Culturagram: Developing and implementing a culturally and ethnically sensitive family assessment tool for people living with dementia and their families

Keywords: Dementia, culture, ethnicity, assessment, patient experience

Duration of project: December 2011 - March 2013
Final report submitted: May 2014

Project leader: Vincent Goodorally, Culture and Ethnicity, Dementia UK

Contact details: Vincent.Goodorally@fote.org.uk

Summary
Dementia is a progressive degenerative condition and at present there is no cure. There are currently about 800,000 people living with dementia in the United Kingdom (UK). Admiral Nurses, specialists in dementia care, provide practical and emotional support to people living with dementia and their carers in the community, care homes and hospitals. They are employed by host organisations (e.g. NHS/charities/private sector) but receive additional professional and practice development support from the charity, Dementia UK.

Whilst they strive to work in a culturally and ethnically sensitive manner, there is no family assessment tool which addresses these important issues in use in the UK to support practice. The Culturagram (Congress, 2008) was developed in the United States to help healthcare professionals to understand the cultural needs of patients and their families.

The Foundation of Nursing Studies’ Patients First Programme in partnership with the Burdett Trust for Nursing supported a project to improve the experience of the assessment process for people living with dementia. The aim of the project was to implement and evaluate the effectiveness of the Culturagram. A number of methods and approaches were used to achieve the project’s aim and facilitate changes in practice. These included engagement of stakeholders; interviews with people living with dementia and carers using emotional touchpoints; adapting the Culturagram and implementing it into practice and evaluating its use. Findings indicated that the modified Culturagram can be used with people from all backgrounds and positive feedback was received from both staff and service users. The project leader observed that staff, people living with dementia and carers struggled with the word ‘culture’ as a concept; phrases like ‘to better understand you as a person and support you’ facilitated engagement with the assessment process in a more effective way. The emotional touchpoint technique used was a powerful way of giving people living with dementia and carers a voice to express their experiences. The project also raised awareness of culture and ethnicity beyond dementia care, for example people with other health needs.

Background
Dementia is an umbrella term used to describe a group of symptoms including memory loss, confusion, mood changes and difficulty with day-to-day tasks. There are many types of dementia, with Alzheimer’s type dementia being the most common. There are currently about 800,000 people in the UK with a diagnosis of dementia and the number is set to
increase with a growing elderly population (Alzheimer’s Research UK, 2013). It is also anticipated that the number of black and minority ethnic (BME) older people will increase over time reflecting immigration patterns in the latter part of the twentieth century (Lievesley, 2010). This will inevitably result in a growing number of people from a BME background with dementia and therefore also the numbers of carers. People living with dementia experience multiple losses including an assault on their personhood as a result of disease processes and caring practices (Kitwood, 1997). Their supporters (families and friends) experience higher levels of carer strain/ill health compared to other disease processes (Newbronner et al., 2013).

Recent national policies and initiatives have highlighted that the needs of people with dementia and their families which stem from diversity, including ethnicity, age, religion and personal care, should be identified and addressed by health and social care staff. There has also been a requirement for healthcare organisations and staff to understand what matters most to patients and to respond to this in new ways, making sure that every contact with a patient counts towards delivering high quality service (Department of Health, 2009).

*Dementia UK and Admiral Nurses*

Dementia UK (Dementia UK, 2014) is a national charity and its vision is ‘people living and affected by dementia will receive compassionate expert care and support that is right for them, to live positive and fulfilling lives’.

Its mission statements are:

- Become the beacon of excellence by providing unrivalled guidance, responsive solutions and innovative thinking to address the challenge of high dementia care
- Influence national policy to ensure that everyone living with dementia has equal and fair access to Admiral Nursing
- Lead the way in innovative and high quality research and development in the best possible dementia care

Admiral Nurses provide psychological support to family carers to help them to understand and deal with their feelings; and practical support, advice and information on dementia, its impact and how to cope with a dynamic and changing situation. Admiral Nurses can also refer on to other services and liaise with other professionals to provide holistic support when it is most needed. Dementia UK is responsible for upholding the professional standards of Admiral Nurse Practice, sustaining Admiral Nurse Services and developing the scope of specialist dementia care practice.

*Practice concerns*

In 2005, ForDementia (the previous name of Dementia UK) carried out an audit of the Admiral Nurse Standards and carers’ satisfaction questionnaires in three Admiral Nurse Services. The results highlighted the issues of access to dementia care for those of a BME background. The Admiral Nurses involved responded to these challenges through discussions in peer group supervision and by implementing local initiatives. A loose network of likeminded nurses began to evolve. The project lead was then employed by Dementia UK to lead a project to address the highlighted issues. In 2010 this loose network undertook a national survey of Admiral Nurses (n=60) to capture their understanding of culture and
ethnicity issues in dementia care. Forty per cent of nurses surveyed reported this was an issue they wished to understand in more depth. A ‘special interest group’ (SIG) was then formed and led by the project lead with the aim of exploring assessment tools that may assist Admiral Nurses in their practice, in relation to culture and ethnicity.

