What Matters in the End

Understanding the End-of-Life needs of Culturally & Linguistically Diverse and Aboriginal communities in Western Sydney Local Health District

ما يهم في النهاية ... فهم احتياجات مرحلة نهاية الحياة لدى المجتمعات المتنوعة ثقافياً ولغوياً ومجتمعات السكّان الأصليين في المنطقة الصحية المحلية في غرب سيدني

आख़िर में क्या मायने रखता है...वेस्टर्न सिडनी लोकल हेल्थ डिस्ट्रिक्ट (पश्चिमी सिडनी स्थानीय स्वास्थ्य डिस्ट्रिक्ट) में सांस्कृतिक और भाषाई रूप से विविध और ऐबओरीजिनल समुदायों के जीवन के अंत की आवश्यकताओं को समझना

最终什么才重要... 了解西悉尼地方卫生区文化 和语言多元化群体和原住民社区的临终需求

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Health Western Sydney Local Health District



Appendices

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Available on request:

Participant information and consent forms for focus groups in English, Arabic, Hindi, and Mandarin Participant information and consent forms for photovoice in English, Arabic, Hindi, and Mandarin Participant information and consent forms for key informants in English Recruitment flyer/s [English, also distributed in Arabic, Hindi, Mandarin]

Appendix 1: Snapshot of Western Sydney Local Health District (WSLHD)



Figure A1.1 LGAs and hospitals in WSLHD

Source: www.wslhd.health.nsw.gov.au/SocialHealthAtlas/

Western Sydney Local Health District encompasses the Local Government Areas (LGAs) of the Hills Shire, Parramatta, Blacktown, and Cumberland (See Figure A1.1). The most recent population census (ABS, 2021) shows that 13.4% of the NSW residents live in WSLHD. It is a growing region and the proportion increased from 12.5% in 2016. Reflecting the inward migration to the region, the population has a lower median age (35 years) than the State (39 years). The Western Sydney region is one of the most culturally and linguistically diverse (CaLD) populations in Australia. Over 50% (51.5%) speak a language other than English at home, compared to the NSW average of 30% (ABS, 2021).

Table A1.1 shows marked socio-economic differences between more affluent areas such as the Hills Shire which have higher weekly household income and larger homes per person to more economically disadvantaged areas like Cumberland. Overall WSLHD has a lower weekly household income and higher density than the NSW averages.

Table A1.1 also shows other variations amongst the LGAs which reflect their cultural character:

- In The Hills Shire: After Australian or English, Chinese and Indian were the most common ancestries. Mandarin first; Hindi third; Arabic fifth most common language other than English spoken at home. This LGA had the highest household income, older residents (median 38 years), and relatively large homes averaging 3.8 bedrooms reflecting its largely established leafy suburban nature.
- In Parramatta LGA: Chinese was the most common ancestry then English Australian and Indian fourth. Other than English Mandarin was the most common language spoken at home: Hindi fourth and Arabic fifth. Parramatta is the most urban of the LGAs with the smallest homes averaging 2.7 bedrooms.
- In Blacktown LGA the third most common ancestry after Australian and English was Indian, and Hindi was the third most common language spoken at home with Arabic fifth and Mandarin eighth. Blacktown also has a relatively high proportion of Indigenous people, just slightly lower than the NSW percent.
- In Cumberland LGA the most common ancestries were Chinese, then Lebanese who are often Arabic speakers. Indian was fifth after Australian and English. Arabic was most common language other than English. Mandarin was second and Hindi eighth.

