HOW CAN WE CO-CREATE SOLUTIONS IN HEALTH PROMOTION WITH USERS AND STAKEHOLDERS?

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HOW CAN WE CO-CREATE SOLUTIONS IN HEALTH PROMOTION WITH USERS AND STAKEHOLDERS?

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Editorial: How can We Co-Create Solutions in Health Promotion With Users and Stakeholders?

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Editorial on the Research Topic

How can We Co-Create Solutions in Health Promotion with Users and Stakeholders?

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INTRODUCTION

Participatory approaches have become an integral part in various fields of public health and health promotion research. These approaches have the potential to allow the production of deeper knowledge of complex health issues by valuing and incorporating the different perspectives and experiences of key actors closely related to the subject of the research (1). The hallmark of participatory research is the establishment of equitable research partnerships with a diverse group of stakeholders such as public health professionals, health activists, government officials, and citizens (2, 3). Participatory or co-creation approaches serve as a guiding principle to ensure stakeholder engagement throughout all the stages of the research and program development phases including developing, refining, and implementing. Originally, co-creation is a concept from management science and software design and is focused on achieving synergistic effects through user participation in the design processes. Co-creation in health promotion aims to improve the life of those who are subjects of research by empowering them to contribute to the research process and outcomes to better advocate for transformative initiatives and changes in public policies that address their health needs (4–7). Such participation asks for a systematic reflection of underlying power relations in the research process through dialog, recursive methods of understanding, joint planning, and co-design. However, reaching a high level of participation from a variety of stakeholders in health research is an exigent process that requires monetary and non-monetary resources. Although both the academic researchers and community co-researchers are considered capable of contributing to knowledge building, often ensuring that all the parties are fully involved in the research process is a hurdle (8) and stakeholder engagement is required (9).

CO-CREATION IN HEALTH PROMOTION

Co-creation is an umbrella term similar to that of participatory design (10). Co-creation is linked to a wide array of methods, among those co-design and co-production (11), but also other approaches such as design thinking, cooperative planning (3, 12), and living lab formats (Dietrich et al.). In health and community settings, co-creation is often depicted as a model of participatory research (13), while others regard co-creation as comprising both the community-based participatory research and integrated knowledge translation (14). In other words, co-creation refers to any act of collective creativity with a wide range of methods and processes on how this can be achieved. However, to this day only, few methodologies detail how to incorporate stakeholders and citizens values with scientific evidence. In order to overcome the challenges for developers of innovative programs, interventions, or services in the field of health promotion and education, more research is needed to articulate and document essential factors contributing to successful co-creation processes.

A useful specification of the co-creation of knowledge definition was recently delivered by Pearce et al. (11) based on a content analysis of existing studies that involve co-creation. The authors have distinguished four collaborative stages of co-creation research, namely, generating an idea (co-ideation); designing the program or policy and the research methods (co-design); implementing the program or policy according to the agreed upon research methods (co-implementation); and the collection, analysis, and interpretation of data (co-evaluation). This special issue presents innovative research in all the four stages of co-creation. We hope you enjoy reading the articles that are briefly described as follows.

ARTICLES IN THE COLLECTION

Addressing the co-ideation stage, the article by Dias et al. outlines the protocol for a migrant community-based project that seeks to optimize health literacy, health promotion, and social cohesion in support of prevention of non-communicable diseases (NCDs) among migrants. This protocol is an example of co-ideation, which is guided by a grounded approach to produce evidence on health literacy needs from key stakeholders and migrant communities. As another article positioned at the co-ideation stage, Choi et al. conducted a mixed method study with teachers and students to understand the needs of school health priorities for rural areas in Peru. This study serves as a starting point to develop a school health program and identifies important priorities that must be considered when designing for remote areas. Also, Onasanya et al. conducted a qualitative study based on key informant interviews and focus group discussions to identify relevant stakeholders for schistosomiasis diagnostics in South-West Nigeria. This study presents a systematic approach to identify stakeholders and classify them into a power/interest matrix according prior to starting a co-creation and co-implementation process.

Three articles address the co-creation stage and focus on collaborative involvement in health intervention design. Dietrich et al. draw from two case studies where researchers co-created virtual reality interventions in an alcohol prevention context. They explore and reflect on two co-creation methods—co-design and living lab—and showcase the different procedures of each approach along with a discussion on the challenges and merits. Ferschl et al. report result from a transdisciplinary research consortium on scientific cooperation and the co-production of scientific outcomes for physical activity promotion. Cheng et al. apply a systematic approach of community co-design to the digital context to generate solutions to improve health and equity outcomes.

Addressing co-implementation, Minian et al. analyze a co-creation process between researchers and patients with lived experiences to co-design resources that encourage behavior change among treatment-seeking smokers. This study can serve as an example of how integrating patients into the planning and delivery of healthcare can contribute to more tailored and effective communication resources. Another article by Kwon et al. analyzes the lessons learned from a case study of school health in a community-based school reopening during coronavirus disease 2019 (COVID-19) pandemic.

Three articles address specific outcomes of co-creation projects. Anang et al. illustrate the lessons learned from “Building on Strengths in Naujaat,” a resiliency initiative with the objective of promoting sense of belonging, collective efficacy, and well-being in Inuit youth. While their creativity and resourcefulness are at the heart of the initiative, this study explores conflicts and pitfalls that accompanied it. von Heimburg et al. explore, using kindergartens as a case setting, how participatory action research can be a tool for transformative practices in a local community. This study shows that how cycles of transformative actions and reflections in co-creation processes bear potential for social inclusion and ultimately for achieving well-being among different stakeholder groups in early childhood development. The other article by Ruiz-Eugenio et al. is a qualitative study on dialogic literary gatherings as co-creation intervention and evaluates its impact on psychological and social well-being in women during COVID-19 lockdown.

AUTHOR CONTRIBUTIONS

CS formulated a draft. SD, TD, AF, and IK revised the manuscript. All authors contributed to the article and approved the submitted version.

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ORIGINAL RESEARCH
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School Health Needs Assessment in Chanchamayo, Peru: A Health Promoting School Project

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Background: School-based health promotion can be particularly valuable in developing countries. However, there is a lack of information about the health needs of Peruvian school students. The purpose of this study was to conduct a health needs assessment to develop strategies for a school health promotion program in a jungle and indigent region in Chanchamayo, Peru.

Methods: This study was conducted using a mixed method approach that included a literature review, national and local statistics, stakeholder interviews, and a survey. Participants of the survey were 210 teachers, 2,504 elementary school students, and 2,834 secondary school students from six 'schools in two planned project implementation regions. A self-administered questionnaire for students was developed based on WHO's Global School-based Student Health Survey. Collected data were analyzed using descriptive statistics, chi-square tests, and *t*-tests for the survey data and content analysis for the interviews.

Results: Weak school health systems were identified, including school health policies, curriculum, trained health care personnel, and health-related facilities and equipment. Common health problems of students were anemia, nutritional deficiency, infectious diseases, tuberculosis, drug abuse, poor hygiene, and sex-related problems. High absence rates from school due to family problems and high dropout rates due to pregnancy were also critical issues. Teachers identified personal hygiene, nutrition, reproductive health, and sex education as high priorities for school health education, while students identified prevention of infectious diseases, nutrition education, psychological health, and healthy lifestyles as priorities. Identified strategies included: establishment of school health policies, curriculum-based interventions, increasing community participation and raising school health awareness, capacity building for health care promotors, training of trainers, and partnership between schools and communities.

Conclusions: Findings from this study will help guide the development and implementation of a school-based health promotion program in Chanchamayo. Multicomponent school-based interventions that consider feasibility and sustainability will be developed and evaluated based on WHO's Health Promoting School concepts.

Keywords: children, adolescent, needs assessment, school health, Peru

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INTRODUCTION

School health is an essential element for achieving education goals by maintaining health and promoting students and staff in schools (1). Students require physical and mental support for development, so it is vital to promote their health through the school system in which students spend most of their day. In addition, school health also has the effect of reducing the consequences of health inequality that result in poor health (2) while improving students' health behaviors, health literacy, and academic achievements (3). Two factors should highlight school health: the practical targets for children, adolescents, and community access and the integrated school health program. Schools should provide disease-prevention interventions with an interest in the health problems of students and their families and provide a variety of integrated health education and activities (4). Thus, school health, which determines a healthy future through education, has emerged as a need requiring long-term projects to promote school health. School-based health promotion projects are especially beneficial in developing countries that are suffering from limited health literacy and a high burden of diseases (3).

Health promoting schools (HPS) developed based on the relationship between health and education by the World Health Organization (WHO) in the late 1980s (2). Components of HPS include "school health policies, the physical environment of school, school's social environment, community relationships, personal health skills, and health services" (5). Whitman (6) suggested the components of HPS based on the WHO framework are school health policies, school health service, school health education, school environment, and community networks. HPS are important in achieving both health and academic goals through prevention of communicable diseases and unhealthy behaviors (1). HPS, where all members of the school community participate in improving health, need a comprehensive approach, rather than only one or two programs (7).

Peru is an upper-middle income country that has recently experienced economic growth. However, severe social and regional disparities arise because rural areas have difficulties gaining access to cities near the Andes and the Amazon (8). In rural areas of Peru, health inequalities are severe, with a poverty rate that is three times higher, an infant mortality two times higher, and a chronic malnutrition three times higher than in urban areas (9). In addition, the adolescent birth rate in rural areas (110 births per 1,000) was higher than in urban areas (58 births per 1,000), according to the Pan American Health Organization (9). Over 90% of children of primary school age and over 80% of children of lower secondary school age were enrolled in school globally in 2019 (10). However, only 80% of the school age population aged 10–19 in Peru were enrolled in school. Moreover, the prevalence of drinking (36.0%), smoking (21.0%), and cocaine use (0.4%) was reported to be high among the school age population in Peru (9). The Global School Health Survey (GSHS) of Peru reported 19.7% of adolescents aged 13–17 had sexual intercourse and only 34% of girls between 15 and 24 years old had knowledge of condom use (11). Health conditions for those of school age are closely related to health conditions in adulthood, and the lifestyle habits formed during this period are continued until adulthood. Therefore, it is essential to improve health for the school age population (12). Thus, programs for school-age children and adolescents in rural areas should focus on promoting health using school-based health promotion.

Health needs assessment guides the procedure to plan and implement health activities based on the health and healthcare needs of a specific group (13). When identifying the appropriate health needs of a community, priorities of community health program can be established, current resources can be identified, and community participants can become involved (14). However, there is a lack of information about the health needs of Peruvian school students. Therefore, the health and education sectors in developing countries need to assess the health needs of their school-age children and adolescents to adapt the school health promotion programs for enhancing their overall well-being. The purpose of this study was to conduct a health needs assessment to develop strategies for an HPS project in a jungle and indigent region in Chanchamayo, Peru.

MATERIALS AND METHODS

Study Design

This study was conducted using a mixed method to understand the needs of school health in rural areas in Peru. The quantitative study involved administering structured questionnaires to students and teachers, while the qualitative study included conducting semi-structured interviews with 15 key informants.

The five components of HPS including school health policies, school health service, school health education, school environment, and community networks (6) were used as a framework to assess health needs in school for both quantitative and qualitative data collection. The project team leading the school health needs assessment and representatives from the Ministry of Health, regional health directorate, provincial government, Chanchamayo City Hall, and regional health center were involved to advise on the project.

Study Sampling

The Perené and Pichanaqui districts in Chanchamayo, where the project of "Public Health Capacity-building project in Chanchamayo, Peru" was initiated by the Korea International Cooperation Agency (KOICA), which was the funding agency, were selected as the two target areas. The people living in the Perené district are more vulnerable to poorer health conditions compared to other regions due to a lack of infrastructure for health care facilities, medical services, schools, and jobs related to unplanned population growth (15). In addition, a high distribution of Aboriginal people live in the forests near Perené (15, 16). This region still has a high incidence of malaria and dengue, and tropical infectious and parasitic diseases remain unsolved health problems (16). Pichanaqui is located next to Perené and one health center in Pichanaqui managed both the Perené and Pichanaqui districts (15).

Six public schools that were located in a populated area were selected for this study (**Figure 1**). First, public schools among the regional schools were selected using a total list of schools. Second, the schools that operated both primary and secondary schools

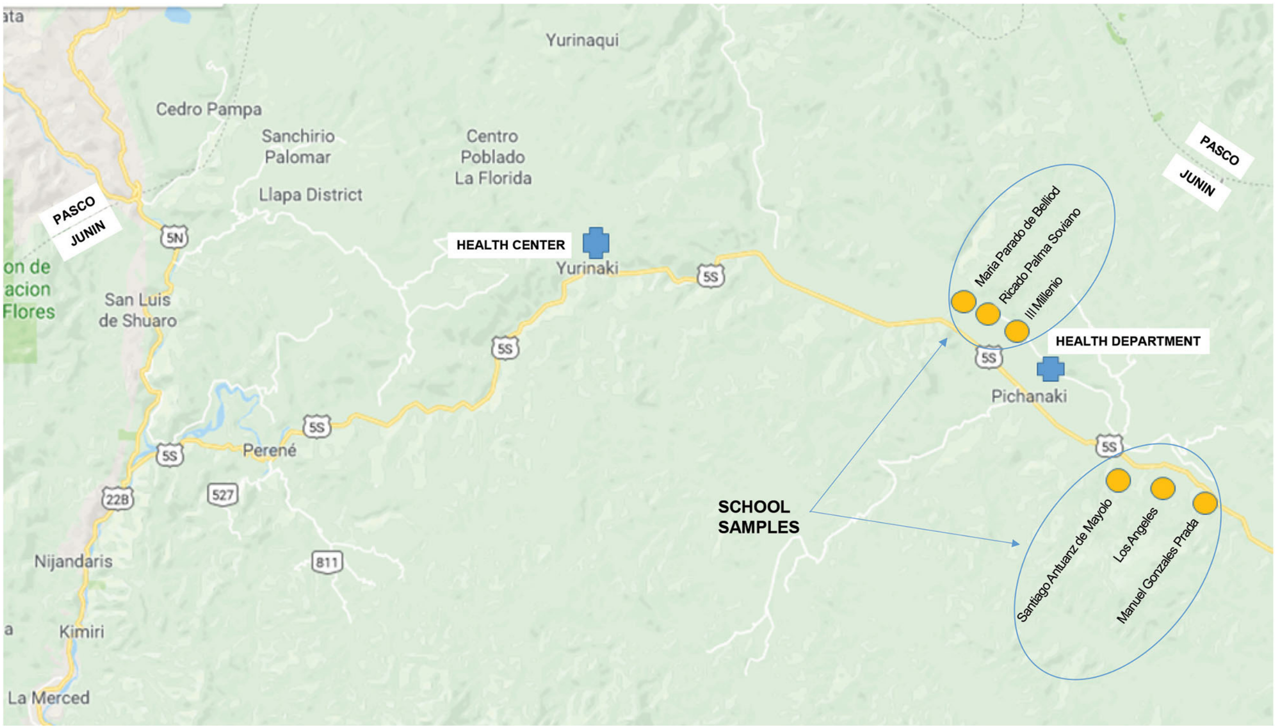

FIGURE 1 | Map of the study area.

were selected. Third, the schools with more than 400 students were selected. Finally, in order to compare the regions between the two selected districts, three schools that had good cooperation with the project in the two districts, respectively, were selected. The final target population was 310 teachers, 3,568 primary school students, and 3,736 secondary school students from the six selected schools. Participants who refused to participate (100 teachers, 1,064 primary school students, and 902 secondary school students) were excluded. As a result, 210 teachers, 2,504 primary school students, and 2,834 secondary school students from six schools participated in the survey.

Regarding key person interviews, the participants included principals of the six selected schools, teachers who were in charge of students' health, and health professionals including a doctor, two nurses, and a health promotor of health center in Perené.

Survey Instrument

The survey questionnaire was developed using a self-administered structured questionnaire based on the WHO Global School-based Student Health Survey Questionnaire (17). Moreover, this instrument was reviewed by the Ministry of Health of Peru and regional health professionals for content validity with the Spanish version and modified to use in this study. The questionnaire for teachers was composed of general characteristics, health problems, health behaviors, and the needs of health education for students which comprised of 44 questions. The number of questions for primary school students and secondary school students were 43 and 57 items, respectively. The questionnaire for students included general characteristics, family health problems, health behaviors, personal relationships, health knowledge, family environment, and health education needs. HIV-related knowledge for secondary school students were given a score of 0 or 1 (0 = wrong answer, 1 = correct answer) among six questions.

The semi-structured interview questions for key informants were developed based on components of HPS and two experts' review of content validity (6). In this study two Chanchamayo health sector experts were requested to evaluate content validity, after which appropriate which modifications were made. In terms of the key person interviews, the questions included the priority of health problems in the areas, major health problems among students and teachers, current school health policies, school health services, school health facilities, school health education, and school health environment such as physical safety, nutrition in the school snack bar, and networking with the community.

Data Acquisition

Representative schoolteachers from six schools were trained on how to conduct the 2 h survey by the Korean nursing faculty from the project team using the written manual, and parents of children in lower levels of primary schools also helped their children to conduct the survey. Informed consent was obtained from each school and from all participants' parents or guardians in advance, and an anonymous questionnaire was used. School health needs assessment was conducted from July to October

2014. Descriptive statistics, chi-square tests, and *t*-tests were used to analyze the general and health-related characteristics and health education program needs.

The semi-structured interviews were conducted from July 14 to 25, 2014. The interviews were conducted at the offices or conference rooms of 15 key informants; one manager of school health in the provincial education department, two directors of the regional health center, 12 school principals and teachers from six schools.

Data Analysis

All quantitative data were analyzed using descriptive statistics including real number, percentages, means, and standard deviations. The interview data were analyzed using an inductive approach by thematic content analysis.

Ethical Approval

The school health needs assessment including a survey and a key person interview received approval from the Regional Health Directorate in Peru and the Korea International Cooperation Agency. In addition, research ethics approval was obtained from the Institutional Review Board of Chosun University (IRB No. 2-1041055-AB-N-01-2019-3) to use school health needs assessment data for secondary data analysis.

RESULTS

General and Health-Related Characteristics of Schoolteachers

More than sixty percent of the participants were female (62.4%). In terms of age, 44.8% were 40–49 years old, 30.0% were 30–39 years old, and 20.5% were more than 50 years old (Mean ± SD = 43.1 ± 8.24).

Most of the teachers graduated from a university (91.9%) and almost 40% of participants had more than 20 years working experience as schoolteachers. Regarding health status, most of the participants reported their health status was fair (58.1%) or good (39.5%). Based on the body mass index, 45.7% were overweight, and 9.5% were obese. Thirty percent of participants reported that they did not exercise and 50.5% did exercise one or two times per week. Most of participants reported they were non-smokers (99.0%) and non-drinkers (79.5%). About 28.0% had a moderate level of stress and 20.0% had a high level of stress. In terms of receiving health education in last year, more than half participated in health education (60.5%) and reproductive health education (51.9%); however, only 39.5% were educated in first aid. Schoolteachers from Pichanaqui were receiving significantly more health education and reproductive health education (72.6 and 57.0%, respectively) than schoolteachers from Perené (38.7 and 42.7%) ($\chi^2 = 23.22$, $p < 0.001$; $\chi^2 = 3.99$, $p = 0.046$).

The mean health knowledge was 2.3 (± 0.47) out of 3. Regarding the needs of health education for students, the highest priority was personal hygiene (46.7%), followed by sexual and reproductive health (24.8%), nutrition (16.2%), and healthy behaviors (6.7%) (**Table 1**).

General and Health-Related Characteristics of Primary Students

Slightly more than half of the participants were male (50.6%) and the family social economic status of most students was at a middle level (65.9%). More students from Perené reported that their family social economic status was a low level (33.2%) compared to the students from Pichanaqui (22.7%) ($\chi^2 = 31.14$, $p < 0.001$). More than half of the students had good health status (59.3%), and more students from Perené (64.2%) answered their health status was good compared to students from Pichanaqui (56.9%) ($\chi^2 = 29.70$, $p < 0.001$). Around 26% of students were either overweight or obese and there was a significant difference between students of Perené and Pichanaqui ($\chi^2 = 15.67$, $p = 0.001$). In terms of accidents near schools, the Perené area (7%) had more traffic accidents than Pichanaqui (4.9%) ($\chi^2 = 13.88$, $p = 0.008$). A quarter of students used the internet and had suffered from being bullied in school. Most of students reported that they washed their hands before having a meal or after going to the toilet; however, more students from Pichanaqui (34.8%) always washed their hands in those times compared to the students of Perené (22.9%) ($\chi^2 = 51.77$, $p < 0.001$). Regarding diet, about 15% of students always ate snacks and more students from Perené (12.5%) answered that they always ate snacks than students from Pichanaqui (6.6%) ($\chi^2 = 54.95$, $p < 0.001$). Likewise, 17.3% of students from Perené and 11.3% of students from Pichanaqui reported that they drank more than two bottles of soda per day ($\chi^2 = 45.66$, $p < 0.001$). Less than half of the students were educated in health education, while most of the students (87.6%) received personal hygiene education. In terms of knowledge about tooth brushing, 40.0% responded with correct answers. Almost a quarter of students reported their family relationships were good (72.2%) (**Table 2**).

General and Health-Related Characteristics of Secondary Students

More than half of the participants were female (53.1%) and most students reported their family social economic status was at a middle level (82.2%). Regarding health status, only 6.4% said their health status was poor. Based on body mass index, 13.9% of the students were either overweight or obese. More than half of the students used the Internet (60.0%) and student responses from the Pichanaqui area (64.3%) indicated more Internet usage than the Perené area (49.1%) ($\chi^2 = 54.91$, $p < 0.001$). Only 3.5% of students reported they were often or always bullied in school and 14.9% sometimes had an experience of bullying in school. Among secondary school students, 5.5% were smokers, 7.8% drank alcohol, and 9.4% had a sexual intercourse experience. The students from the Perené area were more likely to drink alcohol (9.6%) than those from the Pichanaqui area (7.1%) ($\chi^2 = 5.04$, $p = 0.025$) and the students from Perené (13.5%) had significantly more experience of sexual intercourse than the students from Pichanaqui (7.8%) ($\chi^2 = 22.21$, $p < 0.001$). Among the students who had sexual intercourse, the rate of condom use, and contraceptive method use at their last sexual intercourse were 66.7 and 53.2%, respectively.

TABLE 1 | General and health related characteristics of schoolteachers by regions (*N* = 210).

Characteristics	Category	*n* (%)/mean (±SD)			χ^2 (*p*)/t (*p*)
		Total	Perené	Pichanaqui	
Gender	Male	79 (37.6)	30 (40.0)	49 (36.3)	0.28 (0.596)
	Female	131 (62.4)	45 (60.0)	86 (63.7)	
Age	<30 years old	10 (4.8)	4 (5.3)	6 (4.4)	1.53 (0.675)
	30∼ <40 years old	63 (30.0)	26 (34.7)	37 (27.4)	
	40∼ <50 years old	94 (44.8)	30 (40.0)	64 (47.4)	
	≥50 years old	43 (20.5)	15 (20.0)	28 (20.7)	
Highest education level	High school	6 (2.9)	3 (4.0)	3 (2.2)	1.62 (0.445)
	College	10 (4.8)	2 (2.7)	8 (5.9)	
	University	193 (91.9)	70 (93.3)	124 (91.9)	
Working period	<10 years	45 (21.4)	17 (22.7)	28 (20.7)	6.73 (0.081)
	10∼ <15 years	34 (16.2)	18 (24.0)	16 (11.9)	
	15∼ <20 years	50 (23.8)	13 (17.3)	37 (27.4)	
	≥20 years	81 (38.6)	27 (36.0)	54 (40.0)	
Health status	Good	83 (39.5)	1 (1.3)	4 (3.0)	0.92 (0.632)
	Fair	122 (58.1)	42 (56.0)	80 (59.3)	
	Poor	5 (2.4)	32 (42.7)	51 (37.8)	
Body Mass Index	Under-weight	1 (0.5)	1 (1.3)	0 (0.0)	5.90 (0.117)
	Normal	93 (44.3)	34 (45.3)	59 (43.7)	
	Over-weight	96 (45.7)	37 (49.3)	59 (43.7)	
	Obese	20 (9.5)	3 (4.0)	17 (12.6)	
Exercise	None	63 (30.0)	16 (21.3)	47 (34.8)	4.52 (0.104)
	1–2 times/week	106 (50.5)	41 (54.7)	65 (48.1)	
	More than 3 times/week	41 (19.5)	18 (24.0)	23 (17.0)	
Smoking	Yes	2 (1.0)	1 (1.3)	1 (0.7)	0.18 (0.672)
	No	208 (99.0)	74 (98.7)	134 (99.3)	
Drinking	Yes	43 (20.5)	15 (20.0_)	28 (20.7)	0.02 (0.899)
	No	167 (79.5)	60 (80.0)	107 (79.3)	
Stress	No	19 (9.0)	8 (10.7)	11 (8.1)	3.39 (0.335)
	Low	90 (42.9)	35 (46.7)	55 (40.7)	
	Moderate	59 (28.1)	22 (29.3)	37 (27.4)	
	High	42 (20.0)	10 (13.3)	32 (23.7)	
Receiving health education in the last year	Yes	127 (60.5)	29 (38.7)	98 (72.6)	23.22 (<0.001)
	No	83 (39.5)	46 (61.3)	37 (27.4)	
Receiving first aid education in the last year	Yes	67 (31.9)	22 (29.3)	45 (33.3)	0.36 (0.551)
	No	143 (68.1)	53 (70.7)	90 (66.7)	
Receiving reproductive health education in the last year	Yes	109 (51.9)	32 (42.7)	77 (57.0)	3.99 (0.046)
	No	101 (48.1)	43 (57.3)	58 (43.0)	
Health knowledge (3 points)		2.3 (± 0.47)	2.29 (± 0.50)	2.36 (± 0.45)	−0.98 (0.331)
Needs of health education for students	Personal hygiene	98 (46.7)	33 (44.0)	65 (48.1)	4.20 (0.522)
	Sexual & reproductive health	52 (24.8)	21 (28.0)	31 (23.0)	
	Nutrition	34 (16.2)	12 (16.0)	10 (7.4)	
	Healthy behaviors	14 (6.7)	4 (5.3)	22 (16.3)	
	Mental health	9 (4.3)	5 (6.7)	4 (3.0)	
	Prevention of communicable diseases	3 (1.4)	0 (0.0)	3 (2.2)	

TABLE 2 | General and health related characteristics of primary school students by Regions ($N = 2,504$).

Characteristics	**Category**	***n* (%)**			**χ^2 (*p*)**
		Total	**Perené**	**Pichanaqui**	
Gender	Male	1,268 (50.6)	433 (52.5)	835 (49.7)	1.68 (0.195)
	Female	1,236 (49.4)	392 (47.5)	844 (50.3)	
Grade	1	232 (9.3)	112 (13.6)	120 (7.1)	41.10 (<0.001)
	2	450 (18.0)	136 (16.5)	314 (18.7)	
	3	408 (16.3)	100 (12.1)	308 (18.3)	
	4	446 (17.8)	152 (18.4)	294 (17.5)	
	5	427 (17.1)	135 (16.4)	282 (17.4)	
	6	541 (21.6)	190 (23.0)	351 (20.9)	
Social economic status	Low	655 (26.2)	274 (33.2)	381 (22.7)	31.14 (<0.001)
	Middle	1,651 (65.9)	491 (59.5)	1,161 (69.2)	
	High	197 (7.9)	60 (7.3)	137 (8.2)	
Health status	Poor	201 (8.0)	83 (10.1)	118 (7.0)	29.70 (<0.001)
	Fair	818 (32.7)	212 (25.7)	606 (36.1)	
	Good	1,485 (59.3)	530 (64.2)	955 (56.9)	
Body Mass Index	Under-weight	153 (6.1)	48 (5.8)	105 (6.3)	15.67 (0.001)
	Normal	1,697 (67.8)	601 (72.8)	1,096 (65.3)	
	Over-weight	457 (18.3)	124 (15.0)	333 (19.8)	
	Obese	197 (7.9)	52 (6.3)	145 (8.6)	
Type of accident nearby school	No accident	1,892 (75.6)	630 (76.4)	1,262 (75.2)	13.88 (0.008)
	Traffic accident	145 (5.8)	62 (7.5)	83 (4.9)	
	Slight accident	289 (11.5)	75 (9.1)	214 (12.7)	
	Severe accident	71 (2.8)	20 (2.4)	51 (3.0)	
	Other accident	107 (4.3)	38 (4.6)	69 (4.1)	
Using Internet	Yes	624 (24.9)	221 (26.8)	403 (24.0)	2.30 (0.130)
	No	1,880 (75.1)	604 (73.2)	1,276 (76.0)	
Experience of bullying in school	No	1,628 (65.0)	545 (66.1)	1,083 (64.5)	1.24 (0.745)
	Nearly not	270 (10.8)	89 (10.8)	181 (10.8)	
	Sometimes	489 (19.5)	151 (18.3)	338 (20.1)	
	Often & Always	117 (4.7)	40 (4.8)	77 (4.6)	
Experience of violence in school	No	1,685 (67.3)	579 (70.2)	1,106 (65.9)	6.60 (0.086)
	Nearly not	259 (10.3)	74 (9.0)	185 (11.0)	
	Sometimes	454 (18.1)	134 (16.2)	320 (19.1)	
	Often & Always	106 (4.2)	38 (4.6)	68 (4.1)	
Experience of violence at home	No	1,757 (70.2)	599 (72.6)	1,158 (69.0)	12.43 (0.006)
	Nearly not	262 (10.5)	67 (8.1)	195 (11.6)	
	Sometimes	423 (16.9)	131 (15.9)	292 (17.4)	
	Often & Always	62 (2.5)	28 (3.4)	34 (2.0)	
Hand washing before having meal or after restroom	No	73 (2.9)	38 (4.6)	35 (2.1)	51.77 (<0.001)
	Rarely	53 (2.1)	26 (3.2)	27 (1.6)	
	Sometimes	618 (24.7)	236 (28.6)	382 (22.8)	
	Often	987 (39.4)	336 (40.7)	651 (38.8)	
	always	773 (30.9)	189 (22.9)	584 (34.8)	
Tooth brushing per day	Never	52 (2.1)	16 (1.9)	36 (2.1)	8.41 (0.038)
	Once	280 (11.2)	111 (13.5)	169 (10.1)	
	Twice	1,028 (41.1)	315 (38.2)	713 (42.5)	
	More than 3 times	1,144 (45.6)	383 (46.4)	761 (45.3)	
Vegetable intake	Never	66 (2.6)	22 (2.7)	44 (2.6)	12.00 (0.017)
	Rarely	132 (5.3)	46 (5.6)	86 (5.1)	

(Continued)

TABLE 2 | Continued

Characteristics	Category	*n* (%)			χ^2 (*p*)
		Total	Perené	Pichanaqui	
	Sometimes	1,261 (50.4)	450 (54.5)	811 (48.3)	
	Often	484 (19.3)	133 (16.1)	351 (20.9)	
	always	561 (22.4)	174 (21.1)	387 (23.0)	
Snack intake	Never	196 (7.8)	53 (6.4)	143 (8.5)	54.95 (<0.001)
	Rarely	383 (15.3)	109 (13.2)	274 (16.3)	
	Sometimes	1,553 (62.1)	480 (58.2)	1,074 (64.0)	
	Often	157 (6.3)	80 (9.7)	77 (4.6)	
	always	214 (8.5)	103 (12.5)	111 (6.6)	
Soda intake per day	Never	608 (24.3)	139 (16.8)	469 (27.9)	45.66 (<0.001)
	< 1 bottle	827 (33.0)	282 (34.2)	545 (32.5)	
	1 bottle	736 (29.4)	261 (31.6)	475 (28.3)	
	More than 2 bottles	333 (13.3)	143 (17.3)	190 (11.3)	
Receiving personal hygiene education in last 1 year	Yes	2,193 (87.6)	697 (84.5)	1,496 (89.1)	10.84 (0.001)
	No	311 (12.4)	128 (15.5)	183 (10.9)	
Receiving health education in last 1 year	Yes	1,192 (47.6)	384 (46.5)	808 (48.1)	0.55 (0.457)
	No	1,312 (52.4)	441 (53.5)	871 (51.9)	
Knowledge of tooth brushing	Yes	1,001 (40.0)	321 (38.9)	680 (40.5)	0.58 (0.445)
	No	1,503 (60.0)	504 (61.1)	999 (59.5)	
Checking studying or homework from parents	Never	175 (7.0)	64 (7.8)	111 (6.6)	3.63 (0.459)
	Nearly not	130 (5.2)	37 (4.5)	93 (5.5)	
	Sometimes	1,339 (53.5)	449 (54.4)	890 (53.0)	
	Often	214 (8.5)	63 (7.6)	151 (9.0)	
	always	646 (25.8)	212 (25.7)	434 (25.8)	
Relationship with family	Poor	157 (6.3)	67 (8.1)	90 (5.4)	9.00 (0.011)
	Moderate	538 (21.5)	161 (19.5)	377 (22.5)	
	Good	1,809 (72.2)	597 (72.4)	1,212 (72.2)	

In terms of health education, the students from Perené areas received less reproductive health education (62.0%) ($\chi^2 = 79.81$, $p =< 0.001$), HIV/AIDS education (79.5%) ($\chi^2 = 38.05$, $p =< 0.001$), and contraception education (60.3%) ($\chi^2 = 10.76$, $p = 0.001$) than the students from Pichanaqui (78.4, 88.5, and 66.8%, respectively). In addition, regarding knowledge of contraception and pregnancy, more students from Perené reported that they had no knowledge of them (44.5% and 42.9%) than the students from Pichanaqui (28.5 and 41.9%) ($\chi^2 = 7.53$, $p = 0.023$ and $\chi^2 = 15.32$, $p < 0.001$). However, regarding knowledge about HIV/AIDS, the students from Perené (4.06 ± 1.43 out of 6) had significantly higher knowledge than the students from Pichanaqui (3.91 ± 1.39) ($t = 2.41$, $p = 0.016$). The highest priority of health education needs was personal hygiene (34.0%), followed by sexual and reproductive health (30.2%) and healthy behaviors (10.9%) (**Table 3**).

Status of School Health in Target Areas

According to the results of key person interviews, there was no school health concept which managed health problems and prevented diseases among schoolteachers and students in target areas. The limited resources including health professional staff like school nurses, infrastructure, facilities, and health related items were related to a lack of school health concept; neither was there health education in the school curriculum. The school absence rate was reported to be high due to family problems, nutritional deficiencies, and infectious diseases, including worms, and tuberculosis. Furthermore, the school dropout rate was high due to students' pregnancies. However, there was no program, monitoring of basic data, or strategies to solve these problems.

The principals and representative teachers reported the current health problems for students were anemia, communicable diseases, tuberculosis, malnutrition, poor personal hygiene, and sexual problems. In addition, many parents did not provide care for their children because they were busy with their farm work. Regarding current health problems for teachers, the principals and representative teachers reported that stress, gastritis, hypertension, and mental health issues due to family problems were their main health problems. In

TABLE 3 | General and health related characteristics of secondary school students by Regions (*N* = 2,834).

Characteristics	Category	*n* (%)/mean (± SD)			χ^2 (*p*)/t (*p*)
		Total	Perené	Pichanaqui	
Gender	Male	1,328 (46.9)	379 (47.0)	949 (46.8)	0.01 (0.913)
	Female	1,506 (53.1)	427 (53.0)	1,079 (53.2)	
Grade	7	626 (22.1)	197 (24.4)	626 (22.1)	23.31 (<0.001)
	8	662 (23.4)	207 (25.7)	662 (23.4)	
	9	506 (17.9)	162 (20.1)	506 (17.9)	
	10	539 (19.0)	124 (15.4)	539 (19.0)	
	11	501 (17.7)	116 (14.4)	501 (17.7)	
Social economic status	Low	357 (12.6)	113 (14.0)	244 (12.0)	2.20 (0.334)
	Middle	2,320 (82.2)	650 (80.6)	1,680 (82.8)	
	High	147 (5.2)	43 (5.3)	104 (5.1)	
Health status	Poor	178 (6.3)	67 (8.3)	111 (5.5)	12.15 (0.002)
	Fair	912 (32.2)	231 (28.7)	681 (33.6)	
	Good	1,744 (61.5)	508 (63.0)	1,236 (60.9)	
Body Mass Index	Under-weight	174 (6.1)	63 (7.8)	111 (5.5)	6.46 (0.091)
	Normal	2,267 (80.0)	641 (79.5)	1,626 (80.2)	
	Over-weight	320 (11.3)	84 (10.4)	236 (11.6)	
	Obese	73 (2.6)	18 (2.2)	55 (2.7)	
Using Internet	Yes	1,699 (60.0)	396 (49.1)	1,303 (64.3)	54.91 (<0.001)
	No	1,135 (40.0)	410 (50.9)	725 (35.7)	
Experience of bullying in school	No	1,746 (61.6)	511 (63.4)	1,235 (60.9)	2.78 (0.427)
	Nearly not	566 (20.0)	155 (19.2)	411 (20.3)	
	Sometimes	423 (14.9)	109 (13.5)	314 (15.5)	
	Often & Always	99 (3.5)	31 (3.8)	68 (3.4)	
Experience of violence in school	No	1,715 (60.5)	539 (66.9)	1,176 (58.0)	19.4 (<0.001)
	Nearly not	506 (17.9)	121 (15.0)	385 (19.0)	
	Sometimes	502 (17.7)	117 (14.5)	385 (19.0)	
	Often & Always	111 (3.9)	29 (3.6)	82 (4.0)	
Experience of violence at home	No	2,317 (81.8)	659 (81.8)	1,658 (81.8)	2.36 (0.502)
	Nearly not	302 (10.7)	93 (11.5)	209 (10.3)	
	Sometimes	181 (6.4)	44 (5.5)	137 (6.8)	
	Often & Always	34 (1.2)	10 (1.2)	24 (1.2)	
Smoking	Yes	155 (5.5)	51 (6.3)	104 (5.1)	1.61 (0.205)
	No	2,679 (94.5)	755 (93.7)	1,924 (94.9)	
Drinking	Yes	220 (7.8)	77 (9.6)	143 (7.1)	5.04 (0.025)
	No	2,614 (92.2)	729 (90.4)	1,885 (92.9)	
Experience of sexual intercourse	Yes	267 (9.4)	109 (13.5)	158 (7.8)	22.21 (<0.001)
	No	2,567 (90.6)	697 (86.5)	1,870 (92.2)	
Using condom at last sexual intercourse	Yes	178 (66.7)	74 (67.9)	104 (65.8)	0.12 (0.725)
	No	89 (33.3)	35 (32.1)	54 (34.2)	
Using contraceptive method at last sexual intercourse	Yes	142 (53.2)	55 (50.5)	87 (55.1)	2.02 (0.365)
	No	83 (31.1)	39 (35.8)	44 (27.8)	
	Do not know	42 (15.7)	15 (13.8)	27 (17.1)	
Experience of pregnancy	Yes	12 (4.5)	5 (4.6)	7 (4.4)	0.00 (0.952)
	No	255 (95.5)	104 (95.4)	151 (95.6)	
Experience of abortion	Yes	22 (8.2)	11 (10.1)	11 (7.0)	0.84 (0.361)
	No	245 (91.8)	98 (89.9)	147 (93.0)	
Receiving Reproductive health education	Yes	2,090 (73.7)	500 (62.0)	1,590 (78.4)	79.81 (<0.001)

(Continued)

TABLE 3 | Continued

Characteristics	Category	*n* (%)/mean (± SD)			χ^2 (*p*)/t (*p*)
		Total	**Perené**	**Pichanaqui**	
	No	744 (26.3)	306 (38.0)	438 (21.6)	
Receiving HIV/AIDS education	Yes	2,435 (85.9)	641 (79.5)	1,794 (88.5)	38.05 (<0.001)
	No	399 (14.1)	165 (20.5)	234 (11.5)	
Receiving contraception education	Yes	1,841 (65.0)	486 (60.3)	1,355 (66.8)	10.76 (0.001)
	No	993 (35.0)	320 (39.7)	673 (33.2)	
Knowledge of HIV/AIDS		4.0 (± 1.43)	4.06 (± 1.51)	3.91 (± 1.39)	2.41 (0.016)
Knowledge of STD	Well-known	449 (15.8)	111 (13.8)	338 (16.7)	20.58 (<0.001)
	Little known	1,509 (53.2)	396 (49.1)	1,113 (54.9)	
	No	876 (30.9)	299 (37.1)	577 (28.5)	
Knowledge of contraception	Well-known	866 (30.6)	260 (32.3)	606 (29.9)	7.53 (0.023)
	Little known	760 (26.8)	187 (23.2)	573 (28.3)	
	No	1,208 (42.6)	359 (44.5)	849 (41.9)	
Knowledge of pregnancy	Well-known	870 (30.7)	230 (28.5)	640 (31.6)	15.32 (<0.001)
	Little known	906 (32.0)	230 (28.5)	676 (33.3)	
	No	1,058 (37.3)	346 (42.9)	712 (35.1)	
Knowledge of nurture	Well-known	728 (25.7)	196 (24.3)	532 (26.2)	1.54 (0.464)
	Little known	1,199 (42.3)	354 (43.9)	845 (41.7)	
	No	907 (32.0)	256 (31.8)	651 (32.1)	
Knowledge of tuberculosis	Well-known	978 (34.5)	253 (31.4)	725 (35.7)	5.95 (0.051)
	Little known	1,111 (39.2)	341 (42.3)	770 (38.0)	
	No	745 (26.3)	212 (26.3)	533 (26.3)	
Needs of health education for students	Personal hygiene	964 (34.0)	246 (30.5)	718 (35.4)	52.52 (<0.001)
	Sexual & reproductive health	856 (30.2)	217 (26.9)	639 (31.5)	
	Healthy behaviors	309 (10.9)	77 (9.6)	232 (11.4)	
	Nutrition	154 (5.4)	42 (5.2)	112 (5.5)	
	Mental health	51 (1.8)	17 (2.1)	34 (1.7)	
	Prevention of communicable diseases	66 (2.3)	30 (3.7)	36 (1.8)	
	Do not know	434 (15.3)	177 (22.0)	257 (12.7)	

terms of health-related needs for students, the principals and representative teachers reported health education about personal hygiene, reproductive health, and preventing communicable diseases as well as the school's physical environment, including lights, desk, chair, and facilities for sanitation, were needed (**Table 4**).

Components of Health Promoting School

The results of schools' current status by components of HPS found the following: Regarding the school health policy, there was no school health curriculum and no health policy in the schools. Regarding the school health service, five schools did not have a school health room or health personnel in the school. Only one school established a school health room, but there were no health personnel in the school health room. All schools had first aid kits, but most of the medical disposables were not managed. In terms of school health education, six schools had a plan of cooperation with a regional health center to provide health education; however, it was rarely implemented due to a lack of manpower and circumstances. Regarding the school environment, three schools in Perené had old and unsafe environmental conditions and the number of toilets had shortages compared to the number of students, whereas three schools in Pichanaqui had a better school building and facilities. Lastly, regarding community networks, the parents' association was not activated among the three schools in Perené while it was well-activated in the three schools in Pichanaqui. Although all six schools were linked to a local health center, the local health center supported the provision of health education to students irregularly, one to three times per semester, and conducted physical examinations for only two primary school students among six selected schools in the project area.

TABLE 4 | Health problems and needs of health education for students and teachers.

Categories	Contents
Health problems for students	Anemia, communicable diseases including worms and tuberculosis, nutritional deficiency, poor hygiene as well as family problems such as parental indifference, sexual assault in the home, child neglect, so on, psychological problems and sexual problems
Health problems for teachers	Work related stress, lack of energy, digestive problems, gastritis, hypertension, obesity, and family problems
Needs for students	Health education including personal hygiene, nutrition, sexual and reproductive issues, and preventing communicable diseases and school physical environment including lights, desk and chair, facilities for sanitation, so on

DISCUSSION

Insufficient school health policy in health education curriculum, trained teachers, and school infirmary as well as council for school health were drawn by key informants' interviews, and this finding was consistent with the survey results for teachers and students in this study. The differences in attending continuing health education for teachers resulted in their students' health status improving at the primary level and experiencing sexual intercourse at the secondary level. Teachers in the Pichanaqui area more frequently attended reproductive health education than teachers in the Perené area. This finding will result in the goal of a school health policy that prepares students for their future roles in society and prevent social inequalities through school health education about reproductive health for secondary students (18).

Those health problems and needs of students mentioned by the principals and representative teachers correlated with the major findings of the teachers' and students' surveys. However, the variance in their problems based on their enrollment in primary or secondary school was identified. The lower the school year, the more basic hygiene was an issue, whereas the higher the school year, the more sexual, and psychological problems were prominent in the students' survey results.

On the other hand, the perception of primary students in Perené showed that they rated their parents' economic status as low and their family relationships as poor, and their health status was poorer than the respondents from Pichanaqui. Those primary students in the Pichanaqui area had more compliance with hand washing than comparable students from Perené. However, their BMI scores indicating overweight and obesity were higher in the Pichanaqui area than in Perené, whereas snack and soda intake was higher in Perené. These findings regarding the difference of percentages of overweight and obesity in the pre-adolescent age group between Perené and Pichanaqui are similar to those in other studies (19, 20); BMI z-scores were high in middle- and higher-income countries, whereas low BMI scores were found in low income countries. It may explain that BMI disparity in the same province correlates with parents' income, although some studies show that there was no correlation with a BMI of overweight and physical activities (21, 22). If there was no supplementary school health program for healthy school lunches, sport, enjoyment of friends and families, and safety environment at school level (14), those inequity and disparity would be aggravated.

The health problems of secondary students in this study showed that the health behaviors of students in Perené were distinctly different regarding their receiving of reproductive health and HIV/AIDS information as well as contraception health education. They had more knowledge about HIV/AIDS despite insufficient information gathering from school and having less Internet accessibility than in Pichanaqui. This finding is consistent with previous research results that as secondary students displayed more sexually risky behaviors their HIV/AIDS knowledge could be a proxy for general reproductive health knowledge. Because they had started their sexual career earlier, these students had poorer reproductive health knowledge as well as knowledge about unwanted pregnancies (23). However, having better knowledge about HIV/AIDS does not guarantee that they have adequate knowledge; it may indicate that they sought related information more actively (18).

In terms of the health education needs of students, the same priorities between key informant interviews and survey results were found, ranging from hygiene and nutrition to sexual and reproductive health and prevention of infectious diseases by school level. Regarding mental health education, secondary students' need for it was the lowest. This finding runs counter to the high prevalence of suicidal attempts in impoverished urban areas in Peru (24). It may be explained by the distance from their residence to the main capital city takes more than 6 h by car and their way of living in a remote area is less competitive than life in an urban area.

The health problems of teachers were work-related stress, including digestive and cardiovascular problems, however, teachers had the responsibility to care for sick students because there were no school health personnel other than psychological counseling teachers. In terms of health promoting school, each component of it was not well-organized and supported by the five school principals except by one school and local health department. This particular school principal had a concept of health promoting school and endeavored that the school environment would change. However, a systematic approach based on community and parents' participation are needed to guarantee students' health, which will contribute to the healthy community members and the healthy economic growth of the future workforce in Peru.

Multiple contextual and mediating factors are associated with student health status in consideration of the outcome of school health promotion. Those factors identified in this needs assessment provided evidence about how to guarantee students' rights to health in the process of project implementation. Though the difference of health knowledge and behavior related to the economic status of their parents and their parents' involvement in school health decision-making processes, there needs to be a change regarding community participation and a collective program for healthy school environments. All these project activities should be monitored and managed by the project team in collaboration with the provincial health department to guarantee students' rights to health by strengthening school health policy with sustainability.

CONCLUSION

Based on the findings from this study, multi-component school-based interventions were adjusted to increase feasibility and sustainability of the project to the two catchment areas. We adjusted the project action plan based on the five components of health promoting school. These were organizing a council for school health including parents so that they could participate in promoting a healthy environment for their children in school and at home. Another action plan was applying an annual school health plan for training teachers to provide health education to their students and the development of an illustrated manual of school health programs by school teachers especially focusing on inculcating good hygienic habits for primary students and proper decision making regarding reproductive health for secondary students. For sustainable health management in school, regular health check-up for teachers in addition to providing anthelmintic medicine to primary school students for preventing absenteeism from stomach-ache and maintaining learning time in school was suggested. All these activities were implemented throughout the project years, and pre-and post-test evaluation to compare the effect of health promoting schools will be analyzed.

However, due to lack of healthcare personnel, only one out of six schools in the catchment area had a school nurse. Thus, capacity reinforcement by monitoring the school health committee of their annual school health planning and implementation during project activities was important for project accomplishment and sustainability. Furthermore, based on positive results of the project, it was required to monitor whether the changes were implemented on the provincial school health policy through resource network among the health department, education department, and the public health center.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Chosun University IRB No. 2-1041055-AB-N-01-2019-3. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

YC was a major contributor in writing the manuscript and contributed to data collection. SK contributed to critical revision of the manuscript. JK, IK, and ML contributed to the conception and design of this study. All authors read and approved the final manuscript.

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A Community-Based Lifestyle-Integrated Physical Activity Intervention to Enhance Physical Activity, Positive Family Communication, and Perceived Health in Deprived Families: A Cluster Randomized Controlled Trial

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Background: Zero-time exercise (ZTEx) is an approach integrating simple strength- and stamina-enhancing physical activity into daily life. The study evaluated the effectiveness of a community-based lifestyle-integrated physical activity intervention using ZTEx to enhance participants' physical activity, family communication, perceived health and happiness, and family harmony.

Methods: A parallel group, cluster randomized controlled trial was conducted in a sample of 673 participants from eight Integrated Family Service Centers in Hong Kong. The experimental group ($n = 316$) received a physical activity intervention. The control group ($n = 357$) received information on healthy eating. Both groups received three face-to-face intervention sessions (totalling 6 h and 30 min) and 16 text messages. The primary outcome was the change in days spent engaged in ZTEx. Secondary outcomes included changes in sitting time, days engaged in moderate or vigorous physical activities, family communication (encouraging and engaging family members in ZTEx), dietary habits, perceived health and happiness, and family harmony. Self-administered questionnaires were used at baseline and at 3, 6, and 12 months. Mixed effects models with intention-to-treat analysis was used.

Results: Compared with the control group at 3 months, the experimental group showed significantly greater increases of 1.3 days spent doing ZTEx (Cohen's *d*: 0.60), 0.3 days spent doing moderate physical activity (Cohen's *d*: 0.08), 0.3 days encouraging family members to do ZTEx (Cohen's *d*: 0.16), and 0.7 days doing ZTEx with family members (Cohen's *d*: 0.39) during the 7 days prior. At 3 months, the experimental group also showed a significantly greater improvement in perceived health, by a score of 0.2 (Cohen's *d*: 0.14). The effect sizes ranged from small to medium, with similar intervention effects at the 6-month and 1-year assessments. Compared with the experimental group, the control group showed a significantly greater reduction of 0.4 days on which sweetened beverages were consumed (95% CI: 0.01, 0.9, $p < 0.05$, Cohen's d: 0.28). The qualitative results supported the quantitative findings.

Conclusions: Our findings show that a community-based lifestyle-integrated physical activity (PA) intervention can enhance physical activity, family communication, and perceived health in deprived families in Hong Kong.

Trial registration: The research protocol was retrospectively registered at the National Institutes of Health (identifier number: NCT02601534) on November 10, 2015.

Keywords: community-based, theory-based, physical activity, Zero-time exercise, positive family communication

INTRODUCTION

Physical activity has significant positive health effects on all age groups (1). However, a large proportion of the global population (28% of adults aged 18 years or more and more than 80% of school-going adolescents aged 11–17 years) have inadequate levels of physical activity and a sedentary lifestyle (2). Studies have consistently demonstrated that a sedentary lifestyle can contribute to obesity, type 2 diabetes, some types of cancer, cardiovascular diseases, and early death (3). Adults are essential role models for their children, and the reciprocal nature of the adult–child relationship influences the health behavior of both children and adults (4). Exercising with family members has been recognized as the most rewarding activity to benefit one's well-being (5).

Community-based interventions have the potential to achieve population-level impact as they reach target groups in their natural environment (6). The School of Public Health of the University of Hong Kong (HKU-SPH), in collaboration with Caritas–Hong Kong, conducted a community-based intervention entitled "Effective Parenting Programme" to ease parents' frustrations in parenting young children (7). Caritas–Hong Kong is a charitable non-governmental organization focused on care and support for deprived families, including single parents, new arrivals, and low-income families. Deprived families report multiple health problems and lower ratings on happiness scales, grapple with more family problems and are more likely to pay less attention to their well-being than the general population (8). Building on established academic and community relationships (7), HKU-SPH collaborated with Caritas-HK to launch another community-based project entitled "Family Education Project" (FEP) for deprived families to enhance perceived well-being through promoting physical activity and doing exercise with family members.

Most reports of community-based physical activity interventions involving family members in the extant literature have been based in Western countries, such as the United States (9, 10), Canada (11–13), Australia (14, 15) and the United Kingdom (16). These interventions focused on outdoor activities, which may not be as easily applicable to a city like Hong Kong due to environmental, social, and cultural differences (17). Hong Kong is a space-limited, densely populated city with about 95% Chinese, where most parents and children tend to focus on their children's academic performance instead of physical activity levels (18). The majority of people are preoccupied with their daily lives, pay less attention to physical activity or family time, and have the belief that regular exercise is time-consuming and expensive (18, 19). Currently, existing reports of community-based physical activity interventions for Chinese communities target weight control in either overweight/obese adults or children, but not preventive work for the general public (20, 21).

To overcome these barriers, HKU-SPH created "Zero-time exercise" (ZTEx), a new approach to kick-start the integration of simple strength- and stamina-enhancing physical activity, such as simple movements and stretching while sitting or standing, into daily life. ZTEx does not require extra time, money, and equipment, and can be done anytime, anywhere and by anybody (22). ZTEx uses a foot-in-the-door approach to start exercise in small steps, building exercise self-efficacy. This approach is in line with the suggestion from physical activity guidelines for Americans that moving more and sitting less will benefit nearly everyone, and some physical activity is better than none (23). ZTEx can also be an innovative creative fun family activity (e.g., family members of all ages can create and participate in friendly competition games) (24). Examples of ZTEx while sitting and standing include pedaling both legs and standing on one leg, respectively. More examples of ZTEx are shown in our YouTube videos (https://www.youtube.com/user/familyhk3h/videos). Our pilot trials on ZTEx for lay health promoters ($n = 28$), social service and related workers ($n = 56$), individuals with insomnia ($n = 37$) and the elderly ($n = 151$) showed increased physical activity and perceived well-being (22–27).

The current study extended the findings on ZTEx from pilot trials to a large-scale cluster randomized controlled trial (cRCT). Our physical activity (PA) intervention emphasized that ZTEx is easy, enjoyable, and effective and aimed to enhance participants' physical activity, family communication, and perceived well-being. Grounded on components of the Health Action Process Approach for behavioral change (28), the PA intervention and design of text messages targeted cognitive factors for the formation of exercise motivation (e.g., risk perception, exercise self-efficacy, and outcome expectations) and regulatory factors for regular physical activity (e.g., exercise goal-setting and planning, and self-monitoring). Over time, action control was expected to develop and become a habit. This approach is in line with Rhodes's multi-process action control approach for physical activity behavior (29). In addition, we extended the traditional exercise promotion model, which emphasizes service delivery to others, by harnessing the opportunity to treat parents as role models for their family members. Role modeling is a powerful teaching strategy (30), and the approach has been applied to enhance positive health behaviors (such as physical activity) in children (31) and adolescents (32).

We hypothesized that (i) participants in the experimental group would display significantly greater increases in simple strength- and stamina-enhancing physical activity (i.e., ZTEx), physical activity, and family communication through encouraging and engaging family members in ZTEx, as well as improvements in perceived health and happiness, and family harmony; and (ii) the family members of participants in the experimental group would be more physically active than those in the control group. This paper reports the development, feasibility, and preliminary evidence on the effectiveness of the PA intervention.

