NIHR Applied Research Collaboration East Midlands





THE MULTI-ETHNIC LIFESTYLE STUDY QUESTIONNAIRE BOOKLET

- Please read the attached participant information sheet V2. 21/05/2019 before deciding whether or not to take part. Once you have decided that you would like to take part, remove the participant information sheet and keep for your reference.
- Turn over and complete the consent form and questionnaire. Once completed, detach the consent form from the questionnaire.
- Place the consent form in **BOX A** and questionnaire in **BOX B** which you will find on the reception desk in your clinic/surgery.

Principal Investigator: Professor Kamlesh Khunti

INCLUSION CRITERIA

- ✓ Aged 18 years or over.
- ✓ Ability to read and understand English.
- ✓ Has not already completed the questionnaire.
- ✓ Able and willing to complete questionnaire.
- **①** If you **<u>do not</u>** meet the above inclusion criteria, please hand this booklet back to reception.

Thank you for your time.

If you do meet the above inclusion criteria, please continue to complete this booklet >



The clustering of lifestyle behaviours in a multi-ethnic population: A questionnaire study

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study but before you decide whether to take part, it is important that you understand why the research is being carried out and what it will involve. This document is designed to help you decide whether you would like to participate. If anything is unclear or you would like more information, please contact a member of the research team whose details are included at the end of this information sheet.

What is the purpose of the study?

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We know that people with particular lifestyle behaviours, including level of physical activity and diet, can be linked with a higher chance of developing long term conditions including high blood pressure, diabetes and heart disease. We would like to ask people across Leicestershire about some of their lifestyle behaviours to find out the extent to which they may raise the chances of disease, both now and in the future. We would also like to know the effects that living/working in different geographical areas may affect lifestyle habits and risk of disease. We would also like to know how COVID-19 may have changed these behaviours.

Who are we looking for?

We would like adults 18 years old and above, either with or without long term health conditions to take part.

What happens if I decide to take part?

If you decide to take part, the study involves filling in one questionnaire which will take approximately 10 minutes to complete. You will also be asked if we can link the answers in the questionnaire to information held in your hospital and GP records (this is optional).

Who is organising and funding the research?

The study is being organised and coordinated by the University of Leicester and it is being led by Professor Kamlesh Khunti at the Leicester Diabetes Centre.

Do I have to take part?

It is your right to decide whether or not you would like to take part in this study. Your future medical care will not be affected whether you take part or not.

What are the possible benefits of taking part?

You will not directly benefit from taking part in the study. However in addition to helping advance medical and scientific knowledge, if you are happy for us to do so, you may be invited for future research opportunities which may include health education programmes or new treatment options or to take part in focus groups to discuss your experiences of certain health conditions.

Are there any risks in participating?

The main risk posed is the burden of time to complete the questionnaire, to minimise this burden the questionnaire has been kept as short as possible. There is an additional risk that you may be distressed by questions asked within the questionnaire booklet, however the questionnaire has been designed to avoid intrusive or distressing questions where possible, and you are free to withdraw from participation at any time should you feel distressed.

Will my GP be informed?

If you are willing to allow us to link the answers to your questionnaire to information held in your medical record we will notify your GP as they may need to help us access information held at your practice.

Will my taking part in this study be kept confidential?

University of Leicester is the sponsor for this study. If you agree we will be using information from you and your hospital and GP records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Leicester Diabetes Centre will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Leicester Diabetes Centre will collect information from you and your hospital and GP records for this research study if you consent to this. Leicester Diabetes Centre will keep your name, and contact details confidential and will not pass this information to the sponsor. Leicester Diabetes Centre will use this information as needed, to contact you about the research study and to oversee the quality of the study. Certain individuals from University of Leicester and regulatory organisations may look at your hospital, GP and research records to check the accuracy of the research study. University of Leicester will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

When you agree to take part in a research study, the information about your health and care may be provided in an anonymised form to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

You can find out more about how we use your information by contacting the study team.

If I take part, can I change my mind?

You can change your mind about the following for any reason and will not be asked to explain your reasons:

- 1. Allowing us to use the information you provided on the questionnaire
- A. If you contact us to withdraw your questionnaire data from the research before we have analysed it, then we can remove your information, but only if you provided your personal details when you completed the questionnaire.
- 2. Allowing us to link the information you provided to your medical records
- A. If you change your mind about allowing us to link to your medical records, you can choose whether to still allow us to use the information you provided on the questionnaire. If we have already obtained data from your medical record and analysed it, we will not be able to remove your data.
- 3. Allowing us to contact you about future research
- A. You can withdraw consent to being contacted about future research at any time.

What will happen to the results of the study?

The research will be coded (for anonymity) and analysed by the research team before being reported in research reports. The results may also be presented in appropriate scientific journals and conferences but you will not be identified by name in any publications. You will not be directly informed of the results of the study.

