



KAYA_10-22-2025.netcanvas



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SCHEMA VERSION:7

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Contents

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16. Care flows

CODEBOOK

Ego

NODE TYPES



Contact



Household

ASSETS

NETWORK

DementiaSample_24Jul2022.csv



PAGE HEADING

Protocol Citation Information

ITEMS

BLOCK SIZE SMALL**TYPE** Text**CONTENT****Protocol Authors:**

Manderson L, Brear M, Rusere F, Farrell M, Gómez-Olivé F, Berkman L, Kahn K, Harling G.

BLOCK SIZE SMALL**TYPE** Text**CONTENT****Cite Publication:**

Manderson, L., Brear, M., Rusere, F., Farrell, M., Gómez-Olivé, F. X., Berkman, L., Kahn, K., & Harling, G. (2022). Protocol: The complexity of informal caregiving for Alzheimer's disease and related dementias in rural South Africa [version 1; peer review: awaiting peer review]. *Wellcome Open Research*, 7, 220. [<https://doi.org/10.12688/wellcomeopenres.18078.1>] (<https://doi.org/10.12688/wellcomeopenres.18078.1>)

BLOCK SIZE SMALL**TYPE** Text**CONTENT****Study Title:**

The Complexity of Informal Caregiving for Alzheimer's Disease and Related Dementias in Rural South Africa (KAYA)

BLOCK SIZE SMALL**TYPE** Text**CONTENT**

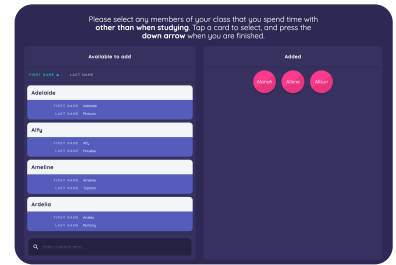
MPIs: Guy Harling, Lenore Manderson

Grant Number: R21AG059145

INTERVIEWER SCRIPT

2

Household ID



DATASOURCE

TYPE	network
NAME	DementiaSample_24Jul2022.csv

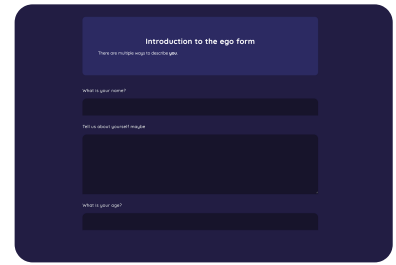
PROMPTS

1. Please enter the Agincourt household ID for the CR

INTERVIEWER SCRIPT

3

Respondent ID



INTRODUCTION PANEL

Respondent ID

Enter respondent identity

FORM

VARIABLE



ego_name

COMPONENT

Text

PROMPT

What is the respondent's name?



kaya_id

Text

Please enter this respondents full Kaya study ID

INTERVIEWER SCRIPT

4

Introduction

This interface has a video with sound.

The video below has sound and is not a video. Some video, but content that can contain formatting



PAGE HEADING

Introduction

ITEMS

BLOCK SIZE	SMALL
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TYPE	Text
------	------

CONTENT	Now I will ask you some questions about your relationships with other people. We will ask you about anyone who lives in the same household as you, as well as other people who are important to you. You may be in contact with these people in person or remotely (e.g., by phone or WhatsApp). I will start by asking for their names in order to refer to these people during our interviews with you. Please tell me the names of people who fit these descriptions.
---------	--

INTERVIEWER SCRIPT

5

Name Generator

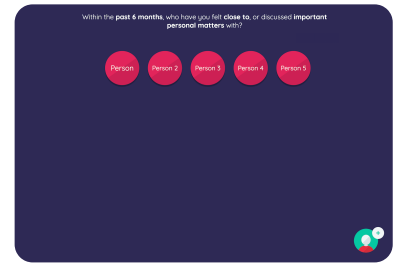
SUBJECT



Contact

VARIABLES

name, tie_care, tie_emotional, tie_household,
tie_informational, tie_instrumental, tie_other,
tie_social



PANELS

1.

TITLE

Existing names

DATA SOURCE

Existing network

PROMPTS

1. A7. INTERVIEWER: Please add CR's name here

VARIABLE

VALUE



tie_care

TRUE

2. A1. Who are the people who live in the same permanent household as you, that is, who you share meals with? This include temporary migrants.

