

Trial Supporter's Contact Details									
Supporter ID	<table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td> <td>-</td> <td></td> </tr> </table>							-	
						-			
Supporter's first name									
Supporter's surname									
Property name or number									
Road Name									
Town/City									
County									
Post code									
Mobile phone number									
Home phone number									
Email address									
<i>Note: To be stored separately from research data. Do not archive.</i>									

PRIDE Feasibility RCT

eCRF Workbook

Supporters

Supporter ID:

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Sponsor:

University of Nottingham

CRF Version:

Final v1.0 – 20 November 2018

Supporter ID:

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Trial Supporter Registration Log

Complete for all participating supporters:

Supporter ID	<table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>-</td><td></td> </tr> </table>								-							
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Supporter initials	<table border="1"> <tr> <td></td><td></td><td></td><td></td> </tr> </table>															
Date of consent (dd-mmm-yyyy)	<table border="1"> <tr> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> </table>															
Supporters relationship to participant	Spouse or partner ☐ Son or daughter ☐ Friend ☐ Neighbour ☐ Professional carer ☐ Other relative ☐ Other* ☐															
*Specify																
Length of time in supporter role for the trial participant	<3 months ☐ 3 months to 1 year ☐ >1 to 2 years ☐ >2 to 4 years ☐ >4 years ☐															
Current supporter	Yes ☐ No ☐															

Supporter eligibility criteria

To be eligible for this trial all the inclusion criteria must be answered Yes	Yes	No
1. Aged 18 or over; there is no upper age limit.	☐	☐
2. Able to engage with and participate in the intervention.	☐	☐
3. Able to provide informed consent.	☐	☐
4. Able to read and communicate verbally in English.	☐	☐

Supporter ID:

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Sign-off statement: Supporter registration

Completed by the researcher conducting the study visit and procedures.

To the best of my knowledge, I confirm that I have made every reasonable effort to ensure that ALL of the data in this Case Record Form is a true, accurate and complete report.

Name

Signature

Date

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Supporter ID:

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Supporter questionnaire completion: Visit 1 - Baseline

Has the supporter returned the questionnaires?	Yes ☐ No ☐													
Reason not completed	Supporter died ☐ Supporter withdrawal of consent ☐ Supporter no longer involved - participant decision ☐ Unable to contact ☐ Participant no longer involved ☐ Other* ☐													
*Specify														
Date completed	<table border="1"> <tr> <td></td><td></td><td></td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> </table>													
Method of completion	In person ☐ Postal ☐													
EQ-5D-5L completed	Yes ☐ No ☐													
Supporter CSRI completed	Yes ☐ No ☐													
Issues with questionnaire completion														

Supporter ID:

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Supporter questionnaire completion: Visit 2 – 3 Month Follow-Up

Has the supporter returned the questionnaires?	Yes ☐ No ☐													
Reason not completed	Supporter died ☐ Supporter withdrawal of consent ☐ Supporter no longer involved - participant decision ☐ Unable to contact ☐ Participant no longer involved ☐ Other* ☐													
*Specify														
Date completed	<table border="1"> <tr> <td></td><td></td><td></td> <td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> </table>													
Method of completion	In person ☐ Postal ☐													
EQ-5D-5L completed	Yes ☐ No ☐													
Global change measure completed	Yes ☐ No ☐													
Supporter CSRI completed	Yes ☐ No ☐													
Issues with questionnaire completion														

Page 6 of 6

PRIDE Feasibility RCT

Supporter Questionnaires

Baseline

Supporter ID:

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Sponsor:

University of Nottingham

CRF Version:

Final v1.0 – 20 November 2018

Completion Date:

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Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- I have no problems in walking about ☐
- I have slight problems in walking about ☐
- I have moderate problems in walking about ☐
- I have severe problems in walking about ☐
- I am unable to walk about ☐

