Final Report

Mobilising the Scottish South Asian communities in the prevention of cardiovascular diseases and diabetes: developing a South Asian Cardiovascular Diseases and Diabetes Task Force (Pilot project)

February 2015 – March 2016

To

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By

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On behalf of the

South Asian Cardiovascular Diseases and Diabetes Task Force members

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1. Summary

By international standards Scotland has a high burden of cardiovascular diseases and diabetes. South Asian populations living in Scotland, especially those in the Pakistani ethnic group, are at even greater risk than the population as a whole. A multidisciplinary, multi-agency research grant proposal submitted to NIHR in 2013, proposed the idea of setting up a South Asian Community Cardiovascular Disease and Diabetes Task Force (the intervention, henceforth Task Force) to tackle the high levels of cardiovascular disease and diabetes in the South Asian populations in Scotland and then evaluating its work. The feedback advised that evidence was required to show that forming such a Task Force was feasible and that working with minority ethnic communities in partnership with researchers, health service and policy makers and third sector organisations was achievable. This report provides that evidence.

Funding of £10K for one year allowed the University of Edinburgh and REACH Community Health Project, Glasgow to coordinate the process of inviting a wide range of organisations and individuals to join the preliminary Task Force, arrange and facilitate 4 Task Force meetings between June 2015 and March 2016, and draft an action plan for a future Task Force to take forward. The four Task Force meetings were complemented with 6 tele-conference meetings between the University of Edinburgh (UoE) & REACH team members, who were coordinating the Task Force from the inception and initiated the formation of the group. Furthermore, there were a number of one-to-one meetings between the UoE/REACH team members and key community individuals, including with representatives from the ethnic minority catering industry to seek their commitment and contribution into the Task Force.

34 people agreed to join the preliminary Task Force and on average about 15-20 attended the meetings. There was overall enthusiasm for the Task Force approach, high levels of participation during meetings and general agreement on the outputs generated.
A Diabetes and Cardiovascular Disease Action Plan for mobilising the South Asian communities in Scotland has been developed collectively by community representatives and organisations, health professionals, policy makers and university researchers. The Task Force and the action plan fit the Scottish Government's current health inequality and health improvement strategies.

Task Force members supported the proposal to seek further funding to continue to develop and implement the action plan over the next 3 years and to seek additional research funding to evaluate the interventions in the action plan.

2. Background

The Scottish population has, by international standards, high rates of cardiovascular diseases (CVD), both coronary heart disease and stroke, and of type 2 diabetes mellitus (DM) and Scotland's health strategy aims to resolve this.[1] (Henceforth, these disorders together will be abbreviated as CVDDM.) It is surprising, and concerning, that the South Asian ethnic groups in Scotland, comprising mostly of people of Pakistani and Indian origins, have substantially higher rates of CVDDM (3-4 times higher for diabetes) compared to the White Scottish population.[2;3] Moreover, cardiovascular disease rates are much higher than in the Scottish Chinese population, which has a similar or lower socio-economic position, meaning that the phenomenon is not simply a result of either migration-specific or economic factors.[3] Some relevant statistics from the Scottish Health and Ethnicity Linkage Study (SHELS) are given in Table 1. These recent findings add to a substantial and reliable body of evidence from across the world, in particular England[4] and other European countries,[5] that South Asian populations are at high risk, even though they may have been born in Indian subcontinent villages and towns that traditionally (and sometimes even now) do not by international standards have high rates of CVDDM. While little is known about the risk of these diseases in young South Asians in Scotland, research in England suggests their future risk is likely to be high.[6] As Table 1 shows the relative excess in cardiovascular diseases is seen particularly in Pakistani populations, both in men and women. This project, in the long term, aims to tackle this problem through a novel alliance of academics, NHS, local government and South Asian organisations/groups and individuals. This alliance will be called the South Asian Cardiovascular Disease and Diabetes Task Force (henceforth SACVDDM or simply Task Force). This Task Force is the central intervention to be developed and evaluated. This report concerns the development of the Task Force.