**Culturagram**

The SIG undertook a literature search using key search words - dementia, ethnicity, culture and assessment. Results indicated that there was currently no validated family assessment tool/framework in use in the UK that specifically addresses cultural and ethnicity issues in relation to people with dementia and their supporters. Gutheil and Heyman (2005) suggest that cultural issues are a crucial but an often overlooked component of the assessment process as is care delivery for culturally diverse older adults.

The Culturagram (Congress, 2008) is an assessment tool developed in the USA to help healthcare professionals understand the needs of culturally diverse communities. It is a diagrammatic aid to assessment (see Appendix 1). Chau (2008) proposed that the Culturagram would help healthcare professionals explore the complexity of the health experience of the Chinese people and other minority ethnic groups in the UK. Parker and Bradley (2011) noted that as it is a USA based tool, it may need modifying for use in the UK because of the different healthcare systems used in each country.

**Patients First Programme**

The project lead made a successful application to the Foundation of Nursing Studies’ (FoNS) Patients First Programme to explore the use of the Culturagram in dementia care practice in the UK. The programme provided a bursary, the support of a dedicated and experienced practice development facilitator and full access to the FoNS Centre for Nursing Innovation website as an Honorary FoNS Associate. FoNS also facilitated workshops to bring together the nurse-led teams supported by this programme. The aims of the workshops were to enable the development of effective strategies for changing practice and provide opportunities for networking and sharing.

**Project Aim**

To improve the experiences of the assessment process for those people living with a dementia and from a BME background and their carers by implementing and evaluating the effectiveness of the Culturagram in three NHS organisations.

**Objectives**

- To enable staff participation in the project
- To capture and understand the patient and carer experience of assessment
- To adapt the Culturagram for use in the UK
- To create a self-assessment version of the Culturagram for service users/carers
- To pilot the use of the Culturagram/self-assessment version
- To evaluate the use of the Culturagram within the assessment process

**Methods and approaches**

Three pilot sites were originally recruited by the project lead to participate in the project. The designated pilot sites were chosen as they employ Admiral Nurses, have different
population demographics and were positive in their commitment to participate. The project lead applied for and was granted an honorary contract for the period of the project, from the NHS trusts that formed the pilot sites. Unfortunately it emerged as the project progressed, that all the sites were experiencing high levels of uncertainty including service redesign, staff redundancies and staff redeployment into other posts and roles. These factors impacted on the planned milestones of the project and meant that it was only possible to progress the project fully within one site - Kingston upon Thames, Surrey. This report will therefore focus on the methods used and outcomes achieved in this one area.

A number of methods and approaches were used to achieve the project’s aim and facilitate changes in practice. These have been summarised in the Table 1.

Table 1- Summary of methods and approaches

<table>
<thead>
<tr>
<th>Method</th>
<th>When this happened</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>• Development of Gantt Chart</td>
<td>November 2011</td>
</tr>
<tr>
<td>• Action planning</td>
<td>December 2011, March 2012, May 2012, October 2012</td>
</tr>
<tr>
<td>2. To enable staff participation in developing the project</td>
<td>December 2011</td>
</tr>
<tr>
<td>• Stakeholder analysis</td>
<td>Started February 2012-April 2012, May 2012, August 2012, November 2012</td>
</tr>
<tr>
<td>• Steering group meetings</td>
<td>March 2012</td>
</tr>
<tr>
<td>• Staff awareness sessions</td>
<td>May 2012</td>
</tr>
<tr>
<td>• Values and Beliefs Clarification</td>
<td>June 2012</td>
</tr>
<tr>
<td>• Claims, Concerns and Issues</td>
<td></td>
</tr>
<tr>
<td>3. Capturing service user/carer experience using emotional touchpoint interviews</td>
<td>July - October 2012</td>
</tr>
<tr>
<td>4. Adaptation of Culturagram</td>
<td>October 2012</td>
</tr>
<tr>
<td>5. Developing a self-assessment Culturagram for service users/carers</td>
<td>November 2012</td>
</tr>
<tr>
<td>7. Celebration event</td>
<td>6th February 2013</td>
</tr>
</tbody>
</table>

1.1 Development of a Gantt Chart

At the start of the project, a Gantt chart was developed by the project lead with assistance from the senior nursing lead. A Gantt chart is a type of bar chart, developed by Henry Gantt in the 1910s, that illustrates a project schedule. Gantt charts illustrate the start and finish dates of the terminal elements and summary elements of a project. Terminal elements and summary elements comprise the work breakdown structure of the project. Modern Gantt charts also show the dependency (i.e. precedence network) and relationships between activities. The use of a Gantt chart helped track progress of the project alongside the project lead’s other commitments.
1.2 Action planning
Making change happen in clinical practice requires action planning (O’Neal and Manley, 2007). These authors suggest the use of a self-assessment tool to facilitate action planning. The FoNS facilitator supported and encouraged the project lead to undertake action planning (see Appendix 2). Action planning involves developing a system for the way in which each objective will be accomplished. The project lead found that discussing and sharing the action plans with other project leaders during the FoNS workshops helped to establish clarity about the actions and to identify sources of support. The project lead used the framework for reflection in action adapted from Gibbs (1988) to reflect on events as the project progressed. These processes helped the project lead to continually examine the overall objective and how it would be achieved and evaluated.