Table A1.1	Demographic statistics for	LGAs and total WSLHD	compared to the NS	W population.
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Location	The Hills		Parrama	tta	Blacktow	vn	Cumberl	and	NSW		WSLHD	
	No	%	No	%	No	%	No	%	No	%	No	%
Population	192509		256729		396776		235439		8072163		1081453	
Indigenous	1207	0.6	2079	0.8	11812	3.0	1516	0.6	278043	3.4	16614	1.5
Median Age	38		35		34		34		39		35	
Female	97602	50.7	128108	49.9	198785	50.1	113952	48.4	4084514	50.6	538447	49.8
Ancestry												
Chinese	28141	14.7	57353	22.3	17664	4.5	29748	12.6	581641	7.2	132906	12.3
Indian	17432	9.1	28867	11.2	53712	13.5	20417	8.7	261103	3.2	120428	11.1
Lebanese	847	2.3	9091	3.5	5951	1.5	28014	11.9	177587	2.2	43903	4.1
Language at h	ome											
Mandarin	15678	8.2	31823	12.4	7083	1.8	15777	6.7	270685	3.4	70361	6.5
Hindi	5418	2.8	9590	3.7	17429	4.4	5430	2.3	80051	1.0	37867	3.5
Arabic	3856	2.0	8311	3.2	11687	2.9	33264	14.1	227243	2.8	57118	5.3
Do not speak English at home	74379	38.8	144805	56.4	183558	46.3	154448	65.6	856911	29.5	557190	51.5
Medium household weekly income	2831		2051		2107		1678		1829		1764	
Av. bed- rooms per home	3.8		2.7		3.4		2.9		3.1		3.2	
Av. People per home	3.1		2.6		3.1		3.0		2.6		3.0	

Sources: 2021 Census data https://abs.gov.au/census/find-census-data/quickstats/2021 and https://profile.id.com.au/

Appendix 2: Interview, focus group, and photovoice schedules

Interview schedules (key informants)

Key informant interview schedule (phase 1 – palliative care)

[Researchers] will conduct individual interviews with people holding expertise in palliative care and associated end-of-life services. Interviews will last for no more than 2 hours and will be held online via video conferencing, at a time convenient to the participant.

- 1. Introductions and consent process. Brief overview of the aims of the research and the purpose of the interviews. (5 minutes)
- 2. Can you briefly outline your experience and role working with CaLD or Aboriginal communities?
- 3. In your experience do these communities experience death, dying and caring differently to the majority population? (15 minutes)
- 4. In what ways is their experience different? (15 minutes)
- 5. What services and supports do you believe these communities find useful, and in what ways are they useful? (15 minutes)
- 6. What other support or services do they need and who is best suited to provide this support and/or services? (10 minutes)
- 7. In what ways do existing services and supports need to change in order to be more culturally safe and appropriate? (15 minutes)
- 8. What will it take for these changes to be achieved? (10 minutes)
- 9. Have you anything else you would like to say that would be helpful to this project? (10 minutes)
- 10. Outline of next steps in the research project. Thank you. (5 minutes)

Key informant interview schedule (phase 2 - bereavement)

[Researchers] from Western Sydney University will conduct individual interviews with people holding expertise in providing grief and bereavement support as part of palliative care and associated end-of-life services. Interviews will last for no more than 2 hours and will be held online.

- 1. Introductions and consent process. Brief overview of the aims of the research and the purpose of the interviews. (5 minutes)
- 2. Can you briefly outline your role and experience working with CaLD and/or Aboriginal communities? (5 minutes)
- 3. In your experience do these communities experience grief and bereavement differently to the majority population? (15 minutes)
- 4. In what ways are these experiences different? (15 minutes)
- 5. What are your observations of their experiences of more complex grief or bereavement? What contributes to this? (10 minutes)
- 6. In what ways do you understand people's confidence or even awareness of accessing grief and bereavement services [in these communities]? (5 minutes)
- 7. What services and supports do you believe these communities find useful, and in what ways are they useful? (10 minutes)
- 8. What other support or services do they need and who is best suited to provide this support and/or services? (10 minutes)
- 9. In what ways do existing services and supports need to change in order to be more culturally safe and appropriate? (20 minutes)
- 10. What will it take for these changes to be achieved? (10 minutes)
- 11. Is there anything you feel has been missed out in our discussion today, or anything else you would like to say that would be helpful to this project? (10 minutes)
- 12. Outline of next steps in the research project. Thank you. (5 minutes)

Focus group schedule – Aboriginal group



Dragonfly artwork by Leanne Tobin. Leanne's artwork reflects the vibrancy and transitional motions of the dragonflies as they move through their journey of life.

Yarning about end of life

Have you taken care of someone at the end of their life?

Would you like to share your experience, so that it may help our community?