Table 1 – Some recent Scottish data on CVD (SHELS data, age 30+ yrs) and Diabetes (DARTS data, all ages)

Outcome		White Scottish	Indian	Pakistani	South Asian Combined**
Diabetes mellitus: age standardised prevalence (%) in Tayside, Scotland[2]	M	3%	-	-	10.5%
	F	2.4%	-	-	9.8%
Chest pain hospitalisation or death: age standardised incidence rate ratio[3]	M	100	141.2*	216.2*	-
	F	100	148.6*	243.0*	-
Angina hospitalisation or death: age standardised incidence rate ratio [3]	M	100	110.3	189.3*	-
	F	100	106.4	159.7*	-
Myocardial infarction hospitalisation or death: age standardised incidence rate ratio [7]	M	100	121.2	142.4*	-
	F	100	123.5	129.3*	-
Stroke hospitalisation or death: age standardised incidence rate ratio [7]	M	100	104.8	120.5	-
	F	100	76.5	107.1	-

*The 95% confidence interval excludes 100, the reference value.
**South Asians were identified by name analysis, which is not good at disaggregating subgroups.

Given Scotland's strong emphasis on improving the health of the population while tackling inequalities and inequities in health and health-care, such differences need action. This Task Force is unique in Scotland with a diverse participation of stakeholders and the approach developed here, with strong emphasis on partnerships especially with the community, sits extremely well

with laws and policies including the Equality Act 2010, The Community Empowerment Act 2015, and the Race Equality Framework for Scotland 2016 to 2030. Some of Scotland's legal and policy documents relevant to the proposed Task Force are listed in Box 1.

In 2013 a project to mobilise the Scottish South Asian communities to prevent heart disease and diabetes through a Task Force was developed by a collaboration of researchers, practitioners and community groups (led by Bhopal as proposed PI). The key idea was to set up a Task Force to tackle the long-standing problem of extremely high rates of diabetes, heart disease and stroke in South Asians. The Task Force was envisaged to comprise a partnership of the communities, service sector, university researchers and policy makers. The concept of a Task Force that would aim to stimulate change in South Asian communities gained much support from those the idea was discussed with originally. The proposal was submitted to the National Institute for Health Research (NIHR) which did not fund it but provided important feedback. The most important feedback was that no intervention existed yet. The intervention proposed was the Task Force so this criticism was correct. The second was that the proposal did not draw on direct evidence of working with minority ethnic communities. While the proposers had worked with ethnic minority communities generally, they had not done so directly in relation to this project. This pilot work was done to address these two major criticisms. We now report on whether the Task Force idea is feasible and whether a cogent action plan could be prepared in this collaborative way.

Box 1. Scotland's legal and policy documents relevant to the Task Force

Equality act 2010	http://www.healthscotland.com/equalities/equalityact.aspx#act
The Community Empowerment Act 2015	http://www.gov.scot/Topics/People/engage/CommEmpowerBill
Race Equality Framework for Scotland 2016 to 2030	http://www.gov.scot/Publications/2016/03/4084
Health & Social Care Alliance Scotland National Link Workers Programme	http://www.alliance-scotland.org.uk/what-we-do/our-work/primary-care/national-links-worker-programme/
Health Literacy Action Plan for Scotland	http://www.gov.scot/Topics/Health/Support-Social-Care/Health-Literacy
Scottish Government National Outcomes ('longer, healthier lives'/'tackle the significant inequalities in Scottish society')	http://www.gov.scot/About/Performance/scotPerforms/outcomes

3. Aims and outcomes of the preliminary Task Force

This pilot work was set up as a collaboration between University of Edinburgh and REACH Community Health project, Glasgow. Funding of £5K was provided by Scottish Government and matched by £5K from University of Edinburgh funds. This permitted a central resource to co-ordinate the process to bring people together, administer the meetings and drive the work forwards.

Main aims of the preliminary task Force were:

1. To identify individuals and organisations that could play an important part in either helping fund, support, serve in, or implement the recommendations of the intended Task Force.

2**.** To identify core partners and a potential chairperson for the Task Force.

Outcome: a. A database of potential partners.
b. Identification of potential chairpersons.

3. To set up at least three meetings of a preliminary Task Force during 2015/2016.
These meetings will discuss and offer guidance on:

i. The dimension, causes, and consequences of the high levels of heart disease and diabetes in South Asians in Scotland.
ii. What actions are required to reduce these levels and improve prevention.
iii. The value, principles and likely success of the proposed mobilising the community approach.
iv. The best way for the Task Force to work with the diverse South Asian populations in Scotland.
v. The composition and framework of a future Task Force.
vi. What resources would be needed to maintain the Task Force infrastructure over a 3 year period, and where they might come from.

