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The Review Protocol

Barriers and enablers of lifestyle self-management of South Asians with coronary heart disease

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A Systematic Review Protocol

Barriers and enablers of lifestyle self-management of South Asians with coronary heart disease

General Information

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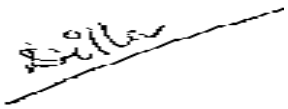
Signature 

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1. Review Title and Timescale

Review Title

Barriers and enablers of lifestyle self-management of South Asians with coronary heart disease

Anticipated Start Date

March 2015

Anticipated Completion Date

August 2015

Review Timeline:

	Date Started	Date Completed
Preliminary scoping searches	November 2013	
Preparation of Protocol	December 2013	
Review and Revision of Protocol	January 2015	
Study searches & obtaining studies		
Piloting of the study selection process & assessment of study relevance		
Formal screening of search results against the eligibility criteria.		
Data Extraction		
Data synthesis		
Quality Assessment		
Writing up of draft report		
Review and Revision of draft report		
Final report		
Dissemination		

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3. Introduction

More than 175,000 people have a heart attack yearly, which equates one person every 2 minutes (Townsend et al 2012). Among the ethnic minority groups in Britain, South Asians share a major burden of this disease. Survivors of heart attacks are at an increased threat of repeated infarction (Mendis 2005). Adopting a secondary preventive approach has the potential to avoid recurrent attacks or deaths thereby reduce health care costs and improve clinical outcome (British Association for Cardiovascular Prevention and Rehabilitation 2011). Consequently, secondary prevention, of which self- management is an important aspect, is considered an efficient and effective strategy to ease the escalating liability of this disease (Nichols et al 2013).

Thus efficient self-management – *defined as an individual's ability to effectively manage the symptoms, treatment, physical, psychosocial consequences and lifestyle changes inherent in living with a long-term condition* (*Barlow 2001*) - of non-communicable disease essentially becomes a key priority. Reviews (Cole et al 2011, De Gucht et al 2013) have shown that lifestyle change alters the course of CHD. Yet lifestyle changes such as physical activity, healthy diet and smoking cessation, often advised after a heart attack is not easy to accomplish as they are often entrenched and entwined in ethno-cultural practices. In addition, these patients are not consulted about what social and emotional support they would prefer to receive to guarantee a therapeutic lifestyle modification, thereby weakening their ability to choose and prioritise, maintain and sustain lifestyle changes for better health outcomes.

One way to conceptualise the necessary knowledge and their reflective application for effective lifestyle change is to explore self-management barriers and enablers from the South Asian perceptive. Focusing on the key influences that are identified to predict uptake, health professionals can tailor support systems to suit the needs and requirements of the community. Likewise, a critical understanding of major barriers and enablers that effect sustenance of therapeutic lifestyles choices may well be exploited by formal programmes to improve on more productive self-management programmes or relapse prevention interventions.

3. Background

4.1. Global burden of CHD and among South Asians

The global epidemic of long term condition or non-communicable diseases (NCDs), namely cardiovascular diseases (CVD), poses a significant health challenge (Astin et al 2014). Cardiovascular disease (defined as disorders of the heart and blood vessels) remains the biggest killer and also results in substantial health care expenditures globally. In Europe, 4 million deaths occur annually from heart disease whilst in England more than 175,000 people suffer a myocardial infarction (heart attacks) yearly (Townsend et al 2012). However, the disease burden shows no egalitarian pattern, with standardized comparisons of prevalence among different ethnicities unmasking a disproportionately high prevalence particularly among migrant South Asians (Scarborough et al 2010).

South Asians (people who share a common ancestry of the Asian subcontinent), represent the largest ethnic minority in United Kingdom (UK) (Office for National Statistics (ONS) 2012) and are at significantly higher risk of developing NCDs such as cardiovascular disease. South Asians in UK suffer a higher incidence of coronary heart disease than their Caucasian compatriots (Scarborough et al 2010) and their admittance rate to hospital with myocardial infarction is twice compared to the general population. Again, prevalence and incidence reveal migrant communities, for example the Punjabi Sikhs, *are at a 3-5 fold higher risk of premature death* due to myocardial infarction (MI) (Galdas et al 2012) underlining the fact that South Asians are most vulnerable groups within their host country health care systems. In addition, NCD-related complications are also more common and develop much earlier in South Asian communities than in Caucasians (Sivia 2011). In the aftermath of, often challenging and life changing, events like acute MI, patients are repeatedly advised to change their lifestyle behaviour whilst participating in secondary prevention programs such as in cardiac rehabilitation.

