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**Health information equity: rebalancing healthcare collections for racial diversity in UK public service contexts**

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**Abstract**

COVID-19 illustrated health disparities experienced by racially minoritised people, with heightened risks faced by Black and South Asian communities lending the issue transparency and urgency. Despite efforts to decolonise medical education, deficits in racial representation in research and resources remain. This study investigates the potential and imperatives for healthcare information services to contribute to health equity through their collections. The literature analysis explores collection management, decolonisation, social justice in librarianship, and Critical Race Theory (CRT) as a framework for change in information contexts. A survey of UK National Health Service (NHS) librarians provides a snapshot of awareness of health information inequity. Semi-structured interviews explore information professionals’ experiences of anti-racism in the system. The findings indicate strong engagement with the need for equitable resources but highlight some barriers to success. Opportunities identified include potential for addressing systemic racism in collection policy, capability of information services to influence, or engage in, authorship and publishing to address gaps, and the need for race-based data standards in healthcare. Synthesis of the findings through a framework of CRT tenets illustrates the relevance and utility of CRT as a tool for pursuit of equity in information practice, scholarship, and education.

**Keywords;** Healthcare Information, Information Ethics, CRT

## 1. Introduction

Health inequalities experienced by racially minoritised groups in the West, and more widely in the Global South, are well documented (Arcaya et al., 2015). Such disparities continue to be reported in the UK (Robertson et al., 2021), despite statements and policies at institutional and national levels supporting and mandating equal treatment and access (NHS England, 2015, HEE, no date). Long-present health and socio-economic inequalities were highlighted and exacerbated by the COVID-19 pandemic (Otu et al., 2020). The disproportionate toll of deaths and illness on Black and South Asian communities in the UK has prompted renewed focus on factors underpinning health disparities (PHE, 2020, Nazroo and Bécaries, 2021, p.1), with disproportionate deaths of racially minoritised healthcare workers (BMA, 2021) particularly illustrative of the issue of systemic racism.

While it is widely acknowledged that there are multiple and complex factors underpinning health inequity, recent challenges to medical education curricula (Change.org, 2020, Melville, 2020) are of particular relevance to healthcare information services. This climate for change presents opportunities to reappraise healthcare information adequacy for increasingly diverse populations. The pandemic has also underscored our contemporary reliance on health data, medical research, and global information sharing. Floridi asserts that there is moral agency in ascertaining adequate and accurate information for decision making (2013, p.22); it is difficult to think of a clearer example of ethical imperatives for information integrity than where health depends on it.

The aim of this study is to advance understanding of the imperatives for healthcare information services and professionals to address structural inequity and systemic racism experienced by racially minoritised patients, through decolonial and social

justice approaches to collection management, and to evaluate the degree to which UK healthcare libraries are aware of the issues and are acquiring and disseminating materials more representative of the UK's racial diversity, including exploring best practice and barriers to progress and an examination of Critical Race Theory (CRT) as a framework for analysis supporting decolonisation work.

An analysis of the literature examines principles of decolonisation in collection management, the context of the social justice movement in librarianship, and the more recent use and positioning of CRT in the information domain. Research methods employed are a survey of National Health Service (NHS) England information services by online questionnaire, and semi-structured interviews with healthcare information professionals. Findings and themes identified across the literature analysis, survey, and interviews are synthesised through a framework of CRT tenets (Leung and López-McKnight, 2021, p.13), including race as a social construct, racism as normal, challenges to dominant ideologies in healthcare and Library and Information Science (LIS), and interdisciplinarity as key to opportunities to address the multiple systemic racisms embedded in information systems and structures.

## **2. Literature analysis**

The study focus is primarily on information in the UK health service, therefore attempts have been made to reference UK sources, however on the topics of social justice, and CRT, UK LIS literature is scant. Effort has been made to reference recent work, published since 2020, reflecting shifts in the domain predicated by both COVID-19 and Black Lives Matter (BLM).

### **2.1 Decolonisation and collection management**

Decolonisation has been a topic of LIS discourse for over a decade, requiring both acknowledgement of coloniality, and action to dismantle resulting power structures,

thereby de-centralising white normativity (Crilly and Everitt, 2022, p.xxiii, Hartland and Larkai, 2020). The movement has more recently impacted on medical education (Lokugamage et al., 2020), where clinical knowledge bases have deeply colonial roots (Roberts, 2011, p.98). Decolonisation of healthcare information can target both deficits in representation and the resultant inequitable outcomes through addressing and challenging inequitable power structures, developing more inclusive curricula, norms, values, and reference materials to encourage person-centred care for more diverse populations (Lokugamage et al., 2020).

Collection policy sets resource parameters for both the present and future (Fieldhouse and Marshall, 2012, p.vii). Shifts in community needs, or in communities themselves, necessitate libraries and information services to adapt (Gerber, 2017). The UK's ethnic and racial diversity is forecast to continue increasing (Otu et al., 2020), predicating ongoing evolution in public services such as healthcare. While health inequality cannot be eradicated through improved representation of diversity (Louie and Wilkes, 2018), collection policies can give operational clarity to equitable aims, such as decolonisation, creating opportunities for tangible change.

A key purpose of healthcare information services is education, both in training and throughout a clinician's career (Weightman et al., 2009). Gerber notes Continuing Medical Education (CME) and librarianship's shared objective of knowledge dissemination as a unifying purpose for information collections (2017). This shared purpose may be pivotal in dissemination of knowledge now known to have been deficient in earlier career training, building on the benefits and impact of decolonisation in medical education.

Medical libraries have been pioneers in using impact assessments to measure and report their efficacy in practice (Robinson, 2010, p.212, Brettle et al., 2016). Positive impact

depends on provision of accurate and adequate resources, however. Information for healthcare is conventionally produced by a narrow group of authors through ‘traditional’ publishing routes (Robinson, 2010, p.72). Leung and López-McKnight assert LIS’s ‘foundational role’ in gatekeeping knowledge (2021, p.7), with traditions and processes upholding legacy power structures, potentially excluding marginalised voices (Inefuku and Roh, 2016, Delgado Bernal and Villalpando, 2002). Instantiation of more diverse, representative, and therefore impactful, information in the healthcare knowledge base may require LIS innovation. To this end, Herther (2020) advocates for information professionals to influence vendors and creators, while Gwynn et al. (2019) propose LIS involvement in authorship.

## 2.2 Social Justice, an LIS value

LIS’ long established social justice discourse is foundational to pursuit of racial equity through collections and resources; a contemporary iteration of the ‘common good’ ethos espoused by Lankes (2016, p.105). Information professionals have, however, been criticised for avoiding difficult choices under cover of neutrality (Gibson et al., 2017), with Hudson asserting that neutrality makes libraries ‘sites for the perpetuation of white supremacy’ (2017). Morales et al. call for library services to prioritise both theoretical and practical social justice, action alongside intention, to counter this (2014), while Clarke (2019) encourages libraries and librarians to ‘self-decolonise’.

Critical librarianship has been central to contemporary LIS social justice discourse and reflective activism (Garcia, 2015). However, critiques of the movement include perceptions of social media contingency, disconnect from practice, performativity, exclusion, and inaccessibility (Ferretti and MICA, 2020, Nicholson and Seale, 2018, p.2). To be an effective vehicle for inclusion, critical librarianship must be inclusive itself and must deliver action, not just reflection. Greater potential for social justice may lie in

engagement with organisational policies than the individual advocacy considered typical of critical librarianship (Nicholson and Seale, 2018, p.2).

Hudson critiques a singular focus on staff diversity as limiting social justice impact in LIS, exhorting the profession to instead adopt multi-pronged 'anti-racisms' (2017).

