formed through umbrella organisations, both generalist and specific, have a particular part to play. Although funding for patients' organisations has increased in the United Kingdom, there is still no long term commitment to support the work of these organisations or to use their potential to the full, as is happening in the Netherlands, for example (box).[17]

Conclusion

Partnerships with patients should not be seen as good in themselves. They are rather one route to a better life for people living with long term medical conditions, especially when these partnerships allow patients to have a greater degree of control over their lives and access to services that are of better quality. Partnerships between patients and clinicians can also help make better use of health professionals' time. Partnerships are not a panacea, nor is partnership a simple term to be used unthinkingly. If constraints hindering the development of partnerships are tackled, they could make a real difference to patients and clinicians.

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Participatory research maximises community and lay involvement

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Participatory research attempts to negotiate a balance between developing valid generalisable knowledge and benefiting the community that is being researched and to improve research protocols by incorporating the knowledge and expertise of community members. For many types of research in specific communities, these goals can best be met by the community and researcher collaborating in the research as equals.

Methods

This integrative review is based on a search of medical, nursing, and social science databases and ethical research codes. The material selected had to be significant theoretical works, source documents, or concrete examples of participatory research. We assessed the texts on the basis of our own experiences as members of Native communities (LEC, MLMcC, CMR) and researchers (WLF, NG, ACM, MLMcC, PLT) in participatory research projects. The preliminary draft was reviewed by a wide range of researchers and community members. The members of the North American Primary Care Research Group reviewed and accepted the final draft as a ploicy statement for participatory research. This article summarises that document (the full document can be found at http://views.vcu.edu/views/fap/napcrg98/exec.html).

> ## Summary points
>
> The knowledge, expertise, and resources of the involved community are often key to successful research
>
> Three primary features of participatory research include collaboration, mutual education, and acting on results developed from research questions that are relevant to the community
>
> Participatory research is based on a mutually respectful partnership between researchers and communities
>
> Partnerships are strengthened by joint development of research agreements for the design, implementation, analysis, and dissemination of results
>
> Results of participatory research both have local applicability and are transferable to other communities

Why participatory research?

Participatory research began as a movement for social justice in international development settings.[1] It was

Key terms

A community is a group of people sharing a common interest—for example, cultural, social, political, health, economic interests—but not necessarily a particular geographic association[1]

Participatory research is the process of producing new knowledge by "systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change"[1]

Collaboration in participatory research is a partnership among equals with complementary knowledge or expertise

A partnership is a mutually respectful relationship based on sharing responsibilities, costs, and benefits leading to outcomes that are satisfactory to all partners

developed to help improve social and economic conditions, to effect change, and to reduce the distrust of the people being studied.[2] Although different applications and labels include "action research" and "participatory action research,"[1–3] all provide a framework to respond to health issues within a social and historical context.

Collaboration, education, and action are the three key elements of participatory research. Such research stresses the relationship between researcher and community, the direct benefit to the community as a potential outcome of the research, and the community's involvement as itself beneficial. "When people form a group with a common purpose, investigate their situation, and make decisions … [they] are transformed—losing fear, gaining confidence, self-esteem, and direction."[3] A goal is that research subjects should "own" the research process and use its results to improve their quality of life.

Although participatory research uses familiar qualitative and quantitative research methods, it can itself be health promoting by enhancing resiliencies that exist in all communities.[4] Especially in disadvantaged communities, it assists with self empowerment by removing barriers and promoting environments within which communities can increase their capacity to identify and solve their own problems.[5]

Collaborating with communities

Participatory researchers in North America have partnered with unions, women's organisations, and disadvantaged or disempowered peoples such as American Indian, Alaska Native, Canadian First Nations, and Inuit peoples.[6 7] They have also partnered with groups not usually considered to be communities, such as people in hazardous work environments, astronauts, and people with a specific disease.[8]

Research can entail varying degrees of participation. Much conventional research limits interactions between researchers and subjects to instrumental relationships prescribed in the protocol. Other research has more involvement of subjects but does not share power in decision making and thus is not "participatory." Even multicentred, randomised clinical trials can be done in true partnership with communities—to maximise community benefits, minimise community harms, and incorporate the social context—while preserving the trials' scientific rigour.[16]

The Royal Society of Canada outlined the nature of collaborative relationships and steps to achieve them and offered guidelines and categories for classifying participatory research projects.[1] Attributes of researchers and community members contributing to successful partnership and outcome include ability to build respectful relationships and engender trust; awareness of political issues; self awareness of biases and perspectives; tolerance for complexity, unpredictability, and conflict; seasoned group process skills and commitment to equality of relationships and conflict resolution.[12 17]

