

“Our experience of Covid-19”

Survey Report

MAY 2020

Presented by:

City & Hackney OPRG Planning Group on behalf of,
and with grateful thanks to, our **106 OPRG survey respondents**

Members:

Cynthia White (*Chair*) | Paul Higgins (*Deputy Chair*) | Shirley Murgraff | Paula Shaw
Sophie Ibotson (*OPRG Coordinator, Age UK East London*)

Table of Contents

1	SURVEY DESIGN and METHODOLOGY	2
2	SURVEY RESPONSE: Overview	3
3	SURVEY RESULTS: Confidence levels	5
4	PROFILE of RESPONDENTS	
	(i) Demographic profile	6
	(ii) Health profile and status	8
5	QUANTITATIVE DATA: selected tables (by ethnicity, age, gender)	11
	<i>Table 1 (a,b,c):</i> Needed/not needed to see GP since Covid-19	11
	<i>Table 2 (a,b,c):</i> Spoken/not spoken to GP since Covid-19	12
	<i>Table 3 (a,b,c):</i> Would avoid/not avoid A&E due to infection fears	13
	<i>Table 4 (a,b,c):</i> Eating as well/not eating as well since Covid19	14
	<i>Table 5 (a,b,c):</i> Getting/not getting enough exercise since Covid-19	15
	<i>Table 6 (a,b,c):</i> Getting/not getting enough social contact since	16
	<i>Table 7 (a,b,c):</i> Having/not having enough family contact since	17
	<i>Table 8 (a,b,c):</i> Feeling lonely often, sometimes, rarely, never	18
	<i>Table 9 (a,b,c):</i> Worried about catching Covid-19	19
	<i>Table 10 (a,b,c):</i> Worried about people relied on catching Covid-19	20
	<i>Table 11 (a,b,c):</i> Rely/can't rely on family, friends, neighbours for help	21
	<i>Table 12:</i> Patients' information sources regarding Covid-19	22
6	QUALITATIVE DATA: IN RESPONDENTS' OWN WORDS (Summary)	23
	<i>Table 13(a):</i> AUKEL follow-up to respondents' issues & enquiries	25
	<i>Table 13(b):</i> Further action required	25
7	SUMMARY TABLES: OVERALL IMPACT OF LOCKDOWN	26
	<i>Table 14 (a,b,c):</i> Physically worse, no worse, better	26
	<i>Table 15 (a,b,c):</i> Mentally worse, no worse, better	27
	<i>Chart I:</i> Respondents' feelings about their health	28
	<i>Chart II:</i> Respondents' feelings about ability to 'cope'	28
8	CONCLUSIONS: Towards Recovery, Resilience and Risk-Management	29
9	PRIORITIES and ACTION	34
10	Appendices	38
	<i>Appendix 1:</i> Feedback from 'open-ended' questions (full transcript)	39
	<i>Appendix 2:</i> Survey cover letter and survey schedule	46
	<i>Appendix 3:</i> Leaflets mailed with questionnaire	54
	<i>Appendix 4:</i> Unanswered survey questions: by topic	55

1 SURVEY DESIGN and METHODOLOGY

- We opted for a 100% membership survey, a copy of which is attached (*Appendix 1*). We also invested in stamped, addressed return envelopes to facilitate and maximise the response.
- We risked a packed questionnaire (**85** questions including **7** 'open-ended' sections to provide for supplementary responses), hoping that isolated older people might be more willing in current circumstances to spend the time needed to give us substantial feedback.
- Questions were designed to be clear, straightforward and relevant to the known circumstances and needs of our Members, whilst giving scope to respondents to enlarge upon them and suggest others.
- We took care to cover practical issues (often overlooked in attitudinal studies) such as difficulties in obtaining key consumables e.g. hearing aid batteries or getting repairs done.
- We also used the opportunity to 'seed' the questionnaire with 'stimulus' questions – topics intended to alert respondents to (for example) safety issues, services they might need, or new service developments (*e.g. Coordinate My Care*), and prompt them to seek further help. The survey concluded with encouragement not to delay seeking hospital treatment out of fear of contracting Covid-19.
- The purposes of the survey, and the key role respondents could play in helping to inform and guide commissioners in understanding older people's care needs and enhancing their services, were strongly emphasised.
- It was also vital that our survey carried with it the message that the OPRG was also offering Members an opportunity to connect with us in other ways, and that we were happy just to talk with them, or if needed, refer them to Age UK East London or other appropriate services, for advice, information or other help. Please see [Table 15](#) for a summary of the issues and actions generated by this parallel process.
- Signposting slips with contact details for the OPRG, Age UK and other key agencies were included separately for **retention and future guidance**.
- The OPRG Planning Group agreed the survey schedule before signing it off. **Four** of us assisted with the mail-out from our own homes under social distancing, facilitated invaluablely by our Age UK OPRG Coordinator.
- The mailout (with one via email) commenced on 13 May 2020.

2 SURVEY RESPONSE: Overview

106 (23%) of the **460** survey schedules distributed were returned over an extended period (approximately 6 weeks), no deadline having been given. We opted to allow extra time and to delay analysis to ensure every respondent's voice would be heard.

(i) Non-disclosure

Respondents were given a guarantee that all the information they provided would be treated confidentially, with a further offer of anonymity if preferred. **37** schedules were submitted anonymously. **18** respondents did not disclose their **ethnicity**, **13** did not reveal their **age**, and **6** did not state their **gender**.

Comments on survey design

22 respondents commented on the survey design as follows:

Respondents' comments on survey design	No. of responses
The survey being too long	6
Format is not accessible e.g. writing too small, questions embedded in text are challenging for those with learning disabilities, should have the same format throughout	3
Ableism: "Suffer" when used in relation to conditions	2
Confusion about the nature of the survey e.g. how much help could be offered (healthcare services)	1
Pleased with the work we are doing on behalf of older people	7
Changes to content of the survey e.g. common- sense questions raised – 'of course we can't have social contact, we're not allowed to', mention practice nurses, include a question about caring responsibilities	3
Looking forward to resuming meetings	1

(iii) Unanswered questions

The significance of unanswered questions in the survey is hard to assess. The 'digital divide' amongst respondents, **only 27 of whom said they had access to email**, may explain why **44 (42%) ignored the question entirely**.

The response to other questions is, to say the least, idiosyncratic, mirroring the diverse condition, circumstances, morale and attitudes of older residents largely confined under lockdown. The volume of questions was clearly physically taxing for some – they told us so! – and fatigue may have limited responses as the survey progressed.

Good response levels were achieved for most health matters but there was poor engagement with safeguarding issues (e.g. *scamming and other aspects of financial security*). Respondents may have also shied away from the more ‘uncomfortable’ probing of how careful they were with credit cards and bank details etc. On the medical front, fears about coronavirus, safety, future access to care and treatment, and the mounting challenges of ‘coping’ under Covid-19 may have fuelled a sense of denial and an unwillingness to confront certain issues.

On the other hand, there is a sense of suppressed scorn filling the multiple blanks in place of replies to such questions as, “*have you ever given your bank details to someone you don’t know?*” Or an enquiry about “*having enough social contact*”. One respondent (no doubt speaking for many) scathingly queried how we thought people could have any contact since they couldn’t go outside. We should also allow for the fact that the questions themselves may have been difficult to grasp, or meant different things to different people, depending on their knowledge, understanding and current state of mind and physical health.

Given that many respondents provided detailed and often lengthy answers via our 7 ‘open-ended’ questions, albeit selectively, it may be that some felt they had nothing further to add and opted to save their energies for the topics that they saw as most relevant to themselves rather than to us, a bias in the response pattern that merits deeper analysis.

The highest overall non-response levels (20-25%) were for: *safety outside the home, coping with everyday tasks, lending out credit cards, catching coronavirus, safety at home, future availability of usual treatments, caring adequately for oneself, and the future availability of home-care*. However, individual respondents show very different patterns, e.g. one whose sole answer was to the disability question. A full record of unanswered questions is given in [Appendix 4](#).

3 SURVEY RESULTS

Confidence levels

The survey results, whilst they are clearly informative and illuminating, should be treated with caution. They cannot claim to be representative of all older residents in the City of London and Hackney, or comprehensive in reflecting their circumstances and needs. This was not a sample survey and responses to it were therefore unstructured. The demographic profile shows a definite skew towards the upper age-bands, a heavy preponderance of females, and a sizeable majority of respondents self-identifying as “white” (British and non-British).

What of the 77% of OPRG Members we did not hear from? Whilst it might reasonably be inferred that the survey has captured feedback from people who have most to say, it may also be true that they are the most highly-motivated members of the group and those best able to respond. It still leaves open the strong possibility that **non-respondents may include those who may be in greatest need but are least able to express it via the survey method.**

There are also concerns about areas of possible **under-reporting** within the survey itself. Given the known socio-economic characteristics of the older population, particularly in Hackney, it is surprising that so few respondents alluded to financial difficulties. Natural reticence may account for this: similarly the poor response to “*staying safe*” which probed the growing incidence of scams and risks of fraud associated with giving out credit card and banking details. There is evidence, particularly in the City population, that victims can be shamed into silence. Different methods and channels are likely to be needed to gain a fuller picture, and notably with regard to financial and physical abuse.

In these circumstances, it is vital to pay close attention to the evidence of every single response: whilst not counting as a ‘majority’ view, it may nonetheless stand as proxy for the hidden needs and sufferings of many who cannot make their voices heard. The key characteristics of older people are their individuality and cherished independence requiring a personalised approach in assessing feedback and using it to meet their needs.

4 PROFILE OF RESPONDENTS

Demographic profile

a Ethnicity, Age, Gender

We did not provide a standard set of categories for ethnicity. Rather, we chose to ask respondents to self-identify. This may have caused uncertainty for anyone unfamiliar with answering standard ethnicity questions on monitoring forms at meetings, but we wished as far as possible to avoid ‘labelling’ issues.

By Ethnicity	Count	%
Black and Black British	32	37%
Asian and Asian British	6	7%
White (British, European, North American)	46	53%
Other (Cypriot, Jewish, Mixed)	3	3%
Group Total	87	100%
Undisclosed	18	17%
N/a	1	1%
Grand Total	106	100%

By Age	Count	%
50-59	6	6%
60-69	11	10%
70-79	34	32%
80-89	35	33%
90+	7	7%
Group Total	93	88%
Undisclosed	13	12%
Grand Total	106	100%

By Gender	Count	%
Female]	74	74%
Male	26	26%
Group Total	100	100%
Undisclosed	6	6%
Grand Total	106	100%

b Living Alone – Do you live alone?

