When one size does not fit all: Using participatory action research to co-create preventive healthcare services

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Abstract
Organized screening programs have proved effective at reducing cervical cancer in Sweden by offering early detection of precancerous cells. However, participation rates vary across groups of women. The purpose of this paper is to explore how participatory action research contributes to (re)designing cervical cancer screening programs to better meet local residents’ needs and expectations. The paper examines the Pap smear testing barriers encountered by foreign-born women. It is also reported how different actors within the healthcare system as well as civil society can work together to address these barriers and improve healthcare services. Moreover, the paper contributes to action research methodology by demonstrating how participatory inquiries benefit from quantitative monitoring of improvement initiatives.

Keywords
Participatory action research, foreign-born, cervical cancer screening

Introduction
Screening programs, which offer early detection of precancerous cells, have proved successful in preventing cervical cancer in Sweden, with a 60% decline in the
mortality rate during the past 40 years (Scientific Assessment of Health Technology, 2008). The standard practice is mobilizing women between 23 and 60 years to take a Papnicolau (Pap) smear test every three to five years depending on age. A national study shows that more than three-quarters of the women who died from cervical cancer had not taken a Pap smear test within the recommended intervals (Andraee et al., 2012). In the Western Region of Sweden, about 80 women are diagnosed annually with cervical cancer, 20–25 of whom die (Västra Götalandsregionen, 2010).

Fifteen percent of the Swedish population was born outside of Swedish borders (Statistiska centralbyråns, 2014). In Gothenburg, the country’s second-largest city, the corresponding figure is 23%. One-fifth of Gothenburg’s population lives in the northeastern section, an area in which about half of residents are foreign-born (Göteborgs stadsledningskontor, 2013). In this part of the city, income and educational levels are low. Unemployment rates are higher than in the rest of the city, and many families live on social benefits (Göteborgs stadsdokument, 2010). On the other hand, the area has many positive characteristics, including cultural diversity, nature sites, markets, and many associations, businesses, and events, including Sweden’s largest carnival (Fagerberg, 2012). Nevertheless, the area scores high in indicators of poor health such as obesity, smoking, and physical inactivity. The rates for circulatory disease and chronic obstructive lung disease also are high (Olsson & Panifilova, 2009). Similarly, only 57–64% of local women took the Pap smear test compared with 82% in the Western region of Sweden as a whole. The regional goal is that no parish should have less than a 70% participation rate (Strander, Holtenman, & Westlund, 2011; Västra Götalandsregionen, 2010).

Given that the cervical cancer screening programs reach the majority of the targeted women in Sweden and save lives by early detection of precancerous cells, research suggests that further cervical cancer incidence and mortality reduction efforts should focus on reaching nonparticipants (Andraee et al., 2012). Various factors have been identified regarding screening program nonparticipation, such as sexual orientation (Aaron, Markovic, & Danielson, 2001), geographic residence (Eaker, Adami, & Spareå, 2001), age and educational level (Lockwood-Rayemann, 2004), as well as country of birth (Azerkan et al., 2011). The last factor will be reviewed in this paper since it was the factor deemed locally relevant.

The project may be understood on the basis of the action research cycle as described by Coghlan and Brannick (2010), with the pre-step dealing with context and purpose. In the constructing and planning action steps, participants assess the issues prior to the following step of taking action. In the concluding step, actions are evaluated and fed back into the next action cycle.

Many participatory action research projects conducted among aggrieved and disregarded groups seek systematic change. However, change for the better is not always evident because monitoring progress and measuring outcomes are often less articulated in these types of projects (for example, see Castillo-Burguete, Viga de Alva, & Dickinson, 2008; Chiu, 2008). This inquiry highlights the benefit of including such measurements in participatory action research initiatives.
In this project, data was collected both qualitatively—through diaries, notes from meetings and focus group discussions—and quantitatively, with questionnaires used for specific interventions, and the number of Pap smears in northeastern Gothenburg compiled on a monthly basis. A participant in the project constructed control charts (Bergman & Klefsjö, 2010) to analyze the effect of the various interventions. Other analyses were primarily conducted by the authors and shared and discussed with the involved actors in the project. The approach of combining qualitative and quantitative methods was selected in order to strengthen drawn conclusions; for example, by showing that a certain intervention was successful both narratively and statistically.