2. Enabling staff participation in developing the project
The National Health Service constitution (Department of Health, 2013) describes staff engagement and participation as a key ingredient in empowering staff to put forward ways to improve services for patients and their families. The project used various methods to facilitate this engagement process.

2.1 Stakeholder analysis
To identify the potential stakeholders involved in the project a stakeholder analysis was undertaken. The Admiral Nurse Team leader and their line manager assisted the project lead in identifying all the potential stakeholders. A template (Wenger et al., 2002; See Appendix 3) was then used to organise the stakeholders in order of importance and to decide the most appropriate ways of communicating with them about the project. The following stakeholders were identified:

- people living with dementia and their carers
- wider multidisciplinary team
- trust management
- external partners – statutory and voluntary sectors

The information gathered from the stakeholder analysis assisted the project lead in identifying the best ways of engaging with individual participants, their level of power/influence and deciding the composition of the steering group. The stakeholder analysis helped the project lead in ensuring the most effective communication methods were used and in establishing a model. The model included planned meetings (same place, same time), notice boards (same place, any time) and e-mail (any place/anytime). However, as the project progressed, the project lead found that the analysis had not identified all the stakeholders. For example, following the patient and carer interviews, people living with dementia and their carers highly rated the outpatient staff (administrative and clerical staff). On reflection this group of staff should have been involved in the project from the beginning.

2.2 Steering group
A steering group was established to guide the development of the project and also to ensure full engagement of key local people. The local Admiral Nurse Team leader and line manager supported the project lead in ensuring membership matched local stakeholders
and also helped with the logistics of meeting rooms and venues etc. Terms of reference for the steering group were developed by the project lead in collaboration with the group (see Appendix 4).

The steering group comprised of Admiral Nurses, team leaders, the medical lead, the social work lead and the Nurse Director. The steering group met five times within the period of the project to discuss and monitor progress, offer expertise and leadership as well as provide key links to the trust’s governing structures. Lack of administrative support resulted in the project lead seeking group members to take minutes and the project lead typing and circulating notes.

2.3 Awareness-raising sessions
Three awareness raising sessions about the aims and objectives of the project were facilitated with local stakeholders; both internal to the NHS organisation and externally with local collaborators. The purpose of these sessions was to provide an opportunity for stakeholders to find out more about the project and to share their views and concerns. It was felt important to engage stakeholders at the earliest point possible to facilitate early adoption and change of practice.

A leaflet was also developed to provide further explanation of the project and included details like:

- Time and place of meetings
- Project title, overview and aim
- Governance issues
- Need for project

The awareness sessions were well attended (n= 40) and there was a keen interest in the issues of culture and ethnicity not just in dementia care but with other client groups. The sessions lasted between 20 and 30 minutes.

Comments made included:

- What does it mean to be White British? I sometimes struggle with this (Nurse)
- I never ask my patients about their beliefs and values. I will bear that in mind in future (Consultant Psychiatrist)
- This has made me think about the usefulness of cultural awareness compulsory training (Manager)
- At present we cannot really demonstrate that we are practising in a culturally sensitive manner (Manager)

2.4 Values and beliefs clarification exercise
The clarification of beliefs and values is a prerequisite of the person-centred nursing framework (McCormack and McCance, 2006) and as Dewing (2007) discusses, values and beliefs underpin all professional practice. A values clarification exercise (Manley, 1992) is a tool frequently used within practice development to develop a common shared vision and purpose. It is the starting point for cultural changes in the workplace. The project lead facilitated a values clarification exercise at the pilot site. The participants included the Admiral Nurse (n=1) and the wider multidisciplinary team (n=18).
The questions posed were:

• I (we) believe the ultimate purpose of assessment is ...
• I (we) believe this purpose can be achieved by ...
• I (we) believe the factors that enable this purpose to be achieved include ...
• I (we) believe the factors that hinder this purpose to be achieved include ...
• Any other factors ...

To facilitate the contribution of all, participants were invited to write their individual views in response to the questions on sticky notes. They were also informed that their responses would be used for the purposes of the project only. The project lead then randomly got participants into groups, which were then tasked to craft the individual comments from “I believe” to “we believe” and into team statements. The randomisation of the groups was done in order to get a balanced mix of disciplines and seniority. The workshop was tagged as part of the business meeting as this was the only opportunity to meet all the staff. Participation in the workshop was very high and all staff stayed for the duration of the workshop.

Staff comments were:

• *Made a change to do something that is relevant to our work*
• *Enjoyed the exercise*

The project lead typed up and circulated the notes for the benefit of people not able to attend.

**Example vision statements**

“We believe the ultimate purpose of assessment is: To identify need, understand the person / what is important to them, any concerns they have - as a basis for planning care and support and with regards to context.”