Ethnicity	Yes		No		Unanswered		Total
	%	Count	%	Count	%	Count	
Black and Black British	69%	22	28%	9	3%	1	32
Asian and Asian British	83%	5	17%	1	0%	0	6
White (British, European, North American)	70%	32	30%	14	0%	0	46
Other (Cypriot, Jewish, Mixed)	67%	2	33%	1	0%	0	3
Group Total	67%	61	30%	25	3%	1	87
Undisclosed	50%	9	29%	7	11%	2	18
N/a	1%	1	0%	0	0%	0	1
Grand Total	67%	71	30%	32	3%	3	106

Age	Yes		No		Unanswered		Total
	%	Count	%	Count	%	Count	
50-59	50%	3	33%	2	17%	1	6
60-69	64%	7	27%	3	9%	1	11
70-79	68%	23	32%	11	0%	0	34
80-89	71%	25	29%	10	0%	0	35
90+	57%	4	43%	3	0%	0	7
Group Total	67%	62	31%	29	2%	2	93
Undisclosed	69%	9	23%	3	8%	1	13
Grand Total	67%	71	30%	32	7%	3	106

Gender	Yes		No		Unanswered		Total
	%	Count	%	Count	%	Count	
Female	78%	58	20%	15	1%	1	74
Male	46%	12	50%	13	4%	1	26
Group Total	70%	70	28%	28	2%	2	100
Undisclosed	0%	0	83%	5	17%	1	6
Grand Total	66%	70	31%	33	2.8%	3	106

In total, how many people live alone	Count	%
Yes	71	69%
No	32	31%
Unanswered	3	100%
Grand Total	106	100%

Health profile and status

13 respondents said they were being “**shielded**” with **14** receiving food parcels. Only 1 person reported having had coronavirus, but **15** mentioned having “**new** (unspecified) **illnesses**” during the pandemic. Asked about **existing medical conditions** including **disablement**, significantly, **all 106 respondents reported on these** as follows and in the table below:

a Walking is difficult (by ethnicity, age and gender)

	Yes		No		Unanswered		Total
Ethnicity	%	Count	%	Count	%	Count	
Black and Black British	50%	16	47%	15	3%	1	32
Asian and Asian British	17%	1	67%	4	17%	1	6
White (British, European, North American)	45%	21	54%	25	0%	0	46
Other (Cypriot, Jewish, Mixed)	67%	2	33%	1	0%	0	3
Group Total	46%	40	52%	45	2%	2	87
Undisclosed	67%	12	28%	5	6%	1	18
N/a	100%	1	0%	0	0%	0	1
Grand Total	50%	53	47%	50	3%	3	106

	Yes		No		Unanswered		Total
Age	%	Count	%	Count	%	Count	
50-59	17%	1	67%	4	17%	1	6
60-69	27%	3	73%	8	0%	0	11
70-79	44%	15	53%	18	3%	1	34
80-89	67%	23	31%	11	3%	1	35
90+	71%	5	29%	2	0%	0	7
Group Total	51%	47	46%	43	3%	3	93
Undisclosed	46%	6	54%	7	0%		13
Grand Total	50%	53	47%	50	3%	3	106

	Yes		No		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	46%	34	51%	38	3%	2	74
Male	62%	16	38%	10	0%	0	26
Group Total	50%	50	48%	48	2%	2	100
Undisclosed	33%	3	33%	2	17%	1	6
Grand Total	50%	53	47%	50	3%	3	106

b Medical conditions

Respondents reported more fully on their health than on any other topic.

73 specified at least **one ‘condition’**

33 cited **2 or more co-morbidities**

43 reported **disablement and at least 1 other ‘condition’**

9 reported **disablement** (but no other condition)

24 reported having neither a disability nor any other ‘condition’.

Medical conditions (as self-described)	Female	Male	Not given
Anaemia	1	-	
Arthritis	14	4	1
Asthma	5	1	
Autism	1		
Autoimmune disease	1		
Balance problems	1		
Cancer	2	2	
Cardiac	1	1	
Crohn's Disease	1		
Diabetes (Types 1 and 2)	3	3	
Disablement, learning difficulties	1	2	1
Eye condition/impairment	5	4	
Gout		1	
Hearing impairment	3		
Hypertension	10	5	
Oedema		1	
Orthopaedic incl. mobility (wrist, back, hip, knee)	9		
Osteoporosis	1		
Prostate enlargement			1
Pain, stiffness, sciatica	2		
Rash	1		
Respiratory problems	1		
Sjogren Syndrome	1		
Stroke	1	1	
Vascular	1	1	
Total	66	26	3

c Patients' experience of Primary Healthcare, Secondary Healthcare and Social Care during Lockdown. (Summary data from 'closed' questions).

Asked what medical services they needed to support them during 'lockdown' and to what extent these were accessible and supplied, patients reported as follows:

- 50** had spoken to a GP (**34** said they "didn't need to").
- 10** needed to use 111.
- 64** mentioned appointments being cancelled.
- 41** specified the cancellation of hospital treatments.
- 6** were admitted to hospital, whilst **61** said they would avoid A&E due to infection fears (15 did not answer).
- 6** were receiving district nurse visits and **6** home-care visits.
- 7** had been bereaved, of whom **4** felt they lacked support.
- 4** mentioned difficulties in obtaining medications.
- 3** reported not wanting to take their medications.

The greatest reported patient need was for dental treatment (**41**) of whom **5** said it was 'urgent', followed by eye treatment (**35**) of whom **11** said it was 'urgent', and toe-nail cutting (**31**). **35** respondents feared they would not get the treatments they needed and **19** felt similarly about possibly being denied home care. **64** respondents were anxious about catching Covid-19 (22 did not answer), **58** feared contracting it in hospital whilst **43** were concerned about their helpers becoming infected. (See [Tables 1-13](#) below for full listings disaggregated by Ethnicity, Age and Gender).

d Contextual health risks (see also [Tables](#) below)

In addition to health risks associated with service reductions, patients reported a number of contextual health risks arising from lockdown including: "not getting enough exercise" (**60**), feeling anxious (**51**), "not sleeping as well as usual" (**34**), problems in getting food (**12**), and "not eating as well as usual" (**8** with 10 not answering).

In an overlapping picture, **30** revealed their diminishing ability to carry out everyday tasks; **22** admitted they were "not coping"; **15** were "struggling" and **10** said they "needed help". Regarding the particular risks associated with **social isolation**:

- 60** reported "not getting as much social contact as they needed";
- 45** felt they were getting "not getting enough contact" with family, friends and neighbours;
- 51** said they experienced loneliness "much of the time" or "sometimes".

For the **59** regular worshippers in Faith groups, the loss of this important form of social contact and mutual support may have been especially hard to endure.

5 QUANTITATIVE DATA: selected tables
(by ethnicity, age and gender)

Table 1(a)	Needed / <u>not</u> needed to speak to my GP since Coronavirus – by Ethnicity						
	Needed		Not Needed		Unanswered		Total
Ethnicity	%		%		%		
Black and Black British	34%	11	38%	12	28%	9	32
Asian and Asian British	17%	1	50%	3	33%	2	6
White (British, European, North American)	28%	13	67%	31	4%	2	46
Other (Cypriot, Jewish, Mixed)	67%	2	33%	1	0%	0	3
Group Total	31%	27	54%	47	15%	13	87
Undisclosed	33%	6	44%	8	22%	4	18
N/a	100%	1	0%	0	0%	0	1
Grand Total	32%	34	52%	55	16%	17	106

Table 1(b)	Needed/not needed to speak to my GP since Coronavirus – by Age						
	Needed		Not Needed		Unanswered		Total
Age	%	Count	%	Count	%	Count	
50-59	33%	2	50%	3	17%	1	6
60-69	36%	4	64%	7	0%	0	11
70-79	32%	11	56%	19	12%	4	34
80-89	31%	11	57%	20	11%	4	35
90+	0%	0	57%	4	43%	3	7
Group Total	30%	28	57%	53	13%	12	93
Undisclosed	46%	6	15%	2	38%	5	13
Grand Total	32%	34	52%	55	16%	17	106

Table 1(c)	Needed/not needed to speak to my GP since Coronavirus – by Gender						
	Needed		Not Needed		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	28%	21	57%	42	15%	11	74
Male	46%	12	42%	11	12%	3	26
Group Total	33%	33	53%	53	14%	14	100
Undisclosed	17%	1	33%	2	50%	3	6
Grand Total	32%	34	52%	55	16%	17	106

Table 2(a)	I've spoken / <u>not</u> spoken to my GP since Coronavirus – by Ethnicity						
	Yes		No		Unanswered		Total
Ethnicity	%	Count	%	Count	%	Count	
Black and Black British	56%	18	31%	10	13%	4	32
Asian and Asian British	0%	0	50%	3	50%	3	6
White (British, European, North American)	41%	19	59%	27	0%	0	46
Other (Cypriot, Jewish, Mixed)	100%	3	0%	0	0%	0	3
Group Total	48%	40	48%	40	8%	7	87
Undisclosed	60%	9	40%	6	17%	3	18
N/a	100%	1	0%	0	0%	0	1
Grand Total	47%	50	43%	46	9%	10	106

Table 2(b)	I've spoken / <u>not</u> spoken to my GP since Coronavirus – by Age						
	Yes		No		Unanswered		Total
Age	%	Count	%	Count	%	Count	
50-59	50%	3	33%	2	17%	1	6
60-69	55%	6	36%	4	9%	1	11
70-79	38%	13	50%	17	12%	4	34
80-89	51%	18	49%	17	0%	0	35
90+	57%	4	43%	3	0%	0	7
Group Total	47%	44	46%	43	6%	6	93
Undisclosed	46%	6	23%	3	31%	4	13
Grand Total	47%	50	43%	46	9%	10	106

Table 2(c)	I've spoken / <u>not</u> spoken to my GP since Coronavirus – by Gender						
	Yes		No		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	43%	32	46%	34	11%	8	74
Male	50%	13	46%	12	4%	1	26
Group Total	45%	45	46%	46	9%	9	100
Undisclosed	83%	5	0%	0	17%	1	6
Grand Total	47%	50	43%	46	9%	10	106

Table 3(a)	I would avoid going to A&E because I'm afraid of getting infected – by Ethnicity						
	Yes		No		Unanswered		Total
Ethnicity	%	Count	%	Count	%	Count	
Black and Black British	52%	20	22%	7	16%	5	32
Asian and Asian British	67%	4	17%	1	17%	1	6
White (British, European, North American)	61%	28	33%	15	7%	3	46
Other (Cypriot, Jewish, Mixed)	33%	1	67%	2	0%	0	3
Group Total	61%	53	29%	25	10%	9	87
N/a	100%	1	0%	0	0%	0	1
Undisclosed	39%	7	28%	5	33%	6	18
Grand Total	57%	61	28%	30	14%	15	106

Table 3(b)	I would avoid going to A&E because I'm afraid of getting infected – by Age						
	Yes		No		Unanswered		Total
Age	%	Count	%	Count	%	Count	
50-59	50%	3	33%	2	17%	1	6
60-69	82%	9	18%	2	0%	0	11
70-79	56%	19	35%	12	9%	3	34
80-89	63%	22	23%	8	14%	5	35
90+	71%	5	14%	1	14%	1	7
Group Total	61%	58	29%	25	10%	10	93
Undisclosed	23%	3	38%	5	38%	5	13
Grand Total	58%	61	28%	30	14%	15	106

Table 3(c)	I would avoid going to A&E because I'm afraid of getting infected – by Gender						
	Yes		No		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	64%	47	22%	16	15%	11	74
Male	38%	10	50%	13	12%	3	26
Group Total	57%	57	29%	29	13%	14	100
Undisclosed	67%	4	17%	1	17%	1	6
Grand Total	58%	61	28%	30	14%	15	106

Table 4(a)	I'm eating / <u>not</u> eating as well as usual – by Ethnicity						
	Eating as well		Not eating as well		Unanswered		Total
Ethnicity	%		%		%		
Black and Black British	72%	23	9%	3	19%	6	32
Asian and Asian British	67%	4	17%	1	17%	1	6
White (British, European, North American,)	87%	40	7%	3	7%	3	46
Other (Cypriot, Jewish, Mixed)	67%	2	33%	1	0%	0	3
Group Total	79%	69	9%	8	11%	10	87
Undisclosed	67%	12	17%	3	17%	3	18
N/a	100%	1	0%	0	0%	0	1
Grand Total	77%	82	10%	11	12%	13	106

Table 4(b)	I'm eating / <u>not</u> eating as well as usual – by Age						
	Eating as well		Not eating as well		Unanswered		Total
Age	%		%		%		
50-59	50%	3	33%	2	17%	1	6
60-69	82%	9	9%	1	9%	1	11
70-79	82%	28	12%	4	6%	2	34
80-89	86%	30	3%	1	11%	4	35
90+	29%	2	14%	1	57%	4	7
Group Totals	77%	72	10%	9	13%	12	93
Undisclosed	77%	10	15%	2	8%	1	13
Grand Total	77%	82	10%	11	12%	13	106

