pacific Islanders’ compared to ‘Whites’ separately. N= Total population size. 1 = the outcome found. N/A = Not applicable/ Not studied.

A study comparing the uptake of any screening modality for ‘Hispanics’ compared to ‘Whites’ suggested lower uptake on univariate analysis (OR:0.61 95% CI 0.46- 0.81 in 2000; OR:0.62 95% CI 0.52-0.75 in 2003; OR:0.65 95% CI 0.53-0.79 in 2005). However, this difference disappeared when confounders like age, sex, income and location were accounted for.[22] In comparison, three studies suggested a significantly lower (HR: 0.75; 95% CI 0.68-0.83, p=0.01)[18] or likely lower (OR: 0.73 95% CI 0.58-0.92)(N=9,575),[14] (OR: 0.92 95% CI: 0.92-0.93 2007-2009; OR: 0.95 95% CI: 0.95-0.96 2010-2013)[24] uptake for Hispanics compared to Whites on multivariate analysis utilising any screening modality. Here a combination of age, sex, co-morbidity, income, education, medical region and also insurance were accounted for. It is unclear why differences in outcome are seen in these similarly designed studies.

Two smaller scale studies with populations of only around 1 000 showed no difference between uptake on univariate and bivariate analysis.[17,20]

Analysis characterised by modality of screening suggested a decreased uptake for colonoscopy (OR: 0.81 95% CI: 0.79-0.83 2007-2009; OR: 0.86 95% CI: 0.85-0.86 2010-2013); increased uptake for flexible sigmoidoscopy (OR: 1.03 95% CI 1.02-1.05 2007-2009; OR: 1.09 95% CI 1.07-1.11 2010-2013) and decreased uptake for FIT/gFOBT (OR: 0.89 95% CI: 0.88-0.90 2007-2009; OR: 0.96 95% CI: 0.95-0.97 2010-2013) in one large study.[24] Similar results of less uptake for colonoscopy[25,40] and stool[19,38] are seen in smaller studies. Of note Harmon et al. 2014 classified their Hispanic population as ‘US born Latinos’ or ‘Mexican born Latinos’ however did not study the effect of acculturation.[38] When both flexible sigmoidoscopy and colonoscopy are combined, variable results with either a less likely uptake[28] or no difference[19] in uptake is seen for ‘Hispanics’.

In Ramai et al. 2019, the Black ethnic group contributed to the majority population and was used as the control (46.6%). They suggest that Hispanics in Brooklyn, New York are at greater risk than 'Blacks' (OR: 0.72, 95%CI 0.54-0.95, P=0.02) regarding the uptake of FIT.[26]

The results of a further 2 studies were difficult to interpret due to the combination of ethnic categorisations. As per the Health Beliefs Model, participation in screening varies between ethnic groups due to different health beliefs[43] therefore combining 'Non-Hispanic Blacks' and 'Hispanic' ethnicities<sup>41</sup> or 'Non-white', 'Hispanic' and 'Multiracial'[39] into single groups may not provide an accurate outcome of uptake behaviour. Nevertheless, the result of OR: 1.932 (p<0.01) is still in keeping with the hypothesis that ethnic minorities are at greater risk of non-participation in CRC screening in the former study.[41] The combination of multiple ethnic categories or a small population group may be why no difference in uptake was seen in the latter study for 'Non-White and Hispanic and Multiracial'.[39]

A single study further sub-characterise Hispanics: Although a less likely result is seen for colonoscopy uptake in 'Mexicans', no significant difference is seen in 'Puerto Ricans', 'Central/South Americans', 'Cubans', 'Dominicans', 'Other Hispanics' and 'Hispanics' likely because of insufficient power.[42]

### **Asians:**

The third broad ethnic category most commonly studied was 'Asians'. The 'Asians' group included descriptions of 'Asian', 'Asian/Pacific Islander', 'South Asian or

Asian Indian', 'South East and East Asian', 'Chinese', 'Hong Kong Chinese', 'Vietnamese', 'Filipino', 'Japanese', 'Korean' and 'Other Asian' (Table 1).