The logic of the action research cycle also explains the structure of the paper. First, in the Pre-step section, previous research on screening program barriers for foreign-born women and interventions to overcome these barriers are presented, as well as examples of previous community-based participatory research with ethnic minorities. This section also provides the context of the project. In the following sections, Constructing and Planning action, the identified barriers and solutions in northeastern Gothenburg are presented and the project’s overriding principles are outlined. Next, Taking action accounts for the public interventions that were carried out, followed by the results of these interventions in the section of Evaluating action. The Discussion section deals with how the study findings connect to previous research and reflects on the whole action research project and some study limitations. The project’s wider relevance concludes the paper, not least by showing the paper’s demonstration of how participatory inquiries may benefit from quantitative monitoring of improvement initiatives.

Pre-step

Foreign-born women and cervical cancer prevention

Azerkan et al. (2011) found that foreign-born women’s participation in cervical cancer screening was lower than Swedish-born women’s. Nonparticipation in the screening program increased the risk of cervical cancer at least fivefold for both Swedish-born and foreign-born women. In a previous study, immigrant women overall proved to have a higher relative risk of cervical cancer than Swedish-born women (Azerkan, Zendehdel, Tillgren, Faxelid, & Sparén, 2008). Beiki, Allebeck, Nordqvist, and Moradi (2009) noted that the risk of cervical cancer varied greatly within a group of foreign-born women, depending on country of origin and age at migration. Further research is needed, but a local report suggested the necessity of targeting foreign-born women in screening programs (Olsson, 2011).

Negative preventive healthcare experiences seem to have had an impact on women’s participation in Swedish cervical cancer screening programs (Blomberg, Ternestedt, Törnberg, & Tishelman, 2008) as well as in the United Kingdom (Abdullahi, Copping, Kessel, Luck, & Bonell, 2009). Nonparticipation can also be explained by a lack of knowledge regarding preventive healthcare services.
(Abdullahi et al., 2009). In a study about Somali women in the US and preventive healthcare, most subjects stated they would not go to a physician if they were not sick (Carroll et al., 2007). In a Swedish study of women that did participate in the cervical cancer screening program, it was evident that the women were previously socialized into accepting preventive gynecological examinations (Forss et al., 2001). Other barriers may include difficulties understanding the term cancer or fear of a cancer diagnosis (Emami & Tishelman, 2004; Kiger, 2003), as well as the belief that there is no cure, or similar fatalistic attitudes (Abdullahi et al., 2009; Kiger, 2003). Previous research also suggests that barriers are primarily practical and administrative, such as childcare needs, difficulties with transportation, rescheduling of appointments or lack of time (Abdullahi et al., 2009; Emami & Tishelman, 2004; Kiger, 2003; Matin & LeBaron, 2004; Naish, Brown, & Denton, 1994). Studies also identify language as a barrier to understanding the purpose of the test (Abdullahi et al., 2009; Matin & LeBaron, 2004; Naish et al., 1994).

Blomberg, Ternestedt, Törnberg, and Tishelman (2008) found that the organizations providing the screening services are perceived as impersonal and anonymous. To avoid this, various campaigns could be launched to reach foreign-born women in lieu of printed, translated material (Anderson, Mullins, Siahpush, Spittal, & Wakefield, 2009; Carroll et al., 2007). Studies also highlight oral traditions, rather than written, for spreading vital information in different cultures (Abdullahi et al., 2009; Comerasamy, Read, Francis, Cullings, & Gordon, 2003). Emphasizing information transmitted verbally or via nontraditional media could encourage women to undergo Pap smear tests, as could using women’s social networks where this information could be given by friends, healthcare staff or key actors within the same cultural context (Carroll et al., 2007; Kiger, 2003; Samuel, Pringle, James, Fielding, & Fairfield, 2009).

Community-based participatory research with ethnic minorities

Israel, Schulz, Parker, and Becker (1998) argued that one of the key rationales for community-based research included assessing not only the impact of marginalization, but also ways to reduce and eliminate it. For example, Gregory, Lester, O’Neill, and Gray (2005) participated with women with diverse educational and ethnic backgrounds with the objective of providing a course in community and career development. Letiecq and Schmalzbauer (2012) forged partnerships with Mexican migrants in a new rural destination in the US. Hok-Bun Ku (2011) initiated an action research project in an ethnic minority community in a Chinese province, aiming to enhance women’s income, promote a new form of collectivism, protect the traditional culture, and strengthen local cultural identity and confidence. Other studies have adopted an action research stance in order to find solutions to including immigrant populations in work life (Ataöv, Brogger, & Hildrum, 2010), or to identify, and find solutions to, acculturation problems (Okigbo, Reierson, & Stowman, 2009). Similar to this study, Chiu (2004) involved
both health professionals and local minority ethnic women in participatory action research in order to promote cervical cancer screening.

