

# Research Participation in Rural areas: Issues and solutions

Professor Andrea Tales  
Dr Rebecca Sims  
Dr Emma Richards  
Dr Alun Meggy  
Dr Charles Musselwhite  
+others....

Source of information: Workshop/CADR Conference 2019



<b>Why are people living in rural communities in Wales less likely to participate in ageing- and dementia-related research?</b>	<b>Potential solutions</b>
<p>Lack of Information:</p> <ul style="list-style-type: none"> <li>• Lack of rural meeting places where people might be able to hear talks about research</li> <li>• Lack of rural GP surgeries and long waiting lists mean that recruitment might have finished before they can be told about a research opportunity by the GP surgery</li> <li>• Perception that people in rural communities were not needed and that the research was not for them.</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure funding is available to include as part of recruitment a series of small research information meetings/mini-conferences (rather than single larger meetings where people will have to travel further).</li> <li>• Greater liaison and engagement with rural community groups and other organisations <ul style="list-style-type: none"> <li>○ Farmers Union Wales</li> <li>○ Merched y wawr</li> <li>○ Women’s Institutes</li> <li>○ District nurses/community workers</li> <li>○ Welsh Government</li> <li>○ Office of National Statistics (possible help with recruitment strategies)</li> </ul> </li> <li>• Reach out specifically to isolated communities; arrange visits and local talks and home visits</li> <li>• Develop community /organisational-based ‘Research Champions’ who can act as important links between researchers and communities</li> <li>• CADR to make a directory of researchers and communities</li> <li>• Advertise the CADR data-base...include a research database?</li> <li>• Advertise in local newspapers (particularly Welsh local ones), newsletters, weekly papers, local radio/tv</li> </ul>

	<ul style="list-style-type: none"> <li>• Posters in local shops, post offices, community centres</li> <li>• All communications/adverts in Welsh and English</li> <li>• Greater interaction from researchers; ensure results from previous studies involving community/individuals is fed back to the participants.</li> <li>• Work more with charitable organisations</li> <li>• Work more closely with Join Dementia Research</li> </ul>
<p>Concern about who may be able to care for the person they look after whilst they are taking part: For example:</p> <ul style="list-style-type: none"> <li>• A person living with dementia/cognitive impairment</li> <li>• Children</li> <li>• Grandchildren</li> </ul> <p>Similarly, a person living with dementia may be concerned about having to ask for someone to accompany them or to help them take part.</p>	<p>Ensure that appropriate facilities (and relevant finances required for them) are included within the research protocol and funding and that such 'facilities' are well advertised. For example:</p> <ul style="list-style-type: none"> <li>• Trained helpers to be with the person being cared for whilst the carer is taking part in research (either at their home or within the research setting) and similar support for the needs of an individual living with dementia who would like to take part.</li> <li>• Consider group/community research formats where everyone can be involved at the same time...communal care/support/inclusion</li> <li>• The researchers to help with such arrangements</li> <li>• Charitable organisations</li> </ul>
<p>Financial Concerns: For example:</p> <ul style="list-style-type: none"> <li>• Transport costs</li> <li>• Care costs (see above)</li> <li>• Refreshment costs</li> <li>• Accommodation costs if research venue is at a distance</li> </ul>	<p>Ensure that appropriate facilities (and relevant finances required for them) are included within the research protocol and funding and that such 'facilities' are well advertised. For example:</p> <ul style="list-style-type: none"> <li>• Booking transport and accommodation in advance for all those taking part and who may need to accompany them</li> </ul>
<p>Transport</p> <ul style="list-style-type: none"> <li>• No longer able to drive</li> </ul>	<p>Ensure researchers travel out to participants where /when possible</p>

<ul style="list-style-type: none"> <li>• No longer own a car</li> <li>• No one to provide lifts</li> <li>• Lack of public/shared transport</li> <li>• Cost of taxis/other transport</li> <li>• Long distances to travel to research venues; too tiring</li> </ul>	
<p>Research Location</p> <ul style="list-style-type: none"> <li>• Closure of rural facilities where research might have been able to take place; rather than the participant travelling to the research venue.</li> </ul>	<p>Although this is not possible for all research....</p>
<p>Stress for the person living with dementia/cognitive impairment and carers</p> <ul style="list-style-type: none"> <li>• Care worries/worries about living with dementia</li> <li>• Stress</li> <li>• Tiredness, lack of time &amp; support</li> <li>• Fear/worry that an individual may not be able to participate through the medium of Welsh</li> <li>• The effects of changes in cognition, health and wellbeing.</li> </ul>	
<p>Computer technology in rural areas:</p> <ul style="list-style-type: none"> <li>• Lack of internet</li> <li>• Lack of broadband and thus consistent and reliable usability: lobby Gov about this.</li> <li>• Lack of home or community computers) especially in social housing)</li> </ul>	<ul style="list-style-type: none"> <li>• Don't just rely on internet advertising for research studies</li> <li>• Contact people by letter/phone: don't over-rely on e-mail/social media</li> </ul>

<ul style="list-style-type: none"> <li>• Can result in difficulties with on-line sign up.</li> <li>• Can be a barrier to hearing about studies and identifying research events and opportunities</li> <li>• Inability to or lack of confidence in using computers/e mails/internet</li> <li>• Fear of technology-related identity theft</li> </ul>	
<p>Other</p> <ul style="list-style-type: none"> <li>• Different health board structures</li> </ul>	
<p><b>Researcher-based issues</b></p>	
<ul style="list-style-type: none"> <li>• Costs: Some grant bodies do not fund participant transport costs, outreach activities, researcher transport costs, refreshments costs, recruitment costs/advertising, mass posting of letters</li> <li>• Ethics: data sharing/contacting people/permissions</li> <li>• Researcher time: multiple academic demands/ time constraints</li> </ul>	