GRIID: survey of international rural dementia care service providers

GRIID (Gateway to Rural International Initiatives in Dementia) is an international team of dementia researchers, practitioners and service providers seeking to advance the provision of dementia care support and services in rural areas internationally. It is recognised that health professionals, care workers, practitioners, educators, service commissioners, providers and academics require access to information that can assist them in meeting the needs of people living with dementia and their caregivers in rural areas. In order to provide a repository of information as an accessible international website, information was gathered via an online survey.

The surveys objectives were:

- To collect information, experience, knowledge and ideas about rural dementia services from practitioners, educators, service commissioners and providers, and academics within dementia care services (worldwide).

- To collect examples of effective and innovative rural dementia services to create a central repository for networking and support.

Method

Survey Monkey software was used to create a user friendly survey which was sent to Alzheimer Associations across the world with the support of Alzheimer Disease International. Following the first distribution of the survey, the Dillman approach was adopted and two reminder emails were sent out both two and three weeks following the initial survey email. The survey was closed four weeks after the initial email with a total of 71 participants responding to the survey.

The survey included a total of 21 multiple choice, scale response and open ended questions in addition to encouraging the participant to expand on responses when possible. Prior to starting the survey, participants were asked to consent to the terms of the research before proceeding. Only those who consented were able to continue to the survey, if consent was not given the participant was redirected to a 'thank you' page and were unable to continue, 1 person took this route (70 participants continued).

Key findings

The data has been analysed using SPSS and key findings have been established:

- 56% of respondents are unaware of a dementia strategy/plan in their country.
- 47% of respondents are unaware of whether or not it mentions rurality.
- 60% of respondents are unaware of any innovative service provision in rural areas in their countries.
- 89% of respondents agree that rural dementia services experience greater challenges than urban services.
- 80% of respondents agree that connecting rural services through a web platform can improve service *design*.
- 69% of respondents agree that connecting rural services through a web platform can improve service *delivery*.
- 78% of respondents agree that connecting rural services through a web platform can improve the evidence base of services.
- 67% of respondents agree that connecting rural services through an IT infrastructure is possible in their region.
- 75% of respondents say that priority has <u>NOT</u> been given to rural dementia care in their country.
- 76% of respondents say that rurality is an important issue for service provision in their country.

*The results below are presented in two statistical formats:*

1. '*Percentage*': proportion of the total number of respondents to the questionnaire. These results are displayed as a descriptive analysis.
2. '*Valid percentage*': proportion of the total number of respondents who answered each specific question. These results are displayed as graphs using SPSS.

Descriptive summary of questions and responses

Q2: What country are you from?

Of the 56 (80%) respondents who answered this question, a total of 31 countries were represented from a variety of continents (Europe, Africa, Asia, North America and Australasia). The highest response rates came from Australia (9 respondents / 12.86%) and Indonesia (8 respondents / 11.43%). Of the remaining 39 respondents; Ireland (7.14%), India (5.71%), Belgium (4.29%) Bangladesh, New Zealand and the UK (2.86% each) provided the next highest response rates. This was followed by 21 countries represented by one respondent each.

Graph: results of analysis using SPSS (valid percentage):
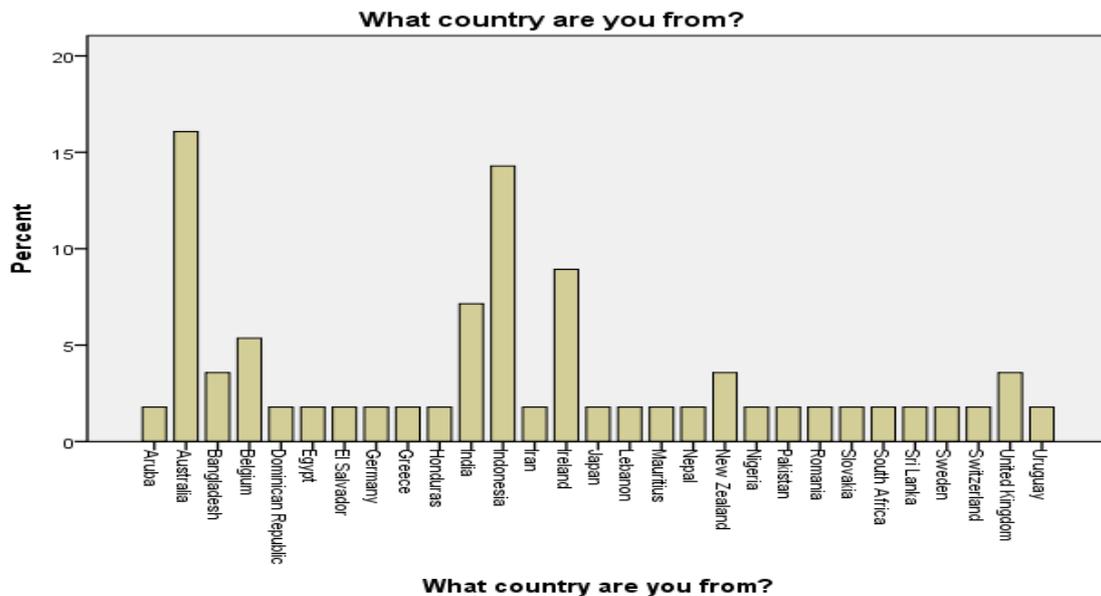
Q3: What region do you live in?