The context of the project

Compared to those of other Western countries, the Swedish healthcare system is highly decentralized, with the county councils and municipalities financing and providing healthcare services within their respective areas (Swedish Association of Local Authorities and Regions, 2005). The Western Region of Sweden constitutes the second largest county council in the country. The region’s cervical cancer screening program follows the national recommendations (Socialstyrelsen, 2012), in which women between 23 and 50 years of age are invited to have Pap smear tests every third year, and every fifth year for women between 50 and 60. The regional screening program is the responsibility of the primary care organization in collaboration with the regional cancer center that coordinates and monitors the screening program. Within the primary care organization, the midwives at the local antenatal clinics administer the Pap smear tests and send them for analysis (Västra Götalandsregionen, 2014). In the local context of this project, the women could primarily get a Pap smear test at three local antenatal clinics. They could also decide to take the test at the gynecological clinic of the local hospital.

Both authors are political scientists with experience as officials in healthcare administrations at various levels. At the time of this project, the first author was working on quality improvement of healthcare services at a regional level from an equity perspective. The second author was working in health promotion at the hospital in the project location. With a shared interest in increasing equity in healthcare, the authors initiated the project in the spring of 2010, enlisting the help of gynecologists, midwives, and nurses from the hospital’s recently opened gynecological clinic. Early in the first meeting, the issue of relatively low local participation in the cervical cancer screening program emerged. The clinicians, who had worked in other parts of the city, found the low participation rates among women in this area particularly worrying because, during the few months the gynecological clinic had been open, they had detected many cellular changes that could lead to cervical cancer. The authors and the staff at the gynecological clinic discussed possible reasons why local women were not getting tested. At the following meeting, national and international research regarding foreign-born women’s nonparticipation in screening programs was discussed. The authors also tried to identify previous national efforts to target foreign-born women in cervical cancer screening projects by contacting persons believed to have knowledge about it. These contacts revealed that provision of translated information about Pap smears seemed to be the dominant procedure. However, this method had not increased participation in the northeast part of Gothenburg, which prompted a search for alternatives. Only a few activities could be identified for increasing program participation, such as a mobile unit that targeted women in low-participation areas. Previously, the most successful intervention in the concerned area of
Gothenburg had been a project a few years prior that aired test information on the radio in different languages. In light of the current low levels of local participation in the cervical screening program, and the lack of tailored initiatives to increase this participation, the purpose of the project was to improve the screening program to better meet local residents’ needs and expectations.

**Constructing**

Considering the previous research studies and practices, the staff at the hospital’s gynecological clinic and the authors discussed both the barriers to taking the test and interventions that might increase participation in the screening program. Because the screening program was coordinated at the regional level and tests were mainly administered at local antenatal clinics, representatives of these units were invited to the subsequent meetings. During the next few months, meetings were held at least on a monthly basis and the idea to launch a joint project to increase awareness of cervical cancer prevention took shape. The two heads of the local antenatal clinics and the coordinating midwife took greater responsibility in the group as the local hospital staff began to withdraw. In addition to these meetings, the authors held separate meetings with the midwives and nurses at the three local antenatal clinics. The authors also held meetings with the coordinating gynecologist and midwife of the regional cancer center. An outside researcher with considerable experience in healthcare improvement projects also participated in these latter meetings to share ideas and propose useful methods for the project.

Previous research highlights the action researcher’s obligation not to serve as an expert telling people what to do (Coghlan & Brannick, 2010; McNiff & Whitehead, 2009; Whyte, Greenwood, & Lazes, 1991). Participating healthcare staff and the authors were convinced that the expertise and unique knowledge and skills of a particular group of local women—the so-called *doulas*—were equally as important as professional, healthcare skills. In northeastern Gothenburg, doulas support new parents during pregnancy and childbirth and are well established within their respective minority cultures. A total of 20 doulas speaking 10 languages shared the cultural background of the parents they supported and functioned as interpreters of culture as well as language. The doulas were already well known and respected among the locals at the time of the project. Previous experience indicated that the collaboration between midwives and doulas had the potential to create more equal distribution of healthcare (Västra Götalandsregionen, 2009).

An overview of the project is shown in Table 1.

**Focus group with the doulas**

To explore the relationship between previous research and the local context, a focus group was conducted with the doulas to bring their experiences into the project. The authors acted as facilitators during the focus group discussion,
which focused on identifying barriers facing local women in terms of taking the Pap smear test, as well as solutions to increase participation. The verbal data concerning barriers was analyzed using an Ishikawa diagram, which is a tool that identifies the root causes of a problem (Bergman & Klefsjö, 2010).

