Research Methods

Participatory methods for research prioritization in primary care: an analysis of the World Café approach in Ireland and the USA

Anne MacFarlane\textsuperscript{a,\*}, Rose Galvin\textsuperscript{b}, Madeleine O’Sullivan\textsuperscript{a}, Chris McInerney\textsuperscript{c}, Eoghan Meagher\textsuperscript{a}, Daniel Burke\textsuperscript{a} and Joseph W LeMaster\textsuperscript{d}

\textsuperscript{a}Graduate Entry Medical School, Faculty of Education and Health Sciences, University of Limerick, Limerick, Ireland \textsuperscript{b}Department of Clinical Therapies, Faculty of Education and Health Sciences, University of Limerick, Limerick, Ireland \textsuperscript{c}Department of Politics and Public Administration, Faculty of Arts, Humanities and Social Sciences, University of Limerick, Limerick, Ireland \textsuperscript{d}Department of Family Medicine, School of Medicine, University of Kansas, Kansas City, KS, USA.

\*Correspondence to Anne MacFarlane, Faculty of Education and Health Sciences, Graduate Entry Medical School, University of Limerick, Limerick V94 T9PX, Ireland; E-mail: anne.macfarlane@ul.ie

Abstract

\textbf{Background.} There are increasing imperatives for patients and members of the public to engage as partners in identifying health research priorities. The use of participatory methods to engage stakeholders in health care in research prioritization is not commonly reported.

\textbf{Objective.} This article analyses the use of World Cafés as a participatory method for research prioritization with marginalized communities in Ireland and the USA.

\textbf{Methods.} The principles of purposeful and snowball sampling were followed in both settings and a diverse range of community and health care stakeholders participated (\(n = 63\) Ireland and \(n = 55\) USA). The principles for a classic World Café were employed but there were novel features in each setting as well. Stewart \textit{et al.}’s (Patients’ and clinicians’ research priorities. Health Expect 2011; 14: 439–48, conceptual framework for patient engagement was adapted and used to comparatively analyse the strengths and weaknesses of the World Cafés, focusing on agenda setting, engagement with research processes, interactional features and outputs.

\textbf{Results.} Design principles for World Cafés were found to align with high-quality patient engagement for research prioritization in both settings. They served to facilitate meaningful collaboration among stakeholder groups in research prioritization (\textit{research agenda setting}) and explored research priorities (\textit{engagement with research}). The café ambience, emphasis on hospitality and self-facilitation created an environment for dialogues within and across participating groups (\textit{interactional features}). There was a commitment to follow-up actions with reference to possible subsequent research (\textit{outputs}).

\textbf{Conclusions.} The World Café is a valuable, participatory, flexible method that can be used with community and health care stakeholders for research prioritization with marginalized communities.

\textbf{Key words:} Community-based participatory research, collaboration, health priorities, primary health care, patient engagement, retrospective study.
Introduction

There are increasing imperatives for patients and members of the public to be engaged as partners in identifying research priorities to optimize the design and delivery of a more patient-centred health service (1–4). This is associated with two main drivers (3): first, moral or ethical imperatives around patient empowerment and civic responsibility which emphasize that the public have a right to shape the research agenda; second, instrumental imperatives to optimize research features and impact which emphasize that the public are needed to make sure researchers are asking relevant questions. It is a requirement for research funding in North America and the UK (2,3) and is being given increasing attention by health funding agencies in other European countries such as Ireland.

A recent systematic review of research prioritization with patients and clinicians found that a sizeable literature is available (2) Voting exercises and consensus methods, such as Delphi techniques, were identified as frequently used methods (2). However, the use of participatory methods to engage stakeholders in the identification of research questions, while a central tenet of participatory health research (5), was not identified. This is surprising given that the rich tradition of community-based participatory research offers valuable insight for patient and community engagement (1,3,4,6) and there is a growing body of literature about the relevance of participatory methods as valuable ‘material practices’ that researchers can employ to enable meaningful participatory spaces, particularly for those from marginalized communities (7,8). This warrants further investigation to expand the methods available for research prioritization.