“We believe the ultimate purpose of assessment is: To collaborate and build rapport in order to gather information, identify needs, assess risk and devise an appropriate action plan.”

**2.5 Claims, concerns and issues**

Fourth generation evaluation (Guba and Lincoln, 1989) uses claims, concerns and issues to gain the views and perspectives of stakeholder groups. Claims are favourable assertions about a topic (in this case the Culturagram). Concerns are unfavourable assertions about the topic. Issues are questions that any reasonable person might ask about the topic and usually arise from the concerns. Following on from the values clarification workshop, a claims, concerns and issues workshop was held at the pilot site. The participants included the Admiral Nurse (n=1) and the wider multidisciplinary team (n=18).

Staff were invited to write their claims, concerns and issues on sticky notes and put them on three flipchart sheets. Different colour sticky notes were used for claims, concerns and issues. Members could use any number of sticky notes per heading but in order to enable
theming, only one statement per note was encouraged. These were then themed by the project lead and are displayed below:

Table 2 - Themes emerging from the claims, concerns and issues exercise

<table>
<thead>
<tr>
<th>Claims</th>
<th>Inclusive, stress, collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concerns</td>
<td>Does not address the issue of skills, needs rather than strengths focused</td>
</tr>
<tr>
<td>Issues</td>
<td>Time, duplication/paperwork</td>
</tr>
</tbody>
</table>

As part of the exercise the project lead then invited staff to reframe the concerns e.g. ‘I don’t have time’ into questions such as ‘how can I/what will help?’

Time is an important issue for both staff and carers. A discussion then took place on how to make the best use of time and promote collaborative working with carers. It was at this point that the idea of a self-assessment tool was further developed. Staff also generated their own solutions on how to store any information gained from using the Culturagram – administrative staff would scan and attach the document to the main electronic data records. The project lead made notes and shared them widely with the steering group afterwards to ensure all members of staff were kept informed.

3. Capturing the patients’ and carers’ experiences of assessment using the touchpoint interviews

The purpose of the interviews was to gain an insight into patients’ and carers’ experience of the assessment process – what worked well for them and the things that caused them concern. The emotional touchpoint technique (Dewar et al., 2010) is one of several methods recommended by the NHS Institute for Innovation and Improvement for capturing patients’ experience. This fresh innovative approach to involving patients was exciting but the thought of using this technique to talk to people living with dementia and carers created anxiety for the project lead. The project lead was very concerned about the fear of failure and causing harm in trying new methods. However support from the FoNS facilitator and regular clinical supervision enabled the project lead to work with this process.

To involve people living with dementia and carers in the interviews, the project lead contacted the managers of Dementia Cafés within the pilot site. Dementia Cafés provide a safe, comfortable and supportive environment for people with dementia and their carers (members) to socialize. As well as offering a range of fun and engaging activities, Dementia Cafés give the members a chance to get information and advice and talk to others with similar problems. Led by qualified staff with considerable experience in dementia care and supported by local volunteers, these regular social groups improve well-being and reduce isolation for whole families (Alzheimer’s Society, 2014).

The project lead explained the project to the managers of the Dementia Cafes and asked if they would be prepared to raise awareness of the project with the members. The managers of the café made the initial approach to the members and sought their permission to invite the project lead to their meetings. The project lead felt it was important to establish a rapport and gain trust with them in the first meeting. Time was therefore spent getting to know them and generally helping out. At the second meeting, a more detailed explanation about the
project was given. Members were informed that confidentiality would be ensured, that the data would be used only for the purpose of the project, that they had the right to withdraw at any time and that written consent forms would be used.

Potential participants were requested to submit their names to the manager in the first place. This was important as the managers had greater understanding of the members and their circumstances and the level of support they may need prior to and after the interviews. The managers arranged the interviews to minimise disruption to their daily activities. The interviews were carried out by the project lead in the relaxation room at the Dementia Café. This proved to be effective as there was no disturbance. One couple consented to the interview being conducted at home. This was more convenient and less disruptive for the carer and the person living with dementia.

Four couples (person living with dementia and their partner) were interviewed. They were given the choice of being interviewed separately but all chose to be interviewed together.

The project lead invited participants to think about the experience of attending the memory clinic – before, during and after the appointment, but were free to talk about anything else they felt important. They were presented with a number of cards (n=34) with emotion words printed on them (negative and positive statements) and asked to choose as many as they wished to express how they were feeling before the assessment, during the assessment and after the assessment. They were then invited to talk about why they chose the cards. The project lead recorded the cards they chose and wrote brief notes on their stories. This was also checked for accuracy with the interviewees before closing the discussion. The interviews lasted between 45 and 60 minutes.

Table 3 shows the words selected by the people living with dementia and carers to describe their experiences:

<table>
<thead>
<tr>
<th></th>
<th>Before the assessment</th>
<th>During the assessment</th>
<th>After the assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Powerless (n=5), frustrated, sad, lonely, insecure, anxious, unsure</td>
<td>Welcome, hopeful, involved, safe, shocked, unimportant, disappointed</td>
<td>Disappointed, relieved, understood, encouraged and supported</td>
<td></td>
</tr>
</tbody>
</table>

The powerless statements (see below) were used by both carers and people living with dementia.