Table 1. Overview of the project.

<table>
<thead>
<tr>
<th>Steps in cycle</th>
<th>Time period</th>
<th>Main participants</th>
<th>Project activities</th>
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<tbody>
<tr>
<td>Pre-step</td>
<td>Early spring 2010</td>
<td>Staff at the gynecological clinic of the local hospital, first and second authors.</td>
<td>Discussion of the problem in the local context and which stakeholders to involve. Investigation of previous research and practices.</td>
</tr>
<tr>
<td>Constructing</td>
<td>Late spring 2010–Spring 2011</td>
<td>Staff at the gynecological clinic and the three local antenatal clinics, the doulas, coordinating midwife and gynecologist, outside researcher, first and second authors.</td>
<td>Key stakeholder involvement. Discussions with the doulas to discover barriers to the problem in the local context and potential interventions.</td>
</tr>
<tr>
<td>Planning action</td>
<td>Fall 2010–Spring 2011</td>
<td>Staff at antenatal clinics, the doulas, patient association, coordinating midwife and gynecologist, outside researcher, information officials, first and second authors.</td>
<td>Determining what interventions to launch and where and when to launch them. Defining the project’s overriding principles crucial for success.</td>
</tr>
<tr>
<td>Taking action</td>
<td>April 2011–March 2012</td>
<td>Midwives at the local hospital and the antenatal clinics, the doulas, patient association, coordinating midwife, information officials, first and second authors.</td>
<td>Launch of interventions: outreach activities, oral communication to local women, information in media, and so on.</td>
</tr>
<tr>
<td>Evaluating action</td>
<td>May 2011–June 2012</td>
<td>Midwives at the local hospital and the antenatal clinics, the doulas, coordinating midwife and gynecologist, outside researcher, first and second authors.</td>
<td>Continuous evaluation of interventions during the campaign and post-campaign evaluation of interventions and the project.</td>
</tr>
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The doulas believed that one major Pap smear barrier was unfamiliarity with the purpose of the test. One doula said:

I don’t believe that the women deliberately avoid going. It’s about not knowing, they don’t know what it is. That’s why they don’t do it.

In addition, both test mobilization efforts and terminology were felt to be difficult to understand, even for the doulas themselves who had lived in Sweden for a long time. Poor knowledge of Pap smear testing could also be explained by unsatisfying information from women’s home countries, where Pap smear tests were seldom explained. The doulas also believed that the reasons for not taking the test could be explained by some women being unfamiliar with preventive healthcare as a whole—the women only contacted the healthcare system if there was a specific health-related problem.

In our countries, you don’t visit a gynecologist or someone until it’s time to give birth.

Many of the doulas said that the women from their cultures feared the sheer word cancer, which prevented them from having the test taken. Many women did not want to know.

You know, most people from my culture don’t want to take the Pap smear test because they are afraid that something will be found.

The doulas believed that many women had never taken a test and that even though they understood the purpose, they were afraid of the situation as well as the examination itself. One doula said:

Many of them never had the test taken. Many of them never sat in a chair like that.

The subject of women’s reproductive organs and sexual behavior was believed to be too awkward to discuss. The doulas said that some parents prevented their daughters from taking the test because they thought the only way to get infected was through sexual contact. They did not see the point of the test, believing that their unmarried daughters were not sexually active. However, the doulas believed that Pap smear testing had to be discussed in order to raise awareness and to mobilize women to undergo the tests.

Just handing out pamphlets isn’t enough […] most people just throw them away.

It is really important to discuss it.

One doula suggested the introduction of a special Pap smear day—a whole day where the community focused on Pap smear testing and information in different
languages. On such a day, the doulas could help with childcare, since lack of available childcare could be a reason for some women not to take the test. Also, it was evident that the doulas had good access to various community networks and that discussing cervical cancer screening in these networks, using women’s mother tongues, could possibly increase awareness and participation. The doulas believed that once the women understood the purpose of the Pap smear test, they would spread the word to their family members and to friends.

Barriers identified in the focus group that matched previous research included the notion that the women do not have knowledge about the reasons for taking the Pap smear test. Many of the women do not have previous experience of preventive healthcare services (Abdullahi et al., 2009; Carroll et al., 2007) and thus do not get in touch with the healthcare service unless there is an actual health problem. Taking into account the experiences of the doulas, more practical barriers coincide with previous findings in the literature, most notably childcare needs and difficulties to reschedule appointments (Abdullahi et al., 2009; Naish et al., 1994). Moreover, they are unfamiliar with, or even fear, the concept of cancer (Emami & Tishelman, 2004; Kiger, 2003). However, unlike in other studies, the focus group with the doulas did not name negative experiences with healthcare as a barrier (Abdullahi et al., 2009; Blomberg et al., 2008), and fatalistic attitudes also were not mentioned (Abdullahi et al., 2009; Kiger, 2003).