In this article, we focus on the use of World Cafés as a participatory method for patient and community engagement in research prioritization. The World Café is ‘a simple yet powerful conversational process for fostering constructive dialogue, accessing collective intelligence and creating innovative possibilities for action, particularly in groups that are larger than most traditional dialogue approaches are designed to accommodate’ (9:p3). There are an integrated set of design principles and graphics, developed in a guide by the World Café Community Foundation (http://www.theworldcafe.com/), which are free to copy and distribute for hosting ‘conversations that matter’ (see Figs. 1 and 2). These principles and graphics emphasize the importance of creating a hospitable environment (i.e. a café-style ambience) in which individual and collective knowledge and ideas can be shared. In a World Café, all participants are regarded as experts of their own lived experience and experiential knowledge. There is no pressure to reach consensus, as diverse perspectives are encouraged and valued (see Box 1 for a summary of World Café procedures).

With some notable exceptions (9–11), World Cafés have not been reported in academic primary care for research prioritization. This article analyses the use of World Cafés for this purpose in Ireland and the USA. The analysis is based on an opportunistic collaboration between participatory health researchers in the two settings. We provide (i) a comparative description of how this method was applied in Ireland and the USA and (ii) a conceptual analysis of its strengths and weaknesses.

Methods

Irish study: context and design

The University of Limerick in the mid-West of Ireland has a strong commitment to conducting research that has regional relevance (http://www.ul.ie/about-ul/broadening-horizons-2015–19). Based on a collaboration between the Department of Politics and Public Administration and the Graduate Entry Medical School at UL (established in 2007), a cross-sectional World Café method was chosen for exploring research priorities for a primary health care research group (established in 2011).

In keeping with the research group’s broad perspective on primary health care (12) and interdisciplinary health services research with marginalized communities, target stakeholder groups included community organizations, community participants, academics, clinicians and health service planners/policy makers in the region. Sampling and recruitment followed the principles of purposeful and snowball sampling (13), drawing on existing contacts between the university and relevant agencies: community-based organizations working with migrants, Irish Travellers, women who had experienced domestic violence, people with disabilities and people living in poverty, clinicians working in primary care in the Health Service Executive (HSE) and academics in the Faculty of Education and Health Sciences at the University of Limerick.

Two participatory World Cafés were organized in May 2013, one in each of two geographical regions. Approximately 140 people were notified and there were 63 participants: 31 in café 1 and 32 in café 2. There were a mix of stakeholders from community (n = 30), academic (n = 15), allied health service (n = 12) and other backgrounds comprising education and private health service providers (n = 6) in each café.

Four questions were drafted by the research team and finalized in consultation with community and health care stakeholders. The final set of questions moved from general questions about health and well-being to specific questions about areas that focused on research priorities—see Supplementary Data File 1.

Participants were all English-speaking and they facilitated their own discussions. Participants could draw or otherwise represent ideas as individuals or as a group. Self-recording was used to allow less confident participants to write or draw their contribution and not necessarily articulate or defend their perspective in a larger group. Subsequently, when viewing the recorded data as a large assembled group, all participants used stickers to indicate which issues they thought were priorities for research.

After the two cafés, the data were computerized and analysed by the university research team using NVivo software following the principles of a thematic analysis (14). Preliminary findings of this thematic analysis were shared in report format with all participants by email and feedback was invited and used to inform the final draft (15).

Figure 1. Principles for hosting Cafes. Reproduced from The World Cafe Toolkit Principle Stamps by Nancy Margulies www.theworldcafe.com under creative commons licence (ccby) https://creativecommons.org/licenses/by/3.0/ © 2015 The World Café Community Foundation.
Data analysis after a World Café and without participants’ input was novel. The rationale for this was to enable the university team to become familiar with the shared and differential findings across the two geographical settings. This was important for the follow-up actions: information about research priorities was compared with existing research strengths in the primary health care research group and the wider health research community in UL with a view to (i) clarifying the relevance of ongoing university research for the region and (ii) exploring the scope for new partnership research in each site. This has contributed to a successful research proposal about migrant health. Findings about health research priorities will also be embedded into a new Campus Engage Unit in the university to support the work into the future (http://www.ul.ie/engage/).