Asia is the largest continent in the world with an accompanying diverse mix of ethnicities. Where studies have categorised ethnicity by sub-regions of Asia such as 'South Asia or Asian Indian', the accompanying studies looking at its corresponding specific ethnic groups e.g. 'Indian', 'Nepalese' etc. have been included only. 'Asian' has therefore been reviewed separately. Definitions have been provided within the accompanying text.

In total 4/29 studies looked at 'Asian', 6/29 for 'Asian/Pacific Islanders' and 9/29 at some combination of a specific other sub-region/category of Asian ethnicity as described above.

All four studies looking at 'Asians' conclude that they are significantly less likely ( $p < 0.05$ ) than 'Whites'[18,28,39] and 'Blacks'[26] with regards to uptake of screening irrespective of analysis type, screening modality used or time period (Table 4).

'Asian-Pacific Islanders' is a term used primarily in the USA to describe "A person with origins in any of the original peoples of the Far East, Southeast Asia, South Asia, or the Pacific Islands".[44] Although Hawaii is an American state, the majority population has consisted of Asian- Pacific Islanders (80.9-51% from the 1900-2000)[44] and therefore the 2 studies including Hawaiians will be discussed here.[37,40] A single study looked at Pacific Islanders (Polynesia, Micronesia and Melanesia) alone.[25]

Multivariate analysis of ‘Asian-Pacific Islanders’ shows predominantly (5/6 studies) no difference result for all modalities of screening (Table 4). [24,29,30,32,42]

Breakdown analysis according to modality in one study suggests a lower uptake for colonoscopy (OR: 0.82 95% CI 0.80-0.84 in 2007-2009; OR: 0.89 95% CI 0.88-0.90 in 2010-2013) but higher uptake for flexible sigmoidoscopy (OR: 1.12 95% CI 1.11-1.14 in 2007-2009; OR: 1.11 95% CI 1.10-1.14 in 2010-2013) and FIT/gFOBT (OR: 1.09 95% CI 1.07-1.10 in 2007-2009; OR: 1.09 95% CI 1.08-1.10 in 2010-2013). [24] Unfortunately significance wasn’t assessed.

Two studies evaluated the effect of Hawaiian ethnicity. Both showed a significantly lower uptake compared to ‘Whites’ ( $p < 0.05$ ). [37,40] The category ‘Asian-Pacific Islander’ or ‘Pacific Islander’ was not included in these two studies.

A single small study (N=163) showed a significantly lower uptake of colonoscopy only for ‘Pacific Islanders’ compared to ‘Whites’ (OR: 0.08, 95% CI 0.02-0.44,  $p < 0.05$ ). [25] Unfortunately this result doesn’t explain the no difference result of ‘Asian-Pacific Islanders’ when the result for ‘Asians’ is also significantly less likely. Further larger studies are therefore needed for clarification.

‘South Asian’ or ‘Asian Indian’ is defined as including the countries Afghanistan, Bangladesh, Bhutan, Maldives, Nepal, India, Pakistan and Sri Lanka. [45] 4 studies looked at ‘South Asians’ or ‘Asian Indians’ compared to ‘Whites’ [31,32,34,42] three of which support the hypothesis of lower uptake regarding CRC screening. [31,32,42] The largest of these studies suggest that they are significantly less likely to take up screening (OR: 0.6 95% CI: 0.4-0.9,  $p < 0.05$ ). [32] One other study was carried out in Hong Kong, where the majority population is ethnically Chinese and the National

language is Chinese and English. Here, Asian Indians are significantly less likely to take up screening (OR: 0.42 95% CI:0.28-0.62 p<0.001).[36]

A study looking at colonoscopy as the modality of screening also suggests a significantly less likely uptake (OR:0.34 95%CI: 0.16-0.76, p<0.05).[42]

Szceपुरa et al. 2008 characterises its Asian Indian population by race and compares it to 'Non-Asians'. [35] The study was carried out retrospectively from a pilot BCSP run in Coventry and Warwickshire in the UK in 2000-2002 and 2003-2005 where the predominant population is 'Whites'. An assumption can be made then that the 'Non-Asians' reference group is predominantly 'Whites'. In keeping with this then, South Asian 'Muslims', 'Hindu-Gujaratis', 'Hindu-Other' and 'Punjabis' all have a significantly lower uptake compared to 'Non-Asians'/'Whites'.