Planning action

Participation of the civil society did not stop with the doulas. When the project began, a patient association had created massive media attention with its short films about young people and cancer. The project sought to partner with the association to make similar films in various languages about cervical cancer prevention. In the planning phase, information officials representing different organizational units were involved because many planned interventions included designing and disseminating information. The authors held various meetings with the involved actors of a specific intervention, rather than meeting all participants as a whole group. By spring 2011, meetings intensified to a weekly schedule. The project participants were excited about the upcoming campaign and eager to launch the interventions; however, some healthcare professional outside the project group who had prior experience working with the doulas were concerned that the doulas would talk about topics they had not mastered, such as medical issues. For this project, a midwife trained the doulas about Pap smears and prepared them to present the information and answer questions from the community.

Based on meeting discussions, the authors developed certain principles as the foundation not only for making the project successful but also to create a sustainable change in the local context.

We achieve more together than alone!
The principle was developed since the cervical cancer screening program involved many healthcare organization functions and different expertise was needed to reach out with information. Collaboration between different professions was also believed to bring new knowledge and perspectives into the improvements’ design and execution. With many involved participants, the burden of multiple interventions could be shared. Also, local women would be encouraged to collaborate; by bringing a friend while taking a Pap smear, the women would have emotional support, simultaneously solving the problem of childcare being unavailable.

**Use local strengths and gain trust!**

While the northeast part of Gothenburg was problematized in the media, there were strengths compared to other parts of the city. A lot of people were involved in different associations, and informal venues, such as shops and public places, were common for discussions. The established doulas created credibility to the local population and enabled information to be conveyed in many of the women’s mother tongues.

**Spread a positive message!**

To avoid the screening program being perceived as anonymous, the project was made more personal, positive, and appealing with the message: “Make an active choice for your health—take the test!” Since the focus group revealed that there was a risk that women in the area did not know that cancer could be prevented or treated, communicating health promotion clearly and as positive as possible was believed to be important. The positive message was also believed to create a better and more creative working environment for the involved actors. As part of this principle, nontraditional information channels were also used, such as social media and radio, to communicate in an appealing way.

Based on the three principles, the authors, information officials, and healthcare staff planned a campaign to elucidate and spread the importance of taking the test and to provide practical information relating to it.

**Taking action**

The campaign was launched in April 2011. During the campaign year, meetings were held at least monthly with the actors involved in the specific interventions. Prior to major interventions, meetings, phone calls, and emails were more frequent. These periods were rather busy, but no significant problems occurred. By the time the campaign was launched, leaflets and information folders had been translated into a number of languages, based on statistics of the most commonly spoken languages in the area. During spring and fall, the midwives and the doulas participated in various events to spread the message. Information in different languages was aired on the local radio and exposed in waiting rooms, newsletters, the
internet, and places where the women in the area usually gathered; for example, laundry rooms, pharmacies, and association facilities. Special events were arranged and postcards, posters, pins, textile bags, and monitors showing the project logo-type were placed around the area. To make information accessible for women who were not able to read, a phone service was introduced, making it possible to get information about Pap smear testing read in Arabic and Somali.

Halfway through the campaign, the use of a mobile unit (“the Pap smear bus”) was initiated at strategically located places in the northeast part of the city. The bus had previously been used by another council in Sweden; its use was refined for the Pap smear bus. With a fixed schedule made visible in different places in the area and communicated through local papers, women were well informed where the bus was located at a certain day. The three antenatal clinics and the local hospital collaborated and contributed with staff. Two midwives facilitated the tests and the doulas were at all times visible around the bus, talking to people passing by and convincing them of the importance of taking the test as well as asking them to spread the word to their friends. Some stakeholders from the rather complex screening organization were concerned whether Pap smear testing would be implemented adequately in the mobile unit. To address this concern, newsletters were sent regularly in which practitioners, politicians, officials and others were informed about the project’s activities and progress.

Early in 2012, a Facebook site was launched, creating a forum for discussion and information about Pap smear tests. Together with the patient association, three films (in Arabic, Somali, and Swedish) were made about Pap smears. Inspired by what one of the doulas had said during the focus group, a special Pap smear week was launched in the northeast part of the city in the spring of 2012, offering special opening hours as well as information about Pap smear testing in the local community. An additional appeal and special information were sent out to women in the area that had not had the test in the previous five years. The local hospital changed its routines and began to inform all women visiting the hospital about Pap smear testing.