4.2. Secondary prevention Strategies – Cardiac Rehabilitation (CR)

There is no acknowledged cure for cardiovascular disease and the only method known to reduce and slow the disease progression is patient education, lifestyle modification along with

concordance with cardio-protective medicines. Therefore, after cardiac events such as myocardial infarction, patients are usually advised to change their lifestyles which mainly involves dietary changes, smoking cessation and increased physical activity levels. Literature iterates (Cole et al 2011, De Gucht et al 2013) changes made in physical activity, diet and smoking habits can alter the course of CHD and impede its progression and is associated with reduced cardiac mortality, cardiac readmissions and non-fatal re-infarctions. The synergystic effect of therapeutic lifestyle on patient outcomes in above areas has helped develop several evidence-based self-management approaches in CR programmes (Sivia 2011). Achieving such lifestyle change to minimise the CHD progression is a critical component of CR programmes (Davidson 2010).

However, addressing these lifestyle factors, including but not limited to attitude towards diet, exercise and life style, which is central to the control and management of CHD, are embedded and entrenched in ethnocultural practices as well as beliefs (Davidson 2010). Irrefutably, the receptivity and the capacity to make and maintain lifestyle choices are predisposed by a patient's beliefs and culture, for the choice to moderate behaviour is grounded in their unique culture. As such, it is important to emphasize that lifestyle interventions that focus on behaviour changes may not see desired outcomes; as behaviour changes may not necessarily be within individual control.

Therefore, despite the persuasive evidence surrounding the clinical outcomes of managing lifestyle modifications for people with CHD, many struggle to take up and maintain therapeutic lifestyles. As such policy recommendations are not fully transformed to better health outcomes as only 50% of patients comply with such guidance. For instance, merely a third of individuals experiencing a cardiac event such as heart attack, participate in CR (National Audit of Cardiac Rehabilitation 2010). Moreover, patients who make successful lifestyle changes initially, often revert back to old habits. For instance, approximately seventy five percent of those who quit smoking, return to smoking within a year (Hughes et al 2004) and fifty percent of dieters recover lost weight after a year (Curioni et al 2005), (Murray et al 2013).

Regardless of highlighting certain specific themes in the literature affecting the self-management needs of individuals (Galdas et al 2012), there is a paucity of appropriate support systems for self-management among population in general and South Asians in particular. However, appreciating the factors that enable or inhibit lifestyle self-management is critical in developing effective recommendations for lifestyle self-management. For this purpose, reviewing studies is important in understanding patients' perceptions of the barriers and enablers to modify these lifestyle changes.

4.3. Previous reviews – what do they elucidate?

Several reviews have been undertaken pertaining to different aspects of self-management, many of which targeting specific conditions such as diabetes (Deakin et al 2005) or mental health conditions (Duncun et al 2010), types of intervention such as lay-led programmes (Foster et al 2007) or on specific outcomes such as medicines adherence (Haynes et al 2008). These studies show people who engage in self-management tend to be predominantly white, Male, well-educated with good communication skills, believe in their own ability and control and efficiently utilise available support network. Thus existing self-management support services have tended to engage only a minority of population; with major 'knowledge gaps' remaining, especially around the challenges faced in making lifestyle changes.

Myriad literature have also provided in-depth survival descriptions and recovery experiences subsequent to an event such as MI (Emslie 2005), but relatively few focused upon the barriers encountered in modifying/making lifestyle changes. Earlier reviews on lifestyle changes have focused primarily on uptake or adherence to cardiac rehabilitation programmes (Jackson et al 2005), or on modifying the lifestyle prior to a cardiac event (Murray et al 2013). Less attention has been focused upon the barriers and enablers involved in the process of lifestyle self-management from the participant's perspective. This review proposes to address this 'knowledge gap' by answering the following research question: What are the barriers and enablers to lifestyle self-management among South Asians?