There was a 72.86% (51 respondents) response rate. The USA (2 respondents) was represented in this question but was not represented in question two. Details of more than one region were provided for Australia, Belgium, Indonesia, India, Ireland, USA and the UK.

Q4: What is the estimated size of your region?

47 respondents (67.14%) answered this question. 25 respondents (35.71%) estimated their region size to be between one and ten million. The remaining responses (22) mainly fell into the 100 thousand (+) and 10 million (+) categories. Four responses confirmed region sizes to be larger than 50 million (+). Two responses did not supply an actual figure.

Q5: What sector do you work in?

There was an 80% (56 respondents) response rate. Most respondents (32) work within the voluntary sector (45.71%); followed by the private sector (21.43%) and then the public sector (12.86%).

Graph: results of analysis using SPSS (valid percentage):
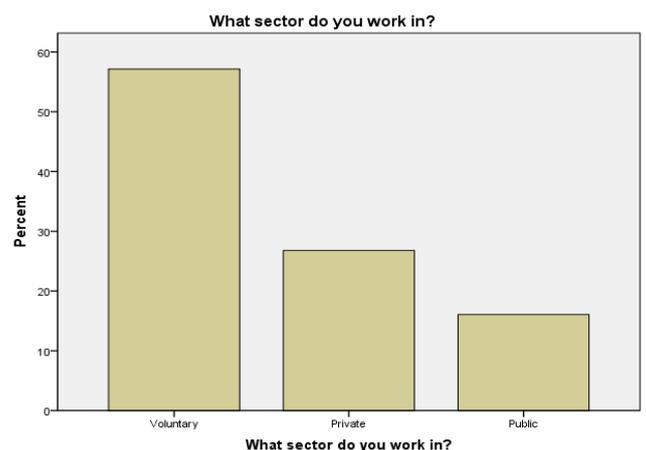
Q6: Are you completing this on behalf of an Alzheimer's association?

A total of 57 (81.43%) respondents answered this question, 53 respondents (75.71%) were completing this on behalf of an Alzheimer's Association.

Q7: Please specify the name of the organisation you are a member of?

50 respondents (70.43%) answered this question. The name of at least one organisation was provided for each country (excluding Mauritius, Slovakia and the USA where no organisations were noted). More than one organisation was provided for Australia, Indonesia, India, UK and Zimbabwe.

Q8: Does your Country have a dementia strategy/plan that you are aware of?