'South East Asia' or 'East Asia' is defined as including the countries Myanmar, Thailand, Malaysia, Laos, Cambodia, Vietnam, Indonesia, Singapore, Philippines, Andaman and Nicobar Islands of India, East Timor, the Christmas and Cocos Islands for 'South East Asia'<sup>46</sup> and the countries China, Japan, Korea, Taiwan, Hong Kong and Macau for 'East Asia'. [47]

One study carried out in the Netherlands, compared, 'South East Asians or East Asians' to Dutch Whites. This showed them to be significantly less likely to take up stool-based screening (OR:0.56, 95% CI:0.46-0.69, p<0.01).[38]

A further six studies looked at subcategories of 'South East Asian' or 'East Asian' i.e. 'Chinese', 'Vietnamese', 'Filipino', 'Japanese' and 'Korean'. [32,34,37,40,42] Of these, a no difference result was seen consistently for 'Japanese' (5/5 studies)[31,32,34,37,42] and 'Vietnamese' (3/3 studies)[31,32,34] populations.

Results were more mixed for Chinese, Filipino and Korean ethnicities:

Three[33,34,42] of five[31,32,34,37,42] studies suggest no difference in uptake for 'Chinese' ethnicity compared to 'Whites' even when modality of screening is taken into account.[34] Two studies suggest a significantly decreased uptake.[31,37] Both studies are of a reasonable population number and accommodate for confounding factors.

Three[32,34,37] of five studies[31,32,34,37,42] suggest a significantly less likely uptake of screening irrespective of modality for 'Filipino' participants compared to 'Whites'. The remaining two suggest no difference.[31,42] When modality of screening is specified, there is no difference in uptake for gFOBT (OR:0.80 95% CI:0.55-1.18) a less likely uptake of a combination of flexible sigmoidoscopy, colonoscopy and proctoscopy (OR:0.68 95% CI:0.48-0.97  $p<0.05$ )[34] but no difference for the uptake of colonoscopy on its own (OR:0.97 95% CI:0.33-2.37  $p>0.05$ ).[42] This suggests a probable acceptance to trial flexible sigmoidoscopy suggesting similar health behaviour as 'Blacks' and 'Hispanics'.

Two[31,32] of three studies[31,32,34] suggest Koreans are significantly less likely than 'Whites' to take up screening. These studies are large and do not differentiate between the screening tool used (N= 23,345 and 52,491).[31,32] A smaller study (n=19,489) with a smaller proportion of Koreans (1.3%) suggests that there is no difference for uptake of gFOBT (OR:0.55 95% CI:0.30-1.04), a combination of flexible sigmoidoscopy, colonoscopy and proctoscopy (OR:0.82 95% CI:0.52-1.29) or for all of these modalities combined together (OR:0.78 95% CI:0.51-1.19).[34]



## DISCUSSION:

Different ethnicities may have different cultural and health beliefs, and different levels of education and understanding, that results in decreased participation in screening. This has been shown to be true for ethnic South Asian women undertaking breast and cervical cancer screening in the UK[48-51] and for South Asians in the US undertaking any form of preventative screening including CRC screening.[52] Similar poor compliance has been shown in Australia amongst indigenous Australians as compared to their counterparts.[53]

Our study reviews in depth the association between ethnicity and CRC screening and highlights trends that suggest 1) No global consensus in ethnicity categorisation 2) A varying relationship between ethnicity and CRC screening uptake although largely ethnic minorities are less compliant even after adjusting for factors like health insurance and socioeconomic status which could be confounders for this effect. As per this review, these minorities include in particular 'Blacks', 'Hispanics', 'Asians' and 'South Asian/Asian Indian'. Interestingly also, we see from studies that analysed uptake over time[21,22,24,35] that initiation or existence of a screening programme in itself does not alter uptake over time despite theories of 'diffusion of innovation'[54] and that as far as screening modalities go for ethnic minorities at increased risk of poor compliance seem to prefer flexible sigmoidoscopy compared to colonoscopy or stool testing.