SELF-CARE

- I have no problems washing or dressing myself ☐
- I have slight problems washing or dressing myself ☐
- I have moderate problems washing or dressing myself ☐
- I have severe problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities ☐
- I have slight problems doing my usual activities ☐
- I have moderate problems doing my usual activities ☐
- I have severe problems doing my usual activities ☐
- I am unable to do my usual activities ☐

PAIN / DISCOMFORT

- I have no pain or discomfort ☐
- I have slight pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have severe pain or discomfort ☐
- I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

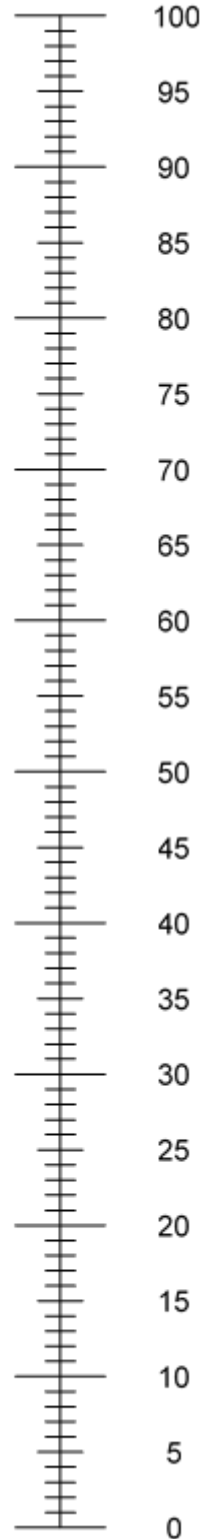
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- I am severely anxious or depressed ☐
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- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health
you can imagine

Supporter ID:

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Relevance

The questions in this section
asked about things that are
relevant to me

Strongly agree ☐

Agree ☐

Neither agree nor disagree ☐

Disagree ☐

Strongly disagree ☐

Supporter ID:

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Client Service Receipt Inventory

1. Do you live with your relative (the participant)?	Yes ☐ No ☐ <i>Continue to q2</i> <i>Go to q5</i>					
2. How many people are there in your household?	Number of adults (including supporter) <table border="1"><tr><td></td><td></td></tr></table> Number of children under the age of 16 <table border="1"><tr><td></td><td></td></tr></table>					
3. What kind of accommodation do you live in at the moment? (tick one box)	Council-rented housing ☐ Housing-association rented housing ☐ Private rented housing ☐ Owner-occupied housing ☐ Other housing ☐					
Please describe other housing						
4. Is your accommodation "sheltered" housing (has a warden or scheme manager on-site)?	Yes ☐ No ☐					
5. Which of the following best describes your current employment situation? (tick the one box that applies best to your situation)	In paid employment ☐	Go to q6				
	Retired ☐ Unable to work ☐ Unemployed and looking for work ☐ At home and not looking for work (e.g. housewife / husband) ☐ Doing voluntary work ☐ Student ☐ Other ☐	Go to q8				
Please describe						

Supporter ID:

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If employed:

6. What is your current job(s) / occupation(s)?

7. Number of hours you work per week in all the jobs you do

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If unemployed / unable to work / at home / retired:

8. When were you last employed? (Month / Year)

M	M	M	

Y	Y	Y	Y

9. What was / were your most recent job(s) / occupation(s)?

10. Have you given up or cut down on work in order to provide care for your relative?

Yes, given up work ☐

Yes, cut down ☐

No ☐

Go to q11

Go to q13

If gave up or cut down work:

11. When did this happen? (Month / Year)

M	M	M	

Y	Y	Y	Y

If cut down work:

12. By how much did you cut down on work each week?

		Hours per week
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Supporter ID:

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If you live with the participant:

13. On a typical day, how much time do you spend looking after / providing help for your relative?
(Tick if yes)

- Provides no help in a typical day ☐
- Less than 1 hour ☐
- More than 1 hour and up to 2 hours ☐
- More than 2 hours and up to 3 hours ☐
- More than 3 hours and up to 5 hours ☐
- More than 5 hours and up to 10 hours ☐
- More than 10 hours, but not overnight ☐
- More than 10 hours and / including overnight ☐
- Other ☐