METHODS

Design

A cRCT randomized eight Caritas–Hong Kong Integrated Family Service Centers (IFSCs) into the "PA intervention" experimental group or the "healthy eating" control group at a 1:1 ratio by creating a random sample in Microsoft Excel. The randomization sequence was generated by a research staff who was not involved in the recruitment process, intervention, or data collection. Both groups comprised four IFSCs. Each IFSC conducted two to three classes (20–40 participants per class) on different days of the same week with identical content and duration of sessions. This arrangement enabled participants to choose the most convenient day of the week for them to attend.

Participants

The FEP was publicized in all participating IFSCs. Individuals who were interested in the FEP were recruited if they fulfilled the following inclusion criteria: (i) had ethnic Chinese parents; (ii) aged 18 years or older; (iii) had at least 1 child aged between 3 and 17 years; (iv) could read Chinese; (v) received primary education or higher; and (vi) had a mobile phone that could receive text messages. The social workers of the participating IFSCs obtained informed written consent from all individual participants of their centers.

Intervention

Pre-intervention Phase

A working committee was formed (comprising a public health academic, a medical officer, a nurse, and three registered social workers) to co-design and refine the intervention and questionnaires through a two-phase process to enhance the feasibility, relevance, and appropriateness of the intervention and questionnaires. Phase 1 included a pre-study discussion group of 10 frontline social workers who commented on the first version of intervention and questionnaires in May 2015. Based on their comments, the intervention and questionnaires were modified. Phase 2 included a pilot trial conducted for 18 community participants in June 2015 to assess the acceptability and comprehensiveness of the second version of intervention and questionnaires. The format and content of the intervention and questionnaires were finalized by the working committee after reviewing and incorporating community participants' comments and suggestions.

Intervention Phase

Two social workers from the working committee conducted the FEP at the eight Caritas–Hong Kong IFSCs from July 2015 to September 2016. In the experimental group, 11 Zero-time exercise intervention classes were implemented for 357 participants from four IFSCs; in the control group, 12 healthy eating information classes were conducted for 316 participants from the other four IFSCs. Each class recieved three face-to-face sessions totalling 6 h and 30 min and 16 text messages as part of the intervention, and a post-intervention feedback collection session. **Figure 1** shows the essential components and strategies of the theory-based intervention. **Table 1** shows the objectives of each session of the experimental and control groups.

Experimental Group

In the experimental group, Session I was a 2 h and 30 min "knowledge and motivation enhancement" session (July to September 2015). We first enhanced participants' risk perception by discussing the likely consequences of physical inactivity and promoted exercise self-efficacy by introducing ZTEx. We aimed to increase participants' intrinsic motivation for being active and demonstrated how the exercises, such as raising both heels while standing, raising both feet and legs off the ground while sitting, or stretching, could be integrated into daily life. The participants were encouraged to access the ZTEx YouTube videos with different themes (e.g., for students, https://www.youtube.com/watch?v=mCTd37xEk5s; elderly, https://www.youtube.com/watch?v=EJXR0crHjZA&t=47s; integration of daily life, https://www.youtube.com/watch?v=vnKqDrHsP8k; and family games, https://www.youtube.com/watch?v=JMd_D2ndFJU), for the details of ZTEx physical activity components, movements, and applications. The participants were encouraged to share the links with their family members and do daily exercises together with family members.

We helped participants to come up with realistic expectations by sharing our personal experiences (i.e., benefits and barriers) with regular ZTEx. Participants were encouraged to share what they had learned and engage their family members through ZTEx and fun family games. We highlighted the importance of praise when involving family members through exercise because showing appreciation has been recommended as a way to strengthen family communication (33). Prior to the end of the session, we asked the participants to set their exercise goals, provide activity details (e.g., time, types of exercises, targeted family members), and document this plan on a take-home exercise record worksheet. Goal-setting has been reported to facilitate the self-regulation of physical activity behavior

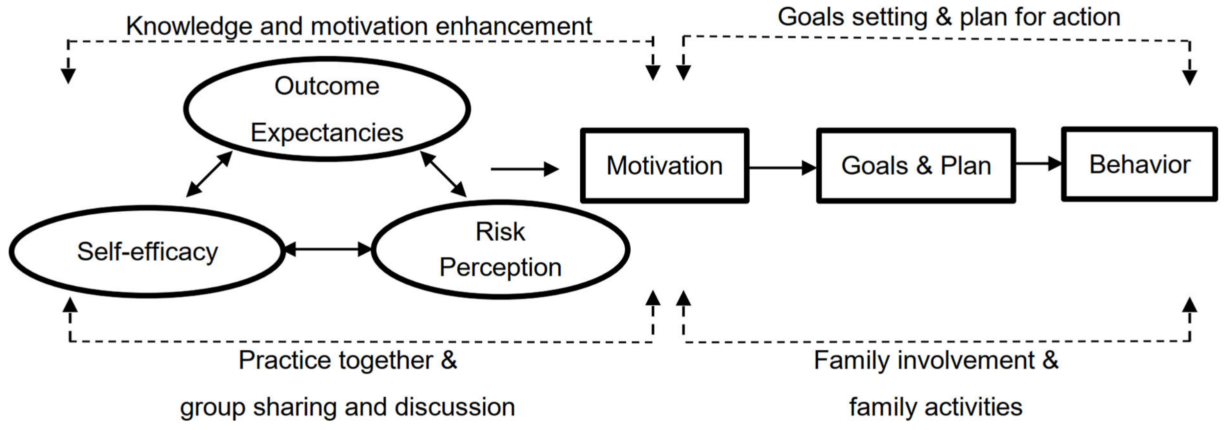


FIGURE 1 | The essential components and strategies of the theory-based intervention.

TABLE 1 | The objectives of each session for the experimental group and control group.

Sessions	**Experimental group** **Physical activity (PA) intervention**	**Control group** **Healthy eating information**
Baseline (Session I) knowledge and motivation enhancement session (2.5 h)	To increase participants' health awareness and risk perception of of physical inactivity (30 min); To introduce ZTEx and enhance participants' confidence toward exercising regularly (1 h); To help set realistic desired outcomes of regular Zero-time Exercise (30 min); and To set exercise goals and make plans for action (30 min).	To increase participants' health awareness and risk perception of diabetes and overweight (30 min); To enhance participants' confidence toward having a healthy diet (1 h); To help set realistic desired outcomes of having a healthy diet (30 min); and To set goals and make plans for implementing a healthy diet (30 min).
3-month follow-up (Session II) experience sharing session (1.5 h)	To assess the effectiveness of the intervention (15 min); To strengthen participants' intrinsic motivation for actively doing physical activity (25 min); To enhance participants' self-efficacy for doing ZTEx regularly (25 min); and To enhance participants' confidence in being role models for exercising regularly for their family members (25 min).	To assess the effectiveness of the intervention (15 min); To strengthen participants' intrinsic motivation for having a healthy diet regularly (25 min); To enhance participants' self-efficacy for having a healthy diet regularly (25 min); and To enhance participants' confidence in being role models for having a healthy diet for their family members (25 min).
6-month follow-up (Session III) family involvement session (2.5 h)	To assess the effectiveness of the intervention (15 min); To directly introduce ZTEx to family members (45 min); and To provide joyful, memorable family time and family game time (1 hour 30 min).	To assess the effectiveness of the intervention (15 min); To directly introduce healthy dietary habits to family members (45 min); and To provide joyful, memorable family time and family game time (1 hour 30 min).
1-year follow-up feedback collection session and holistic health talk (2.5 h)*	To assess the effectiveness of the intervention (15 min); and To highlight the importance and methods of enhancing holistic health and introduce information on healthy eating (2 h and 15 min).	To assess the effectiveness of the intervention (15 min); and To highlight the importance and methods of enhancing holistic health and introduce information on ZTEx (2 h and 15 min).

Zero-time exercise (ZTEx) refers to simple strength- and stamina-enhancing physical activity.
** Post-intervention feedback collection session was not part of the intervention.*

(34), and self-monitoring was identified as a promising strategy to increase physical activity (35). A physical activity kit was given to each participant. The kit comprised a leaflet with pictorial instructions for basic exercise movements, a 1-liter dumbbell-shaped water bottle and a handgrip to serve as reminders to do ZTEx regularly, and a magnetic clip to hold the exercise record worksheet. Participants were expected to record their daily ZTEx and exercise with family members on the record worksheets, which also served as reminders to maintain exercise habits.

Session II was conducted 3 months after the initial session (October to December 2015) and was a 1 h and 30 min "experience sharing" session. We highlighted successful examples and feelings of achievement, discussed the barriers to doing physical activity, and explored various solutions to these barriers with the participants to enhance their exercise motivation, goal-setting, and action-planning for regular physical activity. We encouraged the participants to actively participate in the session by getting involved in discussions and sharing their experiences, since an active approach has been shown to be more effective than a passive approach involving didactic educational talks (36). As a result, the participants gained confidence in becoming role models for their family members (25, 31).

Session III, which took place 6 months after the initial session (January to March 2016), was a 2 h and 30 min "family involvement" session. A maximum of three additional family members per participant were invited to join this session. We introduced ZTEx to the participants' family members and actively encouraged them to do ZTEx together, using a game-based approach, by completing tasks from the on-site game sheets. The last session was a 2 h and 30 min "feedback collection" session at 1 year after the initial session (July to September 2016). This 1-year follow-up session was not part of the intervention. It aimed to collect feedback from the participants and provide holistic health information; in the case of the experimental group, information on healthy eating was provided.

As part of the FEP, 16 text messages were sent to the participants, including six monthly text messages in the first half of the study and 10 bi-weekly text messages in the second half of the study. **Supplementary Table 1** shows the text messages for the experimental and control groups. Text messages for the experimental group were focused on physical activity. We encouraged the participants to share the text messages with their families. Reinforcements created by text messaging and periodic prompts may increase the likelihood of exercising (37), and periodic prompts have been recognized as an effective method to encourage and reinforce healthy behavior (38).

Control Group

Content for the control group was focused on healthy eating rather than physical activity and ZTEx. The control group received the same number of sessions as the experimental group, on the same schedule, and with the same total duration. The control group also received an identical number of text messages as the experimental group. However, the text messages for the control group were focused on healthy eating.

Fidelity Checks

For each intervention session, two staff members (one from the academic institution and one from the IFSC) independently completed fidelity checklists for the session. The fidelity assessment aimed to standardize the quality of the intervention, including the key components to cover and the time spent on each component. The listed objectives for each session were achieved and completed within the expected period.

Data Collection

Self-administered questionnaires were used at baseline and at the 3-month, 6-month, and 1-year assessments. One member from each participant's family also completed a brief questionnaire at the 6-month assessment. Four focus group interviews were conducted to obtain participants' feedback after the completion of the FEP in September 2016. Participants' feedback on the quality of the intervention content and on-site observations of participants' responses to the intervention were collected for triangulation of the qualitative and quantitative findings.

Measures

Simple Strength- and Stamina-Enhancing Physical Activity (ZTEx), Sedentary Behavior, and Physical Activity and Fitness

Participants' engagement in simple strength and stamina-enhancing physical activity was assessed by asking two questions. The first asked the number of days on which the participant had engaged in such physical activity during the prior 7 days; responses ranged from "0 days" to "7 days." The second question asked the time spent doing ZTEx on one of those days; responses were categorized into units of time (one unit of time was $\leq$15 min), including: "0 = none," "1 = $\geq$1 - <15 min per day," "2 = $\geq$15 - <30 min per day," and "3 = $\geq$30 min or more per day." The units of time spent doing ZTEx during the prior 7 days was calculated by multiplying the units of time of spent doing ZTEx with the number of days on which the participants had engaged in ZTEx during the prior 7 days.

Questions from the short form of the International Physical Activity Questionnaire—Chinese version (IPAQ-C) were used to assess participants' sedentary behavior and physical activity by asking for their self-reported sitting time and the number of days on which they engaged in at least 10 min of moderate and vigorous physical activity, respectively (21). The questions were: "On a typical weekday in the last 7 days, how many h per day did you typically spend seated?"; "During the last 7 days, on how many days did you do at least 10 min of moderate physical activity?"; and "During the last 7 days, on how many days did you do at least 10 min of vigorous physical activity?" The internal reliability of the Chinese version of the questionnaire was high, with an intraclass correlation coefficient of 0.79 (39).

A foot-pedaling physical fitness performance game was conducted at the beginning of each session. The participants were required to sit on a stable chair (about 43 cm in height) with their back touching the seat pan, arms, and hands held straight down by their sides, hips flexed, knees slightly bent, and hamstrings lifted off the chair. The participants were required to pedal (as if on an imaginary bicycle) with a rhythm of ~1 cycle per second. Their hamstrings should not touch the chair, and their soles should not touch the ground during the process. The participants counted and recorded the number of cycles of foot-pedaling completed in 2 min.

Sweetened Beverage Consumption

We assessed sweetened beverages consumption by asking the number of days on which participants consumed sweetened beverages in the last 7 days. Responses ranged from "0 days" to "7 days."

Family Communication

We assessed the extent to which participants involved family members by asking two questions: "During the last 7 days, on how many days did you encourage your family to do simple strength- and stamina-enhancing physical activity?"; and "During the last 7 days, on how many days did you do simple strength- and stamina-enhancing physical activity with your family?." The responses ranged from "0 days" to "7 days."

Perceived Well-Being

Perceived well-being was assessed by asking three questions related to health, happiness, and family harmony (40): "Do you think that you are happy?"; "Do you think that you are healthy?"; and "Do you think that your family is harmonious?." The responses to each item ranged from 0 (not happy/healthy/harmonious) to 10 (totally happy/healthy/harmonious).

Family Members' Simple Strength and Stamina-Enhancing Physical Activity Practice

At the 6-month follow-up, one family member (aged 18 years or older) from the participant's family reported the number of days on which they had done simple strength- and stamina-enhancing physical activity by themselves in the last 7 days. The responses ranged from "0 days" to "7 days."

Reactions to the Intervention Content and Design

We asked participants to grade the quality and utility of the intervention and its contents. The participants were asked "How much did you like the intervention?" and "How feasible is it to incorporate the exercises you have learned into your daily life?" Responses were made on an 11-point Likert scale, ranging from 0 (very unsatisfied/totally not feasible) to 10 (very satisfied/very feasible). Participants were also asked "Would you recommend this workshop to your friends and family?" with response options of "Yes" or "No."

Statistical Analysis

The calculation of the sample size was conducted by comparing the number of days in which the experimental group and control group did simple strength- and stamina-enhancing physical activity in the 7 days prior to filling out the questionnaire at the 3-month assessment. To detect a medium effect size of 0.5 with 80% power and a 5% false-positive rate, we needed 80 individuals per group. We took the intracluster correlation as 0.05 to account for the clustering effect of the IFSCs. With eight IFSCs, we needed 84 participants per group under each IFSC. Allowing for 10% attrition, we needed 352 individuals per group.

Analyses were conducted using Stata (version 13.0). All significance tests were two-sided with $p < 0.05$ indicating statistical significance. An intention-to-treat (ITT) analysis was conducted, with missing values replaced by the baseline values of the outcome variables. A mixed-effects model was used to examine the intervention effects of the PA intervention. With this mixed-effects model method, (i) the extra covariance between repeated measurements was taken at the baseline, 3-month, 6-month and 1-year assessments; (ii) the clustering effect of individuals under the same IFSC and class was treated as a random effect; and (iii) the baseline values of the outcome variables were treated as covariates. We first examined the consistency of the intervention effect over time by testing for the significance of the interaction term of group-by-time in the analysis. A significant interaction effect meant that there were significant differences between groups over time. Where evidence of a group-by-time interaction effect was found, the intervention effects at the 3-month, 6-month, and 1-year assessment are reported separately. Where no interaction effect was found, the overall intervention effect is reported.

Participants' demographic characteristics, including marital status, educational level, and monthly household income significantly differed between the experimental group and control group; these were considered to be potential confounders (**Table 2**). Sensitivity analyses were conducted, including (i) an ITT analysis with adjustments for the potential confounders (e.g., age, sex, marital status, educational level, monthly household income); (ii) a complete case analysis on those who completed all assessments at baseline, and the 3-month, 6-month, and 1-year follow-ups; and (iii) a complete case analysis that adjusted for the potential confounders.

The focus group interviews were conducted by an experienced researcher from the working committee. All qualitative interviews were audiotaped and transcribed verbatim in Chinese. Two project members, one of whom had attended the interviews, coded the transcripts. The transcripts were analyzed using thematic framework analysis, following the guidelines recommended by Morse and Field (41). A mixed-methods design was used to interrelate and interpret the qualitative and quantitative data to validate the results (42).

RESULTS

Participants

Of the 728 participants who registered for the FEP, 673 participants (92% female and 46% aged 30–39 years) attended Session I as part of the experimental group ($n = 357$) and control group ($n = 316$) and were included in the analysis. Thirty-two participants (22 from the experimental group and 10 from the control groups) were absent from Session II, and 21 participants (7 from the experimental group and 14 from the control group) were absent from Session III. Twenty-seven participants (19 from the experimental group and 8 from the control group) did not attend the post-intervention meeting at the 1-year follow-up. The remaining 593 participants completed the assessments at all time points. **Figure 2** shows the flow of the participants. **Table 2** shows significant differences in educational level, marital status, and monthly household income between the experimental and control groups. No significant differences in participant characteristics were observed between those who participated in the focus group interviews and those who did not. No harm or unintended effects were detected in either group.

Changes in Simple Strength- and Stamina-Enhancing Physical Activity (ZTEx), Sedentary Behavior, Physical Activity, and Fitness

Both groups reported significant increases in ZTEx and physical activity ($p < 0.001$) but no significant changes in time spent sitting ($p > 0.05$) at all time points. Compared with the control group, the experimental group reported significantly greater increases in days engaged in ZTEx: 1.3 days at 3 months (95% confidence interval [CI]: 0.9, 1.8, $p < 0.001$), 1.2 days at 6 months (95% CI: 0.8, 1.6, $p < 0.001$) and 0.9 days at 1 year

TABLE 2 | Characteristics of all participants, participants who completed 1-year follow-up, participants who participated in the focus group interviews, and participants who did not participate in the focus group interviews ($n = 673$).

	All participants			**Participants who completed the 1-year follow-up**			**Focus group interviews**		
	Experimental group ($n = 357$)	**Control group ($n = 316$)**	***p*-value**	**Experimental group ($n = 309$)**	**Control group ($n = 284$)**	***p*-value**	**Participated ($n = 32$)**	**Did not participate (n= 641)**	***p*-value**
	***n* (%)**	***n* (%)**		***n* (%)**	***n* (%)**		***n* (%)**	***n* (%)**	
Sex									
Female	327 (92)	293 (93)	0.59	265 (92)	264 (93)	0.52	31(97)	589 (92)	0.31
Male	30 (8)	23 (7)		44 (8)	20 (7)				
Age			0.62						
18–<30 years	12 (3)	13 (5)		8 (2)	9 (3)	0.85	0 (0)	25 (4)	0.52
30–39 years	160 (45)	149 (47)		139 (45)	134 (47)		15 (47)	294 (46)	
40–49 years	150 (42)	118 (37)		129 (42)	109 (38)		15 (47)	253 (39)	
≥50 years	35 (10)	36 (11)		33 (11)	32 (11)		2 (6)	69 (11)	
Education level			<0.001***						
Primary and below	33 (9)	64 (20)		31 (10)	61 (22)	<0.001***	3 (9)	94 (15)	0.41
Secondary and tertiary	270 (91)	252 (80)		278 (90)	223 (78)		29 (91)	547 (85)	
Marital status			<0.001***						
Married	275 (77)	203 (64)		240 (78)	180 (63)	<0.001***	25 (78)	452 (71)	0.36
Widowed/divorced/unmarried	82 (23)	113 (36)		69 (22)	104 (37)		7 (22)	189 (39)	
Household monthly income			<0.001***						
CSSA and < HK$10,000	119 (34)	161 (53)		103 (33)	147(52)	<0.001***	10 (31)	270 (42)	0.22
HK$10,000 or more	238 (66)	155 (47)		206 (67)	137 (48)		22 (69)	371 (58)	

Between group comparisons: $^{***}p < 0.001$.

CSSA, Comprehensive Social Security Assistance.

US$1 = HK$7.8.

(95% CI: 0.4, 1.3, $p < 0.001$). The effect sizes ranged from small to medium (Cohen's d: 0.40–0.60) (**Figure 3A**). Compared with the control group, the experimental group reported significantly greater increases in time engaged in ZTEx: 4.3 units of time (one unit of time is <15 min increase) at 3 months (95% CI: 3.1, 5.5, $p < 0.001$), 2.6 units of time at 6 months (95% CI: 1.4, 3.7, $p < 0.001$), and 1.6 units of time at the 1 year with small to moderate effect sizes than the control group (95% CI: 0.9, 3.3, $p < 0.001$, Cohen's d: 0.37–0.76) (**Supplementary Figure 1**).

However, compared with the control group, the experimental group only reported a marginally significantly greater increase, of 0.3 days spent doing moderate physical activity, with small effect size (Cohen's d: 0.08), at all time points (95% CI: 0.1, 0.6, $p = 0.079$) (**Figure 3B**). There were no significant differences in the changes in vigorous physical activity and sitting time between the two groups (**Figures 3C,D**).

In terms of physical fitness, compared with the control group, the experimental group showed a significantly greater increase of 20 s in the duration of foot pedaling with large effect size at the 1-year assessment (95% CI: 7.9, 31.3, $p < 0.001$, Cohen's d: 1.73), but not at the 3 and 6-month assessments (**Supplementary Figure 2**).

At the 1-year focus-group interviews, participants in the experimental group reported that laziness was a significant barrier to maintaining their exercise habits. They reported having a more active lifestyle than before receiving the intervention.

"[Zero-time] exercise is excellent and could be widely promoted. However, my laziness made it difficult for me to establish my exercise habit." (A housewife, 40–49 years old).

"Before I knew about [Zero-time] exercise, I was not aware that we could perform the physical activity while waiting for the bus. Now I know I can exercise, particularly during my waiting time." (A female clerk, 40–49 years old).

Change in Sweetened Beverage Consumption

Both groups reported a significant decrease in sweetened beverage consumption ($p < 0.05$). The control group showed a significantly greater reduction by 0.4 days on which sweetened beverages were consumed at all time points with small effect size (95% CI: 0.01, 0.9, $p < 0.05$, Cohen's d: 0.28), compared with the experimental group.

Changes in Family Communication

Both groups reported significant increases in the number of days spent encouraging family members to do ZTEx and doing ZTEx with their family members at all time points ($p < 0.001$). The experimental group reported a significantly greater increase of 0.3 days spent encouraging family members to do ZTEx, with a small effect size (Cohen's d: 0.16), than the control group at the 3-month assessment (95% CI: 0.1, 0.6, $p < 0.05$). The intervention effect was sustained at the 6-month and 1-year assessments

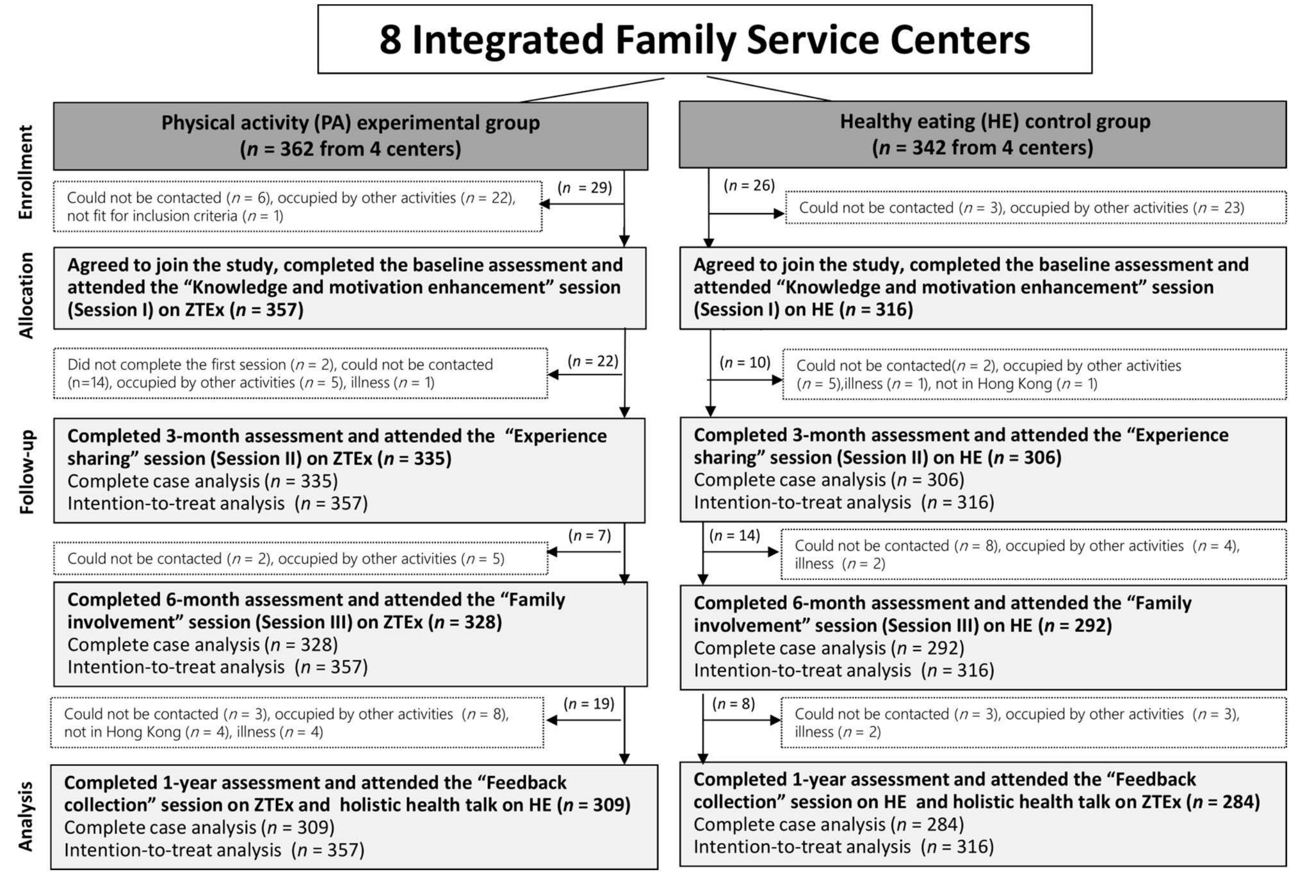


FIGURE 2 | Flow of participants.

(**Figure 4A**). The experimental group reported significantly greater increases of 0.7 and 0.4 days spent doing ZTEx with their family members, with small effect size (Cohen's *d:* 0.19–0.39), at the 3-month and 1-year assessments (95% CI: 0.4, 1.1, $p < 0.001$ and 95% CI: 0.2,0.7, $p < 0.05$, respectively) (**Figure 4B**).

At the 1-year focus-group interviews, participants stated that ZTEx was an interesting topic to discuss with their family members. The participants considered themselves good role models for their family members in terms of integrating simple strength- and stamina-enhancing physical activity into their daily lives.

"I told my son that ZTEx could improve his flat feet and reduce his back pain; he showed great interest in it." (A housewife, 40–49 years old).

"Our relationship was better. At least, we exercised together and had more topics for discussion." (A housewife, 40–49 years old).

Changes in Perceived Well-Being

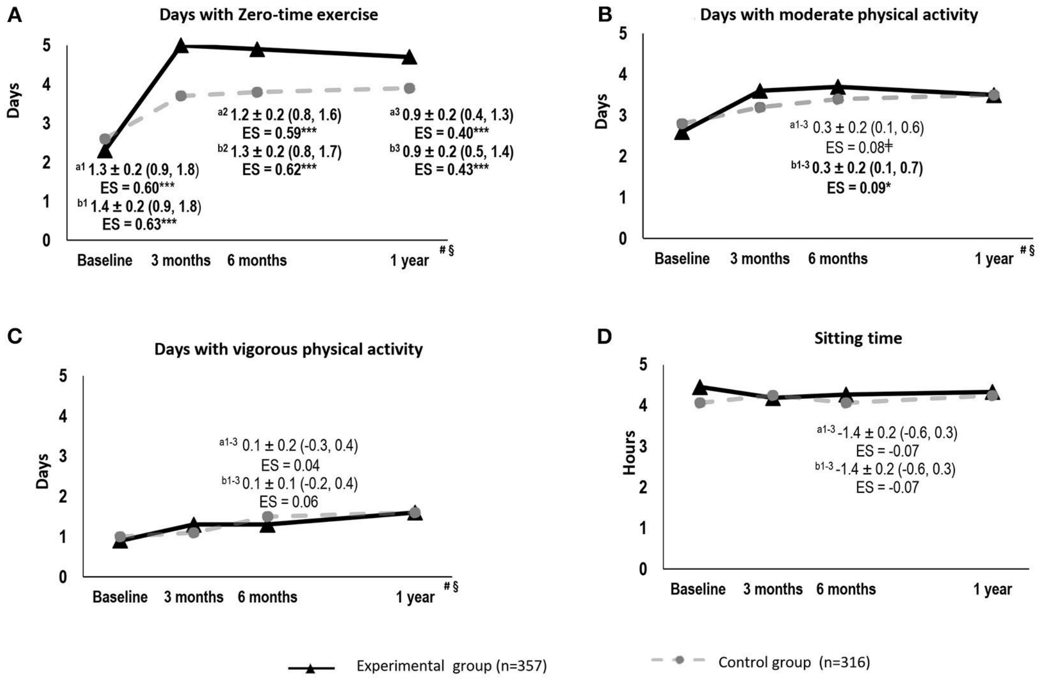
Both groups reported significant improvements in perceived happiness, health, and family harmony ($p < 0.001$) at all time points. The experimental group showed significantly greater improvement than the control group of 0.2 in perceived health, with a small effect size (Cohen's *d*: 0.14) at the 3-month assessment (95% CI: 0.1, 0.4, $p < 0.05$). The intervention effect was sustained at the 6-month and 1-year assessments (**Figure 4D**). However, there were no significant differences in the improvement in perceived happiness and family harmony between the two groups (**Figures 4C,E**).

At the 1-year focus-group interviews, the participants reported improved health, fitness, happiness and emotional control because of regular physical activity.

"After having regular exercise, I felt happier and more energetic than before. My health was improved and blood pressure was better." (A housewife, 30–39 years old).

"[I] walked more than before joining the program and I am much healthier than before." (A female part-time worker, 30–39 years old).

The improvements in perceived well-being (including perceived health, happiness, and family harmony) showed significant positive associations with (i) the increases in days spent doing physical activity (including ZTEx, moderate physical activity and vigorous physical activity) and (ii) the increases in days spent encouraging family members to do ZTEx and doing ZTEx with family members (**Table 3**).



Zero-time exercise refers to simple strength-and stamina-enhancing physical activity
Within group change during 1-year follow-up period: $^{\#}p$ < .001 in PA group and $^{\S}p$ < .001 in HD group
Difference between the change in the experimental and control groups: mean ± standard error (95% confidence interval) at ^{1}3-month assessment, ^{2} 6-month assessment, and ^{3}1-year assessment
[a] Main analysis: ITT analysis
[b] Sensitivity analysis: ITT analysis adjusted for the potential confounders, including age, sex, martial status, education level, and monthly household income
The consistency of intervention effect over time was first examined by the group by time interaction. When evidence of group by time interaction effect was found, the intervention effects at the 3-month, 6-month, and 1-year assessment were reported separately. When no interaction effect was found, the overall intervention effect was reported.
ES = effect size; (Cohen's d): small = 0.20, medium = 0.50, large = 0.80; $^{‡}p < 0.1$ $^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$

FIGURE 3 | The changes in physical activity between the experimental and control groups over time [**(A)** Days with Zero-time exercise, **(B)** Days with moderate physical activity, **(C)** Days with vigorous physical activity, and **(D)** Sitting time]: intention-to-treat analysis.

Family Members' Practice of Simple Strength- and Stamina-Enhancing Activity

In the experimental group, 253 and 166 participants returned the take-home exercise record worksheets at the 3- and 6-month follow-ups, respectively. The homework returned by participants also showed that they and their children did ZTEx at home, indicating acceptance.

At the 6-month follow-up, a total of 620 families (2,480 participants and their family members) joined the family involvement session; 346 family members (one family member per participant, aged 18 years or older) answered the brief questionnaire for family members. The demographics of family representatives and their relationships with principal participants did not differ significantly between the groups (experimental group: $n = 256$, 57% male, 58% aged ≥30–50 years, 52% were spouse; control group: $n = 90$, 49% male, 54% aged ≥30–<50 years, and 49% were spouse). Family members in the experimental group did significantly more simple strength- and stamina-enhancing activity than those in the control group, with a small effect size (mean ± SD: 2.9 ± 2.4 days vs. 2.2 ± 2.4 days, $p < 0.05$; Cohen's d: 0.27) (**Table 4**). From our unobtrusive observation, participants and their children were actively engaged, enthusiastically followed the ZTEx demonstration, and showed enjoyment.

Reactions to Intervention Content and Design

At the 1-year assessment, participants rated both the quality and utility of the intervention content a score of 9.0 ± 1.2. All participants reported that they would recommend this intervention programme to their friends and families.

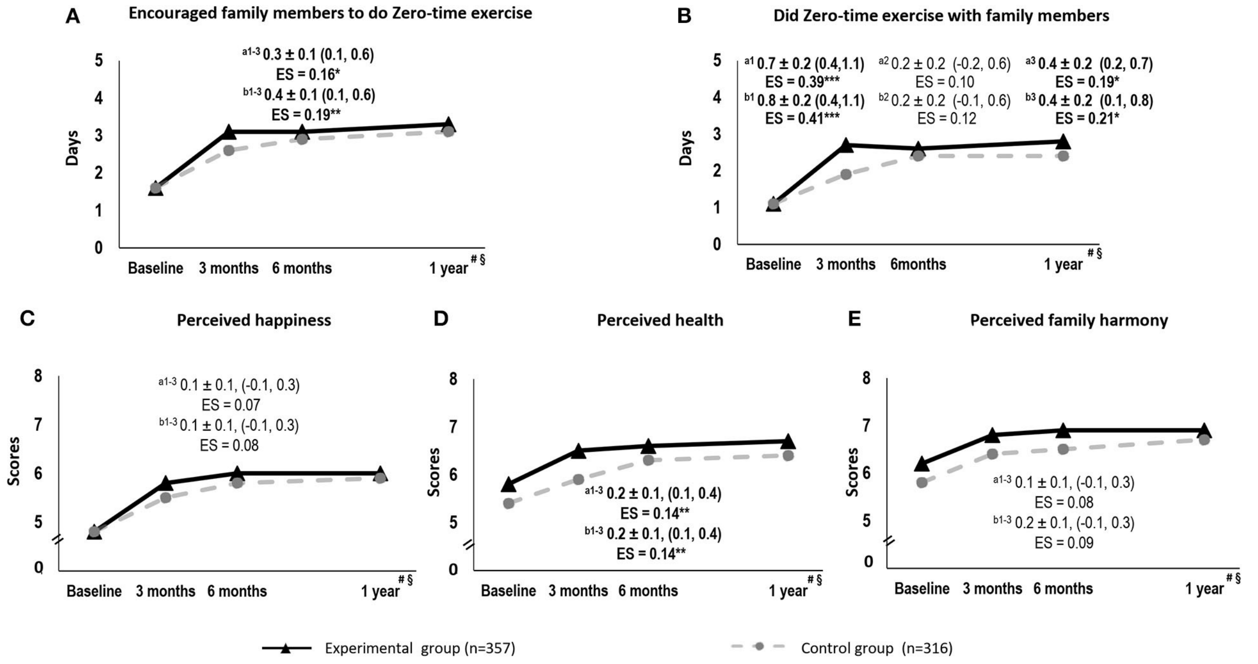
The participants reported that the PA intervention content was comprehensive and practical. Remedial classes offered flexibility to those who were unable to attend the scheduled sessions. The text messages reminded the participants to do regular exercise by themselves and with their family members.

"The [ZTEx] content was simple and easy to understand, and the examples of ZTEx (such as standing with raised heels) were convenient to apply in my daily routine" (A housewife, 40–49 years old).

"When I saw the calendar worksheet, I remembered to do [ZTEx], then [I would] practice a while." (A female employee, 40–49 years old).

"Electronic messages always reminded us to do [ZTEx]." (A housewife, 30–39 years old).

After performing the main analysis (i.e., the ITT analysis without adjusting for potential confounders), we conducted sensitivity analyses to assess the consistency of the findings. The ITT analysis with adjustment for potential confounders yielded



Zero-time exercise refers to simple strength-and stamina-enhancing physical activity
Within group change during 1-year follow-up period: $^{\#}p < .001$ in PA group and $^{\S}p < .001$ in HD group
Difference between the change in the experimental and control groups: mean ± standard error (95% confidence interval) at ^{1}3-month assessment, ^{2} 6-month assessment, and ^{3}1-year assessment
^{a} Main analysis: ITT analysis
^{B} Sensitivity analysis: ITT analysis adjusted for the potential confounders, including age, sex, martial status, education level, and monthly household income
The consistency of intervention effect over time was first examined by the group by time interaction. When evidence of group by time interaction effect was found, the intervention effects at the 3-month, 6-month, and 1-year assessment were reported separately. When no interaction effect was found, the overall intervention effect was reported.
ES = effect size; (Cohen's d): small = 0.20, medium = 0.50, large = 0.80; $^{ǂ}p < 0.1$ $^*p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$

FIGURE 4 | The changes in family communication and perceived well-being between the experimental and control groups over time [**(A)** Encouraged family members to do Zero-time exercise, **(B)** Did Zero-time exercise with family members, **(C)** Perceived happiness, **(D)** Perceived health, and **(E)** Perceived family harmony]: intention-to-treat analysis.

similar findings to the main analysis, except for the intervention effect on moderate physical activity. The experimental group reported significantly greater improvements in this regard (by 0.3 days), with a small effect size (Cohen's *d*: 0.09) at the 3-month assessment (95% CI: 0.1, 0.7, $p < 0.05$). The intervention effect was sustained at the 6-month and 1-year assessments (**Figures 3**, **4**).

The complete case analyses, with and without adjustment for potential confounders, also showed similar findings to those of the main analysis, except for the findings in relation to moderate physical activity. The experimental group reported significantly greater improvements in this regard (by 0.5–0.6 days), with small effect sizes (Cohen's *d*: 0.24–0.26) at the 3-month assessment (95% CI: 0.1, 1.0, $p < 0.05$). The intervention effect was sustained at the 6-month and 1-year assessments (**Supplementary Figures 1–3**). Compared with the control group, the experimental group reported significantly greater improvements by scores of 0.2 in personal happiness (95% CI: 0.1, 0.4, $p < 0.05$; Cohen's *d*: 0.14) and 0.2 in family harmony (95% CI: 0.1, 0.4, $p = 0.037$; Cohen's *d*: 0.16), with small effect sizes, at the 3-month assessment. The intervention effect was sustained at the 6-month and 1-year assessments (**Supplementary Figure 4**).

DISCUSSION

This cRCT demonstrated that the PA intervention was effective in enhancing physical activity, family communication, and perceived health among deprived families in Hong Kong. This intervention showed the benefits of simple stamina- and strength-enhancing physical activity, the feasibility of using low-cost methods to have regular exercise, and the applicability of conducting a community-based physical activity intervention. The qualitative data provided additional evidence to support the effectiveness of this intervention.

The intervention used to enhance physical activity differs significantly from most of the interventions reported in the extant literature. The interventions in the literature comprised 18 sessions (16), 16 sessions (9), 8 sessions (10, 14, 43), and 5 sessions (11, 13). Our intervention comprised three face-to-face sessions (totalling 6 h and 30 min) and 16 text messages, making it shorter than most of the interventions in the extant literature. With the advancement of information communication technology and high levels of mobile phone usage in Hong Kong, we made good use of text messaging to promote physical activity. Text messages have been recognized as effective reminders and an important method to deliver health-related information to individuals

TABLE 3 | The associations between participants' changes in physical activity and family communication and the changes' in well-being at different time points (n = 673).

***n* = 673**		**Changes in physical activity#**				**Changes in family communication#**	
		ZTEx	**Moderate physical activity**	**Vigorous physical activity**	**Sitting time**	**Encouraged family members to do ZTEx**	**Did ZTEx with family members**
Changes in perceived health#							
At 3-month	*r*	**0.179*****	**0.149*****	**0.125*****	−0.029	**0.151*****	**0.154*****
	p	<0.001	<0.001	0.001	0.451	<0.001	<0.001
At 6-month	*r*	**0.092***	**0.082***	0.061	0.018	**0.138*****	**0.097***
	p	0.017	0.033	0.115	0.635	<0.001	0.011
At 1-year	*r*	**0.110****	**0.150*****	**0.147*****	−0.012	**0.156*****	**0.150*****
	p	0.004	<0.001	<0.001	0.765	<0.001	<0.001
Changes in perceived happiness#							
At 3-month	*r*	**0.145*****	0.049	**0.085***	−0.043	**0.152*****	**0.124*****
	p	<0.001	0.201	0.028	0.271	<0.001	0.001
At 6-month	*r*	**0.083***	**0.079***	**0.145*****	−0.064	**0.129****	**0.087***
	p	0.031	0.042	<0.001	0.098	0.001	0.024
At 1-year	*r*	**0.157*****	**0.139*****	**0.217*****	−0.008	**0.166*****	**0.190*****
	p	<0.001	<0.001	<0.001	0.842	<0.001	<0.001
Changes in perceived family harmony#							
At 3-month	*r*	**0.099***	0.034	0.067	−0.016	**0.147*****	**0.108****
	p	0.010	0.385	0.082	0.680	<0.001	0.005
At 6-month	*r*	0.065	0.028	**0.118****	0.006	**0.165*****	**0.105****
	p	0.093	0.469	0.002	0.878	<0.001	0.007
At 1-year	*r*	**0.129****	**0.084***	**0.157*****	0.036	**0.174*****	**0.159*****
	p	0.001	0.029	<0.001	0.346	<0.001	<0.001

 # The change from baseline to the specific time point.
ZTEx, Zero-time exercise refers to simple strength-and stamina-enhancing physical activity.
The association between two variables was compared by Pearson correlation.
*r = correlation coefficient; *p < 0.05, **p < 0.01, ***p < 0.00.*

because it reduces the barriers of situational constraints (44, 45) and offers a cost-effective and acceptable method to deliver health education and promotion (46).

Our intervention used a foot-in-the-door approach, a compliance tactic to start with the easiest first step, the idea being that small demands are easier to meet (47). This approach has been applied in various fields such as the promotion of tobacco control and regular physical activity (48, 49). We promoted integrating simple strength- and stamina-enhancing physical activity into daily life and advocated that performing some physical activity (even a light amount) is better than not performing any physical activity. This belief is consistent with the recommendations of the 2018 Physical Activity Guidelines Advisory Committee Scientific Report (23).

We also emphasized that ZTEx could be easily personalized with no extra cost. This is important as barriers of money and time have been reported as critical deterrents when initiating exercise (50), particularly in deprived groups. Our PA intervention requires few resources to disseminate and is easily applicable to various settings, particularly in cities with limited space, such as Hong Kong. Our intervention was well-accepted by the parents in Hong Kong, although the majority of parents and children tend to focus on academia rather than exercise and are often preoccupied with daily tasks (18). The acceptance of the intervention may be attributed to the feasibility of the suggested exercises, which can be done at home and in office settings and thus easily integrated into daily lives. The well-structured curriculum of this intervention is easy to replicate and implement for further research. The current study also showed positive associations between increased ZTEx engagement by oneself and with one's family as well as improvements in well-being in terms of perceived health, happiness, and family harmony at all time points. These findings suggest that this community-based intervention may have potentially significant positive effects on mental and physical outcomes.

We acknowledge that there are certain limitations to the study. First, since the majority of our participants were females (only 8% of FEP participants were male), the findings would be more applicable in females than males. Second, the control group showed increases in physical activity, family interaction, and well-being. This could be due to the dissemination of a similar type of health-related information (healthy eating) in the control group, which may influence participants' health awareness. Third, considering that validated questionnaires were unavailable, we self-developed our outcome-based questions to assess the participants' practices in relation to doing simple strength- and stamina-enhancing physical activity by themselves and with their family members. Fourth, owing to resource

TABLE 4 | Demographic characteristics of family representatives who answered the brief family questionnaire and their relationship with principal participants ($n = 346$).

	Experimental group $n = 256$ n (%)	Control group $n = 90$ n (%)	p-value
Sex			
Male	151 (57.0)	45 (48.9)	
Female	114 (43.0)	47 (51.1)	0.18
Age group			
<30 years	40 (15.6)	20 (22.0)	
≥ 30–<50 years	149 (58.0)	49 (53.8)	
≥ 50 years	68 (26.5)	22 (24.2)	0.38
Relationship with principal registered participants			
Spouse	133 (52.4)	44 (48.9)	
Parents or parents-in-law	33 (13.0)	11 (12.2)	
Sons or daughters	54 (21.3)	26 (12.2)	
Sisters or brothers	4 (1.6)	1 (1.1)	
Friends or other relatives	30 (11.8)	8 (8.9)	0.63
	Mean ± SD	Mean ± SD	
Days engaged in ZTEx	2.9 ± 2.4	2.2 ± 2.4	0.024*

*Between group comparisons: *P <0.05.*

constraints, we were unable to objectively assess the accumulated duration of physical activity; we only measured the self-reported days engaged in physical activity. Self-reported moderate and vigorous physical activity values can be higher than objective values, particularly in inactive participants (51). Fifth, as the intervention was a community-based intervention and the questionnaires had to be kept at a reasonable and manageable length for participants, we were unable to assess changes in all of the cognitive factors for the formation of exercise motivation and regulatory factors for regular physical activity. Sixth, we did not use physical activity level as inclusion criteria. Our participants could have included both people who were active and inactive, and we might have overlooked the need for more exercise for inactive participants. Seventh, fewer family members than we had participants completed the family physical activity questionnaires because the staff of some IFSCs were not aware that they needed to deliver the questionnaires at the 6-month family involvement session. Lastly, we only collected feedback from family members aged 18 years and over who joined the family sessions and did not collect feedback from all family members at all time points because of resource constraints. We did not collect feedback from family members on their changes in family happiness, health and harmony, and did not identify the additional effects of text messaging on traditional face-to-face interventions. To further understand how intervention effects can be sustained and maintained for longer periods, future studies should aim to identify specific intervention components effective for community-based intervention delivery; identify and assess changes in cognitive and regulatory factors such as risk perception and self-monitoring; and assess the frequency and interactivity of messaging, and time of delivery.

The community-based lifestyle-integrated PA intervention, using behavioral change strategies such as the foot-in-the-door approach and involving family members, was assessed through comprehensive quantitative and qualitative evaluations. The preliminary evidence showed the positive effects of the intervention on enhancing physical activity, perceived health, and family communication, and the intervention could serve as a new model to promote a healthy lifestyle in the community. The community-based lifestyle-integrated PA intervention involving family members has the potential to benefit more people and other service sectors such as elderly service.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because the sharing of data to third parties was not mentioned in subjects' consent. Requests to access the datasets should be directly contact corresponding author.

ETHICS STATEMENT

This study involving human participants were reviewed and approved by The Institutional Review Board of The University of Hong Kong/Hospital Authority Hong Kong West Cluster. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

TL and SS led the conception and design of the intervention and assessments and were closely involved in data interpretation and manuscript revision. AL was a major contributor for the intervention design and coordination, analyzed and interpreted the data, and was responsible for drafting the manuscript. CF was a major contributor to the intervention design. AW was a major contributor to the intervention design and coordination between HKU-SPH and Caritas–Hong Kong. LH was involved in the statistical analysis of the data. EL was involved in the intervention design, oversaw the IFSC units involved in the study, and played a key role in the implementation of the intervention. DL was involved in the intervention design and played a key role in the coordination of the IFSC units involved in the study. JT coordinated the IFSC units involved in the study and played a key role in recruitment, intervention implementation, and data collection. All authors read and approved the final manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2020.00434/full#supplementary-material

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A Stakeholder Analysis of Schistosomiasis Diagnostic Landscape in South-West Nigeria: Insights for Diagnostics Co-creation

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Background: Schistosomiasis, one of the neglected tropical diseases, is a water-based parasitic disease of public health importance. Currently, tests for *Schistosoma haematobium* infection either demonstrate poor specificity, are expensive or too laborious for use in endemic countries, creating a need for more sensitive, cheaper, and easy to use devices for the diagnosis of schistosomiasis. To ensure engagement during the process of device development; and effective acceptance and use after the introduction of diagnostics devices for *S. haematobium*, there is a need to involve stakeholders with varying power, interest, and stakes in device co-creation, as well as those relevant for later use situation in the diagnostic landscape. The main goal of this study is to identify and analyze relevant stakeholders for co-creation using a power-interest matrix.

Materials and Methods: The study was based on an action research methodology using a case study approach. A contextual inquiry approach consisting of 2 stages: stakeholder identification and interview; and stakeholder analysis was used. The field part of the study was carried out in Oyo State, Nigeria using a multistage cluster purposive sampling technique based on the category of stakeholders to be interviewed predicated on the organizational structure within the state and communities. A mix of qualitative research techniques was used. Identified themes related to power and interest were mapped and analyzed.

Results: We identified 17 characteristics of stakeholders across 7 categories of stakeholders important for schistosomiasis diagnostics. Most of the stakeholders were important for both the co-creation and adoption phase of the device development for diagnostics. However, not all stakeholders were relevant to co-creation. Key Stakeholders relevant for diagnostics co-creation demonstrated significant social power, organization power, and legitimate power bases. Most of the stakeholders showed significant interest in the device to be created.

Discussion: The power and interest of these stakeholders reveal some insight into how each stakeholder may be engaged for both co-creation and device usage.

The involvement of relevant actors who will also be important for co-creation and implementation, will simplify the engagement process for the critical stakeholders, increase the ability to manage the process, and increase diagnostic device acceptability.

Keywords: schistosomiasis, stakeholders, co-creation, diagnostics, power, interest

BACKGROUND

Schistosomiasis, one of the 20 Neglected Tropical Diseases (NTDs), is a water-based parasitic disease of public health importance. The disease, which currently affects over 250 million people, is endemic in Sub-Saharan Africa (1, 2). There are five different types of species causing schistosomiasis infection: *Schistosoma haematobium* affecting the urinary tract; *Schistosoma mansoni*, *Schistosoma japonicum*, *Schistosoma intercalatum,* and *Schistosoma mekongi* affecting the intestine. *S. haematobium* and *S. mansoni* infections are common in Africa (2, 3). Of these species, *S. haematobium* is the most prevalent parasite in Nigeria affecting an estimated 30 million people yearly (1, 4). *S. haematobium* infection is endemic in many rural and agrarian communities in Nigeria that interact with water through subsistence farming, fishing, washing activities, and water recreational activities (5, 6). The constant contact with water containing *S. haematobium* cercariae released from the Bulinus snail, which occurs regularly, often results in re-infection with the disease, and this impacts on the data on disease prevalence (1, 3–5). Since adult worms have been documented to live in humans for as long as 30 years, most long-term residents of endemic areas become infected or re-infected with schistosomes at some point in their life (7) leading to a vicious cycle within the communities. Besides, depending on the stage of the infection, a wide range of clinical symptoms may occur, many of which are hard to distinguish from several other diseases (5). However, it is a notable cause of morbidity with many infected persons experiencing hematuria, dysuria, bladder-wall pathology, and hydronephrosis (8). Although Nigeria has one of the largest schistosomiasis disease burdens in the world, currently, there is no accurate national data on the prevalence of the disease (1). While the country currently undertakes a large-scale deworming exercise of school-age children in endemic zones with praziquantel (9), addressing diagnosis among adults who are not covered by mass administration of praziquantel is a challenge to the disease control.

Nigeria currently tackles schistosomiasis through a 2-step approach: case management and a control program (1, 10). In the case management approach, cases are diagnosed at the primary care level. For the control program, Nigeria has a schistosomiasis control program wherein school-aged children are given praziquantel for the treatment of schistosomiasis. Schistosomiasis is common among children with the highest intensity of infection found in children between ages 5 and 15 years (11), but it is also known that women and men carry a high risk of urinary schistosomiasis due to social and occupational activities such as farming and washing, especially in areas with poor water, and sanitation services (1). In this respect, there are concerns about missed diagnosis for several reasons. First, several persons do not pass bloody urine which is characteristic of the disease (12). Second, the current control program does not include adults in mass drug administration (1, 9) which means that several adults are likely to have schistosomiasis and are not being treated. Third, *S. haematobium* infection is mainly diagnosed currently using microscopy to detect parasite eggs in urine specimens which is not sensitive in detecting light infections of <50 eggs per 10 mls of urine (13), is labor-intensive, and sensitivity of diagnosis depends on the skill of the laboratory personnel (5, 6, 12). Also, egg excretion in urine varies daily and can be complicated by interaction between the host and the parasite (14). Other tests for detecting *S. haematobium* infection either demonstrate poor specificity, high cost, or painstaking logistics for use in endemic countries (6, 15). Besides, some of these tests are more useful during the elimination phase of the control which has not been reached by a large number of countries (16). As such, there is a need for more sensitive, cheaper, and easy to use devices for the diagnosis and control of schistosomiasis.

To address these issues, the project INSPiRED—INclusive diagnoStics for Poverty RElated parasitic Diseases in Nigeria and Gabon, was initiated to explore ways to create a new device for the diagnostics of *S. haematobium* infection within the context of countries with a high disease burden such as Nigeria using a human-centered approach. The project aims to design easy to use, affordable, and reliable diagnostics devices which may deliver the most effective and efficient step toward schistosomiasis control, aligned with the country's model of care. The device to be co-created is a smart optical device for the diagnosis of schistosomiasis (17) which will be developed from a sustainability point of view and not a profit point of view (18, 19). We regard sustainability in the context of ecological, financial, and social consequences of the device to the society which is most visible through a continuous process of improvement exemplified by the co-creation process (20). The devices will eventually be locally manufactured using locally available materials and components. This will reduce the cost of production, reduce dependence on imports, will enable local and maintenance, and contribute to the economy of countries that are willing to adopt the device.

A crucial first step in the designing of the new device is the proper understanding of the schistosomiasis diagnostics landscape in the context of use for several reasons. First, prompt, accurate, and timely diagnosis is important for schistosomiasis control. Since treatment with praziquantel is cheap and readily available, easy to use diagnostics appears to be critical to schistosomiasis control.

Second, a diagnostic device is only effective if it is designed for its context, and this context is complex and deserves an in-depth study. In this situation, several factors such as the people, process, technology, customer requirements, and innovation need to be addressed (21) through multi-stakeholders input at all stages of development, testing, evaluation, and advocacy for adoption. This implies that stakeholders need to give insight into the process and context-of-use of the technology, including device requirements and the innovation context. The alternative to this co-creation process is a top-down approach focusing on the technology itself which has been reported to have limited successful outcomes due to variation between contexts of use and the design context (22). Besides, the complexity of the context, in this case, the social and healthcare context, cannot be detected in detail from a distance. Since the social context is a critical influencer of the stakeholders' outlook, the stakeholders within this social context can be viewed as both static in terms of the operational arrangement of stakeholders (network structure); and dynamic in terms of stakeholder roles, interactions, flows, and interdependencies (23, 24) which have to be taken into consideration during co-creation. Since stakeholders also vary in background, power, interest, and stakes; the complexity of the stakeholder co-creation process must be effectively managed to achieve the expected outcome. Consequently, there is a need to understand how the actors or stakeholders in this context interact through both stakeholder identification, and understanding of the stakeholder network structure and dynamics. As such, it is important to involve stakeholders in the entire device development process.