Morales et al. (2014) call for LIS to address both bodily representation and structures of power and privilege, with a parallel discourse occupying the UK medical domain, Wong et al. documenting a shift 'from a diversity-oriented to a decolonial framework' in medical education (2021). Meghji (2021) notes CRT's use in the legal domain as a tool for 'an institution that was supposedly race-neutral... to work against its structural racism', a positioning that suggests its potential as a framework for LIS decolonisation, mirroring the shift from a narrow focus on diversity.

### 2.3 CRT as a library and information tool

Stauffer notes CRT's surprisingly low profile in LIS, given its utility as a framework for analysis (2020), notably useful where provisions of law are for equality of opportunities and access, not outcomes (Meghji, 2021), as has been the case in healthcare. However, Dunbar notes a recent, gradual adoption in LIS discourse (2021), while Leung and López-McKnight propose CRT as 'a central philosophy' for LIS (2021, p.7) and enumerate tenets core to contemporary understanding of CRT as relevant in the information context (2021, p.13).

CRT was introduced to UK academia through education scholarship (Warmington, 2020), an association that continues (Meghji, 2021). Gibson et al., however, find that LIS education itself provides 'little to no exposure to CRT' (2018). Inclusion of CRT in LIS curricula may serve to further integrate the LIS and education domains, enabling information professionals to undertake more impactful social justice and decolonisation



initiatives, particularly in environments with an educational remit such as in healthcare.

LIS, science, and medicine share practices of categorisation and classification. Roberts attests that science lends racial classifications false legitimacy (2011, p.27). Delgado and Stefancic (2017, p.9) and Bonilla-Silva (1997) note the dehumanising effect of such hierarchies and categorisations, notwithstanding their falsity and contingency. It is difficult to reconcile such foundational misconceptions and harms with expectations of scientific and informational integrity. However, Delgado and Stefancic establish a cornerstone of CRT in the assertion that adoption of colour-blindness, and avoidance of categorisations, may impede elimination of systemic racism and resultant disparities, proposing instead an ‘aggressive color-conscious’ approach (2017, p.27).

Race is a necessary element of health data, with racial categorisations exposing under-representation, risks, and inequities (Otu et al., 2020, Yearby, 2021). The trend and the necessity are for increasing ‘acquisition and utilisation of disaggregated [race] data’ (Lester et al., 2020), in order for research and resources to become more representative. Otu et al. herald the treatment of race in UK COVID-19 data as indicative of the future, emphasising connections between race, socioeconomic determinants, and health disparities (2020). Saini, however, cautions risks of race-based causation assumptions (2019, p.214). Not only data standards, but ethical frameworks for nomenclature, data management, critical analysis and appraisal must be applied, with CRT serving as a potential reference point.

#### 2.4 Literature analysis summary

This topical review of the LIS and interdisciplinary scholarly communications landscape has established that collection and resource management form key elements of decolonisation practice, and that collection policy is a powerful signal for standards and

priorities driving equity and social justice. Strong links between healthcare information provision and education, from training to CME, have been established, with decolonisation emerging as a trend in both medical education and the information domain. Longstanding imperatives for the pursuit of social justice through information services and librarianship have been identified in the literature, with objectives of completeness and accuracy, in terms of diverse racial representation, asserted as a matter of both information ethics and collection efficacy. CRT has been appraised as an emerging LIS discourse and has been found to be an appropriate tool for analysis in scholarship and decolonisation initiatives, such as in collection management, given its acknowledgement in the LIS literature, links to education discourse, utility in disambiguating and justifying racial categorisations for information management, and the aptitude of CRT tenets for naming and examining a breadth of systemic and structural racisms.

### **3. Research approach**

The research objectives for this study are:

- Investigation of the scholarly discourse around library services and collections as forces for social and racial justice through a thorough but selective literature analysis including an exploration of collection management, decolonisation, and the healthcare information context; an examination of librarianship's social justice movement; and a review and subsequent application of CRT tenets as a framework for analysis in the LIS domain, and a potential tool for decolonisation initiatives.
- A snapshot evaluation of the degree to which UK healthcare information services are aware of information disparities and are actively involved in the pursuit of racial equity in healthcare information, through survey methodology. Data collection for the survey comprised an online questionnaire, distributed to NHS

England information services, exploring participation in Equality, Diversity, and Inclusion (EDI) initiatives, acquisition and promotion of inclusive and representative resources, and awareness of topics including racial health disparities, under-representation, the General Medical Council (GMC)'s statement on medical curricula (Melville, 2020), and the 'Mind the Gap' resource (SGUL, 2020).

- A series of interviews with NHS information professionals for triangulation of the literature analysis and survey data. Semi-structured interviews revisited the survey questions and probed for further details around personal experiences and impressions of EDI initiatives in the NHS, of acquisition of EDI resources, or of searches for resources specific to treatment of racially minoritised patients. Feedback on best practices or potential barriers to progress was also sought in order to contextualise attitudes to, and experiences of, systemic racism in healthcare information services.

The study employed a mixed methods strategy. Interviews served to illustrate the literature analysis and survey results with qualitative examples, surfacing contemporary issues underpinning the findings (Axinn and Pearce, 2006, p.18, Pope and Mays, 2020, p.2). The increasing use of mixed methods in LIS, particularly in the healthcare domain, as confirmed by Hayman and Smith's methodological review (2020), supports this approach. The study was given ethics approval by the institution's Computer Science / Library and Information Science Ethics Committee.

The survey listed 25 questions. 18 were multiple choice, scaled questions and seven were free text boxes enabling respondents to comment or clarify. It was distributed to 180 NHS England information services via a Health Education England (HEE) mailing list. 33 responses were received, with 32 validated and reported in the data.

Five NHS library professionals with involvement in collection management volunteered for semi-structured interviews as a result of the survey. Interviews included critical incident technique. A further interview was arranged with a clinician user of NHS information services who had participated in a multi-disciplinary team project aiming to eliminate racial discrimination in NHS telephone services triage.

There are some limitations to acknowledge in the study. The researchers are white and have no lived experience of systemic racism or of disparity of treatment based on race and acknowledge the potential to miss some of the nuance in the literature, language, and analysis.

The survey could not command the response an official audit would secure.

Furthermore, those who respond to surveys differ from those who do not (Denscombe, 2017, p.26), with studies showing 'highly opinionated' respondents as more inclined to participate (Connaway and Radford, 2016, p.108) creating a response bias effect. Axinn and Pearce highlight interview participants' inclination to present themselves positively (2006, p.51) and inviting those with a particular interest in EDI to interview exacerbates this likelihood of bias. Questions were carefully worded around participants' experiences of barriers to EDI work and resource acquisition to allow for commentary on resistance or ambivalence around the topic, in an attempt to gain a more rounded view.

The construction of scaled answer categories to preference subjective participant perceptions of their experiences over empirical data is recognised as having limited the quantitative value of the results, terms such as 'highly aware', 'somewhat aware', 'often involved', and 'sometimes involved' were used to capture participant's impressions rather than to quantify EDI participation. Participant demographics were not collected as part of the survey, this may have provided some additional insight.

One response was discarded, as it appeared to be an attempt to troll the survey in opposition to EDI discussion rather than give a meaningful response. Redaction was resolved to retain data integrity in the survey, not to deny the possibility of racism in this context.

Health organisations in the UK frequently use the acronym BAME (Black, Asian and minority ethnic) and the phrase ‘ethnic minority’ to denote a totality of racially and ethnically minoritised people. This is now recognised as unhelpful practice, such phrases grouping disparate populations together, erasing individual and community identities (Crilly and Everitt, 2022, p.xviii, Aspinall, 2021). The questionnaire for this research mirrored some of this phrasing before clearer thinking on this issue was encountered in the literature.