- 1. What is your understanding of the term 'palliative care'?
- 2. In your culture is the place someone dies important or less important than other rituals and customs?
- 3. If things got much worse and your friend did need to be admitted to hospital, are there any special customs or things that would help her or her family at this time?
- 4. Who might be involved in making decisions about her medical and supportive care, and about whether she needs to go to the hospital?
- 5. What kind of things would make being in hospital easier or better for her and her family/community?
- 6. What are your thoughts about prolonging life or stopping treatment?
- 7. What if she wanted to die at home?
- 8. What kind of help would be most important for her and her family?
- 9. Who might the family ask for help and support?
- 10. How important are religion and spirituality for your community at end of life?
- 11. Are there any special funeral rites or customs in your community?
- 12. What things might help or benefit the family afterwards?
- 13. What are the five most important things the medical and supportive care workers need to know about your cultural needs when someone in your community is dying?

If you have any questions after the discussion, please contact [Aboriginal Supportive & Palliative Care Worker]

Focus group schedule – CaLD groups

These questions can be used or adapted if people want to tell their own stories about caring and focus on the key things we want to know.

Vignette for Hindi, Arabic, and Mandarin-speaking focus groups:

We would like to imagine that you have been a long-time friend of a 61-year-old widow from your community, who lives with her daughter's family. Until recently she was very active in her community and worked as a schoolteacher. She had a heart operation eight years ago and has been receiving specialist treatment over the last ten years. But lately her condition has been getting worse. After a series of tests, she is told that her condition is extremely serious.

The aim of treatment now is to help her live as long and as comfortably as possible.

The specialist suggests that she goes to see the palliative care team at the local hospital for their help with things like pain, swelling, and indigestion.

Possible questions from the researchers:

1. What is your understanding of the term 'palliative care'?

Hospital care

- 2. If things got much worse and your friend did need to be admitted to hospital, are there any special customs or things that would help her or her family at this time?
- 3. What kind of things would make being in hospital easier or better for her and her family/community?
- 4. What are your thoughts about prolonging life or stopping treatment?

Dying at home

- 5. What if she wanted to die at home?
- 6. Who might be involved in making decisions about her medical and supportive care, and about whether she needs to stay in the hospital?
- 7. What kind of help would be most important for her and her family?
- 8. Who might the family ask for help and support?

Rituals and customs

- 9. In your culture is the place someone dies important or less important than other rituals and customs?
- 10. How important are religion and spirituality for your community at end of life?
- 11. Are there any special funeral rites or customs in your community?
- 12. What things might help or benefit the family afterwards?

5 most important things

13. What are the five most important things the medical and supportive care workers need to know about your cultural needs when someone in your community is dying?

Photovoice schedules – Aboriginal and CaLD participants

In this project, we are interested in learning more about your experiences of care and caring at times of life limiting illness, death, dying and grief. In particular, what has been helpful or meaningful for you/your community and what services you have found useful or believe could be useful. As a photovoice participant, we invite you to take photos that represent this or are metaphors of this.

Telephone/email follow-up schedule:

The participants will have indicated at time of original consent whether they wish the follow up to be via telephone or email. Either way, the questions will be the same. This stage will be in a conversational style, in English. The [Research Assistant] will take field notes of the conversations:

- 1. Hellos and check in. How is it going?
- 2. Have you managed to take any photos? If yes: can you tell me what of and what that has been like? If no: have you some ideas about how you might start? Is there something you want to take a photo of but feel you can't? What needs to happen for you to get started?
- 3. Has it been easy for you/difficult? Tell me a bit more about that.
- 4. Do you think you have finished/nearly/soon? (Remind people of the process for returning the cameras and set date and place for 1:1 in-person interview).

1:1 in-person interview schedule: [NOTE: photovoice interviews were conducted online due to COVID-19]

The interviews will be conducted in English at a mutually convenient place. Interviews will last 2 hours and will be audio recorded and transcribed. They will be conducted by [a researcher].

Introductions. Renegotiating consent. Remind people it is a research project, check that they are still happy for the interview to be audio recorded. Remind them about how the photos could be used. Discuss the implications of any photos showing an identifiable person. Signing of 'use of photos' section in consent form, as applicable. Brief description of the purpose of the interview: to discuss the photos; to choose photos for the book; and to begin to develop the person's narrative/story.