Qualitative studies in Western Countries have revealed that Asian, Hispanic and Black individuals do not participate in CRC screening because of ideas of screening as not part of their culture, embarrassment, emasculating for males, their own ethnic diet being protective against cancer or using their own religious/cultural medicines

being sufficient to protect against cancer.[55] In particular ‘Latino’ and ‘African Americans’ feared bowel preparation and felt that undertaking a colonoscopy would threaten their masculinity;[55] ‘South Asians’ have a cultural taboo against storing faeces.[56] These reasons would explain the decreased compliance overall but also explain why flexible sigmoidoscopy, with no stool handling and less bowel preparation is more palatable to these minorities as per our review.

In addition, with the increasing incidence of CRC cancer, earlier median age of onset of CRC in ethnic minority groups, significantly greater proportions of <50 year olds in ethnic minority groups developing CRC compared to ‘Whites’, lower survival rates in ‘Blacks’ and increasing minority populations within metropolitan cities like New York and London secondary to immigration, it may be prudent to consider offering flexible sigmoidoscopy screening in the first instance to these individuals.[16,26,57]

Acculturation is the concept of adaptation, where an immigrant begins to adopt the culture and behaviours of the host country.[58] Greater acculturation has been associated with improved CRC screening uptake for Chinese, Japanese, Korean and Filipino ethnicities.[59-61] This effect may account for the results seen in the systematic review: Majority no difference results for Chinese, Japanese and Vietnamese participants. It may also be worth considering that organised screening programmes have existed in these countries since 1992 for Japan, 2008 for China and 2004 for Korea[7] and therefore the concept of CRC screening is not as foreign.

In the UK, multiple attempts have been made to improve uptake of CRC screening overall via public health campaigns,[62] a text message trial[63] and national trials[64] but no large scale intervention has been put in place to specifically target ethnic minorities. The UK is transitioning into offering FIT instead of gFOBT. One of

the benefits of this is less stool handling however this on its own is unlikely to bridge the inequality gap. Studies looking at FIT do in-fact show that this gap still exists.[26]

Greater primary care involvement which could include simple encouragement during visits, group discussions within community centres or use of promotional/educational adverts in ethnic community media channels seem better designed to target high risk ethnic groups.[65,66] It should be made clear however, that every country or region will have its own mix of ethnic minority groups and therefore policy holders should target those relevant to that area.

#### **a. Strengths and limitations**

This is an all-encompassing review of ethnicity in CRC screening worldwide. Unfortunately, due to the nature of the review and heterogeneity of the included studies (large age range, variation in ethnicity categorisation, modality of screening investigations, study design), a meta-analysis was not appropriate. Furthermore, as the bulk of the studies (25/29) were from the USA, the results are most applicable here and may be less generalisable to other countries.

#### **b. Implications for practice**

We hope that the results of our systematic review convince policy makers globally of the need for conformity around ethnicity definition and collecting ethnicity data to accurately determine the relationship between each specific ethnic group and utilisation of screening programmes and screening modalities in each region. The end goal would be to target particularly vulnerable ethnic communities and decrease the discrepancy in uptake.

In the UK especially, general practitioners (GPs) have the ability to improve uptake through education and endorsement of participation.[67,68] Campaigns to encourage GP endorsement of participation may be an initial starting point to decrease discrepancy in uptake. If health inequality regarding uptake is challenged, this will likely translate into improvements in completion of screening as well. It has been suggested that ethnic minorities even after a positive screening stool test fail to complete their diagnostic endoscopic investigation.[16]

### **CONCLUSION:**

Discrepancies in CRC screening are multi-factorial and complex, of which ethnicity plays an important role. Although seemingly intuitive this is the first systematic review that summarises the association between poorer uptake of screening in particular ethnic minority groups in relation to modality of screening and highlights the presence of significant variations in ethnicity classification globally. Further consistent international collative research is required to assist in identifying specific barriers to participation in specific ethnic groups so that campaigns can be initiated to correct this.

### **Additional Information:**

### **Consent for Publication:**

All authors consent to the publication of this work.

### **Author Contributions:**

All four authors have contributed equally to data collection, analysis and write up. Mr Nikhil Pawa in addition contributed to the conceptualisation and design of the study.

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