## **4. Research findings**

### **4.1 Survey results**

The full questionnaire with response data is available (O’Driscoll, 2022, appendix E).

All 32 survey respondents reported being involved in collection management and resource dissemination and promotion, validating the suitability of the sample population, illustrated in Fig.1.

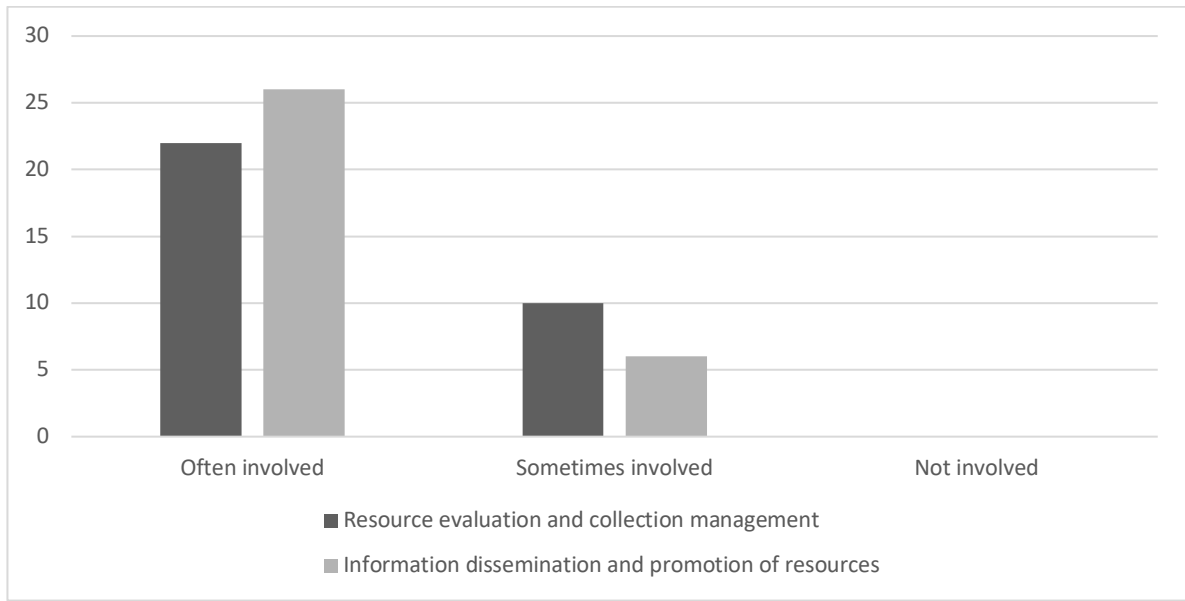


Fig.1 Collection management involvement [n=32]

Respondents were only somewhat less likely to be involved in EDI work compared to collection work, as illustrated by Fig.2, which depicts only four respondents, as not involved in EDI work, and 88% or 28 respondents as involved: 18 'sometimes', and 10 'often'. This indicates that a majority of responding NHS information professionals are aware of racial equality as an organisational priority. One respondent commented that services 'are becoming much more aware... the issues are being raised more within the [t]rust', and another affirmed that their service 'have been working with EDI networks... to build awareness of the library service and how it can support EDI initiatives (sic) and causes'.

97% of respondents confirmed awareness of racial health disparities in the UK, with 47% highly aware and 50% somewhat aware, as illustrated in Fig.3.

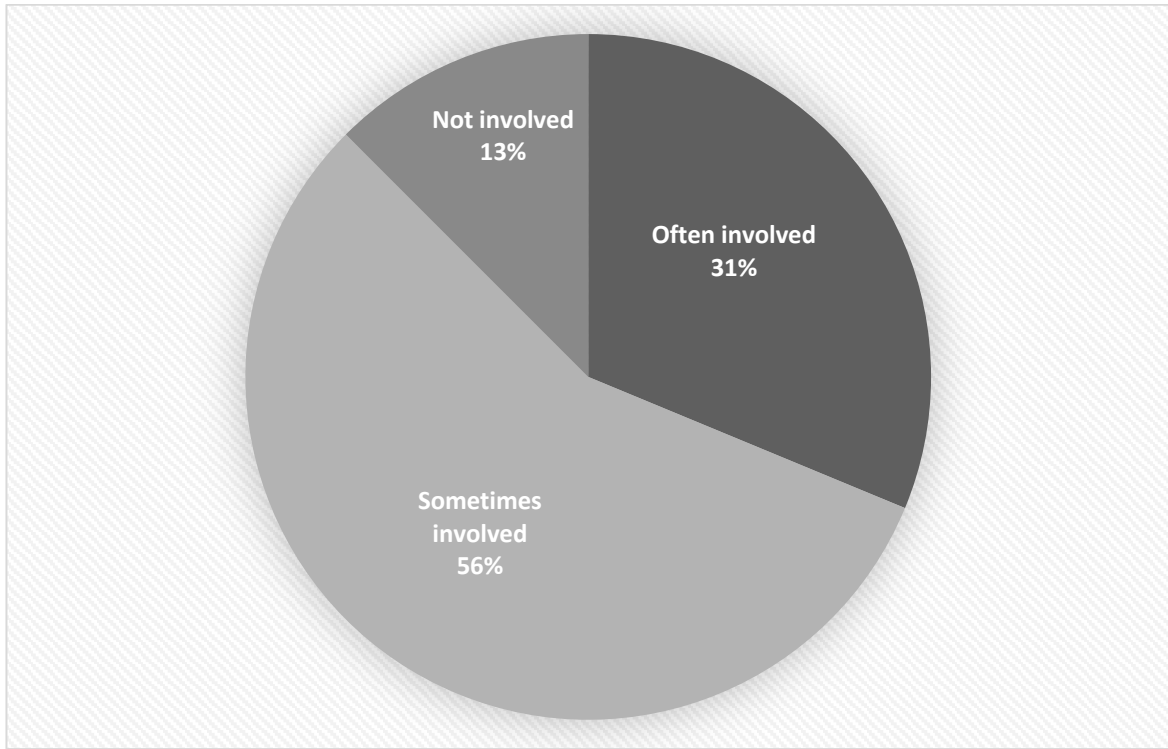


Fig.2 EDI initiatives involvement [n=32]