Evaluating action

Evaluation was carried out both throughout the project and at its conclusion; therefore, interventions that did not work as expected could be modified or corrected. For example, when the doulas discovered they could not always answer the public’s questions, they were provided with additional training from a midwife. Practical matters could be corrected rather quickly, such as getting electricity to the mobile unit and providing the doulas with umbrellas when needed.

The evaluation was conducted both quantitatively and qualitatively. Quantitatively, the number of Pap smears each month during the campaign year was collected for northeastern Gothenburg. These numbers were compared on a monthly and annual basis with the two previous years. The number of tests continued to be collected after the campaign year to evaluate the project’s sustainability.
In particular, a control chart helped to track the effect of the interventions. Certain individual activities were monitored quantitatively; an example was the Pap smear bus, where questionnaires were used to compile information such as the age and mother tongue of the women who took the test in the bus, as well as whether they had taken the test previously. Qualitatively, the authors kept a diary of the development of the project, and the midwives also kept a diary to reflect on the activities around the Pap smear bus. By the end of the project, a second focus group discussion was conducted with the doulas to understand how the interventions had worked in the field and the experiences of the doulas themselves. The mix of quantitative and qualitative methods proved supplementary. For example, the narratives of the doulas demonstrated that the Pap smear bus was an appropriate activity with which to reach out to the locals. Statistically, the constructed control charts reinforced that conclusion.

During the campaign, April 2011 to March 2012, there were 42% more Pap smear tests conducted as compared to the same period a year before (Figure 1).

Data collection started as soon as the interventions were launched with all Pap smear tests taken in the area matched on a monthly basis with interventions (Figure 2). Project intervention duration varied; for instance, except for a break during the summer months, radio information aired during the whole period. In addition, doula participation, information in the local paper, and occasional information given during local events also continued throughout the project. Other interventions were introduced in various stages and ran until it ended (for example, the telephone service and the Facebook campaign); still other interventions ran for a limited period of time (for example, the Pap smear bus and, obviously, the Pap smear week).

Figure 1. Number of Pap smear tests.
The single most intense intervention was the Pap smear bus. In total, more than 400 tests were taken during the eight weeks the bus was in operation. The bus also created a forum for dialogues about Pap smear testing as well as other aspects of women’s health. The midwives helped women write their own referrals about different gynecological concerns. The questionnaire responses showed that more than one-third of the women taking a test in the bus had never taken it before. Most of the women took the test because they had heard about the bus from friends, family members, or the doulas. However, the tests taken in the bus could not explain the dramatic increase of tests taken during the fall alone; the number of tests at the three antenatal units showed a significant increase as well.

The midwives facilitating bus tests kept a diary during the two months: despite technical issues, thunder and heavy rain, there was a lot of activity around the bus. Men, women, and children were curious and asked a lot of questions. The midwives noticed appreciation regarding the actual bus services as well as the gift given to the women that took the test. Several men brought informational material back to their female relatives. The doulas worked intensively to inform participants verbally and through handing out written information. They looked after the children while the women took the test and acted as a link between the midwives and the women, for example, by interpreting. The midwives also noted that women across the city had heard about the bus and came to take the test.

Figure 2. Interventions and number of Pap smear tests.
Healthcare professionals noticed that groups that were not known for taking Pap smear tests now participated. During the project, no unmotivated Pap smear tests were taken. The standard procedure of only facilitating the test if the woman had not taken a test within a three-year period was followed. The midwives estimated that twice as many women had wanted to take the test in the bus, but had had one too recently.

In March 2012, the campaign ended. The project was regarded a success and two years later, Pap smear test numbers continued to be far greater than before the campaign. One reason could be that the women had started to spread the message of taking the test in their own communities—a gratifying fact since oral information received from friends or relatives was something regarded as particularly important to achieve sustainable change. As the project ended, plans were made not only to institutionalize successful interventions in the local context, but also to spread the experiences to other geographical contexts and screening programs.

**Discussion**

Of the three developed principles of the project, at least two are in line with action research: collaboration and gaining trust through local strengths. As Coghlan and Brannick (2010) emphasized, desired action research outcomes are not only solutions but also learning. To start with, in complex organizations such as the cervical screening program, many kinds of competence are required to change things for the better. In this project, the collaboration principle was reinforced as the project proceeded. As many participators were involved, the democratic aspect of action research (Bargal, 2008; Bradbury & Reason, 2003; Coghlan & Brannick, 2010) became even more important. The authors’ decision not to act as experts proved to be appropriate. Instead, they acted as designers, gathering and analyzing data, overseeing interventions, and mobilizing the competence needed for the project, whether it was the doulas’ culturally specific, local competence or the healthcare staff’s professional skills and knowledge.