VARIABLE

VALUE



tie_household

TRUE

3. A2. Over the last 6 months were there any other people who you could confide in or talk about your life and problems? For example, when you are feeling sad, anxious or upset.

VARIABLE

VALUE



tie_emotional

TRUE

4. A3. Over the last 6 months, were there any other people who could give you information or advice in relation to an important life decision? For example, a health or employment problem, or moving to another place?

VARIABLE	VALUE
 tie_informational	TRUE

5. A4. Over the last 6 months, were there other people who you could ask for help with doing things? This might include tasks inside or outside your home, borrowing small things (food, money), or helping you get a job?

VARIABLE	VALUE
 tie_instrumental	TRUE

6. A5. Over the last six months, were there any other people who you really enjoyed spending time with. This might include people who you might go out with, or who you visited, or who visited you?

VARIABLE	VALUE
 tie_social	TRUE

7. A6. Is there anyone else who is especially important to you not listed already?

VARIABLE	VALUE
 tie_other	TRUE

FORM

Title: Add people's names

VARIABLE	COMPONENT	PROMPT
 name	Text	What is this person's name?

INTERVIEWER SCRIPT

6

Contact details

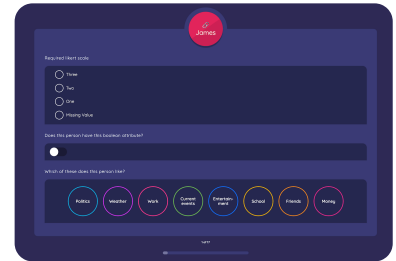
SUBJECT



Contact

VARIABLES

alt_age, alt_gender, alt_names, alt_time



INTRODUCTION PANEL

Contact information

Now I will ask you some questions about each of the people you have just listed.

FORM

VARIABLE



alt_names

COMPONENT

Text

PROMPT

Please provide this person's full name, including any nicknames



alt_gender

ToggleButtonGroup

B2. What gender is this person?



alt_age

Number

B3. How old is this person?
If you do not know for certain, your best guess is fine



alt_time

Number

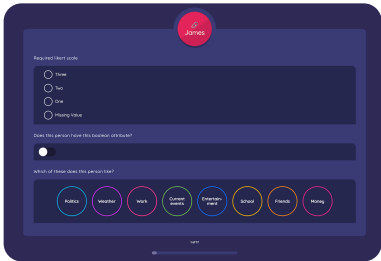
B7. How many years have you known this person (your best guess is fine)

INTERVIEWER SCRIPT

7

Contact details part 2

SUBJECT	 Contact
VARIABLES	alt_relate, alt_reside



INTRODUCTION PANEL

Contact information

Now I will ask you some questions about each of the people you have just listed.

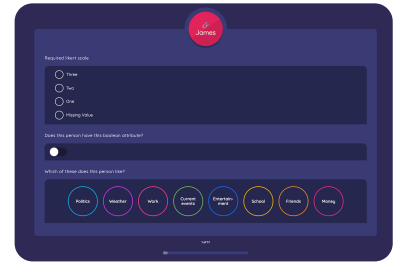
FORM

VARIABLE	COMPONENT	PROMPT
 alt_reside	RadioGroup	B1. Where has this person resided over the past 6 months?
 alt_relate	RadioGroup	B6. What relation is this person to you?

INTERVIEWER SCRIPT

8

Alter location village specify



SUBJECT



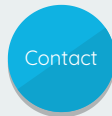
Contact

VARIABLES

alt_reside, alt_village

NETWORK FILTERING

RULES



Contact

where



alt_reside

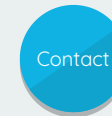
is exactly
equal to**Within Agincourt, but
not your village**