Looking at the photos together over light refreshments. This stage also includes the throwing away of any photos people do not wish to be used in future.

People invited to talk about their photos. Use prompt questions for discussion, as needed:

- 1. What is your overall impression of the photos?
- 2. What stood out to you/interested you?
- 3. Do you think there are any connections/similarities between some of the photos?

- 4. What do you think the photos 'say' overall, about the needs of end of life care in your community?
- 5. What do they say about care/caring and about what is helpful or meaningful?
- 6. What do they tell us about the experience of death, dying and caring in your community and how people can be helped during these times?
- 7. Are there themes or an overall message?
- 8. What else would you like us to know about your photos?

4. Choose photos for book. Which (4) photos do you think you would like to use for the book? Which speak most clearly and powerfully about what you want to say/tell others?

5. Decide on process for written narrative. Now we need to think about writing a page or so which captures the things you want to say/your story. Shall we start doing this now? Do you want to think about it and get back to us with some ideas? Would you like us to write a draft and then send it to you?

6. To finish, agree on time frame for writing the story/narrative and clarify roles.

Note: the research questions below could be used as further prompts toward the end of the interview if needed/not already talked about - researcher to note if any such prompts are used.

- 1. How did you experience [name]'s final months?
- 2. What was the best experience you or [name] had during that time?
- 3. What traditions or cultural practices were important during [name]'s final months?
- 4. How was his/her place of death decided?
- 5. What health/support services were most important during [name]'s care?
- 6. What happened after [name]'s death?
- 7. What, if anything, would you change about [name]'s experience of dying?



Appendix 3: Death literacy survey results summary

In all, 203 people completed the Deatlh Literacy Index (DLI) online survey. This WSLHD community sample consisted of 83 Mandarin speakers, 60 Hindi speakers, 36 Arabic speakers, and 24 Aboriginal respondents.

Overall means and confidence intervals for the DLI and subscales

The following two tables (A3.1 and A3.2) show the mean scores for the DLI and its subscales in comparison with other samples taken over the past four years. In the first table, WSLHD scores are compared to representative samples collected from panels consistent with the demographic profile of the four target populations. It shows that for almost all scales and subscales the community sample responding in WS LHD had higher scores than the representative samples from Brisbane South PHN, the National population, and those people from the cultures of interest who completed the National survey.

The WSLHD scores are significantly higher on almost all scales but this likely reflects the nature of the sampling process. The national representative samples are taken from panels where the respondents are paid to do a number of surveys, so they do not need to be attracted to a particular topic. In contrast the community surveys (in Table A3.2) tend to attract people interested in the topic who therefore have higher death literacy. It is interesting to note that the people from the four cultures of interest in the national sample had lower DLI scores than the general population. Brisbane South had higher scores which a was mainly explained by having older respondents (a predictor of high death literacy).

Table A3.1 DLI and subscales for the WSLHD in comparison with the Australian population, subsample from the population for the 4 cultural groups, and Brisbane South population

DLI scales and subscales	WSLHD Mean (N=203)	Confidence Interval for WSLHD Low- er bound	Confidence Interval for WSLHD Up- per bound	2019 Na- tional mean (N=1200)	2019 National mean for the 4 cultural groups (N=145)	Brisbane South PHN population Mean (N=1200)
Factual knowledge	4.59	4.25	4.91	3.11^	2.48^	3.5^
Experiential knowing	6.52	6.21	6.83	5.93^	5.60^	6.0^
Practical	5.08	5.26	5.85	4.95^	4.12^	5.3
Talking support	6.06	5.69	6.39	5.53^	4.56^	5.9
Hands on care	5.57	4.74	5.41	4.37^	3.68^	4.6^
Community	5.50	5.17	5.82	4.36^	4.05^	4.7^
Accessing Help	5.81	5.46	6.19	4.21^	3.62^	4.4^
Community Groups	5.18	4.83	5.52	5.04	4.47^	4.9
DLI	5.54	5.33	5.79	4.70^	4.06^	4.9^

Notes: 1. * Indicates community sample means that are statistically higher than the WSLHD sample

^ Indicates community sample means that are statistically lower than the WSLHD sample

2. All scores ranged 0 to 10

3. National figures are based on the 2019 DLI survey.

4. In the WSLHD sample 30 respondents omitted answering an item of the DLI. Because they had answered almost all the questions it was reasonable to substitute their missing items with the mean for that item. In that way there were no missing values for the DLI and its subscales.