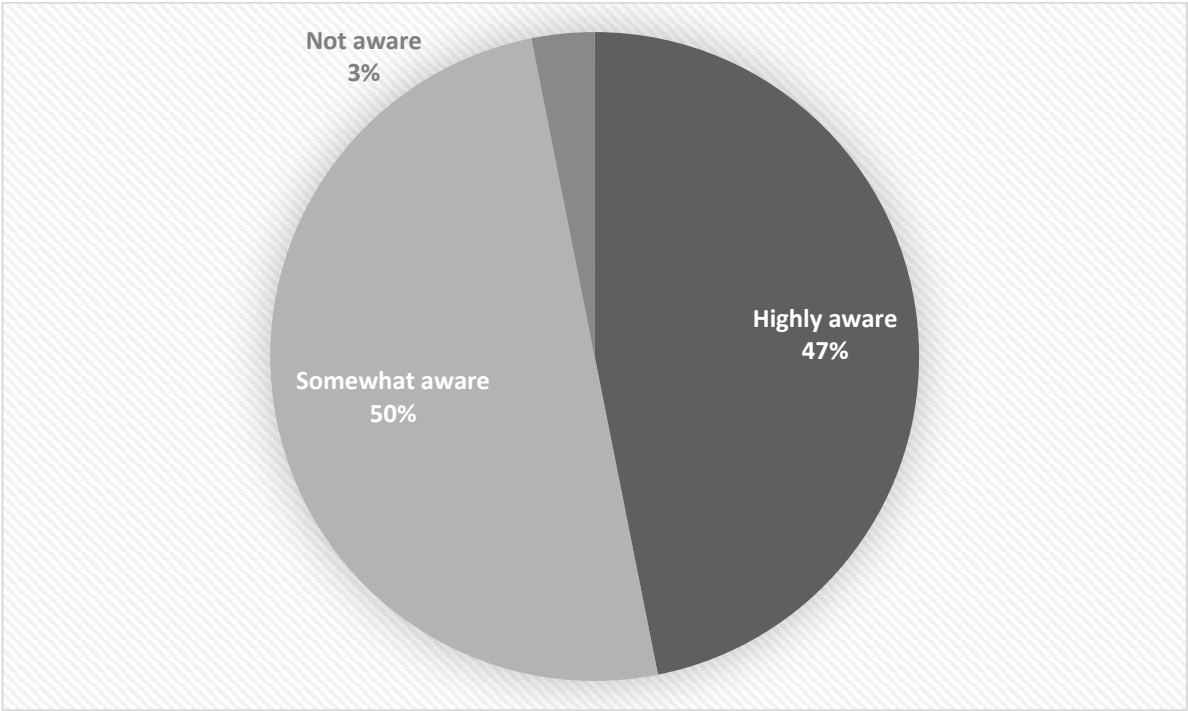


Fig.3 Awareness of UK health disparities [n=32]

Fig.4 illustrates respondents' awareness of racial under-representation in the medical knowledge base. 78% of respondents, or 25, characterised themselves as 'aware' of under-representation in medical research, with 22%, or seven respondents 'highly aware', and 56%, or 18, 'somewhat aware'. 72 % of respondents, 23 in total, identified as aware of under-representation of racially minoritised patients in reference resources, with six, 'highly aware' and 17 'somewhat aware'. Awareness was highest with regard to under-representation of black and brown skin in reference imagery, with 88% of respondents characterising themselves as aware, including 15 being 'highly aware', 13 'somewhat aware', and only four responding as 'not aware', indicating a widespread acknowledgment of under-representation, and therefore racial bias, being a norm in collection resources.

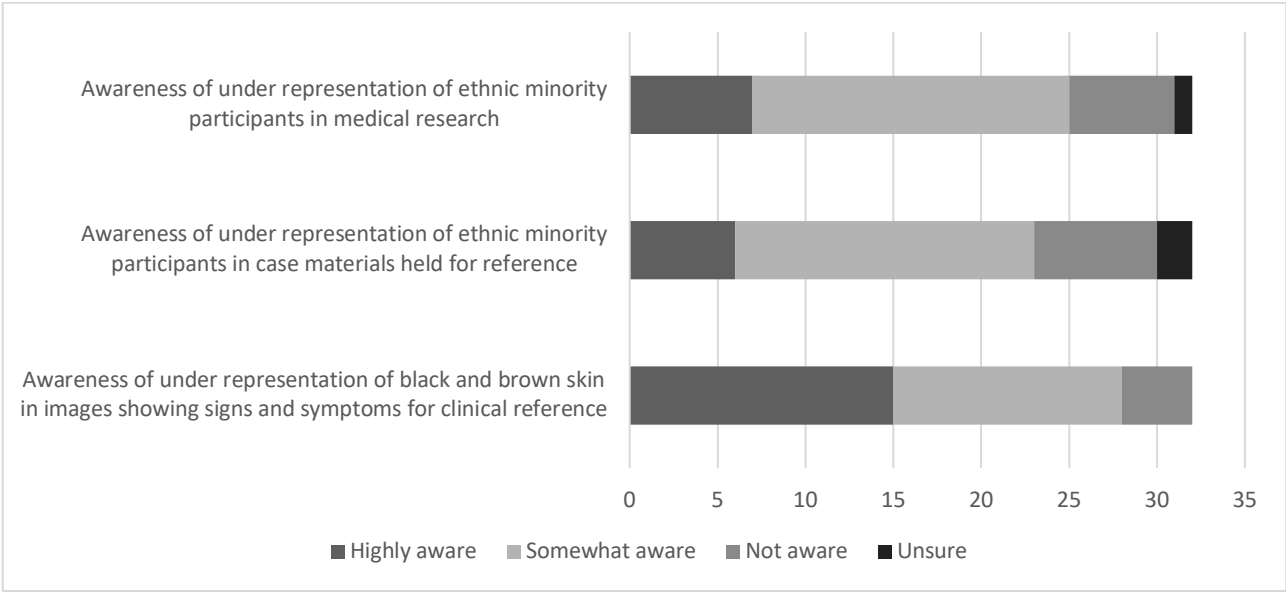


Fig.4 Awareness of under-representation of ethnically minoritised participants in research and resources [n=32]

A majority of 29 respondents, 91% of the total, confirmed their belief that NHS information services can contribute to reducing health disparities, with 12 expressing this to be probable, and 17 as definitely possible, as depicted in Fig.5. Two respondents registered the opinion that it is 'probably not' possible for information work to contribute to health equality, and one was 'unsure'. No respondents selected the 'definitely not' option.

The only two respondents to assert that information services could 'probably not' affect racial health disparities were within the cohort of 'not involved' in wider EDI work at all, as depicted in Fig.6. This may suggest that wider EDI involvement correlates with confidence in the potential for services and resources to contribute to health equity.

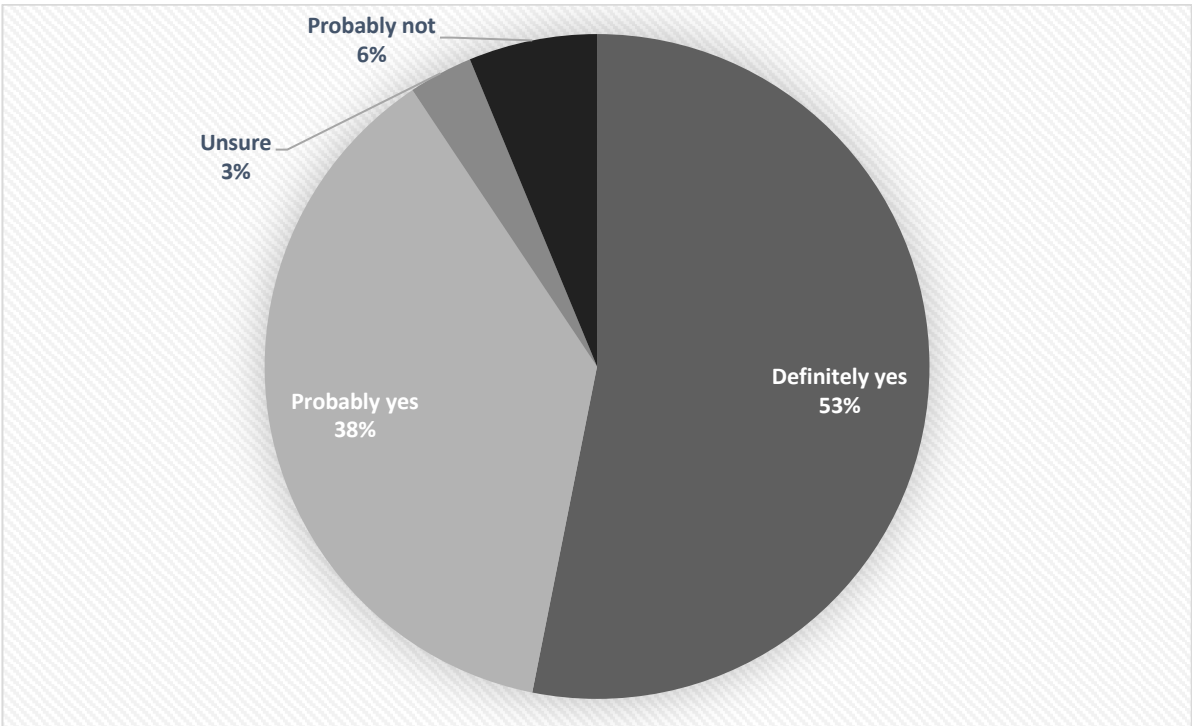


Fig.5 Belief in information services' ability to contribute to health equity [n=32]