- *Nothing I can do to improve the situation. I can only maintain it* (Male Carer having to deal with changes in role)
- *Can't make any changes - no power. People make statements ... do this/do that ... nobody sits down/give reasons* (person living with dementia/ex business man)
• *Can’t do anything about the issues* (Carer and retired nurse dealing with GP)
• *Can’t do much. Can’t drive anymore* (person living with dementia/racing enthusiast)

Participants commented that the emotional touchpoint technique had helped them to talk about their experiences and that they valued the opportunity to do so.

Comments from the interviewees were:
• *Really enjoyed it. Why did nobody ask me these questions before?* (Carer)
• *We have been through it before. Hope we can help others through your work* (Person living with dementia)
• *I was down and out. She (doctor) greeted me with a smile/shook my hands and asked how I was ... said there were lots of ways we can help. My world lifted* (Carer)
• *Different doctors all the time ... looking at the computer most of the time ... may as well be not there* (Carer)
• *Shocked ... too much information too soon* (Carer)
• *Hate this test ... what day is it ....humiliating* (Person living with dementia)

The data (emotion card choices and statements) were themed by the project lead and fed back to the steering group with explanation notes while ensuring anonymity. The project lead felt this was important as it would also enable the steering group members to think of possible solutions ahead of sharing it with any the wider staff groups.

The project lead received feedback that the steering group was initially astounded by the findings. Verbal comments such as “oh!” and non-verbal communication involving body language and posture (covering mouth and frowns) suggested the steering group were shocked at how different the patients’ experiences were from their espoused values and beliefs about patient care. Managers wanted to know more about the circumstances, to unpick the feedback - who, when, what. On the other hand clinicians saw the opportunity to reflect on their own practice and the practice of their supervisees. The project lead had anticipated this and facilitated the meeting to enable members to re-focus on the aims and objectives of the project. This helped members find possible solutions and create an action plan (see Appendix 6).

There was consensus at the meeting that the administrative staff played an important role - this should be acknowledged at the following business meetings in their presence. Some of the solutions e.g. yearly appointment with psychiatrist were beyond the scope of the project but were worthy of consideration. Others were around design and layout of consulting room and time factors. Both had financial implications and were not achievable. Sharing the comment from one carer - ‘*just give us a simple explanation and we will understand. We are not stupid*’ appeared to be a *light bulb* moment for the members. The importance and usefulness of the emotional touchpoint technique was highlighted.

### 4. Adaptation of the Culturagram

In order to foster a sense of ownership of the Culturagram tool and to involve staff more in the project, a further workshop was held. The participants (N=18) were Admiral Nurse (1), community mental health nurses (5), consultant psychiatrist (1), social workers (5), psychologist (1), occupational therapist (1), manager (1) and support workers (3).
Participants were invited to look at the original Culturagram and to consider, collectively, the following questions from Parker and Bradley (2011):

- What right do I have to ask these questions?
- How would I feel if someone asked me these questions?
- Why am I asking these questions?
- What will I do with the answers?

The project lead suggested the team work in three groups - to look at selected headings of the Culturagram and apply the above criteria. The groups were also asked to suggest alternative wording within the spirit of the framework. This exercise provoked a lot of discussion. Some of the headings were considered straightforward and reasonable e.g. communication. Other headings were considered a bit vague and irrelevant e.g. length of stay in the country (for indigenous population) or difficult to ask e.g. oppression /racism, discrimination and legal status. However staff concluded that they were relevant but needed to be altered to e.g. experiences of health and social care so that any misconceptions can be addressed. Total consensus e.g. changing legal status to entitlements could not be achieved and it was agreed that it would be addressed following the pilot.

5. Developing a self-assessment Culturagram tool for service users and carers

It is well documented that time and power differentials are factors that affect the quality of the assessment (Parker and Bradley, 2011). The project lead sought to address this issue by involving people living with dementia and carers in the development of a self-assessment Culturagram that could be completed prior to assessment. One carer with personal experiences of the mental health service volunteered to comment on the layout of the assessment form and writing up the guidelines for patients and carers.

6.1 Piloting the self-assessment

The project lead sought to identify the usefulness of the self-assessment tool for people living with dementia and carers, who had already had an assessment of their needs and were attending the day hospital. Staff explained the project to potential participants and handed out the self-assessment forms. Participants were invited to complete the self-assessment form and give feedback on its usefulness. Ten self-assessment Culturagram forms were handed out. Five completed forms were returned but only two provided feedback.