SKIP LOGIC

ACTION

SHOW

RULES



Contact

where



alt_reside

is exactly
equal to**Within Agincourt, but
not your village**

INTRODUCTION PANEL

Village of residence

Please specify where this person lives

FORM

VARIABLE



alt_village

COMPONENT

CheckboxGroup

PROMPT

Please specify which village
this person lives in

INTERVIEWER SCRIPT

9

Alter location specify other

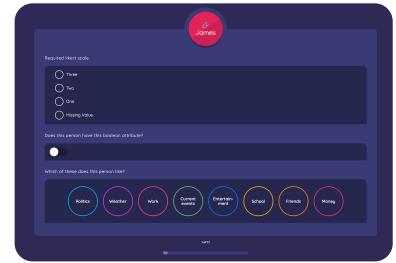
SUBJECT



Contact

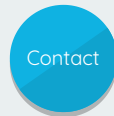
VARIABLES

alt_other_loc, alt_reside



NETWORK FILTERING

RULES



Contact

where



alt_reside

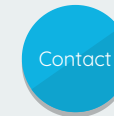
is exactly
equal to**In South Africa, but
not Agincourt**

SKIP LOGIC

ACTION

SHOW

RULES



Contact

where



alt_reside

is exactly
equal to**In South Africa, but
not Agincourt**

INTRODUCTION PANEL

Alter location, specify

Please specify where this person lives

FORM

VARIABLE



alt_other_loc

COMPONENT

Text

PROMPT

Please specify where this
person resides

INTERVIEWER SCRIPT

10

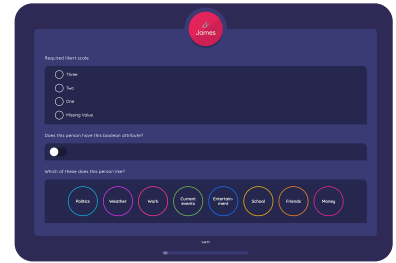
Alter relationship specify other

SUBJECT

Contact

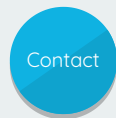
VARIABLES

alt_relate, alt_relate_oth



NETWORK FILTERING

RULES



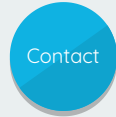
where



alt_relate

is exactly
equal toOther
relation

OR



where



alt_relate

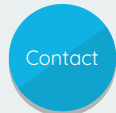
is exactly
equal toOther
relation

SKIP LOGIC

ACTION

SHOW

RULES



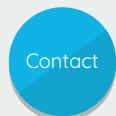
where



alt_relate

is exactly
equal toOther
relation

OR



where



alt_relate

is exactly
equal toOther non-
relation

INTRODUCTION PANEL

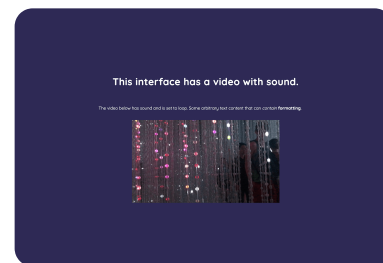
Specify other relationship

Please specify other type of relationship

FORM

VARIABLE	COMPONENT	PROMPT
alt_relate_oth	Text	B6a. Please specify what other relationship this person is to you

INTERVIEWER SCRIPT



PAGE HEADING

Support provision and receipt

ITEMS

BLOCK SIZE	SMALL
TYPE	Text
CONTENT	Now I'm going to ask you about the frequency of support you provide and or receive from the people you have just named. In each question, the response options are Every day or almost every day, a few times a week, once a week, a few times a month, once a month, less than once a month, or never.

INTERVIEWER SCRIPT

12

Support flows - hidden



SUBJECT



Contact

VARIABLES

ego_name, flw_argue, flw_prv_adv, flw_prv_emot,
flw_prv_instr, flw_rec_adv, flw_rec_emot,
flw_rec_instr, flw_seen, flw_unseen

SKIP LOGIC

ACTION

SHOW

RULES



has



ego_name

that is exactly equal to **ZZZ**

PROMPTS

- Over the past six months, on average how often have you seen this person? Is it Every day or almost every day, a few times a week, once a week, a few times a month, once a month, less than once a month, Never.