Third, there is a multiplicity of stakeholders with this context. Initially influencing and involving them in designing the new diagnostic device seems to be a proper approach to co-creation (23–26). Co-creation has a large role to play in the generation of new knowledge and ideas, development of new insights into existing interventions, and concept development (27, 28). To ensure that diagnostic devices are useful in the context for which they are created, it is critical to involve end-users and other important stakeholders through the entire co-creation process. Such involvement will likely lead to increased uptake of the created product. It has been reported that stakeholders perceive a sense of ownership through active participation in the development of diagnostic devices leading to a more efficient solution to achieving positive societal changes (29). To co-create a robust solution, there is a need to identify the stakeholders who are likely to interact with the product. Identification of stakeholders who are important for this process, and understanding their characteristics can help address the gaps and challenges that can impact on device development. Besides, the fact that stakeholders have different views on the problem of schistosomiasis diagnostics and differing solutions means that stakeholders will have different important insights to contribute (30). Although it appears that the government is the most visible stakeholder, it is important to note that other stakeholders such as health workers and patients can impact on the design and use of a diagnostic device for schistosomiasis.

After the stakeholder identification, it is important to analyze the stakeholders using key characteristics that are useful during the process and life cycle of device development. Stakeholder analysis is a process that defines aspects of a phenomenon affected by a decision or action, identifies individuals, groups, and organizations affected by or that can affect those parts of the phenomenon; and prioritizes these individuals and groups for involvement in the decision-making process (31). Stakeholder analysis is useful for assessing their knowledge about the schistosomiasis diagnosis as well as their interests and power. Consequently, our study aims to describe how to effectively identify, select, and analyze important stakeholders for co-creation, as well as identify potential stakeholders for the adoption and implementation of a schistosomiasis device for large scale use.

Although there exists a need to involve important stakeholders when addressing the schistosomiasis diagnostic landscape, there is little information on the required techniques to do so (30). Moreover, in the field of NTDs, it appears that there are no studies on the involvement of stakeholders in the co-creation of a device or the context for design specifically for *S. haematobium*, to the best of our knowledge. There are, however, several studies on NTDs that involve stakeholder analysis (32–38). For these studies, stakeholders are usually identified through purposive sampling (32–35, 37). Most of the studies involved stakeholders at the macro-level (32, 34, 37, 38) with a few studies involving stakeholders at the community level (33) or both (35). However, using purposive sampling alone for stakeholder identification means that some stakeholders who are not in the same network with the identifying stakeholders might be missed.

We also did not find any framework for stakeholder identification and analysis fully tailored for NTD research. Also, we did not find any guidelines or frameworks for the co-creation of diagnostic devices for schistosomiasis. In this paper, we will present a framework for stakeholder identification based on our understanding of the healthcare system and schistosomiasis context in Nigeria, and a contextual inquiry framework (39) used by Van Woezik et al. (30). We will present the results of applying this framework to a stakeholder identification process during the process of co-creation of services, devices, and policy with stakeholders. We will also present our analysis of relevant stakeholders' power, interest, and stakes for device co-creation using a power-interest matrix. We will close the paper by discussing how such a strategy might help to identify relevant stakeholders within a specific field of study and to develop ways of engaging and co-creating with stakeholders based on the outcome of the analysis.

METHODS

The study used an action research methodology with Oyo State, Nigeria, as a case study. Qualitative data collected include key informant interviews, in-depth interviews, focus group discussions, expert recommendations, and document analysis. The qualitative method of data collection is rich and reveals the complexities and the depths of what can be abstracted for stakeholder analysis.

Research Approach

We used a contextual inquiry approach, similar to work done by Van Woezik et al. (30). This consists of 2 stages: stakeholder identification and interview; and stakeholder analysis using the qualitative data to create a power-interest matrix.

Stakeholder Identification

We defined a stakeholder as any person, group, or organization who should be or is involved in schistosomiasis diagnosis based on Freeman's definition of a stakeholder (39). The first stage of the process consists of 3 levels of inquiry using a mixed approach into the context of stakeholders important to the research (**Figure 1**).

1. Literature scan: First, we identified stakeholders based on the literature on NTD research (4, 40–42) as well as policy documents on schistosomiasis in Nigeria (9, 11).
2. Expert panel recommendation: After identifying stakeholders from literature, we involved 2 experienced experts from public health research and clinical medicine, respectively to validate and make suggestions on other stakeholders who were important to the diagnostic landscape in Nigeria.
3. Snowballing: We used a snowballing technique in which we asked all interviewed stakeholders to identify other stakeholders that might be important to schistosomiasis diagnosis in Nigeria.

The outcome of the first two steps of the contextual inquiry process led to the creation of stakeholder categories based on the conceptualization of the demand and supply aspect of healthcare diagnostics for schistosomiasis using stakeholder characteristics (**Table 1**). The final list of interviewed stakeholders was validated through a 2-step process. First, all identified stakeholders were selected based on meeting at least 3 of the following criteria which were developed from the research question in **Figure 1**: (1) suggestion by experts and/or stakeholders, and/or literature (2) having a clear stake in schistosomiasis diagnostic landscape, and/or (3) being a potential end-user of the to-be-developed diagnostic device, and or (4) having a strong influence on the demand of the to-be-developed diagnostic device. Second, the generated list was finally reviewed by 2 experts from public health research and clinical medicine, respectively using a binary approach of Yes/No. The final stakeholder categories of stakeholders and a list of important stakeholders were agreed upon by all members of the team.

Study Setting and Sampling Approach

Based on stakeholder categories in **Table 1**, the field part of the study was carried out in Oyo State, South-West Nigeria. The state has a moderate prevalence of schistosomiasis infection (1, 4). For category 1–3 stakeholders, we used a multistage cluster purposive sampling technique. Two local government areas (LGA); urban and rural, respectively were selected based on ecological factors such as closeness to rivers which were known reservoirs of *S. haematobium* infection. One ward from each local government structure was also selected based on ecological factors. Based on information available from the local governments on recently treated schistosomiasis cases (category 1 stakeholder), we selected and interviewed category 2 and 3 stakeholders based on geographical proximity to the area of residence of category 1 stakeholders. Category 4–6 stakeholders were sampled using purposive sampling. The sample size is difficult to determine a priori because of the explorative nature of this research. However, our final sample size was considered sufficient when it met the following criteria: (1) a minimum of 30 interviewed stakeholders based on recommendations by Marshall et al. (43); (2) when theoretical saturation is reached by no new mention of stakeholders from the snowballing technique. A respondent was considered a good fit when he/she met the criteria in **Table 1** and was validated by the 2-step process described earlier.

Stakeholder Interview and Analysis

We carried out qualitative (In-depth and Key informant) interviews and Focus Group Discussions (FGD) with stakeholders. The questions asked depends on the stakeholder background and experience. However, questions asked include normative ideas on *S. haematobium* infection, interaction with formal and informal health care, current diagnostic landscape, and diagnostic challenges and limitations. Consent was given before the interviews. Ethical approval for the study was obtained from the Ethical Review Committee of the College of Medicine, University of Ibadan, Nigeria (NHREC/05/01/2008a).

Interviews were transcribed and translated where applicable. Transcripts were reviewed by two researchers, entered into atlas.ti version 8.4 and coded using the deductive thematic analysis method. A researcher coded the interviews and created a coding manual. Two other researchers validated this.

All researchers within the team independently validated the identified themes related to power and interest. Power was defined as "the level of influence a stakeholder has in the diagnosis of *S. haematobium* infection" (30). The sources of power could include: political, economic, social, cultural, historical, and/or organizational factors (26, 44). The expression of these sources of power (power bases) includes reward, coercion, information, legitimate, expert, and referent which can be derived from political, economic, social, cultural, historical, and/or organizational factors (26, 44). Interest was defined as "value abstraction to the new diagnostic device for the diagnosis of *S. haematobium* infection" (45). Interests could either be "expressed" or "implied/ manifested" in direction and willingness-to-use magnitude (46).

Based on the results of the analysis, stakeholders were further categorized into four levels of analysis of stakeholders based on the four-level model of the healthcare system, which was adapted from Reid et al. (47). The themes were analyzed based on the level in which stakeholders fall into. Thereafter, stakeholders were ranked based on their power and interest, which were valued on a scale of 1–5, with 1 meaning low level and 5 meaning the highest level of power and interests, respectively similar to the ranking by Hyder et al. (48). The results of these analyzed stakeholders were mapped to identify stakeholders who were important to co-creation into players, context setters, crowds, and subjects (49).

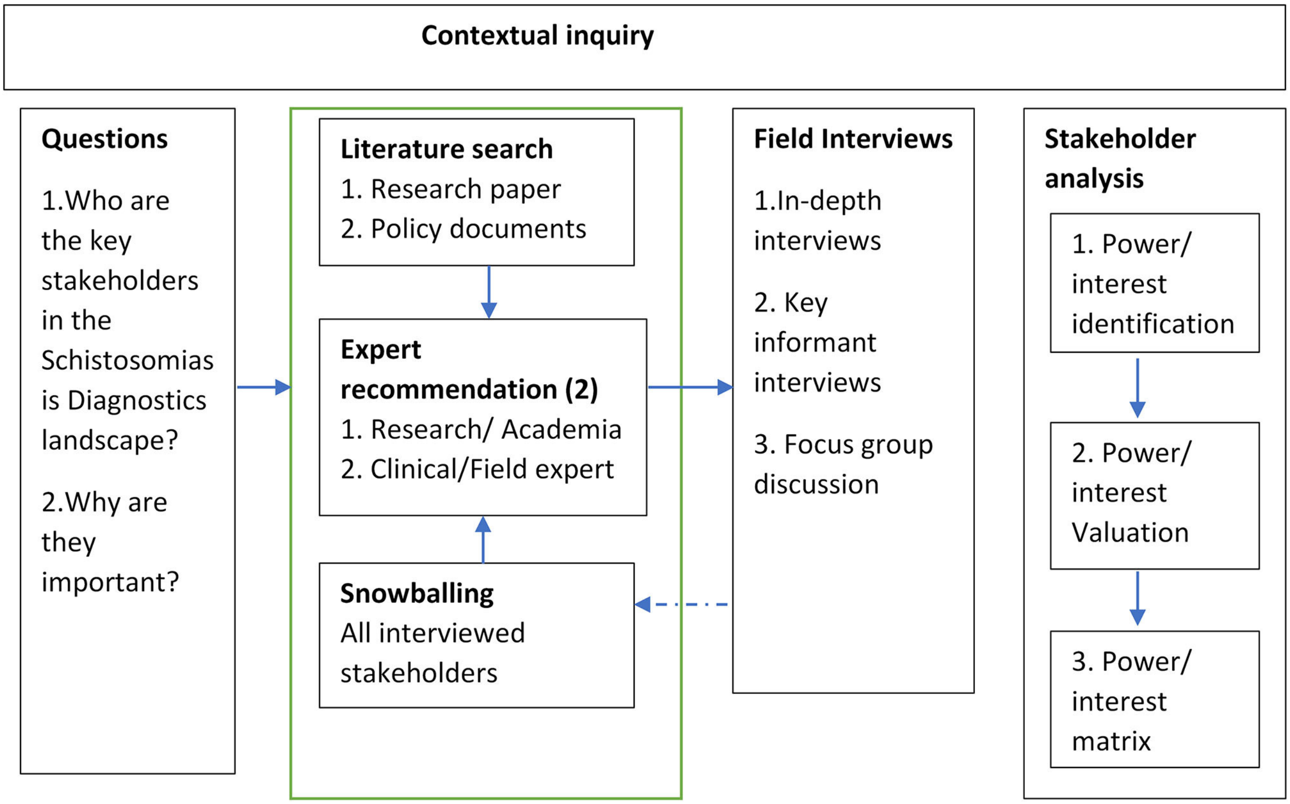

FIGURE 1 | Process map of contextual inquiry into the schistosomiasis diagnostics landscape.

TABLE 1 | Stakeholder categorization for diagnostics co-creation.

Category	Characteristics
1	Persons/parents of children who have been previously diagnosed and or treated for *S. haematobium* infection within the last 3 years.
2	Stakeholders within the community that can impact the patient's decision to access care (diagnostics, and or treatment).
3	Stakeholders within the formal health system (both public and private) who can diagnose and or treat patients with schistosomiasis.
4	Stakeholders within the government who are in charge of programs/processes to identify, and or treat schistosomiasis.
5	Stakeholders in Non-Governmental Organizations (NGOs) that contribute to schistosomiasis diagnosis, and or treatment within the state.
6	Stakeholders in academia who are working in the Neglected Tropical Disease field.
7	Stakeholders that finance diagnosis and or treatment of Neglected Tropical Diseases.

RESULTS

Stakeholder Characteristics

A total of 17 stakeholder characteristics were identified across the 7 categories (**Table 2**). This yielded a total of 36 stakeholders to be interviewed. Thirty three stakeholders were interviewed. One stakeholder (religious body) was not interviewed based on the large variance in types and modes of operation of religious bodies, 2 other stakeholders (State Disease Surveillance and Notification Officer (DSNO) and Federal NTD officer) were not available for interviews.

As can be seen from **Table 2**, the literature scan identified 6 stakeholder characteristics, 5 stakeholder characteristics were identified by experts and by snowballing, respectively.

Figure 2 has a breakdown of the number of stakeholders according to the location. Twenty stakeholders performed a singular role, 13 stakeholders performed 2 roles, while another 2 stakeholders performed 3 roles concurrently. At the local government level, the location of the community (rural or urban) did not significantly determine the multiplicity of roles.

Stakeholders' power and interest in schistosomiasis diagnostics were further analyzed by categorizing stakeholders into four levels which were adapted from Reid et al. (47). Based on this level of analysis (**Figure 3**), Stakeholder categories 1–2 falls within the micro-level or community level, stakeholders within category 3 fall into the health care level; stakeholders in category 4 fall within the organizational level

TABLE 2 | Stakeholder characteristic and identification for co-creation.

Stakeholder category	Role	Method of identification	Number interviewed
1	Parent/guardian of children with schistosomiasis	Literature review	5
2	Community leader	Expert	1
	Patent Medicine Vendor (PMV)	Expert	1
	Traditional healer	Expert	1
	Community mobilizer	Snowballing	1
3	Doctors	Literature review	1
	Community Health officers	Snowballing	1
	Laboratory scientist/Technician	Literature review	5
	Community Health Extension Workers (CHEW)	Literature review	2
4	Primary health care (PHC) coordinator	Literature review	2
	NTD officer	Literature review	3
	Disease surveillance and notification Officer (DSNO)	Snowballing	2
	Teachers	Snowballing	2
5	NGO	Literature review	1
	Community-based organization (CBO)	Expert	0
6	Academia	Literature review	3
7	Financing	Expert	1

**One interview was an FGD.*

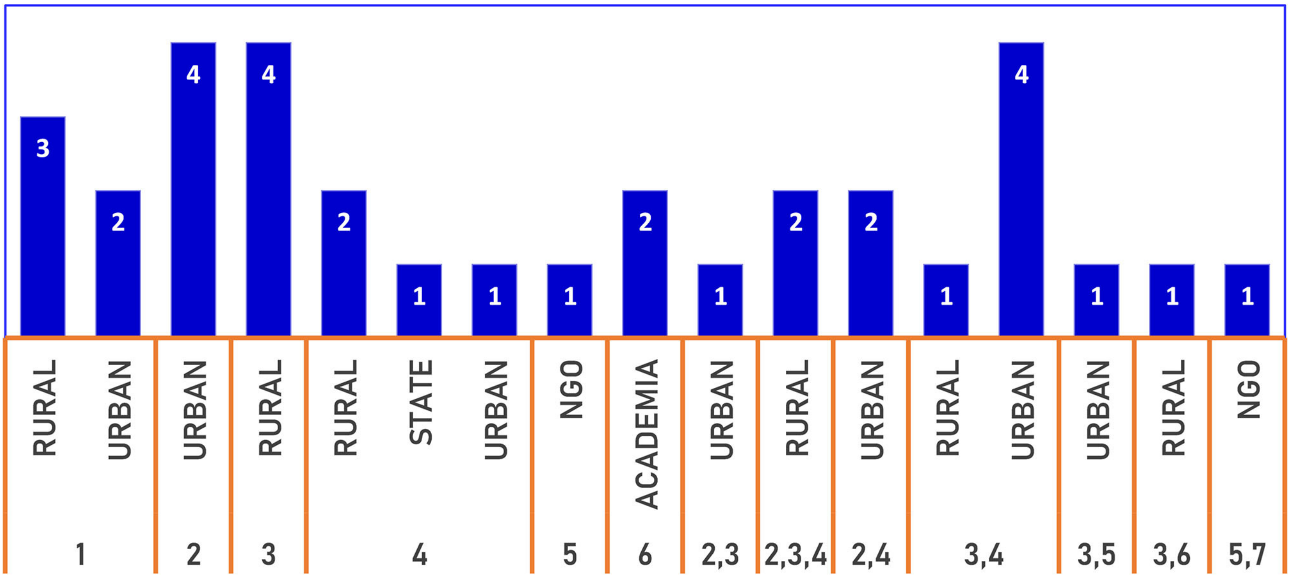

FIGURE 2 | Stakeholder characteristics.

and category 5–7 stakeholders fall into policy/economic environment. Some stakeholders fall within 2 or more categories based on their multiple roles. Stakeholders relevant for diagnostics co-creation had significant social power, organization power, and legitimate power bases at each level of analysis. All stakeholders were influenced both by other stakeholders within their level and by the next level of stakeholder within the lower and higher concentric circle (**Figure 3**).

We also found stakeholders that were important for both co-creation and adoption of technology. Although the initial focus was on diagnostics co-creation, we were also able to identify some stakeholders from the interview transcripts who did not fall into the diagnostic co-creation categories but may

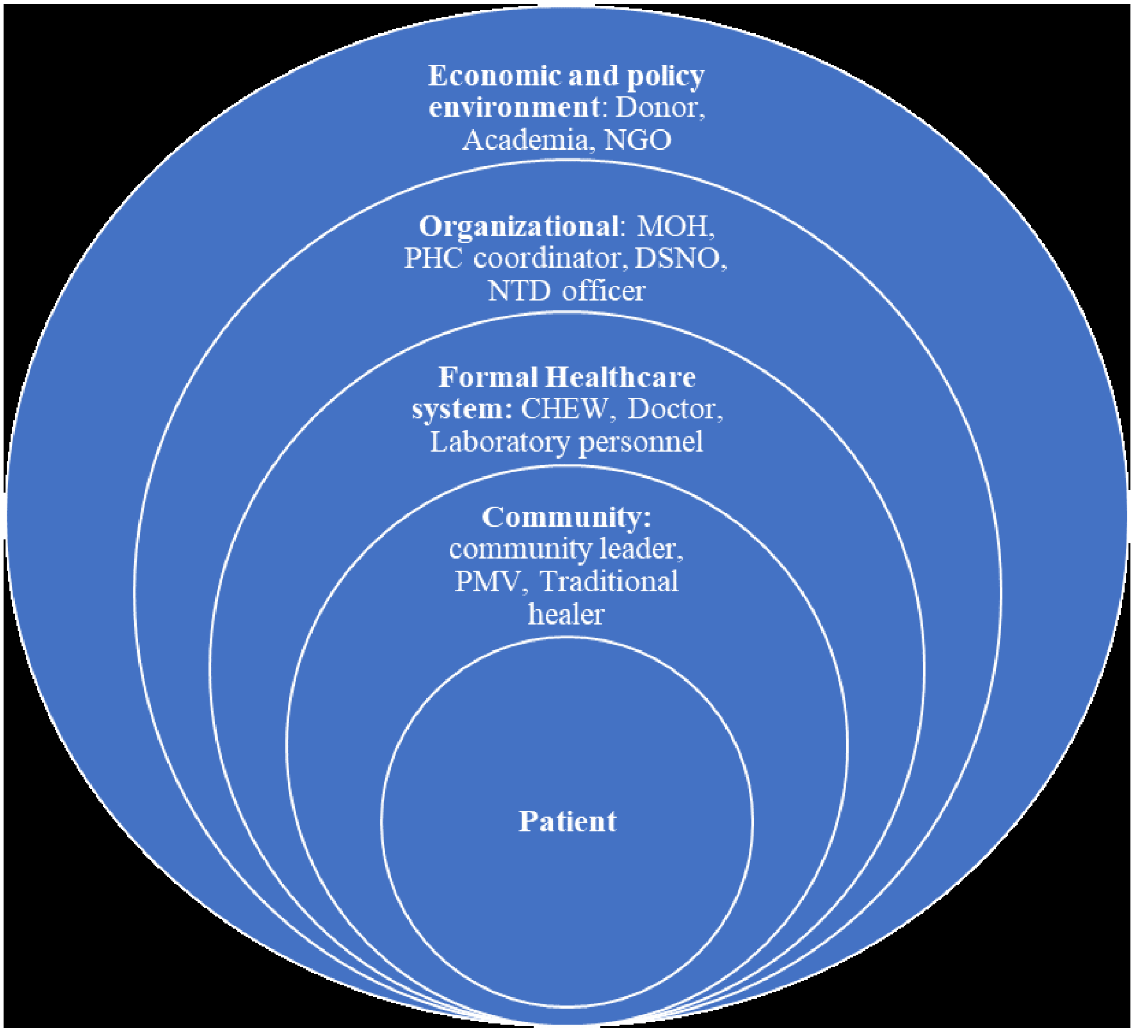

FIGURE 3 | Stakeholder categorization within the health system.

be important for the adoption of the device based on the 2-step validation process for all stakeholders. However, these do not show the complete extent of stakeholders for adoption and implementation (**Table 3**).

Stakeholder Power/Influence Thematic Analysis

All the important stakeholders that were interviewed, demonstrated varying types and levels of power. A summary of this can be found in **Table 4**.

Community-Level Stakeholders

Community-level stakeholders demonstrated varying levels of power. These stakeholders consist of individuals: patient's parents/guardians, traditional healer, community leader, community mobilizer, and Patent Medicine Vendor (PMV), all embedded within the same community network.

Patient

All the patients or their guardians individually did not demonstrate any significant power. However, collectively, they have a great source of social power which determines the demand for healthcare. The decision to access healthcare was made based on either financial situation, social relationships, trust and or ease of access to the formal health system (CHEW or Doctor) or other sources of healthcare (PMV, traditional healer). This social power is important to drive the use and demand for diagnostics. This power did not significantly differ between rural and urban areas. However, guardians in the urban areas were more likely to use a hospital as a first step than using other sources of treatment.

> "*Mummy* (referring to community mobilizer) *asked him to go to the hospital and she also informs his dad because she is closer to him, so they take him to the hospital and he was treated and they ensure that he is okay before he traveled.*" Patient's guardian, male, urban area.

TABLE 3 | Stakeholder characteristics and stage of device lifecycle.

Characteristics	Stage of the device development lifecycle
Parent/guardian of children with schistosomiasis	Implementation/adoption
Community members	Co-creation and Implementation/adoption
Community leader	Co-creation and Implementation/adoption
Patent Medicine Vendor (PMV)	–
Traditional healer	–
Market associations	Implementation/adoption
Community health committee	Implementation/adoption
Community mobilizer	Co-creation and Implementation/adoption
Doctors	Co-creation and Implementation/adoption
Community Health officers	Co-creation and Implementation/adoption
Laboratory scientist/Technician	Co-creation and Implementation/adoption
Community Health Extension Workers (CHEW)	Co-creation and Implementation/adoption
Primary health care (PHC) coordinator	Co-creation and Implementation/adoption
Primary health care board director	Implementation/adoption
NTD officer (State and LGA)	Co-creation and Implementation/adoption
Disease surveillance and notification Officer (DSNO) (State and LGA)	Co-creation and Implementation/adoption
Teachers	–
NGO	Co-creation and Implementation/adoption
Community-based organization (CBO)	Co-creation and Implementation/adoption
Academia	Co-creation and Implementation/adoption
Financing	Co-creation and Implementation/adoption
Biomedical Engineer	Co-creation and Implementation/adoption
National Center for Disease control	Implementation/adoption
Media	Implementation/adoption
Politicians	Implementation/adoption
Equipment suppliers	Implementation/adoption
Federal Ministry of Health	Co-creation and Implementation/adoption
World Health Organization	Co-creation and Implementation/adoption

For rural areas, the patient was more likely to take some other steps, before accessing healthcare

> "*When that illness started with the child, he was running temperature and we gave him herbs but it was not effective… We gave him paracetamol and yet there was no difference, … later saw him urinate and sighted blood in his urine… We waited for our husband to come back. When he comes back he took him to daddy (referring to CHEW) at… we did not know about the disease, and he took care of it.*" Patients' parent, female, rural area.

Traditional Healer

The traditional healer demonstrated some degree of power over patients seeking care. Power was based on cultural and social factors. A traditional healer could also demonstrate referent power by referring non-improving cases to the hospital.

> "*…so I gave him traditional herbs, they are what we had previous knowledge of and when he drank it, he was cured." Apart from that one, he also brought his boss to me, … we treated his boss with the same herbs we used to treat him. So when he was okay I told him to go for further treatment at the hospital and to check if you are totally cured*' Traditional healer, male, urban area.

The traditional healer also mentioned the patient's autonomy in seeking diagnosis and treatment

> "*People in those days (in the past) listen to advice but nowadays people do not take advice anymore*" Traditional healer, male, urban area.

Community Leader

The community leader demonstrates some form of legitimate power over the community but this power is limited to giving advice. The inherent power source of the community leader may likely impact on power demonstrated as those with cultural/historical power source may demonstrate more power.

> "*so when such a thing occur we normally advise the parents to carry such children to the hospital*" Community leader, male, urban area.

Community Mobilizer

The community mobilizer demonstrates some form of social power based on relationships and could also demonstrate expert power depending on training.

> "*the way we interact, you can see that as I got here now, they started greeting me… because of the relationship I have with them… and clinically we diagnose them I mean we treated them clinically because there is no laboratory to confirm it*" Community Health Officer and Community Mobilizer, male, rural area.
>
> "*yes we serve as the interface between the government and the people of this community, so we usually sensitize them about their health, their environment… those (patients) that can manage to go (to the hospital) without any problem and has an assistant, I ask them to go, and those that are too weak to go by themselves like (an) emergency, I followed them.*" Community mobilizer, female, urban area.

PMV

The patent medicine vendor's (PMVs) source of power came from social relationships, expertise, and had the power to refer patients to seek care. There are two types of PMVs: mobile and resident. Resident PMVs have more power over the patient's care and access to diagnosis

> "*If they are ill and it is body temperature that just started, so I will give hem drugs for two days, sometimes if there is no changes we refer them to the health center*" PMV, female, urban area.
>
> "*I usually greet and ask them about their health when they pass by my shop, sometime some will thank me for the drugs I gave them the day before and that it's effective while another may come to report that the medicine was not effective and request for another kind.*" PMV, female, urban area.

Resident PMVs viewed their power over disease diagnosis to be limited to what was acceptable by law. Due to their presence within the locality, they could easily be identified and liable to the law.

> "*…so far it won't affect us, you know there is nothing that the police don't investigate, so if it won't affect us and the police won't disturb us, no problem*" PMV, female, urban area.

Health Care Level Stakeholders

This level of Stakeholders includes Doctors, Nurses, Community Health Officers (CHO), Community Health Extension Workers (CHEWS), Laboratory Scientists/Technicians. They work within the clinical aspect of the health care system.

CHEWS/CHO/Doctors

The CHEWS/Doctors are the first level of entry into the healthcare system. Due to the limited number of personnel within the healthcare system, CHEWS/CHOs are in charge of smaller primary health care centers and health posts that are close to the communities, while Doctors were in Charge of larger health centers. The CHEW, CHO, and Doctor demonstrated power as experts. However, the CHEWs also demonstrated social power based on their continuous residence within the community leading to the formation of relationships with members of the community.

> "*… I have more information, so they really do not have a lot of options than to follow my instructions; this is not in all cases but it happens most the time…If I tell them that I want to admit them, then they do not have a choice. If they refuse to stay, this is not a prison and they can leave. It depends on how you talk to them anyway*" Doctor, male, urban area.
>
> "*.. (Patient)came into the clinic with complaints and then he followed my boss (Senior CHEW) into town for proper diagnosis where tests were carried out on him. After everything, my boss told me they got drugs and that it was schistosomiasis*" Junior CHEW, Health Center, Rural area
>
> "*...At times if I want to go and I run into people passing by going toward the area with their bikes, they often assist me.*" Junior CHEW, Female, rural area.
>
> "*I think I might have seen about two to three cases (of schistosomiasis). When this happens, the first thing we do after noting their complaints is to refer them to the MOH(medical officer of Health).*" CHO, female, urban area.

Laboratory Personnel

Laboratory personnel demonstrated power as experts with technical knowledge. Their power over patients was limited and they only had contacts with patients through a referral from doctors. That did not have power over treatment or what diagnostic test to carry out.

> "*Yes, at that point you, whatsoever analysis is requested from the physician, at the end of my own analysis once I see a result, I have that privilege to also recommend…suggestive. So, it now depends on the physician by the time the patient reports back to the physician*" Laboratory scientist, male, NGO, urban area.
>
> "*our job is to analyze the specimen and report. Then the doctor decides on how to act on our result…they get referred by doctors to here from various hospitals... and people come here on their own… But mostly they are referred here by doctors*" Laboratory scientist, male, private lab, urban area.
>
> "*we first go for microscopy and if there is schistosomiasis, we refer them to the doctors for treatment*" Laboratory technician, female, Health Center, urban area.

Organizational Level Stakeholders

Organizational level stakeholders were those in charge of programmatic parts of schistosomiasis control as well as gathering and using information about schistosomiasis for program planning. These include the Medical Officer of Health (MOH), Primary Health Care (PHC) coordinator, Disease Surveillance and Notification Officer (DSNO), and the Neglected Tropical Disease Officer (NTD) and teachers.

Primary Health Care (PHC) Coordinator/MOH

The PHC coordinator /MOH is in charge of primary care at the local government levels demonstrated legitimate power because of their position within the organization part of the healthcare system, as well as expertise based on training.

> "*by virtue of my position can relate with other line ministries, department, and agencies, international organizations…that want to partner with the local government on health matters to implement any program as far as the health system of the local government is concerned." I get referrals and at the same time, I do refer people, depending on the case that presents itself. My staff can refer patients to me or invite me to manage a case at the facility level'* MOH and PHC coordinator, male, urban LGA.
>
> "*I see to the affairs of the PHC department in general. I also coordinate the staff in terms of their duties, supervise them, and then if there is any need for recommendation for any of them from the state government, I will make those recommendations*" PHC coordinator, female, rural LGA.

However, the level of power of these officers to address schistosomiasis and recommend a line of action is limited by other stakeholders that do not have a direct relationship with schistosomiasis diagnostics.

> "*There are enough skilled people outside but the government did not recruit them. I cannot recruit them by myself, they are usually recruited by the State Primary Healthcare Board.*" PHC coordinator, female, rural LGA.
>
> "*It takes a collaborative effort of my office, the office of the political officeholders. The politicians are the ones who initiate policies and they decide if they want to expand and add more to the existing facilities. They determine the felt need of the people in the community that they serve. When they go to the people and the people tell them that they need a healthcare facility, they work on it. Then, they will refer to me. The process goes from top to bottom, it rarely goes bottom-up.*" MOH and PHC coordinator, male, urban LGA.

NTD Officer

The NTD officer is primarily in charge of the programmatic aspect of the schistosomiasis control. They demonstrate technical power because of their position. They were also in charge of

TABLE 4 | Stakeholder power and interest ranking.

Stakeholder category	Role	Power type	Power rank	Interest rank
1	Parent/guardian of children with schistosomiasis	Social, coercion	2	2
2	Community leader	Social, legitimate	2	1
	Patent Medicine Vendor (PMV)	Social, referent	2	1
	Traditional healer	Social, cultural	2	1
	Community mobilizer	Social, informational, referent	3	3
3	Doctors	Expert, referent	3	3
	Community Health officers	Expert, referent	3	3
	Laboratory scientist/Technician	Expert, referent	3	4
	Community Health Extension Workers (CHEW)	Social, Expert, referent	4	5
4	Primary health care (PHC) coordinator	Organizational, Expert, legitimate	3	3
	NTD officer	Organizational, informational, social	3	3
	Disease surveillance and notification Officer (DSNO)	Organizational, legitimate, Expert, social, informational	4	4
	Teachers	Informational	1	1
5	NGO	Organizational, legitimate, informational	3	3
	Community-based organization (CBO)	–	–	–
6	Academia	Expert, informational	3	5
7	Financing	Organizational, informational	5	4

the School-based deworming day targeting school-age children for treatment for schistosomiasis. They also have ties with the community and could leverage social connections within the community.

> "*We only currently handle kids from ages 5 to 14, adults are also prone to the risk and we have seen cases of adults passing blood in urine. This is why several adults have been asking when we will carry out a program like this for them. So, it is necessary for both adults and not the children alone… Maybe the next time we have a meeting with the state, we would bring up that they should extend the range of reach to cater for people 15 years and above because they also swim in the rivers and they can end up infecting the ones we've treated if they are not included*" NTD officer, female, urban LGA.
>
> "*We do surveillance. We try as much as possible to pass messages to the community leaders so that they will be aware of it, so whenever they see signs, they will be able to call on me to inform me about the cases, and then, there will be a linkup between myself and the community.*" NTD officer, male, rural LGA.

The State had legitimate organizational power over the schistosomiasis control program. However, the Federal government determined the overall strategies for schistosomiasis control based on policy.

> "*because the state does not have the authority to that (address schistosomiasis through policy). It always comes from the federal level. The guidelines we use are from the federal level and our hands are tied without the federal ministry of health." State NTD Officer.*

Disease Surveillance and Notification Officer (DSNO)

These officers are in charge of monitoring and reporting notifiable diseases including schistosomiasis. They directly work with health facilities and demonstrate strong legitimate power over health facilities, both private and public, and at all levels of care (primary, secondary and tertiary healthcare) within their jurisdiction.

> "*We have weekly and monthly reporting. Whenever they see something of such nature such as blood in the urine, they will send a text message notifying me that there is a case of this nature and on monthly basis, they will sum all the activities for the weeks and send it to me. I have a column that indicates schistosomiasis. Whenever such a case has been reported to me, I must go and investigate in all health facilities… I have to contact the higher authority which is the state disease, surveillance officer. Then we go together and make verification.*" DSNO, male, urban LGA.
>
> "*The health workers there will treat the patient and document it. We will then send the record to the state.*" DSNO, female, rural LGA.

Teachers

Teachers only featured strongly within the treatment aspect of the schistosomiasis control program. They, however, have limited powers overtreatment and no power over the diagnosis of schistosomiasis.

> "*we announce it to them that there is deworming, some of them came some did not come to school and some who came like one he*

> *was always tapping me that her mother said she should not take any medicine*" *Primary School Teacher*, Urban area.
>
> "*then it depends on the condition if it one that requires an immediate attention. For example, a kid that has a cut and was injured and he is bleeding several of them have been taken to private clinics around here, the principal pay for their treatment, teachers raising money taken to him, to attend to them at that first day. . . there were children that have been rushed to hospitals by the school, the parents will come, meet them in the hospital where they were taken to so it depends on what happens.. that will determine. . .* " Participant 3, FGD, Secondary school, urban area.

Policy/Economic Environment Stakeholders

These stakeholders have a wider level of impact and they interphase with more than one level of the health system simultaneously. These include interaction with both the community level, local Government, State Government, and or at the Federal government level. They include academia/researchers, Non-Governmental Organizations (NGOs), financing/donor organizations.

Non-Governmental Organizations (NGO)

We identified three main NGOs. One of the NGOs [Association of Reproductive and Family Health (ARFH)] worked within disease diagnostics and the second, the World Health Organization (WHO) performed a technical function. While the third (Evidence action) provided technical function as well as funding support. The WHO function appeared to have stronger legitimate powers by performing supervisory roles. The WHO did not have a state-based NTD officer. This was only present at the national level. However, other officers within the state office filled the gap when needed.

> "*This may be due to the fact that I do not really look into it but in my supervisions, I have barely seen cases of schistosomiasis. . . I think the surveillance..is poor for schistosomiasis. With good surveillance system, I think we will easily pick up quite a number of cases. Many of the factors that might predispose to schistosomiasis is present*" WHO state technical officer.

Financing

Financing appeared to be one of the greatest sources of power. Financiers had legitimate power as well as the power to coerce the state and the federal government to address schistosomiasis diagnostics. One NGO primarily performed some financing activity targeting schistosomiasis control through the school-based deworming exercise. The NGO also has informational power to bring about change.

> "*I do not think that schistosomiasis is really prioritized and there is probably no funding line for it. Funding is also a big issue. No matter the charges, the funders have their interest. If they insist that they want to fund a certain disease, other diseases will suffer.*" WHO state technical Officer.
>
> "*we basically provide technical assistance for the government to be able to carry our deworming. . . It involves anything from policy, advocacy, planning and collection and distribution of the drug, monitoring the program and. . . so we supply, we provide funding for them, we also provide the technical know-how, working with the state. . . well, we went to the government to say we would have to work with them to carry out a state-wide deworming program so in a way should I say we initiated it but it's the government program. . . and we do not, we are not the one that provide the drugs, the drugs are provided by the federal ministry of health, it's a free donation. . . through WHO and WHO is the source of supply*" Country Director, Evidence Action.

Academia/Research

We found three persons in Research and who all performed dual roles. Two were both doctors and researchers, while one was as both a researcher and a laboratory scientist. Researchers exhibited powers as experts based on technical knowledge and could identify other stakeholders as well as reach out to these stakeholders. As such, they had some form of informational power.

> "*. . . based on the report we had, what we did was to get the NGOs working in those areas to get to their local health authorities to let them know of the problem of schistosomiasis because the cases found here were actually from the local health authorities who gave us the medications for free.*" Researcher and Doctor, male.
>
> "*I think the program covers all local government what I now do not know is if they've been able to identify some high-risk regions in the state and have intensified program in those regions as compared to the places with low risk,. . . but I know the program, the NTD program is state-wide thing*" Researcher and Doctor, female.
>
> "*I want to talk about one, political will, because there are a lot of politics that go around which—you have planned something and because of one thing you don't they just stop it all of a sudden.*" Researcher and Laboratory scientist, male.

Stakeholder Interest Thematic Analysis

Most of the interviewed stakeholders were interested in the device and its use for the diagnosis of schistosomiasis. **Table 4** shows the grading of their level of interest.

Community-Level Stakeholders

Members of the community did not show a strong interest in the device due to a lack of understanding of how the device works, low level of awareness of the disease, and also because they looked up to the health workers to make certain decisions about diagnosis and treatment. However, other stakeholders were able to give insight into the patients' perspectives on this device.

> "*yes, you need sensitization because if you don't sensitize them, they will not know the value of this*" CHO and Community Mobilizer, female, rural area.
>
> "*If the government provides equipment that can bring out result instantly*" Guardian, female, urban area.

Healthcare Level

Medical personnel appeared to be interested in the device improving the diagnostic process and increasing efficiency, especially in hard to reach areas.

> "*I think that's a good idea, and it will be a good development like in the case of malaria...so, it's just a welcome idea*" CHO and Community mobilizer, rural LGA.
>
> "*I know that you people are always moving forward, so I look forward to whatever advances you can make you know to make life easy for us here*" Laboratory scientist, Private lab.
>
> "*If such a device is brought to this healthcare facility, I think it will be easier for us to diagnose patients if such a case is brought to us.*" CHO, Health center, urban LGA.

Organizational Level

At the organizational level, the PHC coordinator and NTD officers were interested in the device easing workflow and improving diagnosis, thereby helping their output.

> "*If you can innovate one that can be appropriated for the ease of local use without microscopy, it will be good since it will be something easy to work with*" PHC coordinator and MOH, male, urban LGA.
>
> *Yes. This is because some will not give you the consent to take their children's urine. We need to convince them totally before samples can be taken...Connecting with the DSNO and going to the UCH (tertiary hospital) takes a very long time. The result also takes time to arrive. It will be better if the diagnosis is done at the PHC level.* PHC coordinator, female, rural LGA.

For the NTD officers, the introduction of the device would increase the effectiveness of their work and reduce waiting times for the conformation of cases from secondary and tertiary hospitals.

> "*There is no machine. We do have labs but we are limited to some tests to be carried out at the LGA level. We have to take the samples to UCH (tertiary hospital) to test if it is schistosomiasis...We have lab scientists at the LGA now but the materials they need are not available. If there are materials and equipments to use, they should be able to work*" NTD officer, male, rural LGA.
>
> "*It should let us know people that are coming down with schistosomiasis...*" NTD officer, male, urban LGA.

Policy/Economic Environment Level

At this level, all stakeholders were interested in the device improving schistosomiasis diagnosis and reducing the impact of disease within the state.

> "*Diagnosis is key. For example, tuberculosis control starts with diagnosis before anything can be done. To do this properly, we have to strengthen the labs as the diagnosis and the confirmation of the cure end in the lab. We are advocating point of care devices that could make a diagnosis of some of the public health diseases without a lot of sophistication*" WHO state technical officer.
>
> "*but I think it's...it's potentially a game-changer as to how we do field surveys for Schisto and STH so it's something personally I would really like to get involved in*" Country Director, Evidence Action.

Researchers mentioned the importance of the device's input in quick diagnosis and its importance as a quick screening tool for those with infection or highly endemic regions.

> "*They will get the buy-in. If it is for schistosomiasis, the private facilities in places where they have a high burden of that will be interested*" Researcher and Doctor, male.
>
> "*People will embrace it. I'm so sure of that... In fact, already I'm falling in love (with the device)*" Researcher and Laboratory scientist.
>
> "*So if there are better diagnostic test or methods or stuff, that might be able to help so that there are no missing cases, there are obviously missing cases, and I feel that even the few, the ones that we see, they can be picked earlier before it gets to the stage of frank haematuria. They can be picked earlier if we have easy-to-use diagnostic or screening test kit.*" Researcher and Doctor, female.

Stakeholder Classification and Ranking

Based on the stakeholder power base, and interest evidence available from the interviews, 2 interviewers/researchers read through the transcripts and ranked stakeholders for co-creation according to their power and interest independently (**Table 4**). Any differences in the ranking were resolved by a more senior researcher.

Stakeholder Power/Interest Matrix

Based on the ranking of the stakeholder power and interest, stakeholders for co-creation were mapped into a power interest matrix to identify stakeholders who were important to co-creation. Stakeholders could fall into the following categories (**Figure 4**): players, context setters, crowds, and subjects (49).

From our analysis, the stakeholders important for co-creation clustered into two categories: "crowd" and "key players." The "crowd" stakeholders are characterized by low power and low interest. This category is predominantly made up of community-level stakeholders within stakeholder categories 1 and 2. They may have a high impact if they act together toward a goal.

The "key players" stakeholder group consists of category 3–7 stakeholders except for the community mobilizer who falls under category 2 stakeholder. These stakeholders demonstrate high power and high interest. These stakeholders also fall within the organizational, healthcare, and policy/financial environment levels of the healthcare system. Although these players appear to have a high influence/power, these do not necessarily mean high impact since they cannot enforce acceptance by the patients and the community. No stakeholder fell within the category of stakeholders with high interest and low power (subjects) or those with high power and low interest (context setters).

DISCUSSION

This study assessed and mapped stakeholders' interest, influence/power, and position within the schistosomiasis diagnostics landscape concerning the development of a device for improved diagnosis of schistosomiasis. Engaging and co-creating with stakeholders in diagnostic device development and adoption is known to be important for successful deployment and use of diagnostic devices. We improved upon an existing framework for stakeholder identification and applied it to the stakeholder identification process for co-creation. This framework can also be used to identify implementing

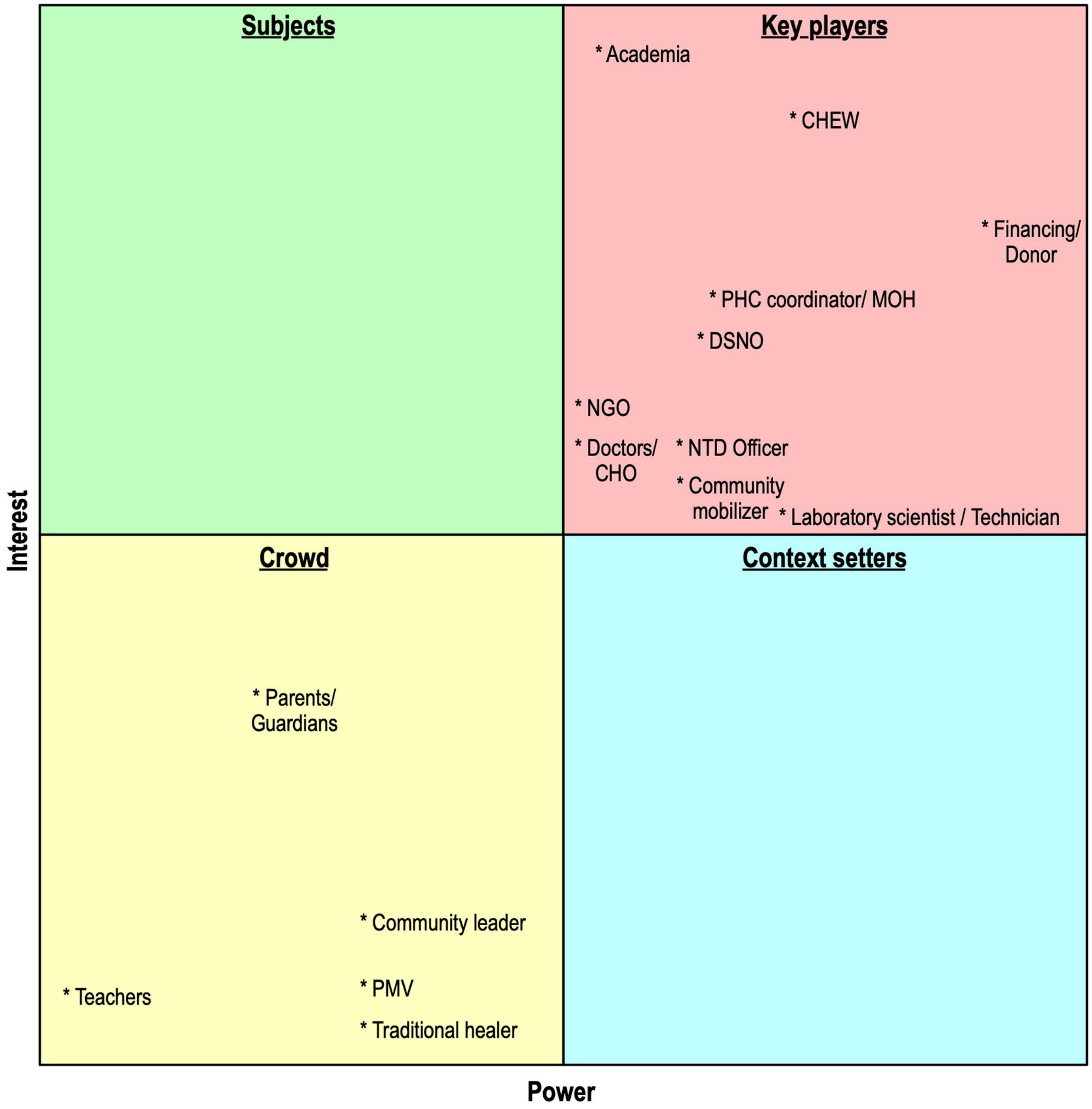

FIGURE 4 | Stakeholder mapping using a power/interest matrix.

stakeholders. We also analyzed relevant stakeholders' power, interest, and stakes for device co-creation using a power-interest matrix. This strategy will help to identify relevant stakeholders within the field of study and develop ways of engaging stakeholders based on the outcome of the analysis. To the best of our knowledge, this is the first study using a three-stage stakeholder approach to co-creation for a device for *S. haematobium*.

Key Findings

Evidence from the analysis indicates two main uses of stakeholders: co-creation and adoption. It is also clear that some stakeholders fall into both the co-creation category and the implementation category. This is similar to what was found by van Limburg (50).

Among stakeholders for co-creation, most of the identified stakeholders within a formally organized system showed greater interest in the development of the device to either improve their work or increase efficiency. This suggests that the non-availability of point of care devices can impact on disease management of schistosomiasis. Although stakeholders at the community level had a low interest, this is likely due to low awareness of the disease, especially in its early stages or in cases of light infections (12, 42). Besides, the consequences of non-treatment are not probably clear to them due to the long time-to-complication seen in the disease (1, 2, 7).

The community-level stakeholders appear to demonstrate a low level of influence when analyzed individually. However, since the social power type was more common among these stakeholders, the stakeholders acting together can demonstrate a high level of power (26, 51, 52). For instance, they can decide not to allow the use of devices for testing within the community during large scale implementation. They can also refuse to go for testing based on their beliefs about the disease. As such, regardless of their low level of interests and power, it is important to keep them informed on device development processes such as prototypes for testing and as well as awareness campaigns that may precede device testing and adoption (29). Regular updates to the community will increase mobilization and buy-in, as well as the willingness to pay for schistosomiasis testing.

The most important type of stakeholders for our co-creation plan are the key players. These stakeholders demonstrated high levels of power by acting as key players within the health system (medical and organizational) and policy environment. These stakeholders are important for device co-creation and validation. The key players are important for strategizing and guiding product development. For instance, laboratory personnel can give insight to the peculiar challenges of equipment used within this context which may be different from the environmental context of the device developers. As expected, the financing/donor stakeholder has the highest level of power within stakeholders for co-creation because of the problems of financing healthcare and programs within the developing country context. It is well-known that donors strongly determine the direction of health policy within the context of Lower Middle-Income Countries (LMICs) (26). Engaging and working closely with these stakeholders will improve device design as well as increase acceptability by stakeholders who are important to adoption and implementation.

Limitations

One limitation of our study was that we did not interview some stakeholders, for instance, political actors and media, who may be important for implementation, as well as the Federal Ministry of Health (FMOH) staff who may be important for co-creation in our interviews. However, these do not strongly influence the results of our work. It is known that the FMOH as a stakeholder is primarily involved in giving policy direction for schistosomiasis control and elimination (9). State governments are by law able to domesticate the policy and adopt what works for them by actively engaging with other non-state actors directly. Results of what works and progress on the schistosomiasis control program are usually reported to the FMOH. As such, we believe, we can leverage existing communication channels between the state and federal ministry to engage with stakeholders within the federal ministry during co-creation.

In respect of stakeholders for implementation, political actors especially were not interviewed because of the rapidly changing political landscape (52) in the state at the time of data collection and the long-life cycle of device development which creates problems with reengaging every new political actor throughout the device development lifecycle. Since co-creation is a major step in the life cycle of device development before the implementation phase, we believed that interacting with these co-creating stakeholders can increase our visibility within the healthcare context. Moreover, since some stakeholders are important for co-creation and implementation, our continuous engagement with these co-creating stakeholders would help to further identify other important stakeholders for implementation and adoption, as well as influence these implementing stakeholders (52). Finally, it is important to have a working prototype of the device first before involving other important implementers such as political actors and the media.

Another limitation is that some of our findings may not be generalizable to other parts of the country. Nigeria is a multi-ethnic society with ethnic groups concentrated in different regions. As such, the culture of the predominant ethnic group can affect how stakeholders interact with each other, how stakeholder roles are assigned, and the power dynamics within the schistosomiasis diagnostics landscape. For instance, in some parts of Nigeria, religious leaders may be a stakeholder within some communities. However, we believe this may not affect the result and the interpretation of the power-interest matrix for co-creation.

Future Directions

In the future, we plan to further identify the value proposition of stakeholders for device development, as well as explore relationships between the stakeholders using social network analysis for both co-creation and implementing stakeholders. Identifying how stakeholders collaborate and communicate can aid in stakeholder engagement leveraging on the relationship ties to achieve mass acceptance and application of the diagnostic device.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

Ethical approval for the study was obtained from the Ethical Review Committee of the College of Medicine, University of Ibadan, Nigeria (NHREC/05/01/2008a). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

AO determined the overall structure of the study and the protocol and aligned it with the inputs from MK, OO, JD, and JV. AO analyzed the data with input from MK and OO.

All authors reviewed the analyses, interpretation, reporting for critical content, and read and approved the final manuscript.

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Co-designing eHealth and Equity Solutions: Application of the Ophelia (Optimizing Health Literacy and Access) Process

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Background: The unequal access, challenges and outcomes related to using technology have created the digital divide, which leads to health inequalities. The aim of this study was to apply the Ophelia (Optimizing Health Literacy and Access) process, a widely used systematic approach to whole of community co-design, to the digital context to generate solutions to improve health and equity outcomes.

Methods: This was a mixed method study. A cross-sectional survey was undertaken at 3 health organizations in Victoria, Australia using the eHealth Literacy Questionnaire (eHLQ) as a needs assessment tool. Cluster analysis was conducted to identify subgroups with varying eHealth literacy needs. These data, combined with semi-structured interviews with clients, were used to generate vignettes representing different eHealth literacy profiles. The vignettes were presented at co-design workshops with clients and health professionals to generate solutions for digital health services improvement. Expert validation and proof-of-concept testing was explored through mapping the process against Ophelia guiding principles.

Results: The cluster analyses identified 8 to 9 clusters with different profiles of eHealth literacy needs, with 4 to 6 vignettes developed to represent the eHealth literacy strengths and weaknesses of clients at each of the 3 sites. A total of 32, 43, and 32 solutions across 10 strategies were co-created based on ideas grounded in local expertise and experiences. Apart from digital solutions, non-digital solutions were frequently recommended as a strategy to address eHealth literacy needs. Expert validation identified at least half of the ideas were very important and feasible, while most of the guiding principles of the Ophelia process were successfully applied.

Conclusion: By harnessing collective creativity through co-design, the Ophelia process has been shown to assist the development of solutions with the potential to improve health and equity outcomes in the digital context. Implementation of the solutions is needed to provide further evidence of the impact of the process. The suggested inclusion of non-digital solutions revealed through the co-design process reminds health organizations and policymakers that solutions should be flexible enough to suit individual needs. As such, taking a co-design approach to digital health initiatives will assist in preventing the widening of health inequalities.

Keywords: co-design, eHealth literacy, health equity, digital divide, digital health, ophelia process, eHLQ

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INTRODUCTION

Technological advancement has ushered in a new frontier for health care delivery on a personal level. From seeking information to making appointments, monitoring health to managing health records, eHealth or digital health has revolutionized how health information and services are accessed and used in recent years (1–3). In the wake of the COVID-19 pandemic, telehealth has become an important tool in providing patient consultations and treatments during lockdown. The health care industry describes the pandemic as a "breakthrough event" for digital health and expects the acceptance and usage of digital health solutions will continue to increase (4). The World Health Organization (WHO) also acknowledges that digital technologies have the potential to play a major role in improving public health and recommends prioritizing development and use of health technologies to advance the health-related aims of the Sustainable Development Goals (5). However, not everyone has the same access or skills to take advantage of the benefits and convenience of digital health.

The unequal access, challenges and outcomes related to using technology have created a gap between users and non-users or unskilled users, described as the digital divide (6–9), leading to the potential widening of health inequalities in the age of eHealth (10, 11). The WHO also cautions that innovation and technology should be used to help reduce inequities instead of becoming another mechanism for leaving people behind (12).

Studies of the digital divide relating to health found that barriers faced by the digitally disadvantaged populations can be linked to low eHealth literacy (13–15), defined as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" (16). For any eHealth or digital health solutions to be adopted, it is posited that the eHealth literacy needs of users must be addressed (16–18). Besides, it is recommended that user-centered principles, with requirements of users as the primary focus (19), be applied in digital health intervention development (20, 21). In line with the user-centered principles is the co-design approach (22). It has been advocated that patients and the workforce should take a more direct and active role in identifying, implementing and evaluating health care solutions (22–24). Robert et al. even argue that patients are indeed the biggest resources for quality of care improvement (24). This approach uses the lived experience of users for service design, with users as active advisors and consultants (19). It is described as "collective creativity as it is applied across the whole span of a design process" (22), and the approach has been found to develop a sense of ownership among users (25–27). Co-design is considered best practice in research for indigenous people in Australia, Canada, and New Zealand and the power-sharing between developers and users can serve "to reduce inequality and empower vulnerable communities" (28).