Outcome:
a. A draft work agenda for a future Task Force.
b. An action plan to mobilise South Asian communities in the prevention of diabetes and heart disease.

3.1 Aims of the future Task Force

(See appendix 3 for full details).

- Work with Scottish South Asians to improve understanding of the causes and consequences of cardiovascular diseases and diabetes and to implement community-based interventions which may bring about lifestyle changes to a) prevent and b) improve management, of these diseases.
- Provide added value to Scottish Government and NHS policies and initiatives aimed at reducing health inequalities particularly within the South Asian communities in Scotland.

4. Report on achievements

4.1 Preliminary Task Force membership and meetings

We contacted a wide range of individuals and organisations to ask for volunteers to sit on the Task Force. A letter of invitation and a summary of the key issues were circulated to relevant professionals, services, and groups. The majority responded positively. 34 people were identified initially and agreed to join the task force (see appendix 1). Four meetings were held between June 2015 and March 2016. 30 people attended at least one meeting and participation was very constructive and enthusiastic. Main foci of the four meetings were:

1. Review of current understanding of cardiovascular disease and diabetes including what has already been tried to address the problem in particular in the South Asian population.
2. Examples of past and current interventions and initiatives. Development of a set of community based strategies which may bring about the desired change and how these could change people's behaviour.
3. Development of appropriate messages and methods to deliver messages to the communities to encourage community participation in the Task Force's suggested interventions. Discussion of the

likely success of the proposed mobilising the community approach. Incorporation of the discussions into a draft Task Force action plan.
4. Sign off the report on the work of the Preliminary Task Force and the action plan for a future Task Force. Discuss potential sources of funding to continue the Task Force.

4.2 Key points to successful achievement of setting up the Task Force
The existing working collaboration between the University of Edinburgh researchers and REACH provided the base for inviting a wide range of organisations and individuals to join the Task Force. Appropriate documents were drafted describing the aims and objectives for the pilot work. There seemed to be general enthusiasm about the idea of a Task Force and for the proposed community mobilising approach.

In addition to the immediate work of the preliminary Task Force there were other developments of informal links and networks, which may lead to further collaboration and new initiatives to tackle the problems of heart disease and diabetes in the South Asian population.

4.2.1 Weaknesses identified
One area which was not so successful was obtaining active participation from the business sector such as South Asian caterers and restaurants, even although several people and organisations showed strong interest and support in principle. Our discussions and engagements with several South Asian catering business representatives make us believe strongly that their participation into a future task force can be achieved. We need to invest a little more time to engage with them and sustaining the Task Force for a few more years will certainly help in this process.
We have still to identify a community co-chair for the Task Force. Our suggestion for the future Task Force would be to identify someone – not necessarily a current Task Force member - who would be interested and could be offered some training and support to take on the role.

4.3 Drafting an Action plan
We collaborated with research colleagues from Australia who have carried out similar community mobilisation work albeit on a different health area. They provided valuable input to the process for developing a Task Force action plan, principles for implementing the plan and its evaluation and identifying appropriate outcomes. This resulted in an action plan template as a basis for the Task Force to develop and adapt for its aims.

At the Task Force meetings members formed small groups to develop and discuss the content of the proposed action plan. The interaction between health and government professionals, researchers, third sector organisations and community representatives resulted in pertinent and sometimes novel ideas and suggestions, but also re-enforcement of existing approaches, and understanding of barriers and interventions. Interestingly, the individual sub-groups' outputs often followed similar themes and messages.

The Task Force meetings allowed ideas for the action plan to be developed collectively avoiding a 'top down' approach. This resulted in the components of the plan being broadly based and focusing on a wide range of behaviour change targets.

The Task Force as a whole was in agreement about the considerable scale of the challenge to engage the communities and achieve behaviour change. Consensus was obtained for the components of the final action plan from all active members of the group (see Appendix 3).

4.4 Framework for a Future Task Force

4.4.1 Purpose and remit

There was agreement that a future Task Force would provide a multidisciplinary, multi-ethnic platform to work alongside and contribute to, local and national level organisations and initiatives aiming to reduce health inequalities. The diverse membership with a wide range of skills could provide added value to current structures to focus on reducing the burden of heart disease and diabetes in South Asian populations in Scotland.