USA study: context and design
The Bethel Neighbourhood Centre (BNC) has an established service relationship with immigrants and refugees in Kansas City (KC), specifically Bhutanese Chin and Karen refugees and Latin American immigrants. In 2015, through funding from the US Patient-Centered Outcomes Research Institute, the project convened the Centre for Immigrant and Refugee Research and Clinical Evaluation (CIRRCLE). CIRRCLE is composed of community members, health advocates, academic researchers and health care providers whose goal is to work collaboratively to identify and address gaps in health and health care. After an initial engagement process, diabetes mellitus-related health care was identified by an Advisory Panel, composed of two leading local members from each community, as the priority health issue to be explored in the project.

A series of five longitudinal World Cafés, based on the classic procedure (see Box 1), were subsequently conducted in 2015, once every 2 months. Participants were recruited from the Advisory Panel members’ communities and from health care systems serving those communities. Sampling and recruitment followed the principles of purposeful and snowball sampling. The US study drew on existing contacts between BNC and agencies serving the participating communities, i.e. refugee resettlement agencies, health care systems, local entrepreneurs and the Refugee Healthcare Division, the Kansas Department of Health and Environment and primary care academics at the University of Kansas Medical Center. Approximately 200 people were notified and there were ~45–55 participants at each café. There were representatives from five communities: Burmese Karen-speaking, Burmese Chin-speaking, American Spanish-speaking, Bhutanese Nepali-speaking and English-speaking health care system stakeholders. All participants were either themselves people with diabetes mellitus or relatives/carers of people with diabetes mellitus from the same household.

Each café had a particular focus relating to the management of diabetes in the community (see Supplementary Data File 2). Before and after each World Café, the Advisory Panel discussed and fine-tuned questions based on emergent findings. Additional discussions were also held with individual Advisory Panel members to identify any gaps in the World Café discussions.

Participants were invited to sit in groups of 8–12 and a member of the group agreed to act as scribe for the group as they discussed questions. Because a different language was spoken at each table, when discussants began to discuss a new topic, rather than the discussants moving, the paper tablecloth containing the notes from the prior tables rotated and participants stayed together with their language-concordant scribe. The bilingual scribe (literate in English and the language of that ethno-linguistic community) remained at the table and provided a summary to the group regarding the discussion to that point and then served as a facilitator and scribe for the group. This was a novel feature of the World Café procedure to address the multilingual nature of the participants.
Box 1. Overview of the classic procedure for a World Café method

World Café—general procedure (http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/)

A World Café requires a Café host to facilitate the event. The host often has a small team of 2–4 colleagues to help organize the space and ambiance and to support the café process.

Participants are welcomed to the café and invited to sit in groups of 4–5 participants at separate tables. The facilitator sets the context to the event, and introduces the principles of a World Café (Fig. 1) and the ground rules for participation (Fig. 2). Participants are then invited to discuss a single, broad question, e.g. ‘what are your most important barriers to receiving health care from your current health care provider/practice?’ Participants brainstorm answers to the question and discuss the topic briefly.

The tables are covered with white paper ‘tablecloths’ and participants are provided with pens and markers. This means that participants can take notes on the paper tablecloth if they wish to illustrate the ideas that emerge from the discussions. At the end of the ‘table’ discussion (which typically lasts about 15 minutes), participants rotate as a group to another table to discuss a different question or issue with a new group of participants.

Participants usually self-facilitate their own discussions, reinforcing the view that there is no hierarchy in the group. Sometimes a scribe is used to record discussions. The scribe remains at the table to provide a brief summary to the incoming group about the discussion that took place in the preceding group, and then serves as scribe for the incoming group. This encourages cross-fertilization of ideas and knowledge. As succeeding groups respond to the question, a rich set of responses is built up.

After all groups have rotated around all tables (so that each group has responded to each question), it is important to share knowledge from all the discussions with the full participant group. This can be done by placing the ‘tablecloths’ on the walls so participants can walk around and see each other’s ideas.