Table 4(c)	I'm eating / <u>not</u> eating as well as usual – by Gender						
	Eating as well		Not eating as well		Unanswered		Total
Gender	%		%		%		
Female	81%	60	9%	7	9%	7	74
Male	73%	19	15%	4	12%	3	26
Group Totals	79%	79	11%	11	10%	10	100
Undisclosed	50%	3	0%	0	50%	3	6
Grand Total	77%	82	10%	11	12%	13	106

Table 5(a)	I feel I'm getting / <u>not</u> getting as much exercise as I need – by Ethnicity						
	Getting as much		Not getting as much		Unanswered		Total
Ethnicity	%		%		%		
Black and Black British	25%	8	56%	18	19%	6	32
Asian and Asian British	17%	1	67%	4	17%	1	6
White (British, European, North American)	35%	16	61%	28	4%	2	46
Other (Cypriot, Jewish, Mixed)	67%	2	33%	1	0%	0	3
Group Total	31%	27	59%	51	10%	9	87
Undisclosed	28%	5	56%	10	17%	3	18
N/a	100%	1	0%	0	0%	0	1
Grand Total	31%	33	58%	61	11%	12	106

Table 5(b)	I feel I'm getting / <u>not</u> getting as much exercise as I need – by Age						
	Getting as much		Not getting as much		Unanswered		Total
Age	%		%		%		
50-59	33%	2	50%	3	17%	1	6
60-69	18%	2	64%	7	18%	2	11
70-79	29%	10	65%	22	6%	2	34
80-89	34%	12	57%	20	9%	3	35
90+	29%	2	29%	2	43%	3	7
Group Total	30%	28	58%	54	12%	11	93
Undisclosed	38%	5	54%	7	8%	1	13
Grand Total	31%	33	58%	61	11%	12	106

Table 5(c)	I feel I'm getting / <u>not</u> getting as much exercise as I need – by Gender						
	Getting as much		Not getting as much		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	28%	21	61%	45	11%	8	74
Male	38%	10	58%	15	4%	1	26
Group Total	31%	31	60%	60	9%	9	100
Undisclosed	33%	2	17%	1	50%	3	6
Grand Total	31%	33	58%	61	11%	12	106

Table 6(a)	I feel I'm getting / <u>not</u> getting as much social contact as I need – by Ethnicity						
	Getting as much		Not getting as much		Unanswered		Total
Ethnicity	%	Count	%	Count	%	Count	
Black and Black British	25%	8	56%	18	19%	6	32
Asian and Asian British	33%	2	33%	2	33%	2	6
White (British, European, North American)	35%	16	57%	26	9%	4	46
Other (Cypriot, Jewish, Mixed)	0%	0	100%	3	0%	0	3
Group Total	30%	26	56%	49	14%	12	87
Undisclosed	28%	5	56%	10	17%	3	18
N/a	0%	0	100%	1	0%	0	1
Grand Total	29%	31	57%	60	14%	15	106

Table 6(b)	I feel I'm getting / <u>not</u> getting as much social contact as I need – by Age						
	Getting as much		Not getting as much		Unanswered		Total
Age	%	Count	%	Count	%	Count	
50-59	33%	2	50%	3	17%	1	6
60-69	27%	3	64%	7	9%	1	11
70-79	38%	13	53%	18	9%	3	34
80-89	20%	7	66%	23	14%	5	35
90+	29%	2	57%	4	14%	1	7
Group Total	29%	27	59%	55	12%	11	93
Undisclosed	31%	4	38%	5	31%	4	13
Grand Total	29%	31	57%	60	14%	15	106

Table 6(c)	I feel I'm getting / <u>not</u> getting as much social contact as I need – by Gender						
	Getting as much		Not getting as much		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	30%	22	55%	41	15%	11	74
Male	27%	7	62%	16	12%	3	26
Group Total	29%	29	57%	57	14%	14	100
Undisclosed	33%	2	50%	3	17%	1	6
Grand Total	29%	31	57%	60	14%	15	106

Table 7(a)	I feel I have / <u>don't</u> have enough contact with family, friends and neighbours – by Ethnicity						
	Have enough		Don't have enough		Unanswered		Total
Ethnicity	%	Count	%	Count	%	Count	
Black and Black British	53%	17	38%	12	9%	3	32
Asian and Asian British	33%	2	50%	3	17%	1	6
White (British, European, North American)	48%	22	46%	21	7%	3	46
Other (Cypriot, Jewish, Mixed)	67%	2	33%	1	0%	0	3
Group Total	49%	43	43%	37	9%	7	87
Undisclosed	44%	8	38%	7	17%	3	18
N/a	0%	0	100%	1	0%	0	1
Grand Total	48%	51	42%	45	9%	10	106

Table 7(b)	I feel I have / <u>don't</u> have enough contact with family, friends and neighbours – by Age						
	Have enough		Don't have enough		Unanswered		Total
Age	%	Count	%	Count	%	Count	
50-59	50%	3	33%	2	17%	1	6
60-69	27%	3	64%	7	9%	1	11
70-79	50%	17	47%	16	3%	1	34
80-89	51%	18	37%	13	11%	4	35
90+	29%	2	43%	3	29%	2	7
Group Total	46%	43	44%	41	10%	9	93
Undisclosed	62%	8	31%	4	8%	1	13
Grand Total	48%	51	42%	45	9%	10	106

Table 7(c)	I feel I have / <u>don't</u> have enough contact with family, friends and neighbours – by Gender						
	Have enough		Don't have enough		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	50%	37	42%	31	8%	6	74
Male	46%	12	42%	11	12%	3	26
Group Total	49%	49	42%	42	9%	9	100
Undisclosed	33%	2	50%	3	17%	1	6
Grand Total	48%	51	42%	45	9%	10	106

Table 8(a)		I feel lonely much of the time/sometimes/rarely/never – by Ethnicity									
	Much of the time		Sometimes		Rarely		Never		Unanswered		Total
Ethnicity	%		%		%		%		%		
Black and Black British	9%	3	38%	12	16%	5	22%	7	16%	5	32
Asian and Asian British	0%	0	33%	2	17%	1	33%	2	17%	1	6
White (British, European, North American)	7%	3	37%	17	30%	14	20%	9	7%	3	46
Other (Cypriot, Jewish, Mixed)	33%	1	33%	1	0%	0	33%	1	0%	0	3
Group Total	8%	7	37%	32	23%	20	22%	19	10%	9	87
Undisclosed	11%	2	50%	9	6%	1	28%	5	6%	1	18
N/a	0%	0	100%	1	0%	0	0%	0	0%	0	1
Grand Total	8%	9	40%	42	20%	21	23%	24	9%	10	106

Table 8(b)		I feel lonely much of the time/sometimes/rarely/never – by Age									
	Much of the time		Sometimes		Rarely		Never		Unanswered		Total
Age	%		%		%		%		%		
50-59	17%	1	67%	4	0%	0	17%	1	0%	0	6
60-69	0%	0	27%	3	27%	3	36%	4	9%	1	11
70-79	15%	5	32%	11	21%	7	24%	8	9%	3	34
80-89	3%	1	40%	14	20%	7	29%	10	9%	3	35
90+	14%	1	57%	4	14%	1	0%	0	14%	1	7
Group Total	9%	8	39%	36	19%	18	25%	23	9%	8	93
Undisclosed	8%	1	46%	6	23%	3	8%	1	15%	2	13
Grand Total	8%	9	40%	42	20%	21	23%	24	9%	10	106

Table 8(c)		I feel lonely much of the time/sometimes/rarely/never – by Gender									
	Much of the time		Sometimes		Rarely		Never		Unanswered		Total
Gender	%		%		%		%		%		
Female	7%	5	42%	31	23%	17	18%	13	11%	8	74
Male	12%	3	35%	9	12%	3	35%	9	8%	2	26
Group Total	8%	8	40%	40	20%	20	22%	22	10%	10	100
Undisclosed	17%	1	33%	2	17%	1	33%	2	0%	0	6
Grand Total	8%	9	40%	42	20%	21	23%	24	9%	10	106

Table 9(a)		I'm worried about catching Coronavirus – by Ethnicity					
	Yes		No		Unanswered		Total
Ethnicity	%	Count	%	Count	%	Count	
Black and Black British	56%	18	25%	8	19%	6	32
Asian and Asian British	67%	4	17%	1	17%	1	6
White (European, British, North American)	63%	29	20%	9	17%	8	46
Other (Cypriot, Jewish, Mixed)	100%	3	0%	0	0%	0	3
Group Total	62%	54	21%	18	17%	15	87
Undisclosed	50%	8	11%	2	39%	7	18
N/a	100%	1	0%	0	0%	0	1
Grand Total	61%	64	19%	20	21%	22	106

Table 9(b)		I'm worried about catching Coronavirus – by Age					
	Yes		No		Unanswered		Total
Age	%	Count	%	Count	%	Count	
50-59	67%	4	0%	0	33%	2	6
60-69	73%	8	9%	1	18%	2	11
70-79	62%	21	24%	8	15%	5	34
80-89	72%	25	11%	4	17%	6	35
90+	29%	2	43%	3	29%	2	7
Group Total	65%	60	17%	16	18%	17	93
Undisclosed	31%	4	31%	4	38%	5	13
Grand Total	61%	64	19%	20	21%	22	106

Table 9(c)		I'm worried about catching Coronavirus – by Gender					
	Yes		No		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	62%	46	15%	11	23%	17	74
Male	62%	16	27%	7	12%	3	26
Group Total	62%	62	18%	18	20%	20	100
Undisclosed	34%	2	33%	2	33%	2	6
Grand Total	61%	64	19%	20	21%	22	106

Table 10(a)	I'm worried that the people I depend on may catch Coronavirus – by Ethnicity								
	Yes		No		Unanswered		n/a		Total
Ethnicity	%		%		%				
Black and Black British	47%	15	31%	10	22%	7	0%	0	32
Asian and Asian British	17%	1	67%	4	17%	1	0%	0	6
White (British, European, North American)	30%	14	52%	24	15%	7	2%	1	46
Other (Cypriot, Jewish, Mixed)	67%	2	0%	0	0%	0	33%	1	3
Group Total	37%	32	44%	38	17%	15	2%	2	87
Undisclosed	56%	10	17%	3	28%	5	0%	0	18
N/a	100%	1	0%	0	0%	0	0%	0	1
Grand Total	41%	43	39%	41	19%	20	2%	2	106

Table 10(b)	I'm worried that the people I depend on may catch Coronavirus – by Age								
	Yes		No		Unanswered		n/a		Total
Age	%		%		%		%		
50-59	50%	3	0%	0	50%	3	0%	0	6
60-69	27%	3	55%	6	18%	2	0%	0	11
70-79	38%	13	47%	16	12%	4	3%	1	34
80-89	54%	19	34%	12	9%	3	3%	1	35
90+	14%	1	14%	1	71%	5	0%	0	7
Group Total	42%	39	38%	35	18%	17	2%	2	93
Undisclosed	31%	4	46%	6	23%	3	0%	0	13
Grand Total	41%	43	39%	41	19%	20	2%	2	106

Table 10(c)	I'm worried that the people I depend on may catch Coronavirus – by Gender								
	Yes		No		Unanswered		n/a		Total
Gender	%		%		%		%		
Female	41%	30	41%	30	18%	13	1%	1	74
Male	46%	12	38%	10	12%	3	4%	1	26
Group Total	42%	42	40%	40	16%	16	2%	2	100
Undisclosed	17%	1	17%	1	67%	4	0%	0	6
Grand Total	41%	43	39%	41	19%	20	2%	2	106