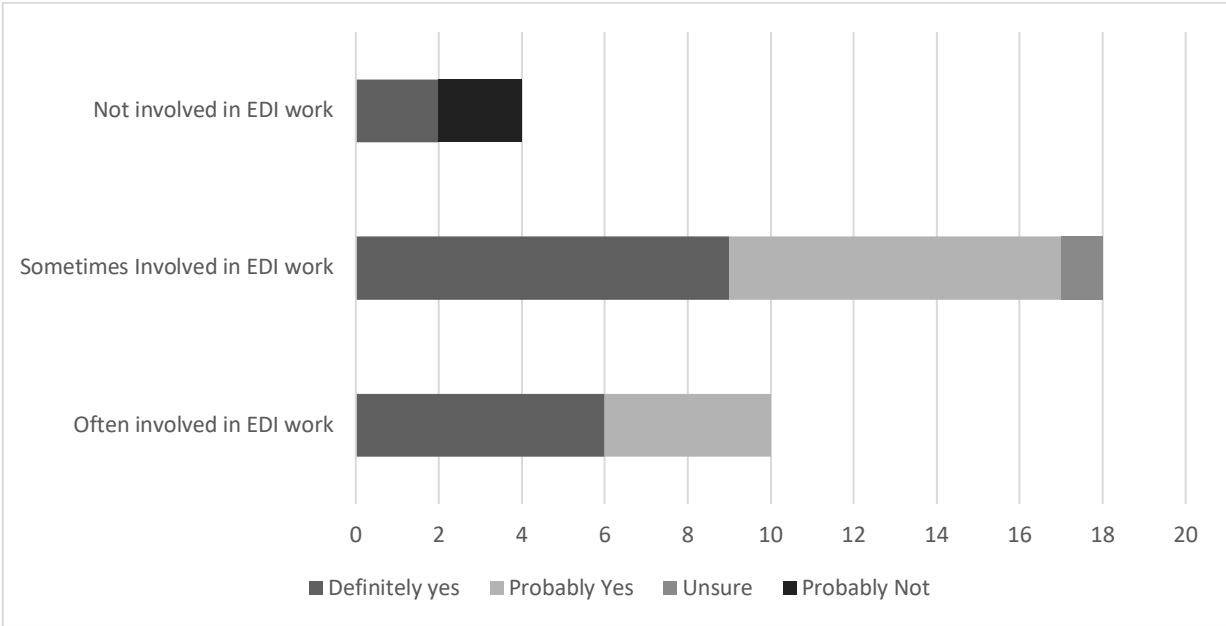


Fig.6 EDI involvement correlation to belief in contribution to health equity [n=32]

In order to better understand the perspective from which respondents were answering, experience of different EDI workplace initiatives was queried, as illustrated in Fig.7. Here 31 respondents, 97%, indicated that they had taken part in EDI initiatives, five describing having experienced ‘a lot’, 15 ‘several’ and a further 11 ‘not many’. Only one respondent reported experiencing ‘none at all’. 90%, or 28 of the respondents, had experienced staff diversity initiatives, with two respondents reporting ‘a lot’, 14 ‘several’ and a further 12 ‘not many’. 23 respondents, or 72%, reported some experience of decolonising or diversifying collections, comprised of four with ‘a lot’ of experience, eight recounting ‘several’ experiences and 11 reporting ‘not many’. 16 respondents, 50% of the base, had attended unconscious bias training, comprising of three reporting ‘a lot’, seven ‘several’ and six ‘not many’ of these trainings. These findings suggest that EDI activity is established and somewhat commonplace in NHS settings, with most staff having participated in initiatives and trainings around staff diversity and bias.

The least established application of EDI work was in monitoring for systemic bias in research, with no respondents indicating ‘a lot’ of experience. Three respondents indicated ‘several’ experiences, seven confirmed ‘not many’ and a majority of 63%, or 20 respondents, indicated no exposure to this practice, suggesting that EDI experiences in the healthcare information environment are more focused on interpersonal equality, inclusion, and diversity than on resource-oriented applications addressing systemic racism.

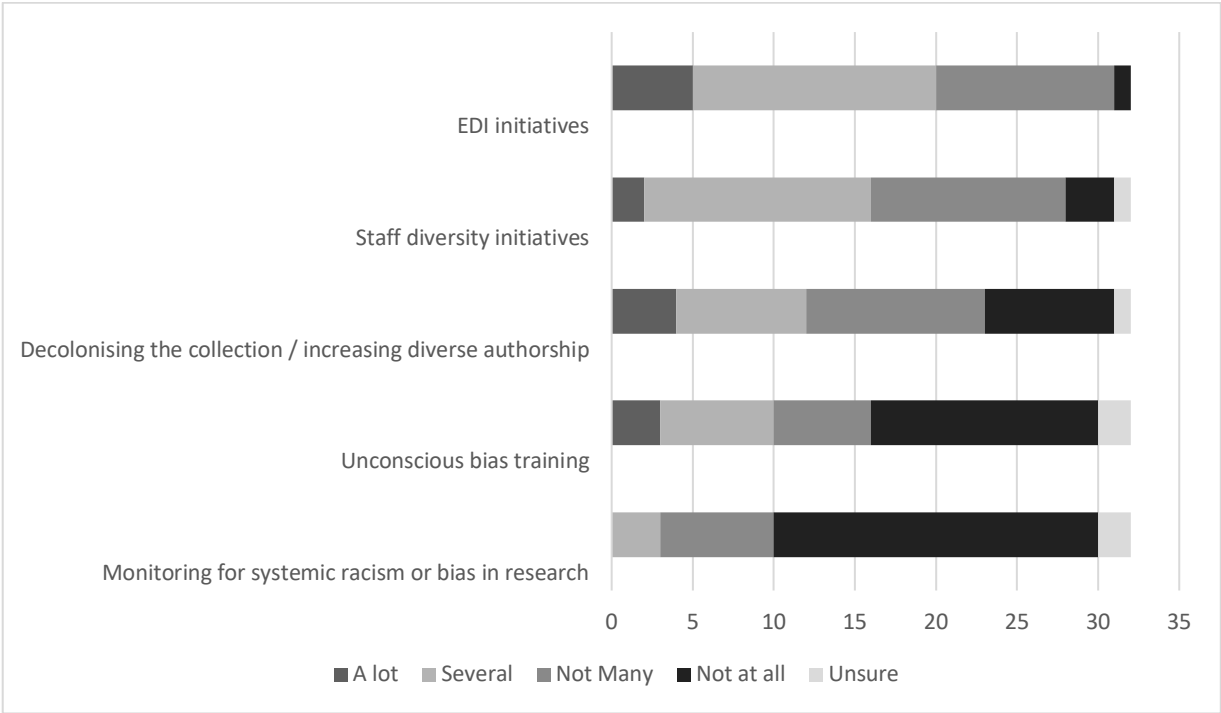


Fig.7 Breakdown of participant EDI initiative experiences [n=32]



As depicted in Fig.8, 11 respondents, 34 % of the total, confirmed awareness of the GMC's 2020 statement committing to updating medical curricula to reflect the diversity of the UK population, with a further 15 being unaware and six 'unsure'. Of those confirming their awareness or being 'unsure', seven reported having added resources to the collection following the statement, six reported increasing promotion of diverse materials to medical students, and nine to clinicians. One respondent commented that their service 'are unclear how best to diversify our collection or how to evaluate it'. Five respondents confirming awareness of the statement report being unsure whether new materials were added, and five report not adding anything new, suggesting a need for both stronger organisational promotion of statements and policies pursuing equity, and better guidance on action required in response.