Ethics

Until recently, ethical codes have concerned individuals primarily as passive subjects of research. Community harms and benefits, and active community participation in research, are increasingly recognised.[18] Australian and Canadian codes describe the ethical conduct of research with Native communities in participatory research terms.[19 20] Universities and Native organisations and communities have developed ethical guidelines and checklists.[7 10 13 21 22] Most guidelines cover all four phases of research—design,

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The girls race in the annual "Racers for health" was organised by Kahnawake physical education teachers, the staff of the Kahnawake Youth Center, and the Kahnawake schools diabetes prevention project

Examples of participatory research projects

Kahnawake schools diabetes prevention project, Canada[9]
This participatory research project is being conducted with a Mohawk community (population 7000) in Canada. The long term goal is primary prevention of type 2 diabetes, by promoting healthy eating and increased physical activity among 6-12 year old children. Kahnawake is represented through a community advisory board of 25 volunteers from the health, educational, political, recreational, social, spiritual, economic, and private sectors and the full time project staff.

The community is a full partner. It participated in *(a)* developing the goal and objectives, *(b)* planning and implementing the intervention and evaluation, *(c)* outlining the obligations of researchers and community in the code of research ethics,[10] *(d)* collecting and interpreting data, *(e)* reviewing lay and scientific publications, and *(f)* disseminating results. Their collective wisdom adds a perspective that broadens interpretations, increases the project's effectiveness, helps to decrease harm and improves the credibility of oral and written results, which saves the community from potential stigmatisation. The community had substantial influence by requesting that the project focus on children (which matched the scientific theory that lifestyles are learnt at an early age); by reaffirming to the funding agency that the two community schools should be analysed together, because comparisons by schools would be contrary to community values; and by convincing researchers to postpone a food services intervention until there was greater community acceptance. The community was responsible for implementing and enforcing a schools healthy nutrition policy, increasing physical resources by building a recreation path, and expanding social resources with a dozen new yearly events. Finally board members ensure cultural relevance, promote the objectives, and are community role models for healthier lifestyles.

Early evaluation described baseline measures from Kahnawake and the comparison community.[9] The board and researchers are currently analysing data from the four year evaluation. This project, however, has demonstrated Kahnawake's self empowerment, increase of physical and social capacity, and how the participatory model improved the research to benefit the community. In turn, the community sustained the project with its own funds for one year, when grants were not available, and is using the newly acquired knowledge, skills, and experiences for continuing healthcare planning.

Nutrition education for low income, urban women, Halifax, Canada[11]
The study, based on participatory research with a community organisation, addressed nutritional inequities, empowering a group of socially disadvantaged women to initiate collective action to improve their nutrition.

Boston healthy start initiative, United States[12]
This federally funded project was associated with a decrease in infant mortality and showed that communities had a major role in redefining services and power relationships in health programmes.

Wai'anae cancer research project, Hawaii[13]
The community participated in all phases, from the development of a grant proposal through to data interpretation. Culturally appropriate interventions increased breast and cervical cancer screening among Native Hawaiian women, improved health services, increased the women's research skills, and produced economic benefits.

Injury prevention programme, Motala, Sweden[14]
This project doubled the use of infant car seats. The municipality formed a safety board and continued the project after the researchers handed it over to local practitioners.

Primary care health facilities, Soweto, South Africa[15]
This project involved all stakeholders in the process of developing primary health facilities.

implementation, analysis, and dissemination—and have underlying principles and obligations similar to covenantal or familial ethics.[18 23]

Participatory research is strengthened by local, jointly negotiated, ethical codes or agreements that ensure the sharing of leadership, power, and decision

A parent sponsored healthy breakfast for Kahnawake elementary school children, showing the transfer of healthy activities from the Kahnawake schools diabetes prevention project to the community

making from design to dissemination.[24] These local codes should identify the ethical and political issues; reflect local culture, needs, and interests; and maximise close collaboration between the researcher and community partners.[10] The partners should agree on their roles and responsibilities, desired outcomes of the research, measures of validity, control of the use of data and funding, and channels to disseminate findings.[1 7 10 12 13 24] Some communities, for example, have requested—and researchers have agreed—that publications will include dissenting views of both researchers and community, if the partners cannot agree on the interpretation.[10]

Discussing all results with the community allows for joint interpretation of the data. This increases the cultural and internal validity of the results and so strengthens the science; minimises harms (for example, external stigmatisation of individuals and the community, self stigmatisation, and community disruption); and maximises benefits.[7 10 13 21 25 26] Important outcomes of ethically sound participatory research have included ongoing capacity building of collaborators—for example, training, and better infrastructure, data collection, and storage—stronger receptivity to collaboration by researchers, stronger community voice in policy, and greater mutual trust.