Yet, in a recent systematic review of eHealth interventions targeted at socially disadvantaged groups who are most at risk of low eHealth literacy, it was found that user-centered principles were not discussed, and eHealth literacy needs were generally not considered. User involvements were usually in the form of focus groups for needs assessment which involved limited respondents or at usability testing when the intervention was already designed (29). The findings reflect the growing concern that there is a lack of frameworks or guidelines to inform the development of digital health solutions that meet eHealth literacy needs (30), and disadvantaged populations are overlooked in digital health solution design (31). As such, vulnerable groups are at risk of becoming marginalized in the digital age (29, 32).

With a co-design approach as one of the guiding principles, the Ophelia (Optimizing Health Literacy and Access) process is a method for co-creating solutions to improve access, equity and outcomes by addressing health literacy needs (25, 26). Studies have found considerable success in using the Ophelia process to co-design intervention ideas, using the Health Literacy Questionnaire (HLQ) as an assessment tool. In systematically applying the process to 9 health sites in Victoria, Australia, 21–78 intervention ideas within each of the sites were generated (26). Another application in a Melbourne public hospital setting produced 15 potential solutions across 3 key themes for the improvement of hospital care and services (33). A cardiac rehabilitation setting in Denmark also applied the Ophelia process and generated 47 unique ideas to improve the unit's health literacy responsiveness (34). Using intervention ideas generated from the Ophelia process, BreastScreen Victoria of Australia has recorded significantly increase in the number of screening bookings among women of culturally and linguistically diverse backgrounds (35). There are also other Ophelia projects currently underway in several European countries as part of the WHO National Health Literacy Demonstration Projects (34). However, to date, the Ophelia process has not been used to develop digital health solutions.

The aim of this study was to determine if the Ophelia process can be adapted into the digital context and applied to co-design solutions addressing eHealth literacy needs. By harnessing local wisdom from users and stakeholders as recommended in the process, it was expected that ideas grounded in local experience and expertise can lead to eHealth solutions for the improvement of health and equity outcomes.

MATERIALS AND METHODS

This was a mixed method study undertaken at Victoria, Australia from March 2018 to April 2019. Ethics approval was obtained from the Deakin University Human Research Ethics Committee (HEAG-H 146_2017).

Settings and Respondents

Participating organizations included 3 health sites: (1) a private primary care medical practice (i.e. practice which clients may be required to pay additional consultation fees) in metropolitan Melbourne (Site 1); (2) a not-for-profit community health service in metropolitan Melbourne (Site 2); and (3) a private primary care medical practice in regional Victoria (Site 3). The inclusion criteria were: (1) aged 18 years or older; (2) with or without any health condition; and (3) able to complete the questionnaire in paper-based format, web-based format or face-to-face interview. Exclusion criteria were: (1) experiencing obvious cognitive or mental health issues; (2) clinically unwell as deemed by their treating health care professionals; and (3) insufficient English to complete the questionnaire and do not have a family member or carer to assist them.

The Ophelia Process

The Ophelia process is built on the foundations of intervention mapping, quality improvement collaboratives and realist synthesis as previous described (25) and is guided by 8 principles described in **Table 1**.

The process involves 3 phases: (1) identifying needs; (2) co-design of interventions; and (3) implementation and evaluation (see **Figure 1**). Health literacy needs of target users are usually assessed by the HLQ, a multidimensional health literacy needs assessment tool (36). The HLQ was developed using a grounded, validity-driven approach aimed to assess people's experiences in understanding, accessing and using health information and services (36, 37). It has demonstrated strong construct validity and reliability in various contexts and settings (36, 38–40). The HLQ consists of 44 items representing 9 dimensions of health literacy: (1) Feeling understood and supported by health care providers; (2) Having sufficient information to manage my health; (3) Actively managing my health; (4) Social support for health; (5) Appraisal of health information; (6) Ability to actively engage with health care providers; (7) Navigating the healthcare system; (8) Ability to find good health information; and (9) Understanding health information well-enough to know what to do (36). The results from the HLQ needs assessment help create health literacy profiles which are then developed into vignettes, depicting the lived experience of people facing different health literacy challenges. These vignettes/stories are then presented at co-design (ideas generation) workshops with target users and frontline health professionals to harness local wisdom and generate solutions. These ideas are then acted upon based on organizational priorities and go through implementation, evaluation and ongoing improvement (25, 26).

The current study sought to undertake Phase 1 of the Ophelia process and the instrument for needs assessment was replaced with a questionnaire used for assessing eHealth literacy.

Step 1 – Project Set-Up

Three health organizations participated in the study seeking to understanding the eHealth literacy needs of their clients and generate ideas to improve health and equity outcomes at their organization.

Step 2 – Data Collection and Extraction

This step involved using the eHealth Literacy Questionnaire (eHLQ) as the needs assessment tool. Cluster analysis was then conducted to identify subgroups with varying eHealth literacy needs. The results were combined with semi-structure interviews to develop vignettes to be presented at the co-design workshops at Step 3.

The eHealth literacy questionnaire (eHLQ)

The multidimensional eHealth Literacy Questionnaire (eHLQ) was used rather than the eHealth Literacy Scale (eHEALS) (30, 41) because the eHEALS has a limited focus on information searching or evaluation (42) and is unsuitable for the cluster analysis and vignette development. The eHLQ was developed using a grounded, validity-driven approach (43). Through concept mapping workshops and an international online survey, the perspectives and experiences of a wide range of eHealth stakeholders including patients, health care providers, health informatic professionals, public health researchers and computer scientists, were integrated and 7 domains of eHealth literacy were identified:

(1) Using technology to process health information;
(2) Understanding of health concepts and language;
(3) Ability to actively engage with digital services;
(4) Feel safe and in control;
(5) Motivated to engage with digital services;
(6) Access to digital services that work; and
(7) Digital services that suit individual needs (44, 45).

Validity testing of the tool showed satisfactory evidence of construct validity and reliability across various settings (45). The eHLQ consists of 35 items with 7 scales representing the 7 dimensions of eHealth literacy. Each scale has 4–6 items, relating to a 4-point response option of strongly disagree, disagree, agree and strongly agree. Scale scores are calculated by averaging the item scores within each scale with equal weighting, each with a score range of 1–4 (45).

A cross-sectional survey was undertaken at the 3 health sites using the eHLQ. Recruitment of respondents was undertaken by approaching all clients present in the waiting area during set times at each site. A respondent information form was provided, and the completion of questionnaire was regarded as implied consent. Respondents were provided with the options of self-administration by paper or online or face-to-face interview. The interview option was provided so that people with likely low eHealth literacy could easily participate to maximize participation, equity, and quality of the research.

Additional demographic data including date of birth, sex, postcode, language spoken at home, education, health status, perceived health status, and use of technology were collected. Contact information of respondents was only collected if they indicated that they were interested in taking part in the semi-structured interviews and/or workshops.

Cluster analysis

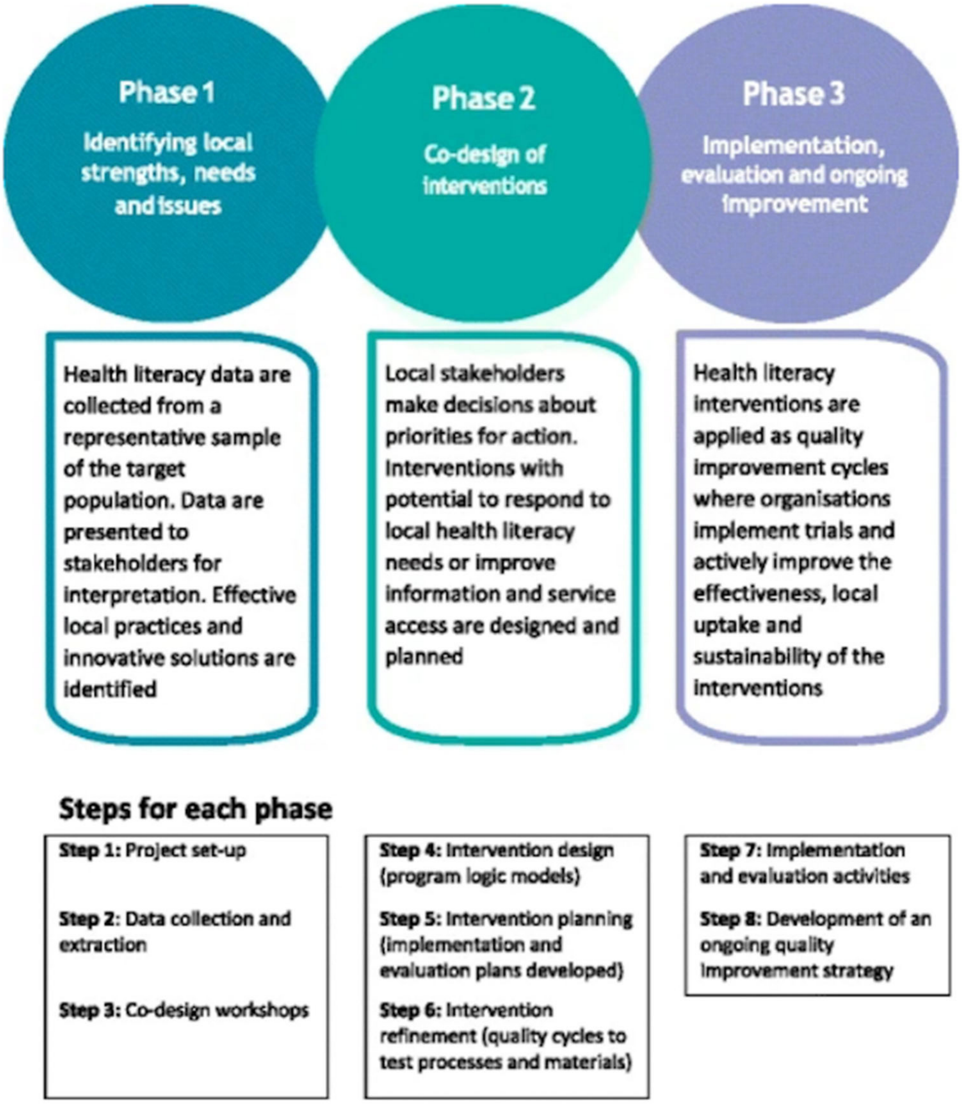
Cluster analysis is an analytical method for examining multivariate data and identifying groups of homogeneous observations (46, 47). It has been advocated as a patient-tailored approach to provide better understanding of heterogeneity among patient groups to allow for personalized and efficient interventions (48–50). To ensure equity planning for interventions, the Ophelia process recommends the use of cluster analysis, based on the 7 scale scores of the eHLQ, to classify target users into groups with different sets of eHealth literacy strengths and limitations.

To perform a cluster analysis, different techniques can be undertaken and which method to use depends on the type of variables, the aim of the analysis as well as intuition of the researchers (46, 47, 51). The approach used in the Ophelia

TABLE 1 | The 8 guiding principles of the Ophelia (Optimizing Health Literacy and Access) process*.

Principle	Description
P1. Outcomes focused	Improved health and reduced health inequities
P2. Equity driven	All activities at all stages prioritize disadvantaged groups and those experiencing inequity in access and outcome
P3. Co-design approach	In all activities at all stages, relevant stakeholders engage collaboratively to design solutions
P4. Needs-diagnostic approach	Participatory assessment of local needs using local data
P5. Driven by local wisdom	Intervention development and implementation is grounded in local experience and expertise
P6. Sustainable	Optimal health literacy practice becomes normal practice and policy
P7. Responsiveness	Recognize that health literacy needs and the appropriate responses vary across individuals, contexts, countries, cultures, and time
P8. Systematically applied	A multilevel approach in which resources, interventions, research and policy are organized to optimize health literacy

P, Principle.
**Adapted from Beauchamp et al. Table 1, p. 5 (26).*



Health literacy data are collected from a representative sample of the target population. Data are presented to stakeholders for interpretation. Effective local practices and innovative solutions are identified

Local stakeholders make decisions about priorities for action. Interventions with potential to respond to local health literacy needs or improve information and service access are designed and planned

Health literacy interventions are applied as quality improvement cycles where organisations implement trials and actively improve the effectiveness, local uptake and sustainability of the interventions

Steps for each phase

Step 1: Project set-up

Step 2: Data collection and extraction

Step 3: Co-design workshops

Step 4: Intervention design (program logic models)

Step 5: Intervention planning (implementation and evaluation plans developed)

Step 6: Intervention refinement (quality cycles to test processes and materials)

Step 7: Implementation and evaluation activities

Step 8: Development of an ongoing quality improvement strategy

FIGURE 1 | The Ophelia (Optimzing Health Literacy and Access) process. Source: Reproduced from Beauchamp et al. Figure 1, p. 5 (26).

process is hierarchical cluster analysis using Ward's method for linkage (25). A total of 3–20 solutions were specified in the current study.

For the selection of an optimal clustering solution, 2 main criteria were used based on the Ophelia process. The first was to examine the standard deviation of the scores. A standard deviation of above 0.6 indicated considerable variation within the cluster, however, it should also be noted that standard deviation could be high for small clusters. The second criterion was to consider the demographic data linked to the clusters. Two groups with quite similar eHealth literacy profiles but different demographics might require different strategies. Hence, demographics of the clusters needs to be considered. While there are other recommendations such as ignoring extremely small clusters or using statistical tests to validate group differences (46, 47), these methods are not applicable to the Ophelia process. As the purpose of the analysis is to generate targeted solutions, small groups still deserve attention following the equity driven guiding principle of the Ophelia process (**Table 1**). Hence, each solution needs to be examined carefully for the final optimal solution.

There is no consensus on what constitutes an adequate sample size in cluster analysis to generate a stable solution (50). Given the 3 diverse settings, a minimum of 100 respondents was estimated for each site, based on the experience in other Ophelia settings (26, 33, 35, 52). The treatment of missing values involved excluding a scale if over 50% responses were missing for a certain respondent, in accordance with the HLQ scoring in the Ophelia process. Any respondent with one or more scale scores missing was excluded from the analysis (53). Data analysis was performed using IBM SPSS Version 25.0 (RRID:SCR_002865) (54). The selection of cluster solutions was initially undertaken by one researcher (CC) and then reviewed by and discussed with another researcher (RHO).

Semi-structured interview

The purpose of the semi-structured interview was to gain insight into people's experiences in using digital health and provide context for the vignettes (25, 26). Respondents were mainly from the cross-sectional survey who agreed to take part and provided contact information. Oral consent was obtained if they agreed to be interviewed.

Each semi-structured interview was conducted over the phone and took about 30 minutes, covering their experiences of using technology. There were also questions specific to the use of digital health, privacy and whether they had support to use technology. Based on the interviewee's eHLQ scores, further questions were asked why they scored low on some scales. Respondents were also encouraged to discuss any other personal experiences or express their views on using eHealth. Notes were taken during the interview while the interviews were audio-recorded with consent from the respondents.

The data from the interviews were anonymized and combined with the cluster analyses to develop vignettes depicting the various experiences of how people used health information and services.

Step 3 – Co-design Workshops

Each co-design workshop is a brainstorming session for respondents to respond to the needs expressed in the vignettes, and usually requires 2–3 hours with 6–12 respondents (55). For this study, 1 community member workshop and 1 frontline health professional workshop were held at each site. Community members were recruited from the cross-sectional survey where respondents had provided contact details or referred by their health services. Frontline health professionals were recruited by senior managers of the organizations. All respondents provided written consent.

Each workshop started with an introduction of the project and an overview of the eHealth literacy survey results. Then, vignettes were discussed using the following guiding questions: (1) Do you know someone like this person/recognize this person in your clients? (2) What are this person's main problems? (3) What could be done to improve this person's health? and (4) What could community organizations/your organization do if there are lots of people/clients like this person?

Thematic analysis of the ideas, using mainly an inductive approach based on the content, was undertaken for each site. The ideas were further categorized into four levels: individual, family, practitioner and policy levels as described in the Ophelia process (25, 55). The analyses were undertaken by 1 researcher (CC) and results were reviewed by and discussed with another researcher (RHO).

Evidence for Application of the Ophelia Process

Expert Validation of Co-designed Solutions

Expert validation (56, 57) through experts (3 managers or staff of the participating sites) served as initial evidence of the potential usefulness of the solutions. Respondents were recruited by senior managers of the organizations. The solutions from the co-design workshops, thematically summarized, were organized into a questionnaire where the ideas were rated in terms of their importance and feasibility as well as to provide an estimation of the current situation. The rating was from 1 "not important at all" to 5 "essential," similarly, feasibility was rated from 1 "not feasible at all" to 5 "highly feasible and can be fully implemented," and current situation, was rated from 1 "never implemented" to 5 "fully implemented."

Proof-of-Concept of Application

A proof-of-concept was defined as successful application of the 8 Ophelia guiding principles for an Ophelia project (26). The results of this study were mapped against the 8 guiding principles (**Table 1**), to determine how well the principles had been operationalized. The evaluation served as evidence for the feasibility of using the Ophelia process in the digital context.

RESULTS

Respondents Characteristics and Overall eHealth Literacy

A total of 207, 206, and 117 questionnaires were collected at Site 1, Site 2, and Site 3, respectively. Respondents aged from 18 to

TABLE 2 | Sociodemographic characteristics of respondents of Site 1 (metropolitan primary care medical practice), Site 2 (metropolitan community health), and Site 3 (regional primary care medical practice).

Characteristics*	**Site 1 (*n* = 207)** ** *n* (%)**	**Site 2 (*n* = 206)** ** *n* (%)**	**Site 3 (*n* = 117)** ** *n* (%)**
Age (mean, SD) years	53.1 (19.4) Range: 19–93	61.4 (18.3) Range: 18–94	55.1 (16.6) Range: 24–91
Sex			
Female	125 (60.4)	124 (60.2)	74 (63.2)
Male	80 (38.6)	82 (39.8)	43 (36.3)
Education			
Primary school or less	4 (1.9)	2 (1.0)	0 (0.0)
Completed primary school	9 (4.3)	11 (5.3)	1 (0.9)
Did not complete secondary school	20 (9.7)	31 (15.0)	18 (15.4)
Completed secondary school	40 (19.3)	42 (20.4)	26 (22.2)
TAFE^/trade certificate/diploma	56 (27.1)	46 (22.3)	39 (33.3)
Completed university	74 (35.7)	69 (33.5)	33 (28.2)
Language at home			
English	137 (66.2)	122 (59.2)	108 (92.3)
Other	69 (33.3)	84 (40.8)	9 (7.7)
Socioeconomic status **			
IRSD 1 – 2 (lowest)	89 (43.0)	0 (0.0)	29 (24.8)
IRSD 3 – 4	2 (1.0)	1 (0.5)	3 (2.6)
IRSD 5 – 6	42 (20.3)	51 (24.8)	19 (16.2)
IRSD 7 – 8	66 (31.9)	69 (33.5)	0 (0.0)
IRSD 9 – 10 (highest)	2 (1.0)	76 (36.9)	63 (53.8)
Private health insurance			
Yes	116 (56.0)	75 (36.4)	60 (51.3)
No	89 (43.0)	124 (60.2)	57 (48.7)
Longstanding illness (may have more than one)			
None	105 (50.2)	72 (35.0)	50 (42.7)
Arthritis	29 (14.0)	58 (28.2)	31 (26.5)
Cancer	1 (0.5)	10 (4.9)	3 (2.6)
Heart disease	29 (14.0)	43 (20.9)	18 (15.4)
Diabetes	18 (8.7)	41 (19.9)	9 (7.7)
Respiratory condition	7 (3.4)	20 (9.7)	15 (12.8)
Anxiety	29 (14.0)	25 (12.1)	17 (14.5)
Depression	30 (14.5)	27 (13.1)	13 (11.1)
Other	31 (16.9)	38 (18.4)	19 (16.2)
Perceived health status			
Good to excellent	169 (83.7)	140 (68.0)	94 (80.3)
Fair to poor	34 (16.3)	58 (28.2)	23 (19.6)
Ownership of digital device (may have more than one)			
Computer/laptop	149 (72.0)	134 (65.0)	94 (80.3)
Mobile phone or smartphone	186 (91.6)	169 (84.9)	108 (92.3)
Tablet	100 (48.3)	85 (41.3)	58 (49.6)
Other	4 (1.9)	3 (1.5)	0 (0.0)
Average number of devices owned (mean, SD)	2.2 (0.9)	2.0 (1.0)	2.2 (0.8)
Use of digital communication platform (may have more than one)			
Email	155 (74.9)	141 (65.0)	102 (87.7)
Text message	159 (76.8)	139 (67.5)	102 (87.7)
Facebook	115 (55.6)	85 (41.3)	69 (59.0)
Twitter	14 (6.8)	10 (4.9)	7 (6.0)
Instagram	53 (25.6)	32 (15.5)	19 (16.2)

(Continued)

TABLE 2 | Continued

Characteristics*	**Site 1 (*n* = 207)** **n (%)**	**Site 2 (*n* = 206)** **n (%)**	**Site 3 (*n* = 117)** **n (%)**
Snapchat	26 (12.6)	10 (4.9)	15 (12.8)
WhatsApp/WeChat	55 (26.6)	48 (23.3)	11 (9.4)
Blogging	5 (2.4)	5 (2.4)	5 (4.3)
Forum/chat room	10 (4.8)	9 (4.4)	7 (6.0)
Other	8 (3.9)	5 (2.4)	4 (3.4)
Number of platforms used (mean, SD)	3.0 (1.9)	2.4 (1.8)	2.9 (1.5)
Looked for online information	158 (76.3)	140 (68.0)	98 (83.8)
Monitored health digitally	68 (32.9)	70 (34.0)	45 (38.5)

*SD, Standard deviation; ^TAFE, Technical and Further Education; *Characteristics presented as n (%) unless otherwise stated; **Socioeconomic status is classified by IRSD10 – The Index of Relative Socio-economic Disadvantage Decile 2016, ranking within Australia. This index is based on information provided by the Australian Bureau Statistics (58). Postcodes are divided into 10 ranks with higher number indicating more advantaged suburbs.*

94, with about 60% of them being female. About one-third of the respondents had university education. At least one-third at Site 1 (33.3%) and Site 2 (40.8%) spoke a language other than English at home while Site 3 respondents were mostly English-speaking clients (92.3%). Site 2 had the highest proportion of respondents who reported having some form of long-term chronic health condition (65%), comparing to Site 1 (49.8%) and Site 3 (57.3%). Use of technology was the highest among Site 3 respondents with 80% used a computer or laptop while Site 1 had 72% and Site 2 only had 65%. The use of the internet for information was also the highest among Site 3 respondents (85%), comparing to Site 1 (75%) and Site 2 (68%). See **Table 2** for details.

The overall eHealth literacy scores are presented in **Table 3**. The 3 sites demonstrated very similar scores. Most respondents appeared to have relatively good knowledge about their health conditions but might not always use technology for health. While they generally were comfortable with the security of eHealth systems, Site 2 respondents seemed to be not as confident as respondents of the other two sites. The scores also showed that many respondents from the 3 sites did not consider digital services met their needs.

TABLE 3 | eHealth literacy scores of participants of Site 1, Site 2, and Site 3.

Scales	**Scores (mean, SD)** **Score range: 1 (low) – 4 (high)** **Site 1 (*n* = 207)**	**Site 2 (*n* = 206)**	**Site 3 (*n* = 117)**
1. Using technology to process health information	2.56 (0.61)	2.57 (0.66)	2.66 (0.49)
2. Understanding of health concepts and language	2.92 (0.43)	2.96 (0.41)	2.92 (0.38)
3. Ability to actively engage with digital services	2.66 (0.70)	2.61 (0.72)	2.71 (0.60)
4. Feel safe and in control	2.83 (0.49)	2.78 (0.50)	2.95 (0.45)
5. Motivated to engage with digital services	2.59 (0.54)	2.64 (0.59)	2.67 (0.48)
6. Access to digital services that work	2.64 (0.46)	2.61 (0.45)	2.67 (0.43)
7. Digital services that suit individual needs	2.43 (0.58)	2.43 (0.57)	2.44 (0.54)

Vignettes Developed

Cluster Analyses

Due to missing data, 198, 200 and 112 respondents were included for the cluster analyses of Site 1, Site 2, and Site 3, respectively. The results identified 8 (Site 1), 9 (Site 2), and 8 (Site 3) groups of respondents with different eHealth literacy profiles. The profiles from the cluster analyses were then combined with demographics, health conditions and technology use to provide a detail picture of the characteristics of each profile (see **Table 4** for eHealth literacy profile of Site 1 and **Supplementary Tables 1**, and **2** for profiles of Site 2 and 3).

As shown in **Table 4**, among the 8 clusters of Site 1, 3 clusters (Clusters A to C) had generally higher scores across the 7 scales and 5 clusters (Clusters D to H) had lower scores but with different patterns. While the overall eHealth literacy scores of Site 1 demonstrated that respondents generally felt safe with digital health systems, the cluster analysis uncovered people from Cluster F who tend to report otherwise. Site 1 also had a "cluster" with only one member. The "cluster" was retained because older community members tended to refuse to participate in a survey about eHealth and this "cluster" provided some insights into a group of older people who were most likely being left behind in the digital age. For Site 2, the 9 clusters demonstrated very different patterns (see **Supplementary Table 1**). People from Cluster B with higher scores in scales relating to technology use had scores in "Scale 6 Access to digital services that work" and "Scale 7 Digital services that suit individual needs" comparable to the lower eHealth literacy clusters. There were also 2 clusters (Clusters D and F) reporting lower scores in "Scale 4 Feel safe and in control," indicating lack of trust in eHealth systems for the people from these clusters. While the overall eHealth literacy scores of Site 3 in Scale 4 was higher than the other 2

TABLE 4 | Example of and eHealth literacy profiles based on an eight-cluster solution for Site 1 respondents.

Cluster	A	B	C	D	E	F	G	H
Number of respondents	6	24	39	51	43	17	17	1
% in sample	3.0	12.1	19.7	25.8	21.7	8.59	8.59	0.51
eHLQ Mean score (SD)/ Score range: 1–4								
1. Using technology to process health information	3.73 (0.24)	3.27 (0.33)	2.73 (0.31)	2.69 (0.40)	2.21 (0.25)	2.51 (0.30)	1.38 (0.32)	1.00
2. Understanding of health concepts and language	3.93 (0.16)	3.43 (0.34)	2.98 (0.22)	2.90 (0.28)	2.68 (0.28)	2.66 (0.40)	2.85 (0.37)	1.20
3. Ability to actively engage with digital services	3.77 (0.15)	3.40 (0.40)	3.11 (0.33)	2.67 (0.46)	2.33 (0.45)	2.57 (0.35)	1.36 (0.36)	1.00
4. Feel safe and in control	3.83 (0.23)	3.28 (0.47)	2.93 (0.24)	2.72 (0.32)	2.80 (0.23)	1.93 (0.31)	2.79 (0.38)	1.60
5. Motivated to engage with digital services	3.77 (0.23)	3.17 (0.34)	2.79 (0.23)	2.71 (0.25)	2.21 (0.30)	2.54 (0.44)	1.69 (0.40)	1.00
6. Access to digital services that work	3.56 (0.29)	3.08 (0.39)	2.90 (0.22)	2.72 (0.30)	2.35 (0.22)	2.20 (0.31)	2.11 (0.29)	1.17
7. Digital services that suit individual needs	3.46 (0.46)	2.96 (0.34)	2.98 (0.14)	2.40 (0.29)	2.09 (0.32)	2.02 (0.13)	1.41 (0.40)	1.00
Sociodemographic characteristics								
Mean age	52.7	44.3	50.0	51.4	57.0	49.3	71.3	93.0
% Female	83.3	62.5	61.5	54.9	58.1	58.8	76.5	100.0
% Do not speak english at home	16.7	25.0	25.6	31.4	34.9	47.1	64.7	100.0
Average education	5.6	5.0	5.1	5.0	4.6	5.4	2.8	2.0
Average IRSD10	7.2	5.9	6.4	5.2	5.8	6.3	3.9	3.0
% Have private health insurance	50.0	54.2	61.5	58.8	60.5	64.7	17.7	0.0
Health conditions								
% No long-standing health condition	50.0	62.5	56.4	47.1	39.5	58.8	47.1	0.0
% Arthritis	16.7	4.2	10.3	9.8	16.3	17.7	23.5	100.0
% Cancer	0.0	0.0	0.0	0.0	0.0	0.0	5.9	0.0
% CVD/heart disease	0.0	8.3	12.8	21.6	14.0	5.9	17.7	0.0
% Diabetes	16.7	0.0	7.7	11.8	11.6	5.9	11.6	0.0
% Respiratory condition	16.7	4.2	2.6	2.0	0.0	5.9	5.9	0.0
% Anxiety	16.7	20.8	7.7	13.7	16.3	23.5	5.9	0.0
% Depression	16.7	12.5	10.3	15.7	20.9	17.6	0.0	100.0
Average number of health conditions	1.2	0.7	0.6	1.0	1.0	0.8	0.8	2.0
Average self-perceived health status	2.0	2.4	2.6	2.8	2.9	2.7	3.0	3.0
Technology use								
% Use computer	100.0	83.3	89.7	68.6	69.8	94.1	17.7	0.0
% Use mobile phone/smartphone	100.0	95.8	94.9	94.1	86.0	100.0	52.9	0.0
% Use tablet	66.7	62.5	64.1	51.0	30.2	58.8	23.5	0.0
Average number of digital devices	2.7	2.5	2.5	2.1	1.9	2.6	0.9	0.0
% Use email	100.0	91.7	89.7	80.4	60.5	88.2	11.8	0.0
% Use text messaging	100.0	91.7	87.2	84.3	60.5	88.2	41.2	0.0
% Use facebook	83.3	79.2	64.1	60.8	46.5	41.2	17.7	0.0
Average number of digital platforms	4.7	3.0	3.6	3.0	2.2	2.9	0.9	0.0
% Looked for information online	100.0	91.7	89.7	80.4	62.8	94.1	17.7	0.0
% Monitored health digitally	66.7	62.5	48.7	23.5	18.6	52.9	0.0	0.0

The eHLQ scores are highlighted using the traffic light system of color coding as recommended in the Ophelia process (56). Cells colored green represented higher scores, the range of yellow represent medium scores and red indicate lower scores. Education is represented by 6 categories: 1 = Did not complete primary school, 2 = Completed primary school, 3 = Did not complete secondary school, 4 = completed secondary school, 5 = Completed trade Certificate/Diploma/TAFE, 6 = Completed University or above. IRSD10 = The Index of Relative Socio-economic Disadvantage Decile 2016, ranking within Australia. This index is based on information provided by the Australian Bureau Statistics (58), postcodes are divided into 10 ranks with higher number indicating more advantaged suburbs. Self-perceived health status is represented by 5 categories: 1 = Excellent, 2 = Very good, 3 = Good, 4 = Fair, 5 = Poor.

sites, there were also 2 clusters (Clusters A and D) with lower scores in Scale 4, indicating concern for online security (see **Supplementary Table 2**). For the 2 clusters with the lowest scores in scales relating to technology use in Site 2 and Site 3, both clusters had scores in "Scale 2 Understanding of health concepts and language" that were comparable to the other higher eHealth

TABLE 5 | Description of clusters and vignettes.

Cluster	Description	Vignette developed
Site 1		
A	Tech-savvy and well-resourced	No
B	Young and digitally active	No
C	Good digital skills, healthy and digitally active	No
D	Average digital skills but digital active	Yes
E	Not interested in using technology but think eHealth is fine	Yes
F	Willing to use technology but not for health with concern about privacy	Yes
G	Good understanding of health with limited digital skills	Yes
H	No access or skills to use technology and limited understanding of health	No
Site 2		
A	Tech-savvy and well-resourced	No
B	Tech-savvy but poor access to useful digital services	No
C	Good digital skills and comfortable with eHealth	No
D	Good digital skills but concern about privacy	Yes
E	Limited digital skills but think eHealth maybe useful	Yes
F	Good digital skills but concerns about privacy and poor access to suitable digital services	Yes
G	Not interested in using technology but think eHealth is fine	Yes
H	Limited digital skills and not interested in technology	Yes
I	Good understanding of health and do not see technology useful	Yes
Site 3		
A	Tech-savvy, healthy and well-resourced	No
B	Tech-savvy with confidence in eHealth systems	No
C	Good digital skills and good understanding of health	No
D	Good digital skills but concern over privacy and poor experience with digital services	Yes
E	Average digital skills with limited access to suitable digital services	Yes
F	Average digital skills with poor access to suitable digital services	Yes
G	Limited digital skills but think eHealth is fine	Yes
H	Limited digital access and skills but good understanding of health	Yes

literacy clusters, indicating strengths among these clusters in this eHealth literacy domain. See **Table 5** for a summary description of the clusters.

Vignettes

Five respondents, one male and four females aged from 53 to 75, were interviewed and provided further insights into people's experiences in using digital health. Based on the cluster analyses and interviews, 4, 6, and 5 vignettes were developed for clusters with different patterns of eHealth literacy strengths and weaknesses for Sites 1 to 3, respectively. A vignette for Cluster H of Site 1 was not generated because there was only one member. See **Table 5** for descriptions of clusters with vignettes developed. See **Table 6** for an example vignette and **Supplementary Table 3** for all vignettes developed for the co-design workshops.

Digital Health Literacy-Related Improvement Activities Arising From Ideas Generation Workshops

Community member workshops included 6, 8, and 7 respondents at Sites 1 to 3, with 12 recruited from the cross-sectional survey who indicated interest and 9 from referrals by managers of the participating sites. Participants of the health professional workshops conducted at Sites 1 and 3 (4 and 5 participants, respectively), were recruited by senior management. The workshop at Site 2, attended by 26 health professionals, was undertaken as part of the monthly program meeting.

The personas embodied in the vignettes were well-recognized as persons or patients familiar to workshop respondents, prompting engaging discussion at all workshops. Some respondents even identified themselves as certain vignettes. The main problems identified by workshop respondents included lack of digital skills, lack of access to credible and reliable online health resources, concern about internet security, inadequate understanding of one's own health condition, using inappropriate digital devices and having eHealth systems that were difficult to use (see **Supplementary Tables 4–6**). The issues were similar across the 3 sites except Site 3 had the unique problem of no access to internet connection due to its regional location. Several respondents also pointed out that not using technology should not be regarded as a problem *("She's got no problem."* – Site 1 community member; *"Technology is not going to make him healthy."* – Site 2 health professional).

At Site 1, 4 vignettes were presented which generated 32 solutions from the 2 workshops. Thematic analysis revealed 9 themes or strategies across the 32 ideas. Three of the strategies related to technology use such as providing access and support to skill training and reliable resources. Other strategies were more diverse such as ensuring effective communication with clients, harnessing social support, motivating clients to engage with own health, using multi-disciplinary approach to health care, capacity building for health professionals and ensuring access to both conventional and digital health services. A total of 17 ideas were targeted at the individual level, 11 at the policy level and 2 each for the practitioner and family levels. At Site 2, 6 vignettes were presented which generated 43 solutions across 10 themes where 15 were targeted at the individual, 17 ideas on the policy level, 5 on the practitioner level and 6 on the family or social level. At Site 3, 32 solutions were generated from 5 vignettes representing 10 strategies, where 24 were targeted at the individual, 6 at the

TABLE 6 | Example of a vignette – Cluster G (Maria) of Site 1.

Number of respondents	% in sample	Mean age	1. Using technology to process health information	2. Understanding of health concepts and language	3. Ability to actively engage with digital services	4. Feel safe and in control	5. Motivated to engage with digital services	6. Access to digital services that work	7. Digital services that suit individual needs
17	9	71.3	1.38	2.85	1.36	2.79	1.69	2.11	1.41

Maria is a cheerful 82-year-old grandma with primary school education. She speaks limited English but can manage basic daily conversations. Living with her husband, she has two daughters and five grandchildren, who live close by. Having arthritis does not stop her from doing what she loves most – cooking for her family.

Maria's daughter gave her a mobile phone last year and her grandson tried to teach her to use it without success. They ring her, but she never answers her phone either because she doesn't hear the phone ring, or she just keeps pressing the wrong buttons. The buttons are just too small, and she can hardly see them.

Reading text messages is another next to impossible task. She has given up learning as she believes she will die soon, so, there is no need to learn these "new" digital technologies. She notices that her family doctor types her information into his computer, but she has no idea what that means. She knows you can find health information on the internet, but she strongly believes that you should always ask health professionals for advice, not the internet.

policy level and 1 each for the practitioner and family levels. The themes at Sites 2 and 3 were the same as Site 1 except the two sites had an additional strategy about technology, which was to provide eHealth systems that meet different needs. See **Table 7** for the thematic analysis results of strategies, number of solutions and some examples of solutions at the 3 sites.

While the strategies were generally consistent across the 3 sites, some of the solutions could be very similar but some were unique to a certain site. Common solutions around technology use included providing access to technology training programs, support clients to choose appropriate digital devices, and give links to reliable and trustworthy websites. Another common solution recommended was to provide physical handout or different formats of health information, demonstrating that eHealth literacy needs could be met by both technological or non-technological solutions. In addition, the solutions might focus on the skills of individual clients but could also target health professionals such as ensuring clinicians had adequate resources to support clients. Advocating the government in terms of electronic health records safety was another common solution suggested to address people's concern over privacy and security. However, the practice of each organization could also lead to some unique solutions. For example, for the strategy of "Ensure effective communication to meet individual needs," Site 1 had the idea of "Ensure the data collected at online booking are available at the patients" appointments' as online booking was available in this site. For Site 2, this strategy included the idea of "Ensure interpreters are available for culturally and linguistic diverse communities" as this site had a culturally diverse client base. Details of the solutions are presented in **Supplementary Tables 4–6**.

Evidence for the Application of the Digital Ophelia Process

Rating Questionnaire

The intervention ideas rating questionnaire was completed by 4, 3, and 3 executives or staff members at Sites 1, 2, and 3, respectively. About half of the ideas were rated very important or essential and many ideas were rated feasible by individual respondents at all sites. There were no clear unimportant solutions. There were also a range of opinions on estimated current practice. See **Supplementary Tables 4–6** for the very important or essential ideas rated by all respondents at the 3 sites.

Proof-of-Concept Application

In mapping the results of the study against the 8 guiding principles of the Ophelia process (**Table 1**), many of the principles were mostly or partially applied while further evidence was required for the sustainable principle (P6) as this study only involved Phase 1 of the process. One of the aims of this study was to specifically develop intervention ideas for health improvement (P1 Outcome focused). However, sites generally viewed the project as a pilot project and did not see it as their own initiative for system and services improvement, leading to partial application of this principle. By using the eHLQ for eHealth literacy needs assessment, the vignettes provided insights into the eHealth literacy challenges of different client groups and helped identify local needs (P4 Needs-diagnostic approach). The participation of community members and health professionals at co-design workshops ensured that relevant stakeholders were engaged (P3 Co-design approach), providing local wisdom (P5 Driven by local wisdom) to help generate responsive actions addressing the different needs of clients (P7 Responsiveness). For the needs assessment using the eHLQ, respondents were provided with the option of face-to-face interviews to ensure that older people and people with lower literacy were included as an equity driven strategy. The cluster analyses further ensured that small groups facing eHealth literacy challenges were included, leading to intervention ideas such as non-digital or culturally appropriate health information to meet the diverse needs of different client groups. Hence, P2 Equity driven was mostly applied. The solutions co-designed at the workshops spanned across 4 levels including the individual, family, practitioner and policy (P8 Systematically applied) but feasibility of the implementation of the ideas needed to be established. Besides, evidence for the sustainability (P6) of the ideas required further application of the remaining Ophelia phases. A summary of the evidence on how the 8 guiding Ophelia principles have been operationalized are presented in **Supplementary Table 7**.

TABLE 7 | Co-designed strategies and number of solutions.

Strategies		Number of solutions		
		Site 1	Site 2	Site 3
1	Provide training or encourage use of technologies	7	4	5
	Examples of solutions: • Advertise or provide access to technology training programs • Provide a "digital navigator" to interact with clients in the waiting room to provide information or assist in using digital devices • Support clients to choose appropriate digital device(s)			
2	Provide access to reliable and trustworthy eHealth resources	3	3	5
	Examples of solutions: • Give clients specific links to navigate to appropriate websites • Sharing of consumer-focused eHealth resources between partner organizations • Establish a way that the clinic's recommended digital services and apps can be easily downloaded by clients to their own devices			
3	Support clients with concerns on privacy and security of eHealth systems	3	5	3
	Examples of solutions: • Educate clients on how eHealth services are provided with security and privacy considerations • Advocate government to take responsibility in ensuring the safety and security of electronic health records • Provide a health summary in physical form if client decides not to use electronic health records			
4	Provide technologies and eHealth systems that meet different needs	–	3	1
	Examples of solutions: • Involve users when developing websites or digital technologies to match their needs and skills • Advocate government to ensure electronic health records are up to date • Ensure organization information technology systems are working smoothly to work with clients efficiently			
5	Ensure effective communication to meet individual needs	4	8	2
	Examples of solutions: • Provide health information in multiple formats such as prints, audio, video, diagrams, large print or appropriate languages • Encourage clinicians to use plain language and write down information and instructions for clients • Support practitioners with access to culturally appropriate resources			
6	Harness family and social support	4	9	1
	Examples of solutions: • Encourage volunteers, friends or family members to provide regular practice in using technologies through one-on-one coaching or mentoring • Encourage and support family members to manage health for the elderly • Provide a space and opportunities for social networking among clients to share good health information			
7	Motivate clients to actively engage with own health	6	3	6
	Examples of solutions: • Educate clients about their health conditions, assist them to set up personal goals and link their interest to health-promoting activities • Connect clients' interest to technologies and provide positive experiences such as using iPad to demonstrate exercise or provide feedback during consultations • Provide access to community educators or nurses to promote understanding of own health condition			
8	Use a tailored and multi-disciplinary approach to health care	2	2	5
	Examples of solutions: • Refer clients to key services, e.g., mental health, exercise, etc. • Support clinicians with better access to medical history of clients (with clients' consent) to facilitate a team-approach to health care • Provide a comprehensive multi-disciplinary "one-stop-shop" in one session with content that really helps clients			
9	Build capacity for evidence-based practice	1	2	1
	Examples of solutions: • Ensure health professionals have a genuine understanding of available health education courses • Provide clinicians with ongoing professional development on eHealth • Explore best practice and health evidence and support clinicians with ongoing professional development			
10	Provide access to conventional and digital health services	2	4	3
	Examples of solutions: • Connect with clients using appropriately tailored communication platform • Provide clients with summaries of medical history and/or medication in printed formats • Keep in mind that there are people who are "out of the web" in strategic planning			

DISCUSSION

By using the Ophelia process with the eHLQ as the needs assessment tool, numerous solutions to improve health and equity outcomes were generated in 3 disparate health settings. While similar strategies were identified across the settings, solutions that addressed the specific needs of subgroups and were fit for the local context were suggested by clients and health professionals through co-design. About half of the ideas were rated very important or essential by the relevant executives or staff of the participating sites and the proof-of-concept also showed that most of the guiding principles of the Ophelia process were applied. As such, a clear and reproducible pathway to co-designing solutions in the digital context has been demonstrated in this study. The results also demonstrate that the Ophelia process can be adapted into the digital context and applied to co-design solutions addressing eHealth literacy needs.

A feature of the Ophelia process is the use of vignettes to provide real-life stories of people facing challenges in using digital health. The vignettes were derived from the eHLQ, a multi-dimensional tool assessing the 7 domains of eHealth literacy. As such, the experience was not restricted to digital skills or evaluating online health information; motivation, privacy concern, interaction of digital health systems or understanding of health concepts were also assessed. Understanding the various aspects of eHealth literacy will have implications for the planning of solutions to address eHealth literacy weaknesses. For example, addressing privacy concerns instead of simple digital training will likely be more useful to motivate people should internet security stand in the way of using technology. On the other hand, people with limited digital skills but who believe that digital health is useful will likely benefit from some skills training.

A strength of the Ophelia process is the use of cluster analysis to gain in-depth understanding of the needs of subgroups. The pattern of the total scores of each organization was similar (**Table 3**). If these scores and descriptions are to be used to "tailor" digital health solutions, these organizations may end up providing a limited range of similar solutions for their clients. By using cluster analysis, 8 to 9 clusters with different patterns of eHealth literacy strengths and weaknesses in each setting were identified. These clusters provided valuable additional information and insights into the different needs of various client groups. While the overall mean scores indicated that clients were generally comfortable with the security of eHealth services, there were clusters within all 3 organizations that expressed privacy concerns, especially in Site 2 where 19% of the sample (clusters D and F) had doubts over how their health data were used (**Supplementary Table 1**). Hence, in using traditional analysis such as mean scores and descriptions to "tailor" solutions, the privacy concerns of 19% of Site 2 clients will likely be overlooked. If a widescale digital solution was implemented in Site 2 based on the total scores, about on fifth of the clients may hesitate to adopt the new service. The cluster analyses also revealed certain groups of people who were likely to be facing challenges in the digital age, such as the single-member cluster of Site 1 (Cluster H), a "cluster" that represented older community members who were most likely to have no skills or access to digital technologies. Instead of ignoring these small clusters as recommended in traditional cluster analysis approaches (46, 47), the retention of such clusters as guided by the Ophelia process will be in a better position to promote equity. To bridge the digital divide, it is essential to identify people who are experiencing challenges in accessing and using digital health information and services. As such, their needs are considered when developing and implementing quality improvements and interventions.

The Ophelia approach to develop vignettes also includes examining demographics and personal experiences. The resulting mix of information allows for a lively description of eHealth literacy strengths and weaknesses along with potential factors that may impact eHealth literacy, with the expectation that different solutions may be generated for different vignettes. For example, both Site 1 and Site 2 have a culturally diverse client base and strategies to address language barriers are likely to be needed, while these strategies may not be essential to Site 3 where clients are predominately English-speaking or can communicate in English as they choose to attend a private medical practice. The inclusion of personal experiences derived from the semi-structured interviews also allows users to put a voice into the vignettes and adds valuable insights into the eHealth literacy profiles. For example, the lack of internet infrastructure in the regional area revealed by an interviewee provides clues into one of the reasons for limited access to digital health services. Hence, strategies to meet needs such as the lack of internet infrastructure for regional clients will be required but not for metropolitan users.

The use of vignettes to describe people's needs and challenges in the Ophelia process follows recommendations that vignettes should be used to assist digital health development (58–60). This approach, as in the Ophelia process, generates a safe and pragmatic environment where respondents genuinely engage with familiar and concrete material in text, oral and narrative formats. Respondents then draw directly on their personal practices and experiences to accumulate a wide range of thoughtful and realistic solutions to the multidimensional lives embodied in the vignettes. Respondents frequently recounted their own success stories of helping people facing similar challenges. Community member workshops generate a different mix of solutions with different emphasis when compared with the professionals. In this way, across multiple workshops and with inputs from many different community members and types of professionals, a whole of system solution is incrementally generated. The use of the eHLQ clearly generated diverse and meaningful vignettes that harness the different perspectives and wisdom of community members and health professionals in the co-design process.

The variety of solutions to tackle eHealth literacy needs generated through the co-design workshops is in stark contrast to the current eHealth literacy interventions found in the literature that usually focus only on building digital skills (30, 61). The results also feature ideas targeted at different levels, including family, practitioners and organization policies, providing a holistic approach to solutions instead of placing the burden of change solely on the individuals. A main finding from the co-design workshops is the recommendation of the use of not only digital health, but also conventional health solutions based on eHealth literacy needs. The ideas were in response to the needs of people who might not have access or skills to use technology for health. In fact, many workshop respondents indicated that not using technology should not be regarded as a problem and the strategy of "Providing access to conventional and digital health services" is a consistent theme for all 3 organizations. Thus, the co-design process revealed that a non-digital solution can also be a way to bridge the digital divide. Health organizations need to recognize that technology is only a means, not an end (62). Equitable access should not just refer to access to the same resources. The resources should be flexible enough to suit individual needs as people may be facing different challenges and they should be allowed to lead lives of their own preferences (63). Thus, the Ophelia process has provided an equity driven and responsive approach to co-design solutions in the digital context, without being confined to only digital solutions. This result also resonates with the digital health recommendations of the WHO which stipulates that provision of non-digital services should not be excluded when access, acceptability or affordability of technologies are in question for target communities (12).

To make progress in developing digital health solutions, it is recommended that the Ophelia process be used in the digital context by beginning with needs assessment using the eHLQ or in combination with the HLQ. Armed with an understanding of users' eHealth literacy and health literacy needs, developers can then co-design and implement initiatives through participation to ensure user' needs are addressed. As health services continue to become digitalized, it is high time for health care organizations and policymakers to mandate the use of a co-design and equity driven approach, such as the Ophelia process, to engage with users and ensure digital health systems are adopted to realize the potential of health improvement.

Limitations

A limitation of this study in operationalizing the Ophelia principles is the participating sites viewing the study as a pilot/proof-of-concept study applying only the first of the three Ophelia phases rather than an organizationally-owned and led process to produce service and system improvements for their organizations (3 Ophelia phases). As an underlying aim of the Ophelia co-design approach (25, 26), this reduced sense of ownership may have led to low participation of workshop respondents at the 2 medical practices. Nevertheless, the limited number of workshop respondents at the 2 primary care clinics still generated 32 solutions, shedding light on some important and useful ideas for the clinics. On the other hand, the commitment of senior management in assisting recruitment of respondents throughout the study demonstrated the importance of strong organizational leadership in the implementation of a co-design process. In a recent systematic review of the implementation of care delivery technologies for older adults, organizational leadership was identified as one of the key influencing factors (64). To ensure any co-design program, such as the Ophelia process, can be successfully implemented, strong organizational leadership to create and foster a culture of partnership and engagement among the workplace is essential (65, 66).

It should also be noted that the 3 organizations were not highly digitally active at the time of the study. Their websites were generally simple and straightforward. Only Site 1 offered online appointments and Site 3 had telehealth services while only Site 1 and Site 2 were on Facebook. Further work needs to be done to explore the Ophelia process in digitally active health settings, such as organizations which are active on social media and offer mainly online resources as well as interactive activities. Another possible limitation was the absence of workshop respondents with expertise in information technology who may offer a professional technological perspective to the eHealth literacy needs discussed.

Finally, the ideas were not implemented and evaluated due to the scope of the study. While many of the solutions were suggested based on personal success experiences and the ideas also received the support of expert validation, whether these ideas can assist improvement of health and equity outcomes has yet to be tested. With only Phase 1 of the Ophelia process being undertaken, implementation of Phases 2 and 3 of the Ophelia process for the co-production, implementation and evaluation of interventions is needed to provide further evidence of the feasibility of the process in the digital context.

Conclusion

By harnessing collective creativity, the Ophelia process has been shown to efficiently engage stakeholders in the co-design of digital and other solutions with the potential to improve health and equity outcomes. The co-design process generated diverse solutions targeting individuals as well as family, medical practitioners and organization policies. Of importance is the inclusion of non-digital solutions as one of the potential ways to bridge the digital divide when most current solutions focus only on digital skills. It serves as a timely reminder that health organizations and policymakers must acknowledge and be responsive to the different challenges faced by diverse people to ensure that the digital gap is addressed. Strong organizational leadership is also needed to create a culture of partnership to ensure the success of a co-design process. As such, taking a co-design approach to the development of digital health initiative will ensure that it is not another step toward the widening of health inequalities but a step closer to health equity.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Materials**, further inquiries can be directed to the corresponding author/s.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Deakin University Human Research Ethics Committee (HEAG-H 146_2017). Returning of the survey questionnaire was considered implied consent. Oral consent was obtained from participants of semi-structured interviews. Participants of workshops provided their written informed consent to participate in the workshops.

AUTHOR CONTRIBUTIONS

CC led the data collection, undertook the data analysis, and reviewed by other authors. CC drafted the manuscript. All authors reviewed and provided feedback to all manuscript iterations, approved the final manuscript, and contributed to the conceptualization of the study, methods, and analysis.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2020.604401/full#supplementary-material

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Learning to Fail Better: Reflections on the Challenges and Risks of Community-Based Participatory Mental Health Research With Inuit Youth in Nunavut

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Community-based participatory research (CBPR) is a mine field of moral dilemmas. Even when carefully planned for and continuously critically reflected upon, conflicts are likely to occur as part of the process. This paper illustrates the lessons learned from "Building on Strengths in Naujaat", a resiliency initiative with the objective of promoting sense of belonging, collective efficacy, and well-being in Inuit youth. Naujaat community members over time established strong meaningful relationships with academic researchers. Youth took on the challenge of organizing community events, trips out on the land, and fundraisers. While their creativity and resourcefulness are at the heart of the initiative, this paper explores conflicts and pitfalls that accompanied it. Based on three themes – struggles in coming together as academic and community partners, the danger of perpetuating colonial power structures, and the challenges of navigating complex layers of relations within the community – we examine the dilemmas unearthed by these conflicts, including an exploration of how much we as CBPR researchers are at risk of reproducing colonial power structures. Acknowledging and addressing power imbalances, while striving for transparency, accountability, and trust, are compelling guiding principles needed to support Indigenous communities on the road toward health equity.

Keywords: Inuit, youth, resilience, mental health promotion, community-based participatory research, engaging stakeholders, collaboration, co-production

INTRODUCTION

"Ever tried. Ever failed. No matter. Try again. Fail again. Fail better." This literary quote from Samuel Beckett (1) epitomizes the current state of affairs in community-based participatory mental health promotion with Indigenous communities in Canada. Mental health among Inuit youth is considered a public health emergency of epidemic proportion, with suicide rates among the highest worldwide (2–4). The age groups hit hardest by suicide in Nunavut are 18–27 year olds, followed by 13–17 year olds. Suicide rates are 10 times higher among Inuit compared to the non-Indigenous Canadian population (5). Mental health promotion in youth has been identified as an important goal in suicide prevention in Nunavut (6). Inuit institutions and researchers have emphasized that listening to youth and involving them as partners in the design and implementation of well-being initiatives is imperative (7).

This paper reflects on lessons learnt from "Building on Strengths in Naujaat", a community-based participatory youth suicide prevention initiative, with two main goals: to understand the pitfalls of reproducing social and health inequalities, and to contribute to moving mental health promotion in Inuit communities forward. The method chosen for this study was reflection, postulated as a valid element of social inquiry, which explicitly recognizes the socially constructed character of knowledge about human realities. "Building on Strengths in Naujaat" commenced as a collaboration between Naujaat youth and University of Manitoba researchers (8). It originated from conversations with Naujaat Health Center employees, who emphasized that improving access to mental health services was important but not impactful enough in the context of communities in mourning from so many losses, weighed down by intergenerational trauma, and by economic hardships. Naujaat Hamlet Council Elders requested that, instead of talking about "Inuit youth suicide," the initiative shift the discourse to the role of mutual support and emotional ties within the community, intergenerational dialogue and cultural continuity in the youths' future planning: "Why do we have to talk about suicide all the time? Let's talk about love!" (Agatha Crawford, Naujaat Elder). This stance is supported by the literature. Suicide awareness campaigns were found to increase the risk of suicide becoming entrenched in cultural self-image (9), whereas cultural continuity and community cohesion have been described as protective factors (10–16).

These ideas of approaching the issue of suicide in a different way, while acknowledging the colonial context, made the academic partners consider a community-based participatory research (CBPR) approach. It was regarded as a good fit because it considers dignity, autonomy, and assets of a "community" as a frame of reference that guides research (17). The Inuit tradition of emphasizing community as opposed to the individual presents an advantage of CBPR over traditional mental health promotion measures, which focus on individual-level risk and protective factors. Individual resilience is not necessarily translated into community resilience; and community resilience is a highly dynamic process that is transformed by ever-evolving structural factors such as social, political and economic context, personal relations, and value systems (18). The emphasis on collaboration and mutual learning requires flexibility and reflective professional practice (19). This was seen as a further strength of CBPR as a framework for our project because it prevents, to a certain extent, the reproduction of colonial power relations. Instead, the collaborative process requires the Qallunaat partners to learn about Inuit values, and to acquire a better understanding of how traditional Inuit principles (Inuit Qaujimajatuqangit, IQ) are translated into decision-making and actions. Finally, CBPR focuses on the structural roots of social and health inequalities such as colonial histories, racial and patriarchal oppression, and inequalities in access to power and material resources and aims at collective capacity, efficacy and empowerment as pathways toward social change (20). In the given context, these features made CBPR the best fit for an action-oriented research undertaking.