5. Review Relevance and Rationale

Self-management, whilst proven to successful in 'White' populations, is decidedly challenging for the South Asian patient (Sivia 2011). As such, there is a need for better appreciation and understanding of the factors that affect the self-management of South Asians, for the success and sustainability of lifestyle self-management among these groups. This understanding of influencing factors will help nurture a fertile patient-health professional relationship to develop an 'informed patient', so that self-management programmes can be effectively implemented and scaled up.

Though culture and ethnicity have a significant influence on lifestyle self-management, both remain poorly understood and addressed in CR programmes and services. Pointers towards the barriers to highlight on during 'motivational interviewing' and lifestyle consultations may help health care staff to refine their skills and knowledge leading to more effective client collaborations that can support therapeutic lifestyle changes. Little is known about barriers and enablers of lifestyle self-management among South Asians and to date, there is no comprehensive study which clarifies these factors. Consequently, this review attempts to fulfil dual needs – that of guiding health professionals in increasing the uptake (whilst referring patients for lifestyle support programs) as well as maximising retention (providing efficient and cost effective CR programs).

5.1. The timeliness of the review and its importance to NHS

Around 15 million people in the UK suffer from a NCD resulting in major challenges to the adequate delivery of health and social care services (Wanless 2002). There is a projected loss of approximately £16 billion of UK economy over the next ten years through premature deaths related to NCDs such as heart disease. Campaign for effective self-management is a core response of healthcare systems globally to tackle this challenge. The escalating liability of NCD is also an added impetus to the shift in health care delivery, with supported self-management a core platform for optimizing quality, effectiveness and efficiency of NCD care in the NHS (DoH 2012). The global financial crisis and central government pressure for major savings has meant that even greater focus is being placed on efficiency in health-care delivery.

Thus like most health systems, the NHS is seeking ways to increase efficiency through service redesign. With increasing prevalence of NCDs and the financial pressures facing the NHS in the coming years, offering existing NCD care and services as currently configured – 're-inventing the wheel' – will not be adequate if NHS services are to be sustainable in the future (DoH 2012). However, it is known that existing self-management support services have tended to engage only a minority of the population, with under-representation from black and ethnic minorities such as South Asians.

This review is needed now because though there is already evidence of poorer lifestyle self-management in South Asians, it remains unclear what are the influencing factors to this. In recent years, research into the management of illness has revealed that preventable risk factors, poor engagement in appropriate self-management and reluctance to access available health services justify for a high percentage of mortality and morbidity among South Asians. However, the moderating effect of the barriers and enablers that may have an influence on the lifestyle self-management programs in the NHS has been largely overlooked.

In England and Wales, an intense interest in support for self care, driven by a desire to reduce unscheduled care and improve patient outcomes, has contributed to a plethora of recent Department of Health (DoH) policies and initiatives including: annual National Self Care week (DoH 2010a) Quality, Innovation, Productivity and Prevention (QIPP) work-stream (DoH 2010b). NCDs is one of the priority QIPP work streams; the large scale transformational programme for the NHS that aims to deliver up to *twenty billion efficiency savings* by 2014-2015 (DoH 2012). Policies such as these mandate studies and reviews supporting self-management.

Supporting patients' ability to manage their own condition is the most crucial issue in the management of NCD because of the potential to improve health outcomes, help patients make better use of available NHS support and avoid interventions that are burdensome for patients and inefficient for the NHS (DoH 2012). For example, providing improved self-management support may allow patients to achieve the same or better outcomes, while potentially reducing expensive forms of health-care utilisation (such as hospital use). Delivered on a large scale,

such interventions could help NHS organisations attain productive redistribution of health care services (e.g. from hospital to the community) and potentially reduce the overall costs of care, without compromising on patient outcomes.

A new comprehensive review of the barriers and enablers is, therefore, timely and will allow existing and new data to be reanalysed with a specific focus on the development of relapse prevention programmes. The proposed review is designed to make a conceptual and empirical contribution to the evidence base on both self-management support and South Asian lifestyle modification. Outputs from the project will provide commissioners with clear guidance on lifestyle self-management support needs for South Asians with CHD. The results will help future service delivery and indicate whether NHS commissioners should focus on improving access and acceptability of interventions or look to develop relapse prevention programmes.