Please describe other

If you do not live with the participant:

14. How many hours do you spend each week looking after / providing help to your relative?
(If the carer does not live with the service user)

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15. On a typical day, what tasks do you usually help your relative with?
(Tick as many as apply)

- Personal care ☐
- Helping with finances ☐
- Practical help ☐
- Taking the person to appointments ☐
- Medications ☐
- Keeping the person company ☐
- Making sure the person is safe (supervision) ☐
- Other ☐

Please describe other

16. Other than yourself, do other friends or relatives regularly help / provide care for your relative?

Yes ☐

No ☐

17. If yes, thinking about an average week, and about all such carers, for how many hours do they help / provide care for your relative?
(If no, write 0 in boxes and go to next question)

		Hours per week
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18. Have any friends and relatives taken time off paid work over the last 3 months to help / provide care for your relative?	Yes ☐	No ☐			
19. If yes, can you estimate the total number of days relatives / friends have taken off work over the last 3 months to help / provide care for your relative? (If no, write 0 in boxes and go to next question)	<table border="1"> <tr> <td></td><td></td><td></td> </tr> </table> <i>Total days</i>				

<i>Travel costs</i>					
20. In the last 3 months, have you accompanied your relative to any clinic, hospital, or day services for his / her condition?	Yes ☐ No ☐ <i>No further questions</i>				
21. If yes, over the last 3 months, how many times did you accompany your relative?	Number of times per week <table border="1"><tr><td></td><td></td></tr></table> Number of times in last 3 months <table border="1"><tr><td></td><td></td></tr></table>				
22. How did you normally travel to get to the services your relative used (e.g. to go to your GP surgery or hospital)? If you used more than one form of transport please say how you travelled for the main / longest part of your journey.	Walked ☐ Cycled ☐ Took the bus ☐ Took the train ☐ Took a taxi ☐ Drove the car ☐ Took hospital transport ☐ Went by ambulance ☐ Other ☐				
23. How long did it normally take to travel there from home?	Number of hours <table border="1"><tr><td></td><td></td></tr></table> Number of minutes <table border="1"><tr><td></td><td></td></tr></table>				
24. If you normally travelled by public transport, what was the cost of the fare in one direction (cost of a one-way ticket)?	£ <table border="1"><tr><td></td><td></td></tr></table> pence <table border="1"><tr><td></td><td></td></tr></table>				
25. If you normally travelled by taxi, what was the cost of the fare in one direction (cost of a one-way ticket)?	£ <table border="1"><tr><td></td><td></td></tr></table> pence <table border="1"><tr><td></td><td></td></tr></table>				

Supporter ID:

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26. If you normally travelled by car, how many miles / kilometres did you travel to get there (one-way journey)?

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Miles ☐

Kilometres ☐

27. If you normally travelled by car, if you had to pay for parking, how much did you pay?

£

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pence

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3 Month Follow-Up

Supporter ID:	-
Sponsor:	University of Nottingham
CRF Version:	Final v1.0 – 20 November 2018

Completion Date: - -

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Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- I have no problems in walking about ☐
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- I have severe problems in walking about ☐
- I am unable to walk about ☐

SELF-CARE

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ANXIETY / DEPRESSION

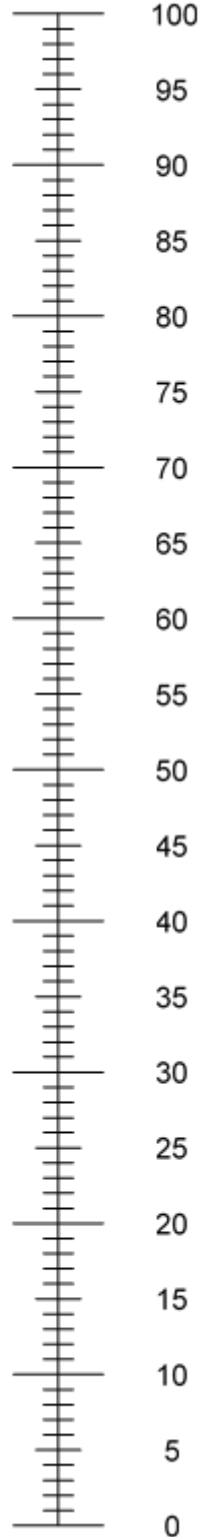
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The best health
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Supporter ID:

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Relevance

The questions in this section asked about things that are relevant to me	Strongly agree	☐
	Agree	☐
	Neither agree nor disagree	☐
	Disagree	☐
	Strongly disagree	☐

Change

Compared to 3 months ago when your friend/relative started in the study, how would you rate their general wellbeing now?	Much worse	☐
	A bit worse	☐
	No change	☐
	A bit better	☐
	Much better	☐
Compared to 3 months ago when your friend/relative started in the study, how independent do you feel they are now?	Much more independent	☐
	A bit more independent	☐
	No change	☐
	A bit less independent	☐
	Much less independent	☐

Supporter ID:

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Client Service Receipt Inventory

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M	M	M	

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Hours per week

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Yes ☐

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Miles ☐

Kilometres ☐

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£

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pence

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6 Month Follow-Up

Supporter ID:	-
Sponsor:	University of Nottingham
CRF Version:	Final v1.0 – 20 November 2018

Completion Date:

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Under each heading, please tick the ONE box that best describes your health TODAY.

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SELF-CARE

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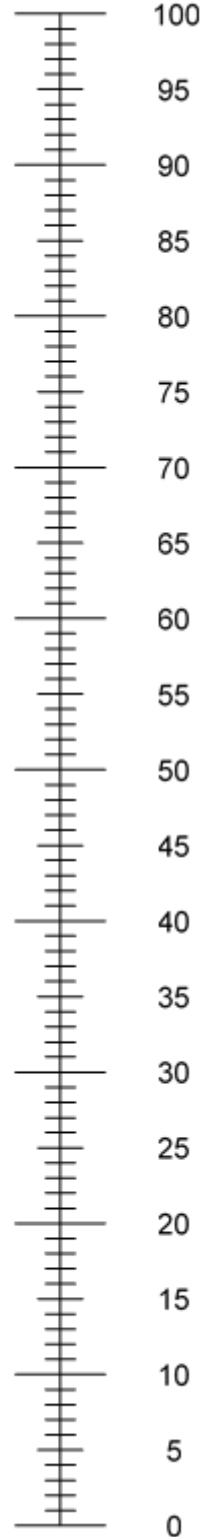
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- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health
you can imagine

Supporter ID:

						-	
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Relevance

The questions in this section asked about things that are relevant to me	Strongly agree	☐
	Agree	☐
	Neither agree nor disagree	☐
	Disagree	☐
	Strongly disagree	☐

Change

Compared to 6 months ago when your friend/relative started in the study, how would you rate their general wellbeing now?	Much worse	☐
	A bit worse	☐
	No change	☐
	A bit better	☐
	Much better	☐
Compared to 6 months ago when your friend/relative started in the study, how independent do you feel they are now?	Much more independent	☐
	A bit more independent	☐
	No change	☐
	A bit less independent	☐
	Much less independent	☐

Supporter ID:

						-	
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Client Service Receipt Inventory

1. Do you live with your relative (the participant)?	Yes ☐ No ☐ <i>Continue to q2</i> <i>Go to q5</i>					
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4. Is your accommodation "sheltered" housing (has a warden or scheme manager on-site)?	Yes ☐ No ☐					
5. Which of the following best describes your current employment situation? (tick the one box that applies best to your situation)	In paid employment ☐	<i>Go to q6</i>				
	Retired ☐ Unable to work ☐ Unemployed and looking for work ☐ At home and not looking for work (e.g. housewife / husband) ☐ Doing voluntary work ☐ Student ☐ Other ☐	<i>Go to q8</i>				
Please describe						

Supporter ID:

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If employed:

6. What is your current job(s) / occupation(s)?

7. Number of hours you work per week in all the jobs you do

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If unemployed / unable to work / at home / retired:

8. When were you last employed? (Month / Year)

M	M	M	

Y	Y	Y	Y

9. What was / were your most recent job(s) / occupation(s)?

10. Have you given up or cut down on work in order to provide care for your relative?

Yes, given up work ☐

Yes, cut down ☐

No ☐

Go to q11

Go to q13

If gave up or cut down work:

11. When did this happen? (Month / Year)

M	M	M	

Y	Y	Y	Y

If cut down work:

12. By how much did you cut down on work each week?

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Hours per week

Supporter ID:

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If you live with the participant:

13. On a typical day, how much time do you spend looking after / providing help for your relative?
(Tick if yes)

- Provides no help in a typical day ☐
- Less than 1 hour ☐
- More than 1 hour and up to 2 hours ☐
- More than 2 hours and up to 3 hours ☐
- More than 3 hours and up to 5 hours ☐
- More than 5 hours and up to 10 hours ☐
- More than 10 hours, but not overnight ☐
- More than 10 hours and / including overnight ☐
- Other ☐

Please describe other

If you do not live with the participant:

14. How many hours do you spend each week looking after / providing help to your relative?
(If the carer does not live with the service user)

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15. On a typical day, what tasks do you usually help your relative with?
(Tick as many as apply)

- Personal care ☐
- Helping with finances ☐
- Practical help ☐
- Taking the person to appointments ☐
- Medications ☐
- Keeping the person company ☐
- Making sure the person is safe (supervision) ☐
- Other ☐

Please describe other

16. Other than yourself, do other friends or relatives regularly help / provide care for your relative?

Yes ☐

No ☐

17. If yes, thinking about an average week, and about all such carers, for how many hours do they help / provide care for your relative?
(If no, write 0 in boxes and go to next question)

		Hours per week
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18. Have any friends and relatives taken time off paid work over the last 3 months to help / provide care for your relative?	Yes ☐	No ☐			
19. If yes, can you estimate the total number of days relatives / friends have taken off work over the last 3 months to help / provide care for your relative? (If no, write 0 in boxes and go to next question)	<table border="1"> <tr> <td></td><td></td><td></td> </tr> </table> <i>Total days</i>				

<i>Travel costs</i>					
20. In the last 3 months, have you accompanied your relative to any clinic, hospital, or day services for his / her condition?	Yes ☐ No ☐ <i>No further questions</i>				
21. If yes, over the last 3 months, how many times did you accompany your relative?	Number of times per week <table border="1"><tr><td></td><td></td></tr></table> Number of times in last 3 months <table border="1"><tr><td></td><td></td></tr></table>				
22. How did you normally travel to get to the services your relative used (e.g. to go to your GP surgery or hospital)? If you used more than one form of transport please say how you travelled for the main / longest part of your journey.	Walked ☐ Cycled ☐ Took the bus ☐ Took the train ☐ Took a taxi ☐ Drove the car ☐ Took hospital transport ☐ Went by ambulance ☐ Other ☐				
23. How long did it normally take to travel there from home?	Number of hours <table border="1"><tr><td></td><td></td></tr></table> Number of minutes <table border="1"><tr><td></td><td></td></tr></table>				
24. If you normally travelled by public transport, what was the cost of the fare in one direction (cost of a one-way ticket)?	£ <table border="1"><tr><td></td><td></td></tr></table> pence <table border="1"><tr><td></td><td></td></tr></table>				
25. If you normally travelled by taxi, what was the cost of the fare in one direction (cost of a one-way ticket)?	£ <table border="1"><tr><td></td><td></td></tr></table> pence <table border="1"><tr><td></td><td></td></tr></table>				

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26. If you normally travelled by car, how many miles / kilometres did you travel to get there (one-way journey)?

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Miles ☐

Kilometres ☐

27. If you normally travelled by car, if you had to pay for parking, how much did you pay?

£

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pence

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