Table 11(a)	I rely / <u>can't</u> rely on family, friends and neighbours to help me when I need it – by Ethnicity						
	Rely		Can't rely		Unanswered		Total
Ethnicity	%	Count	%	Count	%	Count	
Black and Black British	66%	21	13%	4	22%	7	32
Asian and Asian British	33%	2	50%	3	17%	1	6
White (British, European, North American)	80%	37	11%	5	9%	4	46
Other (Cypriot, Jewish, Mixed)	33%	1	67%	2	0%	0	3
Group Total	70%	61	16%	14	14%	12	87
Undisclosed	72%	13	0%		28%	5	18
N/a	0%	0	100%	1	0%	0	1
Grand Total	70%	74	14%	15	16%	17	106

Table 11(b)	I rely / <u>can't</u> rely on family, friends and neighbours to help me when I need it – by Age						
	Rely		Can't rely		Unanswered		Total
Age	%	Count	%	Count	%	Count	
50-59	50%	3	17%	1	33%	2	6
60-69	82%	9	9%	1	9%	1	11
70-79	68%	23	15%	5	18%	6	34
80-89	71%	25	17%	6	11%	4	35
90+	71%	5	14%	1	14%	1	7
Group Total	70%	65	15%	14	15%	14	93
Undisclosed	69%	9	8%	1	23%	3	13
Grand Total	70%	74	14%	15	16%	17	106

Table 11(c)	I rely / <u>can't</u> rely on family, friends and neighbours to help me when I need it – by Gender						
	Rely		Can't rely		Unanswered		Total
Gender	%	Count	%	Count	%	Count	
Female	69%	51	15%	11	16%	12	74
Male	69%	18	15%	4	15%	4	26
Group Total	69%	69	15%	15	16%	16	100
Undisclosed	83%	5	0%	0	17%	1	6
Grand Total	70%	74	14%	15	16%	17	106

Patients’ information sources regarding Coronavirus

In response to the CCG’s request to find out where patients are getting their information about Coronavirus from, we asked respondents to circle the sources they used from a basic list, and to add others where appropriate. The ‘prompt’ list featured newspapers, radio, TV, ‘phone calls, chats with friends, neighbours and family, in the post, hand-delivered through the door, by Email, or the Internet. **10** respondents ignored this question. The responses from the remaining **96** are listed below ([Table 12](#)).

The highest figures quoted are drawn from the ‘prompt’ list we supplied and may have been influenced by it to the exclusion of other, less obvious NHS and local information points. For example, we did not specify local radio. Given that radio is second only to TV in getting information to patients, the potential value of using local radio to customise messaging for Neighbourhoods and cultural groups would be worth further investigation. The results also highlight the importance of “word of mouth” information flows, especially in pooling wisdom and experience in tough times where official sources and ‘experts’ are routinely distrusted.

Table 12	“Where do you get your information from?”				
Prompt list	%	Count	Added by Respondents	%	Count
TV	77%	74	Info from OPRG	3%	3
Radio	58%	56	Online sources	2%	2
Chats with friends, family and neighbours	44%	42	GP/GP Practice	2%	2
Newspapers	40%	38	Daily Briefings	2%	2
Internet	39%	37	Local Authority	2%	2
Phone calls	35%	34	Healthwatch, HAPIA	2%	2
In the post	27%	26	Council tenants’ run group (PleydellTMO)	1%	1
Email	22%	21	Information from Freeholder Anchor House	1%	1
Hand delivered	16%	15	Bank	1%	1
			Age UK	1%	1
			GLE Covid Hub	1%	1
			Text/Mobile/Whatsapp	1%	1
			CCG	1%	1
			Unanswered	9.4%	10

6 QUALITATIVE DATA: IN RESPONDENTS’ OWN WORDS (Summary)

A major contribution to the survey was the information contributed by respondents via their answers to ‘open’ questions, where they were able to stress, and enlarge upon, issues they were particularly concerned about, or comment on areas not covered elsewhere in the survey.

Respondents contributed **141** comments or queries in this way. **7** of these additional submissions were made on their own paper and a further **5** were submitted separately by telephone and email. A brief summary of this feedback is given below. (Please see [Appendix 1](#) for **full transcript**).

Topic areas: summary

- 1 **Healthcare and social care needs – 43**
of which:
 - Primary care – 10
 - Secondary care – 5
 - Social care needs (incl. adaptations) – 8
 - Eyes – 5
 - Feet – 3
 - Hearing – 3
 - Dental – 2
 - Coronavirus – 3
 - Coordinate my Care – 3
 - 111 – 1
- 2 **Repairs and Maintenance** (general home, appliances, devices) – 16
- 3 **Shopping and Nutrition – 15**
- 4 **Information and communications – 12**
- 5 **Finance and Legal – 8**
- 6 **Social Isolation and Bereavement – 8**
- 7 **Exercise – 6**
- 8 **Transport and Mobility – 5**
- 9 **Carers’ issues and needs – 3**

Brief commentary on responses

- 1

It is significant that so many respondents felt the need, and made the considerable effort, to expand upon their answers in an already lengthy questionnaire. It suggests strong feelings or concerns about certain issues. Very few topics were introduced that were not already covered by the questionnaire. Respondents seemed mainly to want to enlarge upon the dichotomous answers they had already given. However, we should be cautious about assuming that they had no other major concerns. Reticence may have played a part, also memory issues.
- 2

Furthermore, the survey was designed to prompt feedback across a wide range of experience, and these ‘cues’ may have favoured certain areas at the expense of others we didn’t probe for example, perceived inequalities in service access and delivery, now emerging as a dominant concern due to the recent exposure of the disproportionate death toll amongst BAME patients and staff.
- 3

The fact that **18 respondents were unwilling to record their ethnicity** does give cause for concern. Did they fear that by stating it their views might be taken less seriously? Or were they uncertain how to describe themselves? (As stated earlier, and contrary to usual practice, we gave no categories but elected to give respondents the opportunity to self-define.)
- 4

The nature and tone of these comments begins to characterise how these older people view the pandemic, how they are reacting to it (with varying degrees of equanimity) and their key areas of difficulty or need. For some, not being able to replace a light bulb or a hearing aid battery, or get to the bank, are serious matters and evidently crucial to their sense of safety and well-being.
- 5

The sudden loss of normality is what principally concerns a number of respondents who just want to know when the old order of things will be restored. For many older people, change is an enemy especially when there has been no time to prepare for it. The ‘open-ended’ questions were also seized upon by a few respondents to register long-standing, negative perceptions of treatment received (or denied).
- 6

It is important when listening to these concerns to remember that we may not be hearing from those unable to express their views fully in writing (or indeed, at all). Respondents have drawn our attention to their learning difficulties and the physical demands of manually completing the questionnaire. We will be taking account of these limitations in future surveys and responding to them.
- 7

As stated earlier, some service issues were raised separately by respondents via telephone or email. Some were dealt with via Age UK East London and other agencies on receipt – others remain to be actioned. (See [Tables](#) (13a) and (13b).

Follow-up by AUKEK

Table 13(a)	Follow-up to issues and enquiries generated by the survey
Referral	Action
Dial-a-ride and taxi card application forms	Referred to AUKEK Information and Advice service
Home repairs: bathroom light, damage to ceiling caused by flooding	Referred to AUKEK I&A
Gas and electricity supplier	Referred to Shine and AUKEK I&A
Receiving parking fines despite blue badge	Referral to AUKEK Advocacy
One new member	
Caribbean home meals	Justice Food Alliance
Home repairs	AUKEK I&A (Unable to contact, left various voice messages, sent letter about how to get in touch)
Home repairs: floods in house	Referred to AUKEK Advocacy service
Laptop repairs	Newham New Deal partnership online support hotline and Trust a Trader recommended (Unable to contact, left various voice messages, sent letter about how to get in touch)
Home repairs: step in and out of flat is too high, council won't lower it despite tripping	AUKEK I&A

Table 13(b) Further action required
Digital assistance for older people – free equipment, training
People with disabilities spending time in a long queue
Resumption of services and coming out of lockdown – some confusion about which rules affect them (having spoken to clients since lockdown restrictions have changed)

7 SUMMARY TABLES: Respondents' overall view of the impact of lockdown on their health and well-being

Overall, the experience of lockdown and the disruption to their normal patterns of life caused **25** of the **106** respondents to feel “**physically worse**” and **20** to feel “**mentally worse**” than before the pandemic. But a few claimed actually to “feel better”, and **82** said they were generally “**coping**”. Long experience of the vicissitudes in life, and of facing these alone in later years, may well have fortified their resilience and their capacity to ‘keep on carrying on’.

Table 14(a)	Physically I feel worse/no worse/better than I did before Coronavirus – by Ethnicity								
	Worse		No worse		Better		Unanswered		Total
Ethnicity	%		%		%		%		
Black and Black British	13%	4	72%	23	3%	1	13%	4	32
Asian and Asian British	50%	3	17%	1	17%	1	17%	1	6
White (British, European, North American)	24%	11	67%	31	4%	2	4%	2	46
Other (Cypriot, Jewish, Mixed)	33%	1	67%	2	0%	0	0%	0	3
Group Total	22%	19	66%	57	5%	4	8%	7	87
Undisclosed	33%	6	50%	9	6%	1	11%	2	18
N/a	0%	0	100%	1	0%	0	0%	0	1
Grand Total	24%	25	63%	67	5%	5	8%	9	106

Table 14(b)	Physically I feel worse/no worse/better than I did before Coronavirus – by Age								
Age	Worse		No worse		Better		Unanswered		Total
	%		%		%		%		
50-59	0%	0	67%	4	17%	1	17%	1	6
60-69	45%	5	45%	5	0%	0	9%	1	11
70-79	21%	7	65%	22	9%	3	6%	2	34
80-89	23%	8	66%	23	3%	1	9%	3	35
90+	14%	1	86%	6	0%	0	0%	0	7
Group Total	23%	21	65%	60	5%	5	8%	7	93
Undisclosed	31%	4	54%	7	0%	0	15%	2	13
Grand Total	24%	25	63%	67	5%	5	8%	9	106

Table 14(c)	Physically I feel worse/no worse/better than I did before Coronavirus – by Gender								
Gender	Worse		No worse		Better		Unanswered		Total
	%		%		%		%		
Female	22%	16	64%	47	5%	4	9%	7	74
Male	35%	9	62%	16	4%	1	0%	0	26
Group Total	25%	25	63%	63	5%	5	7%	7	100
Undisclosed	0%	0	67%	4	0%	0	33%	2	6
Grand Total	24%	25	63%	67	5%	5	8%	9	106

Table 15(a)	Mentally I feel worse/no worse/better than I did before Coronavirus – by Ethnicity								
	Worse		No worse		Better		Unanswered		Total
Ethnicity	%		%		%		%		
Black and Black British	13%	4	72%	23	0%	0	16%	5	32
Asian and Asian British	50%	3	17%	1	17%	1	17%	1	6
White (British, European, North American)	17%	8	70%	32	7%	3	7%	3	46
Other (Cypriot, Jewish, Mixed)	0%	0	100%	3	0%	0	0%	0	3
Group Total	17%	15	68%	59	5%	4	10%	9	87
Undisclosed	28%	5	61%	11	6%	1	6%	1	18
N/a	0%	0	100%	1	0%	0	0%	0	1
Grand Total	19%	20	67%	71	5%	5	9%	10	106

Table 15(b)	Mentally I feel worse/no worse/ better than I did before Coronavirus – by Age								
	Worse		No worse		Better		Unanswered		Total
Age	%		%		%		%		
50-59	17%	1	50%	3	17%	1	17%	1	6
60-69	27%	3	64%	7	9%	1	0%	0	11
70-79	24%	8	65%	22	6%	2	6%	2	34
80-89	17%	6	66%	23	3%	1	14%	5	35
90+	0%	0	100%	7	0%	0	0%	0	7
Group Total	19%	18	67%	62	5%	5	9%	8	93
Undisclosed	15%	2	69%	9	0%	0	15%	2	13
Grand Total	19%	20	67%	71	5%	5	9%	10	106

Table 15(c)	Mentally I feel worse/no worse/better than I did before Coronavirus – by Gender								
	Worse		No worse		Better		Unanswered	Total	
Gender	%		%		%		%		
Female	21%	15	66%	49	5%	4	8%	6	74
Male	15%	4	73%	19	4%	1	8%	2	26
Group Total	19%	19	68%	68	5%	5	%	8	100
Undisclosed	17%	1	50%	2	0%	0	33%	2	6
Grand Total	19%	20	67%	71	5%	5	9%	10	106

Chart 1: "How are you feeling overall?"