What if I am harmed by the study?

It is very unlikely that you would be harmed by taking part in this type of research study. However, if you wish to complain or have any concerns about the way you have been approached or treated in connection with the study, you should ask to speak to the study team who will do their best to answer your questions. If you remain unhappy and wish to address your concerns or complaints on a formal basis, you should contact Patient Information & Liason Service at pils.complaints.compliments@uhl-tr.nhs.uk. The Firs, c/o Glenfield Hospital, Groby Road, Leicester LE3 9QP. Freephone: 0808 178837

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against University of Leicester but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

What do I do if I decide to volunteer?

Please read this participant information sheet before deciding whether or not to take part. Once you have decided that you would like to take part, remove the participant information sheet and keep for your reference. Turn over and complete the consent form and questionnaire. Once completed, detach the consent form from the questionnaire. Place the consent form in box A and questionnaire in box B which you will find on the reception desk in your clinic/surgery. You can take the questionnaire home to fill in and bring it back to the clinic/ surgery when convenient.

If you still have any questions about the study, please feel free to contact the study team:

Tel: 0116 258 8047

Email: lifestylestudy@uhl-tr.nhs.uk

Address: Leicester Diabetes Centre, Leicester General Hospital, Gwendolen Road, Leicester, LE5 4PW

Once you have finished reading this participant information sheet please decide whether or not to take part.

Once you have decided (that you would like to take part) please remove the participant information sheet and keep for your own records/your reference.

Please complete the consent form on the next page, detach and place in BOX A. Please complete questionnaire and place in BOX B.

CONSENT FORM

Thank you for taking the time to read the participant information sheet (Version V2. 21/05/2019). Your answers will be combined with the answers of other members of the public. By analysing this data we hope to better understand the health needs required to ultimately deliver improved healthcare to people living in the region.

Please confirm your consent to take part in the study by completing the information below:

I consent to being contacted in the future about further research.

🗆 Yes	
🗆 No	
I consent to data linkage to my h	nealth records.
🗆 Yes	
🗆 No	
If you have answered yes to eith	er of the above questions please fill in your contact details below
Forename	Middle name
Surname	
Address	
Preferred telephone no.	
Email	
NHS Number (if known)	
Date of Birth	GP Surgery
	being shared with other researchers and organisations nisations or companies in this country and aboard.
Signature:	Date: D D M M Y Y Y Y
Print Name:	
If you have any further queries	about this study please contact the study team:
Tel: 0116 258 8047	Email: lifestylestudy@uhl-tr.nhs.uk

CONSENT FORM

MEL

Section 1. About You

Sectio	n T. About You				MEL
1 Wh	at is your gender identity	2			
	Male		Female		Prefer not to say
	Other (How would you de	escribe	e your sel	f)	
2 W/b	· · ·				
2. WI	at is your date of birth?	Y	Y Y		
3. Wh	at is your height?				
	feet in	nches		OR	cm
4. Wh	at is your weight?				
	stone	lbs	(OR	kgs
5. Wh	at is your waist measure	ment?			
		cm	(OR	inches
6. Do	you have a spouse or par	tner li	ving with	you?	
	Yes		No		
7. Wh	at is your ethnic group?				
	White				Asian / Asian British
	English /Welsh / Scottis Irish / British	h / No	rthern		Indian
	lrish				Pakistani
	Gypsy or Irish Traveller				Bangladeshi
	European				Chinese
	Any other White backgro please describe	ound			Any other Asian / Asian British please describe
	Black / Black British				Mixed
	African				Asian and White
	Caribbean				Black African and White
	Any other Black / African background, please desc		ibbean		Black Caribbean and White Other Mixed background please describe
	Other				etter mixed backyround please describe
	Arab				
	Any other background (p	lease	descrihe)		

OUESTOMMARE

8. We	ere you born in the UK?		
	Yes		No (If you answered 'no') could you tell us the country of your birth and the year in which you moved to the UK
	Country of birth		
Ye	ar you moved to the UK		
9. WI	hat is your highest educational qu	alificat	ion?
	None		
	GCSE or equivalent		
	A-Levels or equivalent		
	Undergraduate degree		
	Postgraduate degree		
	Doctorate		
	Other (please specify)		
10. WI	hich of the following best describ	es your	daily activities?
	Employed full-time		
	Employed part-time		
	Self-Employed		
	Unemployed		
	Student		
	Seeking work		
	Retired		
	Long term sick		
	Homemaker		
	Other (please specify)		
11. lf a	applicable, what is the postcode f	or your	main place of work during the last 4 weeks?
	Post code		
lf not	known please give your work add	lress:	

