Protocol

Social care access for BAME and LGBT+ populations: A rapid realist review

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1. Overview

The Department of Health and Social Care (DHSC) and the National Institute for Health Research (NIHR) identified "inequalities within adult social care" as a priority research area and commissioned the School of Health and Related Research (ScHARR) at the University of Sheffield to deliver this work under the National Institute for Health Research (NIHR) Evidence Synthesis Centre contract. The DHSC has asked SCHARR to produce an evidence review to support primary research and evaluation of ethnic differences in provision and experience of adult social care in England.

The research request from NIHR was "Addressing diversity and inequalities in access to social care services". Further discussion between ScHARR and DHSC (Leanne Dew) has identified two specific population groups of interest – people who are from BAME backgrounds and people

who are LGBT+. The agreed focus of this review will be on access to adult social care and will include access for BAME adults and LGBT+ adults. The research will take the form of a rapid realist review.

2. Definitions

Adult Social care

We are using the definition of social care from the Health Foundation "…care and support for people who need it because of age, illness, disability or other circumstances. It ranges from help with essential daily activities, such as eating and washing, to participation in all aspects of life, such as work or socializing. Social care can be provided in people's homes, to enable independent living or help with recovery after illness and, if home care is no longer an option, provide a safe space for people to live in supported housing, residential or nursing homes". (Thorlby et al., 2018). In addition to this definition, as part of our wider consideration of access issues, we will also look at wider support for accessing social care, such as information, support and signposting.

Diversity and inequalities

Under the Equality Act 2010, we understand the following characteristics to be protected from discrimination in the workplace and wider society - age, sex, gender reassignment, disability, ethnicity, sexuality, religion, pregnancy and marriage. There is also an intersection between these characteristics that frequently enhances discrimination and inequalities. In terms of access to healthcare, evidence has often focused on inequalities of access and outcomes for groups such as children, older people, members of minority ethnicities, men/women, and socio-economically disadvantaged people (Dixon-Woods et al., 2006). This review will use evidence relating to two specific groups (BAME and LGBT+) but these may also include reference to other protected characteristics.

Access

The review will consider access in terms of the notion of candidacy (Dixon-Woods et al., 2006) and not consider access to be a static and fixed relationship. "Candidacy describes the ways in which people's eligibility for … attention and intervention is jointly negotiated between

individuals and … services… Candidacy is managed in the context of operating conditions that are influenced by individuals, the setting and environment in which care takes place, situated activity, the dynamics of face-to-face activity, and aspects of self (such as gender), the typifications staff use in categorising people and diseases, availability of economic and other resources such as time, local pressures, and policy imperatives." This definition from Dixon Woods et al is particular to healthcare access and we acknowledge that it may not be as relevant when considering social care access - in particular the role of the identification and definition of social care needs by individuals, as opposed to the diagnosis of healthcare needs in a healthcare setting.

In the review we will address whether individuals recognise a need for social care (as per the expanded definition above) (either themselves, informal or formal carers or health/social care professionals), the availability of care, awareness of services and eligibility (which may include local authority/NHS recognition, assessment processes, navigation). In addition, the review will also consider that access touches upon issues of provision, experience and satisfaction and that these issues may help to explain further access.

3. Background

Scoping work within the DHSC has reviewed some existing evidence. From this review of literature, several themes regarding reasons for unequal access to care for BAME groups emerged. These included (1) Lack of knowledge of services (2) Fear of discrimination (3) A complex relationship between care delivered by family members and delayed access to social care and (4) A low uptake of personalisation.

In addition, the review also identified three specific reasons for lower satisfaction with care, which may also relate in part to access issues. These are (1) linguistic and cultural barriers (2) Dissatisfaction with care received and (3) Diversity blindness – e.g. treating BAME people as a single group

Potential recommendations to better meet the needs of BAME social care users that were identified in this review, included: community based services and micro-providers, increase in

uptake of personalised budgets, linguistic and communication improvements and person-centred care – e.g. to explore ethnic matching vs. non ethnic matching in care provision.

This review and preliminary scoping in the area has indicated that there is a relatively small evidence base relating to access to social care for BAME and LBBT+ populations. Therefore, working with DHSC, ScHARR proposed that a realist synthesis might be a useful, policy focused product. Given the requirement to complete the research in six months, this will be a rapid realist review, using established methods (Saul et al., 2013).