There is generally an effort at this time by the café facilitator and/or scribes to summarize and co-analyse the responses (so similar responses are grouped together under one representative phrase and unique responses/comments remain unique). Follow-up possibilities for action are also discussed. Participants are then provided with sticky, coloured paper dots and each participant votes, e.g. for their top 3 responses to each question or their top 3 research priorities. This method has been used to maximize participation in large group discussions and provides each participant with an opportunity to have a voice in the generation of responses to questions as well as in the priority the group as a whole gives to responses. The method can be used to prioritize issues of importance to a community as well as actions that may be taken.

The research questions prioritized in the US cafés will guide development of future research proposals. Additional plans include monthly training on patient-engaged research methods to Advisory Panel members and updates on ongoing research initiatives to optimize community engagement and participation among these community groups.

While there were differences between the design of the World Cafés in Ireland and the USA (see Table 1), it is possible to analyse the strengths and weakness of the World Café approach as applied in these settings. For this, we draw on Stewart et al.’s (2) conceptual framework for engagement, which refers to agenda setting, engagement with research processes and outputs. Stewart et al. (2) also refer to group composition and contributions, and we have labelled these as interational features (see Table 2).

Results

Agenda setting

The use of Participatory World Cafés in Ireland and in the USA served to purposefully and collaboratively involve stakeholder groups in the identification of research priorities. This commitment to purposeful engagement is an inherent strength of the World Café method because, by its very design, the aim is to bring stakeholders together for a specific conversation. Similarly, the commitment to collaborative engagement is an inherent strength because the whole aim of the World Café method is to build collective knowledge through dialogues and to share decision making. It would be a breach of World Café principles for researchers to consult with World Café participants about research ideas and, then, to make the decisions about priorities themselves.

This principle is enacted in several ways, including the scope for participants to self-record their ideas on the ‘tablecloths’, the lack of pressure to achieve a consensus and the final voting process which gives each individual their own power to vote. Consequently, in both settings, this allowed diverse groups of participants, who would otherwise not typically interact with each other for dialogues about health issues, to develop a mutually agreed list of research priorities.

It was a departure from the classic World Café procedure that there was post-café thematic analysis of the data in Ireland. However, the post-café analysis did not change any of the participants’ decisions about research priorities. It was not regarded as a ‘better’ or more advanced analysis of the data. It simply had a different purpose: to identify shared and differential findings to inform next steps for partnership research with the university and these communities.

A potential weakness in the World Café procedure in this regard is that the manner in which café participants conduct priority setting may obscure differing priorities by participating communities in the interest of gaining an overall joint prioritization of responses to a given question. This potential problem was well addressed in the US cafés by asking members of each ethno-linguistic community to use a different colour for the stickers they used to prioritize responses to questions.

Engagement with research process

In both settings, participants were explicitly asked for their views on research priorities by asking what issues were of most concern to them. Researchers did not make any inferences about research priorities. Again, this is an inherent strength of the World Café procedure. It reflects a genuine interest in exploring diverse perspectives and connecting these with each other to generate new collective intelligence.

The World Café approach may affect researchers’ full understanding of these diverse perspectives about research prioritization because, while the set of responses to a World Café question are quite rich, the recorded responses typically lack detail and each identified response is not explored with the same depth that
is used in other qualitative methods such as in-depth interviews. This exemplifies why it is so important to have sufficient time for the summary and co-analysis at the end of the café with the fully assembled group. This is an opportunity for everyone to examine the identified priorities and clarify any ambiguities or other gaps in understanding.

Interactional features

There were a number of differences in the interactional features between the World Cafés in Ireland and the USA (see Table 1). Despite these differences, in both countries there was adherence to the integrated set of design principles and ground rules for World Cafés (16) (see Figs. 1 and 2). The physical space and ambiance were as important as any other aspects of the encounter. This emphasis on a hospitable environment should not be underestimated. It reflects a core value on participants’ knowledge of the topic being explored but, also, their skills to discuss and debate these with each other. Thus, the World Café values contributory and interactional skills and seeks to ‘activate’ both in the dialogues.