4.4.2 Resources required

The Task Force agreed that the community mobilisation approach had merit and that further funding should be sought in order to continue this work. The majority of current members expressed agreement to continue their involvement with the proposed future Task Force. The consensus was that funds for 3 years would allow the Task Force to achieve its goals and evaluate the impact of the interventions. To allow representatives from 3rd sector and voluntary organisations to participate consistently and sustainably in the Task Force, funding will be required to cover costs of their time.

4.4.3 Draft work agenda identified by the Task Force

Some of the prioritised actions agreed were:
1) Secure the modest resources to continue the work of the Task Force, especially moving forward with the action plan in appendix 3 and figure 1.

2) The development of a certificated course to train people as community champions/ambassadors on diabetes and CVD prevention.

3) To produce an updated directory of relevant services, groups, activities and materials for diabetes/CVD prevention. A Facebook page could provide a platform for this information and link to existing websites and resources such as the The Health and Social Care Alliance Scotland's ALISS digital information service (A Local Information Support System) and specific health related information eg Diabetes UK, South Asian Health Foundation, BHF and Chest Heart & Stroke.

4) Identify a range of specific, relevant and achievable outputs which could demonstrate progress towards improving equality in the Scottish population and helping South Asians live longer, healthier lives. These would align to Scottish Government's national outcomes as described in http://www.gov.scot/About/Performance/scotPerforms/outcomes.

5) Seek research grant funding to work with research colleagues to carry out and evaluate the interventions in the action plan as part of a research project (as in the application to NIHR mentioned in the background). In practice, this means rewriting the original grant application. We have identified that NIHR are specifically seeking applications which involve communities and evaluate the effectiveness and costs of the approach. We feel confident that a revised proposal would be much stronger than the one submitted in 2013, which was, even then, supported by most of the referees who examined it.

5. Conclusions

Task Force Members represented a multi-ethnic, multi-disciplinary community and a wide range of government, academic, health service and third sector organisations plus community representatives. It proved difficult to obtain active participation from business such as retail and catering/restaurant etc although there was strong verbal support from those we contacted. Meetings were relatively well attended and all present contributed constructively and enthusiastically. The resulting Diabetes and Cardiovascular Disease Action Plan was developed collectively by a diverse group representing those working with, and providing services for, the South Asian populations in Scotland. The Task Force and the proposed action plan interventions are very pertinent to the Scottish Government's current health inequality and health improvement strategies and could complement initiatives such as the primary care Link Worker programme.

Members agreed that the Task Force approach has shown its value, that its core goals are achievable and fundable and that it should seek appropriate funding to continue. The successful development and delivery of the pilot Task Force with a diverse membership testifies to the importance of a complementary collaborative partnership work between a third sector organisation (REACH Community Health Project) and an academic institute (University of Edinburgh).

The most important result of this work is to demonstrate, in response to feedback from NIHR, that setting up a Task Force of the kind we had envisaged is feasible and that working in partnership with the communities is achievable. We hope this report will be the basis of a discussion of funding. Having set the Task Force up, we could now continue to develop it with £10,000 per year over 3 years i.e. £30K in total. If this can be achieved, we will return to NIHR with a revised research grant application. Generally, NIHR funded the research components but expects other organisations to fund the intervention itself. Given our experience, the new grant application will be less onerous and possibly less costly than the original one. The case will also be stronger given new published research on the burden of the problem of cardiovascular disease and diabetes in South Asians in Scotland, including experience on approaches to behaviour change in a recent randomised controlled trial (PODOSA) on the prevention of diabetes.[8]

Acknowledgements
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Appendix 1 Membership of the SA CVD and Diabetes Preliminary Task Force