This article renders insights into challenges and learning opportunities from "Building on Strengths in Naujaat." To this end, it analyzes the team's reflections through the lens of three overarching themes: the need to bridge conflicting expectations and pressures of academic Qallunaat (white, non-Inuit) and Inuit community partners; the inherent danger of perpetuating colonial power structures; and the challenges of navigating complex layers of relations within the community. Through analyzing our respective narratives, experiences and thoughts from an equity perspective, the three themes are placed in a theoretical context. The purpose of this paper is to explore how much we as CBPR researchers, while intending to promote collaboration, collective efficacy, and social and health equity, are at risk of reproducing power imbalances. Our reflections are intended to help prepare teams for CBPR with marginalized populations, to support critical reflection of their roles, and to contribute to discussions among the academic community (21). Most importantly, they are intended to make space for strong Indigenous voices, and to point to the power imbalances that get in the way of health equity (22).

In section Materials and Methods we describe a brief history of the "Building on Strengths in Naujaat" initiative, including its conceptual grounding in CBPR principles, and the method of reflection. In section Results the themes illustrating conflicts and dilemmas encountered in the process of implementing the initiative are presented. In section Discussion we summarize the lessons learnt.

MATERIALS AND METHODS

Research Setting: "Building on Strengths in Naujaat" Initiative

"Building on Strengths in Naujaat" is a youth suicide prevention initiative that came together as a response to a need formulated by community members. Young people, their parents and grandparents, nurses, and teachers expressed the pain of losing a family member, a friend, a patient, or a student to suicide and wished to contribute to a future with an emphasis on hope, creativity, and better opportunities for youth to live up to their fullest potential. This made CBPR a perfect framework for engagement. "Building on Strengths in Naujaat" involves community members and Qallunaat researchers as partners at all stages of the initiative. The goal is to build capacities,including a deeper appreciation of Inuit ways of knowing and knowledge of the Inuit concept of well-being for academic partners, as well as coping skills collective agency and efficacy for community partners, and to eventually achieve community ownership of the project.

The initiative is guided by an all female team [observed to be common in coproduction research (23)], comprised of two Inuit youth group leaders (SP & SI), and three Qallunaat researchers (PA, EG, NG). While SP and SI are at home in Naujaat, Nunavut, Canada, the Qallunaat are residents of Winnipeg, Manitoba, Canada (PA & EG), and of Leipzig, Germany (NG). Naujaat based authors are both young mothers. (SI) has an Office Administration degree from the Arctic College and is employed by the Health Center as Community Oral Health Coordinator. (SP) has past experience as a volunteer firefighter and is currently working for the Co-op gas station. The first author (PA) works in Naujaat for 6 weeks annually in a clinical capacity as a child and adolescent psychiatrist. Overall she has spent over 200 days in the community since 2014. The senior author (EG) has visited Naujaat twice for a week each visit, and together with PA provides clinical services as a family therapist to the community via telehealth on an ongoing basis. Second author (NG) is a Public Health researcher with experience engaging marginalized populations in research in different contexts. Having come up with the initial idea for a CBPR approach, she continues to provide a critical perspective on equity and the structural determinants of health. Her geographical distance proved indispensable for questioning what we otherwise tended to take for granted, but one of the authors (SP) saw this as an obstacle to her ability to fully comprehend the reality on the ground in Nunavut.

The academic partners (PA, NG, EG) formulated the written portion of this paper; however all ideas and lessons learned were co-produced and reviewed in oral discussions with the community co-authors (SP, SI). Naujaat based co-authors requested to be the voices of the youth group without standing out. We agreed to avoid mentioning their opinion directly, as it was perceived as possibly threatening future employability at the Health Center, as well as reigniting family conflicts. Other members of the youth group who contributed to our discussions chose not to go on record out of similar concerns.

The idea for this study was formulated in dialogue with Naujaat Hamlet Council, Naujaat Health Committee, and Naujaat Elders. It was repeatedly stated by Elders that looking at the positives, at strengths and hopes, is crucial for building resilience. We outlined that the academic partners could help by supporting the youth in developing their visions of a healthy community. Our target population were young people residing in Naujaat between the ages of 16–25 years. Their wishes and ideas received a central role in the design of the study as the starting point of all project activities. Inuit youth were designated as co-creators of the action plan. Collaboratively, community and academic partners chose activities, applied for funding, executed them, and reflected on the benefits to the individual, the family, and the community. The ultimate goal of this youth suicide prevention initiative was to co-produce a sense of agency and ownership that will promote Inuit self-determination and well-being, in accordance with National Inuit Strategy on Research (24).

To illuminate the wishes, hopes, and dreams of the youth of Naujaat as a first step, the project started out with a series of six **focus groups** in April 2017. Two of the authors (SP & SI) helped to shape the questions for the focus groups, recruited participants and co-led the focus groups together with our colleague Dr. Maria Bronson, PA and EG. Themes that emerged from these groups were cultural identity and pride, sense of belonging, plans and visions for the future. To refine and consolidate these themes we conducted 12 **individual interviews** with group members. (A detailed description of the methodology and findings from the focus groups and interviews will be reported elsewhere.).

After finishing the focus groups, weekly youth group meetings developed; they built on the themes to co-produce interventions. Initially, a Qallunaat high-school teacher helped organize weekly meetings. After she left the community, the meetings stopped for several months, and resumed after a new teacher took on the organizing task. The reasons for a designated organizer were multilayered. Initially, the meetings took place in the Public Health Room of the Health Center, and the nurse in charge insisted on an "adult" (unspoken but implied: "Qallunaat") supervisor. Later, the meetings took place at the Tusarvik Elementary School, and a teacher was needed for supervision. Additional reasons for a designated organizer were capacities to contact group members, buy snacks, and help with provisions for trips out on the land. As youth juggle responsibilities of school, work, raising children (nieces, nephews, and siblings in addition to their own babies) and helping family Elders, this coordinating role was more manageable for a volunteer teacher.

The "Building on Strengths in Naujaat" youth group organized activities that included various sports tournaments, fundraisers, sewing circles, a presentation series, and trips out on the land (ranging from day trips to three night camping trips). One of the authors (SP) was in charge of an athletic committee that applied for Tusarvik gym use, recruited community members, appointed referees, and announced rules and awards for the spontaneously built teams. Soccer, floor hockey and volleyball tournaments were put together. All teams were passionate and the audiences cheered; fun was the ultimate measure of success. Other committees took on organizing fundraising bake sales, penny sales, and sewing circles.

The most exciting activity proved to be **trips out on the land**, with staff of the community health care center. Youth group members who were otherwise hard to engage took on leadership roles. Academic partners and health staff needed guidance every step of the way. Youth decided what provisions to take, who to hire as guides, and how much gas was needed. On the way, stories were told about other trips, challenges, tragedies, and legends. Youth who were branded as trouble-makers in the community flourished while camping. They looked out for others, fetched water for the kettle, and refilled gas in the common stove. In the non-clinical setting clinical measures for protective and risk factors were replaced by a sense of purpose, a sense of belonging, and group cohesiveness. Seeing resilience in action transformed our partnership. Experiencing and sharing valuable moments became a fundamental goal of our collaboration.

The COVID-19 pandemic suspended all group activities. Youth group meetings, interviews and collection of qualitative outcome measures will resume after the pandemic restrictions have been lifted.

Research Method: Reflection

This paper reflects on the experiences, challenges and insights of the "Building on Strengths in Naujaat" team. To this end it draws on ongoing reflection and evaluation processes that accompanied the project's implementation. These include the research team's observations and discussions, and informal unrecorded conversations with youth, their parents, and grandparents, Hamlet Council, Elders, Hamlet administrators, as well as Non-Inuit teachers, and nurses, who resided in the community between 2017 and 2020.

Reflection has been described as an important mode of learning in action-oriented and community-engaging types of research. It figures centrally in cyclical processes of "(1) action, (2) concrete experience, (3) reflective observation, (4) abstract conceptualization, and new action" (25). Critical reflection as a valid element of social inquiry is thus closely related to a hermeneutic-dialectic epistemology, which explicitly recognizes the socially constructed character of knowledge about human interactions and realities. This, in turn, requires coproduction researchers to gain awareness of their own norms and perspectives, their embeddedness in their political, socio-economic, racial, cultural and gendered position, and to question entrenched patterns of reactions and behaviors – including the framing of problems and research questions, the design and implementation of data collection, and the execution of analyses and interpretation (26). Robertson suggests that in this process the researchers' reflections and their contextualization serve a triple goal of contributing to theory development, gaining practical insights that will help improve practice, and facilitating emancipatory awareness and action (27).

Minkler (21) characterizes CBPR with marginalized populations as a "challenging but highly promising approach." Her discussion of power imbalances and ethical dilemmas addresses racism, tensions between insiders and outsiders and conflicting interests within a community. Introspection, transparency, and open dialogue emerge as foundational guidelines for future CBPR projects (21). Mindful engagement in the context of careful consideration of costs and benefits and more reflective acknowledgment of unavoidable ethical conflicts in co-production can create novel and unexpected results. Joint decision-making by researchers and stakeholders can produce exciting outcomes when executed with proper care and reflection (23). The self-reflective process is essential for understanding the impact of power, identity, and positionality in CBPR. It helps to achieve team cohesion and is integral in making sure the research is not re-colonizing the population that makes itself vulnerable by exploring complexities (22).

In line with this concept of reflection, the "Building on Strengths in Naujaat" team has retrospectively collected pertinent episodes in the project implementation process, identified key challenges, conflicts and learning moments, and discussed related cognitive and emotional experiences. The discussions led to a mapping of the different episodes and experiences around three themes: conflicting values, expectations and pressures of academic and community partners; the dangers of reproducing colonial power structures; and the challenges of navigating complex layers of relations within the community. These three themes posed challenges for our collaboration and at the same time taught us valuable lessons about the role of relationship building as the foundation of CBPR with marginalized populations.

RESULTS

The following section will elaborate on these three themes and ultimately relate them to the overarching question of how CBPR can avoid reproducing colonial power structures, and instead address (current and historic) conflicts, faults and failures to live up to its promise of contributing to greater equity.

First Theme: Struggles in Coming Together as Academic and Community Partners

The world of academia and the world of our community partners march to very different beats (28). Throughout the initiative, differences between the two worlds became manifest in various ways and posed challenges to the academic and community partners in genuinely coming and working together. In the following, we will relate three key differences: different timelines, different values, and different expectations from the initiative.

In the early phase of this project, senior researchers attempted to dissuade us from embarking on this journey by pointing out that the time investment will not pay off in terms of publications. Their prediction was accurate. Five years later, this is our second paper. Most of the academic partners' time is invested in relationship building and re-building amidst changing composition and context of the youth group, and the management of conflicts and logistic challenges. Extracting publishable results is a painstakingly slow process, when it happens at all.

All the while, the academic partners were still going too fast for the community partners. In the clinical milieu, the question "How long have you been coming to Naujaat?" is commonly asked of psychiatrists. For some patients the right answer is "three years", and others do not view outsiders as trustworthy, even after 8 years. Youth and academic partners spent time together, shared snacks and Caribou burgers, while jointly formulating interview guidelines. Nonetheless, the answers given in both individual interviews and focus groups were mostly safe, indicating that the youth perceived the process as rushed. We realized that more consistent and reliable relationships were required to ask deeper questions. According to Attachment Theory, exploration starts after a secure attachment has been established. A pattern of consistent reliable interactions in tune with the needs of the individual will generate a safe haven from which exploration can be launched (29).

In order to get permission to "dig deeper" into the youths' dreams and visions for a better future, we had to figure out how to visit the community; that is, how to be present, attend to, and take part in ordinary life. Visiting is an essential part of community cohesiveness in Naujaat. The doors are unlocked, no one is expected to knock or ring a bell. Coming over does not require a purpose, you can just come to spend time together. Being together does not require talking. People are comfortable with silence. We also had to learn how to present ourselves at these occasions: whether and how to show vulnerability, humility, and helplessness. When one of the authors (PA) brought her daughter to attend first the Tusarvik Elementary School and later Tuugaalik Junior High, it helped her to connect in many different ways as a parent and as a non-professional human being. Leaving behind the Qallunaat attributes of talking fast and talking too much, finishing other people's sentences, and having the answer for every question, proved to be very beneficial. It is through slowing down and refocusing our efforts from collecting "useful data" to getting to know each other, that the diversity of opinions, the complexity of intergenerational respect and estrangement, and the dynamic systems of working within the colonial institutions and resisting their uniformity came to light.

Differences in values (unconsciously) held by the academic partners and the community threatened to undermine the initiative before it had even started. The academic partners approached the Hamlet Council to help identify youth with leadership potential in order to begin recruiting participants for the youth group. To their great surprise, this request was turned down, even though the Hamlet voiced unequivocal support of the initiative. As it turned out, "leadership" is not a universally positive concept. For the Inuit community the concept of leadership implies "singling out" individuals and thus runs counter to their values of equity, cohesion, and mutual help. Following consultations with Qallunaat high school teachers, the academic partners came up with a draft list of names (including the co-authors' names SP & SI); and the Hamlet Council gave its approval without hesitations.

In addition to addressing the discrepancies between academic timelines and Inuit etiquette, and between Western and Inuit values, another challenge stemmed from the partners' divergent expectations and pressures. From the initiative's beginning, the academic partners endeavored to generate funding in order to ensure the initiative's continuation. However, as with many participatory projects, securing sustainable funding proved extremely tedious, with the lack of precise outcome measures being the main reason for rejection of grant proposals. Presetting outcome measures, however, contradicted the Inuit youth's legitimate demand for an opportunity to their own visions and plans. And while the academic partners fully supported a process where the community partners would identify their path toward a better understanding of Inuit resiliency and well-being – the pressure remains to ensure the initiative's sustainable funding within existing funding structures.

Similarly, academic and community partners expect different outputs from the initiative. Academic partners need publishable research results, which are, however, abstract and irrelevant for the community partners (unless they provide travel opportunities like conference presentations). For the members of the youth group, in the short run, the excitement of going out on the land as a group, the joy of being in charge, smiles and happiness of braving the cold on the qamutiik (large traditional sled), were important signifiers of success. In the long run, SP and SI expect concrete results on the ground. The initiative will eventually be measured by the job opportunities and recreational resources created, training courses completed and translated into respectable jobs, and housing crises resolved. Anything less than that will be viewed as a let down.

Second Theme: the Danger of Perpetuating Colonial Power Structures by Embedding the Project in Existing Infrastructure

At different stages of the initiative, the academic partners felt that both individual-level factors (e.g., socio-economic and professional status) and socio-political context made them tread a thin line between guiding the initiative and facilitating youth agency. Within that area of tension, the second theme reflects on a confrontation that ensued around issues of space and agency. Initially, "Building on Strengths in Naujaat" used the large Public Health Room in the newly constructed Naujaat Health Center. However, with new Health Center administration, the group no longer had access to the Health Center. For some time, meetings were held at a private residence of an Elder, which was problematic, because not everyone was comfortable entering the home. When the regional health authority representative offered to provide space for the group, it seemed a plausible solution at first. The youth group was offered a chance to embed its activities in existing health service infrastructure. This would also mean that participant recruitment and the scope of activities would be determined as part of a collaborative effort of the group and the health services.

The group's integration into existing health service infrastructure could have helped to resolve material challenges for the group. However, both the academic partners and the youth each had a separate set of concerns. The youth noted that the space on offer was not a safe space. They were also wary of aggressive recruitment of new group members from part of the health staff, as this would jeopardize the sense of safety within the group that had been created over time. Nonetheless, the youth were undecided whether to accept the offer.

The academic partners perceived the health services' offer as a risk of institutionalized takeover. Their main concern was that the (non-Inuit) health staff would not pay attention to the needs of the group and would impose a different structure and set of goals. From the academic partners' point of view, the initiative's main goal at that stage was for the group to learn to be in charge of all activities. The concept of enhancing a sense of agency in the young people appeared to be at risk of being sacrificed for convenience and structural support.

The academic partners eventually "protected" the youths' autonomy and ownership of the project and declined the offer on behalf of the group. As much as the youth group explicitly agreed with the decision, this step raised complex ethical questions ultimately related to colonial legacy of the health care system (30, 31). Yet, by distancing the group from the opportunity to be embedded in institutionalized hierarchies, the academic partners took a paternalistic approach potentially disregarding the capacity of the Inuit youth to resist, to resolve the dispute with administrators, and to reform existing structures. While the academic partners felt supported by SP and SI in this decision, it is hard not to see the parallel in the paternalism of both approaches.

Third Theme: the Challenges of Navigating Complex Layers of Relations Within the Community

The third theme includes disagreement with community Elders over the distribution of project resources. A main goal of the initiative is that the youth group lead processes of decision-making each step of the way. They are encouraged to come up with ideas for activities, plan and implement them. By this token, among other activities, the youth organized sewing circles that would bring together Elders (as sewing instructors) and youth. Sewing circle planning included details of which materials to purchase, and which Elders would accompany the sewing circles. Hours and hours were spent on debating the details of fur trim, lace, warm lining, and zippers. The anticipation was mounting, everyone was looking forward to a week of creating new jappas (fur-trimmed winter jackets). Yet, without warning, anticipation turned into a whirlwind of frightened phone calls from youth and teachers to the academic partners, a perfect storm of misunderstandings. It turned out that several community Elders who were included in the planning from the start, and strongly supported giving youth autonomy and promoting agency in youth, expected to be given the project funds along with the autonomy to distribute them based on their personal preferences. While this was inconceivable for the academic partners, every youth group member explained how important it is to listen and not to contradict Elders.

This conflict was emblematic of the dual loyalty of Naujaat youth. Respecting Elders is one of the cornerstones of Inuit identity. In addition to the lived experience that would help people learn to survive out on the land, close to 75% of Inuit parents and grandparents are first or second generation residential school survivors. They are revered by the youth not only for their resilience, courage, and overcoming trauma, but also as keepers of the past who have learned how to deal with the present. Against this backdrop, it was not surprising that the group members capitulated and stated that they would be fine with giving away all the resources allocated to the sewing circle to the Elders. We were facing the prospect of antagonizing a group of Elders, with potentially devastating consequences for our standing in the community. The alternative, appeasing the Elders, would come at a cost to the integrity of the group process, not to mention risking the transparency of the funding distribution.

One of the authors (PA) was chosen to talk to the Elder she had the strongest relationship with, to clarify the misunderstanding, and explain that detailed plans were debated by the youth group and why it would be crucial to the spirit of youth empowerment to execute them accordingly. Strong emphasis was put on the fact that we must follow the protocol submitted to the funding authority and therefore this was the only action permissible within the funding mandate. The conversation was heated, albeit respectful. The sewing circles moved ahead as planned by the youth group and were a huge success, with the participation and support of Elders who were not involved in the dispute.

In this particular incident, the goal of empowering Inuit youth to make their own decisions collided with the more culturally rooted expectation of not contradicting Elders. Insights into the origins of this disagreement, how it unfolded, and its sequalae are an invaluable experience of what youth are reporting as complex negotiations between tradition ("Never talk back to an Elder.") and fast-moving renewal of cultural identity ("My commitment to the group/my workplace/my own future requires me to contradict."). Being caught between "old" and "new" rules, integrating IQ principles into workplace commitments, educational aspirations, and family planning is hard. This ambivalence offers a fertile ground for emotional blackmail ("If you leave the community, you are no longer my grandchild"), threats ("If you don't let me collect your paycheck…"), and alienation that has been commonly associated with families of residential school survivors (32). The importance of promoting intergenerational dialogue amidst these tensions has been pointed out to us by the Hamlet Council at the onset of "Building on Strengths in Naujaat" and remains one of the main pathways for our future endeavors.

DISCUSSION

This article reflects on the risks of reproducing inequalities through CBPR, the researchers' best intentions notwithstanding. It does so through the exploration of three themes, which describe challenges encountered in the process of "Building on Strengths in Naujaat", a participatory suicide prevention initiative with Inuit youth.

The first theme puts the project's lengthy and non-linear development in the context of conflicting demands of academic funding and career advancement on the one hand, and longitudinal relationship-building in communities on the other hand. University career and funding structures promote research that yields pre-defined and immediate results; whereas Inuit etiquette values spending time together, listening respectfully, watching, and participating. It takes years to understand the diversity of voices and the significance of connections to family and land, and to engage in dignified creation of trust. This painstaking process is unattractive for funders; and it does not pay off in academic credit. If ignored, however, the research process is liable to miss its target and leave communities with a (legitimate) sense of exploitation (33).

Academic communities could help to diminish the tensions between academic and communities' demands. If universities, funding agencies, and scientific journals genuinely believe that community participation and diversity (for instance, in views, experiences, and kinds of knowledge) are valuable assets for science, better accommodation for participatory research and for a plurality of voices ought to be built into the design of career pathways, stipends, grants, and publications. At the same time, we also call on the participatory research community to step up efforts to facilitate the inclusion of participatory research in mainstream academia. Among other contributions, co-production researchers can act as reviewers for grant proposals and manuscripts; and they can formulate frameworks to help unfamiliar reviewers, editors, and readers assess the quality and outcomes of participatory research initiatives. The question of making academic findings relevant to the community remains the core task of the co-production process.

The first theme furthermore draws attention to CBPR researchers' need to be able to step out of themselves and critically reflect on the basic values that inform their actions (34). This first (near-)failure of our initiative reminded us of the importance of cultural humility and "two-eyed seeing." Referring to Indigenous and Western points of view, the concepts of cultural humility and "two-eyed seeing" imply an acknowledgment that all perspectives and values are context-specific and therefore limited (35). While the community partners practice two-eyed seeing on a daily basis, the academic partners had to realize their limitations and need for further learning.

The second theme points out a "parallel process" of reproducing colonial protectionalism while fighting a colonial approach to institutionalization. "Building on Strength in Naujaat" has hitherto missed the opportunity to engage the team in a critical exploration of the colonial legacy of the health care system (36). In hindsight, the challenges and conflicts arising from the initiative's integration in the health services would have provided an opportunity to better understand current power structures in access to and provision of health care, and to explore youths' perspectives on the purely non-Inuit medical staffing of the Health Center, dismantled local midwifery, and mental health interventions with little regard for local cultural values. Hence, in retrospect, we ought to have more trust in our community partners' abilities to work within hierarchical institutions and in their willingness to dare, struggle, and fail rather than presume their need of protection. Given that trust, we, the team, could have seized the conflict as an opening of a dialogue with the health services, and furthermore, as a vehicle for transformation. This process in itself can be understood as promoting mental health and resiliency.

The third theme illustrates that Elders who welcomed our vision of enhancing the capacity and agency in young people at the same time expected us to adhere to the traditional way of respecting Elders. Accommodating the Elders' wishes would have produced resentment among the youth, with potentially destructive effects on the group process. This conflict caused major disruption, injury and pain for all partners involved. It showed us the limits of collaboration, dealt a blow to a strong collaborative spirit that included our relationships with the Elders, and their participation in the genesis of the group. Moreover, it strained familial ties for some of the youth. The conflict epitomizes the complexity of being embedded in a community with strong cultural values that pose irresolvable dilemmas when faced with Western norms. According to Harari (37), contradictions are inherent within every human culture, and propel us to change. The dialectic of being rooted in Inuit Qaujimajatuqangit ("What Inuit always have known to be true") on the one hand, and on the other hand needing to adapt to modern day challenges is ongoing for young people in Naujaat. Tensions are amplified by the rigidity of rules passed on through generations, by very recent cultural genocide, and by additional stressors related to the direct aftermath of colonization such as food insecurity, overcrowded housing, high unemployment rates, lack of vocational and postsecondary education options in the community. For the academic partners, the take-home message from this theme is that we must develop a sense for the depth and emotional intensity of the dilemmas that CBPR projects can inflict on community partners, so we can empathically support each other through inevitable heart-breaking conflicts.

The limitations of this reflection paper include the imbalance of academic perspective receiving more attention than the community co-authors' perspective. Spending less time together as a team due to the COVID-19 pandemic contributed to this imbalance. We wholeheartedly support Alethea Arnaquq-Baril's proclamation that all research in Inuit Nunangat (Inuit Homeland) should be led by Inuit, should be relevant to Inuit, and should benefit Inuit communities (38). Her statement echoes Inuit Tapiriit Kanatami (ITK) calls to Inuit governance in research, aligning funding with Inuit priorities in research, Inuit ownership of data, and increasing capacity in Inuit Nunangat research (24). There is no doubt that a clear articulation of Inuit Nunangat research priorities, sustainable funding for research relevant for Inuit communities, investing in broadband access, and most importantly "Partner[ships] with governments and research institutions to develop Inuit-specific training and education programs to foster future generations of Inuit researchers" (24) will be incredibly helpful to future CBPR initiatives. Current examples of such partnerships pave the way to Inuit leadership in research (39). Qaujigiartiit Health Research Center in Iqaluit provides resources and networking opportunities for Indigenous scholars and allies working with circumpolar communities. One of the goals of NISR is the establishment of Inuit Nunangat University. Our partnership with Naujaat youth would be much more balanced if community partners could earn University credits for the work on this project while using Inuktitut and being evaluated in accordance with IQ principles, acknowledging oral contributions, activitiesandcommunity commitments (SI).

We continue to believe that CBPR provides an important framework for mental health collaboration and suicide prevention in Inuit Nunangat. Following lessons will help guide theory and practice in the future:

- Paying attention to ongoing relationships on the ground (SP).
- Continuous presence in the community furthers the development of relationships (SI).
- Critical introspection/reflection on values is a vital aspect of the CBPR process (NG).
- Ongoing discussion among team members on expectations and pressures as they arise is crucial.
- Conference and workshop travel is an enriching and eye-opening experience that would otherwise not be available to community members (SP).
- Awareness of historic and current conflicts with institutions, and how they may affect the work in the community is necessary (PA, EG).

- Ongoing recruitment of new members is important in that it allows for growth and development of the youth group (SP, SI).

Overall, "Building on Strengths in Naujaat" taught us that co-production with community partners is a worthwhile yet tenuous balance between a mutually rewarding collaboration and potential damage to the community and to research integrity; between promoting change and undermining community values; and between mobilizing resources and reinforcing inequalities. The promotion and development of mental health in Inuit Nunangat must take into account these opposing forces. If we don't pay attention to the dilemmas created by colonization and traditional values, we run the risk of reinforcing dysfunctional patterns. "Building on Strengths in Naujaat" was established with the objective of providing a group of Inuit youth with the experience of agency and ownership of the initiative. This was to promote a sense of belonging, resiliency, collective efficacy, and ultimately well-being. Framed by the wider context of colonization, issues of conflicting demands, autonomy from existing power and community structures, and cultural values in relationships with community members all impact the initiative's process and outcomes. However, from our experience, acknowledging the mine field of power imbalances while openly addressing current and historic faults and failures, provides learning opportunities that can help make Indigenous mental health collaborative research a more effective resource to support communities on their meandering path toward greater health equity.

DATA AVAILABILITY STATEMENT

All relevant data is contained within the article. To protect the confidentiality of our community partners, no further data will be made available.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by (1) Human Research Ethics Board, University of Manitoba (2) Nunavut Research Institute. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

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All authors contributed to the conception, formulation, and revisions of this article.

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Co-designing Behavior Change Resources With Treatment-Seeking Smokers: Engagement Events' Findings

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Background: Primary care organizations are well-suited to help patients change their unhealthy behaviors. Evidence shows that risk communication and self-monitoring of behavior are is an effective strategy practitioners can use to promote health behavior change with their patients. In order for this evidence to be actionable, it is important to understand how patients would like this information to be communicated and to operationalize the self-monitoring resources. The objective of this study was to co-create resources that encourage behavior change based on the scientific evidence and from patients with lived experiences.

Materials and Methods: Twenty-seven individuals who participated in a smoking cessation program and engaged in at least one other unhealthy behavior joined one of two engagement events. Each event was 3 h in duration and consisted of two exercises that provided support to participants in reaching a consensus about the types of messages they would like to receive from their practitioner as well as self-monitoring resources they would prefer to use. The first exercise followed an adapted version of the Consensus Methodology developed by the Institute of Cultural Affairs Canada, while the second exercise was in accordance to the Nominal Group Technique.

Results: Participants' preference was to have practitioners convey messages to promote health behavior change that include positive affirmation and to monitor all their health behaviors using a single self-reported tracking sheet.

Conclusions: This paper features the use of engagement events to reflect upon and identify potential resources that treatment seeking smokers prefer to receive while attempting to modify unhealthy behaviors. These resources can be used by health care providers in primary care settings to support health promotion interventions and assist their patients to increase their likelihood of adopting positive changes to risk behaviors.

Keywords: engagement event, co-design, smoking cessation, diet, alcohol, stress, behavior change interventions, physical activity

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INTRODUCTION

Behaviors, such as excessive alcohol consumption, physical inactivity, and poor diet, are associated with an increased risk of mortality from numerous chronic conditions including cardiovascular disease, cancer, and stroke (1–6). In Canada, as well as globally, the development of strategies to reduce the prevalence of multiple unhealthy behaviors that are scientifically rigorous and patient-oriented is long overdue.

Although policy level interventions that address root causes of the behavior are most effective (7–10), for some individuals, clinical interventions may also be necessary for successful behavior change to be achieved (11–13). There is substantial evidence showing that when health care providers address health behaviors with their patients they can have a significant effect on their patient's efforts to achieve smoking cessation (14, 15), reduce harmful alcohol consumption (16), increase exercise (17), as well as attain positive changes in diet (18), mood (19), stress (20), and sleep (21, 22).

Behavior change techniques (BCTs) are considered to be the smallest active ingredient of an intervention that work to promote change in an individual (23). BCTs are theorized to operate by either enhancing factors that can facilitate the behavior change or by minimize the factors that would typically inhibit the behavior change (24). In 2010, a systematic review of behavior change techniques found that, relative to other techniques, "risk communication" and "self-monitoring of behavior" were effective strategies practitioners can use to promote health behavior change with their patients (25). It has been postulated that self-monitoring BCT works by allowing users to regulate their behavior, specifically encouraging behavioral, and/or cognitive skills for managing or changing behavior (24). Within Michie et al.'s BCT taxonomy (23) these two techniques fall within "1. Goals and Planning" specifically "1.6 Discrepancy between current behavior and goal" (for risk communication) and "2. Feedback and Monitoring," specifically "2.3 Self-monitoring of behavior" (for self-monitoring) (23) However, while the benefits of self-monitoring are well-established (26, 27), the effectiveness of risk communication is not as clear; a recent systematic review of reviews, found that providing risk communication by itself does not lead to behavior changes that are sustained over time (28).

To make these research findings more meaningful and actionable, there is a need to contextualize these findings in the lives of people with lived experience. Including the perspectives of people with lived experience is known to improve the effectiveness and value of the programs aimed at improving population health (29–31). Given that our plan was to embed a behavior change resource into an Ontario-wide smoking cessation program, called the Smoking Treatment for Ontario Patients (STOP) program, we wanted to understand the perspective of STOP participants. Specifically how health care providers should communicate the need to change behaviors (including exploring the need for risk communication) and what self-monitoring resources they would use.

The STOP program is an established smoking cessation program implemented in primary care settings across Ontario, Canada, which offers up to 26 weeks of smoking cessation treatment, consisting of nicotine replacement therapy and behavioral counseling, at no cost to the patient. In addition to smoking, over 90% of STOP participants self-report two or more unhealthy behaviors. In January 2019, with funding from the Public Health Agency of Canada (PHAC) and the Medical Psychiatry Alliance (MPA), a new initiative called Picking Up the PACE (Promoting and Accelerating Change through Empowerment) was introduced into the STOP program to support practitioners address modifiable risk factors (e.g., physical inactivity, poor diet) with their patients. Based on the results of two co-creation events, Picking Up the PACE developed an online tool that encourages practitioners to (1) Communicate to patients the need for health behavior change and (2) Provide self-monitoring resources. The co-creation of the tools and messages allows users to have a voice on how health promotion programs and products are designed and offered. This is important given that there is promising evidence that participatory approaches to health promotion, that accounted for patient-identified priorities, ultimately lead to better patient outcomes (32).

This manuscript describes the methodology we used to co-create health promotion tools (self-monitoring worksheets and messages health care providers can use to communicate with their patients the need to change their behaviors). We used the guiding principles outlined in the Strategy for Patient-Oriented Research Patient Engagement Framework (32), namely inclusiveness, support, mutual respect, and co-building. We combined these with the recommendations that emerged from co-creation events. There is sufficient evidence on effective behavior change techniques and strategies for implementation in practice (25). However, the characteristics of the target population determine the appropriate implementation strategy (33). Therefore, co-creation with end-users can provide the necessary guidance to researchers on effective implementation strategies that might not be described in published literature (34). In addition, we describe activities we did to facilitate effective co-creation of these health promotions tools.

MATERIALS AND METHODS

Recruitment

Eligibility criteria included:

- A former or current participant of the STOP program who consented at the time of enrollment in the STOP program to be contacted for future research studies, lived in the Greater Toronto Area, and had shared at least one phone number.
- At the time of enrollment into the STOP program the participant reported at least one of the following risk factors:

Abbreviations: AUDIT-10, Alcohol Use Disorder Identification Test; PHAC, Public Health Agency of Canada; ICA, Institute of Cultural Affairs Canada; MPA, Medical Psychiatry Alliance; NGT, Nominal Group Technique; PACE, Promoting and Accelerating Change through Empowerment; STOP, Smoking Treatment for Ontario Patients.

- ○ Physical inactivity - classified as being below the Canadian Physical Activity Guidelines (<150 min/week of moderate-to-vigorous activity) (35).
- ○ Low levels of fruits and vegetable consumption - classified as being below Canada's Food Guide (2007); which recommends at least 7 servings for women and 8 servings for men per day (36).
- ○ Risky drinking - determined by using the Alcohol Use Disorders Identification Test (AUDIT-10) (37). A score of $\geq$ 3 (women) and $\geq$4 (men) was classified as risky drinking (38).
- ○ Low coping skills for stress - defined as a response of "Poor" or "Fine" to questions about one's ability to handle day-to-day demands and unexpected problems.
- ○ Trouble sleeping - determined using the third item in Patient Health Questionnaire; (39, 40). A score of 1 or more on this question was classified as having trouble sleeping (40).

Eligible participants were contacted by the STOP program's research personnel once every 1–3 days until they either connected with the participant or had reached a maximum of 5 call attempts. Our goal was to recruit 22 participants for the first engagement event (Group 1) and 24 participants for the second engagement event (Group 2). These numbers were chosen given that researchers have found that a group size of 30 people or less is ideal to capture diverse experiences, allows the opportunity for all participants to contribute (41) as well as simplifying logistics (room size capacity and budget).

Participants were provided with an honorarium of $70 dollars for attending the 3 h engagement event.

Procedure

Each engagement event was broken down into three main components.

1. A brief presentation of the scientific evidence related to the effect of modifiable risk factors on tobacco use and effective strategies for changing these risk behaviors.
2. A consensus building activity to decide the type of messages health care providers should share with their patients to communicate the need to change their behaviors. This activity followed an adapted version of the Institute of Cultural Affairs Canada (ICA) consensus building methodology (42). Thus, the following steps were performed:

    a. Brainstorm individually: The facilitator stated the purpose of the exercise; to answer the question: *"What type of a message should your practitioner tell you, in order to encourage you to make changes to some behaviors that are putting you at risk?"* Participants were given time to individually reflect on different examples of messages and brainstorm ideas. Examples of messages were adapted from existing messages that have been used by other organizations (e.g., Canadian Society for Exercise Physiology, Heart and Stroke) or research studies (43–45). As a part of their reflection, participants were also asked to choose the messages they liked or disliked.

    b. Brainstorm as a group: Participants were asked to work in small groups (2–4 participants) to share their ideas. The purpose of these discussions was not to reach agreement, but to enhance clarity of each idea. Each small group wrote their ideas on approximately 4 cards. Each card contained a single clear idea about the type of message the participant would like to receive. If two or more participants had the same idea, only one card would be written representing this idea. This way, we were able to minimize duplication yet preserve diversity.

    c. Share ideas with the larger group: The facilitator gathered the cards, read them aloud and placed them on the wall.

    d. Clustering ideas: Once 10 cards were on the wall, the facilitator asked the group to state which cards were similar, in order to form clusters. Similar cards were placed together in a column. Once a column had three cards, a symbol was placed above the three cards so that the cluster could be named without naming the idea. The facilitator continued reading the remaining cards and asked participants if each card belonged to as existing cluster or a different cluster. To allow emerging insights to evolve, participants were discouraged from naming clusters until all the cards were up on the wall.

    e. Naming the cluster: The facilitator read each of the cards in a cluster aloud and guided the group to explore the meaning behind the cluster. The group gave each cluster a name.

    f. Reflect on final product and experience: As a large group, participants were asked to reflect on what they liked and what could be improved upon.

3. An adapted Nominal Group Technique (NGT) (46) to clarify what features a self-monitoring tool(s) should include. NGT is a structured format that facilitates group brainstorming and encourages contributions from everyone. This activity involved six steps:

    a. Stating the purpose: The facilitator stated the purpose of the exercise; to answer the question: "*What type of self-monitoring tools would you like your health care provider to give you?*"

    b. Sharing examples: Different types of self-monitoring tools such as combined and individual tracking sheets were shared with the group. Participants were asked to complete each self-monitoring tool in order to acquire a more comprehensive understanding of the structure of each tracking sheet. Individual tracking sheets were defined as resources that have only one risk factor on each page. Combined tracking sheets have two or more risk factors on the same page. These resources were either taken from other organizations (i.e., American Heart Association) or were created by Picking Up the PACE.

    c. Recording ideas: Participants were asked to individually reflect and write down their approval/disapproval of each tool and brainstorm new ideas.

    d. Discussing ideas: Each participant was asked to share with the group one idea about each tracking sheet. Each new idea was recorded by the facilitator on a separate piece of flipchart paper. Participants were encouraged to ask questions to clarify any ideas that were shared.

e. Voting on ideas: A dotmocracy system, in which participants were each given 10–12 dot stickers for voting, was conducted. Participants could place all dots on one flipchart paper (containing one idea) or distribute them across several ideas.
f. Reflect on final product and experience: As a large group, participants were encouraged to reflect on what they liked and what could be improved upon.

Based on feedback received from the first event (Group 1), some minor modifications were made to the NGT exercise for the second event (Group 2) including: providing more time for reflection (additional 15 min), reducing the number of examples shared (from 9 examples to 6), and providing more structured questions for individual reflection such as whether they would use the resource and if so, for how long. Also, due to logistics reasons, participants in Group 1 were provided with 12 dot stickers each while those in Group 2 were provided with 10 dot stickers each.

Analysis

Thematic analysis, "a method for identifying, analyzing and reporting patterns within data" (47) was conducted with the participants, during the events, to allow for further discussion of the findings. In the consensus building activity, the analysis phase was initiated when the generated idea cards were read aloud and displayed on the wall for the participants to view together. To ensure everyone was familiar with the ideas presented, participants were given time to examine the cards. Then, participants were asked to think critically about the similarities and differences between the ideas and to cluster similar ideas together. Thus, emergent themes were developed and participants assigned a title/label to the clusters they created. This concluded the analysis process for this activity. The final stage, reflection, was a comprehensive, all-inclusive analysis where participants reflected and shared the extent to which each title card (theme) contributed to an understanding of what the message that communicate the need for health behavior change should contain.

The second activity, which used the NGT, included a combination of qualitative and quantitative methods to elicit feedback from participants (48). The analysis phase was initiated during the large group session and a thematic approach was used to determine participants' preferred way of self-monitoring their risk behaviors. Participants were first asked to reflect individually and then, as a group, and share what they liked or disliked about the self-monitoring resources as well as express any additional features that should be considered. These suggestions (themes) were placed on the wall and participants were given time to review and compare the different themes. Participants were then asked to vote on each theme. The results of the voting became the main outcome of interest for the activity. The written responses from the individual reflection section of this activity were reviewed post-event to provide additional context to the final results.

TABLE 1 | Demographic information of participants who attended the events†.

Variables	Group 1	Group 2
Individual-level	**(*n* = 9)**	**(*n* = 18)**
Age in years (mean, sd)	56.7 (9.3)	53.1 (12.5)
Male, *n* (%)	5 (56%)	10 (56%)
High school diploma or higher, *n* (%)	4 (44%)	17 (94%)
Household income above 40 k, *n* (%)	0 (0%)	2 (11%)
Currently employed, *n* (%)	2 (22%)	6 (33%)
Daily smokers, *n* (%)	8 (89%)	17 (94%)
Proportion of participants who have quit at least once in the past year, *n* (%)	5 (56%)	9 (50%)
Importance of quitting rating (mean, sd)	8.6 (2.2)	9.4 (0.8)
Confidence in quitting smoking rating (mean, sd)	8.5 (1.7)	6.9 (2.7)
Proportion of participants with at least one physical comorbid condition‡, *n* (%)	5 (56%)	5 (28%)
Proportion of participants with at least one psychiatric comorbid condition§, *n* (%)	7 (78%)	13 (72%)
Proportion of participants with substance use disorder¶, *n* (%)	3 (33%)	5 (28%)
Organization type		
Family Health Team, *n* (%)	3 (33%)	6 (33%)
Community Health Centre, *n* (%)	6 (67%)	10 (56%)
Addiction Agency, *n* (%)	0 (0%)	2 (11%)

†*The sum of percentages may not equal 100% due to rounding.*
‡*Physical comorbid conditions include heart disease, stroke, diabetes, chronic obstructive pulmonary disorder, rheumatoid arthritis, cancer.*
§*Psychiatric comorbid conditions include depression, anxiety, schizophrenia, bipolar disorder.*
¶*Excludes tobacco and caffeine.*

RESULTS

Participants

Nine of 22 invited participants agreed to participate in Group 1, while 18 of the 24 invited participants agreed to participate in Group 2. Unexpected hospital and family commitments were the primary reasons given by patients for not attending the engagement events. The demographic information for both groups is presented in **Table 1**. Most participants (93%) had a household income of <$40,000 (CAD), which is below the median income in Canada. This is considered to be low income for a four person household (49, 50). Low socioeconomic status has been associated with a greater likelihood of having modifiable risk factors (51–53) and presents additional barriers to successful behavior change (54–56). As a result, representation from this population provides an opportunity to better understand how interventions need to be tailored and delivered.

Consensus Building Activity – Messages Focusing on Need to Change Health Behaviors

Participants were asked to brainstorm and generate ideas about the types of messages they wanted health practitioners to convey to their patients. Group 1 and Group 2 generated 14 and 19 ideas, respectively. Facilitators NM and ML guided participants to cluster the ideas into groups and to categorize each cluster. By the end of the exercise, Group 1 created five clusters and Group 2

TABLE 2 | Cluster categorization from the consensus building activity.

Question: What type of a message should your practitioner tell you; in order to encourage you to make changes to your risk factor?

Group 1	Group 2
Positive Reinforcement	Positive Compassion. Emphasis on Mental and Emotional Well-being
Pro-active/Never a Failure/ Positive Affirmation	Encouraging Practitioners to be Aware of Patient's Circumstances and Resources
Empowering with More Information	Strategies for Patients/Use Psychological Techniques and Raise Awareness
Reality Check	
Have Visuals to Help Your Patient	

TABLE 3A | Group 1's dotmocracy results for the types of self-monitoring resources (tracking sheets).

Ideas	Vote
Combined Tracking Sheet with More Room (Example F)	22
Apps	15
Easy and Simple Alcohol Tracker (Example D)	13
Multi-Risk Factor Tracking Sheet (Example B)	12
Smoking and Mood Biweekly Tracking Sheet (Example E)	9
Sleep Diary Tracker (Example G)	6
Separate/Individual Trackers	4

TABLE 3B | Group 2's dotmocracy results for the types of self-monitoring resources (tracking sheets).

Ideas	Vote
Multi-Risk Factor Tracking Sheet (Example B)	55
Smoking and Mood Biweekly Tracking Sheet (Example E)	28
Physical Activity Tracking Sheet (Example A)	23
Alcohol Only Tracking Log (Example D)	21
Physical Activity and Healthy Eating Tracking Sheet (Example F)	11
Smoking, Alcohol, and Mood Tracking Sheet (Example C)	6
Apps	0
Able to Journal and Explain Thoughts/Events	0
More Information About Just One Behavior	0
Offer More Than One Type of Tracking Sheet so Patients Have a Choice	0

created three clusters. Group 2 was not aware of the clusters that Group 1 had created. The categories that groups had chosen for their respective clusters can be found in **Table 2**.

Participants from both groups created categories which reflect their preference of practitioners communicating messages that provide positive reinforcement, affirmation and compassion. They also recommended empowering patients with more information and raising awareness. Group 1 preferred practitioners to also provide patients with reality checks (comments that would make patients recognize the risks of their unhealthy behaviors), while Group 2 wanted practitioners to be more aware of the patients' circumstances.

NGT – Self-Monitoring Resources

Both groups were provided examples of two types of self-monitoring resources: individual and combined tracking sheets. After allowing for individual reflection, participants were asked to share ideas about which self-monitoring resources they preferred and what should be included in a tracking sheet. Each new idea was recorded on separate flip chart papers. At the end of the discussion, participants were asked to vote using dot stickers on the idea(s) they preferred the most. In Group 1, each participant was given 12 dot stickers and was allowed to vote on more than one idea. **Table 3A** shows all the ideas that Group 1 generated and is ordered from highest to lowest by the number of votes. This same exercise was repeated with Group 2. Due to logistical reasons, participants in Group 2 were provided with 10 dot stickers each. The results of Group 2's dotmocracy can be found in **Table 3B**.

DISCUSSION

During the two engagement events, participants expressed a preference for healthcare practitioners to provide health behavior messages that included positive reinforcement, compassion, and affirmation. Participants discussed a greater need for information that would provide empowerment and allow the patient to participate in any decisions regarding prevention or treatment. The majority of participants preferred to monitor their behavioral changes through a single page self-reported tracking sheet that included all of the risk behaviors that the participant was attempting to change. Participants perceived the Multiple Risk Factor Tracking Sheet as being simple, efficient, informative, and provided an opportunity to make connections between risk behaviors. Furthermore, the majority of participants who selected the Multiple Risk Factor Tracking Sheet expressed interest in using it for at least a 1-month period. Such compliance with completing the Multiple Risk Factor Tracking Sheet would provide greater insight in the behavioral change process. Other tracking sheets offered to participants were perceived to be time consuming and too long.

Integrating patients into the planning and delivery of health care requires effective communication between both parties; patients and health care practitioners (57). When communicating to patients, practitioners can either choose to frame health information by emphasizing the attainment of beneficial or positive outcomes (gain-framed messages) or the costs or negative outcomes (loss-framed messages) (58, 59). The findings from this study encourage the use of gain-framed messages when discussing behavioral changes with participants. This is consistent with research published in recent years demonstrating gain-framed messages to be effective at promoting physical activity (60), intentions to consume adequate quantities of fruits and vegetables (61), and smoking cessation (62).

This study outlines a methodology that can alleviate some of the tensions that exist between two key values in health promotion—namely, evidence-based approaches to population health and public and patient engagement (63). Participants provided valuable insight into the wording and structure of messages. Furthermore, participants co-developed a self-monitoring resource that is simple and efficient. Due to participant involvement in the creation of these tools, it is expected that uptake of the tools will be enhanced as participants will be more receptive to messages that communicate the need for health behavior change and more likely to complete the self-monitoring resource. The intent of this study was not to provide information on the adaptability or effects of messaging and self-monitoring techniques on behavioral change, but rather to inform the messages and self-monitoring tools that STOP health care providers could use with their patients. These resources are currently being used in the STOP program and are part of an Ontario wide study, Picking Up the PACE (64). Future research in the field of co-creation should consider examining how co-created materials impact the effectiveness of interventions.

This study has some limitations. First, participants were required to attend each engagement event in-person. Consequently, our sample of participants was restricted to individuals residing in the Central Toronto area. This may have potentially created a selection bias in which the views and opinions of the recruited participants may not have been representative of those individuals residing throughout Ontario. Furthermore, since the invitation for the engagement event was distributed by the Center for Addiction and Mental Health, the institution that implements the STOP program, there is a risk of social desirability bias. Participants may have felt compelled to provide responses that may appear more favorable to the facilitators. That being said, none of the facilitators were known to the participants prior to the event and had no role in their clinical care. Given that 41% of invited participants did not attend the engagement events, an additional limitation is the inclusion of possible response bias. However, the feedback provided by the participants who attended (e.g., positive messages) coincides with existing literature that shows gain-framed messages are effective for health behavior change (60–62). Moreover, we hosted two separate engagement events with separate groups of people and the feedback from both groups was very similar. Given the consistency in the results, we believe we achieved saturation using this methodology. While our sample of participants were primarily older, this is quite representative of the target population of the intervention as the average age of participants in the STOP program is 52 years old.

CONCLUSIONS

The results of these engagement events will be used to inform the design of an online tool developed by the PACE initiative to help guide practitioners with addressing multiple health behaviors in the STOP program. We will develop health behavior messages that communicate positive messages and these messages will be incorporated into our tool. As well, the Multiple Risk Factor Tracking Sheet will be adapted and incorporated into the PACE intervention for practitioners to offer to their patients in supporting their efforts in monitoring their behaviors.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, upon reasonable request.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by The Center for Addiction and Mental Health. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

NM, ML, and PS developed the original concept of this study. NM and ML conducted the patient engagement event. NM, ML, and WR wrote the first draft of the research paper. All authors participated in the critical revision of the manuscript, contributed to the study design, read and approved the final manuscript.

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BRIEF RESEARCH REPORT
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Co-creating Virtual Reality Interventions for Alcohol Prevention: Living Lab vs. Co-design

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Addressing the need for collaborative involvement in health intervention design requires application of processes that researchers and practitioners can apply confidently to actively involve end-users and wider stakeholder groups. Co-creation enables participation by focusing on empowering a range of stakeholders with opportunities to influence the final intervention design. While collaboration with users and stakeholders during intervention design processes are considered vital, clear articulation of procedures and considerations for various co-creation methodologies warrants further research attention. This paper is based on two case studies conducted in Australia and Denmark where researchers co-created virtual reality interventions in an alcohol prevention context. This paper explored and reflected on two co-creation methods–co-design and the Living Lab—and showcased the different processes and procedures of each approach. The study demonstrates that both approaches have merit, yet highlights tensions in distinguishing between the application of each of the respective steps undertaken in each of the processes. While a lot of similarities exist between approaches, differences are evident. Overall, it can be said that the Living Lab is broader in scope and processes applied within the Living Labs approach are more abstract. The co-design process that we applied in the first case study is described more granularly delivering a clear a step-by-step guide that practitioners can implement to co-design solutions that end-users value and that stakeholders support. An agenda to guide future research is outlined challenging researchers to identify the most effective co-creation approach.

Keywords: co-creation, co-design, Living Lab, virtual reality, prevention, alcohol, adolescents

INTRODUCTION

Collaboration with users and stakeholders during intervention design is recommended, but clear documentation of the procedures and considerations for different co-creation methodologies have only recently emerged (1–4) with the need for more work to guide practice and understand relative effectiveness of different co-creation approaches noted. Co-creation ensures that programs are designed with those that are ultimately the recipients of a health intervention. Co-creation is an umbrella term that gained popularity in the early 2000s emerging in areas including (but not limited to) management (5) and software design (6). Co-creation literature focuses on centering service solution development on users, originating from participatory design work dating back to the early 70s (6). Numerous methods have emerged over time and include design thinking (2), co-design (7), co-production (8), and Living Labs (9) highlighting a range of different approaches that can be implemented for intervention co-creation. This paper highlights and contrasts two popular co-creation approaches, namely co-design and the Living Lab.

Co-design is a scientific method of data collection with the aim of including consumers affected by a health intervention (4). Co-designed programs have demonstrated effectiveness across health (10) and environmental issues (1) and thus demonstrated value for researchers, users and society at large (11). More recently, the need to include wider stakeholder groups during the intervention design process has been identified (4) and processes seeking to involve stakeholders within the co-design process to ensure that user solutions identified are feasible have emerged (12). Co-design processes ensure that emphasis is placed on empowering participants and that all solutions emerging from co-design are user centered and stakeholder supported. Recent co-design process models (4, 12) have begun to articulate the necessity to think beyond ideation and gauge how user generated ideas can be translated into effective intervention programs that are endorsed by end-users and stakeholder groups.

The Living Lab methodology is defined as *"a design research methodology aimed at co-creating innovation through the involvement of aware users in a real-life setting"* [(9), p. 139]. Living Labs have been applied in urban settings (13), entrepreneurial settings (14), professional development (15), and dementia interventions (16), but all take very different structures and forms. Publications on Living Labs began to emerge in the early 2000s and have been predominantly set up and reported within the European context (17). The existing literature has positioned Living Labs as a design method that aims to achieve innovation by setting up environments that allow for end-users to experience and contribute to the solution throughout the developmental stages (9). In other words, it provides a unique setting for collective innovation involving heterogeneous stakeholders such as but not limited to citizens, customers, policy makers, researchers, educators, businesses and universities (18, 19). Living labs remain however significantly underexplored in the academic literature and require further empirical exploration to demonstrate more clearly the scope, benefits and limitations to the approach. Schuurman et al. point out "*…[the literature] positions Living Labs too much as an "everything is possible" concept that resembles an empty box, in the sense that you can put whatever methodology or research approach inside*" [(17), p. 12].

This paper aims to provide a methodological comparison between two co-creation methods (co-design and Living Lab) to highlight key considerations as well as a comparison of both processes. This study draws its data from two virtual reality case studies, namely a co-design study conducted in Australia and a Living Lab study delivered in Denmark where researchers co-created virtual reality (VR) interventions in an alcohol prevention context. Both virtual reality interventions consist of the simulation of a party situation in which the user can experiment with different communication and behavioral options and both virtual reality interventions are aimed at strengthening alcohol resistance skills. The method section provides the contextual background as well details around how each method was applied to co-create the virtual reality interventions. Next, the paper summarizes the findings and critically discusses and contrasts both co-creation processes.

METHOD

Case Description of the Co-creation Cases

Blurred Minds VR House Party

The first case study describes and summarizes the research team's experience with the co-design process to co-create the Blurred Minds VR House Party (20, 21). The seven-step co-design process of (1) resourcing, (2) planning, (3) recruiting, (4) sensitizing, (5) facilitating, (6) reflecting, and (7) building for change (see **Table 1** below) was used (4). Process and outcomes evaluations for the Blurred Minds House Party are reported in Dietrich et al. (20). This sequential step-by-step process was developed to guide the discovery of new, innovative intervention ideas (4).

VR FestLab

The second case study describes and summarizes the research team's experience with the Living Lab method. The Living Lab method was applied to co-create a gamified (VR) simulation—VR FestLab (25). User experiences for VR FestLab are reported in Guldager et al. (24).

This project used the Living Lab process which was comprised of six individual steps namely (1) exploration of key concepts, (2) concept design, (3) prototype design, (4) innovation design, (5) testing the product, and (6) evaluation of the process and the product (26) (**Table 2**).

RESULTS AND DISCUSSION

This study was informed by two case studies conducted in Australia and Denmark where researchers co-created virtual reality interventions within an alcohol prevention context. This paper explored and reflected on two co-creation methods–co-design and the Living Lab—and showcased the different processes and procedures of each approach. This paper makes two important contributions. First, it provides a methodological comparison of two different co-creation approaches that were used to design VR interventions. Second, it demonstrates that both approaches have merit, yet highlights tensions in distinguishing between the application of each of the respective steps undertaken in each of the processes. While a lot of similarities exist between approaches, differences are evident. Overall, it can be said that the Living Lab is broader in scope and processes applied within the Living Labs approach is more abstract. The co-design process that we

TABLE 1 | Co-designing the Blurred Minds VR House Party.