The emphasis on self-facilitation may mean that the intention for each participant to contribute their thinking or listen respectfully to others does not necessarily happen. This may not be noticed by a café host, whereas a trained focus group facilitator may notice this more readily. In our experience, it was valuable to have a small team to host the cafés so that they could observe interactions, answer queries and encourage adherence to the ground rules at each table.

Outputs of engagement

In both settings, priorities were identified (see Table 3). The identified priorities were subsequently mapped to those of potential

<table>
<thead>
<tr>
<th>Table 1. Comparative analysis of differences between the World Cafés in Ireland and the USA (* denotes a novel feature)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ireland</strong></td>
</tr>
<tr>
<td>Cross-sectional design—one-off café event in two geographical locations</td>
</tr>
<tr>
<td>Smaller groups of 4–6 participants per table</td>
</tr>
<tr>
<td>English-speaking participants only</td>
</tr>
<tr>
<td>Multiple community groups represented</td>
</tr>
<tr>
<td>No scribe used for recording discussions</td>
</tr>
<tr>
<td>Co-analysis during the World Café plus post-café thematic analysis by university team*</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2. Conceptual framework for engagement, adapted from Stewart et al. (2)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Agenda setting</strong></td>
</tr>
<tr>
<td>Purposeful priorities identified by asking stakeholders’ views</td>
</tr>
<tr>
<td>Consultative researchers listening to stakeholders and then making decisions informed by the stakeholders’ views</td>
</tr>
<tr>
<td>Collaborative approach to decision making about priorities between researchers and stakeholders</td>
</tr>
<tr>
<td><strong>Engagement with research process</strong></td>
</tr>
<tr>
<td>Direct questioning to stakeholders about their views on research priorities</td>
</tr>
<tr>
<td><strong>Interactional features</strong></td>
</tr>
<tr>
<td>Researchers value stakeholders’ contributory skills, their knowledge of topics</td>
</tr>
<tr>
<td>Researchers value stakeholders for their interactional skills, abilities for critical thinking and debating research topics and priorities</td>
</tr>
<tr>
<td><strong>Outputs</strong></td>
</tr>
<tr>
<td>Priorities identified and followed up with direct link to subsequent research</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 3. Summary of priority issues for further research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ireland</strong></td>
</tr>
<tr>
<td>• Improve people’s knowledge and understanding of primary health care services</td>
</tr>
<tr>
<td>• Develop health promotion activities for chronic conditions</td>
</tr>
<tr>
<td>• Focus on the specific needs of certain social groups, e.g. migrants, people with disabilities, older people, men’s health, travellers</td>
</tr>
<tr>
<td>• Focus on sustainable community, physical space and resources and leadership across the life course</td>
</tr>
<tr>
<td>• Find out what works well and implement it in practice</td>
</tr>
<tr>
<td>• Put the community at the heart of health service planning and delivery</td>
</tr>
</tbody>
</table>
research partners (in local and/or national stakeholder groups), with the stated aim to further develop research grant proposals. Again, this reflects an important strength of the procedure which is that the café is closed with specific information on follow-up actions. This stimulates researchers to think beyond the generation of data about research prioritizations to the development of an action plan before conducting the café events.

Discussion

Summary of findings

Our comparative analysis of the use of Participatory World Cafés in Ireland and the USA demonstrates that this method encourages purposeful, collaborative engagement with heterogeneous groups of stakeholders regarding research prioritization for primary care health service improvement. In keeping with the principles of a classic World Café procedure, there was attention across both settings to stakeholders’ contributory and interactional skills as well as connections between the identified research priorities and subsequent research. The similarities and differences in the facilitation of the World Cafés across the two countries demonstrate that these collaborative approaches can be replicated and adapted in different settings. Researchers should consider the use of the World Café method when planning research prioritization projects.

Comparison with existing literature

World Cafés are not commonly used as a method in research prioritization in the primary care setting (2). We identified three additional research studies that successfully used a participatory World Café method to explore health services research prioritization in the primary care setting in mental health, healthy ageing and the delivery of HIV rehabilitation services (9–11). Our analysis adds to this literature by explicating the adaptation of the classic World Café procedure in different settings, highlighting novel features and providing a conceptual analysis of engagement in setting research agendas.