In the second Table WSLHD scores are compared to five other community samples. Three of these areas, Blue Mountains, Care Beyond Cure Tasmania and St Nicholas Hospice, had experienced compassionate communities interventions designed to increase death literacy so it is perhaps a tribute to those programs that they have higher DLI scores. South-West Sydney PHN (SWS PHN) was just beginning its intervention and like WSLHD, it has a high degree of cultural diversity. It has similar DLI scores to WSLHD.

Table A3.2 DLI and subscales for the WSLHD in comparison with community samples from SWS PHN, Brisbane South PHN, Blue Mountains, northern Tasmania, and St Nicholas Hospice UK

DLI scales and subscales	WSLHD Mean (N=203)	SWS PHN Mean (N=32)	Brisbane South PHN Mean (N=101)	Blue Moun- tains Mean (N=134)	St Nicholas Hospice, UK Mean (N= 106)	Care Beyond Cure, TAS Mean (N=121)
Factual knowledge	4.59	3.8^	5.7*	4.4	4.6	5.3*
Experiential knowing	6.52	7.2*	7.3*	7.7*	7.3*	7.4*
Practical	5.08	6.2*	6.5*	6.8*	6.7*	7.0*
Talking support	6.06	7.1*	7.3*	8.1*	7.5*	6.8*
Hands on care	5.57	5.2	5.8*	5.5*	5.8*	7.2*
Community	5.50	5.1	6.0*	5.9*	5.1	6.1*
Accessing Help	5.81	4.9^	6.1	6.0	5.0^	6.4*
Community Groups	5.18	5.3	5.9*	5.8*	5.1	5.7*
DLI	5.54	5.5	6.4*	6.2*	5.9*	6.5*

Notes: 1. * Indicates community sample means that are statistically higher than the WSLHD sample p<.0005 ^ Indicates community sample means that are statistically lower than the WSLHD sample

2. All scores ranged 0 to 10

Demographic profiles of the four cultural groups

Table A3.3 shows that there were differences among the four cultural groups on the DLI with Aboriginal respondents having significantly higher scores followed by Mandarin speakers, Hindi speakers and then Arabic speakers. This pattern held for all the subscales with the exceptions of the experiential knowing scale where there were no differences among the groups and the Community scale for which Arabic speakers had higher scores than Hindi speakers.

	Experi- ential	Factual ***	Practical ***	Talking support ***	Hands on Care ***	Commu- nity ***	Access- ing help ***	Support groups ***	DLI ***
Arabic-speaking	6.40	3.53	4.95	5.30	4.60	5.16	5.13	5.19	5.01
Hindi-speaking	6.81	3.64	6.04	6.48	5.59	4.71	4.85	4.56	5.30
Mandarin-speaking	6.25	5.32	5.08	5.62	4.54	5.96	6.31	5.61	5.65
Aboriginal	6.94	5.60	7.05	7.73	6.38	6.36	7.54	5.18	6.59
Total	6.52	4.59	5.57	6.07	5.08	5.50	5.81	5.18	5.54

Table A3.3 Mean scores for DLI and subscales for each cultural group

Notes: 1. *** p>.0005 indicates cultural groups are different from one another

2 All scores ranged 0 to10

In the 2019 National survey, Age, and related variables such as being retired or widowed, having children, plus Belief in an after-life or Religious or spiritual background, were all related to the DLI. In the present WSLHD survey, these demographic variables differed among the four cultural groups. However, Cultural group was the key variable and other demographics were no longer significant when Cultural group was included in the analysis. The demographic variables which related to the DLI after Cultural group was included, were: Talking to their neighbours; Being in the workforce, Educational level, Speaking English at home and Years living in Australia.