There was a 78.75% (55 respondents) response rate. 27 respondents (38.57%) answered 'No' and 24 respondents (34.29%) answered 'Yes'. Four respondents (5.71%) answered 'Don't know'.
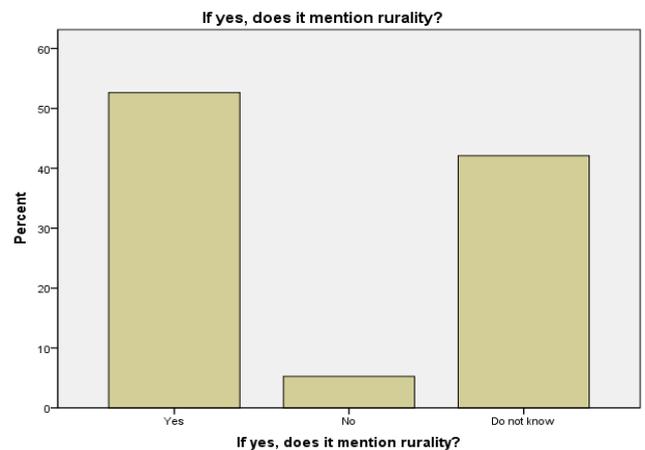
Graph: results of analysis using SPSS (valid percentage):
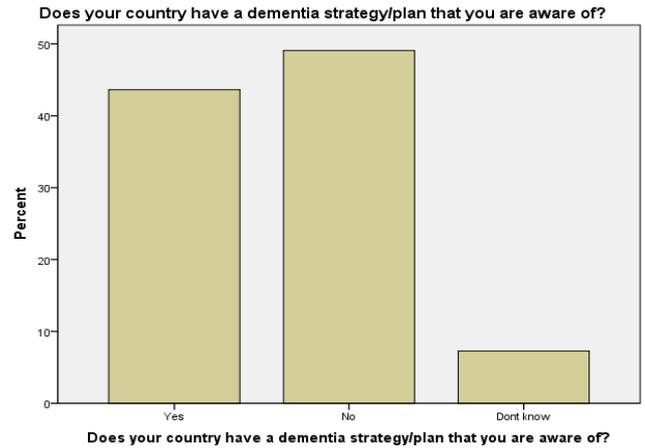
Q9: If yes, does it mention rurality?

Of the 24 respondents (34.29%) who answered 'Yes' to question 8, 19 of these respondents (79.17%) answered this question. 41.67% (10 respondents) answered 'Yes', 4.17% (1 respondent) answered 'No' and 33.33% (8 respondents) 'Did not know'.

Graph: results of analysis using SPSS (valid percentage):


Q10: Do you believe that priority has been given to rural dementia care within your country?
Scale question options 1 – 10 (1 = lowest score / 10 = highest score)

There was a 67.14% response rate (47 respondents). 12 respondents (17.14%) selected scale numbers 6 – 10. Scale number 6 was selected by 6 respondents (8.57%). Scale numbers 7, 9 and 10 all had 2 responses each.

35 respondents (50%) selected options in the lower half (5 - 0) of the scale. 11 respondents (15.71%) selected scale number 1. Scale numbers two and three were selected by 9 respondents (12.86%) each, suggesting that there is a common belief that rural dementia care is given very low priority.

*Graph: results of analysis using SPSS (valid percentage):*
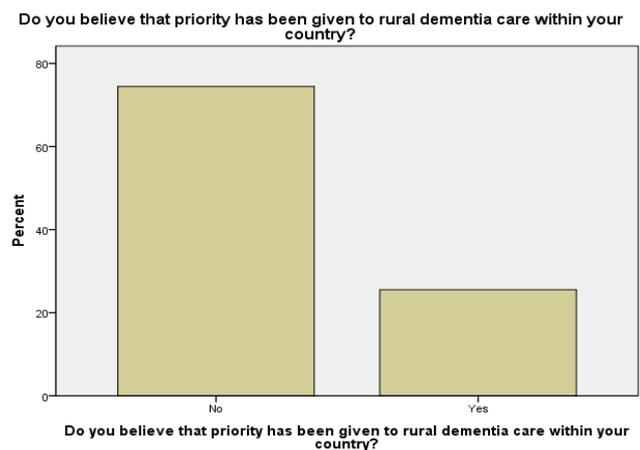
Q11: Do you find rurality to be an important issue for service provision in your organisation?
Scale question options 1 – 10 (1 = lowest score / 10 = highest score)

46 respondents (65.71%) answered this question. The lower half of the scale (5 – 0) had a total of 11 respondents (15.71%). The lowest scale option (1) was selected by 6 (8.57%) respondents. Four respondents (5.71%) selected scale number 5.

50% of responses (35 respondents) selected between scale numbers 6 and 10. 16 of these respondents selected scale number 8 (22.86%). 7 respondents (10%) selected the highest scale option of 10, suggesting that most respondents find rurality an important issue for service provision.