Other research prioritization studies have adopted consultative approaches and inferred research priorities (17,18), and have tended to draw on either clinicians’ and patients’ contributory or interactional skills (19,20). Our analysis shows that these features would not be compatible with a World Café because they are counter to core design features that emphasize the importance of collaborative decision-making and connecting diverse experiences. While consensus methods are very common in the literature (2), there is no requirement for consensus in a World Café. Unlike Delphi methods, participants’ data are never removed from analysis because all data is recorded and voted on. This is a powerful, tangible sign to participants that their views have been listened to and faithfully recorded, even if they are not highly ranked in the prioritization process.

Strengths and weaknesses

The projects drew on existing networks and established relationships for design, sampling and recruitment. The use of these networks served to optimize participation among marginalized communities that are ‘hard to reach/easy to ignore populations’ (8). The participants and contexts were very different, which may to some degree obscure context-specific differences. However, our analysis has shown that, regardless of these differences, the process worked well in both settings.

Given the opportunistic nature of this retrospective comparative analysis, we did not identify a priori parameters for the conduct or comparative analysis of the cafés reported here and we cannot offer a comparative analysis with other methods for research prioritization. However, we did draw on a published framework for engagement in setting research agendas (2) to conceptually organize our findings. This has enabled us to identify inherent strengths and limitations of the World Café method. We acknowledge that our analysis is based on our observations of the World Cafés and that it would be ideal to have evaluation data from the participants themselves. Despite the identified limitations, the World Café is found to be a valuable method for research prioritization in primary care because its core design principles emphasize physical, social and material features of high-quality patient engagement (2,7).

Areas for further research

Further research should explore the use of the café method to optimize the design and delivery of a more patient-centred health service across the spectrum of conditions managed in the community. We also agree with Forsythe et al. (1) that it would be important to understand the systematic characterization of engagement encounters more fully with, e.g. process and formative evaluations over time.

Conclusion

The World Café is a valuable, participatory, flexible method that can be used with diverse community and health care stakeholders for research prioritization. We highly recommend its use and creative adaptation to explore research priorities for primary care research, particularly with marginalized communities.

Supplementary material

Supplementary material is available at Family Practice online.

Declaration

Funding: Irish study: Funding from the Graduate Entry Medical School (GEMS) University of Limerick—Strategic Research Fund 2012 and Summer Student Scholarships 2014 and 2015. US study: Funding was received from Patient Centered Outcomes Research Institute (PCORI). Ethical approval: Irish study: Ethical approval was sought from the ethics committee of the Irish College of General Practitioners (ICGP) in February 2013. Following consideration the committee decided that the World Café activity did not require formal ethical approval, as per letter from the chair of the Research Ethics Committee ICGP, 9 April 2013. US study: Ethical approval was not required for the US World Cafés, because the organization conducting the study was not an entity for which this was legally or ethically required. Conflict of interest: none.

Acknowledgements

Irish study: We are grateful to colleagues who supported recruitment, particularly Dr Siobhan O’Connor—Primary Health Care Programme for Travellers in Clare, Orla Ni Eil—itClare Immigrant Support Centre (CISC), EmployAbilityClare, Limerick and Clare Education and Training Board (LCEBT), Ennis Community Development Project (CDP), Active Retirement, Clare Special Initiative for Travellers (SIFT) and Dr Maura Ashhead and Dr Bernie Quilllan of the University of Limerick. We are also grateful to all World Café participants for their time and interest.
US study: Midwest Pipeline Award Program Office colleagues at the Minnesota Public Health Institute, who provided program guidance; Bethel Neighbourhood Center colleagues, who supported sampling, recruitment and project administration; all CIRRCLE participants. Stakeholders included physicians and staff from the University of Kansas Medical Center, Mercy and Truth Clinic of Kansas City; Special Populations Health Office of the Kansas Department of Health and Environment; Ruben Zaragoza, Zaragoza & Associates, LLC.

References