Co-design process	Application to Blurred Minds VR house party
Resourcing	A systematic literature review investigated the application of VR to alcohol education interventions (22). Additional resources were reviewed to gain further insights into VR's latest technological developments to ensure that solution development would reflect the latest technological VR standards. The team also consulted with two film and one VR expert throughout the development process.
Planning	A multi-disciplinary team of researchers with expertise in social marketing, gamification, and service design planned the co-design sessions. The team prepared components of the co-design session, such as the development of a run-sheet, screening survey, group activities, and design tools (21).
Recruitment	Leveraging existing school network contacts, the team recruited a group of students from a public secondary school. Close collaboration with the teacher of the school ensured that we were able to set expectations for the sensitization and co-design workshop phases as well as secure a location on school grounds to run the workshop [more details available in (21)].
Sensitizing	Adolescents had the opportunity to test pilot versions of four newly developed online games for Blurred Minds. This sensitizing phase provided students with a relevant and fun way to engage with the notion of alcohol education resources prior to taking part in the co-design session.
Facilitation	The session commenced with screening survey, a brief introduction of the research team as well as highlighting the aims of the workshop. Next, the team showed an interactive simulation experience and a head-mounted VR display to showcase what type of virtual reality experience the team was aiming to create. Four teams were formed by the researchers and teams were provided with tools to help them co-create a virtual house party that would appeal to them. They were also encouraged to role play, experience interactive videos and wear beer goggles to help them understand the purpose and aim of the session in a playful manner. Design tools in form of butcher paper, stickers, markers, coloring pens and post-it notes were distributed. The workshop finished with short presentations of each student team showcasing their work to the entire group [more details available in (21)].
Reflecting	All data derived from the developed ideas as well as the presentation transcripts were coded and thematically analyzed. These user insights were taken into consideration when producing the final version of the Virtual House Party scripts and when planning production details. Co-design in this case provided important insights into ensuring that both the language used and the party setting depicted were realistic for the young audience. The final scripts and party planning were created with professional script writers and film producers.
Building for Change	The team consulted a wide stakeholder group prior to production of the VR experience including alcohol and drug experts, a VR expert, and two experienced film producers with an interest in interactive storytelling using VR. The VR simulation was developed and focused on strengthening self-efficacy and changing attitudes toward excessive drinking (20). The script was written around key theoretical outcome measures (underpinned by Social Cognitive Theory) and was filmed using a 360° video camera to provide users with an experience that would resemble a real-life scenario. More details on the VR intervention development and Blurred Minds as well as preliminary effectiveness findings are published in (20).

applied in the first case study are described more granularly delivering a clear a step-by-step guide that practitioners can implement to co-design solutions that end-users value and that stakeholders support. Both approaches were able to be utilized to develop innovative VR interventions that have demonstrated initial successes (20, 23–25). Next, we discuss consideration for each of the processes from two major perspectives namely the fuzzy front end of both processes followed by reflection on the divergence and convergence of both approaches.

From Fuzzy to Clear: The Starting Point of the Co-design and Living Lab Processes

During the co-design process, the *resourcing* stage marks an important step that informs all subsequent co-design stages of the co-design process. It provides researchers with the opportunity to collaborate closely with key stakeholders to ensure that all voices are heard prior to embarking on the subsequent six steps of the process. This can take many shapes and forms (e.g., expert interviews, literature reviews, surveys) and in this case featured a systematic literature review to understand the current state of knowledge of VR in alcohol education (22). While this information delivered a peer review evidence-based understanding of VR interventions for young people, data was outdated and it did not deliver understanding of the current possibilities that VR afforded. For this, a film and VR expert were recruited into the team to help set more realistic goals for the overall project and for the respective co-design session with students. This stage was very useful to provide the necessary clarity to inform subsequent co-design process stages. *Planning*, then operationalised the goals set in the *resourcing* phase by ensuring that all aspects of *recruitment*, *sensitization*, *facilitation*, and *reflection* were organized. The process for *resourcing, planning* and even *recruitment* has been described as highly iterative in Trischler et al. (4). The Living Lab processes suggests that a broader planning stage takes place at commencement which takes into consideration diverse stakeholder views and stresses the importance of creating value for the user and discussing when in the process users can contribute (26). The Living Lab process used in the second case study featured six phases and commenced with the *Exploration of key concepts* where a big focus was placed on the aim and scope of the virtual intervention build. It was important to gain information on the previous research project Blurred Minds to understand best practices as well as lessons learned to most cost-effectively create VR FestLab. A wide range of stakeholders were consulted and tasked with identifying who the end-users are, what important characteristics they share, and where users could contribute throughout the Living Lab process (26). In summary, both approaches aimed

TABLE 2 | Using the Living Lab method to co-create VR FestLab.

Living Lab process	Application to VR FestLab
Exploration of key concepts	The existing "VR House Party" film script from the Australian Blurred Minds alcohol education program (21) was revised by the development group, consisting of two prevention practitioners, two prevention scientists, two social marketing scientists, two VR game scientists, one VR game designer, one film production expert and eleven students from a folk high school who represented young end-users. Further, the researcher and VR tool developer from Blurred Minds shared his knowledge and lessons learned from the development, delivery and evaluation of Blurred Minds with the group. The group explored the existing Blurred Minds VR game and reflected on their experiences hereof. Finally, the development group co-created a list of elements which should be maintained, changed or added in order to make the prototype of the Danish VR simulation fit contextually and culturally to a Danish party setting.
Concept design	Based on the output from the exploration stage and facilitated by the film production and VR game design expert, the students co-created a film script for the gamified VR simulation. The film script was presented to the development group through role-play and flow-charts of the storyline and a list of improvements and changes was created. This stage resulted in a film-manuscript which included a comprehensive storyboard and descriptions of the characters to be casted.
Prototype design	The students from the development group produced the 360-degree videos for the VR simulation in collaboration with the film production expert and the game design researcher. The students were responsible for casting and directing the boarding school students (aged 15-17 years) who served as actors. The videos were optimized with the support of a professional film editor. Next, the videos were combined in a game engine platform and interactivity elements were added, resulting in version 1 of the digital prototype. More details on the development of the tool are published in (23).
Innovation design	Version 1 of the digital prototype was presented to the development group by the two VR game scientists. At this stage, the film students were not represented in the development group, because they had graduated from the school. The remaining group (prevention practitioners, prevention scientists, social marketing scientists, VR game scientists, VR film production expert) examined and explored the prototype and shared their experiences and feedback about the prototype. This stage resulted in a co-developed list of priorities for improvement. The digital prototype was improved accordingly (version 2). Additional graphical elements were added to improve the user experience and to guide the user.
Testing the product	The improved prototype (version 2) was tested with 31 boarding school students (average age 16 years) focusing on usability, technical qualities and user satisfaction and general feedback. A list of issues resulted from this and minor improvements were made for version 3 of the digital prototype. More details on the results of the pilot testing are described in (24).
Evaluation of the process and product	To evaluate the co-creation process, the development group shared their experiences of developing and pilot testing the VR game at a meeting. An outcome of this was a co-created list of lessons learned.

to pinpoint a clear aim of the project, and both processes identified expert stakeholders to inform the subsequent user focused process.

Divergence and Convergence of Both Approaches

While the seven-step co-design process focusses on preparing for the specific co-design sessions with users and stakeholders through *sensitization* and *facilitation*, the Living Lab process is more focussed on the creation of an initial *concept design,* followed by a more concrete *prototype design*, and a more finalized *innovation design*. It is important to achieve incremental improvements while carefully ensuring that user and stakeholder voices are heard throughout these key procedural steps. For example, a concept needs to be detailed enough so that end-users can understand and engage with the initial concept, while allowing room for open and constructive exploration of other concepts during end-user engagement. Concepts can take the form of storyboards, visual narratives and other mock-ups (26). It is important to note that these concepts have also been brought to co-design sessions, however these are covered in the initial stages of the co-design process (*resourcing & planning) (4)*. Next, the Living Lab process outlines a *prototype design* stage which selects the winning *concept design* from the previous step and then articulates—and potentially builds a mock-up entailing "basic functions, workflows and interfaces" [(26), p. 34]. Taken together, the Living Lab process places much greater emphasis on prototyping than co-design. For example, in the Danish context researchers ended up with three iterations of the prototype while in in co-design only one prototype was built. This is an important distinction and leaves room for co-design processes to be improved.

During the co-design process the focus is directed toward end-user and stakeholder engagement during co-design sessions. Specifically, *sensitizing* allows for participants to appropriately engage with the aims of the co-design workshops (27). This can be playful, serious or creative. We used online games to engage adolescents with relevant and fun content to spark creativity and provide them with a fun environment that would foster creativity and would help them understand what the Blurred Minds program aimed to do. *Facilitation* welcomes participants and uses warm-up activities to assist in developing trust, empowering participants to contribute and foster creativity and collaboration among team members. Sensitisation and facilitation are very specific steps ensuring user and stakeholder engagement and empowerment during co-design are evident. Interestingly, both are however not visible in the Living Lab processes discussed (26). While this marks an important divergence of both processes, it demonstrates important and very helpful information that facilitators of Living Labs would benefit from. Currently, Living Lab resources refer to interviews and observations with users to ensure that their needs are met. However, users are not necessarily viewed as experts of their own experiences but rather as a checkpoint in an innovation process.

Next, the co-design steps focus their attention on a detailed and immersive *reflection* following the co-design sessions. It is important to note that the co-design process at this point has not yet commenced a more detailed prototype development which is significantly different from the Living Lab process. *Reflecting* completes the analysis of all obtained data from the co-design workshops which often features a mix of qualitative and quantitative data (28, 29) and more recently stakeholder input to assess feasibility of user generated ideas (12). These learnings can then be derived into key insights that shape the direction of the intervention development while carefully gauging feasibility, project team capacity, and target audience wants and needs (4, 30). Finally, and only at the *building for change* step, the process asks for the development of prototypes which should be based on the insights generated through the six previous steps. It is also important to note that this is a newer and more recent addition to co-design process (4), where stakeholder input is sought to assess feasibility of user generated ideas (12). Moving forward, working closely with experts, stakeholders and end-users to build concrete prototypes through fast moving iteration cycles is recommended as an addition to existing co-design processes to ensure that prototypes get tested to compare and contrast user acceptance of generated solutions. The Living Lab process as it was applied in the Danish case concluded with *testing of one product* with end-users and with *evaluation of the product and process* with all stakeholders involved in the process, but evaluation might also be included in addition during earlier Living Lab stages (26).

Limitations and Future Research

This study is not without limitations. First, whilst these two co-creation methods were undertaken in the same context (alcohol education for adolescents), Blurred Minds did inform the VR FestLab, meaning that the VR FestLab benefitted from the early learnings gained in the design, implementation and evaluation of Blurred Minds. This may have influenced the dynamics and outcomes achieved during the Living Lab process. However, we are not able to articulate the scale of this influence on the process. We note that many different descriptions of co-design processes and Living Lab approaches exist. It is important to contrast and distinguish the various co-creation approaches to assist researchers and practitioners seeking to understand the relative strengths and weaknesses of approaches. By comparing and contrasting approaches assumptions can be questioned and enhanced understanding can be gained. Both, Living Lab and co-design, still lack empirical research and we know relatively little about the effectiveness of various approaches. Future research should replicate this methodological comparison simultaneously and compare the processes and the outcomes, such as differences in the participants' engagement level and a final outcome evaluation to permit a full cost benefit analysis. This research agenda will enable understanding of how programs can be co-created most effectively into interventions that are capable of achieving desired outcomes.

Conclusion

Co-creation requires bringing together a group of people that collectively design relevant and engaging health intervention solutions without a dominant single voice taking over the process. This study contrasted two case studies that aimed to co-create virtual reality interventions within an alcohol prevention context. Both, the co-design and the Living Lab method, demonstrated utility to design innovative health intervention solutions that have demonstrated initial positive successes.

DATA AVAILABILITY STATEMENT

The data analyzed in this study is subject to the following licenses/restrictions: Additional information can be made available. Requests to access these datasets should be directed to t.dietrich@griffith.edu.au.

AUTHOR CONTRIBUTIONS

TD wrote the first draft of the manuscript and participated in the data collection and analysis of the Australian case study. CS was responsible for and participated in the data collection of the Danish case study and contributed to the drafting of the manuscript. JG, LV-H, and PL participated in the data collection for the Danish pilot study. TD and CS were principle investigators of the respective studies, had the lead in its conception and coordination. All authors contributed to the manuscript, critically reviewed its content, and have read and agree to the published version of the manuscript.

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Qualitative Study on Dialogic Literary Gatherings as Co-creation Intervention and Its Impact on Psychological and Social Well-Being in Women During the COVID-19 Lockdown

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Background: Dialogic Literary Gatherings (DLG) are evidence-based interventions implemented in very diverse educational and health settings. The main elements that make DLG a co-creation intervention and promote health during the COVID-19 crisis lockdown are presented. This study focuses on the case of a DLG that is being promoted by an adult school in the city of Barcelona.

Methods: This qualitative study was conducted using a communicative approach. Seven in-depth interviews with participants in the online DLG have been conducted. Five of them are women without higher education ranging from 56 to 85 years old and two are educators of this school.

Results: The main results are 2-fold. First, the factors that make DLG a co-creation intervention, such as egalitarian dialogue and dialogical creation of knowledge in the decision-making process, are found. Second, the results show how DLG is contributing to creating a supportive environment that breaks the social isolation of confinement and improving the participants' psychological and social well-being.

Conclusions: The findings from this study contribute to generating knowledge about a co-creation process between adult education participants and educators in education and health promotion during the COVID-19 lockdown, which could be replicated in other contexts.

Keywords: co-creation, dialogic literary gathering, health promotion, adult education, COVID-19

INTRODUCTION

The COVID-19 pandemic has already caused more than half a million deaths worldwide. Although the USA, Brazil, Mexico and the United Kingdom are the countries with the most deaths, if the ratios for countries with populations >1 million are calculated, Spain would have the third highest death rate with 60 deaths per 100,000 people, behind Belgium with 86 and the United Kingdom with 69 deaths per 100,000 people, according to data updated on 9 August 2020 (1).

On 15 March 2020, a state of emergency in Spain went into effect and, as in many other countries in the world, a mandatory quarantine was established. The restrictions also included the closure of schools, universities, nonessential businesses, and any leisure establishments. On June 21, the last extension of the state of emergency in this country ended, starting what has been called the new normal.

There is still very little evidence of the impacts of the COVID-19 pandemic lockdowns on physical and mental health in older people, as well as the impacts of health and well-being interventions developed by community-based organizations to address these effects (2, 3). However, there is substantial previous evidence on social isolation and loneliness as risk factors strongly related to depression, anxiety and cognitive decline affecting the psychosocial well-being and health conditions of older adults (4–6).

For this reason, an urgent global call for action to mitigate the consequences of the lockdown on the physical and mental health of older adults has been expressed by international organizations and the scientific community (7–9). The WHO points to anxiety and feelings of isolation as factors that deteriorate people's mental and physical health since people are without the closeness of loved ones, family routines and support networks, increasing the perceived risk of death and illness (10). The UN recently launched a policy brief on the impacts of COVID-19 on older people, including measures strengthening social inclusion and solidarity during physical distancing, increasing their access to digital technologies, and their participation in decision-making processes for policies and interventions that affect their lives (11). Preliminary studies have analyzed evidence-based approaches that can address the problems of social isolation and loneliness in older people, including promoting social connections as a public health message, mobilizing the resources of family members and community networks, and developing innovative technology-based activities to improve social connections (5, 12).

Co-creation processes and participatory community-based approaches to design and implement health promotion and education interventions can contribute to effective responses at this historic moment of unprecedented global challenges created by the COVID-19 pandemic (13). Participatory approaches including end-users and stakeholders in public health research and health promotion and education have been increasingly implemented over the past two decades. There is much literature on how these participatory methods have been developed and specifically on how end-users have been included in community-based participatory research. Different concepts have been used for these approaches that also have different emphases. One concept is the co-creation of evidence, defined as the approach that integrates the best existing research evidence with other types of evidence available such as patient expectations (14). Some have deepened approaches in which existing research evidence is combined with the knowledge and experience of the directly affected communities, creating evidence from intersubjective knowledge and egalitarian dialogue (15). These approaches have promoted processes known as the Dialogic Recreation of Knowledge (DRK) in those dialogues that recreate the existing evidence on interventions that improve the living conditions of communities to respond the priorities and needs of a particular community (16) or involve end-users and stakeholders in the whole research process and the implementation of the intervention for a greater social impact (17–19). Some studies focus on how to include the most vulnerable groups, such as the elderly, in the co-creation process. Examples include the design of interventions to reduce sedentary behavior and promote physical activity (20); the design of local smoking cessation services including focus groups with smokers and ex-smokers with long-term illnesses, serious mental health problems and minority ethnic communities (21); and the promotion of community resilience processes regarding how a community addresses emergencies and other persistent and emergent threats such as severe weather and dangerous exposure to it (22).

The Dialogic Literary Gathering (DLG) is an educational intervention for the collective creation of knowledge and meaning based on the reading of the best literary creations of humanity and the subsequent dialogue between all the participants (23). Longitudinal studies carried out for more than 10 years with people close to the elderly have shown that the mortality of regular readers is reduced by 20% (24). Other studies have found that reading quality literary works increases the capacity to better understand others, facilitating empathy and pro-social behavior; in contrast, popular fiction does not stimulate this capacity (25, 26).

The first DLG was initiated in 1980 at the same adult school that has participated in this study. Currently, there is a DLG movement that involves more than 9000 pre-school, primary, secondary and adult education schools in Europe and Latin America in the framework of the Schools as Learning Communities and the extension of the Successful Educational Actions projects (27–31). As well as the DLG have been transferred to prisons and primary care health centres in Spain. There is extensive evidence on how the implementation of the dialogical learning principles on which DLGs are based promotes the cognitive, social, and emotional improvement of participants, regardless of their age, educational level and cultural background (32–37). Research that presents how online DLGs have been implemented in primary and secondary schools in Spain to promote supportive environments during the COVID-19 pandemic lockdown has been published very recently (37).

There are two goals of this preliminary study. First, the study aims to identify the elements that have been part of the co-creation decision-making process between educators, volunteers, and participants that drives the recreation and implementation of an evidence-based intervention, the DLG, during the lockdown from April to July 2020. The DLG was held to promote social connection and well-being in a group of adults and older adults of an adult school in the city of Barcelona. Second, this study seeks to collect DLG participants' perceptions of the impacts on their psychological and social well-being.

MATERIALS AND METHODS

This section first, outlines the ethics statement. Second, the hypotheses and research objectives are presented. Third, the contextualization of the Adult School La Verneda-Sant Martí and the DLG is introduced. Finally, the process of data collection and analysis using interviews with a communicative approach is explained.

Ethics Statement

This study has been approved by the Ethics Board of the Community of Research on Excellence for All (CREA). The study has followed the official guidelines for ethical issues of the European Union H2020 research program and the Declaration of Helsinki (38) for informed consent, data protection and privacy.

Before starting each interview, the researcher informed the participants about the voluntary nature of the involvement, the aim of the study, and the confidentiality and anonymity of the information collected with the sole objective of developing the study. Participants were informed of their right to stop being part of this research at any time before the publication of the results. In the informed consent, permission was requested for the audio recording of the interviews and the publication of the study results.

Hypothesis and Research Objectives

The hypothesis of this study is that DLG has a positive impact on psychological and social well-being in women involved during the COVID-19 lockdown.

This study responds to two research objectives:

(1) To identify the elements that have been part of the co-creation process between educators, volunteers, and participants that drives the recreation and implementation of the online DLG during the lockdown from April to July 2020.
(2) To collect the perceptions of the educators and participants on the impacts of DLGs on psychological and social well-being.

Bibliographic Sources for Contextualization the Case

In order to contextualize the adult school in which the study was conducted, a review of the articles published in indexed journals on this school was carried out. The works of authors who form part of the theoretical basis of DLG have also been reviewed.

The Verneda-Sant Martí Adult School and the DLGs

The Verneda-Sant Martí Adult School (39) is named after the neighborhood of Barcelona in which it is located. This school was created in 1978 through the initiative of a small group of residents in the neighborhood. With the end of the Franco dictatorship in Spain, a seven-story building that had belonged to the female section of the dictatorial movement was left empty in the neighborhood. Neighbors organized to advocate that the building be used as a space for social, health, cultural and educational projects. At the time, illiteracy rates among the population, especially women, were very high. In the end, the building hosted a nursery school, a library, different social and health services, and the Verneda-Sant Martí Adult School.

Since its inception, this adult school has been a key entity in the social and cultural transformation of the neighborhood. Together with other entities, it promoted a neighborhood movement through which joint actions have been coordinated from different spheres, such as the campaign "Let's break the silence against gender violence" in which social, educational and health organizations are involved, that is still alive now. This school has always worked in coordination with the neighborhood's primary healthcare centre. It is common for the doctors at this healthcare centre to refer cases of old people with mental health problems, such as depression, to this school. Recently, a DLG overseen by the adult school has been started in the healthcare centre. The DLG is coordinated by a retired nursing assistant who is also a participant in one of the DLGs conducted in the adult school. The impacts of participating in the DLG on the health of the people from the healthcare centre will be the subject of future studies. The present study only focuses on the online DLG developed in the scope of the adult school during the lockdown.

Two of the main characteristics that define this school since its foundation are the following: (1) All the actions that it implements are based on the best existing evidence on which actions improve the learning, well-being, values, emotions and feelings of adults and (2) It is a democratic school in which end-users participate in all decision-making processes and the needs of the most vulnerable groups such as people without basic academic qualifications are favored. Due to these reasons, this school is managed by two associations of participants, Ágora and Heura, where the latter represents women. In this school, the word "participant" is used instead of "end-user" or "student" when referring to adults who do not have higher academic degrees and participate in school activities, including all decision-making spaces. In addition to the team of educators hired by the two associations, this school has more than 100 volunteers. The volunteers include university professors who started the project 40 years ago as neighbors and educators of adults, as well as women who have become literate in this school and who now teach other people, among other very diverse profiles.

The model of democratic education for adults of the Verneda-Sant Martí Adult School is known by the scientific community in the educational field. It was the first Spanish pedagogical experience published in the Harvard Educational Review (40), and it is also the subject of other studies published in internationally prestigious academic journals such as the Teachers College Record of Columbia University (41).

One of the successful educational actions carried out at this school since 1980 is the DLG. A DLG is a space for the collective creation of knowledge through the best literary works that humanity has created. A DLG is based on dialogic learning, an evidence-based approach that collects the interdisciplinary contributions of learning sciences that focus on interactions and community involvement (23, 42–47). Its operation is based on the choices of the participants reading the literary work. The number of pages to be read before the session is agreed upon. Each person reads those pages and selects a paragraph. DLG sessions are normally held once a week with a duration of one-and-a-half to 20 h. During the DLG session, the participants stand in a circle. One person is the moderator. This person asks if there are people who want to read their paragraph, and then sets the turns in which they speak. The first person begins to

TABLE 1 | Participants' profiles.

Profile	Code	Gender	Age range	Academic level
Educator	E1	Male	45–50	Higher education
Educator	E2	Female	25–30	Higher education
Participant	P1	Female	70–75	Basic education
Participant	P2	Female	70–75	Basic education
Participant	P3	Female	55–60	Basic education
Participant	P4	Female	55–60	Basic education
Participant	P5	Female	80–85	Basic education

read the paragraph and explains why it was chosen. Opinions do not try to explain what the author meant. The person who reads the paragraph explains what that paragraph has evoked, be it an opinion or a reflection. Anyone else who wants to comment on the paragraph read is allowed a turn to speak. When the discussion of that paragraph is over, the next person, in turn, reads his or her paragraph. This same procedure is repeated until all the paragraphs are read. One of the fundamental criteria of a DLG's operation is respect for all the opinions and different ways of thinking.

As in every school in Spain, this school was closed on 13 March 2020 due to the physical distancing measures decreed in Spain during the COVID-19 pandemic. With the closure, all face-to-face activities, including DLGs, ceased. For many of the participants, most of them older women, some of them living alone, that meant the abrupt disappearance of one of their main weekly social activities.

Data Collection and Analysis: Interviews Using a Communicative Approach

This qualitative study has conducted seven interviews, including interviews with five women who participated in the online DLG during the lockdown and two educators who have moderated and provided technical support to the DLG, using a communicative approach. The interviews were collected from July 16th to 20th when Spain was no longer in a state of emergency and the lockdown was over. Nevertheless, it was decided that the interviews be conducted through video calls as a preventive measure to minimize the possibility of COVID-19 infection. The criterion for selecting the interviewees was their willingness to take part in the study.

It should be noted that there was already close collaboration between the research team and the school. Some of the researchers on the team have collaborated with this school for more than 10 years, and this collaboration took place for 20 years for some of them. The researchers explained the study proposal to the coordinator of the educators' team. The coordinator then informed the DLG participants of the researchers' proposal and requested their participation. All the people agreed with the study. Among these people, five participating women, in addition to the two educators, volunteered to participate in the study. The profiles of the people interviewed, and the codes assigned to them are listed in **Table 1**.

The interviews collect the postulates of the communicative methodology of research (15, 36, 48). The interviews using a communicative approach are conducted as open conversations in which the researcher shares the existing evidence with the interviewee. In turn, the person interviewed contrasts this evidence with his or her experience. Through an egalitarian dialogue between the researcher and the researched person, an interpretation of reality is reached. In the egalitarian dialogue, the force of the arguments prevails and there is no power relationship (46). An interpretation is considered to be valid not because of the position of the power of the person who performs it, such as the researcher over the investigated person, but rather because of the strength of the arguments on which it is based, regardless of who makes that argument.

In the interviews, evidence on the elements that make up a co-creation process and the factors that contribute to improving the psychological and social well-being of people in lockdown situations was shared. Thus, a dialogue was established in which the participants contrast this evidence with their experience.

The interviews were recorded and kept in a folder on the cloud of the University of Barcelona that was shared with the members of the research team. The main contributions for each of the two research objectives were transcribed. These contributions were turned into an Excel document shared by the research team. The citations that correspond to elements that had been part of the decision-making process between educators and participants, the process of implementing the DLG and the impacts on the psychological and social well-being of the participants were classified. Once the information was analyzed, the results were sent to all the participants. In some cases, in the feedback, the participants specified some of the information given. All the participants agreed with the final interpretation of the results obtained and the conclusions.

RESULTS

First, the key elements of the co-creation decision-making process for the recreation and implementation of the online DLG during the lockdown are presented. Specifically, these elements include how the decision process was carried out and how the participation in the online DLG of the maximum number of people was promoted. Second, participants' perceptions of the impact that their involvement in the DLG has had on their psychological and social well-being during the confinement are collected.

Dialogic Literary Gathering as Co-creation Intervention to Promote Psychological and Social Well-Being During the COVID-19 Lockdown

Co-creation in the Decision-Making Process Between Educators, Volunteers, and Participants

As in much of the world, the closing of schools was a shock to both educators and participants. For the women who participate in the weekly DLG, most of whom are older and live alone, it meant the sudden loss of one of their main social activities.

Educator 2 is the coordinator of the educators' team and has been working in this school for 4 years. She explained that the democratic decision-making background of this school helped to address the situation. A few days after the closure, a video meeting was held to assess the possibilities of continuing online activities during the confinement. Educators, volunteers, and participants were involved in this encounter.

Some of the volunteers are social sciences and education researchers seeking to overcome inequalities. One of these female volunteers expressed the importance of continuing the school's activities during the lockdown. As an academic, she offered evidence of the benefits of promoting online meetings as supportive environments to break feelings of isolation. The female participants were clear from the beginning that something had to be done despite the difficulties. Educator 2 states how the team of educators alone would not have been able to do everything that was finally done. Some of them had also never used platforms for video meetings and online classes.

It was not only the proposals of the academic volunteers and the commitment of the educators that made proposals that allowed the school to overcome the situation. The participants also contributed valuable ideas so that online connections could be possible. The participants knew what specific help they needed to be able to connect to online activity. Educator 2 explained how participant 2 and others proposed very useful ideas on how the DLG could be carried out online. Some of the ideas were to make a short and very simple guide on how to download and how to use the video meeting app, to make the guide available to everyone, and to guarantee technical support for each connection through phone calls to whoever needed it. It was agreed that educators and volunteers would ensure this process as much as possible. This is how Educator 2 describes it:

> We educators, of course, could not have done it alone. Some of us were also afraid of technology. There were a lot of people who finally got connected that had never participated in a video call, nor almost knew how to use their smartphone. Two important things happened: one is to have volunteer advisors, who have a lot of experience in adult education, and know the school very well. They were the ones who said at the beginning, "something has to be done here"; and two, the participants, like P2, were the ones who said, "we can do it this way". So yes, it was super joint. What we did was to get it going and ensure technical support. Without those two things, advisors and participants, it wouldn't have been possible (E2, 04:05).

Another decision agreed upon at that meeting was that conducting the DLG would be a priority. Specifically, it was decided that two DLG sessions would be held, one session for each of the 2 weeks of confinement decreed by the government of Spain. The argument behind this decision was shared by educators, volunteers, and participants alike. This argument is based on existing evidence that a DLG is an educational action of collective knowledge creation that improves learning, values, emotions, and feelings. All agreed that the online DLG was an ideal activity to perform during the lockdown.

The next decision focused on which literary work would be read for those two DLG sessions. Some of the women participate in one of the DLGs that are traditionally held in this adult school. Therefore, they already have a list of works that they would like to read for the first time or in some cases read again. Among the different proposals they made, it was finally decided to read three stories from *The Arabian Nights* for the first session. It was considered that since the stories were short, only a few could be selected for discussion in each session so that a story would not be only partially discussed during the session when it was not yet known how long the confinement would last.

The first session of the online DLG was held on Saturday, April 11. It was so successful that the participants asked that it be held weekly during the weeks of confinement, and it was. At that time, it was already known that the state of emergency would be extended. Finally, a DLG was held every Saturday from 6 to 7:30 p.m. until June 20. During that period, all the tales of *The Arabian Nights* were finished. The next day, the state of emergency was lifted. However, the new normality did not allow the return to normal activity in the adult school either.

Even though the academic year in Spain ends that week in June, this adult school, since it is managed by the associations of participants, decided years ago to be open the month of July as well. Under the slogan "The school opens in July," a range of cultural and training activities are held every July. In a second meeting, it was decided to continue with the DLG online for the whole month of July. This time they chose to read the *Chronicle of a Death Foretold* by Gabriel García Márquez. This is how educator E1 explains it:

> A proposal of different classical works was made by the participants when *The Arabian Nights* were finished. I was in the process of choosing the book to read in July. Different works were proposed, and now we are reading from García Márquez: *Chronicle of a Death Foretold*. Both the participants and we made proposals; the proposal that came out was from a participant who said that it was a book that could be easily finished in July (E1, 11:50).

Promoting the Participation of as Many People as Possible in the Online DLG

Once the decision was made to carry out the online DLG, the priority was that the activity reached as many people as possible. For this purpose, a phone call was made to all the people participating in the different DLGs of the school. This was done to reach all the people since many of them do not have e-mail or online social network accounts or do not use them assiduously. Educator 1 (3:00) explained how these calls would be the educators' first contact with many of the participants since the confinement began. There was a concern for the participants' well-being and knowing how they were doing. Many of them needed to talk and share how they were feeling and how they were living during the confinement situation. They were then informed that the DLG would be conducted online and how they could connect to the Zoom video meeting app where it would take place. They were also given simple guidelines on how to use Zoom on their computer or mobile phone. This educator explained how they were sensitive to the issues related to these calls so that no one would feel guilty about not being able to participate, especially at a time when some people were very focused on how the pandemic was developing and some even already had a relative who had COVID-19.

Educators and volunteers were available through WhatsApp or by phone to provide technical support to those who needed it to connect to Zoom. During the development of the DLG online, one of the educators moderated the discussion and other people, sometimes educators and volunteers, were available in case someone during the connection needed technical support and a call had to be made. Educator 1 explains how they logged in before the start time of the DLG to provide this support. He stated that the technical support was hardly needed when the different sessions of the DLG were taking place.

> On DLG day, we used to go online earlier to provide technical assistance. During the discussion, I was the moderator, but there were other people, one or two, who acted as technical support. In the end, people were doing very well, but if there was a problem a call was made (E1, 18:30).

Educator 2 explained (E2, 08:50) that another of the decisions made to promote participation was that there should be a free online version of the book chosen. If this had not been the case, it would have been difficult to participate because the libraries were closed or people would have to buy a book under the circumstances of the confinement, which would have been an additional difficulty for older people who do not usually buy items online, in addition to the economic costs. Finally, ∼30 people participated in each online DLG session. In each of the sessions, the dialogical criteria with which the traditional DLG worked were maintained. This implied that the moderator at the beginning of each session reminded the participants of the importance of respecting different opinions, keeping their turn to speak and that priority will be given to people who had not yet spoken to facilitate the participation of those who have more difficulties to intervene. This is how educator 2 explains it:

> The interaction has been the same (as in the traditional DLG) because what was done when moderating was the same. Well, first, we all learned that we had to have the microphones off and only the microphone of the person who had the floor was open. After having made it clear that and how to request the floor, the operation has been the same as in the traditional DLG. The moderator explained the criteria and asked who had a paragraph to read. Then, people raised their hand, the moderator noted. The moderator gave the floor to the first person. The first person reads his or her paragraph and explains why he or she had chosen it. Then, the moderator opened the floor again in case anyone wanted to comment on the paragraph read. This continued until all the paragraphs were finished (E2, 11:30).

Impact of the DLG on the Psychological and Social Well-Being of Participants During the COVID-19 Lockdown

Both the educators and the female participants in the interviews stated that participating in the DLG during confinement has had a positive impact on the participants' psychological and social well-being; some participants have even reported that they have felt better physically. The factors in the online DLG that participants perceived as having a positive impact on their well-being are presented.

Good Literature, Egalitarian Dialogue and Respect for the Others' Opinions Improve Psychological and Social Well-Being

Respect for others' opinions, even if the opinions are different from one's own opinions, is one of the criteria for the functioning of the DLG and one of the factors that all the participants pointed out as having a positive impact on their well-being. There is previous evidence that the reading of quality literary works such as universal classics increases individuals' capacity to understand other people, facilitating empathy and pro-social behavior, by deepening the psychology of the characters and the reasons for their actions. In the DLG, this evidence can be corroborated, and it is also reinforced by the dialogues that are given on fragments of the text. P1 asserts that having participated in the DLG has improved her mental and physical health before and even more during the lockdown. She states that a feeling of freedom is created by the atmosphere of respect for all opinions that counteracts the limitations of the physical distancing. This is what she said:

> The gatherings have improved my mental and physical health during the lockdown and before. At the gathering, reading the book is different. An atmosphere of freedom is created because while you respect what others say, they also respect you. It has always helped me and in the lockdown more because you are very limited without being able to get out and meet other people (P1, 13:00).

P3 also refers to the fact that the DLG pushes her to socialize and better manage her human relationships, thus feeling more encouraged. This is how she explained it:

> It makes you feel more encouraged. Always the psychological, or the emotional, is related to the physical, it makes you have another drive. It pushes you to face human relationships (P3, 09:58).

P4 reflected on how literary quality books, such as the one read in the DLG, make her think and have "touched her inside." Her affirmation is in line with existing evidence on how the simple reading of a good book changes the brain by increasing neural connections (49–51). She adds that it makes her feel alive and see life from a new perspective:

> All good books touch you inside. They deal with issues in a deep way that makes you think, see life differently. People who don't have a taste for reading don't know what they're missing; for me, reading brings a lot of life to me (P4, 19:30).

DLG as a Supportive Environment Overcoming Feelings of Isolation and Improving Self-Esteem

Educator 1, who moderated all the sessions of the online DLG, explained some of the assessments that the participants have made. They said that the online DLG was "like a window open to the world" (E1:14:10) or "like meetings in which we became more and more friends every week" (E1, 16:00). E1 claims that the DLG during the confinement has allowed the participants to continue to have contact and created an environment in which they felt even more united than before (E1: 14:40). The creation of supportive environments and the promotion of a sense of community during confinement have been identified by the recent scientific literature as two of the elements that have contributed to lessening the feeling of isolation (2). Many of the participating women live alone. The DLG has been one of the activities that have helped them overcome the feeling of isolation and minimize the distress of the situational uncertainty, fear of illness, and stress caused by listening to the daily news or because of the amount of misinformation that has spread through social networks (52). This is how P2 who lives alone explains it:

> It helps you mentally because you can talk to someone. It's not the same to see people on the screen and be in dialogue with them than to receive a message from WhatsApp. Because there is stress... you think when you wake up: let's see if the news has improved and it doesn't, on the contrary, every day it was worse. DLG has really helped me. If the world had totally shut down, if everything had gone silent, it would have been harder. At least, the hour or 2 h of the DLG helped me (P2, 21:00).

Some of the participants and educator E2 affirmed that the supportive environment that has been created in the DLG has helped to increase self-esteem. The fact that the educators demonstrated confidence and believed that they would be able to participate in a DLG online when some of them had very few digital skills helped them to believe in themselves and to think that they were capable of doing it, thus, increasing their self-esteem when they saw that they had finally achieved it. Educator 2 (14:40) and (participant 1 03:20) commented that in the beginning, it was challenging for the latter to connect, but as the weeks passed and she had the support of the educators, volunteers and other participants of the DLG, these difficulties disappeared. Participant 5 also explains how she has received support from educators, volunteers, and other participants in the DLG online. She claims that this support has had an impact on improving her self-esteem and well-being:

> The school and the DLG is one of the places that have helped me the most. It's like raising my self-esteem, because when you think you can't, and you don't believe in yourself, but suddenly there's someone who believes in you, you grow up and you try to better yourself and in the end, you succeed (P5, 17:40).

DISCUSSION AND CONCLUSION

This preliminary study is the first to analyse the impact of a co-creation intervention, an online DLG, on the psychological and social well-being of women and older women during the lockdown period of the COVID-19 crisis. Specifically, seven interviews using a communicative approach were carried out with women and educators who participated in this intervention within the framework of the activities organized by an adult school in a neighborhood of Barcelona, Spain. Despite being a preliminary study that includes a few interviews, it makes two valuable contributions. First, it provides knowledge about the successful elements for co-creation within the framework of a decision-making process for the implementation of an intervention that breaks the feeling of isolation during the lockdown, especially among older women with basic levels of education and few digital skills. Second, it offers qualitative evidence on how the online DLG has had a positive impact on their psychological and social well-being during that period from participants' perspective.

This study has responded to the call to action made by international organizations such as the UN and the WHO (10, 11), as well as by the scientific community (4, 7, 53, 54), to develop public health policies and community networks to address the consequences of social isolation and loneliness on older adults during the physical distancing measures implemented due to the crisis of the COVID-19 pandemic. Social isolation and loneliness are important risk factors that have been linked to poor psychological and physical health (5). This study responds to the call by offering evidence that this co-creation intervention could be recreated in other contexts and adds to previous evidence on its potential for scalability and transferability (32, 33, 37, 55–59).

Dealing quickly and effectively with the psychosocial consequences of this lockdown on older people has made the co-creation processes of community networks implementing health promotion interventions even more meaningful in recent months. Very recently, a co-creation methodology was developed to identify those health professionals who require emergency mental health because of the COVID-19 crisis in Scotland through expert advisory groups of stakeholders (60). However, at the time of the writing of the current article, no studies had been published on the development of co-creation processes to alleviate the psychological and social consequences of the lockdown due to the COVID-19 pandemic on adults and older adults.

The debate on the impact of community-based participatory approaches in decision-making, design and implementation has intensified over the past 10 years in public health research (17, 22, 61–63). Previous literature has highlighted the difficulties of making these processes co-creative with those vulnerable groups that are the hardest to reach (20, 21). This study provides knowledge that contributes to the identification of the successful elements for co-creation in decision-making processes with vulnerable groups, such as older women with a basic level of education.

The decision-making process between the educators, volunteers and participants of this school regarding what type of activity would be promoted during the lockdown responds to what is known in public health and health promotion research as evidence-informed decision making (EIDM) (14). Some studies have pointed out that to be able to develop EIDM processes from co-creation or participatory community methodologies, relationships of trust and mutual respect between academics, stakeholders and end-users are necessary (18, 19). In the school involved in this study, these relationships exist and are maintained over time. For example, some of the volunteers who have participated in the decision-making process are academics in the fields of social sciences, education, and health promotion.

Some of these volunteers have been involved with this school for years. These people are involved due to their social commitment as academics, without receiving any economic benefit, to ensure that the school maintains the principles with which it was created: the implementation of evidence-based interventions and that the decision-making processes are democratic, based on an equal dialogue between all the people involved, and always prioritize the needs of the most vulnerable groups.

The decision-making process for the implementation of the online DLG during the lockdown is based on existing evidence that this intervention is a successful educational action that improves cognitive, social and emotional well-being (33, 35, 36, 64). However, this process of decision-making and implementation goes beyond the EIDM and responds to the so-called dialogic recreation of knowledge (DRK) (16, 32, 37). In the DRK, academics together with the stakeholders and end-users of a community start with the existing evidence on educational, social and health promotion actions that have been shown to improve the living conditions of communities in very different contexts. What differentiates the DRK from other EIDM processes is that an equal dialogue is established between academics, stakeholders and end-users based on how that evidence can be recreated to address the priorities and needs of a particular community. In the case of the present study, the DLG, an evidence-based intervention, is recreated to overcome the barriers of implementing it online during the lockdown period with adults who have basic levels of education and few digital skills. A recently published study has also focused on the DRK of online DLGs and other online dialogic interventions promoted by primary and secondary schools to create supportive environments during the lockdown in Spain (37).

This DRK process is based on the existing evidence, which is provided by the academics involved in it. The contributions made by the academics, educators and participants are valid according to the arguments on which they are based and not according to power relations, such as that of a female academic regarding a woman with a basic level of education (65, 66). All those involved in that decision-making process agreed that the DLG was an ideal activity to carry out during the lockdown to break the social isolation. The arguments provided by the different parties helped to overcome the barriers to implementing such an online activity during this period. Furthermore, the contributions of the women participants were especially valuable. They knew what concrete help they needed and how they must be helped to be able to connect to a virtual platform and follow the online DLG. The predisposition of the team of educators and volunteers who collect the contributions of these women provides technical and human support that makes it possible for women with basic levels of education and few digital skills to finally be autonomous on these virtual platforms and follow the online DLG weekly.

The perceptions of the positive impact on their psychological and social well-being expressed by the participating women are in line with existing evidence already referenced on the impact of the DLG. In addition, the perceptions of some of the female participants have also pointed out that the positive impact of the DLG in breaking down feelings of isolation and minimizing the anxiety generated by uncertainty and the fear of getting sick has been even more important during the lockdown period. Thus, the online DLG contributes to minimizing the risk factors for the deterioration of the psychological and social well-being and health of older people during confinement that have already been reported in other studies (5, 7, 54).

From the participants' accounts, it has been identified that the online DLG has had a positive impact on their well-being during confinement not only because it is a virtual space for social relations but also because of the principles on which this intervention was based. The reading of quality literature, the respect for others' opinions and the respect for turns to speak generate a dialogical environment in which the participants feel free to express their opinions and reflections. They also report that the type of book they read and the sharing of the reflections that these readings evoke impact them positively by offering them new perspectives on life. These dialogues and interactions in the online DLG facilitate the creation of a sense of community and a supportive environment also identified by previous studies as key elements to overcome the feeling of isolation (67). For example, not just the educators and volunteers have provided technical support to the participants. The female participants in the online DLG have been helping each other to overcome difficulties with connections.

PRACTICAL RECOMMENDATIONS

The online DLG could be a kind of co-creation intervention that can be promoted in an intersectoral partnership between clinical and community-based organizations to reduce the social isolation of the elderly and promote a supportive environment through remote connectivity, as recently suggested by other preliminary studies (2). An online DLG could be a complementary intervention to other services to engage and support older adults during the difficult periods of physical distancing from the pandemic by building on existing or creating new practices in the community. Two limitations must be considered so that this intervention can be implemented in other contexts. The first is the poor digital abilities of some older people. The second is that not all people have access to electronic devices with internet access. Regarding the first limitation, this article provides evidence on how to overcome it. Regarding the second limitation, more research is needed on the social impacts of future projects that this school is working on to obtain public and private funding to increase access to these devices among isolated older people.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethics Board of the Community of Research on Excellence for All (CREA). The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

LR-E: contributed to the conceptualization of the study under the research line of successful educational actions overcoming inequalities that women with no academic qualifications face, in the framework of the Ramon y Cajal grant and revised and edit the final version. AT and SG-C: collected the data. LR-E, AT, SG-C, and BV-C: contributed to the formal analyses and discussion of the data. LR-E and BV-C: drafted the manuscript. All authors have made substantial contributions and have read and agreed to the published version of the manuscript.

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School-Based Participatory Response for Reopening During the COVID-19 Pandemic: A Case Study of a Metropolitan High School Implementing the Health Promoting School

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Purpose: This study aimed to analyze how a private high school in Seoul developed and executed a "school disinfection strategy" to ensure the students' right to study in a safe environment, and also to analyze the lessons learned from this process.

Methods: This was a case study of school health in a community-based school reopening during the COVID-19 pandemic. The study target was a 64-year-old private high school with 12 classes for each grade with a total of 1,100 students.

Results: A "school disinfection strategy" was set up at individual and class environment levels to protect students from the risk of infection. In addition, school health activities were carried out with a "personal protection safety belt" and "community protection safety belt" for effective implementation. To ensure a safe educational environment for high school students and to ensure smooth execution of face-to-face classes (in-person teaching), the "prevention safety belt strategy" was introduced in accordance with governmental guidelines to sequentially implement various preventive measures necessary to guarantee environmental safety of schools. Activating personal prevention safety belts by checking the symptoms of students when entering the school and during each class, and providing self-made disinfectants by spraying alcohol on wet-wipes were cost-effective and sustainable methods used in this school to prevent the spread of infection.

Conclusions: The experience of developing a prevention safety belt strategy to adapt the guidelines of the local education office to the school situation was presented. Focusing on the school community, as well as individual students and teachers, the concept of prevention safety belts helped to unite and stimulate voluntary participation of students in health promotion activities.

Keywords: school disinfection strategy, safe environment, safety belt, health promoting school, school reopening

INTRODUCTION

On January 30, 2020, the coronavirus disease 2019 (COVID-19) was declared as a Public Health Emergency of International Concern (PHEIC) by the Director General of the World Health Organization (1). Accordingly, the government of the Republic of Korea raised the country's Crisis Alert Level from "Attention" to "Serious." Korea's Crisis Alert Level has four stages, wherein "Attention" refers to observing a new infectious disease outbreak overseas, and "Caution" refers to the outbreak entering the country whereupon the government implements measures for isolation to prevent the spread of infection. The first COVID-19 patient was detected in Korea on the day that PHEIC was declared. With the diagnosis of a second case, the national crisis warning level was elevated to "Alert," and with the first COVID-19-related death on February 20 and a surge in cases to 433 on February 23, crisis warning was raised to the highest level ("Serious"). According to the Infectious Disease Control and Prevention Act of Korea, COVID-19 has been identified and categorized as a "Group 1 infectious disease—emerging infectious disease syndrome."

The rapid increase in the number of infected patients was due to the improvement of the national infectious disease response system after the outbreak of the Middle East Respiratory Syndrome (MERS) in 2015. The system proactively checked and confirmed infected patients and effectively blocked further transmission through a tracking investigation (2). Meanwhile, due to the disturbance caused by the outbreak, the academic year which starts at the beginning of March for all educational institutes in Korea, was delayed for a week on February 22, 2020 when the crisis level was raised to "serious." By the end of February, due to the increase in COVID-19 cases, the Ministry of Education postponed the start of school till March 23. However, with the constant rise of the public health crisis, school opening was postponed again, and schools finally opened on April 6.

School closure due to the COVID-19 situation can result in many serious consequences for students in several aspects. As a result of school closure, there was a serious concern that children from low-income families might not be able to receive free or subsidized lunches anymore, which could lead to an imbalance of nutrition and affect children's health, especially in the present circumstances when their families are unable to afford essential food items and other necessities due to the worsening economy (3). Furthermore, a group of experts recommended that prior to the reopening of schools, evidence of low infection rates in the community should be provided and systems to track new cases should be implemented to minimize the risk of infection among students (4).

With regard to school reopening, in the United Kingdom (UK), the Scientific Advisory Group for Emergencies (SAGE) reported seven "returning to school" scenarios, and warned that the push to reopen schools might lead to a new wave of infection (5).

Globally, community infection rates were considered as a critical determinant for the reopening of schools. In addition, the management of a safe school environment was considered as a prerequisite in the process of reopening, combined with a careful approach to minimize the risk of infection. In order to determine appropriate methods for achieving this goal, an indirect understanding of the actual practices in the school reopening process is essential. Therefore, a case study on a community-based school, displaying the experience of school-based participatory response after reopening can provide a suitable model for other schools in different countries during the current pandemic (6).

In Korea, school health includes "health promoting schools framework (HPS)," which was proposed by the WHO in the 1998 Ottawa Charter, to build a school environment that promotes healthy living and working. The HPS approach operates to promote children's health based on six key features: healthy school policies, social school environment, physical school environment, community links, individual health skills and action competencies, and health services (7). In Korea, an HPS pilot project was first carried out in 2009 in 16 Metropolitan and Provincial Offices of Education. Since 2012, the "Health Promotion School Model" has been included as a sub-project of educational innovation for creative school management, carried out by the Ministry of Education, Science, and Technology (8). In particular, links with the community and the formation of consensus among individuals were found to be important factors in the actual implementation of this model (9–12).

The purpose of this study was to analyze how a private high school in Seoul which conducted a health promotion school project, designed and executed a "school disinfection strategy" at a practice level to ensure the students' rights to study in a safe environment. It also aimed to analyze the lessons learned from the entire process. Thus, the current study provides information about necessary measures that need to be taken while preparing for school reopening and can help to reduce trial-and-error for the reopening process. It also contributes to the prevention of infection by guaranteeing students' right to study safely. The findings of this study can prove useful for schools in South Korea as well as other countries.

SETTING AND POPULATION

This was a case study on school health in a community-based school reopening during the COVID-19 pandemic. The study targeted a 64-year-old private high school in Seoul, with 12 classes for each grade level with a total of 1,100 students. This study was conducted with the approval of the principal of the target high school. The authors also requested exemption for the analysis of secondary data from the Institutional Review Board of Chosun University (IRB No. 2020-7-1-2) and received approval for the study from the same review board (IRB No. 2-1041055-AB-N-01-2020-33). This school had conducted a three-year pilot project on health promotion from 2012 to 2014, and even

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Abbreviations: PHEIC, public health emergency of international concern; MERS, middle east respiratory syndrome; UK, United Kingdom; SAGE, scientific advisory group for emergencies; HPS, health promoting school; EBS, Korea educational broadcasting system; KERIS, Korea education and research information service; KCDC, Korea centers for disease prevention and control (renamed as Korea Disease Control and Prevention Agency on September 12 2020).

TABLE 1 | Core strategic approach to online educational platform under COVID-19.

Duration	Focus	Content	Technical support	Teacher assistance	School closure order (duration of closure)
1st to 3rd week of March	Autonomous online learning support	E-learning platform, EBS contents: elementary 4,129, middle school 5,532, high school 18,859 e-text books	Expansion on infrastructure of major platform, preparing the expansion on the simultaneous access, Operation support for schools (3.10∼), teachers (3.16∼)	Operate teacher volunteer groups to support design of online learning and opening online classes	1st: 3.2∼3.6 (1 week) 2nd: 3.9∼3.20 (2 weeks)
4th to 5th week of March	Teachers managed online learning support	Community building through representative teachers and related organization participation	Distance learning using EBS	Online/distance learning guide, improving teachers' competency	3rd: 3.23∼4.3 (2 weeks)
April	Opening of online school by stage	Third year of middle and high school: April 9∼20	Same as the above	Same as the above	4th:4.6∼4.8 (3 days)
		First and second year of middle and high school: April∼ Fourth to sixth year of elementary school: April 16∼	Same as the above	Same as the above	4th:4.6∼4.15 (7 days)
		First to third year of elementary school: April 20∼	Same as the above	Same as the above	4th: 4.6∼4.17 (9 days)

Reference: Ministry of Education (2020). Reorganized from the press release of February 23, March 5, March 17, March 26, March 31 (13–17).

after conclusion of the project, teachers and students voluntarily performed various health promotion activities, such as health-related club activities and after-school health campaigns funded by the school's own budget.

SITUATION AND STRATEGIES

Early Stages of the COVID-19 Pandemic (January to Mid-May 2020)

Four weeks were spent to prepare the school's quarantine policy and COVID-19 manual version 1, since the end of January. After the initial orders for postponement of the new school semester during late February and early March, the Ministry of Education announced that classes will be conducted in an online format (13–17).

In addition, a school reopening preparation team was organized with the Vice-Minister of Education as its head, to manage disinfection and hygiene in schools, support learning, and prepare for reopening by consulting with the Metropolitan and Provincial Offices of Education (13). In order to improve the efficiency of student learning management, the Metropolitan and Provincial Offices of Education established online learning plans for each school, provided feedback for teachers on learning tasks, and established a system for individual online learning for students. This procedure differed for each provincial office. Since the period from the first to third week of March was a preparation period, each provincial office developed an online learning support team by expanding the infrastructure or by supporting teachers in their efforts to conduct online lessons. During the fourth to fifth week of March, before a complete distance learning mode was implemented, an online learning guide was made available and teachers' competency was improved with support from professionals or representative teachers of each school in the same district (**Table 1**). As a result, by the end of March, 2 million people were able to access the Korea Educational Broadcasting System's (EBS) online classes at the same time, and the Korea Education and Research Information Service (KERIS) strengthened 3,000 contents for the elementary and middle school students for the new semester. With the help of a network between the various governmental offices, 497 types of national and general equivalency diploma text books for elementary and middle schools were provided in the form of e-books. By selecting and operating a pilot school's distance learning program, a developmental model for generalized distance learning was established, and with a student information support project, computer and internet expenses for the students in low-income households were provided. This cooperation was possible due to an agreement signed on March 2, 2020 for the support of distance learning by the Ministry of Education, 17 Metropolitan and Provincial offices of Education, the KERIS, and the EBS, which attempted to establish a distance education operating model and reduce information gaps (16).

However, as school opening was postponed four times and online learning became inevitable, a disinfection management team, student learning support team, and distance learning support team were added to this model (17).

Strategic Operation for Safe School and Class Learning Amid the COVID-19 Pandemic

During the pandemic, teaching/learning could be provided through distance education (remote learning). However, face-to-face classes (in-person teaching) with safety measures to prevent infections were necessary for high school students in order to prepare them for University entrance examinations which were postponed to December, provided that the pandemic situation was alleviated.

Therefore, in order to ensure a safe educational environment for high school students and ensure smooth execution of face-to-face classes, a "Prevention Safety Belt strategy" was introduced (**Figure 1**). This was a campaign encompassing personal level four prevention measures such as wearing masks, hand washing, cleaning desks, and maintaining a 2 m physical distance, as well as school environment regulations in accordance with governmental guidelines to minimize the risk of infection.