Graph: results of analysis using SPSS (valid percentage):
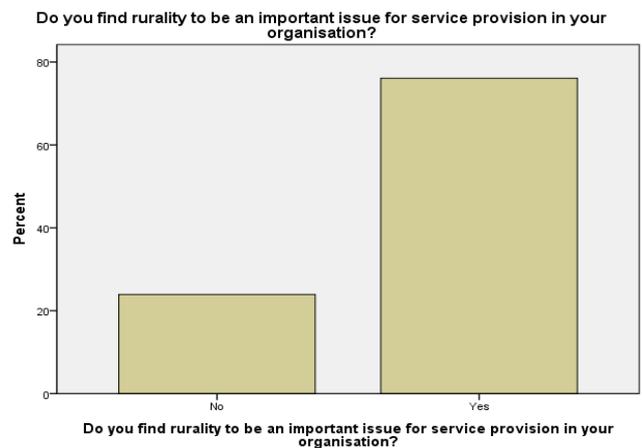
Q12: How is rural defined in your country?

There was as 51.43% (36 respondents) response rate. The answers have been grouped into 6 themes based on; distance, population size, location, industry, infrastructure and other. The majority of responses (18) are defined by location. There is a fairly even distribution between the other themes.

Q13: To what extent do you agree / disagree with the following statements?

There was a 64.29% (45 respondents) response rate.

Rural dementia services experience greater challenges than urban services:

The majority (30%) of respondents (21) agreed with this statement and 15 respondents (21.43%) strongly agreed. Four respondents (5.71%) partly agreed. Five respondents in total selected strongly disagree (1), disagree (2) and partly disagree (2). This suggests that most respondents agree with the above statement.

Graph: results of analysis using SPSS (valid percentage):
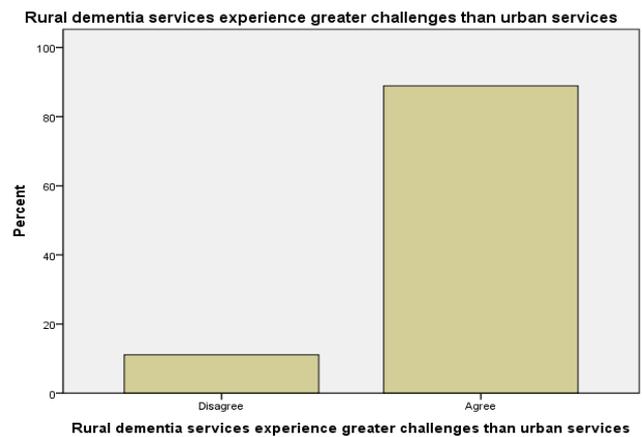
Connecting rural services through a web based platform can improve service design:

The majority (24.29%) of respondents (17) partly agreed with this statement, 15 respondents (21.43%) agreed and 3 respondents (4.29%) strongly agreed. Nine respondents in total selected strongly disagree (3), disagree (2) and partly disagree (4). This suggests that most respondents agree with the above statement.
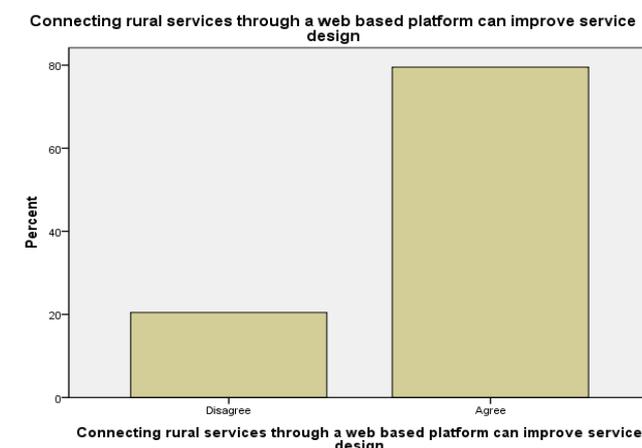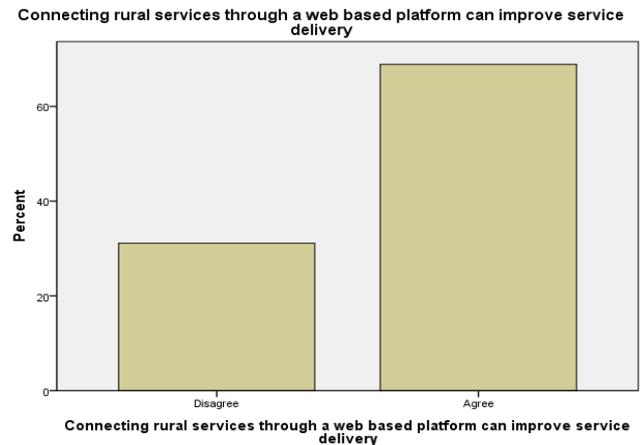
Graph: results of analysis using SPSS (valid percentage):

Connecting rural services through a web based platform can improve service delivery:

The majority (21.43%) of respondents (15) partly agreed with this statement, 11 respondents (15.71%) agreed and 9 respondents (12.86%) partly disagreed. Five respondents (7.14%) strongly agreed and a total of five respondents strongly disagree (3), and disagree (2).   This suggests that most respondents agree with the above statement.