In short, this review can help develop an alternate approach, that is, use the knowledge and understanding of barriers and facilitators of South Asian lifestyle self-management to tailor support programs or pathways in a way available resources are more effectively harmonised to the needs of the South Asian community. Moreover, by systematically targeting individually perceived key barriers to healthy lifestyles can help form a barriers-based framework at the core of CR services and interventions (Murray et al 2012). Thus the proposed review will provide clear guidance that will help NHS decision-makers meet the QIPP efficiency targets. Through this review, one could inform the advance of culturally competent as well as culturally sensitive and culturally competent approaches that can be applied across disease models and areas of clinical practice in the NHS.

6 Review Methodology

6.1. Review Methods

The electronic database for medicine and related professions, Medline, currently holds just under 21,000,000 citations (PubMed 2011) and one more is added every minute. With such a large number of articles available it is unrealistic for practitioners, who may also not have the time or skill, to review them (The Cochrane Collaboration 2012). To reduce the burden on practitioners, publications of secondary research studies (called reviews) retrieve, screen, grade, and synthesise the articles and place the output into accessible formats (The Cochrane Collaboration 2012). The range of style, methodology, and even underpinning philosophy, has dictated that different approaches to reviews can be considered.

A systematic review poses a particular research question, then identifies, selects, evaluates, and synthesizes all the relevant high-quality primary research evidence it can find, and then uses this to answer that question (Popay et al 2005). Traditional systematic reviews are at their most efficient when used with meta-analysis to combine studies that focus on the same research question with the same intervention and the same outcome. When meta-analysis is not possible a narrative approach is used (Popay et al 2005) which is a broad outline of existing evidence. Although meta-analyses are essentially hypothesis testing and deductive, narrative reviews can test hypotheses, but also can be used inductively to build theory.

The outcomes of robust narrative and systematic reviews can be useful for evidence-based medicine. When carried out proficiently, these reviews provide a sound synthesis of current evidence of a declared standard and tend to come with recommendations for practice. It can be seen that either type of review has strengths and weaknesses. The rigour, transparency, and reproducibility of systematic reviews are valued, but the readability, lucidity, and multiple possible outcomes of narrative reviews are similarly appreciated (Popay et al 2005). Those that are not carried out well make a number of common mistakes, and it is the number, and combination of these mistakes that determines if these reviews are useful (Baumeister and Leary 1997). These mistakes include: inadequate coverage of the evidence; focusing on

preferred studies; poor critical appraisal of the material; lack of synthesis, with no ultimate conclusion; selective or partial review of the evidence; and finally presenting assertions as evidence (Baumeister and Leary 1997).

This review aims to synthesise information relating to the barriers and enablers of lifestyle self-management among South Asians. The primary scoping review highlighted the fact that cross-cultural studies could be few and those relatively few studies could be diverse in their foci as well as methodological approaches such that a meta-synthesis or meta-analysis may not be possible. Therefore a narrative review is presented here, an approach expedient in keeping health care professionals conversant on current health care issues, by providing a comprehensive summary of current evidence.

6.2. Review Aim:

Aim: The aim of this current review is to gather evidence of the enablers and barriers of lifestyle self-management from the peer-reviewed literature with an objective to identify, appraise and synthesise research evidence on the barriers and facilitators to lifestyle self-management after a coronary event among South Asians. The review aims to elucidate the main patient perceived factors that influence the continuity of a therapeutic lifestyles or act as barriers/facilitators to the uptake and retention of lifestyle changes/support programmes.

6.3. Review Question:

1. What are the influencing factors – enablers and barriers- faced by South Asians regarding lifestyle self-management post MI?

7. The Search Strategy

7.1. Criteria for Study Inclusion

The review will includequalitative observational studies as well as reviews related to lifestyle behaviours (diet, physical activity/exercise, smoking). Study participants who are adults (≥18 years) who experienced angina, myocardial infarction or living with coronary artery disease.

Studies should focus on participants who have made attempts to successfully or unsuccessfully make changes to their lifestyle, after a cardiac event. This timeframe is chosen because it corresponded to an upsurge in the discourse on self-management.