The collaborative nature not only incorporated different competence, perspectives and mandates, but also led to mutual learning. The doulas were educated by a midwife on two occasions, something both appreciated greatly. The doulas could also provide the midwives with information they would benefit from when encountering the local population at the clinics. The intervention of the Pap smear bus proved to be the most collaboration-intense. The midwives from different units were facilitating tests together and the doulas supported them, for example, by interpreting. Overall, the collaboration was positively received and gave many new insights. To co-create change may also strengthen future ties. Based on previous experiences, there was uncertainty whether the local gynecological clinic and the nearby antenatal care unit would be able to cooperate. However, participation in the project seemed to improve their relationship. The doulas reported the same in their collaboration with the midwives, as well as better confidence as the project proceeded and a feeling that they did something important.
The principle of gaining trust and using established local strengths proved appropriate and was viewed as two sides of the same coin. The aspect of trust has been emphasized by participatory researchers (Israel et al., 1998; Krishnaswamy, 2004) for successful community-based interventions. Early on in the project, it was concluded that translated written information alone was not sufficient to reach all women in areas with a high number of foreign-born citizens. Verbally disseminated information should not be underestimated and already well-established networks play a major role in spreading information from woman to woman (Abdullahi et al., 2009; Comerasamy et al., 2003). In accordance with previous research (Carroll et al., 2007; Kiger, 2003; Samuel et al., 2009), the use of doulas and healthcare professionals to inform women of a shared cultural background creates trust, thus mobilizing women to undergo Pap smear tests. As part of this principle, it was argued that since some women did not show up at the clinics, the clinics should show up where they were. Consequently, the Pap smear bus was parked in various public areas and created a lot of interest.

The campaign itself actualized positivity and proved, like other studies, to be successful (Anderson et al., 2009; Carroll et al., 2007). The positive approach started within project participants, in the hope that it would be mirrored when interventions were begun with community members. By embracing an optimistic attitude, ways to overcome difficulties by looking at strengths and possibilities for doing things differently could be addressed, rather than focusing on barriers and problems.

Naturally, the principles are not isolated from one another, but are mutually reinforcing: embracing a positive approach creates better collaboration, which in turn increases chances for positive interaction with the community members. Similarly, doula collaboration both had an effect on the project and earned community member trust. In addition, the quantitative methods supported the principles of the project by showing that the situation for the underserved population had indeed improved. Applying a participatory approach based on the three principles enables improvement of similar preventive services in other, similar contexts.

Actions were continuously evaluated for improvement. However, not all interventions could be evaluated and fed back into the project. The reason behind this is that the local project can be described as a series of smaller and bigger interventions, planned during approximately one year and launched in the area during the subsequent year-long campaign. These interventions’ duration varied from one day to more or less ongoing during the whole campaign. Therefore, some interventions could be fed back rather quickly whereas others were evaluated first after the project ended.

Carrying out a number of interventions, often simultaneously, is not unproblematic. However, by combining statistical tools such as control charts (Bergman & Klefsjö, 2010) and narratives from doulas and midwives, some conclusions could be drawn. For example, the Pap smear bus was a successful way of reaching out to the locals. “Softer” aspects as well as the “hard” numbers must be evaluated to
ensure that change indeed has occurred. Moreover, using these qualitative and quantitative methods creates synergy. In this inquiry, presenting the quantitative review of the Pap smear tests to the participants was energizing, confirmed the campaign’s effect on the local women, and strengthened collaboration. This synergy also may be a reason for the surprisingly little resistance and trouble encountered during the project. In a post-campaign phase, statistics presented to stakeholders, practitioners, policymakers, and others reinforced that positive change had occurred. In addition, synergies are created by launching many interventions simultaneously, since information reaches the population from various channels.