Graph: results of analysis using SPSS (valid percentage):

Connecting rural services through a web based platform can improve the evidence base of services:

The majority (22.86%) of respondents (16) partly agreed with this statement, 13 respondents (18.57%) agreed and 6 respondents (8.57%) strongly agreed. Five respondents (7.14%) partly disagreed and a total of five respondents strongly disagree (3), and disagree (2). This suggests that most respondents agree with the above statement.

Graph: results of analysis using SPSS (valid percentage):
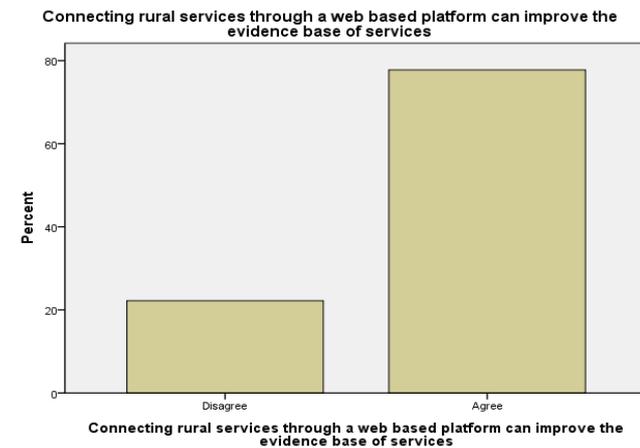
Connecting rural services through an IT infrastructure is possible in your region:

There was a shared majority between respondents who partly agree (12 / 17.14%) and agree (12 / 17.14%). 8 respondents (11.43%) partly disagree and 5 respondents (7.14%) strongly agreed. A total of six respondents strongly disagree (2), and disagree (4). This suggests that most respondents agree with the above statement.

Graph: results of analysis using SPSS (valid percentage):
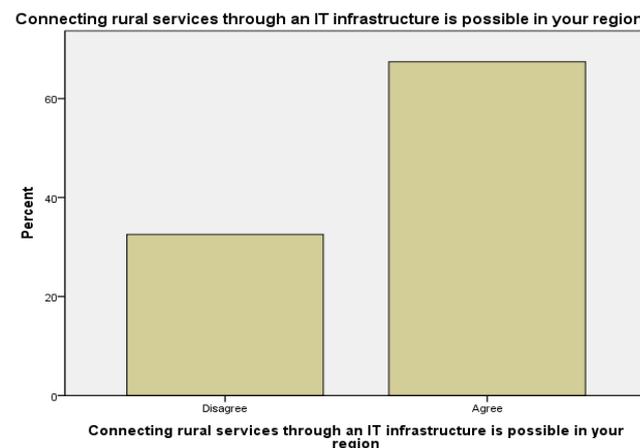
Q14: Please elaborate on the challenges associated with providing rural dementia services in your area.

37 respondents (52.86%) answered this question. The answers have been grouped into 8 themes; financial, transport, distance, client location/ lack of staff, lack of awareness, technology, political and other. The majority of responses (11) confirmed that challenges faced are surrounding client location and the lack of staff. Six

responses were grouped into the lack of awareness theme. The rest of the themes all had between 3 and 4 responses.

Q15: What have you done to overcome these challenges?

There was a 52.86% response rate (37 respondents). The answers have been grouped into eight themes; staff location, clubs/training, collaboration, funding, public awareness, extra services, research and other. The majority of responses (10) confirmed that raising public awareness was a way that challenges have been overcome. There are similar numbers of responses (between 2 and 5) for the remaining themes.

Q16. Are there examples of innovative service provision in rural areas in your region?

There was a 64.29% (45 respondents) response rate. 18 respondents (25.71%) answered 'Yes' and 17 respondents (24.29%) answered 'No'. 10 respondents (14.29%) answered 'Don't know'.