Feedback elicited:
- I am lucky to be receiving all the help I need. This form would be useful to someone not so lucky
- Yes, you will have to talk to my sister. She makes all the decisions

6.2 Pilot the use of the modified Culturagram

The project lead developed guidelines to support and inform staff in the use of the tool and volunteers were sought to pilot the tool in practice. In total three nurse and three social workers piloted the tool. To prepare these staff, the project lead facilitated a workshop for the participating professionals. The aim of the workshop was to provide an opportunity to practise using the Culturagram through role play and to discuss any concerns. Unfortunately
due to work pressure only three participants were able to attend. However the workshop went ahead and participating staff were encouraged to reflect on their experiences of using the Culturagram and to share any learning with the project lead. This learning was then cascaded to other participants. Participants recruited volunteers (people living with dementia) from their caseload and conducted their assessment using the Culturagram as a tool.

Feedback from professionals:

- Service user (White Irish with memory impairment) found it difficult to grasp concept of culture belief/crisis. *We would need a stock list of phrases to make it easier e.g. understanding instead of belief. He definitely enjoyed being seen as a person. He said this has made him think about something - his faith. I will definitely use it again* (Social Worker)
- Service user (White British with marked cognitive impairment) – *difficult to explain to her. I can see how this can help us work in a more person-centred manner* (Social Worker)
- Easy enough to use with service user (Greek Cypriot lady) as *all the questions we would ask in an assessment any way. I particularly liked the questions about community, health experiences and faith* (Community Psychiatric Nurse)
- Service user (White British person living with dementia) can be very prickly especially when talking about her memory. Most of the conversation is with her husband. *On this occasion telling her that we want to better understand you as a person so that we can best help you seem to have made a difference. She opened up and told me so much I did not know - all in such a short time. They both seemed to have enjoyed the interest shown in them* (Community Psychiatric Nurse)
- Carer (British Asian lady) supporting her husband (British Asian). Carer had been stressed in her caring role but has been reluctant to let her husband attend the local day centre, although he enjoyed the days out. *I now realise how lonely she is. Perhaps another approach is needed* (Admiral Nurse)

7. Celebration event

Through the process of action planning it was decided to hold a celebration event to highlight the achievements of the project. Invitation letters were sent out to all stakeholders including FoNS and Dementia UK. Information was also disseminated trust wide through the intranet and at other older people’s teams’ business meetings. Bursary monies from FoNS were used to fund the event. The aims of the event were to disseminate the findings of the project and to celebrate the achievements in improving dementia care.

It was also an opportunity for influential stakeholders for example the general manager to hear about local trust initiatives and the team manager to present the way forward with the project. The event was opened using a short video clip on ‘Culture and ethnicity - issues for us all’. This clip was not specific to those living with a dementia and was intentionally played to highlight the relevance of these issues to people working in other fields. The project lead gave an overview of the project aims, methods and approaches and findings. There was also the opportunity for questions and answers. The event was well attended (n=30).
Feedback from attendees included:

- *We have a large multicultural population. This project fits very well and supports our trust objectives* (General Manager)
- *Powerful video clip* (ex BME carer)
- *Never thought of culture and ethnicity in that way* (administrative staff)
- *I understand the project much better now than in the beginning and I can see how this can make the assessment process more person-centred* (local voluntary sector and dementia café staff member)
- *The self-assessment tool is really innovative and beyond what the authors had written ... lots of potential* (Dementia UK)
- *The project has helped us look at what we do well and where we need to improve. We will implement the aspects of the Culturagram in our practice. Furthermore we are going to offer honorary contracts to two trainee psychologists to use the emotional touchpoint technique within our services* (team manager)

Discussion

**Was the project successful in meeting its aims?**

The Culturagram was introduced, piloted and evaluated on one site and there were varied levels of success on the two other sites. Although all three sites were experiencing high levels of uncertainty such as fears of services closing down, redundancies, special leave and so on, one positive contributory factor to the success of implementing the project in the one site was a stable workforce. The long geographical distances between the sites and the project lead’s base meant that it was hard to access key individuals face to face. E-mails and telephone calls were not always the best ways of communicating as people had different priorities.

**What went well – and why?**

The staff workshops and service user interviews went very well. There were several reasons for this. The first reason is thorough planning. The project lead found discussing the plan with the FoNS facilitator prior to the events very helpful. It helped reduce anxieties and fears and enabled risk taking. The second reason is related to the structure and content of the workshops organised by FoNS for project leads. These resulted in an increase in knowledge about practice development and confidence in trying out different methods and techniques. Finally having regular clinical supervision with a colleague from Dementia UK was beneficial – the supervisor’s style helped the project lead to flourish.

Light refreshments were provided at the workshops and interviews, funded by the bursary from FoNS. Although the outgoing costs were very minimal, the return was huge – staff were happy to work through their lunch period or stay a bit longer to finish off an exercise. The project lead felt that this simple act of giving made people feel valued as individuals. It may also have acted as an unintentional ice-breaker – given that the project lead did not know many of the participants.

People living with dementia and their carers were very keen to participate in the emotional touchpoint interviews - they wanted ‘to make a difference’. Feeding back the patient stories to the staff created some ‘light bulb moments’ and enabled staff to see the patient and carer perspective.
Staff participated with a high degree of commitment in the workshops. The reason for that could be that it was an opportunity for them to think about and discuss something that was relevant and important to them. The initial success helped dispel concerns for the project lead, (staff would be too busy or see this as childish) and increased confidence in risk taking.