4. Rapid realist review rationale

The rationale for undertaking a rapid realist review is

- Rapid realist methods have been specifically developed for work with policy makers (Saul et al., 2013). Close working relationships between review producers (ScHARR) and customers (DHSC) are an integral part of the rapid realist review process.
- The DHSC are already familiar with the evidence base for BAME populations, which is small (and we anticipate the same or similar for LGBT+ populations). In addition the focus of the review is on the UK and England more specifically, which limits the volume of evidence that can potentially be included in the review.
- Realist methods have the potential to generate theories about interventions and why they might work, for whom and in what context, which will be more informative than a traditional effectiveness review, drawing on a small number of studies which are generally not high quality.
- By focusing on critical issues relating to access and prioritising them according to their potential to explain access, we can explore the pathways to access for these two population groups, in order to gain additional benefits from the evidence base.

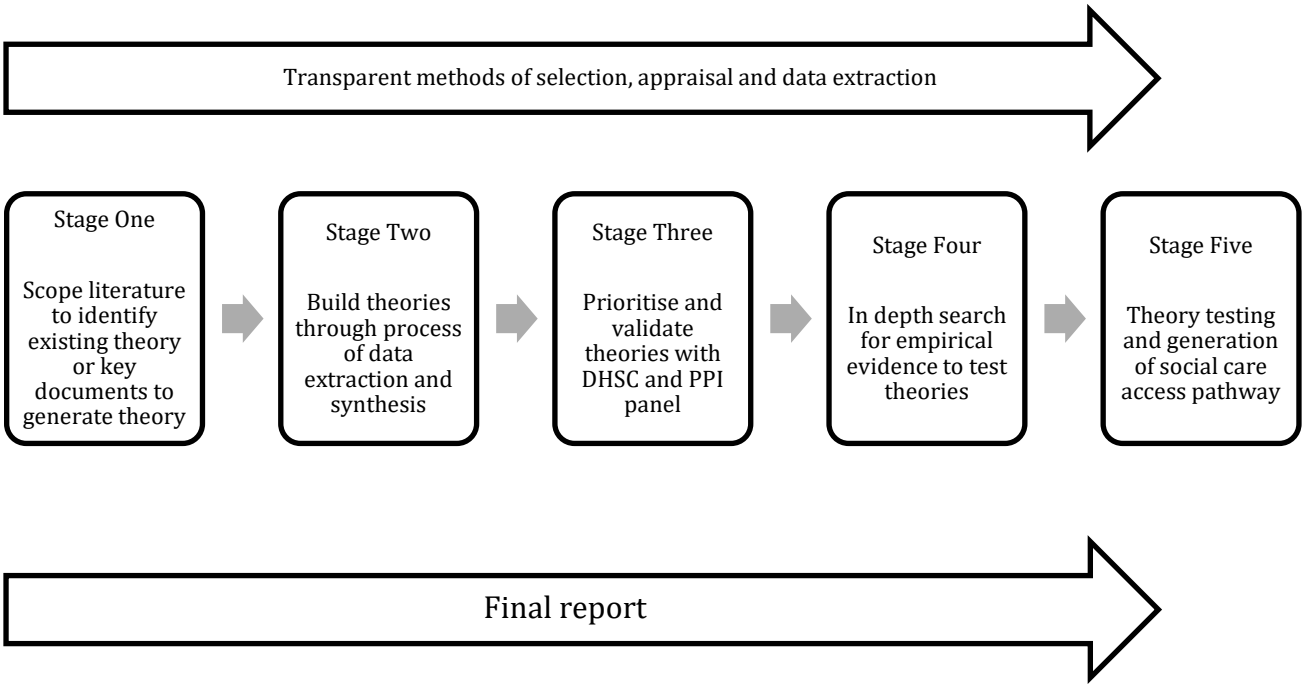
5. Research aim

The research aim is to use rapid realist review methods to explore the contexts that influence access to social care for two specific population groups. Specifically addressing the following research questions

(1) What are the barriers and facilitators to accessing social care for a) BAME and b) LGBT+ populations?
(2) Using IF-THEN-LEADING TO, or Context-Mechanism-Outcome configurations, can we map access to social care on existing access pathways to healthcare (Ford et al., 2016, Bertotti et al., 2018), to provide additional explanations for what influences access to social care?