MEL

12. Have you experienced any of the following long term health conditions?

- Diabetes
- Chronic Obstructive Pulmonary Disease (COPD)
- □ High Blood Pressure
- Depression
- Osteoarthritis
- Asthma
- □ Anxiety/nerves
- □ Stroke
- Heart disease
- Pain
- Memory Problems
- Chronic Kidney Disease (CKD)
- Obstructive Sleep Apnoea
- Other (please specify)

13. Do you currently take any regular medications prescribed or recommended by a doctor or nurse? (Please specify)

14. Do you buy any medications not prescribed by your doctor (e.g. vitamins or minerals, dietary supplements herbal or homeopathic remedies) (Please specify)

Section 2. Your Diet

1. Do you routinely follow any special diet(s)

- 🗆 No
- □ Lactose free
- Gluten free or wheat free
- Low calorie/low fat/weight controlled diet
- Other (please specify)

2. Please tell us a little about the type of food you eat by ticking one of the options for each food below

	Never	Seldom	Once a week	2-4 times a week	5-6 times a week	Once or more daily	Don't know
Fresh fruit (e.g. apples, oranges, pears)							
Green leafy vegetables (e.g. cabbage, broccoli)							
Other vegetables (e.g. peas, carrots, beans, tomatoes)							
Oily fish (e.g. herring, salmon, sprats, pilchards, mackerel)							
Other fish (e.g. cod, tuna, haddock)							
Chicken							
Meat (e.g. chops, roasts, stews)							
Eggs							
Cheese							
Wholemeal / brown bread							

3. Alcohol Intake

How often do you have a drink containing alcohol?

- NeverMonthly or less
- □ 2-4 times per month
- □ 3-4 times per week
- More than 4 times per week

How many units of alcohol do you drink on a typical day when you are drinking? (one unit is equivalent to ½ pint of regular strength beer or lager, 1 single measure of spirit or 1 small glass of wine)

	1-2 units
	3-4 units
	5-6 units
	7-9 units
	10+ units
	often have you had 6 or more units (if female ${ m \bigstar}$) or 8 or more units (if male ${ m \rm}$) on a single ion in the last year?
	Never
	Monthly or less
	2-4 times per month
	3-4 times per week
	4+ times per week
	noking you currently smoke cigarettes?
	No
	Yes If yes how many cigarettes do you usually smoke per day?
Have	you smoked cigarettes previously?
	Yes If yes what was the approximate date you stopped (month/year) M M Y Y Y Y
	No
Do уоц	u use any of the following?
	Pipe
	E-cigarette/Vape
	Shisha
	Chewing tobacco
	Other, please describe

1. How much physical activity do you do per week?

Please tick the boxes **G** for all activities in the left hand column that are relevant to you. Select the days (Monday - Sunday) that you take part in the activity to help with your recall. Then use the right hand column to write how many minutes per week you engage in each activity that you have crossed. Only report physical activity that is; very demanding, leaves you out of breath/struggling to hold conversation and sweating. Only acknowledge bouts of physical activity that are above or equal to 10 minutes in duration at a time.

Activity	М	Т	W	Т	F	S	S	Minutes per week
	Tran	sport i	related	d phys	ical ac	tivity		
Cycling								
Running								
Brisk Walking								
9	Sport a	nd lei	sure ti	me ph	ysical	activit	у	
Jogging/running								
Cycling								
Rugby								
Tennis								
Football								
Badminton								
Squash								
Water Aerobics								
Walking for exercise								
Volleyball								
Weight Training								
Swimming								
Tai Chi								
Skating								
Martial Arts (Judo/ Taekwondo)								
Other (please specify)								
				Total	minut	es per	week	

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2. Ho	ow would you describe your usual	walking pace?
	Slow pace Steady/average pace Brisk pace	
3. Ov Ind	ver the last 7 days on average, how cluding time spent at work, home a	y much time did you spend sitting per day? and during leisure time (This may include time spent ding or sitting or lying down to watch television).
	hours	minutes
4. W	hat type of physical activity do you	ı most enjoy?
	Walking Cycling Swimming Gardening Structured sport (eg team sport Group exercise classes Gym based exercise Other (please specify)	
	ow many hours did you sleep last r n average, how many hours do you	
	ne hears about "morning types" an nsider yourself to be?	d "evening types." Which one of these types do you
	Definitely a morning type Rather more a morning type tha Rather more an evening type th Definitely an evening type	

Section 5. Your Neighbourhood

1. For the following statements, please circle the answer that best applies to you and your neighbourhood. Please circle one answer per statement. In the statements, within easy walking distance means within a 10-15 minute walk from your home.