Table 1: Inclusion Criteria
1. Published after 1990
2. Participants aged 18 and older diagnosed with CHD
6. Ethnic minority population should include any group of South Asians
7. Be in any language, but English translation should be available.
8. Quantitative and qualitative studies will be included.

7.2. Studies to be excluded

Studies that publish data on lifestyle modification experience but did not include participants from South Asian community or where the results of South Asian participants were not available separately, will be excluded from the review. Studies in Non English texts where the English translation is not available will be excluded. Studies that investigate adherence or concordance with medication, studies that focus on selected populations such as mental health service users or other self-management such as alcohol consummation (perhaps these are

distinct bodies of research or considered as a group with specific needs such that their inclusion may result in an unwieldy report), will be excluded.

Inclusion and exclusion criteria will be applied in succession to (1) titles and abstracts (2) full text. The full text will be retrieved for those studies that meet the inclusion criteria and also when there is inadequate evidence to make an informed decision. The inclusion/exclusion criteria will be reviewed to ensure capturing of all possible research for the review and to test the applicability of the keywords. Any changes to this criteria as well as the rationale for the changes will be documented in the full review report to enhance the credibility of the review.

7.3. **Country of Research Focus:** Global

7.4. **Language of the studies**

The language of the reviewed studies will be predominately English, but those that has been translated into English and as such whereby English summaries are available, these will be included in the review. Since translation of studies is not possible due to financial and time constraints, translation of Non-English papers will not be undertaken but all non-English studies will be listed in the appendix.

7.5. **Interventions**

The key interventions of interest include: lifestyle self-management programmes – concerned with healthy eating, physical activity and smoking cessation.

7.6. **Search Strategy**

Database Search Terms, words and phrases: A range of search terms for self-management and long-term conditions developed by the Centre for Reviews and Dissemination (CRD) and scrutinised by University of Salford Academic Librarian.

Population Terms	ethnic* immigra* south asian indo* minorit* racial india* sikh* muslim*, moslim islam* pakistan* gujarat*, gujerat* sri lanka* bangladesh*

	ethno-cultural, ethno cultural panjabi*, punjabi* Indian sub-continent - Gujarat*, Bengal*, Asia, western; India; Bangladesh*; Gujaret*; Pakistan*; Asian*; south* Indian*; Punjab*; Urdu*; Hindi*; Hindu*; ethnic minorities; ethnic minority groups; human*black and ethnic minorities, BME communities.
Disease Terms	chronic disease, coronary ischemic* myocardi* infarct* "heart attack"; "myocardial infarction"; coronary heart disease; "cardiac infarction", CHD
Lifestyle/behaviour	obes*smok* tobacco us* alcohol*barrier*cultural barrier* diet* nutri* food* eat* tradition* prepar* cook* cuisine* physical activit* inactiv* fitness vegetarian lifestyle, life style factor*belief* religious attitude* knowledge self-efficacy* practice* habit*exercise
Intervention/Practice Terms	self manag*, self-manag* self care, self-care self manag* model self-care model* self-care model* prevent* promot* educat* policy interven*behaviour* behavior*empower* skill* community development community interven* disease management treatment* care plan* structured lifestyle modification*language and barrier*; communication barriers cardiac rehabilitation"; enablers; cardiac rehabilitation, secondary prevention,

The above search strategy will be followed and adapted to the search requirements of each individual database, such that the keywords will be customised to the specific database, its subject headings and thesaurus terms. The search terms will be used in all possible combinations. The terminology will be different for each database, but the terms chosen will reflect the following concepts:

7.7. **Keyword terms**

'Lifestyle', 'self-management', 'cardiac rehabilitation', 'myocardial infarction', 'heart disease', 'ischemic heart disease', 'secondary prevention', 'coronary heart disease', compliance', 'adherence', 'barriers' and 'uptake'. These search terms will later be combined with the keywords 'South Asian', 'Pakistan', 'Bangladesh', 'India' and 'ethnic minority'.

* Specialist systematic review databases: • DARE • Cochrane Library Electronic databases

* Specialist Health care and Social Science databases: • EBSCO • MEDLINE • CINAHL • EMBASE • PubMed • Web of Knowledge • PsycINFO • NHS evidence • Health Resource • BNI

* Interdisciplinary databases - Academic Search Premier, ProQuest Dissertations, Theses, Ethos.