Survey participant comments support the analysis, reflecting confusion and frustration at the lack of amplification for such an important shift. While positive responses included: 'Thanks for the heads up!', 'Pleased to see this', others questioned the absence of communication; 'Completely unaware... cannot find anything from any mailing lists or any level of NHS communication', 'Our medical education team have not made us aware of this, nor our library network'.

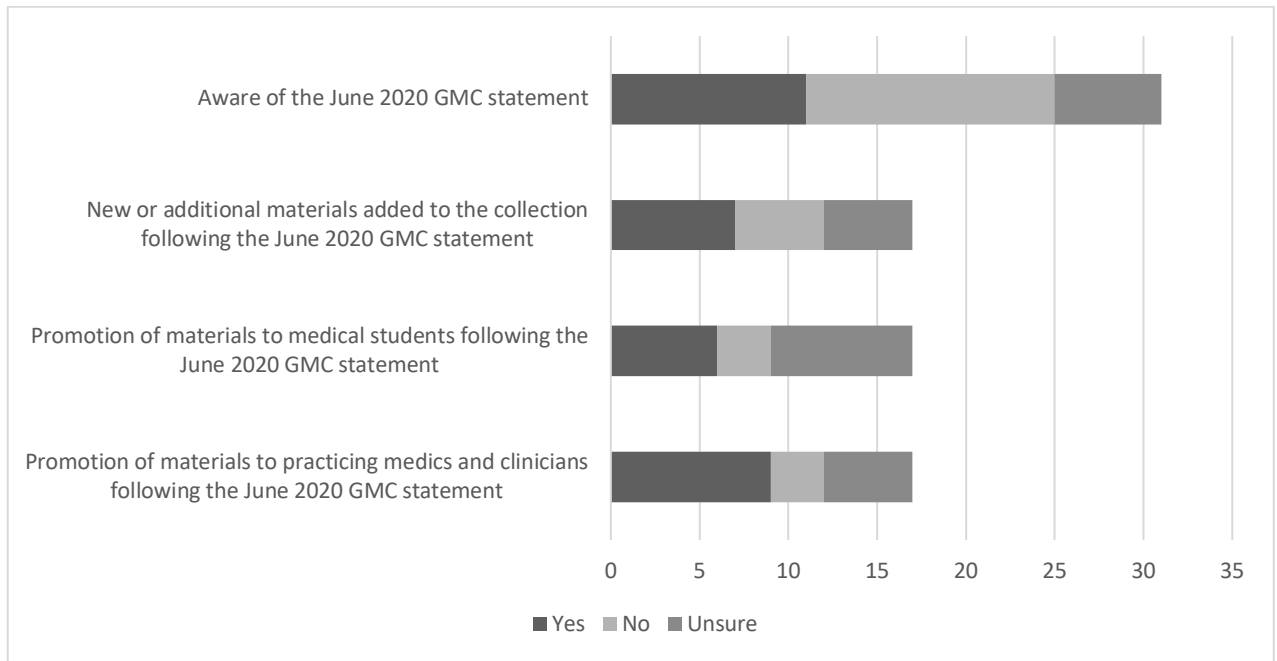


Fig.8 Awareness of the GMC statement on medical curricula [n=31]

66%, or 21 respondents, confirmed awareness of the 'Mind the Gap' resource, with a further nine reporting being unaware, and two unsure. 16 had promoted it to practicing medics, and five had promoted it to students, illustrated in Fig.9.

Comments on 'Mind the Gap' varied from highly positive and engaged; 'Very welcome resource flagged to our collections liaison team', 'We have involved the author in some of our work', 'Thanks for the reminder to promote to students', 'Requested an electronic copy & sent it to our consultant surgeons and BAME champions', to more hesitant; 'Linked to it on website - promotional activities limited due to pandemic and other internal factors', 'Have publicised it but could do better', 'We are aware, but haven't utilised it to any great extent', perhaps indicating an absence of central guidance as to how to manage such 'grey' resources.

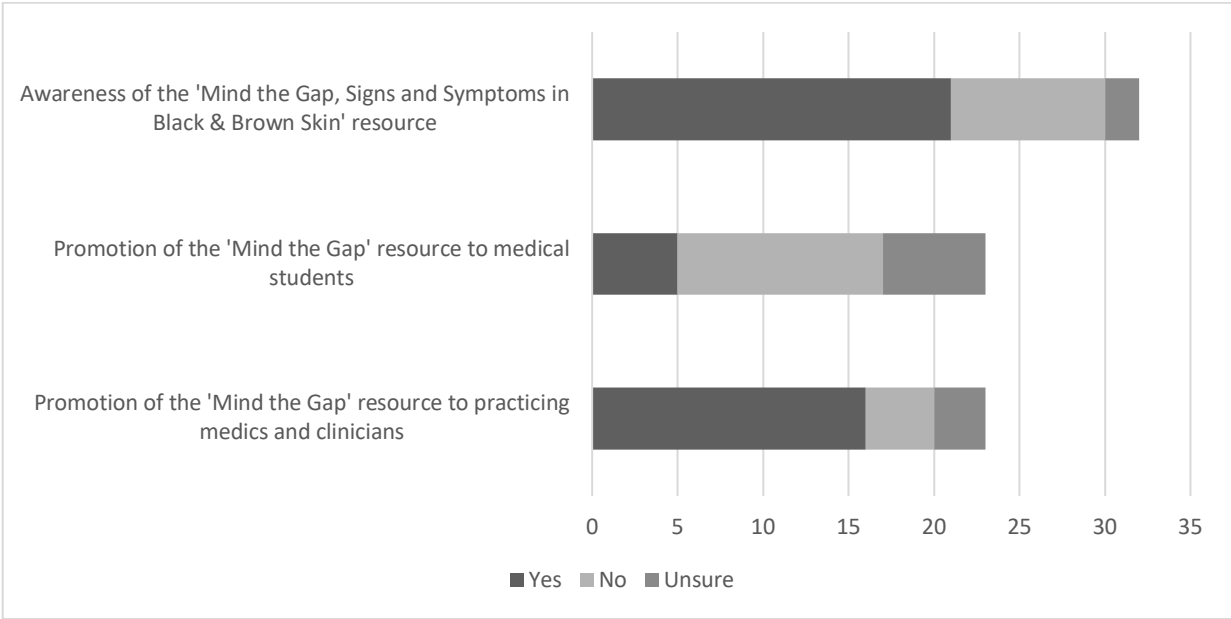


Fig.9 Awareness of the resource 'Mind the Gap: Signs and Symptoms in Black and Brown Skin' [n=32]

## 4.2 Interview results

A thematic table of interview response data is available (O'Driscoll, 2022, appendix H), comprising participant quotes collated into themes identified as the interviews progressed, employing elements of Pickard's constant comparative analysis (2007, p.241). Clear topics emerged as themes relevant to the study.