6. Research Methods

The rapid realist methods have been developed iteratively and are summarised below. This is not an exhaustive description of methods, but indicates the stages of the review. The review will be reported according to RAMESES (Realist And Meta-narrative Evidence Syntheses: Evolving Standards) (Wong et al., 2013) which is the standard reporting standards for this type of review.



- Stage One - Scope literature to identify existing theory or key documents to generate theory

According to Husk et al (2019), in this first stage we will prioritise the rigour and relevance of conceptually rich evidence. We will focus on searching for evidence reviews and any existing theoretical work in the area which will allow us to generate hypothetical explanatory accounts.

- Stage Two - Build theories through process of data extraction and synthesis

Using a structured data extraction process we will develop a greater understanding of the contexts that prevent and enable access to healthcare and the mechanisms that underlie this. This stage will focus on the development of Context-Mechanism-Outcome configurations, also described as If-Then-Leading To chains. We will extract data directly into evidence tables in WORD/Excel in the form of Context Mechanisms Outcomes Configurations (CMOs).. In terms of the quality assessment of the evidence base, we will not assess the risk of bias in individual studies at either Stage Two or Stage Five. Instead we will make an overall judgement on the relevance and rigour of the evidence base to support policy making.

- Stage Three - Prioritise and validate theories with DHSC and PPI panel

We will generate a short report which articulates the emergent theories in the form of If-Then-Leading To chains. We will share these with DHSC and our PPI panel to validate and sense check these, and, given the rapid nature of the review, prioritise the core areas of interest for DHSC in order to search for empirical evidence to test these. This will be done via a teleconference in Mid December with DHSC and in early December with our PPI panel.

- Stage Four - In depth search for empirical evidence to test theories

At this stage, we will prioritise explanatory rich data (Husk et al 2019). We will search for empirical evidence of context-mechanisms-outcomes to test and refine theories developed in Stage Two. This explanatory and rich data will have to meet the following inclusion criteria.

Setting	Adult Social care, as defined in the review protocol
	Evidence from UK settings only, with an emphasis on evidence from England. Where information is available, we will report on the geographical context and highlight evidence from England.
Population	Adults receiving social care Adults from a BAME group Adults who identify as LGBT+
Outcome	Included studies should have an outcome reporting a change in access.

Date limits	2009-2019
Study Type	Any (peer reviewed and non peer reviewed/grey literature)

Any studies that meet our inclusion criteria will be included in the review. However, we will also take a broader view of inclusion where studies have addressed access to social care for other groups or for the population more generally, in order to ensure that we do not exclude any key contexts, mechanisms or outcomes that relate to social care access.

- Stage Five - Theory testing and generation of social care access pathway

Using the review by Ford et al (an NIHR fellowship output) (Ford et al., 2016) as a template, we will develop an access pathway, which will offer a structure for analysis and a series of focal points against which to map context, mechanisms and outcomes, in relation to interventions. This development of this pathway could potentially also incorporate evidence from the NICE pathway on 'People's experience in adult social care services overview' (NICE, 2019). Throughout the process, we will be driven by the evidence to determine whether there should be two separate pathways, for BAME populations and for LGBT+ populations.

Stakeholder and PPI engagement

We will involve the ScHARR Evidence Review PPI panel. In a meeting in October 2019, we asked the panel to answer the following questions in a face-to-face meeting. The panel commented on how interesting they found the review and we are keen to include them moving forward in consultation around the access to social care pathway, including, if possible, representatives from our population groups. At a meeting in early December 2019 we plan to ask the panel to help with the prioritisation of theories in the form of IF-THEN-LEADING TO chains, in parallel with the prioritisation exercise with DHSC.

- What factors do you think might influence access to social care?
- Is there is a difference in accessing healthcare as opposed to social care?
- Have you had any experience of using social care for yourself or others?
- Can you think of any specific challenges for the two groups identified (BAME and LGBT+) in accessing social care? Again, are these particular to social care or would they be the same for healthcare?

