PACER: Program of Patient and Community Engagement Research

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Research Support Service: Scope of Work

BACKGROUND

Patient and community engagement researchers (PACERS) are citizens living with various health conditions (or family caregivers) who are trained to design and conduct health research, using specific adapted methods of qualitative inquiry. PACERs collaborate with health professionals and researchers and engage other patients in research. In PACER, patients are fully engaged in all phases of research from setting agendas, funding and implementation through to the uptake of research suggestions.

The PACER approach was pioneered, implemented and rigorously tested through the Patients Matter project, funded by the Canadian Foundation for Healthcare Improvement (CFHI), and undertaken in collaboration between the Alberta Health Services’ (AHS) Strategic Clinical Networks and the University of Calgary (2011 – 2013).

Upon testing the PACER approach through this initiative, we have learned that PACER has several qualities that distinguish it from most other approaches to patient engagement:

- PACER trains people with significant health experiences to become competent researchers in engagement methods with other patients and families. In training, PACERS gain skills and capacity to collaborate effectively with health professionals and researchers.
- PACER uses a new method of peer-to-peer research that is specifically designed to engage patients, families and communities. The method incorporates adapted qualitative research techniques, research quality standards, and solid ethical principles.
- PACER introduces a new patient voice and new, dynamic patient roles that enable them to contribute to health care organizations in particularly meaningful ways.
- PACER has the potential to engage large groups of patients and promote their active role in their own health and health care.

The innovative PACER approach has proven to be effective, and since its introduction in 2011 has been embraced by many organizations in Alberta, including the AHS, academic and community groups. Several PACERS have been introduced into core committees and working groups of the Strategic Clinical Networks, AHS.

The mission of the PACER Program is to transform the role of patients in health care and health culture through engagement research.
RESEARCH SUPPORT SERVICES

The PACER Program provides research support services to health research teams, health service and policy-making organizations, and community agencies. PACER can be introduced as a part of larger health research projects, flexibly adjusting to the particular research team agendas, infrastructures, target populations and contexts. For example, a PACER group can facilitate meaningful patient input in the designing and testing of a health technology tool, to assure that the tool produced by health and technology experts is particularly responsive to patient needs. Alternatively, PACER can be used in independent research studies conducted by trained patient researchers in consultation with community agencies or health care teams.

Areas of inquiry: PACER method can be beneficial for a variety of purposes, including but not limited to quality improvement initiatives, priority setting scans, health technology development and testing, knowledge translation, clinical trial recruitment, pathway and transition research, concept development, and program evaluation.

Ethical procedures: Ethical considerations and the ethics review needs in relation to the specific topics and settings will be negotiated with the partners. We have tested ARECCI ethical guidelines and worked within a variety of ethical review procedures.

Because of the specifics of the PACER method and ethical procedures, it is desirable to involve PACER in research design and planning in the earliest stages of research initiation.

RESPONSIBILITIES (an example)

PACER shall:
1. Assign a primary patient and community engagement researcher (PACER) to the study;
2. Assign PACER assistants to support the primary researcher;
3. Provide support in designing the research project and writing a proposal;
4. Provide support in assessing ethical risks and planning appropriate ethical review processes together with the client;
5. Provide supervision and mentorship to the primary PACER and assistants;
6. Oversee the study to assure methodological quality and the consistency of PACER methods in the context of a particular study.

Client shall:
1. Provide funding as per agreement;
2. Assure recruitment of potential study participants and refer potential participants to the PACER team who will conduct orientation and consent procedure;
3. Engage PACER researchers through inviting them to partnership council or committee (where applicable);
4. Provide administrative support to the PACER team involved in the study; assure financial flow for travel, supplies, and other expenses as per agreement;
5. Provide administrative and office support to lead researcher.

In collaboration PACER and Client shall:
1. Support recruitment of study participants;
2. Plan and implement appropriate ethical review processes;
3. Support the publication of research findings.
The PACER method has a distinct structure defined as set, collect, reflect (see the diagram below) to ensure that participants are meaningfully engaged throughout the process. One PACER research support unit includes one research cycle of set, collect, and reflect.

1. **Set:** This opening procedure, generally a focus group, invites representative patients and other relevant participants to become advisors and help set the stage for the study by refining the particular protocols (recruitment, locations, alliances), questions and data collection.

2. **Collect:** Particular techniques of data collection and analysis depend on the specifics of research questions and purposes of each given study. This phase can be very flexible and accommodate a variety of research designs by applying specifically adapted techniques such as field observation, purposefully constructed questionnaires and surveys, focus groups, peer-to-peer interviewing, or a combination of these methods.

3. **Reflect:** At this stage, participants from the initial set focus group (item 1) review findings and analysis with the PACER team and suggest knowledge utilization and recommendations for further research. This stage completes the circle of PACER procedures and prepares the data to be shared with the relevant health system.

**SET and REFLECT focus groups are the hallmarks of the PACER method,** serving to ensure a *meaningful patient involvement* and *contextual validity*.

PER theory and methods are taught at both the undergraduate and graduate level in the Faculty of Medicine, Department of Community Health Sciences. Courses in theory and specific methods, as well as internship, are available to both sponsored students and university students who have significant patient experiences.
BUDGET IMPLICATIONS

The Cost of a Unit of PACER Research Support

One PACER unit includes one research cycle of *set, collect, reflect* (see the diagram above). In order to involve a variety of patient groups, a broader outreach to geographic areas, extended timelines (e.g., a five-year study), or other needs, multiple PACER support units may be included, each with a specific design according to the research agenda.

While the costs of this service are being negotiated it is expected that most basic projects will cost **$15,000 per unit**. Funds will go towards the payment to primary PACER researcher and trained PACER assistants, PACER oversight, mentorship and supervision, and non-compensation costs including travel and focus group expenses.

**Example of PACER Budget (One Unit)**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Patient Engagement Researcher</td>
<td>$9,500</td>
</tr>
<tr>
<td>Honoraria for PER assistants or trainees</td>
<td>$1,500</td>
</tr>
<tr>
<td>Travel, parking, expenses and supplies</td>
<td>$2,000</td>
</tr>
<tr>
<td>PACER mentorship, supervision, support</td>
<td>$2,000</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>$15,000</strong></td>
</tr>
</tbody>
</table>