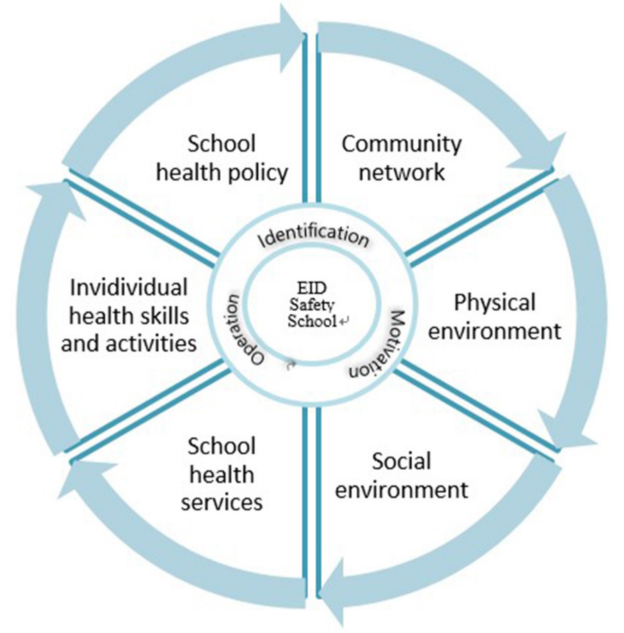

FIGURE 1 | Personal and Community Prevention Safety Belt applied for the school health.

Operation of School Health Committee and Related Action Plans

Before the declaration of PHEIC by the WHO, the school health committee of the target high school discussed a response plan on how to implement safety measures by creating various scenarios. The school health committee is a standing committee, composed of the principal, vice-principal, and managing teachers for student affairs, school life, academic affairs, school administration, and school health; quarterly meetings are held by the committee to discuss key issues. Eight members of this committee met to form the draft of a manual guide on school disinfection strategy in response to COVID-19 every week in the first month, and thereafter, held periodic meetings every month till the present. For effective information sharing, they also used a social network service for group talks on their cellphones. After an offline or online meeting for students' school attending and leaving disinfection process, school environment disinfection and setting up desks and chairs with safe distances between them, and raising awareness and sharing information with parents, all of the tasks were discussed in detail in the cellphone group talk. The school's health teacher coordinated the committee's activities and the principal chaired the committee. The first activity was to establish the school's COVID-19 response plan in accordance with the guidelines of the Department of Education and the Center for Disease Control and Prevention. The committee set a goal to provide a safe learning environment in order to guarantee the students' right to attend school. A response plan was established and implemented for each element of the health promotion school model. In February and March, the main activities were a procurement plan for school quarantine items and planning online classes (**Tables 2**, **3**). The school was able to procure the necessary number of masks, hand sanitizers, and environmental protection equipment with the support of the local government health authorities (18). By the end of April, two masks were provided to each student and teacher, and a certain number were stored in the school dispensary.

Based on the committee's decisions, thermal imaging cameras were installed at the entrance of the school building, each classroom was equipped with a digital thermometer, and a space was allocated for a temporary observation room for students with suspicious symptoms, as shown in **Table 2**. The school's quarantine activities were notified to parents through various methods including letters sent to their homes, Social Network Service (Kakaotalk text message sending), and posts on the school's website homepage. Particularly, 1 week before school reopening, parents were guided to closely observe students at home and not send their children to school if any symptom was identified; these students were to visit the health center near their residential area for testing and notify the school regarding the same.

Through the online classes held in April, students were taught using educational videos produced by health teachers about emerging infectious disease prevention and self-management, as well as the importance of wearing masks, hand hygiene, and social distancing. From May 13, classes began for third year students in the high school, and subsequently for all other grades. Two weeks after the commencement of school, second year students who has been part of a voluntary club on health promotion requested permission to form a club and participate in personal and school quarantine activities. Led by a second-year student, the club had a total of seven members, including two first year students and five second year students. They got involved after the school authorities developed their own disinfection strategy and manual. Therefore, student club activities mainly supported students' compliance of the disinfection guide issued by the school, as well as a 15-min video on the prevention of Corona-blue, recorded by the students and mentored by the school health committee. This video was presented once to students of each grade, in mid-July, before the summer vacation.

TABLE 2 | Core strategic approaches to online education platform in the COVID-19 situation (2020).

	January	February	March	April	May	June
School Health policies	Activation of school health committee	Preparation of COVID-19 Response plan of EWHS	Planning for online class and teachers' competence building	Installation of thermal imaging camera and digital thermometer Quarantine	Identification of symptoms, monitoring and report	Identification of symptoms, monitoring and report
School health services	Agenda gathering for school health committee	Procurement plan for quarantine equipment	Procurement and distribution of quarantine equipment	Preparation of observation room, online education on self-management	Monitoring of school community and individual quarantine	Monitoring of suspicious symptoms and reporting cases to district health center
School environment			Securing environment protection products	Quarantine school environment	Distribution of two masks per person, daily quarantine after school	
Community networks			Refer for test on suspected symptoms		Supplement one day training for schoolteacher	
Individual skills and activities		Notification of delaying school opening: communication letter, SNS, school homepage	Guidance on online education	Online education: adherence to self-quarantine guidelines	Attending class: Wearing masks, hand hygiene, alcohol wipes for cellphone and desk	Student voluntary club for monitoring school community and individual quarantine safety belt
Parent care		Notification of delaying school opening	Notification of online education, self-quarantine of COVID- 19	Notification of online education and preparation for school attending	Guidance of class attendance and returning home upon identification of symptoms	

School Community Prevention Safety Belt

Physical environment, social environment, and community network are the three elements of the health promotion school model which were important in the school community prevention safety belt to enable in-person teaching.

For physical environment prevention, first, an isolated observation room was required for those who exhibited symptoms, and this room needed to be apart from the regular school healthcare room. Therefore, the observation room was placed in a sunlit, well-ventilated space which was adjacent to the healthcare room but separated from the classrooms, and the teachers were notified to direct students with suspicious symptoms to the observation room immediately. Second, during the period of school attendance, all classrooms and other places used by students, such as the cafeteria, restrooms, and hallways, were sterilized by contractual external experts every day after the students were dismissed. In addition, the cleaning staff employed by the school frequently cleaned the entrance of the school building, the door handles of each classroom, and the bathrooms with environmental disinfectants after lunch, each new period, and before and after school hours. Third, thermal imaging cameras were installed at the entrance of the school building to measure body temperature before entering the building. Fourth, at least one digital thermometer was placed in every classroom. Fifth, the desks in the classrooms were rearranged to maintain a gap of at least 1 m or more (19). Since the number of students attending was reduced to only two-thirds of the total students, the school set a bi-weekly attendance policy for first and second year students, and no changes for third year students.

For social environmental prevention, in addition to compliance to the general governmental guidelines, parents and students were informed of the rules that they should adhere to at home. They were asked not to send the students to school if they exhibited any symptoms. In case any symptoms appeared during a class, the student was to be isolated in the observation room immediately and parents were to come and take the child to a nearby screening clinic. Community network has been a catalyst in promoting this prevention safety belt. From mid-January, the guidelines and materials issued on COVID-19 from the Ministry of Education were updated daily, and in order to respond effectively to school health prevention, the Severance Disaster Medical Education Center and the Seodaemun Public Health Center cooperated to provide one-day training on infection management that health teachers/school nurses required in order to prepare for school opening. The training consisted of basic lectures on COVID-19, wearing and changing practice for personal protective equipment level D, response procedures under suspected and confirmed cases of COVID-19, and questions and answers with infectious medicine experts.

This training was requested by the first-line teachers from the hospital's infection control room, and the authorities understood the seriousness of the situation and responded promptly by conducting the training within 2 days.

Personal Prevention Safety Belt

Individual health skills and abilities, school health services, and school policy are the three elements of health promotion school model which are important in personal prevention safety belt to enable face-to-face classes.

TABLE 3 | Main contents of school prevention safety belt.

Category		Detailed contents
Individual prevention safety belt	Checking symptoms	Body temperature (fever), respiratory symptoms, nausea, loss of taste or smell, diarrhea, etc. Overseas travel history of self or family.
	Mask	All the time.
	Providing disinfection supplies	Disinfection products made by schools that contain alcohol in disposable wipes.
School community safety belt	Temporary observation room	Separated space with good ventilation.
	Thermal imaging camera	At the entrance of the school building.
	Disinfection by contracted company	All school facilities before and after school, in between periods, every day.
	Desk spacing in classroom	Keeping maximum distance between students, spacing front and rear as far as possible.
	Prevention supplies	Mask, thermometer, hand sanitizer, environment disinfectant, sterilized (alcohol) wipes.
Standards for attending school and returning home	Managing people in a household in isolation	Students and school staff must stay home if any member of their household is in isolation.
	Managing suspected case	Suspected patient with fever or respiratory symptoms is to be tested and treated at the medical institutions or screening clinic.
	Confirmed case	Students and all staff in self-isolation and convert to distance (remote) learning system. Additional actions to be taken in accordance to the epidemiological investigation.
	Standards for re- attending	(Isolated) When health center declares release. (Suspected symptom) When symptoms are relieved.
Monitoring		Monitoring by student voluntary club activity: Hand sanitizer location, usage, implementation of personal prevention safety belts.

With regard to individual health skills and abilities, teachers and students were instructed to frequently clean their desks and mobile phones with alcohol-included wet wipes for at least 1 minute and also to frequently sterilize their hands with hand sanitizers located throughout the hallways. Before each class began, teachers conducted a health checkup on students, such as body temperature over 37.5°C and respiratory symptoms, and also confirmed whether the masks were properly worn. Above all, it was necessary to continuously monitor students' compliance to hygiene protocols (**Table 3**).

School health services included setting up a temporary observation room, placing necessary disinfectant supplies, taking actions based on standard algorithms upon receipt of students' symptom-related reports from the teacher, contacting parents of any student with fever, and so on. The status of symptomatic occurrence in school members was reported to the competent office of education through a computerized system, and it was possible to check the situation of nationwide confirmed cases and self-isolators in real time.

Regarding school health policy, a school health committee was convened, and training was provided to teachers as described in section School Community Prevention Safety Belt. This training was given first to teachers in charge of the third grade and subsequently to other teachers, since third year students were the first to restart face-to-face learning.

The contingency actions, such as directing persons with suspicious symptoms to go to the nearby screening clinic for appropriate tests and treatment, and if any confirmed case occurs, all students, teachers, and staff must self-isolate and classes should return to distance mode, were clearly documented. Furthermore, for convenient epidemiological investigations, all basic contacts and contact routes for symptomatic individuals were recommended to be recorded.

In addition, detailed guidelines on school health prevention were established, including the following specifics: the quarantine period included self-isolation for 14 days, and those under quarantine would be released if a confirmed negative report was obtained from the screening clinic upon retesting on the 13th day of isolation. As for the suspected cases, they were to return to school only after all symptoms had disappeared.

Special Considerations for Sustainability

Though the school had a strong school disinfection strategy, one teacher tested positive for COVID-19, possibly due to the enforcement of the new governmental guidelines for routine distance in daily life; these guidelines are much less rigid than the strict social distancing guidelines and therefore, there is a greater chance of spread of infection in this scenario. The teacher attended a meeting in the last week of June and experienced some symptoms of COVID-19 after she attended a social meeting outside school on June 21. Four days later, on Thursday morning, she visited the nearby screening center and was confirmed positive for COVID-19 on Friday. This information was reported to the school health committee, and the school authorities decided to close the school and shared this information with students and parents. Classes were shifted to the online mode. Senior (third year) students who had attended classes of this teacher were classified as close contact persons and took the polymerase chain reaction (PCR) tests twice, once on the day when the teacher was confirmed as a positive case and next on the 13th day of self-isolation to determine if they could be released from isolation. The other senior students were classified as "active monitoring" cases for 2 weeks; they were tested on the day when the positive case was confirmed, and were prohibited from visiting multi-use facilities as per the public guidelines. The school reopened for classes 1 week after the teacher had been confirmed positive. However, the senior students in quarantine did not attend. All of the 370 senior students attended school after 2 weeks, when they received PCR negative results. The other first and second year students' school attendance and learning were not affected.

Although training for school environment prevention and individual prevention safety belts for teachers and students was provided repeatedly, it was necessary to monitor actual compliance. A huge budget was needed to purchase and provide disinfectant-included wet wipes to the students as part of the individual prevention safety belt. As an affordable alternative, alcohol was added to plastic-tipped wet wipes (200 sheets) after consulting with community hospital infection control experts. Further, to monitor students' compliance to hygiene protocols, a group of second year students voluntarily formed a club and periodically monitored the consumption of hand sanitizers, inspected the students' individual prevention compliance status, and checked if the hand sanitizers were placed properly in the required places.

DISCUSSION

The strategic development of the prevention safety belts in this case study was not simply an implementation of the guidelines constantly issued constantly by the Ministry of Education and the Metropolitan Office of Education in the changing COVID-19 situation. To ensure the students' right to attend school in a safe school environment, members of the school staff participated actively in the formation of the school health committee. As a strategy for disease prevention, the school community prevention safety belt and personal prevention safety belt were promoted.

The school community prevention safety belt was developed in terms of physical and social environment, and personal prevention activities based on the six health promotion school indicators. In addition, formation of a student club to monitor whether major contents of the prevention safety belts were being followed at the individual level, had a positive effect on the fellow students; such an effect has also been shown in previous studies (10, 11). Activating personal prevention safety belts by checking the symptoms of students when entering the school and during each class, and providing self-made disinfection products were cost-effective and sustainable methods that can be applied easily in other schools. Meanwhile, the prevention safety belt activities led by the school health committee were possible because the teachers' capacity and understanding of school health improved due to the health promotion school experience. In addition, the students' efforts of forming a voluntary group to perform prevention safety activities, such as placing sanitizers in various areas around the school and monitoring the usage and moving flow, can also be applied as a strategy to encourage active participation of students in other schools during the current pandemic.

This study introduced the overall disinfection activities during the process of school reopening amid the COVID-19 pandemic in a high school located in the capital city of Korea, where the health promotion school model was established. In addition, the experience of developing a prevention safety belt strategy to adapt the guidelines of the local education office to the school situation was presented. Furthermore, under the new guidelines of routine distance in daily life, chances of being exposed to the pathogen are much higher. In this case, the school had one positive case; however, they overcame the challenges associated with it since they were well-prepared for such a situation. The teacher took a test as soon as she experienced mild symptoms, and all necessary precautions were taken to prevent the further spread of infection. Focusing on the school community, individual students and teachers, and the concept of prevention safety belts helped to unite and stimulate voluntary participation of the students, which is expected to contribute to the improvement of health maintenance by utilizing the health promotion school indicators under any circumstances.

LIMITATIONS

This case study was conducted to share how a school was able to effectively respond to the public health emergency in the current times. It has some limitations of numerical representation and generalizability because we did not include various high school cases; we investigated only one school due to lack of time. However, we tried to balance various aspects to examine, describe, and suggest a practical strategy and action plan for a school disinfection strategy during an infectious disease outbreak.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

ETHICS STATEMENT

This study was conducted with the approval of the principal of the target high school. The authors also requested exemption for the analysis of secondary data from the Institutional Review Board of Chosun University (IRB No. 2020-7-1-2) and received approval for the study from the same review board (IRB No. 2-1041055-AB-N-01-2020-33). Written informed consent was not required for this study in accordance with national guidelines and local legislation because we only analyzed the committee's meeting minutes without any personal identifiable information.

AUTHOR CONTRIBUTIONS

IK was a major contributor in writing the manuscript, the conception and study design. SK and JSK contributed to critical revision of the manuscript. All authors read and approved the final manuscript.

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Feeling Valued and Adding Value: A Participatory Action Research Project on Co-creating Practices of Social Inclusion in Kindergartens and Communities

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Background: Contemporary public health problems connect to the social determinants of health, with a growing recognition of social inclusion as imperative to sustainable development. In this quest for social inclusion, early childhood and families are of particular interest. Although co-creation is suggested as viable path to support well-being, less is known how social inclusion might be co-created in practice. The aim of this study was to explore how Participatory Action Research (PAR) can be a tool for transformative practices in a local community, pointing to kindergartens as meeting places for recognizing social inclusion as a common value in early childhood.

Methods: A qualitative PAR study was embedded in a Norwegian municipality as an integrated part of their local public health work. The study involved a wide range of participants and stakeholders in three kindergartens and the wider community. Together, we explored potentials for co-creating social inclusion to achieve well-being through cycles of transformative actions and reflections. Reflexive thematic analysis was applied to generate patterns and themes in the data.

Results: The participants formulated and took on ownership to an inclusive agenda through the PAR-process. Acts of inclusion was framed by an intersection between political aims of achieving health and well-being for all and public value co-creation unfolding at the level of the place, in the context of the Norwegian welfare regime. To feel valued and adding value was seen as important aspects for social inclusion. Four themes were generated from analysis; *(1) Co-creating a shared vision of inclusive communities, (2) Becoming aware and empowered through caring, sharing and collaboration, (3) Places and spaces of inclusiveness in kindergartens and beyond, and (4) Valuing and practicing inclusion, and signs of transformative change*.

Conclusions: Through the PAR process, parents, kindergartens employees, community members and policy makers appear to have opened a creative toolbox for inclusive and transformational change through formulating and co-creating inclusion and well-being as public values. The results suggest that local actors might support adaptive social systems

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to taking on relational responsibility for inclusive processes and outcomes in the pursuit of well-being for all.

Keywords: co-creation, health promotion, social inclusion, well-being, empowerment, social justice, participatory action research

INTRODUCTION

With a main focus on "leaving no one behind," the historic and ambitious sustainable development goals (SDG) recognizes that societal development will only be sustainable if it is inclusive (1). Basically, this quest for inclusion is about human rights and human dignity toward health equity and well-being for all (2, 3). Studies shows that lack of social inclusion has severe consequences for individuals, relationships, organizations and communities, as well as the economy and society at large (4–8). Societies across the world still struggle to tackle complex public health problems (9, 10). Reaching the SDG's and promoting well-being for all depend on partnerships and co-creation across the whole of society, as stated in SDG # 17(1). However, reaching goals of inclusiveness and equity remains slow to progress, and transformative action is called for (2, 9, 11, 12). Especially, there is a call for action toward social inclusion in early childhood (13–16).

In the context of welfare, co-creation is described to alter the roles of citizens, users and professionals in ways that supports sustainable public value outcomes (17, 18). Although overall principles of co-creation are relatively well-worked out, there are surprisingly few long-term and comprehensive studies at the micro-level (19, 20). There is also a lack of knowledge on how co-creation processes might be inclusive and socially just (21, 22). This article explores how kindergartens as open social systems in interaction with place and space (e.g., social arenas, organizations, other institutions, and neighborhoods) might achieve common public values through participatory action research (PAR) in a Norwegian municipality. The study interweaves the fields of health promotion and co-creation.

Children are more likely to flourish when their families have the support they need, and where social networks and -conditions caters for health and well-being (5, 15, 23–25). The long-term beneficial effects of high-quality early childhood education is well-documented. It is good for everyone, but particularly beneficial for disadvantaged children (13, 14, 26). Family life is changing, alongside changes in community life, welfare systems and societies. Societal developments aligned with gender equality in work participation and a focus on high-quality education from an early age has accelerated kindergartens to become an important welfare institution in societies across the world (27). Co-creation is described as an approach to improve provision of welfare (17, 18, 28). A Swedish study found that parent engagement and involvement through co-creation enhanced the quality of the kindergartens (29). This study also suggest that parent involvement is not the norm in private and public kindergartens, pointing to a strong tradition of professionalism and passivation of citizens in the welfare state. Although this presumption is not empirically tested in Norwegian kindergartens, it is likely that these findings are transferable due to similarities within the Nordic welfare regime. Parents' engagement in their children's kindergarten values is also documented in Ytterhus' (30) study of Norwegian kindergartens as inclusive institutions for disabled children.

Parental and community engagement is increasingly seen as important to enhance healthy child development and learning (27, 31). According to OECD, countries face challenges related to lack of awareness and motivation from parents, lack of communication and outreach, parents' time constraints to being engaged, and increasing inequity and diversity among parents, with particular challenges associated with engaging ethnic minority parents (27). To address such issues, co-creation is seen as a promising approach (17, 29, 31). However, parent's involvement in kindergartens is still limited, or even restricted, both in Nordic countries and within OECD (27, 29).

By interweaving health promotion and co-creation, the current study builds on two basic premises: First, the objectives of the public sector is to create *public value*, situating the public as key actors in the construction of, and beneficiaries for public value creation (32–34). Second, the function of welfare states is to secure and support the *well-being* of its citizens (35, 36). Public health and well-being for all, leaving no one behind, is thus conceptualized as fundamental public values, with various measures to pursue this goal (37–39).

The view of social inclusion in the current study, builds on Prilleltensky's concept of mattering (7) as "to feel valued by, and to add value to, self, others, work and community" (p. 16). Thus, inclusion refers to results at micro-level, but is only reachable through processes at micro-, meso-, and macro- levels (7, 40). By conceptualizing social inclusion as a process, we rely on three distinct, but interlinked aspects, informed by critical theory; *social justice, relational responsibility*, and transforming *complex, adaptive systems*. These processual perspectives all relate to theoretical entries of transformative actions. First, processes to support social inclusion is viewed through the lens of social justice, coined as "participatory parity" (41, 42). The aspect of parity seeks to identify "*social arrangements that permit all (adult) members of society to interact with one another as peers*" (42) (p. 36). According to Fraser (41), participatory parity demands three distinct, but interlinked, pillars of justice; redistribution (typically economic in nature); recognition (typically cultural and relational in nature) and representation (typically political in nature). To Fraser (41), transformative processes relates to actions within all of these dimensions. Second, we view social inclusion as a process of relational responsibility (43). According to McNamee and Gergen (43) relational responsibility imply dialogical processes with two transformative functions; transforming the interlocuter's meaning-making of an action (e.g., acts of social inclusion and its consequences), and in altering the relationships between the conversational partners themselves. In such a social constructionist perspective, humans are conceived as relational beings (44). Meaning-making processes and the cultivation of inclusion relies on transformative dialogues and interactions where such processes bring people together into transformative and concerted action (45). In addition, we see social inclusion as a process unfolding in complex and adaptive social systems. Complex adaptive systems refer to systems that involve many components that adapt or learn as they interact, where the whole is more complex than its parts, where agents are interacting within a particular socio-ecological context, by adapting to each other's actions (46–49). Further, complex adaptive systems are approached as relationally constituted, where actors might create transformative actions with adaptive capacities in ecological systems (49). Such actions can trigger systemic transformative change, which refer to substantial changes in societal values, mindset, and behaviors (50).

The co-creation logic has recently gained traction within numerous governance areas and is described as a viable approach to tackling complexity aligned with unruly societal problems, and support citizen participation and public value creation in sustainable ways (17, 18, 34, 51–53). Co-creation is referred to as a promising approach to support health promotion, and tackle complexities inherit to health, well-being and equity (54, 55). A co-creation logic is linked to a "paradigmatic shift" in the public sector often referred to as "New Public Governance" (NPG), which is critical to the neo-liberal New Public Management (NPM) perspectives. In a NPM-dominated discourse, welfare is basically seen as a product that is "delivered" to the public/clients (36, 52, 53). While NPM give attention to service and cost-effectiveness, a co-creation logic directs the attention to collaboration, interactive networks, and bottom-up oriented forms of governance (17, 34, 55). The application of co-creation in this article is situated as an approach to pursue public value outcomes and thus embeds other "co-dimensions" such as, co-production and co-design. Co-creation is defined by Torfing et al. (52) as:

> "*a process through which two or more public and private actors attempt to solve a shared problem, challenge, or task through a constructive exchange of different kinds of knowledge, resources, competences, and ideas that enhance the production of public value in terms of visions, plans, policies, strategies, regulatory frameworks, or services, either through a continuous improvement of outputs or outcomes or through innovative step-changes that transform the understanding of the problem or task at hand and lead to new ways of solving it.*" (p. 802).

Recently, advancing the perspectives described above, an approach to welfare coined as "relational welfare" has gained traction in Norway and beyond (36, 55, 56). The notion of "relational welfare" was initially coined by Hillary Cottam, privileging a radical attention on human relationships and relational responsibility (36). Basically, a relational approach to welfare make use of principles from co-creation to transform the relationship between the public and the welfare state, where inclusion and human dignity is key. By focusing on the settings of everyday life in communities, relational welfare connects to key pillars in health promotion (12, 55, 57). Relational welfare ties the concept of welfare to live well and flourish and nurture capabilities for doing so within acceptable structures. However, there is a need for research on how such a framework can be explored in practice.

This study addresses the need for more research on socially just micro-level co-creation, aligned with the need to accelerate health promotion practice. The purpose of this study is three-folded in exploring key elements in micro-level co-creation of inclusion and well-being in a kindergarten setting by focusing on: (1) how new roles might be played out, (2) how co-creation practices might look like, and (3) how public value outcomes might be successful at the micro-level. The research question is: *What are the processes and experiences parents, staff and local communities have in PAR when addressing social inclusion to support well-being?*

MATERIALS AND METHODS

Methodology and Study Design

Based on the transformative purpose and the research question of the current study, PAR methodology was chosen as the research design. PAR is an approach to increase the possibilities for social transformation in specific contexts and situations, by involving stakeholders as active, participating subjects in the research process (58–60). The PAR-process brought together a wide range of stakeholders (see **Table 1**). Acknowledging the research process as a dialogical and relational processes, the study was theoretically based on a social constructionist theoretical stance (44, 56, 61). Accordingly, the PAR-process is conceptualized as a process of interactively co-constructing new knowledge and future-forming actions (62). This implies that PAR is seen as a collaborative, dynamic and abductive process, with ongoing conversations between theory, practice, relationally sensitive dialogues and self-reflections among all actors involved.

Study Context

The study was situated in a Norwegian municipality, where the first author of this article works as a public health coordinator. The second author has two different roles in this project. First, she participated as a parent and have generated data together with the other parents. Second, she is recruited as a co-researcher, because she gives voice to a group of citizens that very often are kept silent. She grew up in what she coins as an "outsider-society," with lived experiences of social exclusion and bullying. The PAR revealed her relevant competencies and interests of academic work. Together with the third author and relevant stakeholders, they came together to nurture social inclusion and well-being for all as a shared public value, and mobilize joint action.

The Norwegian Public Health Act (63), adapted in 2012, was important for developing this study. This act explicitly embraces the social determinants and the "health in all policies" perspectives, and explicitly recognizes the role, responsibility of and accountability systems for the local governance level.

TABLE 1 | Overview over the participants.

Participants	Roles	Total *n*	Within-group variation
Ⓓ First author Ⓢ Second author ◌ Parents ◍ Kindergarten staff ⊜ NGO Village lab ○ Leaders and planners ● Politicians △ Directorate of Health ◬ National parents' organization ▲ Academic researchers	Parents i PFG	10	3 fathers, 7 mothers. Two migrants. 5 newly moved to Levanger. Two were out of work.
	Kindergarten staff in PFG	9	3 leaders, 3 kindergarten teachers, 3 assistants (1 man, 8 women).
	Participants in parents' meetings	105	90 parents, 15 staff
	Leaders and planners	5	1 executive leader, 2 sector leaders, 2 planners/coordinators
	Politicians	6	Members from the local council, representing 6 political parties. 2 men, 4 women.
	NGO Village labs	2	Representing two local communities in which the kindergartens are situated
	Outsider focus group (OFG)	6	Transdisciplinary representation of 4 academics, 1 participant from the Norwegian Directorate of Health, 1 participant from the Norwegian kindergarten parent's organization

Local governments are requested to promote participation and work knowledge-based to engage the local community in its developments aligned with a whole-of-society-approach. The study is based in a Norwegian mid-size municipality with ∼20,000 inhabitants. Since 2014, this municipality had adopted public health and equity in health and well-being as main policy goals in their masterplan, where co-creation was a key strategy [see (64) for details of this policy process]. Thus, the current study is rooted in a local analysis of public health policy priorities in the municipality, in accordance with legislative demands.

To contextualize the study, a description of Norwegian kindergartens is required. In Norway, kindergartens have gone through radical changes during the last decades parallel to becoming a universal welfare institution. In 1975, childcare in Norwegian kindergartens was regulated by a legal Act (65). The kindergartens were organized under the Ministry of children and family affairs as a supplement to family caring. In 2006 there were a radical shift, which gave all children from the age of 1 year of age a legal right to kindergarten access. The responsibility for kindergartens were transferred from the Ministry of children and family affairs to the Ministry of education. They became an educational service and the first step into the public authorities' ambitions of lifelong learning. At date 92.2% of children enter kindergartens in Norway (66), and in the municipality participating in this study, 97.2% of the children are enrolled. Even though all Norwegian kindergartens are regulated by a common framework plan and national legislation (67), the majority of institutions are still private. Municipalities are local authorities for all kindergartens, regardless of organizational form, and are obliged to provide guidance and ensure that practices follow current rules and regulations. The children and the parents involvement are legally regulated to respectively, "be heard" and "participate," e.g., through parents councils and in joint council committees (67). However, these regulations usually regulate that just a few of parents are active and involved.

Participants, Data Sources, and Data Material

The current study involved three kindergartens in a Norwegian municipality, including parents/guardians, kindergarten staff, policy makers, boundary spanning coordinators/advisors, administrative leaders and local politicians from the municipal council. Parents in the kindergartens and kindergarten staff acted as a critical reference group in the study, whereas a strategic sampling of these actors formed a "participant focus group" (PFG) (68). A maximum variation strategy was applied to recruit research settings and contributors in the PFG (i.e., families: socioeconomic status, family structure, ethnicity, and gender; kindergartens: private and public, small and large, rural and urban; policy: across sectors). Selection of parents and staff was done by kindergarten leaders, where a recruitment procedure guided how they approached possible participants (i.e., to suggest participants based on the maximum variation criteria, focusing on people's regular roles as parents and employees, and not make suggestions based on previous engagements).

To ensure ethical issues of confidentiality and anonymity, an initial request to potential participants was forwarded to parents by the leaders of the kindergartens. Subsequently, a list of possible parents/guardians who agreed to be contacted was given to the first author, who contacted them for a written informed consent process. The data in the study consists from different data sources; individual interviews, three subsequent cycles of reflecting teams workshops (RT1-3), written notes, memos and closing reflection schemes from these RT-workshops, data from kindergartens and parents-meetings [including individually (anonymous) written evaluation from parents with closing reflections], and the researchers' diaries/memos at each cycle. In the PFG, we maintained a focus on parents and kindergarten staff, as they (by being significant adults in the kindergarten setting) are key stakeholders of inclusivity. In RT1 parents and staff participated, and in RT2, we included a wider range of relevant stakeholders in the municipality. Finally, to support reflections on transferability and academic novelty resulting from the research, we included an outsider focus group (OFG) of (transdisciplinary) researchers and policymakers at the national level to join our conversation in RT3. See **Table 1** for an overview over research participants, and **Table 2** for details of the data sources and processual and analytical procedures.

Research Ethics

Formally, an ethical approval to conduct the study was granted by the Norwegian Social Science Data Services (NSD; project number 56952). Written informed consent was obtained after a full description of the study to the participants. There are two important ethical dilemmas that needs attention. First, there is always a risk for participants in action research in general (59, 74), and presumably in co-creation, that they felt obliged to satisfy the researcher heading and facilitating the group. This is especially relevant for participants with less formal power related to kindergarten and the local community. We tried to minimize such tensions by using RT-workshops (where participants could talk and reflect without being interrupted, and where we agreed on "rules" for inclusion and recognition). The first author prepared and engaged with participants to empower and support the parents. When addressing power asymmetry, some parents demonstrated a strong motivation to empower other parents in underprivileged social positions to participate, which is also documented by Dyregrov (75). Second, the researchers that participated in the generation of data (author 1 and 2) critically reflected on their own subjectivity at all stages such as avoiding any marginalization of the participants (76). When writing and reporting, all three authors aimed to do this in a respectfully manner toward all participants.

Data Analysis

The data was analyzed through the use of reflexive thematic analysis (TA) (77, 78), following six steps: (1) *Familiarization with the data*, (2) *Coding the data by de-construction*, (3) *Generating initial themes by re-constructing the data material*, (4) *Reviewing themes*, (5) *Defining and naming themes*, and (6) *Writing up*. See **Table 2** for details on the analytical procedure.

Important steps of reflecting together was organized as a series of three RT workshops (79). Step 1–3 in the reflexive TA, based on the initial interviews, resulted in seven preliminary themes which served as conversational resources in the succeeding circles of action and reflections (RT1 and the parent's meetings). The initial themes were: (1) *to be recognized and appreciated*, (2) *relationships and meeting-places which invites for participation*, (3) *diversity as a resource*, (4) *children as relationship- and community builders*, (5) *raising awareness and building culture for inclusion*, (6) *The kindergarten in the community, and the community in the kindergarten* and (7) *A common ground for upbringing and childhood are created by us right now*. After experimenting with inclusive actions in the PAR-process, a revised preliminary analysis was presented and negotiated in RT2 and 3. The entire dataset was finally analyzed by all authors. Data from interviews and RT workshops was initially audio-coded (80) and key sections were transcribed verbatim. Coding and thematizing data were supported by NVivo 12.

The two-stage review procedure in reflexive TA serves as an in-built quality mechanism for generating meaning and key themes, where the proposed themes are reviewed against the coded data and the entire dataset in a transparent manner (77, 78). The analytical procedure was recursive, moving back and forth between the different phases. The initial analysis of the individual interviews was performed by the first author, and then negotiated, reviewed and deepened throughout the research process. Throughout analytical process, a wide range of actors (see **Table 2**) reflected upon the research process, including the conditions affecting the situation of study, thinking interpretively about particular patterns aligned with reflexive engagement with the data. The internal validity of the results was enhanced by the second and third authors' discussions in the analytical process and writing the article together. The quality of the research was addressed through usefulness and "co-impact" (58, 59, 81).

Through the process of analysis, four main themes was generated to frame our results: (1) Co-creating a shared vision of inclusive communities, (2) Becoming aware and empowered through caring, sharing and collaboration, (3) Places and spaces of inclusiveness in kindergartens and beyond and (4) Valuing and practicing inclusion, and signs of transformative change. **Table 3** provides an example of how theme 1 was generated by following the procedure described above.

RESULTS

Four main themes were generated as a "thematic story" responding to the research question: *What are the processes and experiences parents, staff and local communities have in PAR when addressing social inclusion to support well-being?*

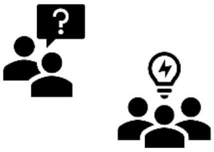
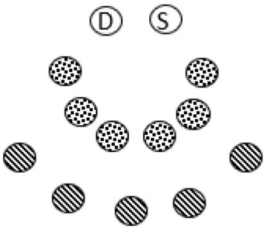
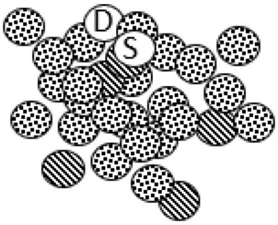
Co-creating a Shared Vision of Inclusive Communities

A shared vision served as a platform for co-creating actions to building a "we-culture" of social inclusion. Throughout the initial interviews with the PFG, grounded in "giving every child the best possible start in life," a common vision was formulated and deliberated throughout the RT workshops:

> *"We work together to create the childhood conditions we desire, for the benefit of all. Together, we have contributed to all children getting the best possible start in life, and that all children and adults feel seen and recognized as an equal and valuable participant in the local community."* (written materials from RT1-3).

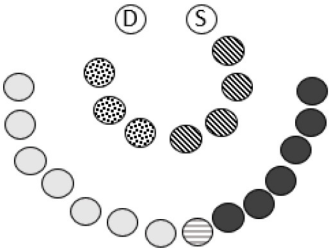
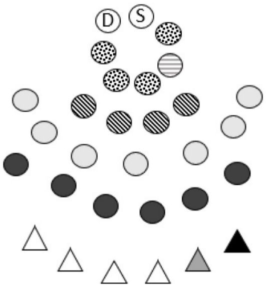
Although the PAR-process included a wide range of stakeholders, the participants did not express disagreements on the formulated vision (which did not change during the study). Instead they were more interested on how they could move on together to realize the vision through joint action. Further, they expressed that they wanted to feel socially connected, to be recognized and included, and to contribute positively

TABLE 2 | Overview of the PAR process.

Stage of the process, data generation and analysis	When was it done?	Why was this done?	How was this done?
Cycle 1: Exploring the context and community inclusion ideals.  *Data*: audio recordings from 19 individual interviews (10 parents, 9 staff), researchers' diaries and memos.	Sept. 2017 → May 2019	*Preparing the context and participants:* Initial interviews with PFG served two main purposes: (1) negotiating meaning-making on inclusion through reflexive dialogues, and (2) preparing the actors for engaging in the research process and enhance trust. The conversations spurred the participants to talk about what they thought was important and allowing them to ask questions to the researcher.	A scoping review and theoretical frameworks were initially explored and used to prepare deliberative interviews (69) with PFG (parents and kindergarten staff), using a semi-structured guide as a conversational resource. The participants themselves chose the setting for the interview. In one of the interviews we used a professional translator. The interviews served as a stepping stone into the further process. The process was inspired by the BIKVA-approach to co-creation (70) but where our design was further developed to fit a dialogical and relational focus on transformative action.
Cycle 2: Discovery on common ideals and planning future-forming actions.  *Data*: video and audio from the RT, workshop notes (3 sheets), researchers' diaries and memos. *Thematic analysis:* step 1–3	May 2019 (RT1) → Sept 2019	*Reflecting team # 1 (RT1):* Engaging participants in the planning of future-forming actions. Negotiating a common dream, reflect on key issues/themes, and deliberate on possible steps to be taken. Disrupting dominant discourses between parents and staff, support reflection, dialogue, and preparedness to act.	Constructing a preliminary thematic analysis from the interviews, presenting and deliberating initial findings with parents and kindergartens staff through RT1 (step 1–3 in the thematic analysis). The RT1 process was inspired by Asset Based Community Development (71) and Appreciative inquiry (72). We asked questions like "How can we create stronger and more inclusive communities among families who have children in kindergarten?" and "Imagine five years ahead, what have we done together to achieve a common vision of inclusiveness?"
Cycle 3: Compiling actions in the kindergartens to improve inclusion. The Key Action was the Parents meetings.  *Data*: Participatory observation, researchers' presentations, diaries and memos, workshop notes from parents (38 sheets), written evaluations from parents (90 forms), 3 memos from kindergarten staff, 3 memos from parents.	May 2019 → Nov 2019. Key actions: Sept. 2019	*Realizing and evaluating new actions:* Based on RT1, we ended up with zooming in on a key action – the parent meeting. This action became an important arena for constricting practices and data in the process, and to efficiently widen the circle of actively involved stakeholders beyond those participating in the PFG. The purpose of addressing the parents meeting was twofold: (1) to deliberate on the dream, raise awareness and empathy, and cultivating a we-culture of common concern and relational responsibility, (2) compile data from a wide range of critical stakeholders.	Author 1 and 2 collaborated with the PFG to plan and facilitate the parent's meetings. The dream and tentative themes from the initial analysis was consolidated with the participants, and we told stories of in/exclusion. The key event of the meetings was sessions of reflections in groups of parents, were also staff, to some extent, participated in the dialogue (inviting staff to join the conversation was requested by the parents themselves). They reflected on short narratives describing children's and parent's stories of being excluded and disvalued, which culminated in questions on how parents and staff could support acts of inclusion in the kindergartens and the wider community. At the end of the meeting, all of the parents individually filled out a written evaluation with closing reflections and suggestions for further actions.

(Continued)

TABLE 2 | Continued

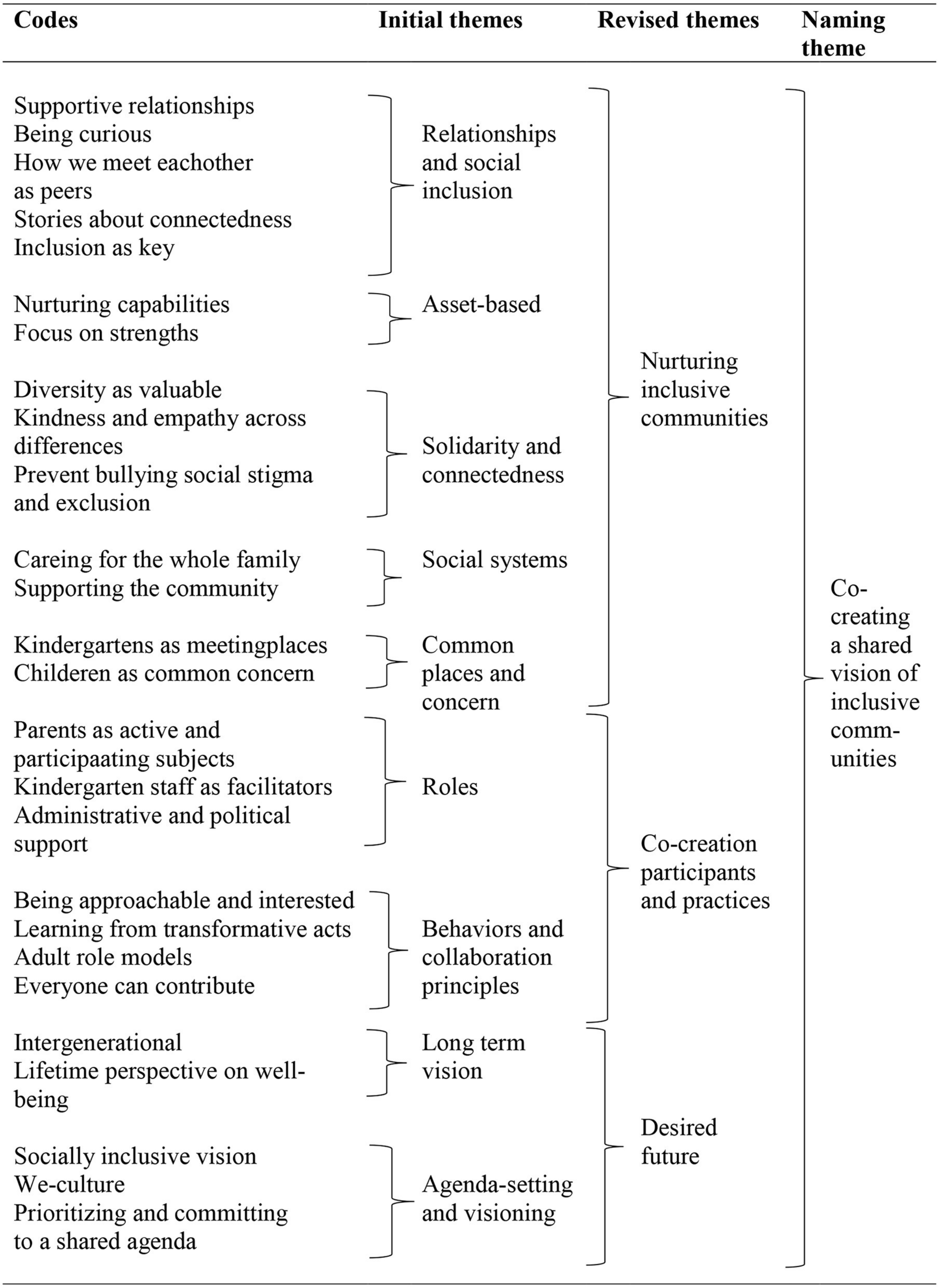
Stage of the process, data generation and analysis	When was it done?	Why was this done?	How was this done?
Cycle 4: Reflecting on experiences, exploring implications.  *Data:* Video and audio from the RT, Participatory observation, researchers' presentations, diaries and memos, workshop notes from participants (11 sheets), written closing reflections from participants (15 forms), 3 memos from kindergarten staff.	Nov 2019 (RT 2)	*Reflecting team # 2 (RT2):* Reflection and dialogue was facilitated to disrupt dominant discourses between kindergarten actors, other sectors, politicians and local NGO's as separate social systems. Reflect on what we had learned from the actions and suggest possible implications for policy development. Tinkering out suggestions on how a "we-culture" made up of inclusive acts might be enhanced.	Initially, the context for the research was explained and framed, and tentative findings from the research was presented by the PFG and reflected upon by the wider group of stakeholders. We posed questions like: "What have you experienced so far, and what are you hoping to happen next?" "In ten years, what has been done in the municipality to enable us to move closer to the vision?", "what would you have been proud to transform?." After deliberation, we organized the participants in groups (max variation of diverse stakeholders within the groups), to deliberate on how we can go on together to achieve the dream.
Cycle 5: Exploring co-impact.  *Data:* Video and audio from the RT, Participatory observation, researchers' presentations, diaries and memos, workshop notes from participants (8 sheets), written closing reflections from participants (9 forms), 3 memos from kindergarten staff. *Thematic analysis:* step 4–6.	Nov 2019 (RT 3)→ Subsequent analysis until August, 2020	*Reflecting team # 3 (RT3)*: Reflections on if, and how, the PAR-process has transformed conceptions of roles and actions in the quest for inclusion. Construct generative and reflexive dialogues toward transformative and sustainable change. Tinkering out what we can learn from the process, impact transferability of learning into other settings, and construct novel knowledge resulting from local experience and meaning-making.	Initially, tentative findings were presented and deliberated. All actors reflected upon what how the PAR-process had an impact on role identities and inclusive actions. We borrowed questions from Pearce (73), such as: (a) what are we making together? (b) how are we making it? (c) what are we becoming as we make this? And (d) How can we make better social worlds together? (p. 53). We examined what we had done and learned, asking questions like: "What might have transfer value to other settings beyond kindergartens, and other municipalities than ours?," "what of these learnings can be important for national guidelines?," "what is theoretically interesting?." Subsequently, all authors analyzed the final dataset and revised the initial themes.

to the lives of others. Even though, that they agreed on a shared vision, they acknowledged that it implied various changes in roles of the actors involved. For the parents, this involved taking on an active role. As one parent said: "*we must take on responsibility for our peers*" (RT3). For the kindergarten staff, a shared vision of inclusive communities entailed re-envisioning their professional mandate to facilitate co-creation in their kindergartens and local communities, and by approaching the parents as resourceful and motivated collaborators in pursuing the vision. Re-envisioning their professional roles also included to address inclusion and well-being of the whole family, beyond the kindergarten's opening hours.

Through the new practices that were developed through the PAR-process, both administrative staff and leaders across sectors reflected upon how such practices can be further developed and used in the municipality. For the politicians, getting knowledge about the new practices became important to humanize policymaking, legitimize co-creation practices, and contributing with new ideas. Developing kindergartens as meeting places and community-builders to co-create inclusion as a public value, was thus a desired aim for parents, as well as for kindergarten and administrative staff, policy makers and other stakeholders involved.

During the PAR-process, a wide range of participants acknowledged difficulties of being included in the community. As a NGO-representative pointed out in RT2: "*Our community is a bit closed.*" Participants said that it is not easy to get to know people in the community, especially if one moves there from other places (domestic and abroad). It was evident

TABLE 3 | Examples of final analysis across the dataset - Theme 1 "Co-creating a shared vision of inclusive communities."



Codes	Initial themes	Revised themes	Naming theme
Supportive relationships Being curious How we meet eachother as peers Stories about connectedness Inclusion as key	Relationships and social inclusion	Nurturing inclusive communities	Co-creating a shared vision of inclusive communities
Nurturing capabilities Focus on strengths	Asset-based		
Diversity as valuable Kindness and empathy across differences Prevent bullying social stigma and exclusion	Solidarity and connectedness		
Careing for the whole family Supporting the community	Social systems		
Kindergartens as meetingplaces Childeren as common concern	Common places and concern		
Parents as active and participaating subjects Kindergarten staff as facilitators Administrative and political support	Roles	Co-creation participants and practices	
Being approachable and interested Learning from transformative acts Adult role models Everyone can contribute	Behaviors and collaboration principles		
Intergenerational Lifetime perspective on well-being	Long term vision	Desired future	
Socially inclusive vision We-culture Prioritizing and committing to a shared agenda	Agenda-setting and visioning		

that social inclusion was an important value for all actors involved, not only for citizens struggling with marginalized and vulnerable living situations. The participants focused on pursuing inclusion, friendship, appreciative curiosity and mutual support as a main strategy to achieve well-being, including to prevent damaging relational patterns such as bullying, neglect, and abuse. They acknowledged the need for social inclusion of all and expressed a commitment to stop and prevent marginalization and exclusion. Especially, they addressed a need for taking on an intergenerational perspective in this pursuit, starting from pregnancy and lasting across the lifespan. One of the parents wrote in her reflections after RT2: "*there is a broad consensus that this* [the dream] *is important and should be a priority.*" Moving on to reflecting on potential impacts, she expressed that she "*expects change from 'midwife to the grave', a structure made in interaction with those participating at any given time (i.e., the people).*"

Aligned with a framing that placed parents, staff and other adults as responsible actors in co-creating social inclusion, the participants also stressed the fact that they all are role models for the community of children. An NGO representative said in RT3: "*to be a good role model. This is where it all begins.*" Aligned with this quote, a parent questioned: "*How can children learn that this* [inclusion] *is the natural thing to do, if we don't practice it in the community of adults?*" Another parent said that it is not inclusion when only those standing outside of community structures are put together as a group: "*Then, it is segregation.*"

The participants described that diversity in kindergartens (e.g., ethnicity, gender, social status, and disability) was as a resource to overcome social exclusion and marginalization. Instead diversity nurture transformative acts of tolerance, empathy and curiosity. For example, participants from the PFG told stories about how parents overcame anxiety and hostility toward minority families, as their own child became best friends with children from minority backgrounds. Other participants told stories of "otherness" and diversity as something that is genuinely interesting for children, pointing to that it is the adults, that bring forward conceptions of diversity as something "strange" or even "scary." Valuing diversity, and at the same time, combating injustice through cultivating empathy and communities of common concern was important issues in the initial interviews and in the RT-workshops. Also, the participants generally expressed that diversity was important for open mindedness, learning and creativity. When reflecting on diversity and entanglement between social systems or groups in the kindergarten, a politician referred to observations of separate social systems in the community. In RT2, talking about the potentials of kindergartens as universal welfare settings, he said: "*I really like the idea of maybe creating some kind of a 'mega-subculture' in kindergartens – 97%, you said? Then, in a way, everyone has a chance to form the social networks you are talking about.*" The participants shared stories about their motivation to engage in co-creation was enabled by a shared vision of creating an inclusive society. Thus, the vision became a common reference and an enabler for transformative action in their everyday life.

Becoming Aware and Empowered Through Caring, Sharing, and Collaboration

Although the participants generally held some awareness of the importance of inclusion at the beginning of the PAR-process, many felt disempowered to act. Across the data, acts of caring, sharing and collaboration was valued as significant for transformative change. In the initial interviews, some of the participants said that people tended to be together, but still segregated in the kindergarten setting. One of the staff described that:

> "*We see it at parenting meetings, those who know each other well, they come and sit down together. And then you have those who are always sitting alone. You can early notice who is on the "outside" in the kindergarten, both among the kids and the parents. They are probably also falling a bit "on the outside" of social life beyond kindergarten. There is something about finding a community outside the kindergarten as well.*"

One of the parents reflected on awareness and empowerment this way:

> "*I believe that we need to open up our eyes a little more. We must create a culture where it is common and natural that we care about each other. It's not like inventing gunpowder, anyway. But of course, why haven't I thought about it earlier, to reach out to this person I do know who is, while he is sitting in the kindergarten and looking at his child, partly alone or alone. Why haven't I done anything about it? If more people are aware, and perhaps if the kindergarten makes us more aware of it, then maybe more people, who are in a well-functioning group outside the kindergarten, can go together to bring them along. It is easier to do this as group or a community.*"

Another parent participating in RT2 put it this way, reflecting on the need for joint action to achieve change:

> "*This is a big job, right? And it's easy to think. Do I have the time for all this in my busy schedule? But then you have to bear in mind that, if I do a little, and you do a little, and you do a little* [pointing out in the room]. *Small things like, a little change, if everyone does it, then we are well on our way.*"

In RT3, one of the parents referred to small acts with potentially large impacts, such as "*giving a smile, despite being busy.*" Across the data, the participants reflected on transformative acts of inclusiveness as "contagious." Paying inclusion forward was described as being aware and empowered to act, not only within the kindergarten setting, but by spreading into other social systems. One parent wrote in the evaluation form after the parent-meeting "*this was an important reminder. Social inclusion, recognizing every individual, and taking the time to do so. We are all important for this community.*" The participants agreed on this, and another parent suggested in RT2: "*The kindergartens, the way you have rigged it, has an impact on the parents as a group.*"

The parents also addressed key barriers and the need for tinkering out responses to tensions and dilemmas. For example, after conducting the first parent meeting, some parents said that the gap between norms and actual practices needed to be reflected upon to enable inclusive actions. In the closing reflections evaluation, reflecting on the impact of discussions on the presented narratives, one parent wrote: "*It was obvious what we should be saying. It is probably not quite so strait forward. Perhaps pose question to challenge us more, like 'why don't you', not only 'what you ought to do'?.*" This input, which came from the first parents meeting, made us revise the questions posed in the subsequent meetings. We experienced that posing such questions led the participants to reflect even more about their own role, and to how to overcome barriers to inclusive and transformative actions.

The parents described micro affirmations and recognition from other families and kindergarten staff as constitutive for their feeling of being a competent parent and being valued. Across roles, the participants recognized that every single person has capacities, abilities and gifts which can support to develop personal capabilities, as well as enhancing the capabilities of others. The parent's expressed that adding value to others, in the kindergarten and community, also added value to themselves. For example, parents with a refugee background referred to a sense of pride and recognition, when they were invited to cook traditional food from their own culture in the kindergarten or could teach the kids some words from their mother language. Others, who had construction skills, expressed that they felt valued by contributing to build the physical environment in the kindergartens.

The participants reflected upon that social inclusion in community life is best done by the community itself, albeit that the public authorities have the legal responsibility. Parents said that it was very important for them to be met by the kindergarten staff in a supportive and appreciative way. They also noted that being recognized by the children and parents in the kindergarten community "*gave a different kind of feeling than when the staff cared about me and the kids*" referring to that other parent's didn't have to do this as a paid job (researcher's memo). The parents said that recognition from children and other parents were constitutive for their feelings of being worthy and empowered. The participants talked about the importance of being met with respect and recognition. The participants enhanced the importance of meeting each other as peers, not as roles constrained with social status (e.g., approached as a doctor, cleaner, migrant, leader or a person with mental health problems). One parent said: "*I had great help from meeting other families on neutral ground in the kindergarten, so that I gradually became part of this community just by being present*" (researcher's memos). The parents said that they meet in kindergartens on equal ground; they take part in the setting because of their children. As some of the participants with lived experience of severe life difficulties reflected in the individual interviews and in the RT's; this is a radically different context than taking part in a welfare setting because you struggle with difficulties such as mental health problems, substance abuse or crime. Parents with lived experience of marginalization said, "*no one wants to be a charity case*" (researcher's memo), and instead emphasized the need to fulfill valuable social roles in the community. Generally, the participants talked about a desire to transform the discourse from being "vulnerable" to being "able," with prospects of joining communities of support.