VARIABLE



flw_seen

- Over the past six months, on average how often have you communicated with this person **without** seeing them, such as by phone, WhatsApp, emails or letters. [Repeat response options if required]

VARIABLE



flw_unseen

- Over the past six months, how often have you **provided** emotional support to this person, such as when they are feeling sad, anxious or upset? [Repeat response options if required]

VARIABLE



flw_prv_emot

- Over the past six months, how often have you **provided** information or advice to this person? [Repeat response options if required]

VARIABLE



flw_prv_adv

5. Over the past six months, how often have you **provided** help to this person, such as tasks inside or outside the home, or borrowing things (including money)? [Repeat response options if required]

VARIABLE



flw_prv_instr

6. Over the past six months, how often have you **received** emotional support from this person? [Repeat response options if required]

VARIABLE



flw_rec_emot

7. Over the past six months, how often have you **received** information or advice from this person? [Repeat response options if required]

VARIABLE



flw_rec_adv

8. Over the past six months, how often have you **received** help from this person? [Repeat response options if required]

VARIABLE



flw_rec_instr

9. Over the past six months, how often have you and this person verbally argued or criticized one another? [Repeat response options if required]

VARIABLE



flw_argue

INTERVIEWER SCRIPT

13

Support flows - circles



SUBJECT



Contact

VARIABLES

flw2_argue, flw2_prv_adv, flw2_prv_emot,
flw2_prv_instr, flw2_rec_adv, flw2_rec_emot,
flw2_rec_instr, flw2_seen, flw2_unseen

PROMPTS

1. C1. Over the past six months, on average how often have you seen this person? Is it Every day or almost every day, a few times a week, once a week, a few times a month, once a month, less than once a month, Never.

VARIABLE



flw2_seen

2. C2. Over the past six months, on average how often have you communicated with this person without seeing them, such as by phone, WhatsApp, emails or letters. [Repeat response options if required]

VARIABLE



flw2_unseen

3. C3. Over the past six months, how often have you **provided** emotional support to this person, such as when they are feeling sad, anxious or upset? [Repeat response options if required]

VARIABLE



flw2_prv_emot

4. C4. Over the past six months, how often have you **provided** information or advice to this person? [Repeat response options if required]

VARIABLE



flw2_prv_adv

5. C5. Over the past six months, how often have you **provided** help to this person, such as tasks inside or outside the home, or borrowing things (including money)? [Repeat response options if required]

VARIABLE



flw2_prv_instr

6. C6. Over the past six months, how often have you **received** emotional support from this person? [Repeat response options if required]

VARIABLE



flw2_rec_emot

7. C7. Over the past six months, how often have you received information or advice from this person? [Repeat response options if required]

VARIABLE



flw2_rec_adv

8. C8. Over the past six months, how often have you **received** help from this person? [Repeat response options if required]

VARIABLE



flw2_rec_instr

9. C9. Over the past six months, how often have you and this person verbally argued or criticized one another? [Repeat response options if required]

VARIABLE



flw2_argue

INTERVIEWER SCRIPT

Please repeat the response options for respondents whenever they seem unsure.

This interface has a video with sound.

The video below has closed captions and subtitles. Some content may not appear if your browser does not support them.



PAGE HEADING

Care receipt

ITEMS

BLOCK SIZE	SMALL
TYPE	Text
CONTENT	The next few questions ask about what help or assistance the people you listed provide to the care recipient and you.

INTERVIEWER SCRIPT

15

Care flows CR

SUBJECT



Contact

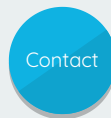
VARIABLES

care_any, care_carers, care_index, tie_care



NETWORK FILTERING

RULES



where



tie_care

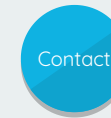
is not **true**

SKIP LOGIC

ACTION

SHOW

RULES



where



tie_care

is not **true**

PROMPTS

1. E1. To the best of your knowledge, does this person provide assistance, care, supervision or companionship to CR?

VARIABLE



care_any

2. E2. How much support do you feel this person provides to **CR**? Is it Too little, the right amount or too much?

VARIABLE



care_index

3. E3. How much support do you feel this person provides to **people who care for CR**? Is it Too little, the right amount or Too much?