Naturally, the participatory approach also has had an effect on the researchers; reflection of one’s own learning as an action researcher is important (Coghlan & Brannick, 2010). The project has challenged many of the assumptions and expectations that were brought into the project, including the decision to target women-only associations for disseminating information, and not mixed gender groups (such as Swedish classes). However, the project showed that many men were interested in the information and passed it on to their female friends and family members. This was rather ironic since the first author had done the same thing; that is, forwarding knowledge about cervical cancer and Pap smear testing to female friends and family members. This experience led to the conclusion that men should be targeted with information concerning cervical cancer prevention. After all, this was in line with a goal of the project: getting all community members to talk about it. Another observation with a gender perspective is that as the project became more known, some people in the healthcare organization thought it unusual that the first author was involved in what was considered typical women’s issues. However, none of the participants in the project seemed to pay any particular attention to it. Prior to the focus group discussions, it was discussed whether interviewer gender would have any impact on the doulas’ ability to talk freely about cervical cancer. After deciding to conduct the focus group together, there were no obvious problems with a male interviewer. Rather, the doulas seemed to be more interested in the cultural background of the first author. They came back to the issue continually as the project proceeded; the fact that the first author had a foreign-born mother became a way of building common ground.

Limitations of the study

There are no birth country statistics for women participating in the cervical cancer screening program in the northeast part of Gothenburg. One cannot know that foreign-born women forgo Pap smears to a greater extent than Swedish-born women. Even so, project interventions mainly focused on foreign-born women. A stereotyping risk exists in grouping these women together just because they are not born in Sweden. Naturally, these women are born in various countries, sometimes having nothing or little in common with each other. However, a significant part of the local population was not born in Sweden and do not have
Swedish as their mother tongue. As pointed out above, previous research indicated that foreign-born women’s participation in cervical cancer screening is lower than for Swedish-born women (Azerkan et al., 2011) and that women participating in cervical screening programs are socialized into accepting preventive healthcare (Forss et al., 2001). Interventions targeting foreign-born women must enable women to receive and understand information about the purpose of Pap smear tests. However, relying on the doulas’ perceptions of barriers is not unproblematic. Contrary to some of the women in the northeast part of Gothenburg, the doulas all speak Swedish and are well established in the society. On the other hand, having the same cultural background as the women they inform and meet on a daily basis enhances the doulas’ role in creating an understanding of the women’s experiences and identifying their needs.

The foreign-born women in the local area were the initial focus, but as the project progressed the doulas and midwives noticed that many Swedish-born women also said they had not been tested because they did not have the money. Pap smear testing available in the project’s mobile unit was free of charge, which the questionnaire responses indicated was a reason why women decided to be tested there. The doulas may not have identified cost as a barrier because they were more integrated into society than other women in the area. Of course, factors other than birth country or language may affect participation in the cervical cancer screening program: for example, socio-economy, age, or income level. However, using only these factors in a study would neglect the effect of discriminating structures and mechanisms in society that groups suffer because they are not born in Sweden (SOU 2006:78).

The project increased the number of Pap smear tests during the year of interventions. However, the context of this finding should be noted. On a cross-regional level, a new booking system was introduced, enabling women to reschedule their appointments themselves. It is not yet sure the extent to which this particular system affected the outcome. Also, the refreshed informational material was a regional initiative and not a direct project intervention. This should also be considered when discussing the project’s impact on women’s participation in the cervical screening program.

Conclusion

This study has demonstrated that an action research approach to collaborating with actors within the healthcare system and civil society may be fruitful. Much of the success of the project can be explained by the involvement of actors with various areas of expertise; for example, communicating culture-specific knowledge, as well as representing different units in the healthcare system, gave the project legitimacy.

By itself, translated written information is not sufficient to increase cervical cancer screening program participation in areas with a significant part of the population being foreign-born. There is a need not only to give residents a greater say,
but also a more active role in designing services. Efforts must be made to take local strengths and institutions already established into account. The experiences from the project suggest that the unique social and cultural context should better be included in preventive healthcare and outreach activities. Since one size does not fit all, more tailor-made healthcare services would better meet the needs and expectations of the population.

Many participatory action research inquiries would benefit from a quantitative monitoring of the project’s progress and outcome. The benefit is twofold: numbers can demonstrate visually that change has occurred and can boost participants’ morale, strengthening collaboration. To include quantitative measurement in action research may be particularly important in a healthcare context, where professionals and decision makers frequently use numbers as quality indicators.

**Acknowledgements**

The authors wish to thank all doulas, gynecologists, midwives, nurses, officials, and others at the antenatal clinics in Angered, Bergsjön, and Gamlestaden, Angered Local Hospital, Födelsehuset, Ung Cancer, Regional Cancer Centre West, and the Swedish Association of Local Authorities and Regions. The authors would also like to express their gratitude to Andreas Hellström, Sylvia Määttä, the anonymous referees and the associate editor Svante Lifvergren for providing helpful and valuable comments on earlier versions of the paper.

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