### Collection policy and acquisitions

Participants were asked about collection policy and EDI guidelines therein. Participant 3 described having developed collection policy locally, including EDI provision, enabling acquisition of resources 'perhaps you wouldn't be able to justify buying were it not for having that clause'. No other participants' collection policies included EDI. Two participants confirmed EDI as a trust priority informing their collection approach, Participant 1 stating 'we respond to larger external policies'. Other participants related EDI acquisitions as reactive to staff network or diversity manager requests, or to wider equality projects.

All participants confirmed recent EDI-led acquisitions, although in limited numbers of books with disparate themes. There was consensus on budget not being a barrier to purchasing ad-hoc texts, but that larger purchases might differ. On probing potential barriers to EDI acquisitions, the need for guidance emerged as a theme. Participant 4 stated 'I've been trying to put together a sort of equality project... that's something I'm struggling with'. Three participants commented positively about a suggestion of national or central policy or guidelines for EDI in resources. Participant 1 suggested that unified EDI collection policy may, in part, create buying power that 'would maybe affect books being published'.

All participants were highly aware of the 'Mind the Gap' resource and had promoted it on launch, indicating awareness of the need for more representative resources.

Participant 3 expressed some concern at the level of focus on one resource, attributing this to the dearth of clinically focused EDI materials available, 'everyone's latched on to that one book because that's the [one] thing'. Three participants expressed concern that libraries may not have access to knowledge for collection EDI or know how to evaluate and acquire such resources.

Three participants reiterated the importance of EDI in information for clinical reference, including raising awareness of racial health disparities. Examples included Participant 2 referencing the importance of skin tone in diagnosing cyanosis, and recent research on pulse oximeters' efficacy on black and brown skin. Participant 3 cited disparities in the mental health sector, with Black men reported as 'overmedicated, and more likely to be compulsorily treated'. Participants highlighted horizon scanning, and communication of clinically oriented EDI current awareness as a key information service contribution.

Four of the five information professional participants related frustration at the absence of contemporary, evidence-based resources for EDI in the clinical context, with Participant 3 commenting 'if the resources aren't there how can we ask suppliers to buy them?', and Participant 1 noting 'the information needs to be there, the books, the resources need to be there'. Participants reported few user requests for information regarding minoritised patients or diverse skin tones and recounted a lack of feedback on 'Mind the Gap'. Participant 1 described the service as 'primarily here for medical books' in reference to the few EDI acquisitions made, highlighting a potential perception of EDI as a non-clinical issue.

Consensus around inequity in healthcare collections coalesced at inequality of representation in research and publishing. Participant 3 highlighted disproportionate focus on disparities rather than solutions, but noted the sector has 'started a bit more talking about these representation issues in research', and related involvement in

outreach to research practitioners as an interdisciplinary initiative. Participant 2 spoke of the challenges of available and interoperable data for 'meaningful' tracking of outcomes and disparities, noting COVID-19 data as a turning point for race in UK health reporting.

#### Wider EDI work involvement

Four of five information professionals reported involvement in staff EDI networks to some extent, with this falling within their core role. Participant 1 stated 'it's just viewed as providing an information service to staff'. Two participants noted the significant personal-time commitments for individuals in EDI leadership positions. Participants agreed that senior support for EDI is evident or somewhat evident, with Participant 4 describing a trust-wide focus on EDI 'mak[ing] sure that we address equality and diversity in... every area'. Participant 3 recounted senior support for EDI from HEE.

Diversity of NHS clinical staff was highlighted by Participant 2 as a positive aspect of the NHS. This contrasts with the ongoing challenge of the whiteness of librarianship, also prevalent in healthcare, noted by Participant 4. All participants demonstrated positive responses to EDI work, and positivity towards improving representation and inclusion in clinical reference and educational materials.

On discussion of the potential racist troll questionnaire response four information professionals felt that it was unlikely from within the information service, though Participant 5 noted a prior library colleague holding somewhat similar views.

Participant 3 described the tensions of raising equality and race issues in the NHS workplace, 'If you... don't talk about these things, it doesn't make them go away it just makes some people feel more comfortable', illustrating the personal challenges of pursuing an EDI agenda. Two participants highlighted ongoing initiatives for NHS management and culture to reflect the diverse NHS workforce.

## Drivers for EDI and change

While COVID-19 emerged as a primary driver for change in the health information landscape, with Participant 6 referencing ‘shocking statistics ... around deaths of Black and ethnic minority doctors’, and Participant 1 remarking on hope that transparency of COVID-19 disparities may prompt changes in research and publishing, interviews also indicated the death of George Floyd and the resultant profile of BLM as key to increased awareness of systemic racism.

Organisational culture and education were also noted as contributors to change and progress. Participant 3 raised the need for education and increased awareness around health disparities, citing disappointing results from NHS staff surveys which indicated poor awareness of inequalities and efforts to remedy them. Three participants expressed a view that several or many fronts of action would be required to address and rectify the information inequalities and health disparities experienced by racially minoritised patient groups. Participant 6 summarised that ‘the more professional strands are behind this the better’.

## 5. Discussion: analysing empirical findings through a CRT lens

The literature analysis, survey, and interviews form a clear picture of the context and imperative for healthcare information services to contribute to racial equity through decolonisation of resources and collections. Further analysis confirms the suitability of CRT as a framework supporting both scholarship and decolonisation practice. EDI work, particularly around diversity, is found to be embedded in the NHS information sector, however this has limited effect on information equity. Common themes across the literature and research indicate clear opportunities for progress. Leung and López-McKnight’s listed tenets of CRT (2021, p.13) enable synthesis and conclusion of the research and will be used as subheadings for the analysis that follows.



Tenet: Race is a social construct

There is consensus across the literature on the non-scientific basis of race, as illustrated by the human genome project (Roberts, 2011, p.26, p.53, Yearby, 2021). Despite this, outdated beliefs around racial characteristics persist in medicine and science (Saini, 2019, p.73, p.120, Massie et al., 2021). Survey findings suggest lower awareness of critical appraisal for racial bias, as discussed by Naicker (2021), compared to other EDI workstreams, indicating a disparity in confidence to interrogate race in the scientific domain. While acknowledged as arbitrary, and non-biologic, racial categorisations are now key metrics in identifying and reducing health disparities (Pérez-Stable et al., 2021). As noted by interview participants, only by naming and tracking race in health data can we move towards solutions to embedded racisms in healthcare.

Tenet: Racism is normal

Institutions without policies to ensure services adapt as populations change risk reproducing systemic racism (Blume and Roylance, 2020). Interviews found only one participating service had EDI provision within collection policy, underscoring this risk. Interview participants related a lack of knowledge and guidance for collection equity, with much current EDI acquisition reactive to requests. Survey data confirms that 72% of respondents had some exposure to diversifying collections, indicating some engagement with decolonisation. There is an opportunity to harness this engagement through policy, guidance, and structured sharing of best practice in active challenge to norms of under-representation.

Persistence of racial health disparities serves as evidence of ongoing systemic racism. Otu et al. (2020) note that Public Health England (PHE)'s June 2020 report detailing heightened COVID-19 risks faced by Black and South Asian populations was unaccompanied by proposals for targeted mitigations. Publications depicting cutaneous

symptoms of COVID-19 fail to show diversity of skin tones, despite these risk profiles (Lester et al., 2020). Interview Participant 3 expressed frustration with the disproportionate focus on the existence and measurement of disparities, in contrast to a dearth of resources for researched, evidenced solutions. Health disparities are reproduced through lack of action for change.