VARIABLE



care_carers

INTERVIEWER SCRIPT

16

Care flows

SUBJECT



Contact

VARIABLES

care_ego



PROMPTS

1. E4. How much support do you feel this person provides to **you**? Is it Too little, the right amount or too much

VARIABLE



care_ego

INTERVIEWER SCRIPT

Ego

Name		Type	Used In
 ego_name		text	Respondent ID Support flows - hidden
 kaya_id		text	Respondent ID



Contact

Name	Type	Used In																								
123 alt_age	number	Contact details																								
alt_gender	categoryal <table><tr><th>VALUE</th><th>LABEL</th></tr><tr><td>1</td><td>Male</td></tr><tr><td>2</td><td>Female</td></tr><tr><td>3</td><td>Other</td></tr></table>	VALUE	LABEL	1	Male	2	Female	3	Other	Contact details																
VALUE	LABEL																									
1	Male																									
2	Female																									
3	Other																									
alt_names	text	Contact details																								
alt_other_loc	text	Alter location specify other																								
alt_relate	ordinal <table><tr><th>VALUE</th><th>LABEL</th></tr><tr><td>1</td><td>Partner/spouse</td></tr><tr><td>2</td><td>Grandparent</td></tr><tr><td>3</td><td>Parent</td></tr><tr><td>4</td><td>Aunt or uncle</td></tr><tr><td>5</td><td>Brother or sister</td></tr><tr><td>6</td><td>Cousin</td></tr><tr><td>7</td><td>Son or daughter</td></tr><tr><td>8</td><td>Grandchild</td></tr><tr><td>9</td><td>Other relation</td></tr><tr><td>10</td><td>Friend, not related</td></tr><tr><td>11</td><td>Other non-relation</td></tr></table>	VALUE	LABEL	1	Partner/spouse	2	Grandparent	3	Parent	4	Aunt or uncle	5	Brother or sister	6	Cousin	7	Son or daughter	8	Grandchild	9	Other relation	10	Friend, not related	11	Other non-relation	Contact details part 2 Alter relationship specify other Alter relationship specify other Alter relationship specify other Alter relationship specify other
VALUE	LABEL																									
1	Partner/spouse																									
2	Grandparent																									
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4	Aunt or uncle																									
5	Brother or sister																									
6	Cousin																									
7	Son or daughter																									
8	Grandchild																									
9	Other relation																									
10	Friend, not related																									
11	Other non-relation																									

Name	Type	Used In												
 alt_relate_oth	text	Alter relationship specify other												
 alt_reside	ordinal <table><tr><th>VALUE</th><th>LABEL</th></tr><tr><td>1</td><td>Your household</td></tr><tr><td>2</td><td>Your village</td></tr><tr><td>3</td><td>Within Agincourt, but not your village</td></tr><tr><td>4</td><td>In South Africa, but not Agincourt</td></tr><tr><td>5</td><td>In another country</td></tr></table>	VALUE	LABEL	1	Your household	2	Your village	3	Within Agincourt, but not your village	4	In South Africa, but not Agincourt	5	In another country	Contact details part 2 Alter location village specify Alter location specify other Alter location village specify Alter location specify other
VALUE	LABEL													
1	Your household													
2	Your village													
3	Within Agincourt, but not your village													
4	In South Africa, but not Agincourt													
5	In another country													
 alt_time	number	Contact details												
 alt_village	categorical	Alter location village specify												

Name	Type		Used In
	VALUE	LABEL	
	1	Agincourt	
	2	Belfast	
	3	Croquetlawn	
	4	Croquetlawn B	
	5	Cunningmore A	
	6	Cunningmore B	
	7	Cunningmore C	
	8	Dumphries A	
	9	Dumphries B	
	10	Dumphries C	
	11	Huntington	
	12	Ireagh A	
	13	Ireagh B	
	14	Ireagh C	
	15	Justicia A	
	16	Khayalami	
	17	Kildare A	
	18	Kildare B	
	19	Kildare C	
	20	Kumani	
	21	Lillydale A	
	22	Lillydale B	
	23	Makaringe	
	24	MP Stream	
	25	Newington B	
	26	Newington C	
	27	Rholane	
	28	Rolle C	
	29	Somerset A	
	30	Somerset C	

Name	Type		Used In
	VALUE	LABEL	
	31	Xanthia	
 care_any	categorical		Care flows CR
	VALUE	LABEL	
	1	Yes	
	2	No	
 care_carers	categorical		Care flows CR
	VALUE	LABEL	
	1	Too little	
	2	The right amount	
	3	Too much	
 care_ego	categorical		Care flows
	VALUE	LABEL	
	1	Too little	
	2	The right amount	
	3	Too much	
 care_index	categorical		Care flows CR
	VALUE	LABEL	
	1	Too little	
	2	The right amount	
	3	Too much	