For the project lead, the project provided an opportunity to learn about one’s self. The experience was akin to mountaineering. There were times to rest (reflect), take detours (networking) and climb the peaks (executing the project). The project lead gained a better understanding of ‘engagement’. The exercises such as the values clarification exercise, listening to patient stories and claims, concerns and issues used in various staff workshops enabled greater participation and engagement by the staff. As a result it helped the project lead to provide effective feedback. At the initial FoNS workshop days, the project teams were asked to rate on a Likert Scale their confidence and skills as practice development facilitators. This exercise was repeated at the end of the project. The project lead became aware of a significant improvement in his facilitations skills as a result of undertaking the project.

Finally, the approaches learned as part of the FoNS programme have also been transferable to other aspects of the project lead’s role. Currently the project lead is using the emotional touchpoint technique in group clinical supervision with colleagues. Another example has been using the emotion cards with paid carers working in a care home for people living with dementia, who found it easier to talk about their experiences using them.

**What did not go well and why?**

Being an outsider to the NHS organisation where the project took place meant a lot of time was required to build relationships and trust and this was not always possible due to the long distances involved and the short duration of the project. Applying and obtaining honorary contracts was also a lengthy and time consuming process, which on occasions impeded the progress of the project.

**What would you differently and why?**

With hindsight the project lead felt it would have been better to have concentrated the project with one team only. Although initially the project benefitted from breadth through using multiple sites, in the end it appeared to have lost out on depth.

The emotional touchpoint technique prompted staff to think about their practice. Repeated use of the technique towards the end of the project could have helped identify if any changes in practice had actually taken place. It also highlighted that people living with dementia can be involved and that they value the opportunity of being involved in the design of any project that concerns them. On reflection the project lead felt that not sufficient time and effort had been given to this design aspect. This should be factored in any future dementia care initiatives.

The project would also have benefitted from an analysis of the team culture at the beginning and the end. This would have highlighted the importance of the administrative
staff in the assessment process and potentially provide evidence that the workplace culture was changing.

Conclusion
The project has raised awareness of cultural issues in the assessment process within one healthcare team, by introducing the Culturagram in a way that is relevant and important to their practice. Despite work and organisational pressures the staff were engaged and expressed a sense of ownership in the project. People living with dementia and carers expressed a desire to contribute to the project despite the initial concerns of the project lead.

Recommendations
- Changing and developing practice requires skilled facilitation skills. Development of these skills in the workplace by an expert facilitator is crucial.
- Healthcare professionals may benefit from using the emotional touchpoint technique. Evidence of person centred and relationship centred practice from people living with dementia and carers’ perspectives would by definition imply working in a culturally and ethnically sensitive manner.

References
Alzheimer’s Research UK (2013) Retrieved from:
http://www.alzheimersresearchuk.org/dementia-information/?gclid=CKSEoxeZvLoCFRDItAod7msAcA (Last accessed 1st May 2014).
Alzheimer’s Society (2014)
http://socialworkpodcast.blogspot.co.uk/ (Last accessed on 31st January 2014).
Dementia UK (2014) Mission Statement and Objectives. Retrieved from:


Appendix 1: Culturagram - a culturally sensitive family assessment tool

Health beliefs

Time in the country

Values about family/structures

Reasons for relocating

Legal status

Oppression
Bias
Discrimination

Contact with religious & cultural institutions/holidays/food

Values about education and work

Impact of trauma and crisis events

Person living with demential
Family members
Others

Language spoken at home

Values about education and work

Impact of trauma and crisis events

Person living with demential
Family members
Others

Language spoken at home

Values about education and work

Impact of trauma and crisis events

Person living with demential
Family members
Others

Language spoken at home

Values about education and work

Impact of trauma and crisis events

Person living with demential
Family members
Others

Language spoken at home

Values about education and work

Impact of trauma and crisis events

Person living with demential
Family members
Others

Language spoken at home

Values about education and work

Impact of trauma and crisis events

Person living with demential
Family members
Others

Language spoken at home

Values about education and work

Impact of trauma and crisis events
The Culturagram is a visual family assessment tool developed in the US by Congress (2004). Congress found that other family assessment tools e.g. the genogram did not fully address cultural and ethnicity issues and that there were cultural differences not just between groups but also within groups.