Graph: results of analysis using SPSS (valid percentage):
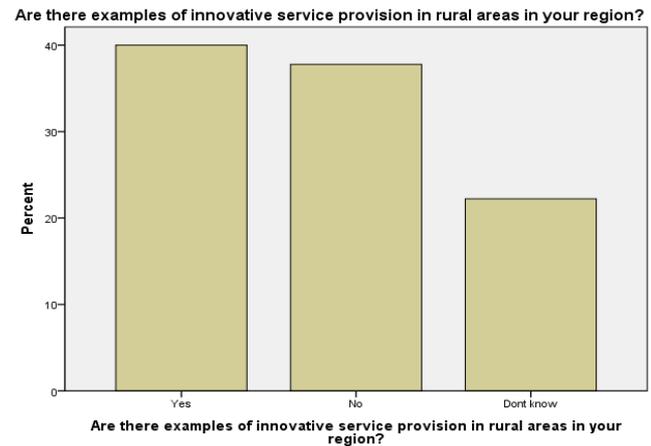
Q17: If yes, how many?

Of the 18 respondents (25.71%) who answered 'Yes' to question 16, 18 respondents (100%) answered this question. 33.33% (6 respondents) confirmed there was 1 example. 16.67% (3 respondents) confirmed 2 examples and 11.11% (2 respondents) confirmed that there were 3 examples. 7 respondents (38.89%) selected 'don't know'.

Graph: results of analysis using SPSS (valid percentage):
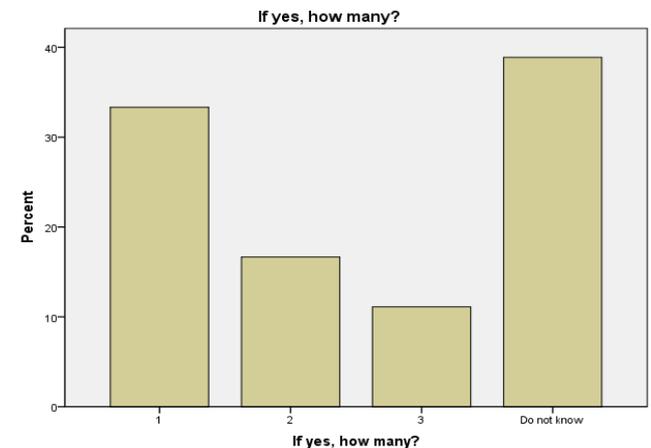
Questions 18, 19 and 20 (combined). If yes please describe the services as specified in the boxes below

Recurrent themes are identifiable across the three examples:

What was the purpose of the project? Themes:
- To provide support and respite for carers and people with dementia
- To enable relationship building for people with dementia
- To provide information about dementia services in the area and information about self care

How is the service funded? Themes:
- Through carer/staff self funding or through gifts/subsidies
- As government or voluntary organisation contributions
- Through local council funding

What key issues/opportunities in relation to improving dementia care did the project address? Themes:
- The wellbeing of both people with dementia and their carers
- Providing information about dementia to raise awareness
- Providing support for both people with dementia and their carers

Describe the how the project has met the needs and expectations of people with dementia and/or their families. Themes:
- By providing additional services for people with dementia (allows them to meet new people and maintain a level of independence and social interaction)

Discuss how the initiative has contributed to innovation or knowledge advancement in the delivery of health services? Themes:
- Has generated activities which people with dementia can participate in meet new people or to change their environment
- Has raised awareness of dementia and created greater understanding

Describe the methods you have used to evaluate the project, if any.
- Various methods used. No predominant theme identifiable

Describe the outcomes of the project or any related findings.
- Increased public awareness