Analysing the demographic variables together to predict DLI score

Because the demographic variables that related to the DLI are not independent of each other (e.g., people who speak English at home are likely to have lived here longer), it made sense to analyse them together to see if some variables are more dominant and account for the variance in the others. Because there were only 203 people in the sample, it was not possible to test all the interactions together so only those with p values of approximately .01 or below were chosen.

Bringing together all the demographic variables that related to DLI individually, we found that only Cultural group [F(3,188)=3.01; p=.031], Years in Australia [F(2,188)=6.43; p=.002], and their interaction [F(4,188)=2.62; p=.036], were significant predictors of DLI score. Figure A3.1 shows the nature of the relationship more clearly. As expected, the Aboriginal people had been in Australia all their lives but there were significant differences among the other groups. 72% of Arabic, 42% Hindi and 8% Mandarin speakers had been here 5 years or fewer. 11% Arabic, 36% Hindi, and 40% Mandarin speakers had been here more than 15 years. Thus, in keeping with overall tends in Australian immigration, Arabic speaking respondents were most recent migrants and Mandarin speakers were the most long-standing [Chi sq (4) = 52.69; p<.001].

The number of years in Australia was the most powerful demographic variable for predicting DLI score [F(2,193) = 6.82; p<.001] plus there was a significant interaction (Figure A3.1) because Arabic speakers of long-standing residence had very high DLI scores, unlike those who were recent migrants. [F(4,193) = 3.15; p=.016]. Years in Australia was clearly the most dominant demographic predictor of DLI which suggests that a key factor for acquiring death literacy is being familiar with Australian culture and systems. Note: the result might have been overly influenced by the fact that all the Aboriginal respondents had been in Australia all their lives, but the same pattern of results was obtained when the Aboriginal group was omitted from the analysis.



Figure A3.1: DLI Scores for each cultural group by Years in Australia

Variables related to end-of-life

The demographic variables did not account for much of the variance in DLI score. Even with all the variables in the model they accounted for less the 20% of the variance (Adjusted R Square = .191). However, the survey also collected data on a number of end-of-life experiences that could help develop death literacy (see Leonard et al 2021 report for details).

Attitudes and actions at end-of-life scales: Table A3.4 shows the means for each of these scales (scaled 1-10), compares them to the 2019 National sample, and shows their relationship to DLI score. All were strongly related to DLI score except for Avoiding death and dying which had a weaker negative relationship.

Table A3.4 Mean scores for attitudes and actions scales for the WSLHD sample and National population

	N	Mean	Std.	95% Confidence interval		2019 National sample	Correlation with DLI
				Lower	Upper		
Discussions of death and dying scale^	153	5.55	2.28	5.18	5.91	4.03***	.474**
Provided emotional support to a carer scale	171	7.49	3.84	6.90	8.07	5.85***	.402**
Being present at the time of death scale	173	5.58	4.07	4.97	6.19	3.67***	.385**
Felt supported around a recent death scale	160	6.03	2.21	5.67	6.38	5.93	.344*
Caring at end-of-life scale	173	4.87	4.38	4.22	5.53	2.86***	.319**
Cultural experience of death and dying scale	179	2.80	2.52	2.42	3.17	2.00***	.319**
Provided practical support to a carer scale	172	5.47	3.77	4.90	6.03	2.26***	.285**
Planning for end-of-life scale	174	2.18	3.52	1.66	2.71	2.49	.250**
Avoiding death and dying scale	177	4.67	2.27	4.33	5.00	4.40	193*

Notes: 1. Note in this survey there were 5 questions about discussions of death and dying whereas there were only 2 questions in the National survey.