		Answer C	ategories	
	1 Strongly Disagree	2 Somewhat Disagree	3 Somewhat Agree	4 Strongly Agree
There are shops to visit within easy walking distance of my home.				
There is a park or open space to visit within easy walking distance of my home.				
There is a sports or leisure centre within easy walking distance of my home.				
It is pleasant to walk in my neighbourhood.				
There are pedestrian crossings to help walkers cross busy streets in my neighbourhood.				
I feel generally safe walking in my neighbourhood.				
The crime rate in my neighbourhood makes it unsafe to go on walks at night.				
It is easy to walk to a bus stop from my home.				
There are few cul-de-sacs (dead-end streets) in my neighbourhood.				
There are a lot of busy junctions in my neighbourhood.				
There are major barriers to walking in my neighbourhood that make it hard to get from place to place (for example, busy roads, railway lines, rivers, hills).				
There are many alternative routes for getting from place to place in my neighbourhood (I don't have to go the same way every time).			O	

		Answer C	ategories	
	1 Strongly Disagree	2 Somewhat Disagree	3 Somewhat Agree	4 Strongly Agree
There are pavements on most of the streets in my neighbourhood.				
There are cycle paths in or near my neighbourhood that are easy to get to.				
There is a verge that separates the streets from the pavements in my neighbourhood.				
There are trees along the streets in my neighbourhood.	Ο			
There are diverse and interesting things to look at in my neighbourhood (e.g. buildings and views).				
There is so much traffic along nearby streets making it difficult or unpleasant to walk in my neighbourhood.				
There is so much traffic along nearby streets making it difficult or unpleasant to cycle in my neighbourhood.				
The speed of traffic on most nearby streets is usually slow (30 mph or less).	Ο			
Most drivers exceed the posted speed limits while driving in my neighbourhood.				
My neighbourhood streets are well lit at night.				
Walkers and cyclists on the streets in my neighbourhood can be easily seen by people in their homes.		0		
There is a high crime rate in my neighbourhood.				

Section 6. Covid-19

Daily routine

- 1. Which of the following have you experienced/followed during the outbreak? Please tick 🗹 all that apply.
 - Social distancing (you limited your face-to-face contact, staying 2 metres from others, exercising only once a day)
 - Self-isolating or household isolating (you have stayed at home for 7-14 days without going out)
 - □ Working from home (you have worked from home when you don't normally)
 - Shielding (you were told to stay at home because of a health risk avoiding any face-to-face contact)
 - Continued going into work
 - O Other e.g. furloughed and asked to take a break from work

Healthcare during covid-19

- 2. During the covid-19 outbreak, have you. Please tick 🗹 all that apply.
 - Attended face-to-face appointments with your doctor or nurse e.g. check-ups or routine examinations
 - Received face-to-face treatment for a health condition
 - Used a digital consultation (i.e. video call) with a healthcare professional
 - Used a telephone consultation with a healthcare professional
 - Avoided seeking advice or medical care
 - Continued with ordering and taking medicines as normal
- 3. How has the covid-19 outbreak affected your confidence/ability to manage your condition (i.e. take prescribed medication)? Please tick 𝗹 one answer.
 - □ I feel more confident/able
 - I feel the same
 - □ I feel less confident/able
 - O Other (please describe)

|--|

4. How has	the covid-19 outbreak affected your wellbeing? Please tick 🗹 one answer.
🗆 l fee	el more anxious/depressed
🗆 l fee	el the same
🗆 l fee	el less anxious/depressed
D Oth	er (please describe)
5. How has	the covid-19 outbreak affected your diet/food choices? Please tick 🗹 one answer.
🗆 lea	t more
🗆 lea	t the same
🗆 lea	t less
D Oth	er (please describe)
6. Has the o	covid-19 outbreak affected your activity levels? Please tick 🗹 one answer.
🗆 lam	n more active
D My	activity has not changed
🗆 lam	n less active
D Oth	er (please describe)
7. How has	the covid-19 outbreak affected your sleep? Please tick 🗹 one answer.
🗆 Isle	eep more
🗆 Isle	eep the same
🗆 Isle	eep less
D Oth	er(please describe)
8. How has	the covid-19 outbreak affected your medication regime? Please tick 🗹 one answer.
🗆 lam	n able to get my medication prescription
🗆 lam	n not able to get my medication prescription
D Oth	er (please describe)

9. Compared to before, has covid-19 affected any of the following conditions? Please tick 🗹 all that apply.

- Diabetes
- Chronic Obstructive Pulmonary Disease (COPD)
- High Blood Pressure
- Depression
- Osteoarthritis
- 🗋 Asthma
- □ Anxiety/nerves
- □ Stroke
- Heart disease
- Pain
- Memory Problems
- Chronic Kidney Disease (CKD)
- Obstructive Sleep Apnoea
- Other (please specify)

10. Where did you complete this questionnaire?

- At a GP surgery
- At a hospital clinic
- At a community venue (community centre/faith centre)
- Other (please specify)

Thank you for your time. Please now put this questionnaire in **BOX B**



The Multi-Ethnic Lifestyle Study is funded by the National Institute for Health Research's Collaboration for Leadership in Applied Health Research and Care East Midlands.

The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

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