BREAKDOWN OF QUESTIONS: 18/19/20	Q18. Example One 17.14%(12 respondents) response rate		Q19.Example Two 4.29% (3 respondents) response rate		Q20. Example Three 2.86% (2 respondents) response rate.	
Questions	No. Responses	Themes identified	No. Responses	Themes identified	No. Responses	Themes identified
What was the purpose of the project?	12	6 themes identified; **support and respite, day care, interaction, service information, service extension and religion**. Support and respite theme was the most popular (5 responses).	3	3 themes identified; **support, relationship building and medical**. Even distribution between each theme.	2	2 themes identified; **relationship building and information.**
How is the service funded?	12	5 themes identified; **Carer/staff, government and voluntary, local council, service provider and external**. Government/voluntary and carer/staff themes had the highest number of respondents (4 each).	3	3 themes identified; **carer/staff/gift, government/voluntary and local council**. Even distribution between each theme.	2	No themes identified.
What key issues/opportunities in relation to improving dementia care did the project address?	12	5 themes identified; **Carer and PWD wellbeing, support, information, afterlife and services**. Carer and PWD wellbeing and support themes had the highest number of respondents (4 each).	3	2 themes identified; **Carer and PWD wellbeing** (1 respondent) and **Medical/medication** (2 respondents).	2	2 themes identified; **Wellbeing and information**.

Describe the how the project has met the needs and expectations of people with dementia and/or their families	12	4 themes identified; **understanding, independence, leisure and respite**. Independence and respite themes had the highest number of respondents (3 each).	3	1 themes identified; **provide services** (1 respondent) and other (2 respondents).	2	2 themes identified; provide services and political.
Discuss how the initiative has contributed to innovation or knowledge advancement in the delivery of health services?	10	2 themes identified; **raised awareness and social inclusion**. Raised awareness theme had the majority of answers (6 respondents).	2	1 theme identified; **leisure**.	2	2 themes identified; **activity and awareness.**
Describe the methods you have used to evaluate the project, if any.	11	5 themes identified; **questionnaires/interviews, meetings, evaluation, feedback and research**. Questionnaires and feedback themes had the majority of answers (3 respondents each).	2	1 theme identified; **activities**.	2	No themes identified.
Describe the outcomes of the project or any related findings.	10	4 themes identified; **intervention, reduced stigma, quality of life and transport**. There was an even distribution between themes but the quality of life theme had 1 more respondent than any other theme (3).	2	1 theme identified; **awareness**.	2	No themes identified.

Q21: To what extent are the following aspects important to making rural dementia services innovative?

There was a 60% (42 respondents) response rate to this question. The below responses suggest that there is a general agreement that the below aspects are either important or very important to making rural dementia services innovative.

Responsive to local need: The majority of respondents (26) selected 'very important' (37.14%) and 12 respondents (17.14%) selected 'important'. 'Very unimportant' was selected by 3 respondents (4.29%) and 'unimportant' was selected by 1 respondent (1.43%).

Accessibility: The majority of respondents (28) selected 'very important' (40%) and 10 respondents (14.29%) selected 'important'. 'Very unimportant' was selected by 1 respondent (1.43%) and 'unimportant' was selected by 2 respondents (2.86%).

Cost effectiveness: The majority of respondents (22) selected 'very important' (31.43%) and 15 respondents (21.43%) selected 'important'. 'Unimportant' was selected by 2 respondents (2.86%) and 3 respondents selected 'neither' (4.29%).

Location: The majority of respondents (21) selected 'very important' (30%) and 17 respondents (24.29%) selected 'important'. 'Very unimportant' was selected by 3 respondents (4.29%) and 'unimportant' was selected by 1 respondent (1.43%).

Type of service: The majority of respondents (19) selected 'very important' (27.14%) and 17 respondents (24.29%) selected 'important'. 'Unimportant' was selected by 3 respondents (4.29% and 2 respondents selected 'neither' (2.86%).

8 respondents (11.43%) selected 'other'. Details provided of other aspects was grouped into four themes; diagnosis, awareness, support and other.

Conclusions

- The majority of respondents are unaware of their countries dementia strategies/plans or whether such strategies include rurality.
- Priority is not given to rural dementia care, yet it is agreed that rurality is an important issue for service provision.
- 'Rural' is defined in many ways. It is mostly defined by geographical location (often in reference to towns or cities).
- It is agreed that rural dementia services face greater challenges than urban services and that rural services would benefit from connecting such services through a web platform.
- Challenges associated with providing rural dementia services are predominately due to a lack of awareness. Raising public awareness was the most popular way to address these challenges.
- Examples of innovative services. Main objectives were predominantly to provide support and respite, to build relationships and provide information. Funding streams were mainly provided by the government, voluntary organisations, local councils or were self funded. The key issues most projects addressed was wellbeing and information providing. Overall the projects believed that they raised awareness.
- It was agreed that accessibility, cost effectiveness, location, the type of service and local need are all important to making rural dementia services innovative.