Name	Type	Used In																
flw2_argue	categorical <table><tr><th>VALUE</th><th>LABEL</th></tr><tr><td>1</td><td>Every day or almost every day</td></tr><tr><td>2</td><td>A few times a week</td></tr><tr><td>3</td><td>Once a week</td></tr><tr><td>4</td><td>A few times a month</td></tr><tr><td>5</td><td>Once a month</td></tr><tr><td>6</td><td>Less than once a month</td></tr><tr><td>7</td><td>Never</td></tr></table>	VALUE	LABEL	1	Every day or almost every day	2	A few times a week	3	Once a week	4	A few times a month	5	Once a month	6	Less than once a month	7	Never	Support flows - circles
VALUE	LABEL																	
1	Every day or almost every day																	
2	A few times a week																	
3	Once a week																	
4	A few times a month																	
5	Once a month																	
6	Less than once a month																	
7	Never																	

flw2_prv_adv

categorical

Support flows - circles

VALUE	LABEL
1	Every day or almost every day
2	A few times a week
3	Once a week
4	A few times a month
5	Once a month
6	Less than once a month
7	Never

Name	Type	Used In																
flw2_prv_emot	categorical <table><thead><tr><th>VALUE</th><th>LABEL</th></tr></thead><tbody><tr><td>1</td><td>Every day or almost every day</td></tr><tr><td>2</td><td>A few times a week</td></tr><tr><td>3</td><td>Once a week</td></tr><tr><td>4</td><td>A few times a month</td></tr><tr><td>5</td><td>Once a month</td></tr><tr><td>6</td><td>Less than once a month</td></tr><tr><td>7</td><td>Never</td></tr></tbody></table>	VALUE	LABEL	1	Every day or almost every day	2	A few times a week	3	Once a week	4	A few times a month	5	Once a month	6	Less than once a month	7	Never	Support flows - circles
VALUE	LABEL																	
1	Every day or almost every day																	
2	A few times a week																	
3	Once a week																	
4	A few times a month																	
5	Once a month																	
6	Less than once a month																	
7	Never																	

flw2_prv_instr

categorical

Support flows - circles

VALUE	LABEL
1	Every day or almost every day
2	A few times a week
3	Once a week
4	A few times a month
5	Once a month
6	Less than once a month
7	Never

Name	Type	Used In																
flw2_rec_adv	categorical	Support flows - circles																
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flw2_rec_emot

categorical

Support flows - circles

VALUE	LABEL
1	Every day or almost every day
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flw2_seen

categorical

Support flows - circles

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1	Every day or almost every day
2	A few times a week
3	Once a week
4	A few times a month
5	Once a month
6	Less than once a month
7	Never

flw2_unseen

categorical

VALUE	LABEL
1	Every day or almost every day
2	A few times a week
3	Once a week
4	A few times a month
5	Once a month
6	Less than once a month
7	Never

Support flows - circles

flw_argue

ordinal

VALUE	LABEL
1	Every day or almost every day
2	A few times a week
3	Once a week
4	A few times a month
5	Once a month
6	Less than once a month

Support flows - hidden

Name	Type	Used In														
flw_prv_adv	ordinal	Support flows - hidden														
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Name	Type	Used In
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flw_rec_emot

ordinal

Support flows - hidden

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flw_rec_instr

ordinal

Support flows - hidden

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name	text	Name Generator														
tie_care	boolean	Name Generator Care flows CR Care flows CR														
tie_emotional	boolean	Name Generator														

Name	Type	Used In
A/B tie_household	boolean	Name Generator
A/B tie_informational	boolean	Name Generator
A/B tie_instrumental	boolean	Name Generator
A/B tie_other	boolean	Name Generator
A/B tie_social	boolean	Name Generator



Household

Name	Type	Used In
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No variables to display.

Resource Library

Network

NAME	DementiaSample_24Jul2022.csv
TYPE	Network
VARIABLES	village, name