***(p<.0005) Indicates where means for WSLHD were significantly higher than those for the National sample.
 **(p<.01) *(p<.05)

Working or volunteering in end-of-life: Formal experiences with end-of-life work and volunteering have been found to be strong predictors of DLI score in the National and community surveys. In this sample:

- The 35 respondents (17.2%) who had worked in end-of-life had higher DLI scores [F(1,164) = 11.6; p< 0.001]
- The 14 respondents (6.9%) had medical training as a doctor or nurse had higher DLI scores [F(1,164) = 8.3; p= 0.004]
- The 37 respondents (18.1%) had volunteered at end-of-life had higher DLI scores DLI [F(1,164) = 3.9; p= 0.049] but not when cultural group was taken into account. Formal volunteering is a Western concept which is often not easily translated so this might account for the difference between these results and those of other surveys.
- 62 respondents (30.4%) had either worked, trained or volunteered in end-of-life.
- Only four respondents were currently the main carer for someone who might die within 12 months

Analysing the end-of-life variables together to predict DLI score

As with the demographic variables, the end-of-life variables that related to the DLI are not independent of each other, so it made sense to analyse them together to see if some variables are more dominant and account for the variance in the others. Cultural group and Years in Australia were included in the analysis to see if the end-of-life variables accounted for the differences in DLI score for the four Cultural groups and Years in Australia.

The results showed that when Years in Australia was in the analysis, Cultural group was not significant and did not contribute to the variance in DLI. Nor was there a significant interaction effect between Cultural group and Years in Australia. So Cultural group was not included in the model below. Overall, the end-of-life variables together with Years in Australia accounted for 46% of the variance in DLI score.

Table A3.5 Years in Australia and end-of-life variables as predictors of DLI

Predictor variable	df	F
Being present at the time of death scale	1	14.63***
Discussions of death and dying scale	1	13.63***
Years in Australia	2	11.47***
Worked, trained or volunteered at end-of-life	1	7.61**
Caring at end-of-life scale	1	4.70*
Felt supported around a recent death scale	1	3.31
Cultural experience of death and dying scale	1	2.18
Provided emotional support to a carer scale	1	1.81
Provided practical support to a carer scale	1	0.19
Planning for end-of-life scale	1	0.05
Avoiding death and dying scale	1	0.05
Total	133	

Notes: 1. a R Squared = .496 (Adjusted R Squared = .446) ***(p<.0005) **(p<.01) *(p<.05)

As shown in Table A3.5, Being present at the time of death scale and the Discussions of death and dying scale were the strongest predictors followed by having Worked, trained or volunteered at end-of-life. Years in Australia was also significant so there were differences in DLI that could not be accounted for by their personal experiences of end-of-life. Caring at end-of-life was also significant but the variance of the other six end-of-life scales was absorbed by these five variables.

The power of the discussions of death and dying to develop death literacy is particularly important given that everyone can be part of such conversations whereas not everyone has the opportunity to be present at the time of a death, provide care for someone at end-of-life, or other end-of-life experiences which improve death literacy. We conclude that there are differences in death literacy amongst cultures, but these differences are not intrinsic to the culture, but rather they relate to familiarity with the Australian health system.

Appendix 4: Cultural advisors and knowledge holders

Prior to commencement of the research, field notes were taken during informal interviews with a total of 20 cultural advisors, 11 of which were people from an Aboriginal, Arabic, Hindi, or Mandarin cultural/linguistic background. Professions amongst them varied and are displayed in Table A4.1 below.

The cultural advisors were mostly nominated by the WSLHD Advisory team and Key Informants, and also sourced through online searches the researchers conducted seeking community representatives throughout the LHD, and from the participants themselves making contact to express their interest in the project.

Some cultural Advisors worked or volunteered for WSLHD while others worked for small community organisations, were self-employed, or were from not-for-profit organisations such as Partners in Culturally Appropriate Care (PICAC), Palliative Care NSW, and Western Sydney University.

Table A4.1 Roles and cultural	backgrounds of the cultural advisors
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Role	Identified background	Frequency
Pastoral care volunteer	Arabic	1
Pastoral care volunteers	Hindi	2
Chaplain	Mandarin	1
Community development workers	Aboriginal	2
Funeral director	Mandarin	1
Funeral director	Aboriginal	1
Leader Hindi cancer support organisation	Hindi	1
Multicultural training, education and support	Hindi	1
Multicultural training, education and support	Arabic	1
Multicultural training, education and support	Other	2
Volunteer coordinators for palliative/ pastoral care	Other	2
Health consumer representatives	Other	2
Hospital social worker	Other	1
Death doula	Other	1
Policy officer palliative care	Other	1