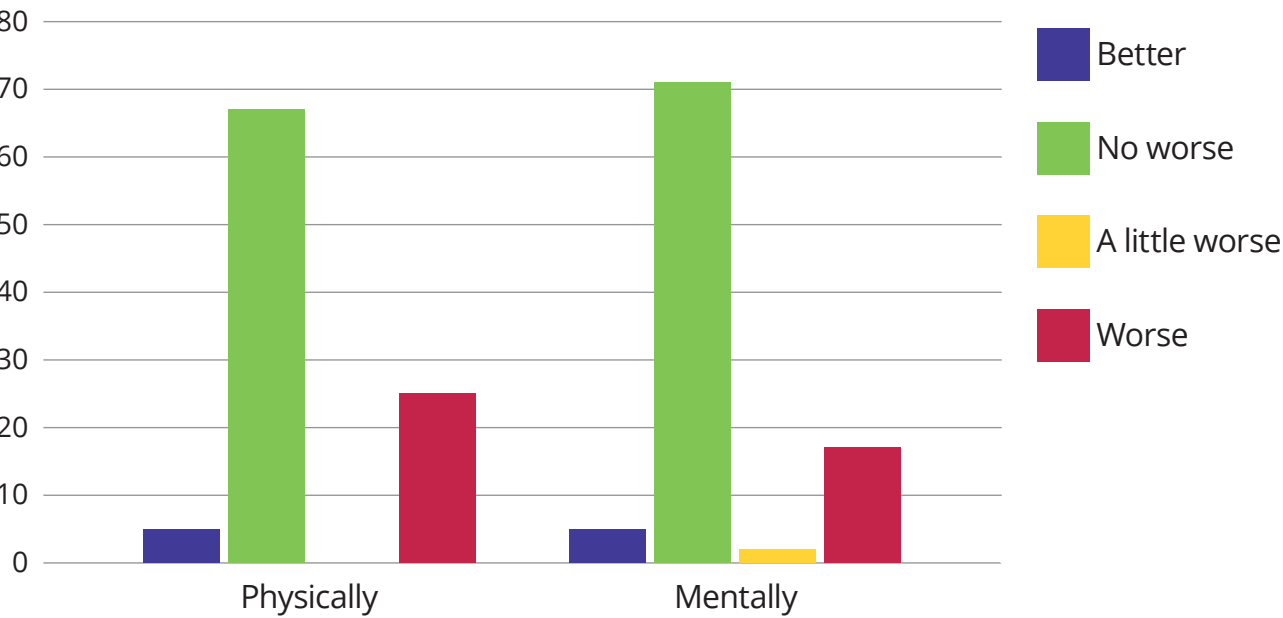
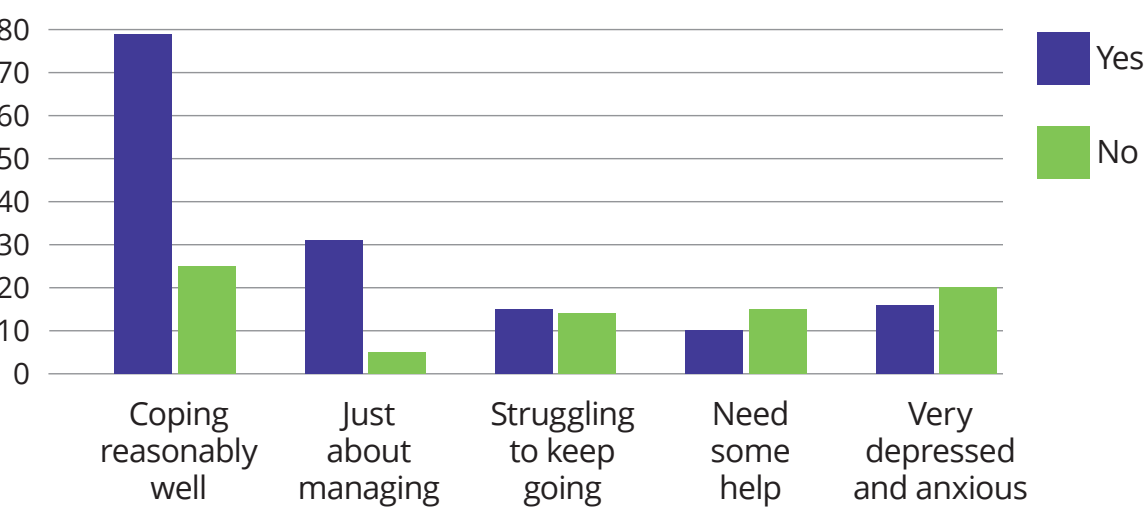


Chart 2: "How do you feel you are coping overall?"



8 CONCLUSIONS

Toward Recovery, Resilience and Risk Management

The OPRG’s aims in mounting this survey are two-fold. First, we wish to offer a channel through which OPRG patient-Members can register their lived experiences of the Covid-19 pandemic with assurance that their voices will be heard and heeded. Second, we are keen to provide primary data that our services can use to guide them in restoring our eroded health and care systems, aid patient Recovery, equip us all to collectively manage Risk and build the Resilience required to meet future emergencies confidently and effectively – the new “three ‘Rs’” of the “new normal”.

To this end, we need to maintain and build stronger patient and public involvement. Future patient participation levels will

depend on the perceived value to patients of spending their time and effort in giving information and making suggestions. It is therefore essential that surveys from all sources should be outcome-focused and that policy-makers, commissioners, and service-givers understand the need to be diligent in giving reverse-feedback (even if the answer has sometimes to be ‘no’ – or ‘not yet’).

Mindful of the distancing effects of regional system drift, it will also be vital to continue to provide accessible, local platforms, such as NHS Community Voice, Healthwatches, Safeguarding groups, our own OPRG and other community organisations to foster local dialogue and cement local patient-provider partnerships.

What does this survey tell us?

We are eager to know what new lessons others may learn from our survey: what myths or stereotypes it may demolish and what basic facts or truths it may reaffirm. Here are our initial conclusions, to be tested by further reflection and valuable information coming in from a plethora of other local surveys completed or underway.

1 Older people must not be thrust into ill-fitting categories: ‘one size fits all’ may be good business for Primark but it grossly disserves and distorts the needs of residents as they age whether in (nationally) designing a ‘shielding’ policy

for the ‘vulnerable’ or (illegally?) making a group-based decision on whether care-home residents should be offered hospital treatment or even resuscitated.

2 It isn’t wise, or helpful, to extrapolate for the many what one older person’s experience suggests. Each case has to be treated on its merits as the quote **“When you’ve met one older person, you’ve met – *one* older person”** sagely affirms. Older people do not generally subscribe to a ‘tribe mentality’ or ‘group think’, but tend to rely on a fund of common sense built up over a lifetime.

3 Though the survey shows an **apparent high degree of conformity to the new behaviour rules** imposed by government with many reacting dutifully to lockdown, there are instances in it (and in conversation) of both strident opposition to, **and quiet rebellion against, the tight restrictions we have been living under.** Whilst some older people have been scrupulous in Staying at Home, Protecting the NHS and Saving Lives, others have protested at the apparently indiscriminate confinement amounting to 'house arrest' imposed upon anyone over 70 years of age, and not all have submitted to it. We have noted reports of trips to the country, or to see distant relatives, and a hairdresser gratefully booked for a home visit.

4 Our 'open-ended' questions have provided an insightful 'litmus test' of life under lockdown, dipping into some people's lives and feelings whilst providing an emotional escape valve for others. (*"I love to speak my mind!"*). They reveal warning signs of **mental stress taking its toll**, but also of determined fortitude and a positive outlook.

5 There is also evidence in some responses of **an idiosyncratic approach to managing health risks** dictated by a fatalistic approach to life which could undermine, or at worst neutralise official prevention policy and practice.

"I came to this country 1980 April. By September I turned into a DIABETIC???? So my HEALTH is much more important than the virus. I'm not bothered about this virus

– I will die anyway with the virus or without virus. What would you do if you were in my shoes?"

Patients in our survey who ascribe their health problems (diabetes, hole-in-the heart, loss of teeth etc.) to societal or service failures may require treatment and care matched to their character as much as to their ailments.

6 Responses confirm that older people rely heavily on the support of family, neighbours and friends to get by in the pandemic but **42% say they are not getting enough contact with them.** Against this background, Safeguarding data show rising levels of abuse at home during lockdown (viz. City and Hackney Safeguarding Adult Board data, 23rd June 2020). **57% feel they are lacking in social contact.** Contact of both kinds has clearly been difficult to manage under lockdown and it may be significant that the absence of the normal escape valve of a trip outside four walls is so strongly felt by older people.

7 The survey demonstrates **the crucial role of mobilising social capital** in a national emergency, and doing so quickly. There is abundant evidence of solitary older people relying on this help, but very little revealing the potentially serious risks where they do not, or cannot, connect with it. This underlines the importance of focusing on unheard voices, their existence suggested by the hints and 'side issues' that people mention, and the advocacy of (a few) concerned peers.

8 Here and there respondents remind us **how important, how effective and how much appreciated these spontaneous community responses have been**, filling gaps whilst normal services reconfigure and staff work from home and testifying that the bedrock of goodwill and solidarity is there to be called upon, and not just in a crisis. Responses such as 'Made in Hackney' food deliveries, the Hackney Mutual Aid shopping service, the City's library book deliveries and building-based support groups, together with the regular telephone calls made to isolated residents in both local authorities, have literally been life-savers. It is an essential auxiliary resource, economically complementing the government's own programme to which we know **older people have themselves contributed**, albeit restricted by distancing requirements.

9 Although the survey did not probe **the contribution of older people** during the pandemic, respondents' feedback demonstrates it: their readiness to self-care to relieve services under pressure, to give advice and encouragement, to check on their neighbours, to help out family members facing hardship, take on child-care and make supportive telephone calls to isolated residents (including to the OPRG Team!). Where digital skills allow, some have joined video-meetings to keep Patient and Public Involvement alive, and have in various ways kept themselves informed and acted as community informants, too.

10 The reservoir of resilience and self-denial that exists in our older people, their ability to 'cope', 'carry on' and contribute, is rooted in a lifetime of experience in dealing with emergencies and life-changing disruption and loss of all kinds, from family break-ups, to war, destitution and disease. **There's a lot wrapped up in just one of these: the clinical term 'co-morbidity'.** (See the table of 'conditions' that our respondents cite). Now that we tend to live longer with such conditions, rather than die early from them, older people are often able to develop coping mechanisms – valuable, transferable skills – which can help with other life-events and be passed on as 'social capital', much like the lettering in Brighton rock.