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What the researcher and participating community should negotiate

- Research goals and objectives
- Methods and duration of the project
- Terms of the community-researcher partnership
- Degree and types of confidentiality
- Strategy and content of the evaluation
- Where the data are filed, current interpretation of data, and future control and use of data and human biological material
- Methods of resolving disagreements with the collaborators
- Incorporation of new collaborators into the research team
- Joint dissemination of results in lay and scientific terms to communities, clinicians, administrators, scientists, and funding agencies

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Solving problems and resolving conflicts

The roles, responsibilities, and contributions of researchers and community members may shift during the lifetime of the project. Partners may change their agendas, with an adverse effect on the research. Membership of the team may change; people with different experiential, theoretical, or methods skills and knowledge may be recruited. Such events are managed best in an established atmosphere of mutual respect. Disagreements and conflict should be anticipated by also having mechanisms in place to address changes of research design, of personnel, and of mind.[7 11–24]

Conclusion

Research traditionally considers individuals and communities as passive subjects. Current developments in health partnerships, ethics, and research methods, plus an expanding recognition of what constitutes expert knowledge needed for research, support the active participation of community members.[25 26] Results of a participatory research project, which are transferable and applicable elsewhere, include new findings and theoretical models, design, procedures for developing community advisory committees and partnerships, and data format and methods of collection. Community specific results include increased local knowledge and capacity, self empowerment, improved health outcomes, and community planning.

Participatory research also has potential problems. Researchers may inadvertently collaborate with a minority section of the population that does not represent the collective interests of the entire community. The time needed for a project may exceed what the researcher can give. Researchers may be left with nothing if a community changes its priorities, as may communities if the researcher leaves for a career change. Another problem is unrealistic expectations for community based projects; a one year project may not produce measurable changes in markers of conditions that developed over generations—for example, HbA_{1c} for diabetes.[27] Participatory research, like all research, is not guaranteed to succeed, but nevertheless it is often rewarding for all partners.

Funding agencies and researchers increasingly recognise that important potential benefits of participatory research exceed its potential costs. Moreover, the lessons learnt in participatory research are applicable to primary health care as it increases lay involvement, encourages community development, and promotes mutually respectful partnerships between researchers and the community.[28]

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Partnerships with children

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Earlier this year a 15 year old girl had her decision to refuse a heart transplant overruled by the High Court,[1] highlighting the issue of partnership with children. The case is the latest of several[2] that have shown how children's participation in decision making and recognising their autonomy and rationality[3 4] can conflict with the need to protect them from making decisions that are not in their long term interests.[5]

Court cases dramatically show the problems of involving children in decision making, but they tend to deal with extreme and unusual examples and have led to uncertainty and anxiety about routinely involving children in decision making. Away from the courts a movement is growing to promote children's rights. Proponents have argued from a position of moral obligation and have called for a code of practice which would emphasise children's rights to information, to express views, and to give or withhold consent provided the child is considered competent by a doctor.[6] Professional bodies and others concerned with children's wellbeing seem to have accepted many of these principles,[7-10] which are based on ethical and moral principles of autonomy, free will, choice, and compassion and have the laudable aim of allowing children's opinions to be voiced, heard, and acted on wherever possible.

However, the evidence suggests that partnership with children enjoys only limited success. Children are given little voice in medical consultations[8 11] and are rarely consulted as partners in the evaluation and planning of health services.[12 13] The aspirations of the children's rights movement will have little chance of being realised until there is more research based evidence about the outcomes of shared decision making, how the competence of children can be assessed, how information can be shared with children, and how shared decision making should be managed in practice.

Outcomes

An important source of resistance to extending the ideals of patient partnership to children is lack of good evidence about the outcomes. Clinicians, parents, and others need to be reassured about the effect on

Summary points

Child partnerships have been debated largely in the context of discussions about children's rights or high profile court decisions

Many obstacles to forging partnerships with children could be overcome with better evidence from research

Parents, health professionals, and others need good quality evidence to reassure them that partnership with children will not produce adverse effects in the long term and to guide them about how to manage partnership

Evaluation of outcomes of childhood interventions needs encouragement from government bodies together with promotion of quality in information for children

children's wellbeing and about issues such as how families, perhaps with the benefit of hindsight, assign responsibility for "wrong" decisions. In assessing the outcomes of partnership, it is vital to include children's perspectives and to be sensitive to how these may change as children develop. Recent developments in methods for assessing child based outcomes have been encouraging. For example, measures of quality of life in children have begun to move away from using parents as proxies and treating children of all ages as having the same concerns. Instead they ask children directly for their views and are developmentally sensitive.[14] The recent use of qualitative approaches is also hopeful.[15] Use of these developments for longitudinal assessment of outcomes of different forms of shared decision making should be a research priority.

Competence

A key anxiety in creating partnerships with children is uncertainty about children's competence and how it