Members listed below attended at least one Task Force meeting

Organisation	Name
University of Edinburgh	Raj Bhopal, Prof of Public health Anne Douglas, Graham Baker, Tasneem Irshad, Research fellows Dr. Marisa De Andrade, Lecturer, Health in Social Science Dr. Juneda Sarfraz, PhD student
Reach Community Health Project	Shabir Banday, Director Padam Singh, Training & Development Officer
NHS Lothian	Mandy MacKinnon, CHP Health Inequalities Smita Grant, CHP Health Inequalities
NHS Greater Glasgow & Clyde	Nicola Fullarton, South Glasgow Health Improvement Team Dr. Nazim Ghouri, Diabetes clinician Uzma Rehman, Public Health Programme Manager (Child & Maternal Health Prof Naveed Sattar, Prof Metabolic Medicine
NHS Heath Scotland	Bill Gray, NHS Heath Scotland/Community food & health Programme Drew Millard, Equalities Intelligence
Scottish Health Council	Gary McGrow, Research officer
Scottish Government	Naureen Ahmed, Public Health Policy
Glasgow City Council	Adam Khan, Social Work
Culture & Sport Glasgow	Harminder Berman, Glasgow Life
Edinburgh & Lothians Regional Equality Council	Mizan Rahman Equality Engagement Officer
Diabetes Scotland	Prajapa Senevirantne, Saqib Abbasi
Dundee International Women's Centre	Fatima Rahman, Vaqar Salimi
West of Scotland Regional Equality Council	Mohammed Razaq, Executive Director
Muslim Council of Scotland	Dr M Adrees, Physician
East Dunbartonshire Council	Manjinder Shergill, Councillor
Glasgow Gurdwara	Sukcharn Kaur
REACH Community Health Project	Shamas Yusaf, Community volunteer
Multicultural Elderly day care centre	Shahida Zafar
Community Members	Kartar Singh Virhia, Dr. Zubeida Akhter Haq

Other organisations expressing support for the Task Force

Organisation
The South Asian Health Foundation
Paths For All
Perth & Kinross Association of Voluntary Service, Minority Communities Hub (MEAD)
Muslim Council for Scotland
NHS Lanarkshire Director of Public health
Edinburgh Sikh gurdwara
South Asian restaurant and catering trade
NHS Greater Glasgow community dietetics service
NHS Lothian Diabetes services

Appendix 2

Costs of the Task Force pilot work

A small budget of £10,000 (£5000 from Scottish Government and £5000 from the University of Edinburgh) was secured. Travel expenses for attending Task Force meetings were reimbursed and, as far as possible, other reasonable costs to allow community representatives to attend.

Budget: £10,000

Expenditure from March 2015 to end Mar 2016

- Meetings (4): 792.00
- Travel expenses for meetings: 558.88
- University of Edinburgh Salary and REACH budget: 8014.76
- Other general costs: 500

Total: £9865.64

Balance remaining: £134.36

Appendix 3. Action plan

Mobilising the Scottish South Asian communities in the prevention of cardiovascular diseases and diabetes. A South Asian Cardiovascular Diseases and Diabetes Task Force Action Plan

The preliminary Task Force developed and agreed the aims, process and model for an action plan to be delivered by a future Task Force.

Aims of the future Task Force

- Help Scottish South Asians understand the causes and consequences of the epidemic of cardiovascular diseases and diabetes in South Asians in Scotland.
- Advise South Asian communities on how to develop & implement community-based strategies and interventions which may bring about lifestyle changes to improve treatment and management of, and also for preventing, these diseases.
- Connect into, and provide added value to, current and future Scottish Government and NHS policies and initiatives aimed at reducing health inequalities particularly within the South Asian communities in Scotland (such as the Primary Care Link Worker programme, the Community Health Exchange Network (CHEX) and the Government's Health Literacy Action Plan for Scotland).
- Help evaluate the principles, value and success of the proposed 'mobilising the community' approach.

Actions towards achieving the aims above

1. Seek funding to continue the Task Force as a partnership between the community representatives, community organisations, health and statutory services and researchers over a 3 year period.
2. Monitor and adjust (if necessary) the current Task Force membership.
3. Prepare a communications plan.
4. Develop detailed proposals for:
   - The composition and framework (eg specifying roles of TF members) of the Task Force.
   - The role of the Task Force eg
     -co-ordinate the messages to be disseminated and the actions to be implemented
     -create consistent messages
     -catalyse the Task Force's action plan to facilitate the implementation of the proposed interventions
     -influence existing structures and future developments to ensure that issues relating to ethnic health inequalities are raised, incorporated and addressed.

   - A certified course (existing or new) for health/link workers for CVD/diabetes. Have a similar course for community champions. Aim for 100 trained people.
   - Create a platform, possibly using social media such as Facebook, to host information on, and links to relevant services, groups, activities and materials for diabetes/CVD prevention.
5. Catalyse the revision and resubmission of a grant application to implement the interventions and, as part of a research agenda, evaluate the effectiveness of the Task Force intervention plan.