11 Health and care services are formulated to address these endemic "long-term conditions". But, **do these 'big issues' in our planning crowd out the lesser, but equally important practical needs?** If a kingdom can be lost for want of a horseshoe nail", can a life be critically damaged for want of a lightbulb or a hearing-aid battery, or a functioning washing-machine, or help in the garden? Our respondents tell us it can: they are more vocal in begging for help with "small, everyday things" than a visit from their GP. It is a long-standing and apparently intractable issue in which both the human and economic costs are unquantified and largely ignored until they culminate in physical or mental collapse – or an adult safeguarding review. The

(sometimes) desperate tone of this feedback indicates the drift:

"My wife has now got a carer on a daily basis, but there's plenty more work to be done in our home... Please let me know what step I should take in my current state of health.. I would greatly appreciate your help... A.S.A.P."

- 12 Comments heralding a deeper issue, our changing times, pose particular challenges in supporting older people through the Covid-19 recovery phase. **Rapid change**, bringing altered routines and disruption to what is deemed 'normal life, is particularly uncomfortable for many older people and can be detrimental to their physical and mental health. This is evidenced by the 3-year average life expectancy of those re-locating to care homes and by survey comments such as this:

"I just wanted back as Normal. NOT CHANGES because that's Not Fair to me. That's why it's Terribly Frustration. I want to complain for what it happening"

- 13 In the short to medium term, respondents are particularly anxious about **cancelled appointments and the lack of information** as to when these will be re-scheduled. In some cases, (e.g. ENT at UCLH) the Department is non-contactable either by 'phone or email, and text messages supposedly sent advising patients of cancellations have not

always been received, leaving people unsure as to whether or not they should present themselves or risk losing an appointment entirely if they fail to appear. There is abundant evidence, within and beyond this survey, of the extent to which **endemic systems weaknesses at every level** are frustrating the best efforts of committed staff trying to operate them, and failing patients.

- 14 **Face-to-face sessions with their professional advisers** remain for many patients the preferred mode of engaging with them. For some it is the only way. Telephone contact has been widely used during lockdown, but there are difficulties for those with hearing impairment, those with language or learning difficulties, or those who need the reassurance of a more sociable, close encounter with a human being before they can confidently unburden themselves. The situation is made all the more acute because human contact is fast being eliminated in society as services and business transactions increasingly become mechanised or handled online. **The 'digital divide' is overwhelming** in our OPRG membership but with some encouraging progress towards wider IT literacy.

- 15 Finally, of prime importance is the ongoing challenge of keeping older people properly informed first by listening to what they say they need to know, and second by ensuring that the resulting messages are timely, presented intelligibly in accessible language and format via the most appropriate media, and **are also distributed to people's homes wherever possible**. Our experience shows that people value information leaflets that can be retained and re-read. We took care to front our survey with a letter of friendly encouragement, but also with some handy information and contact details – making sure that we reminded our members to keep hold of it for future reference.

- 16 The survey has yielded useful data on where people look for information, and has emphasised the particular needs of recipients with learning difficulties, physical impairment and sight or hearing loss (possibly also memory loss).

9 PRIORITIES and ACTION

To underpin Recovery, Resilience and Risk Management in respect of our older residents in Hackney and the City, we **recommend** that **commissioners and service providers consider and respond** to the following list of priority ACTION points based on our survey findings and associated community intelligence. We urge them to:

- 1 Consult with older people directly to provide 'tailor-made' home care that adequately meets individual needs; reverse raised eligibility levels; use lockdown evidence to bid for equalised social care funding.
- 2 *Really Make Every Contact Count* (especially in emergencies); ensure all agencies are primed to observe and assess the health, circumstances and environment of every older person they see or visit, and exchange information to coordinate services and speed delivery.
- 3 Publicise the *Coordinate My Care* scheme more effectively, and help patients sign up to it by mail and telephone as well as electronically; monitor and report on progress towards closer co-working across services with training support that draws upon case-studies provided by patients.
- 4 **Create a dedicated, centrally-held database, accessible to all services, identifying all older people living alone;** build in parallel arrangements for regular telephone checks to update their health and care status.
- 5 Maintain and refine food delivery services to older people to meet dietary and cultural needs; use a Handyperson service to check recipients have a working microwave and fridge.
- 6 Support lunch clubs to provide good nutrition, social contact, and volunteering opportunities.

- 7 Improve the appointments systems in both primary and secondary care and in community services, ensuring patients who require face-to-face consultation have full, unrestricted access to it.
- 8 Enhance medication support, **especially for those experiencing accelerated memory loss and other mental issues** following lockdown, and who **live alone**. Reliable deliveries by pharmacies should be universally available to those requiring them (which some respondents report they are not.) **This is a high-risk area.**
- 9 Intensify efforts to work creatively to inform and safeguard older people against scams and fraud perpetrated by expert criminals exploiting opportunities afforded by lockdown. New IT users may be at high risk.
- 10 Increase joint resourcing of areas affecting health and mobility, notably nutrition, housing, finance, walking aids and street safety; address home safety, and support decent living standards, by offering a low-cost, accessible and timely repairs service for vital aids and equipment and key domestic furnishings and appliances.
- 11 Refine data-sets to capture the diversity of older people, especially in the upper age-groups. **A catch-all "75+" category is wholly inadequate**, demeaning and unacceptable, not least because it signals a disturbing neglect of the detailed profiling needed to supply this (potentially) long-living group with **individualised treatment and care**. Our survey's demographics show a strong 'skew' towards the 80+ age-bands, obliging the OPRG and our partners to better understand their characteristics and needs so that we provide for them appropriately.

12 Above all, **work to counter the negativity and loss of confidence evident amongst many older people who believe they are increasingly viewed as expendable by policy-makers.** They note excessive deaths in care homes, and reports of *en bloc* "do not admit to hospital" and "do not resuscitate" instructions being applied. They are worried by the lack of government plans to boost and upgrade social care despite known service deficits likely to be magnified by the protracted rehabilitation needed by 'long' Covid-19 victims.

13 Conduct a 'systems and pathways' audit to expose fractured, misaligned and uncoordinated service delivery; prompt regional/national bodies to do likewise, in order to more reliably convert sound policy into good practice.

14 We further urge commissioners and service providers to **make a public commitment to:**

- actively promote dignity and respect towards older people (as in 'Make Safeguarding Real') and adopt the OPRG Dignity Code;
- challenge and dismiss negative age-stereotypes that define older people as vulnerable, valueless, non-contributors to society;
- expose and oppose growing covert, illegal age-discrimination;
- demolish 'age' as a value-judgement by widening and facilitating the social inclusion of older people and recognising achievement;
- reinforce meaningful service-user involvement and embed it across all health and care systems at local and North East London (NEL) levels;
- design recovery measures to eliminate the health inequalities affecting older people;
- initiate action to eliminate pensioner poverty, in particular by raising awareness of pension credit entitlement and boosting uptake.

The City and Hackney OPRG is committed to working in close partnership with our two local authorities, our commissioners and local community organisations in mounting a unified campaign to justifiably restore older people's status, condition and confidence wherever it has been eroded. Society has manifestly regressed in tackling inequality of all kinds during this pandemic: we do not re-start from where we stood before it. We therefore need to reaffirm our philosophy of **equity and social justice for all** as benchmarks in our Recovery policy-making and planning.

A measure of the task facing us in taking the positive action required to embed this philosophy as the 'new normal' of Recovery can be judged from these chilling final words from an OPRG survey respondent:

"What life after lockdown?"

"With the continuing infection and death rates in Britain, I would consider myself a fool if I risked my life by leaving the house. I will continue to stay indoors and order food and supplies for delivery.

The government has not given a tuppenny toss about old people, ill people, building workers, supermarket workers, transport workers, and of course health workers and care workers – I could go on. The lockdown

came far too late and thousands were already infected, many of whom have since died. Then it was never a proper lockdown, with hundreds of thousands of people still forced to go to work with no protection.

Thousands of elderly people were sent to care homes to clear hospitals. There they received no health care which is why so many died. People were told to stay home if they had symptoms instead of being immediately hospitalised; other countries have shown that early treatment saves lives.

I stay at home because I realised weeks, even months ago, that the government does not care if I live or die. Our prime minister's warning that we must prepare to lose loved ones gave the game away. To the government human life is cheap. Its messages are full of meaningless words like 'shielding' and 'bubble'. Who invents this stuff? It has eased the lockdown while infection and death rates are still far too high. It was only forced to delay reopening schools by the determined efforts of teachers and their unions. People have been lulled into a false sense of security. More will become ill and more will die.

So that is what I think of the disgraceful treatment of Covid 19 by our government, when they had plenty of time to learn from the experiences of countries like China and do things differently."

Could there be a more powerful call to concerted action?

OPRG Planning Group, 26 August 2020

Appendices

Appendix 1

Patients' verbatim comments, queries and complaints via 'Open-ended' survey questions:

1 HEALTHCARE NEEDS/ ISSUES

a Primary and Secondary Care

- | | |
|--|--|
| <p>1. Experiencing a lot of confusing and frustrating healthcare service issues</p> <ul style="list-style-type: none"> • Contradicting advice from dermatologist and medic • Confusing appointment information • Difficulty getting medicine from chemist because they don't accept cash and refuse to deliver. | <p>11. I need to pick up my new glasses and the hospital has given me, my equipment because I broke my hip</p> |
| <p>2. 111 is helpful as long as you call at the right time.</p> | <p>12. (I need information on) getting my hearing aid repaired, ENT hospital has cancelled all appointments. I am very deaf and having trouble with hearing aids. Not been seen for over a year.</p> |
| <p>3. (Would I) avoid A&E? Possibly, also worried how I would get there.</p> | <p>13. I need to be measured for and to collect my news glasses following an eye test in March 2020.</p> |
| <p>4. Since I was put on insulin my heart got a hole in it.</p> | <p>14. Moorfield (s) gave me some(one) else('s) Laser – my sight is bad.</p> |
| <p>5. I came here in 1980 April but September 1980 I was diabetic???</p> | <p>15. The dentist destroy all my teeth.</p> |
| <p>6. 2006 my hear(t) went il(t)s got a HOLE.</p> | <p>16. Dentist: routine check-up has been cancelled.</p> |
| <p>7. A GP does not do cancer treatment, this is done in the hospital, a GP is not a cancer doctor, there is not any cancer nurses at the GP practice.</p> | <p>17. I was admitted to the mental health ward in hospital but I am out now since April.</p> |
| <p>8. My eye is not very good you can see am struggling to read and write.</p> | <p>18. [I need information on] Dementia.</p> |
| <p>9. I need new glasses. I am a diabetic, with one cataract repaired. The other not yet mature. I am using the old glasses as I cannot collect the new ones.</p> | <p>19. I have severe pain in my right hand thumb, arthritis. I have been recently discharged from operation to that thumb two months ago but can't get back to Guy's hospital. I have asked my doctor to refer me urgently but they (say) the same (thing) that they can't get through. So I am left in limbo.</p> |
| <p>10. I'm in constant pain.</p> | |

20. I feel that I was wrongly put in the shielded list, I don't enjoy being cooped in my flat for that length of time. I am a sensible person and responsible. I would like to be given a choice. I did write to my surgery to ask to take me off the list but I got no response.
21. [re- Coordinate My Care]: If [my GP] thinks I need it he will get in touch
22. How I can register for 'coordinate my care'? (I have had no info from my GP practice).
23. Coordinate my care – my GP surgery called regarding a service I could access but not about (CMC)
24. Need to speak to my practice nurse.

b Social Care needs/issues (including aids and adaptations)

25. Concerned that Hackney Council will only help 1 person at a time in the Household.
26. Hackney Council take too much money for caring.
27. Have a broken wrist – getting support from Made in Hackney and food parcels.
28. The help I need by my family requires them to come into my home so I'm not able to access support, e.g. help me change the sheets on my bed because I have a broken arm.
29. Worried about the people I depend on catching coronavirus: I am self-dependent and would rely on services.
30. How to get help occasionally with specific tasks.
31. How to get help with ordinary everyday things.
32. I am unable to have help with cleaning my home due to social distancing/isolation. I am unhappy about the deterioration of my housekeeping standards.
33. Not had difficulty accessing the services I normally rely on.
34. There have been positives in how I'm being cared for.
35. I have still not steps lowered to get in and out of my flat the council keep stalling and still say I'm not in a wheelchair which is rubbish. I have on several occasions because the step is high and I have difficulty lifting my left up high enough I have tripped and nearly fallen but raised my arms stopping myself.

c Carers' needs and issues

36. (Concerned about) the limits on carers e.g. no time for disabled travel, but no account taken for the carer who has to travel at the same time.
37. You haven't asked if I'm caring for anyone.
38. I am a carer for my adult son who has autism.