It is a collaborative process between the professional and the client/family, which identifies strengths and support systems, what kind of help is needed (if any) and when to offer that help. 
### Appendix 2: Identifying stakeholders and facilitating collaboration, inclusion and participation (CIP)

<table>
<thead>
<tr>
<th>Name of stakeholder/s group and role (if relevant)</th>
<th>Level of: Interest Power</th>
<th>Ideas on how stakeholders can best be involved/engaged</th>
<th>Level/intensity of CIP</th>
<th>What are the consequences of their level of CIP</th>
</tr>
</thead>
</table>
| CEO                                            | High power/low interest  | • Share information  
• Consider open invitation to meetings  
• One to one meetings at key points | • Collaborative relationship  
• Low level of inclusion & participation | • Potential  
• For strategic support  
• May be able to influence other stakeholders  
• Support with dissemination  
• Potential for project resource provision |
Appendix 3: Terms of reference for steering group

Project: Developing and implementing a culturally and ethnically sensitive family assessment tool (Culturagram)

Steering group

Terms of reference

For the purpose of this project as supported by grant funding from the Foundation of Nursing Studies (FoNS), the members of the project steering group will:

- Provide a link to the clinical governance structures within participating trusts
- Support and promote the development of the project in designated clinical areas within the trust
- Monitor and oversee progress of the project in participating trusts
- Assist and support Admiral Nurses/participating healthcare professionals in facilitating the development of the project and in identifying and working with barriers
- Support and offer leadership within the clinical areas in which the project is being developed
- Actively seek to resolve any operational barriers to the facilitation of the project in designated clinical areas
- Offer expertise to the project
- Offer advice and guidance to the project lead in evaluating outcomes and making recommendation for future developments
- Meet approximately every 3 months for the duration of the project
Appendix 4: Values and beliefs about assessing people living with dementia and their family carers

The purpose of this exercise is to find out and clarify the values and beliefs we hold about assessing people living with dementia and their family carers.

In doing this and sharing our thoughts we can begin to look at possible similarities and differences in our thinking as members of a team.

It will also help us to look at things we think need to change and how we can work together to achieve that.

Please answer the following questions as honestly and as best you can.

The responses you provide will be kept anonymously and used only for the purpose of the project.

<table>
<thead>
<tr>
<th>I believe the ultimate purpose of assessment is ...</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe this purpose can be achieved by ...</td>
</tr>
<tr>
<td>I believe the factors that enable this purpose to be achieved include ...</td>
</tr>
<tr>
<td>I believe the factors that hinder this purpose to be achieved include ...</td>
</tr>
<tr>
<td>Other values/beliefs that I consider important in relation to assessment are ...</td>
</tr>
</tbody>
</table>
Appendix 5: Claims, concerns and issues

We believe the purpose of assessment is to collaborate and build rapport in order to gather information, identify needs, assess risk and devise an appropriate action plan.

What is good about this statement?

What concerns you about this statement?

We believe this purpose can be achieved by good communication skills to gain information and build rapport and relationships with those involved and an awareness of potential barriers to this process.

What is good about this statement?

What concerns you about this statement?

We believe the factors that enable this purpose to be achieved include: a holistic assessment of the person’s need using good assessment skills with a realistic time frame including the above.

What is good about this statement?

What concerns you about this statement?

We believe the factors that hinder this purpose to be achieved include: Time and resources, Communication, Language Barriers, Lack of Empathy, Being too process driven and Family dynamics

What is good about this statement?

What concerns you about this statement?
<table>
<thead>
<tr>
<th>Objective</th>
<th>What action is required</th>
<th>Who</th>
<th>By when</th>
<th>Resources/support needed</th>
<th>Comments</th>
</tr>
</thead>
</table>
| 1. Feedback to team about emotional touch points exercise | • Arrange meeting with outpatient/whole team and notify  
• Project lead  
• Provide feedback to OPD/whole team | Deputy manager  
Project lead | 30/11/12 | • Time factors  
• Management support | • Specific feedback to OPD team  
• General feedback to whole team |
| 2. Implementation of culturagram self-assessment in OPD | • Create a Patients First poster  
• Raise awareness of poster with medical/admin staff  
• Raise awareness of project with service users/carers at OPD  
• Engage with service users/carers at OPD | Deputy manager  
Project lead  
Project lead/admin/ Volunteer | 16/11/12  
29/11/12 | • Time  
• Provide refreshments/ FoNS budget  
• Self assessment forms/evaluation  
• Forms  
• Admin support  
• may lengthen clinical time with service users/carers | • Display poster in outpatient? post?  
• patients attending first time/later stage of diagnosis of dementia  
• seek feedback from service users about the form some may want help to fill in the form  
• at a later stage to evaluate if action improved service users experience of assessment |
| 3. Implementation of culturagram within CMHT | • Identify five volunteers  
• Notify project lead  
• Meet with volunteers on individual/group basis  
• Implementation of culturagram  
• Gather feedback from volunteers on culturagram  
• Use feedback to further modify the culturagram if necessary | Volunteers/ Project lead | 16/11/12  
31/01/13 | Time factors | • Quality not Quantity  
• Main Issue Where to file Documentation? |
| 4. Dissemination of project within trust | • Ensure governance group is informed  
• Plan for launch in Jan/feb 2013  
• Identify/invite key stakeholders to launch  
• Identify and book venue  
• Publish launch  
• Make catering arrangements  
• Plan for the day | Local Authority Manager  
Steering group | • Senior management support  
• Time factors | • FoNS/Dementia UK will be invited  
• Opportunity for team to discuss future nursing led/Patients First Projects  
• Opportunity to celebrate and say thank you to staff/carers/Service users |