Principles of the interventions in the action plan

Intervention activities need to be standardised along with the core intervention components, even though the specific activities themselves will differ across communities. The standardised principles might include:

- Multiple intervention activities should be implemented simultaneously, because diabetes and heart disease are complex health problems.
- Active engagement of local businesses, local media, key stakeholders, professional and statutory services, and community members in delivering intervention activities.
- Each community has to implement the same set of core intervention components (to make the intervention standardised), although the approach and actual activities that give effect to each core component will differ across communities (to ensure the intervention is appropriately targeted, tailored and accessible).
- Intervention components must be suitable for evaluation and subsequently evaluated.

Design of the intervention

Figure 1 outlines the area of need, core components, and gives examples of potential intervention activities within each core component

Use targeted, consistent, powerful and empowering positive messages using '4 more of/3 less of' approach. A visual rather than written approach may work best. eg

4 'more' of:

Physical activity
Fruit & vegetable consumption
Uptake of health checks and adherence to treatment plans
Family & friends time

3 'less' of:

Smoking & alcohol
Sugar & saturated fat
Sitting time

Figure 1: **Task Force action plan model**

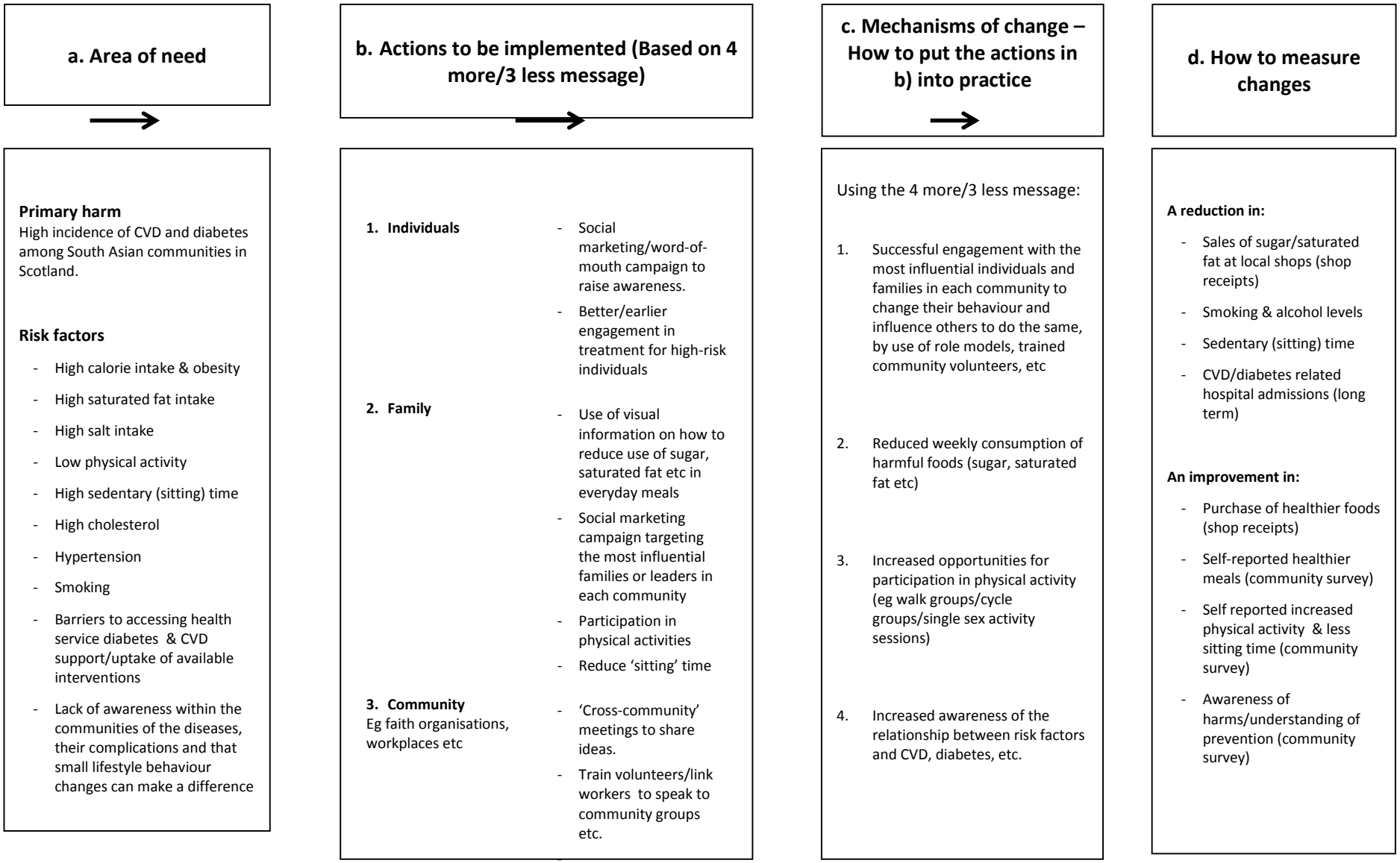
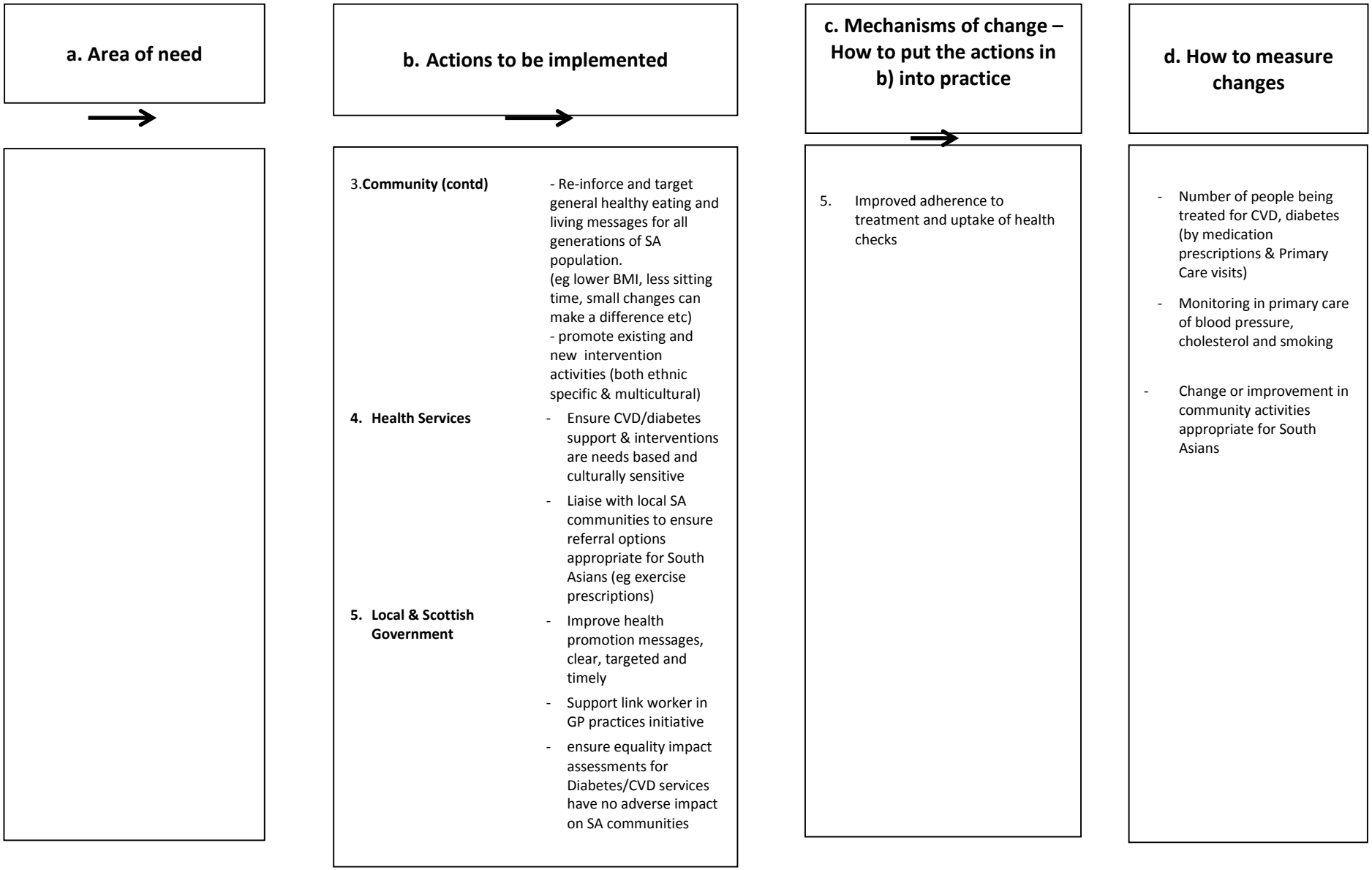


Figure 1: contd **Task Force action plan model**



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