2 CONTEXTUAL HEALTHCARE ISSUES

a Exercise

39. I have always gone for walks prior to getting shielded mainly to stabilise my diabetes. I find it quite difficult to 'walk like I used to' probably due to being "sedate" for a while.
40. Getting exercise but only indoors.
41. Not getting enough exercise because my classes have been cancelled.
42. Going for a walk clears my head.
43. Physically: more creaking for lack of exercise!
44. I wonder if it's worth suggesting online exercise classes (on YouTube etc.) found useful by OPRG members so we can try and keep fit during lockdown? I could suggest a few.

b Social Isolation and Bereavement

45. Enforced isolation when recently bereaved is particularly challenging. It add a major life changing dimension, to the disruption of patterns of normal conduct caused by lockdown. It exacerbates loss of confidence caused by the virus threat, and magnifies fears and feelings of being 'unsafe at home'.
46. I'm worried about getting my Will re-written and new Executors appointed following my husband's death in February.
47. I feel that I was wrongly put in the shielded list, I don't enjoy being cooped in my flat for that length of time. I am a sensible person and responsible. I would like to be given a choice. I did write to my surgery to ask to take me off the list but I got no response.
48. Social contact? only by facetime or email except for my husband.
49. Watching church services on the TV/live stream.
50. I think the Council should take responsibility for pension(ers) who live alone.
51. For people who live alone will feel it more, not able to see anyone. People used to like going to the market for their bargains. It will not be there same again. The market will take time to pick up again. I wish we were given more time to prepare. People have to queue for the shop which is not okay for people who cannot stand for long.
52. The main thing I miss is friends, family and the things I used to do before the lockdown (go to the library, exercise, social activities).
53. Why do u not have record of vulnerable people living along that u can phone to talk to on how they are coping. i.e. I phoned an elderly lady with dementia who only got information on how to stay safe nothing else, so I had to email on her behalf to organisation and council who can help with her needs, and then she gets the help.
54. The lockdown has eased a bit. At the end of the year, I suppose people will be able to see their relatives.

c Covid-19 and Lockdown

- | | |
|---|---|
| 55. I'm not bothered about the virus. It was here since last year, nothing was done and look how many older people died in care homes???? | 58. I just want things to go back to normal (like attending Connect Hackney sessions.) Things are changing but not for me, it's terribly frustrating. I want to complain for what is happening. |
| 56. (There should be a) full public enquiry to be held in Hackney after pandemic/ coronavirus has ended. | 59. What are the latest official information for the origins of the Coronavirus? |
| 57. When are we going to be safe and free? | 60. I need information on when testing and t(r)ack and tracing will be available to all. |

d Communication and patient access to information

- | | |
|---|---|
| 61. I want face to face not telephone consultation. | 71. Accessing information by 'phone can be very stressful and time-consuming; no yellow pages for telephone numbers and horrendous costs for directory enquiries. Don't have a smart 'phone – rely on landline. |
| 62. I think I may not get a July outpatient appt. but I don't know yet. | 72. [24. I have spoken/haven't spoken to (GP)] Respondent wrote: for repeat medication. |
| 63. Wanted to know when foot care would be resumed (Swollen feet, can't get the shoes on, hard feet and nails, causing a lot of discomfort, 90 years old), going between the clinic and the GP. | 73. Communication has generally been inadequate regarding Covid-19. Responses to it very unclear, confusing and often written in a style that is user unfriendly. It has also been sparse and slow to appear. 'Public and Patient Involvement' disappeared overnight under the pressure of crisis management – yet PPI and feedback was vital to guiding and delivering services. |
| 64. Ongoing hospital treatment: I have no information about foot care or ear checks due. | 74. (I) need any information OPRG is giving out that will be of use to me. |
| 65. Where can I obtain urgent dental care? | 75. No information needed, received information from the GLE Covid Hub with useful tel. numbers and addresses and also from the OPRG. |
| 66. Is it possible to get dental, eyes, ears or feet dealt with at the moment? | |
| 67. When (will) medical services e.g. dentist, optical and other services be more accessible? | |
| 68. When will UCLH ENT proceed with my appointment for microsuction? | |
| 69. (I need information on) getting my hearing aid repaired. | |
| 70. (I need information on) nothing – I listen to radio and TV. | |

e Shopping and nutrition

- | | |
|---|--|
| 76. Have niece next of kin come once a fortnight for shopping. | 82. I have plenty of offers with shopping etc. The Catholic Church have offered, the elderly Irish have offered. |
| 77. Impossible to get Ocado to deliver to me, despite being classified as extremely vulnerable because I have not shopped with them regularly enough to qualify. This has upset me (and) seems at odds with the government's aim of getting help to people like me. | 83. My son helps me a lot, he gets my shopping and I phone him if I need anything done, I am very lucky. |
| 78. (I need information on) Help with food shopping. | 84. My son has moved in to help me with shopping etc. |
| 79. No issues getting cash to pay people. Doing my own shopping with credit card. | 85. For a Jamaican neighbourhood-friend, is there a Caribbean home meals delivery services like Made in Hackney (which I receive?) |
| 80. I received a telephone call offering me food parcels – I received my first one a week ago (?5May) from Newham. | 86. Offers of delivery services via Mutual Aid very helpful (Cllr O Wrouth). |
| 81. Food supplies: possibly no worse than anyone else! I used to walk a lot to fit my shopping in many places, it's much more restricted now | 87. Queueing for the shops is not okay for those who can't stand for long period(s). |
| | 88. Eating better because receiving Made in Hackney meals |
| | 89. Diet healthy but more restricted. |

f Repairs and maintenance to the home and appliances/devices

- | | |
|---|--|
| 90. I need help to sort things(s) out, cannot manage. Did have a flood at flat did not get much help from council had to go to friend for 3 nights–nowhere else I could go. | 94. (I need information on) getting my hearing aid repaired. |
| 91. How to get any supplies of batteries for my hearing aid device. | 95. (I need information): bathroom light needs fixing. |
| 92. Washing machine is broken, having to use professional laundry company in the meantime, and it is very costly. | 96. Another big concern is getting devices that one depends on repaired. |
| 93. I have tried to switch my gas and electricity but I am having problems with old appliances. | 97. (I need) home repairs. |
| | 98. I need my light bulbs changed. |
| | 99. I don't need hearing aid batteries now but I might in the future. |

100. I have a CD radio and tape that isn't working.
101. The light in my drawing-room has blown, the ceiling is too high for me to fix. I depend on lamps, not having a bright light depresses me as I enjoy craftwork.
102. I do need repairs to my computer.

103. Trust a Trader for computer service needed.
104. I will like my laptop check out please in there's someone who can offer help during lockdown. I use it all the time.
105. Really need help; help with garden
106. Have issues with repairs to house; particular problem not being looked at.

g Transport and mobility

107. When public transport will be safer, allowing social distancing, enabling more people to travel around the local area for vital necessities?
108. How can I park my new car in the car park on disabled bay with my blue badge displayed on the dashboard but still the ticket officer come and issue ticket 4 times?
109. Want help to get taxi-card and dial-a-ride bus because I used to have a lot of hospital appointments and sometimes I find it not easy to get home.

110. I have noticed that on the roads, they want to make the roads wider, so there is sufficient space. Also I am not sure about the other roads. There won't be enough space for cars. The bus is rejecting people on. This will be a major problem for people who rely on them.
111. I am no longer driving a car, so I worry about getting safe public transport for distances I cannot walk, when the lockdown is lifted I find it quite difficult to walk like I used to.

g Finance and legal issues

112. (I need information) on pension entitlement following bereavement.
113. Ordinary life is getting difficult because I cannot go to the bank because I have to take public transport.
114. LBH has hi-jacked my direct payments account, again without written explanation
115. I have anxieties about completing unaided the winding up of my husband's estate, and helping struggling self-employed family members due to loss of work.

116. I need urgently to contact my bank HSBC to arrange transactions related to accounts and generally what is going on now.
117. McMillan nurses have offered me (help) if I need it with benefits.
118. I manage my income very carefully, missing out on some things in order to pay for others.
119. Scams: I usually hang up the telephone. I try to follow the advice the Police give during OPRG Open Meetings
120. I am worried about the financial situation of family members.

3 ACCENTUATING THE POSITIVE

121. Please note, I live with my family. They do my shopping, cooking housework and personal care I need. I do not need letter from my GP. I am not shielded, I am retired. I am in isolation and can do this as long as I wish, I do not have to answer to an employer.
122. Seem to be getting all I need. I also know where to go for [what I don't have]
123. (I need information on) nothing – I listen to radio and TV.
124. At the moment I am keeping well and I am getting my medication.
125. (I need) NIL, my children support me in times of need.
126. (Nothing to add) I think everything is covered and I answer all the questions okay.

127. I do the best I can to be independent (at home) remembering my vulnerability.
128. In general I'm not worried
129. As an active member of the community and with family and friends I can no longer do so much. This is giving me a rest, a breather and time to catch up on myself.
130. I am coping reasonably well with help.
131. I have a strong faith and have a positive attitude that keep me going.
132. I am being looked after well, thank you.
133. As a retired nurse with 3 nursing qualifications and over 40 years' service in various parts of the NHS, my positive but practical approach keeps me going, together with the help of agencies and individuals like yourself. Thank you so much for all you are doing to reduce the suffering in these fearful times.

Appendix 2

OPRG survey cover letter, and survey schedule



Please keep this letter

Dear Friends,

HOW ARE YOU COPING WITH LIFE IN 'LOCKDOWN'– CAN WE HELP?

Because our OPRG Office is closed, and we sadly can't get together at our normal OPRG Open Meetings, we are writing to all our Members to say 'hello' and to let you know we are still here and working hard on your behalf. We are particularly keen to know **how you are in health**, and **how you are managing under the 'stay at home' and 'shielding' arrangements**.

Our health and social care colleagues are keen to get as much feedback as possible from older people to guide them in providing the support you need, so we have put together the attached survey form which includes some of their questions alongside our own. There is space on **Page 2** for you to tell us about any **problems you (or someone you know) are experiencing which the survey doesn't cover**. We will do our best to sort them out, or (with your permission) put you in touch with the right people to help you.

You don't have to put your name on the survey – but if you do, and give other details about yourself that we've asked for, **we promise to treat this information confidentially**. Please do answer our questions as fully as you can. **YOUR RESPONSE REALLY MATTERS! – the information is valuable.**

NEXT STEPS

CAN WE HELP to make your life better? If you'd like to tell us more about your needs or difficulties, what assistance would make a difference – or just have a friendly chat – please call **Sophie** at the OPRG on **07384 511 701**. She is working from home and would love to hear from you **Mon–Fri 9.30am–5.30pm**.

You can also call **Age UK East London**, or two HELPLINES, one for Hackney residents and one for City of London residents. (Please see enclosed leaflets).