* Reference on the following sites: • National Audit for Cardiac Rehabilitation • British Association for cardiac rehabilitation • NICE cardiac rehabilitation • European Society of Cardiology

* Hand search key journal: • HEART • Circulation • International Journal of coronary nursing, European Journal of Cardiology.

* Other Literature Sources: • Google Scholar - A search using Google Scholar will be conducted using advanced search (limits will be set to .doc, .pdf for documents and .xls and .csv for any possible datasets). Google search terms: myocardial infarction, heart attack, heart failure, cardiac rehabilitation, South Asians, South Indians, Gujaratis, Bangladeshi, Pakistani, Punjabi.

To ensure added breadth to the review, the reference lists of all collated studies will be scanned for significant articles and other relevant documents or studies to determine if the cited works are pertinent to the topic. Experts in the field will be contacted but no grey literature such as unpublished data will be used. Citation tracking will be explored.

All literature searches will be stored in the EndNote X7 17.0.1.9257 library, with separate EN libraries for each online searches (for auditing purposes) with all duplicates removed.

8. Data Extraction

The main reviewer will initially apply the inclusion and exclusion criteria to titles and abstracts. The supervisor will then screen excluded studies to confirm no valid studies are, perchance, left out of the review. Deviations will be resolved through discussion and arbitration between the supervisor and reviewer.

The studies' and key findings will be extracted and organised into a review matrix by the main reviewer. Data will be extracted by the main reviewer with input from the supervisor. The data extraction forms will be piloted on 10 initial papers and modified as required before use. All modifications and rationale for this will be presented in the report. In case of any missing information or if further clarification is needed, the authors will be contacted.

A coding tool will be used to screen the studies collated. Notes will then be compared and any differences resolved in the coding responses through discussion (with the supervisor) for each study.

The findings will be then distilled into themes by the main reviewer. Consensus will be reached between the reviewer and the supervisor on the best way to characterise, present and interpret the themes apparent in the literature. Any incongruities about the thematic representation or interpretation of the key findings will be solved by arbitration and discussion with supervisors.. A summary table of each study as well as an overall summary table will be constructed to highlight the barriers and enablers.

9. Data Synthesis

As the studies identified and collated is expected to be of a diverse nature, a narrative synthesis will be employed. The results will be discussed and tabulated in a way that demonstrates the methodological robustness of each study. The discussion of the findings will initially be scrutinised by the supervisors who will then feedback with comments.

10. Strategy for quality assessment

The review will follow the guidelines of UK DFID, Cochrane Collaboration (Higgins and Green 2011) and NHS CRD standards. The review protocol proposing the search string, inclusion and exclusion criteria will all be scrutinised and discussed initially with the supervisors prior to finalising them. Any modifications or amendments will be noted and a rationale for this will be reported in the final report. Included studies will be quality assessed using Moher et al (2010) for experimental studies and the Critical Appraisal Skills Programme for qualitative studies.

Full text screening of studies, the coding as well as the quality assessment of the accepted papers for review will be conducted by the main reviewer with the support and supervision of academic supervisors.

11. Dissemination/Communication Plan:

Supervisor advice on the most effective methods of presenting information to inform patients and professionals will be sought as well as how to make the most effective use of social media.

At a local level, an attempt will be made to alert clinical commissioning groups in the NHS North of England cluster, to establish a dialogue, inform them of the study and its relevance and stimulate potential demand. Providing opportunities for direct interaction between

researcher and their audience has been shown to positively affect the likelihood of research utilisation of stakeholders.

It is also hoped to arrange presentations and develop appropriate educational materials/sessions as well as user-friendly summaries containing evidence-based actionable messages for broader public and patient audiences such as Cardiac Support Group to facilitate shared understanding of the priorities and actions arising from the findings.

The main reviewer will also seek to publish extensively in conventional academic journals and appropriate University locations, and via social media such as Twitter and Facebook. The reviewer will ensure that the main systematic review is delivered to a standard that will enable it to be abstracted by the Database of Abstracts of Reviews of Effects.

Conflict of Interest: None Known.

Funding Sources: University of Salford.

Plans for Updating the Review: The review will be updated after a period of 36 months or once a significant amount of new primary studies is available.

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