Tenet: Experiences and knowledge of racially minoritised people

Encountering inequality of representation in resources and curricula is experienced as erasure or othering by racially minoritised students and professionals (Hartland and Larkai, 2020). While interviews confirm management and HEE support for EDI work, survey results show diversity as the main EDI workstream within healthcare information services. Greater bodily diversity in the staffing and leadership of information environments benefits the knowledge base through lived experience, and may reduce barriers to change, but underlying structures and systemic inadequacies must also be addressed for inclusion to be meaningful and sustainable.

In recent years an increasingly diverse medical student body has raised awareness of systemic racism in the curriculum (Change.org, 2020, Wong et al., 2021). Mukwende's 'Mind the Gap' is one example of change initiated by a minoritised student (SGUL, 2020). Similarly, LIS has seen calls for marginalised voices to be heard (Ettarh, 2018, Dunbar, 2021). Participant 3 notes the pressures of speaking out against racism and the benefits of silence to the status quo. While listening to racialised voices is key, the workload of rebalancing resources and collections must be shared across the profession, not charged to minoritised colleagues.

Tenet: Interdisciplinarity

LIS inherently lends itself to interdisciplinarity, with adjacent disciplines of publishing and authorship as vehicles for change (Gwynn et al., 2019). Libraries' capacity to

collaborate, whether in establishing data standards, advocating for inclusion, or facilitation of outsider voices, can disrupt power structures (Inefuku and Roh, 2016). This study has not found that the health information sector is ignoring or blocking inclusive resources, rather that the wider information environment has not addressed deficits, and that the pace of change is slower than the pace of increasing awareness and need. To effect change an interdisciplinary approach is essential.

Tenet: Critique of dominant ideologies

Science is assumed to adhere to ideologies of objectivity and evidence. Examining systemic bias in the healthcare domain necessitates questioning this. 78% of survey respondents reported awareness of racial under-representation in research and reference materials, confirming deficits in the knowledge and evidence base. While Participant 3 notes some progress in health research engagement with diverse representation, for science and medicine to be truly evidence-based research data must reflect population diversity and must include racial health disparities and potential solutions.

Critical librarianship discourse debates neutrality as an LIS domain ideology (Bales, 2017, Gibson et al., 2017). The ALA, whose guidance is often cited as the root of library neutrality, has now clarified a non-neutral position of anti-racism (ALA, 2021). It is possible that UK LIS espouses passivity more than neutrality, as illustrated by limited, reactive pursuit of EDI resources reported in interview data. Survey results demonstrate opportunities for more ambitious EDI workstreams in the health information realm, parallel to diversity work, with potential for healthcare information systems to be more active and deliberate in pursuing information equity.

Tenet: Interest convergence

Bell defines interest convergence as the premise that ‘racial equality will be accommodated only when it converges with the interests of whites’ (1980). In the knowledge domain, biased or inadequate information environments are a corruption of our core purpose. Sciences, including medical and information sciences, benefit from completeness and accuracy of records (Pérez-Stable et al., 2021, Lokugamage et al. 2020). There is then interest convergence, based on efficiency, efficacy, competence, and productivity, in ensuring that the full breadth of population diversity is represented in healthcare resources and collections.

Tenet: Totality of systemic racism

While addressing granular instances of systemic racism, such as under-representation in resources, is necessary and urgent, it is important that such instances are contextualised as indicative of the whole; embedded in wider structural inequity (Crilly, 2019). UK health bodies and institutions communicate intent to address health disparities through statements and policies (NHS England, 2015, PHE, 2018, Robertson et al., 2021, HEE, no date). Much operational focus however is confined to staff diversity and workplace equality. While this is important work, it limits scope to one strand of the totality of systemic racisms (Hudson, 2017). CRT as a framework, and decolonisation as a practice, enable a structured and multi-faceted approach to analysis of, and action on, a breadth of systemic racisms.

## 6. Conclusion and recommendations

This study has established the imperatives for healthcare information services in the UK to undertake collection equity initiatives addressing systemic racism, work underpinned by librarianship’s social justice values, and has confirmed the aptitude of CRT as a framework for decolonisation, supporting such praxis. This expectation stands independent of EDI networks and diversity management, being based on information

ethics, knowledge stewardship, collection completeness, accuracy, and efficacy of information for contemporary demographics. Surveys and interviews conducted confirm information services' engagement with and support for EDI work, equitable resources, and best practice in NHS library services. Readiness for change, and awareness of health disparities and information deficits magnifies underlying frustrations with existing resource inadequacies for health equity.

Analysis of the literature affirms the structural, foundational place of collection policy in expressing institutions' priorities and intent, and in focusing services on the users and impacts of information services. Collection policy for EDI is found to be largely absent, or in place locally by exception. Similarly, local awareness of the need for race as a research data point is evident but approaches to critical appraisal for systemic racism, and intent to influence the research community depend on personal and professional initiative.

While themes around LIS professionals as knowledge gatekeepers and arbiters of inclusion and exclusion are explored in the literature, the research found little evidence of healthcare information services as barriers to acquiring or promoting available resources in practice. Interview data suggests that the deficit of inclusion and representation of racial diversity in resources is rooted in shortfalls in research and publishing more than in acquisition and access. Solutions require interdisciplinary work, beyond librarianship's core remit. Stewardship of the health information domain entails an expectation that adequate information be accessible for all users, particularly where risks and vulnerability are transparent. In this case the information may need to be created.

Education is a recurring theme throughout the analysis. Decolonisation campaigns have secured commitment to better representation in medical curricula. Library and

information services must provide resources to meet this commitment. CME is also a significant user need in the domain, yet no clear sense of how revised, more representative content for medical education might reach practicing clinicians emerged. It is key that these resources are promoted through education and CME channels, as distinct from EDI, so that the knowledge is recognised as clinically relevant.

The literature analysis also supports the adoption of CRT within LIS curricula, equipping the domain's scholarship and practice for contemporary social justice expectations. The nascent presence of CRT in the domain, and its alignment and suitability for LIS analysis (Stauffer, 2020), particularly given librarianship's adjacency to education, supports this. In this study CRT was found to be an appropriate and helpful LIS framework for synthesis, enabling interdisciplinary literature and the research to be drawn together and analysed for an informed examination of the roots, structures, and effects of systemic racism in healthcare information. Inclusion of CRT in LIS curricula serves to equip information professionals with a framework for collection and service decolonisation, as a contemporary competency.

The study and analysis have highlighted the following opportunities for policy, practice, and further research.

#### Opportunities for policy and practice

- Creation of central or national EDI collection policies for NHS healthcare information services.
- Local services adoption of EDI collection policies and best practice.
- Separation of racial health information equity from workforce diversity workstreams, using quality improvement and impact frameworks.

- LIS involvement with the creation and adoption of ethical research and data standards, including the standardisation of disaggregated race data where relevant; to include consultation on language and categorisations.
- LIS involvement with research, authorship, and publishing of resources for information equity in healthcare collections, with urgent focus on documented racial health disparities.

#### Opportunities for further research

- Ethical and practice considerations in disaggregated data: devising and agreeing racial categorisations that minoritised groups and individuals both identify with and benefit from.
- LIS institutional infrastructure and interdisciplinarity: whether the occupation of liminal spaces and the prevalence of dotted-line leadership contribute to passivity or reactivity in the absence of clarity.
- Libraries, authorship, research, and publishing: the extent to which information professionals can influence the 'supply chain'.
- The intersectionality of research and resource deficits for both women's and racial minorities' healthcare; the compound effect on health outcomes for Black women.
- Critical race theory in the UK LIS space; would decolonisation initiatives benefit from wider adoption of the framework?
- Comparison with similar studies in other countries.

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