PLEASE NOTE

The local NHS is 'open for business' and ready to safely provide care to people who need it. It is important you do not wait if you need urgent medical help. **Call your GP if you are unwell** (for any reason, not just if you have the virus) and **contact 111** if you think you have the virus.

If it is a serious or life-threatening emergency, for instance if you or a family member have symptoms of a **heart attack** or **stroke**, **call 999 immediately**. If you are told to go to hospital, **it is vital that you go**.

PATIENTS AT VERY HIGH RISK

Patients at high risk are being shielded if they contract coronavirus because of underlying health conditions are being given special protection at home under 'shielding arrangements'. **If you think you should be shielded but have not received a letter from your GP practice** confirming this, please raise the matter directly with your GP.

We will get through this Corona virus emergency by helping each other and trying to stay positive! **THANK YOU SO MUCH for your invaluable help in COMPLETING OUR QUESTIONNAIRE**. Please keep this letter for your information and **RETURN the SURVEY FORM a.s.a.p in the STAMPED, ADDRESSED ENVELOPE PROVIDED**.

Thinking of you warmly, and wishing you well,

Kind regards,
The OPRG Team, 13 May 2020

OPRG SURVEY SCHEDULE

Starts here:

1. MY NAME is (optional): _____
2. MY AGE IS: _____
3. MY ADDRESS is (optional): _____
4. MY TELEPHONE NO. is (optional): _____
5. MY E-MAIL is (optional): _____ 6.(or circle "Don't have")
7. MY GENDER is: Female, Male, Other _____
8. MY ETHNIC BACKGROUND is: _____
9. I LIVE ALONE (**Yes / No**)
10. WALKING IS DIFFICULT FOR ME (**Yes / No**)
11. I HAVE A DISABILITY? (**Yes / No**)
12. I SUFFER FROM THE FOLLOWING CONDITIONS: _____
13. Please let us know here about any information you need.
I NEED INFORMATION ON: _____
14. Please tell us where you get **INFORMATION ABOUT CORONAVIRUS** from. Is it from (please **circle ALL sources**):
Newspapers Radio Chats with Friends TV
In the post By Email Neighbours & Family Phone calls
The Internet Hand-delivered through the door
Anywhere else? _____

15. Is there anything you would like to tell us about that isn't covered in the survey? _____

16. Do you have any other questions or comments for us?

My health and well-being profile

(Please **circle ONE of the choices** in each question):

17. I've **been / haven't been** diagnosed with Coronavirus.
18. I've **received / haven't received** a letter telling me I am being "shielded" at home because my medical conditions mean I'm at very high risk of being infected with Coronavirus if I go out.
19. I've **received / haven't received** a letter from Hackney Council or the City of London Corporation offering to send me food parcels if I can't go out.
20. I've **received / haven't received** a letter from my GP practice telling me about a scheme I could join called "Coordinate My Care".
21. I've **had / haven't had** one or more new illnesses since Coronavirus
22. I'm **taking / don't want to take** my usual medications.
23. I **have / don't have** difficulties getting supplies of my medications.
24. I've **spoken to / haven't spoken to** a GP since Coronavirus.
25. I've **needed / not needed** to speak to my GP since Coronavirus.
26. I've **used** the 111 out-of-hours service since Coronavirus. **Yes / No**
27. If 'Yes' did you find the service **helpful / not very helpful / not at all helpful**? (Please **circle ONE** of these)

28. I've been **admitted / not been admitted** to hospital since Coronavirus.
29. I would avoid going to A&E because I'm afraid of getting infected:
Yes / No
30. **None / some / all** of my scheduled outpatient appointments have been cancelled or postponed due to Coronavirus
31. **None / some / all** of my ongoing hospital treatments have been cancelled or postponed due to Coronavirus
32. I'm **receiving / not receiving** home-care visits.
33. I'm **receiving / not receiving** district nurse visits.
34. I'm recently bereaved. **Yes / No.**
35. If 'Yes', I have support **Yes / No**
36. I **rely / can't rely** on family, friends and neighbours to help when needed.
37. Before Coronavirus I **regularly visited / did not visit** a place of worship.
38. I have **problems / no problems** getting food supplies that meet my needs.
39. I'm **eating / not eating** as well as usual.
40. I have **problems / no problems** getting cash to pay for shopping .
41. I feel I'm **getting / not getting** as much exercise as I need.
42. I'm **sleeping / not sleeping** as well as I normally do.
43. I feel I'm **getting / not getting** as much social contact as I need.

44. I feel I **have / don't have** enough contact with family, friends and neighbours.
45. I feel lonely **much of the time / sometimes / rarely / never.**

Keeping 'shipshape'

46. I **need / don't need** to get my toenails cut.
47. I **need** to visit my dentist. **Yes / No**
48. If 'Yes', is this urgent? **Yes / No**
49. I need to have my eyes examined. **Yes / No**
50. If 'Yes', is this urgent? **Yes / No**
51. I **need / don't need** maintenance or batteries for a hearing aid.
52. I **need / don't need** repairs to my glasses.
53. I **need / don't need** repairs to my TV or radio.
54. I **need / don't need** repairs to my telephone or mobile 'phone.
55. I **need / don't need** urgent home repairs for safety reasons.
56. Anything else? (Please write it here, or **on Page 2**)

Staying safe from criminals and 'scammers'

57. Has anyone you don't know come to your door offering help? **Yes / No**
58. If "yes", did this worry you? **Yes / No**
59. Did you accept their help? **Yes / No**

60. Have you lent anyone you don't know your credit card or bank card to shop or get cash for you? **Yes / No**

61. Has anyone you don't know 'phoned you offering help? **Yes / No**

62. If "Yes" did this worry you? **Yes / No**

63. Did you accept their help? **Yes / No**

64. Have you ever given your bank/ credit card details to a caller you don't know? **Yes / No**

65. Have you ever been the victim of a 'scam' (someone falsely claiming, for example, that you've won a prize, are owed a refund by the Taxman, or that your 'phone is going to be cut off – or someone offering you a Coronavirus test for money? **Yes / No**

66. If "Yes", have these scams increased since C'virus? **Yes / No**

In general, how do you feel about life since coronavirus?

67. I feel more anxious **Yes / No**

68. I feel less safe at home **Yes / No**

69. I feel less safe when I have to go out **Yes / No**

70. I'm worried about catching Coronavirus **Yes / No**

71. I'm worried about getting ill with something else and having to go to hospital where I might get infected. **Yes / No**

72. I'm worried that the people I depend may catch Coronavirus. **Yes / No**

73. I'm worried about money **Yes / No**

74. I feel I'm getting less able to cope with everyday tasks **Yes / No**

75. I feel I'm not looking after myself as well as I would like. **Yes / No**

76. I'm worried that home care won't be there if needed. **Yes / No**

77. I'm worried I can't get my usual treatments (feet, teeth etc.) **Yes / No**

78. **Anything else?** Please write it on **Page 2**

How I'm feeling overall

79. How do you feel about things at the moment?
(Please **circle all** the answer(s) that **best describe your situation**):

a. I'm coping reasonably well **Yes / No**

b. I'm just about managing **Yes / No**

c. I'm struggling to keep going **Yes / No**

d. I really need some help **Yes / No**

e. I feel very depressed and anxious **Yes / No**

Please **circle**:

80. **Physically** I feel **worse / no worse / better** than I did before Coronavirus.

81. **Mentally** I feel **worse / no worse / better** than I did before Coronavirus.

End of Survey

PLEASE RETURN the SURVEY FORM a.s.a.p in the STAMPED, ADDRESSED ENVELOPE PROVIDED.

Thank you!

Appendix 3

Inserts mailed with Questionnaire

Useful Numbers

City and Hackney Older People's Reference Group


To receive help with food and medication, call your local authority helpline:

Hackney: 020 8356 3111 City of London: 020 7606 3030

To report issues and concerns about healthcare services, call your local Healthwatch:

Healthwatch Hackney: 020 3960 7454 City of London Healthwatch: 020 3745 9563

City & Hackney
Older People's
Reference Group



Are you worried about how changes due to the coronavirus may affect your income, benefits, housing and access to help?

Age UK East London have been adapting our **Information / Advice / Advocacy / Befriending** services to meet your needs during the lockdown.

Has there been a change in your income that doesn't seem correct?

Have you had difficulty accessing services that you normally rely on?

Has there been a change in how you are cared for?

Are you waiting for a decision that is taking longer than usual?

Are you feeling lonely and cut off from your friends and community?

If you, or someone you know, needs help of any kind we can be contacted on the details below.

Tel: 020 8981 7124 Email: info@ageukeastlondon.org.uk

Or call Sophie (OPRG Coordinator) at: 07384 511 701

Appendix 4

OPRG COVID-19 IMPACT SURVEY May 2020
Unanswered questions: by topic

a Above 15% threshold for inclusion in tables (30 responses)

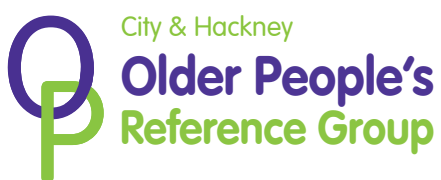
Topic	Not answered by respondents/106	%
Getting food supplies	16	15%
Worried if unknown visitors offer help	16	
Victim of scam(s)	16	
Accepting help from unknown visitors	16	
Relying on help from others	17	16%
Needing to speak to GP during lockdown	17	
Dental needs	17	
Scams increasing?	17	
Bereavement	17	17%
Ethnicity	18	
Dental needs – urgent	18	
Bereavement support	18	
Eye examination – urgent	19	18%
Worried if unknown visitors offer help	19	
Catching Covid-19 in hospital	19	
Getting usual treatments in future	19	
Phone repairs	19	19%
Home repairs for safety reasons	19	
Hearing aid repairs/batteries	20	
Worried about helpers getting Covid-19	20	
Toenail cutting	20	20%
Money worries	20	
Anxiety due to lockdown	20	
Giving out bank details	20	
Safety outside the home	21	21%
Coping with everyday tasks	21	
Lending out bank cards/credit cards	21	
Worried about catching Covid-19	22	
Safety at home	23	22%
Future availability of usual treatments	24	
Self-care	24	23%
Future availability of home-care	27	





b Below 15% threshold for inclusion in tables (32 responses)

Topic	Not answered by respondents/106	%
Problem with walking	3	3%
Living alone	3	
Gender	6	6%
Disability	6	
Medical Conditions	6	
Options of 111	6	
Used 111	7	7%
Overall view of physical health	9	8%
Taking medication	9	
Outpatients' appointments cancelled	9	
Home care visits	9	
Illnesses (new, non-Covid) in lockdown	10	9%
Overall view of mental health	10	
Spoken to GP	10	
Hospital admissions in lockdown	10	
District nurse visits	10	
Contact with family/friends /neighbours	10	
Loneliness	10	
Regular worship	10	
Eating well/not as well	12	11%
Getting exercise	12	
Contracted covid-19	12	
Age	13	12%
Sleeping well/ not as well	14	13%
Access to medication supplies	14	
GP contact re- shielding	14	
Food parcels	14	
Accepting help from unknown callers	14	
Worried about unknown callers	15	14%
Avoiding A&E	15	
GP contact re- Coordinate My Care	15	
Hospital treatments cancelled/ postponed	15	
Eye examinations	15	
Social contact	15	
TV/radio repairs	15	
Access to cash	15	

© City & Hackney Older People's Reference Group, May 2020. All rights reserved.

Design: oakshed.co.uk



 020 8981 7124 /  07384 511 701
 info@ageukeastlondon.org.uk
 OPRG at Age UK East London,
22 Dalston Lane, London, E8 3AZ