7. Outputs and impact

We are keen to produce outputs to meet the needs of the customer. We propose that these might include:

- Theories describing access to social care
- An access to social care pathway for these groups
- A final report, which will indicate the evidence, identified relating to the impact of any identified interventions on costs or use of social services.
- Peer reviewed journal articles
- An evidence Briefing (a short, policy focused summary on what we have learnt from the review)

8. Resources and timeline

The review is to be completed within six months, to meet the DHSC deadline of 31st March 2020. We will have teleconferences at the protocol development, initial theory development and end of the review stages. For staffing resources, we will have 1.4 fte working on this review (EH and LP). Additional resource in kind will be given by AB and EG.

9. References

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Appendix 1 – Proposed search strategy

The search strategy will be iterative and will include a number of stages as outlined in the methods section. The below suggestions are indicative areas in which searching will be undertaken, rather than exhaustive search strings. The search methods adopted will be included in the final report to ensure transparency.

Social care terms

Social work* or Social care* or Social service* or Social support* or "long-term care" OR "care home*" OR "Nursing home*" OR "Residential care" OR "Home care" OR "Homecare" OR "home nursing" OR "Home help"

BAME terms

refugee* or asylum seeker* or (migrant* or immigrant* or emigrant*) or ("first generation" or "second generation") or race or nationali*

(BME or black ethnic minorit* or black minorit* ethnic* or south asian* or bangladeshi* or pakistani* or indian* or sri lankan* or asian* or east asian* or chinese or taiwanese or vietnamese or korean* or Japanese or afro-caribbean* or african-caribbean* or caribbean or african* or black* or afro* or islam* or hindu* or Sikh* or buddhis* or muslim* or moslem* or christian* or catholic* or jew*)

"Emigrants and Immigrants" (MeSH)

Refugees (MeSH)

LGBT+ terms

Bisexual*

Bisexuality (MeSH)

Gay*

Homosexual*

GLB or LGB or LGBT
Intersex
Lesbian*
Queer*
Sexual minorit*
Sexual orientation*
Transgender* or transsexual*
NOT (gay[au] OR "laparoscopic gastric bypass"[tiab] OR "markov state model" OR "multiple source method"[tiab]))

UK filter terms

1. exp United Kingdom/
2. (national health service* or nhs*).ti,ab,in.
3. (english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
4. (gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.
5. (bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham

or “nottingham’s” or oxford or “oxford’s” or peterborough or “peterborough’s” or plymouth or “plymouth’s” or portsmouth or “portsmouth’s” or preston or “preston’s” or ripon or “ripon’s” or salford or “salford’s” or salisbury or “salisbury’s” or sheffield or “sheffield’s” or southampton or “southampton’s” or st albans or stoke or “stoke’s” or sunderland or “sunderland’s” or truro or “truro’s” or wakefield or “wakefield’s” or wells or westminster or “westminster’s” or winchester or “winchester’s” or wolverhampton or “wolverhampton’s” or (worcester not (massachusetts* or boston* or harvard*)) or (“worcester’s” not (massachusetts* or boston* or harvard*)) or (york not (“new york*” or ny or ontario* or ont or toronto*)) or (“york’s” not (“new york*” or ny or ontario* or ont or toronto*))))).ti,ab,in.

6. (bangor or “bangor’s” or cardiff or “cardiff’s” or newport or “newport’s” or st asaph or “st asaph’s” or st davids or swansea or “swansea’s”).ti,ab,in.

7. (aberdeen or “aberdeen’s” or dundee or “dundee’s” or edinburgh or “edinburgh’s” or glasgow or “glasgow’s” or inverness or (perth not australia*) or (“perth’s” not australia*) or stirling or “stirling’s”).ti,ab,in.

8. (armagh or “armagh’s” or belfast or “belfast’s” or lisburn or “lisburn’s” or londonderry or “londonderry’s” or derry or “derry’s” or newry or “newry’s”).ti,ab,in.

9. or/1-8

10. (exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp united kingdom/ or europe/)

11. 9 not 10

Appendix 2 – Proposed data extraction

IF (Actors)	
IF Context)	
THEN (Mechanisms)	
LEADING TO (Outcomes)	
Citation	
Page	
Supporting References	
Notes	