By intersecting visions of inclusion, awareness and joint action, the participants widened their repertoire. The vision was taken forward on the participant's own initiative. In one kindergarten, the parents' initiated events to create a community of mutual support. They highlighted the vision in their written invitation to the other parents. Throughout the study, the aspect of becoming aware of the importance of inclusion was a key issue. One planner said in RT2: *"What you have done in the kindergartens, it is about raising awareness, and what you are doing with us now, it is also raising awareness. And if you manage to find some ways to work like this in the whole local community. Then I believe one can get quite far* [referring to the vision]." Raising awareness *per se* was also linked to ways of doing it, where compassion and enthusiasm was coined as key issues. For example, the participants addressed that *"people who are engaged in a good cause is truly contagious, and what then is a better cause than our children?"* (researcher's memo). When reflecting on the learning from actions made through the study, one of the executive leaders in the municipality said in RT2: "*We know what we should be doing. But still, we don't do it. So, what you have done here, is to tackle this, in ways that has enabled us to talk about what is important, what really counts.*"

The participants also addressed that inclusion doesn't happen in a vacuum. One family lived in the refugee reception center (this story was referred to in RT2, and in individual interviews with parents and staff). A kindergarten staff talked to the mother when they planned the child's birthday party. They translated and forwarded an invitation to the other families in the group. Some of the parents expressed skepticism to come to the refugee center, but the staff gently nudged them to join the party. This gentle nudge made everyone participate. When the initial barrier was crossed, the party became a good experience for all, and especially for the birthday child and its family. The mother expressed the experience this way:

> "*When I was about to enter the hall, I saw that it was completely full, and then I was very happy. What made me especially happy was that they did not think of me, they did not look at me as a refugee, living in an asylum reception center, they just came and looked at me like the rest of the community. It was very special, it was very touching.*" (initial interview)

After the experience of conducting the parent's meeting in a new, inclusive and participatory way, all three kindergartens wanted to continue with this new format. One kindergarten employee said in RT3: "*previously, we haven't really thought about the parent's meeting as a meeting for parents. Rather, it has been about sharing information from the kindergarten.*" Neither parents, nor staff wanted to return to the "old and traditional format." Also, they wanted to continue the practice of strategically placing parents around tables in parent's meetings (e.g., by using the children's names as seating placement to avoid the parents of lumping together with others they already know well). Additionally, they wanted to strengthen an atmosphere for informal conversations, such as sharing a meal together where also the kids could join, and where the staff looked after the kids when the formal meeting began. In one of the kindergartens, the staff expressed in a written memo that the parents wanted a new network meeting, where the kindergarten initially provides some information, and then the parents divide into groups to discuss topics that they are interested in based on their own needs (e.g., screen use, sleeping habits, setting boundaries, creating common "rules" for creating inclusive cultures). By establishing new practices, the kindergartens transformed the parents-meeting as an arena for peer support and community building more than an arena for sharing information from the staff.

Places and Spaces of Inclusiveness in Kindergartens and Beyond

The participants described several spaces and places for supporting inclusion in the kindergarten and beyond. Before entering the PAR-process, most participants related social inclusion to aspects of kindergartens as a welfare service and institution. When reflecting upon how social inclusion can be supported beyond the kindergarten opening hours, one of the staff described the following in the initial interview:

> "*We can support the linkage of social relationships between families in a much, much better way than we do today. It is about taking relational responsibility outside of the kindergarten's opening hours. I believe that we are very good right in our own little "space." But to lift our gaze, to see, to join forces, and to build community beyond the walls of the kindergarten. We've talked a lot about early intervention, but what is that exactly? The most important thing for the kids is to have empowered parents. This has got lot to do about the parents' mental health, and about their social relations.*"

By participating in the study the participants said that they became more aware and empowered to address inclusion inside of the kindergarten setting, but also to expand transformative acts of inclusion beyond its institutional fences.

Through the PAR-process the participants said that, although, they previously had arranged for places and spaces where families could meet within the kindergartens opening hours, they strengthened their efforts to create such arrangements in inclusive ways throughout the process (e.g., monthly gatherings such as eating breakfast or have coffee together, visits with grandparents, concerts etc.). Also, the kindergartens opened for other aspects of inclusive participation within opening hours. One kindergarten invited two of the mothers, who lived at an asylum reception center nearby, to work in the kindergarten 3 days a week on a voluntary basis based on written internship contracts. For the children, this meant extra adults in their setting, who could provide play, support and trust, as well as experiences of diversity and showing tolerance and recognition. For the staff, this meant extra support. For the mothers, this contributed to create a sense of purpose, meaningful activity, new relationships, and learning the Norwegian language. One of the kindergarten staff reflected in a written memo: "*This practice has worked well for all parties; it is a win-win situation.*" When talking about her experiences of the internship, one of the mothers said in RT3: "*It is very good for me. I have a negative result from my asylum application. So, I cannot go to school, I cannot work. I'm just sitting at home. It is very boring. Now, I'm better. When the children are giving me a hug... It just makes me happy.*"

The participants from the kindergartens came up with practical solutions to support families to get to know each other. In the children's wardrobe, some of them chose to hang up pictures of the child, with names not only of the child, but also their parents. Some parents came up with ideas of hanging up pictures of the parents too, to support familiarization. One of the parents said in RT3, learning the names of the children and their parents enables a feeling of "*being someone, not just anyone.*"

When suggesting how the inclusive vision could be realized, the participants talked about the roles and responsibilities of the kindergartens and its staff. One parent wrote this in the evaluation form after the parent's meeting: "*Kindergartens should be taking on a more active role. If they know of somebody who struggles/are excluded, so try to provide support. Connect parents to others and so on.*" This quote illustrates key messages from parents as well as employees. The participants said that the kindergarten staff know a lot about the parents and children, and they have follow-up conversations with parents on a regular basis (formal and informal). When families are in trouble and need additional support from e.g., child protection services or special educational support, the kindergartens often take part in the network of support. Parents that were interviewed who talked about experiences of needing extra support, firmly believed that the kindergartens should have a key role when families are in trouble. This view was also supported by kindergarten staff in the individual interviews as well as in the RT's. Furthermore, all actors recognized the children as a common concern, and that friendships between children could serve as a starting point for bringing parents and families together, and thereby enable reciprocal support. Here, both parents and employees highlighted the function of the kindergarten staff as key for acts of inclusion, for example by "*supporting to introduce parents whose children spend a lot of time together*" (written memo from one of the kindergartens), and at the same time facilitate that all of the children form friendships and participate in play. The kindergarten staff also talked about changes in the formal conversations with the parents (individual meeting with parents), where they started to ask new questions; "what do enjoy doing in your leisure time? Do you know what's going on in your local community and would you like more information? How to overcome barriers to participation, is additional support needed?" Such questions served the purpose of bridging families to participate in other social arenas in the community.

Altogether, the participants expressed a desire to use the kindergarten as a facility beyond opening hours. It was generally a place where parents and children felt safe and familiar, which also was free of charge. One of the parents said:

> "*One of the other parents invited me and my kids to buy pizza as we left the kindergarten. I really wanted to answer "yes," but on my bank account I had like 200 NOK, which was the last amount of money. I had for the next 5 days. Instead of sharing*

> *this information, I quickly replied that, "no, unfortunately, we don't have the time today." If the kindergarten had been open as a playground that very afternoon, so anyone could gather for dinner, no one would have needed to know if I had money on my account, because I could have made the spaghetti I had planned for dinner anyways and taken it with me.*" (researcher's memos)

The parents in the PFG expressed a desire to meet other families in the kindergarten beyond opening hours in much the same way, suggesting meeting there to make dinner together, and for the children to play together in the afternoons and weekends. Across the process, they told stories about such initiatives. This need was also facilitated by the staff, where some of the kindergartens started to not only let the parents use the outdoor facilities after opening hours, but also letting them use the indoor facilities (lending out the keys to parent who took on responsibility for such events). Initiated by the parents in one of the kindergartens, they also arranged an evening for sharing things with each other, where everybody could bring stuff they no longer needed (e.g., toys, clothing, shoes and so on), and they could take home what they could use. They noted that such an arrangement had two purposes; to serve as a social arena, where parents could get to know each other, and to share things, which is good for both the social and natural environment. Another transformative act was that leaders in the municipality started to pay attention to how the built environment could facilitate the kindergarten to be more welcoming and inclusive. For example, when choosing amongst solutions for building another kindergarten in the municipality, aspects of openness and family-oriented practices, attending to the collective and wider community, was preferred.

The participants talked about internet and social media as important arenas. In the parents meeting, the parents also suggested new actions to pursue; to create digital platforms for communication and inviting each other to join activities (such as meeting on the playground or in outdoors in the kindergarten after opening hours). Such platforms also created sharing of a variety of support. In two of the kindergartens, the parents initiated a Facebook-group to keep in touch, share information and material goods, and invite each other to happenings. In the third kindergarten, the parents found another solution, as they believed that it would be difficult to keep track on all the parents, and also acknowledging that not all parents had a Facebook-profile. Instead, the staff and the parents created a list with contact information to all the families, so that they were able to connect.

Moreover, the participants talked about inclusion by bridging families to participate in the wider community. In the initial interviews, the participants in the PFG expressed that a practice to link families to community life (e.g., leisure, education, and work) was not mainstream. Practices attending to inclusion was mainly focused on the kindergarten as an institution, and not bridging participation and relationships into other social arenas. The parents, and especially those who had few relationships to count on, expressed a need for information on where they could meet and form relationships with other families. Throughout the initial interviews, the participants became aware of the multiple roles they have that could support participation and connectedness beyond the fences of kindergartens as an institution. One parent said in the initial individual interview: "*Although I am the leader of* [name of the NGO], *I haven't previously thought about the kindergarten as an arena for recruiting other parents.*"

Throughout the study, the participants became aware of the transformative possibilities to bridge participation from the kindergartens into other arenas. One of the parent's story (documented in the researcher's memos) is an example of this. In the kindergarten, this mother got to know other parents, that invited her to join other activities in the community. She was recruited as a member of a local NGO, which facilitated voluntary work that led her to join a chorus. In this chorus she got to know students at the university, that supported her application (on a special quota, since she didn't have the formal requirements) to take on music teacher studies. Now, she is on her way to her "dream job," and her family is flourishing. Partly inspired by this narrative and similar stories of relational pathways to flourishing, the kindergartens (staff and parents walked alongside) took on new actions to bridge families into other social arenas in the community. In a written memo from one of the kindergartens, the staff wrote: "*The kindergarten writes a letter* [info letter to the parents] *every month - we now expand the letter by including everything that happens of activities for children in the community for the upcoming month.*" Another kindergarten supported this need with hanging up a board in the children's wardrobe where both staff and parents started to share information of what was going on in their community.

Another example of adding value and being valued outside of the kindergarten's fences, was a mutually beneficial relationship with one of the neighbors living close nearby one of the kindergartens. A senior man, who was very interested in music and played various instruments, had a huge collection of instruments in his home. Every year, he invited the kindergarten to visit, playing for the children and letting them try out his instruments. He also took on a role as Santa Clause in the kindergarten every Christmas. This man told the staff that meeting the children was important for his well-being, as he felt valued by and added value to the kindergarten community.

The participants also talked about the built environment as important for bridging possibilities for inclusion and participation. Situating kindergartens at the level of the place, it became apparent that the physical distance to other arenas and the neighborhoods where the families lived was a key factor. One mother who didn't have a car, said that "*it is a bit difficult to visit other families when they live far away*" (initial interview). Across the data, it became visible that closeness matter, not only between people, put also as a spatial dimension, where issues of transport and opportunities to meet others impact on the families' options to engage. It became apparent that when people know their community and the options for participation, they are also enabled to share information and welcoming "strangers" to arenas and settings such as sports facilities, libraries, organizations, schools and playgrounds nearby and so on. The participants also told stories about visiting such places, and where the children later had brought their parents along to these settings, acting as a guide. Furthermore, possibilities to cooperate with other welfare institutions such as nursing homes, providing mutual joy for children and senior citizens, was dependent on closeness within the place (an example provided from one of the kindergartens). Although some aspects of coordination and integration with other institutions and settings already was accounted for, the PAR-process enabled the participants to open a creative toolbox for social change at the level of the place. For example, the participants addressed a need for tools that enabled them to gain knowledge of available resources and options for participation in their communities. Subsequently, this provided arguments for implementing a digital platform to support sharing of information (this digital tool is currently being implemented in the municipality).

Valuing and Practicing Inclusion, and Signs of Transformative Change

Talking about the value of social inclusion, and enabling people to become aware and empowered, was a recurring pattern in the data. In RT2 (after the PRG had presented and reflected on their experiences and learning from new practices and actions resulting from the process), one of the chief administrative leaders in the municipality reflected on what she had heard us talking about, and explicitly became aware of all the NPM-inspired argumentation in the system:

> *"In everyday life, in the kindergarten and at home, we can get stuck by attending to our own busy schedules. I guess it is probably not conceptualized as 'learning outcomes' in kindergartens, but there is so much going on. You have the annual plans, and the planning wheels, and that is probably what they use their time on in parents' meetings. So, we probably don't talk about what really is of importance, that is, how we meet and include each other. That is what you have opened for here. And maybe, in these meeting places, people commit to support each other, because of the ways the processes are designed, to include everybody in reflections on what really is important values for us to create. And then they feel a commitment toward others around them, which I believe is very important."*

The participants acknowledged that we are "in it together" to create the society they wanted to live in. One of the kindergarten staff illustrated this with a trampoline metaphor in RT2:

> "*If we imagine a trampoline, it has many strings attached around for it to bounce. If that trampoline is the child, and the strings are all of us in here in the community; it's child welfare, it's special pedagogic services, it's the kindergarten, it's all of us. If one string after another fails, then the trampoline will not work. But if all are intact, and all are cooperating in the interest of the child, then the child will be fine too.*"

This quote illustrates the acknowledgment of a transdisciplinary, multisectoral and whole-of-society approach in the pursuit for inclusion. This was also visible in the participants' dialogues, when talking about on their own multiple roles. They related to each other more as fellow citizens rather than on their formal roles, and greeted each other with curiosity, respect and empathy. For example, both managers and politicians in the process told stories from their family life and work life, attending to personal experiences of social inclusion and exclusion, and being valued by others. All actors agreed to promote the "we-can-do-it-together" feeling that was enhanced through the research, acknowledging that welfare is something we create together to support individual and collective well-being. One of the parents said RT3: "*we are each other's local environment,*" responding to a need for deepening co-creation.

In RT2 and 3, all the three kindergartens parents and staff said that transformative change was already happening. "*I believe that this has ripple effects, I am already experiencing a friendlier and more inclusive community.*" She further talked about how the process had affected her personally: *"I walk out of this room as a better me, with more thoughts and knowledge about the importance of the village*" (Staff in her closing comments/evaluation). Another example is from one of the parents, reflecting over his experiences on RT2: "*You become aware that much of the power* [for change], *lies among the parents. I was involved in* [the name of the kindergarten] *when you had it there* [the parents' meeting] *and to make them aware that in fact everyone is important for each other. And I agree, there has been more smiles and greetings since then.*" These quotes illustrate experiences from everyday life in face-to-face-encounters that made personal, relational and social change.

The participants said that creating a "we-culture" in kindergartens provides a platform for working together to support nurturing childhood conditions for all children throughout their childhoods and into adulthood. In RT3, one parent said: "*I believe what we have done really matters in the long run, as the children grow up, when they start at schooling, and in upper and secondary school.*" The NGO representative responded: "*If we now collaborate and create the conditions for nurturing childhood environments, it will have a huge impact on the society in the long run.*" When reflecting on learning and impact from the process, participants took on commitments to forward the agenda to other social systems in their communities. The participants also noted that ripple effects of pursuing transformative acts of social inclusion through co-creation was promising and created hope for the future. In RT3, one of the politicians said:

> "*I'm thinking of the butterfly effect, the most exciting part is how this work creates something new outside the target group, like that someone has started to fill their leisure time with something meaningful, getting a job, friendship, further education and so on.*"

He is pointing to a wider range of impact than the children, but where such impact also transmit back to the children. Other aspects reported were about balancing a normative "push" to participate in, and initiate, inclusive activities on a regular basis, pointing to that too much push could lead to stress or resistance. Moreover, they emphasized the importance of face-to-face invitations, saying that it is easier to participate and join a group if you feel sincerely welcomed.

Overall, the participants and stakeholders involved initiated and participated to co-create new tools and their implementation. The participants also talked about the methods and tools used to support reflection and co-creation. One of the parents said in RT2: "*If you are going to move a culture, then the culture is not in the walls, it is in the people. Therefore, I believe that this* [action research] *is a methodology that can create movements, getting many actors on board.*"

The participants described that negotiating power-relations, language barriers and time-consuming aspects appeared as challenging throughout the PAR-process. Although, the parents expressed motivation to participate in co-creation, they were also concerned about balancing individual benefits and needs to adding value to the community. Across the study, the participants pointed to the importance of continuously focusing on social inclusion, in formal meetings and informal dialogues. One of the kindergarten staff shared in RT3:

> "*This we-feeling... We weren't that aware of it before, but now, we get feedback both from staff, but especially from parents, that they connect to and feel this "we-ness." I really feel good about it, because then it is a community, not us versus them or them versus us, but it's we, it is us. And that is something I really carry on with me from this process.*"

The participants said that creating inclusion together should not be "a one-time-happening" or a separate project. Rather, it should become a "*lifetime,*" "*intergenerational,*" and "*mainstream*" approach to transforming acts of social inclusion in the community as the participants agrees upon in RT2 and RT3.

DISCUSSION

The aim of this study was to explore *what are the processes and experiences parents, staff, and local communities have in PAR when addressing social inclusion to support well-being?*. Social inclusion was put on the agenda as the most important common public value. The results suggest that exploring kindergartens as open social systems in interaction with place and space became a promising platform to support social inclusion and well-being for families. The results advocate that parents, kindergartens employees and local communities are able and motivated to co-create practices and acts of social inclusion. Successful micro-level public value co-creation seems to have some crucial ingrediencies; negotiating a shared vision, active facilitation to empower participants (parents, staff, and wider community), and support coordinated and joint action at the level of the place by placing community first, supported by institutions who are held responsible for outcomes. Based on the results while attending to the purpose of the study (i.e., transform roles, practices and outcomes at the micro-level within a co-creational framework), we will organize the discussion around three key issues: (1) *Framing social inclusion as a relational and co-created public value*, (2) *Grounding social inclusion in social justice*, and (3) *Coordinated and integrated systems to support inclusion and well-being*.

Framing Social Inclusion as a Relational and Co-created Public Value

Through the PAR-process, a co-constructed vision through dialogues and reflections acknowledged social inclusion as a shared public value. The results of this study suggest that social inclusion can be framed as relational processes and a co-created value that cannot merely be "delivered" as a transaction or service. Although this study cannot provide a full answer to how social inclusion as a welfare issue can be co-created, the results shed light on promising and future-forming possibilities for inclusive communities. This means that transforming relationships between the state and the people means to create a new interaction that puts more power in the hands of citizens, and emphasizing the public sector should "work with" rather than "doing to" their citizens (36, 82). Although, the dominant welfare discourse in Norway and internationally still connects welfare to "institutions," "professions," and "services" (18, 29, 36, 83), the results from the current study suggest that such a framing can be disrupted and altered by re-envisioning welfare and well-being as a common concern, governed by the public authorities.

The results indicate that the participants altered their role-perception throughout the process, where roles and functions to create social inclusion was about feeling valued and adding value to others; to feel included and to include others. In this way, the results support Prilleltensky's (7) studies on "mattering," focusing on the importance of both "feeling valued" and "adding value" to others and the community. In the case of social inclusion, the relationship between individual and public value seems to be reciprocal and dynamic, where the dynamic nature of relies on meaning-making processes, relating to personal experience and visioning a desired future. At the micro-level in the kindergartens, parents seemed to transform their roles from passive receivers to active co-creators of public value. Importantly, the results suggest that motivation to co-create relied on pursuing visions they themselves found valuable. Moreover, our results highlight that awareness of, and empowerment to act spread from the kindergarten setting and into other social arenas in everyday life. For this to happen, the parents valued a close and reciprocal collaboration with kindergarten staff. For kindergarten staff, the results suggested that the co-creational endeavor implied taking on new roles as facilitators and bridge-spanners for building networks of collective support. The results shows that the staff can act as community "change agents"; to facilitate a shared vision between staff and families, support framing-capacity of inclusion as a co-created value, and actively create conditions to nurturing empathy and empowerment, relational responsibility and collective action beyond the kindergartens' institutional fences. Attending to the micro-level, the role of policymakers, administrative leaders and politicians also changed, where they first and foremost acted as fellow citizens. They listened, learned from, and participated in dialogue with parents and frontline staff, where they contributed with ideas to support further inclusive practices. Our results advise that the "kindergarten community" can lubricate the machinery of inclusion on the community, and to identify, connect, and mobilize people, assets and places for the common good through active facilitation. By this, the participants in our study acknowledged that many actors can contribute to social inclusion, welfare and we-ness as a content-component of welfare and well-being. The hybrid roles depicted here are in line with previously described enabling skills required by professional co-creators at the front line (84).

Our results suggest that social inclusion is a public value that depends on human interaction, and where co-creation might accelerate progress through transformative acts of inclusion. The results of this study propose that social inclusion in community life is best done in the community, by the community, where actors relate to each other as a community of peers rather than upfronting formal roles. Importantly, social inclusion was not only about presence, or allowance to take part. It also depends on being granted full recognition by others, where community integration is important too. Practical implications of these findings advise a need for integrating welfare institutions with community development, increase opportunities for people (parents) to define and actively take part of creating solutions, and support public servant's skills and capacity to co-create at the micro-level. Here, welfare systems serve the function to frame meaning-making dialogues on public value outcomes, facilitate co-creation and joint action, and fill in the gaps when extra support is needed. These suggestions do not advocate to leave the concept of kindergarten as institutions governed by regulation and criteria for service quality, but rather to renegotiate their mandate and practices as meeting places and community builders. Such an expansion of mandate is in line with health promotion templates of working with communities and settings of everyday life to support empowerment and joint action (12, 57).

Grounding Social Inclusion in Social Justice

Our results indicate that kindergartens in Nordic welfare states have the potential to answering to all of Fraser's three dimensions of justice (i.e., redistribution, recognition, representation). However, the acts of social inclusion presented in this article are heavily skewed toward recognition. Although our results to some extent refers to elements of redistribution (for example universal access to kindergartens which caters for diversity and inclusion, acts of sharing material goods within the kindergarten community, and acts of opening doors for parents to participate in education and work-life), central aspects within the redistributive realm relies heavily on politics and representation. Here, the who's, what's and how's in policy making also relates to other aspects of recognition than those addressed in this article, requesting an ecosystem of capacity-building and inclusive representation in democratic processes to make transformative change.

Although our results provide arguments for reframing the welfare content and practices into a grammar of co-created social inclusion and well-being, our research does not provide an argument for welfare state retrenchment. The legal standard of welfare is in the Nordic welfare states are based on re-distribution of economic resources. It is the Nordic approach to welfare that furnishes for (almost) universal enrollment in Norwegian kindergartens. Based on our results, we support Raphael (37) and Esping-Andersen's (38, 39) arguments for pursuing the Nordic approach to welfare as a "gold standard" societal model for health promotion. Rather, the question to be deliberated is how welfare states facilitate action for all, maintain support from the growing middle-class, and mobilize citizens to take part in joint action, independent of social status.

Although our results support that co-creation in kindergarten fits well with new trends for *ad hoc*-volunteering (85), this could rise dilemmas in terms of justice. For example, when parents who are not allowed to work (e.g., asylum seekers or people on social benefits) enter kindergarten as volunteers, there can be a fine line between being valued and accumulate capabilities on one side and adding value as "unpaid staff" on the other, where freedom to earn money might be restricted by law. If kindergarten's incentives for including parents as volunteers are economic, and not built on relational responsibility, such inclusive practices at the micro-level could lead to widen inequities. Furthermore, our results suggest that if the "push" to participate is too hard, people might resist. An unintended consequence of a "participatory imperative" could be shaming and blaming, making the situation even worse for families in struggle. Thus, taking on relational responsibility also should involve to empathize, acknowledge participation as dynamic and fluid, and respecting the right not to participate, without being shamed (86). Based on our results, we recommend that practitioners and policymakers should critically reflect on such possible dark sides and unintended consequences before embarking on new co-creation practices.

Our results frame social inclusion as a common good, bridging fairness to universal well-being. We propose that entangling social inclusion to fairness and well-being can advance the fluid and complex relationship between the welfare state, the settings of everyday life, and community development. Such a reframing of justice implies consequences for policymaking as well as framing capacity in micro-level co-creation processes as mentioned above (8, 14). The results from this study support Heimburg and Ness' (55) arguments for paying attention to relationships as a fourth element to complement Fraser's three-dimensional approach to social justice, by advancing a relational approach to welfare toward well-being for all.

Coordinated and Integrated Systems to Support Inclusion and Well-Being

The results emphasized that to support social inclusion and well-being, the systems should be coordinated and integrated. Our study demonstrates potentials for bringing a wide range of actors together to negotiate new meanings and joint visions and actions through dialogue. Despite arguments to engage parents more actively in early education, the empirical evidence on the contribution parents make is scarce (31). To our knowledge, a participatory whole-systems approach has previously not been studied in a kindergarten setting, and where the present study contributes to fill a gap. Following Andersen (87), a relationally coordinated, co-creation approach loosens up the intersection between public sector organizations and the function systems working in integrated manners to achieve public value. Our results suggest how established views of boundaries between kindergartens as institutions and the wider community can be blurred and relationally coordinated, linking kindergartens to a wider socio-ecological context. However, closeness, not only between people, but also amongst places and spaces seems to cater for coordinated and integrated acts of inclusion. Neighborhoods and the built environment affect how people interact with each other in ways that facilitate social contacts and strengthen social ties (5, 14). Thus, policy implications from our results suggest to physically situate kindergartens by prioritizing collaborative opportunities at the level of the place. Moreover, the results imply practical implications to look at procedures for enrollment, where closeness between families' homes and the kindergarten seems to matter for inclusion. Implementation of action needs to cut across traditional silos and facilitate integrated and coordinated actions to maximize co-benefits within the scope of inclusiveness, fairness and well-being. However, such practices are dependent on the wider conditions and structures for enacting upon inclusiveness (3, 8, 9, 23, 25). Our results show that the ecology of micro-level practices is affected by factors ranging from micro-encounters amongst people to being ecologically impacted by macro-level policy and culture. Based on our results, we propose that transformative micro-level practices can facilitate learning and change amongst in other parts of the system and levels of society, embedded in complex, adaptive systems.

LIMITATIONS

Although we acknowledge PAR as a viable pathway to transformative change, there are several limitations to this study. First, this study had a focus on adult's transformative practices where the children themselves were only indirectly involved. The research could be deepened and strengthened by adding on children's own acts and perspectives. Second, is the democratic imbalance in knowledge and power between family members, researchers, practitioners, politicians and other stakeholders. Although we actively worked to make such imbalances transparent, and proportionately prepared actors to engage, aspects of authority could eventually be a barrier to parity in the process. One aspect is language barriers coupled with having asylum seeker status. This could put some participants in a challenging position in order to openly express honest opinions and critical reflections. Another aspect of "pleasing" in order to achieve a socially desired position could also apply to other participants. Although such aspects of power imbalances always are present in PAR, we worked systematically to make power-imbalances transparent, and had continuous dialogues on these matters to enhance reflexivity in the process. A wide range of actors participated in the analytical process, but it is the author's reflections and constructions who leads on to writing up this study. Thus, the results should be viewed through critical reflexive lenses, where the researcher's roles had influence on the processes as well as analytical process. Moreover, the first and second authors are employed in the municipality that is the setting for this study. Such an "insider-perspective" is constrained with pros and cons, and where self-reflexivity is important. In this study, the OFG acted as a "reflexive tool" to support a critical distance. During the research process, there were few critical comments from the participants, even though we actively invited criticism, both in the RT's and individual (anonymous) feedback loops. Moreover, the processual design was facilitating deliberation to achieve consensus more than exploring tensions (see **Table 2**). This can be a possible limitation because important input could be missed if participants did not feel comfortable to express critical reflections. We acknowledge that the transformative aims of this study colored the lens of the first and second author in conducting the research. The third author did not take part as an insider in the process, and thus contributes with critical distance in the research process. Moreover, a limitation could be the difficulty of distinguishing between what is practiced and what is believed to be ideal in the interviews and RT's. We also acknowledge limitations due to the number of actors involved in the PFG, and that other participant's might have brought in other stories and perspectives. However, this limitation was partly buffered by involving a wider range of stakeholders through the parent's meetings. Finally, one might question the usability of such context-bounded knowledge for future research and theorizing based on results. Even though these concerns can be addressed as a common treat to all qualitative research's validity, they are even more relevant in PAR. Our response here is our nuanced and thoroughly descriptions on PAR's different stages and how it was carried out, where the process itself and our results suggest transferable learning to other settings and research agendas and further theorizing co-creation of social inclusion (59, 81).

CONCLUDING REMARKS

The results from this study points to a necessity of making significant actors aware and empowered to participate in co-creating acts of inclusion and well-being. The micro-level co-creation practices explored in this research propose that the traditional way of defining public institutions might, and should, be questioned, breaking down strict lines between the public and public institutions, and between sectors and professional disciplines. The results indicate that kindergartens as a setting, by involving multiple stakeholders, can create transformative change, even in a short time span. Moreover, not only is it possible, it also was desirable from the perspectives of all participants involved. Overall, the results indicate that public value outcomes can be successfully co-created at the micro-level. Kindergartens can become unique arenas to bolster social inclusion, with potential to contribute solving some of the most pressing public health problems today such as loneliness, mental health problems, abuse and marginalization. Finally, we acknowledge that the concept of inclusion is multidimensional in nature, and dependent on a wide range of actors and societal structures, horizontally and vertically. Maintaining participatory parity, relational responsibility and coordinated, transformative actions in complex adaptive systems relies on strategic planning, (organizational) capacity building and political leadership. We recommend that future inquiry should address such multi-level issues to make the aspiring co-created changes described at the micro-level by our results, truly transformative and sustainable. Ultimately, welfare systems should secure accountability systems to support the profound message of UN's SDG's of "leaving no one behind." and continuously push forward an agenda of inclusion at the micro-level and beyond (9, 38, 88). The research reported here has focused in transformative actions, and not on evaluating effects. Future research should address possible (long term) effects of inclusive co-creation practices on the micro-level by using a wide range of methodology, and importantly also explore how such micro practices connects to processes and actors at the meso- and macro-level.

DATA AVAILABILITY STATEMENT

Relevant data is contained within the article. To protect the confidentiality of the participants, video and audio data will not be made available. Other requests to access the data should be directed to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Norwegian Social Science Data Services (NSD; project number 56952). The participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

DvH was leading the work on initiating, planning and facilitating the PAR process, documentation of data, and writing up the manuscript. SL contributed as a co-researcher throughout all stages of the process. DvH preformed the initial analysis, and where DvH, SL, and BY analyzed the final dataset. DvH and BY revised the manuscript. All authors approved the manuscript.

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Migrant Communities at the Center in Co-design of Health Literacy-Based Innovative Solutions for Non-communicable Diseases Prevention and Risk Reduction: Application of the OPtimising HEalth LIteracy and Access (Ophelia) Process

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The drivers of high prevalence of non-communicable diseases (NCD) among migrants are well-documented. Health literacy is regarded as a potential tool to reduce health inequalities and improve migrant's access to and quality of health care. Yet, little is known about the health literacy needs among these groups and how to address them. This paper outlines the protocol for a migrant community-based co-design project that seeks to optimize health literacy, health promotion, and social cohesion in support of prevention of NCDs among migrants in Lisbon using the OPtismizing HEalth LIteracy and Access (Ophelia) process. This participatory implementation research project starts with a mixed-methods needs assessment covering health literacy strengths, weaknesses and needs of migrants, and local data about determinants of health behaviors, service engagement, and organizational responsiveness. Diverse migrant groups will be engaged and surveyed using the Health Literacy Questionnaire and questions on sociodemographic and economic characteristics, health status, use of health services, and perceived impact of the COVID-19 pandemic. Semi-structured interviews with migrants will also be conducted. Based on data collected, vignettes will be developed representing typical persons with diverse health literacy profiles. Migrants and stakeholders will participate in ideas generation workshops for depth co-creation discussions in simulated real-world situations based on the vignettes, to design health literacy-based multisectoral interventions. Selected interventions will be piloted through quality improvement cycles to ensure ongoing local refinements and ownership development. Through a genuine engagement, the project will evaluate the uptake, effectiveness and sustainability of the interventions. This protocol takes a grounded approach to produce evidence on real health literacy needs from the perspective of key stakeholders, especially migrants, and embodies strong potential for effective knowledge translation into innovative, locally relevant, culturally and context congruent solutions for prevention of NCDs among migrants. Given the diverse communities engaged, this protocol will likely be adaptable to other migrant groups in a wide range of contexts, particularly in European countries. The scale-up of interventions to similar contexts and populations will provide much needed evidence on how health literacy interventions can be developed and applied to reduce health inequality and improve health in diverse communities.

Keywords: migrant health, health literacy, co-design, non-communicable diseases, prevention, inequality, Ophelia, health literacy questionnaire

INTRODUCTION

Non-communicable diseases (NCDs) are by far the leading cause of death globally (1). The European region is particularly affected by morbidity, mortality, and disability related to cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes (2). A substantial amount of this burden is attributable to behavioral, dietary, environmental, and metabolic risk factors (3–5), which has called for attention to the need for improved prevention and treatment (6, 7).

NCD rates tend to be higher among communities that are disadvantaged and socially excluded, especially in high-income countries (6). Migrants are frequently among the most socially vulnerable populations, and they are disproportionally affected by NCDs compared to the host populations (8). In the recent years, migration to Europe has increased. In 2018, 22 million people residing in the European Union (EU) were born in non-EU countries, accounting for 4.4% of the total population (9). Although migrants in Europe appear to have lower prevalence of many NCDs on arrival compared with the host population—the so called "healthy-migrant effect"—morbidity rates, especially for obesity and cardiovascular disease, increase with longer duration of stay (8, 10). Throughout length of stay in the host countries, migrants in general tend to have higher incidence, prevalence and mortality rate for diabetes mellitus, ischaemic heart disease and stroke compared with the host population (10).

The NCD determinants behind health disparity among migrants are well-documented and include poorer socioeconomic conditions, reduced access to information and services, and adoption of unhealthy behaviors related to the new sociocultural contexts (8, 11). Migrants often face difficulties in accessing and using health services due to economic and legal constraints, lack of information about health rights and other individual, sociocultural, economic, administrative, and structural barriers (12, 13). As a result, they often tend to be missed by conventional disease prevention and surveillance programmes, to not receive health information and health education targeted to the mainstream population and to have delayed access to diagnosis and care (10, 14–16). These avoidable determinants impact on NCD care, generating excess downstream public health services costs, worsening NCDs outcomes, and increasing disadvantage and poverty (10).

Health literacy is of great importance to overcome these challenges by enabling people to build on over their own resources, such as previous knowledge and social connectedness. Health literacy is especially critical when working with disadvantaged groups who may lack access to and understanding of health information and health services (17). Health literacy is defined in a wide range of ways for different contexts (18, 19). It includes people's knowledge, confidence and comfort, which develop through daily activities, social interactions and across generations, to access, understand, appraise, remember and use information about health and health care for the health and well-being of themselves and those around them. Health literacy is regarded as a social determinant of health, and improved health literacy in itself is a goal of public health, being one of the key pillars of health promotion (20, 21).

Recent studies in Europe suggest that some members of migrant communities may have limited health literacy (22, 23). This means that these migrants can be unaware of a range of health information resources for prevention and other health promotion activities developed by local health professionals and health institutions (22–25). This situation may be aggravated by lack of awareness of their own rights and potential discrimination. Health literacy has been moving beyond an individualistic conception that focuses on a patient "deficit" or "risk approach," toward a more social and contextualized perspective, as a dynamic social practice that develops in a context, is co-produced in social relations, depends on the resources at hand and, in many cases, is shaped by culture, personal experience, and knowledge (18, 26). This conception reinforces a strengths-based approach to health literacy, which is particularly relevant as many migrants have knowledge on health based on previous experiences and also passed on in their trusted social networks, but often are unaware of their health entitlements and how to navigate the health system (18).

In the NCD prevention context, a challenge has been to understand and meet the health literacy needs of the most disadvantaged and socially excluded populations. This is even more pertinent in the current context of the COVID-19 pandemic, where its adverse impacts are likely to aggravate social and health inequalities. The available evidence on the initial effects of the pandemic shows a disproportionate impact on migrants, especially in Southern European countries (27).

In addition, access to health services has been constrained at expense of COVID-19 care. In these circumstances, the health literacy needs of populations, particularly those most underserved, become even more difficult to address.

In Portugal, as in Europe in general, little is known about health literacy and NCDs in most vulnerable populations, where many migrants are included. This knowledge is crucial to identify and understand the diversity of strengths, needs, and challenges in health literacy of population groups and allows the design and development of bespoke health literacy responses that optimize opportunities to improve equity in access to care (19).

The global and national commitments for improving health outcomes and well-being of all populations, ensuring that no communities are left behind, call for effective implementation of evidence-based interventions and comprehensive approaches. Within a co-design approach, the OPtismizing HEalth LIteracy and Access (Ophelia) process seeks to create, through genuine engagement and participation of community members and other relevant stakeholders, local fit-for-purpose health literacy solutions that address identified needs and taking into account their cultural specificities (19). The Ophelia process embodies a set of principles (see **Supplementary Table 1**) that guide the aims, development, and implementation of structured interventions to improve health and equity (28).

This paper outlines the protocol of a project for the co-creation of solutions that optimize health literacy, health promotion, and social cohesion in support of prevention of NCDs among migrant populations in Portugal using the Ophelia process. To our knowledge, this is the first project applying the Ophelia process with migrants in the EU. It will address the health entities limited knowledge on the bottom-up needs of migrants, especially given the large number of different cultural groups. By having the migrant communities at the front of the co-design process, in true partnership with other stakeholders, they will be central in developing, refining, and implementing meaningful solutions. Enabling the key recipients to take the control can be crucial to develop ownership, which may greatly assist in ensuring that feasible and scalable activities and interventions are developed.

METHODS AND ANALYSIS

The 3-year project "Health Literacy, Health Promotion and Social Cohesion for the Prevention of NCDs among Migrant Populations" was launched in January 2020 and gathers a multisectoral consortium of national and international academic institutions and renowned entities for social, health and community support.

This project follows the Ophelia process (19). The first phase involves a needs assessment covering health literacy abilities, strengths, weaknesses and needs, as well as local data about determinants of health behaviors, service engagement, and organizational responsiveness (**Figure 1**). The second phase consists of co-designing with the migrant communities and other stakeholders a set of multisectoral interventions (covering individual/community, health providers, health and social organizations, and health policy). In the third phase, the co-designed interventions will be implemented and evaluated using quality improvement cycles followed by wider implementation (19).

A community-based participatory research approach is adopted, where relevant stakeholders (migrant communities, academia, health and social sectors, and policy-makers) are engaged actively throughout the different phases (29). Within this process, the project embodies implementation research—an innovative integrated approach linking research to action in order to produce useful evidence that is translatable into effective practices (30). Specifically, this process ensures the outputs are built *in situ* and are needed and wanted by not only the end user, but all the stakeholders involved in implementing and potentially scaling the derived interventions.

Setting

The project is being implemented in the Lisbon district, where most of the foreign-born population in the country reside (31). In 2018, the foreign-born citizens represented 8.6% of the total population in Portugal (10,295,909 residents) and comprised 15.5% of the total population in the capital (Lisbon) (31–34). The most common nationalities are Brazilian, Cape Verdean, British (UK), Romanian, and Ukrainian, with Chinese, Indian, and Nepali nationalities being on the rise (31). Regular migrants (i.e., with authorized residence permit) in Portugal increased 22.9% from 2018 to 2019 (while no official data is available to account for undocumented migrants living in the country) (31).

Despite the acknowledgment that Portugal has some of the most inclusive health policies for migrants (35), research indicates an underuse of health services among some migrant groups, especially those most socially vulnerable, new arrivals, and undocumented migrants (14). Related barriers include lack of information on migrants' health rights and services available, language and cultural differences, stigma, economic constraints, and structural and administrative obstacles (36).

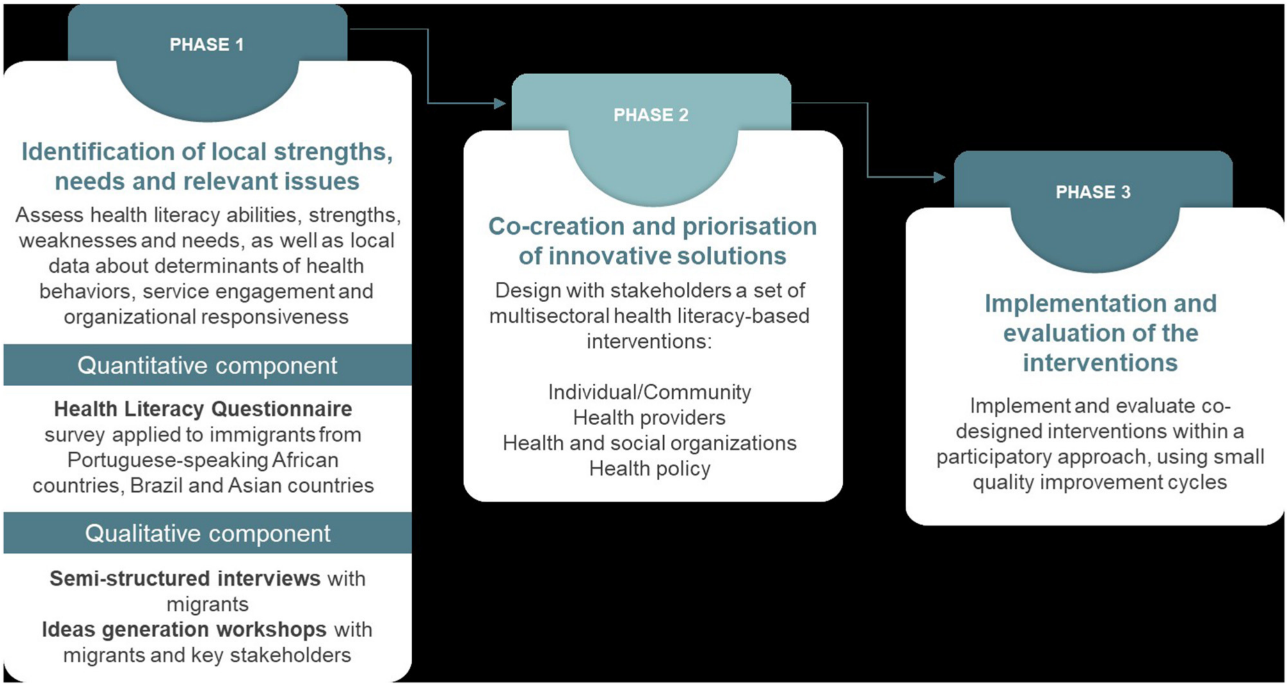
Application of the Ophelia Process

Identifying Local Health Literacy Strengths, Needs, and Relevant Issues

The needs assessment comprises two components: a quantitative component to assess health literacy and identify factors hindering prevention, early diagnosis, and risk reduction of NCDs (including barriers to access and use of healthcare services); and a qualitative component intended to collect complementary information on locally relevant issues on health literacy, social support and integration, NCDs risk factors, prevention and care, services engagement, and organizational responsiveness.

Quantitative Component

The quantitative study consists of a survey conducted with a community-based sample of migrants. The IOM's definition of "migrant" is adopted in this protocol, referring to "a person who moves away from his or her place of usual residence, whether within a country or across an international border, temporarily or permanently, and for a variety of reasons" (37). The inclusion criteria include: being born in a Portuguese-speaking African



Identification of local strengths, needs and relevant issues

Assess health literacy abilities, strengths, weaknesses and needs, as well as local data about determinants of health behaviors, service engagement and organizational responsiveness

Quantitative component

Health Literacy Questionnaire survey applied to immigrants from Portuguese-speaking African countries, Brazil and Asian countries

Qualitative component

Semi-structured interviews with migrants
Ideas generation workshops with migrants and key stakeholders

Co-creation and priorisation of innovative solutions

Design with stakeholders a set of multisectoral health literacy-based interventions:

Individual/Community
Health providers
Health and social organizations
Health policy

Implementation and evaluation of the interventions

Implement and evaluate co-designed interventions within a participatory approach, using small quality improvement cycles

FIGURE 1 | Phases of the project.

country (PALOP), Brazil or an Asian country, being ≥18 years old, speaking Portuguese, English, Arabic, Bengali, Hindi, Mandarin or Nepali, residing in Portugal for 10 years or less, and currently residing in the Lisbon Metropolitan Area, regardless of migration status (i.e., regular, irregular, refugee, or asylum seeker). Individuals who visibly present unstable cognitive and/or emotional status and who are under effect of drugs and/or alcohol that may prevent them from being able to complete the survey are excluded from participation.

For the purpose of sample size calculation it was considered the total number of migrants residing in the Lisbon Metropolitan Area with legal resident status, which according to the data available was 240,963 in 2018 (38), and the existence of 50% of the characteristics under study (i.e., the worst case scenario, as the prevalence of the characteristics to be studied is not known), at a 95% confidence level and with a margin error rate of 5%. It was estimated that a minimum of 384 migrants will be surveyed, but efforts will be endeavored to enrol a higher number of participants of each origin group, in order to strengthen the robustness of statistical analysis and account for the diversity within groups. The percentage of the three origin groups under study was defined based on their distribution in the total migrant population. According to official data, migrants living in the Lisbon Metropolitan Area comprise 63,096 from PALOP, 50,312 from Brazil, and 39,887 from Asian countries (38). Thus, according to the respective proportion, at least 158 migrants from PALOP, 126 from Brazil, and 100 from Asian countries will be recruited.

Stakeholders, such as non-governmental and governmental organizations and migrant associations that work in proximity with migrant communities, were engaged in the project from the start. These partners have collaborating in publicizing the study within the communities and their networks and serving as recruitment sites, where attendees are approached and invited to participate in the study. Also, several informal leaders of the migrants' communities have been invited to collaborate as recruiters of potential participants within their social networks, and as interpreters.

Data will be collected using the Health Literacy Questionnaire (HLQ), available in Portuguese, English, Arabic, Bengali, Hindi, Mandarin, and Nepalese. The HLQ will be administered through an interview by trained bi-lingual researchers to ensure inclusion of people with low educational levels or that experience difficulties with self-administration.

The HLQ is a widely used measure that provides detailed insights into individual and community health literacy strengths and needs across nine distinct domains (see **Supplementary Table 2**), allowing the identification of "profiles" of communities (26, 39, 40). The HLQ has strong construct validity, reliability, and acceptability in several contexts and settings (41–46). In addition, data will be collected on demographics, socioeconomic, and health status (i.e., sex, age, marital status, country of origin, length of residence in Portugal, migration status, educational level, occupation, income level, fluency in Portuguese, self-perceived health status, chronic disease, and incapacity), and use of health services in Portugal (based on the National Health Survey), as well as on the perceived impact of the COVID-19 pandemic in health literacy, health behaviors and access to health services among participants.

Descriptive statistical analyses will be used to assess the health literacy levels of migrants within the nine domains of the HLQ. Computing the mean scores obtained in each dimension will allow to identify possible health literacy strengths and weaknesses in these populations. To understand the association between health literacy levels and the demographic, socioeconomic, and health condition factors that characterize migrants from the different regions of origin under study, a multiple linear regression analysis will be performed. Cluster analysis of HLQ data will be used to identify subgroups of migrants with similar health literacy profiles among the total sample and within each origin group.

Qualitative Component

The following step of the needs assessment consists in semi-structured individual interviews that will be conducted with migrants with NCD risk factors. The cluster analysis will be used to assist with maximum diversity sampling, as a guide to select migrants with diverse patterns of health literacy strengths and limitations, as well as from diverse demographic backgrounds. Up to four migrants per cluster will be interviewed. The main topics to explore in the interviews include the health background of the migrant in terms of risk factor profile (e.g., raised blood pressure and blood glucose, increased weight, family history of chronic disease, as well as behavioral risk factors), information and support they may have received from health entities. The perceived health literacy needs and the areas the participant feels confident about (identified respectively by the HLQ results on the domains with lower and higher scores) will also be explored.

Based on the data from the HLQ survey and the interviews, vignettes that represent typical persons across the clusters will be developed. As per the Ophelia manual (47), they will cover realistic descriptions of the health literacy strengths and weaknesses that influence individuals' ability to protect their health and interact with the health system.

Stakeholders will then be invited to ideas generation workshops where the vignettes are presented and discussed to generate ideas for ways to improve information and services for migrant groups at risk of NCDs. The workshops will last ∼2.5 h and will be conducted *via* a web conferencing facility or face to face. There are four questions that guide the discussion: "Do you recognize people like this in your community?" or "Do you see people like this in your unit/service/organization?"; "What sorts of issues is this person facing?" or "What barriers to navigating the health system this persons may face?"; "What strategies could you use for an individual like this?"; and "What could your organization or community organization do if you had many attendees like this in your organization or community?"

Members of migrant communities, ranging from people recently arrived to successfully settled, as well as migrants with a wide range of health literacy strengths and challenges will be invited to take part in the ideas generation workshops. Relevant local stakeholders responsible for the provision of health care (health practitioners and managers from primary and secondary care), social care (including public, private, not-for-profit organizations), digital health experts, and a variety of other representatives from region-wide non-governmental organizations and local community-based organizations will also participate. Partners with expertise on network and digital health technologies and solutions will participate, given that the internet and social networks are increasingly two of the most important resources for the general population to search for health information and its integration can be of great added value. Overall, at least one workshop with each of the migrant origin groups and three workshops with stakeholders will take place. Each workshop will include ∼5-10 participants. Participants will be recruited using a purposive sample of members of stakeholders' organizations and practitioners within their networks with experience on migrant health. The workshops will be conducted by the research team.

For the analysis of qualitative data, audio recordings of the interviews will be transcribed, and the transcripts will be analyzed through content analysis technique (48). This technique allows systematize the data in key topics and organize it in different categories and sub-categories (49).

Co-creation and Prioritization of Innovative Solutions

Representatives of key migrant groups and relevant local stakeholders responsible for the provision of health or social care to migrant communities in the Lisbon Metropolitan Area will be invited to participate in a set of workshops dedicated to prioritizing and refining the interventions. Overall, the prioritization outcomes will address different levels of the system, namely at individual, community, practitioner, and policy levels.

While it is not possible to predict the specific interventions, they are expected to include pathways and support for migrants' health promoting behaviors, including for adopting healthy lifestyles. They may also cover awareness of health services available, as well as increased information, skills, strategies, and tools to navigate in the local health services, engage and communicate with healthcare providers, and appraise practical support and health information. These potential outcomes will be refined throughout the partnership discussions, and even new outcomes may emerge during this step. Overall, the participatory process will help assure that the defined outcomes will be achieved and meet the real and unforeseen needs.

The research team will facilitate the multisectoral co-design process, including the design of the plans of implementation and evaluation of the selected interventions using a Programme Logic Model aligned with the Ophelia manual (47). The implementation plan will account for the expected challenges/risks related to the pandemic context and the respective measures to mitigate them. The evaluation plan will also consider the potential impacts of the COVID-19 pandemic in the expected outcomes.

A rapid review of scientific publications and gray literature will be also conducted to identify and map interventions that potentially tackle prevention of NCDs. The context of relevant studies will be noted and these data will also inform the prioritization of solutions to be implemented.

Implementation and Evaluation of the Interventions

In the third phase, a participatory implementation research of health literacy-informed solutions will be carried out. Throughout the piloting of the co-designed interventions, quality improvement cycles will be used, whereby organizations develop and implement trials, actively examine and evaluate the immediate and intermediate outcomes, and refine materials and processes to improve the effectiveness, local ownership, uptake and sustainability of the intervention. The health literacy outcomes associated with the tested interventions may be examined with some HLQ scales if relevant. Regular workshops will also take place to provide a venue for stakeholders implementing interventions to share ideas and resources, and to communicate key findings, as a community of practice.

DISCUSSION

This is a pioneering project that will address the health literacy needs of a population who tends to be disproportionately affected by health disparities. As documented in the literature, particularly socially vulnerable migrants tend to present poorer health outcomes than native populations, face increased difficulties in access to health services and, according to the limited evidence available, these populations tend to face increased health literacy challenges (10, 12, 22). Despite the global and national efforts to improve health of those most underserved, such as migrant groups, frequently these populations are understudied, and little involved in the efforts to identify their real needs. This project will assist with reducing this knowledge gap. It has been widely recognized that the promotion of health literacy can be a powerful tool to reduce health inequalities and improve access and quality of health care (26). The project can help to enhance migrant communities and stakeholders' capacity building for health literacy action. This is even more pressing in the current times of COVID-19 pandemic, where social inequalities in health and access to services have intensified, affecting asymmetrically those who are already disadvantaged (50).

This protocol follows the Ophelia process, a community co-design approach that is now being applied in many countries, that operationalizes the health literacy concept on a large scale and whose impacts have been well-documented (28, 40, 51–53). Indeed, Ophelia process has demonstrated to be a feasible approach by which organizations can develop tailored responses to the health literacy needs of their attendees/users, with positive outcomes such as changes in health literacy, behavior, knowledge, and management of risk factors of specific diseases (28, 51, 54–58). The project may provide useful insights related to health literacy research and practice in specific areas where migrant populations face disproportionate adverse impacts, which can inform global efforts on prevention of NCDs.

Through an implementation research that uses a participatory approach from the start, this project takes a systematic and grounded approach to produce evidence on real health literacy needs from the perspective of diverse key stakeholders, giving a particular attention to that of migrants. By developing a mixed-methods needs assessment—a quantitative HLQ survey combined with interviews with migrants and workshops with key stakeholders—we will be able to gather robust, rich and contextualized evidence on health literacy among these populations to inform researchers, health and social practitioners and decision makers. Indeed, this is even more pertinent in the context of the COVID-19 pandemic, where deepening social and health inequalities and increasing constraints in access to health services are resulting in new and unexpected needs. The fact that the needs assessment explores the impacts of the COVID-19 pandemic in health literacy, health behaviors and access to health services will assist in this effort.

Moreover, this project embodies a strong potential for effective knowledge translation into culturally and context congruent solutions that are locally relevant. The active involvement of several stakeholders in all phases of the project will allow to co-design and implement multisectoral interventions, reinforcing its potential for high impact in innovation generation and system reform. This participatory implementation research will pave the way to build and reinforce synergies between stakeholders, with exchange of knowledge and resources, enhancing empowerment of migrant communities, and increasing responsiveness of health and social organizations (59). Additionally, without working beyond the health sector it is not possible to effectively address the complex challenges that societies face in its efforts to improve health and well-being, and reduce inequalities (59). This approach not only helps to address health and well-being challenges that transcend traditional sectoral boundaries, but also promotes good governance by building accountability across sectors and encouraging broader participation in the policy process. Overall, this will potentially strengthen the sustainability of the project beyond its timeframe and contribute to reducing the growing burden of NCDs and the health inequalities affecting most disadvantaged populations.

Despite the strengths of this project, challenges are foreseen in its implementation. Maintaining an active partnership across numerous stakeholders with different competencies, roles, priorities, and expectations of the project outcomes is specifically built into the design, however this critical process requires time, dialogue and resources (29). Care will need to be taken to ensure equitable involvement of all partners with shared power and flexibility to make adjustments throughout the co-creation process. Also, in the current pandemic context, where stakeholders' organizations may already be overloaded, the project may place additional demands on some stakeholders and provide challenges for them to engage in full. The online format of most interactions within partnership during the indefinite COVID-19 pandemic will also require that partners adapt to new ways of connecting and working together, which may be particularly demanding in the phase of co-design of the interventions.

During the implementation of the co-designed solutions, it will be necessary to consider the degree of newness that the interventions will introduce to existing long-established practices in the organizations. Also, individuals with the greatest health literacy challenges are frequently the most socially vulnerable such that additional efforts by researchers are required to build trust and engage these groups in the interventions in a way that is meaningful and safe for them. Strategies, co-designed with and led by migrant communities, will need to be generated to ensure that local capacity building is undertaken in order to assure maximal participation of the key groups and beneficiaries. Another challenge is that, given the timeframe of the project, longer-term impacts and unexpected outcomes of the interventions may be difficult to assess.

CONCLUSIONS

This project will give an equal voice to all stakeholders, including the end users, and will build on the existing local strengths to generate innovation. This protocol follows the Ophelia process, a principles-based health literacy-informed approach to co-designing services and systems that will lead to improved health, access and equity, and to enhanced quality of life and productive engagement in the society. It intends to generate a framework of best practice and suitable tools that can be adapted, considering differences and specificities (e.g., in terms of language, migration status, origins), to a range of contexts and populations with a migrant background, including in other European countries. The potential scalability of interventions to other similar contexts and populations may help produce evidence to further understand what common features, but also what specific contexts play a role in optimizing the efficacy of the interventions. Indeed, this will contribute to better understand how interventions can interact with different contexts to produce similar outcomes and what level of flexibility is needed to build, design and implement context-congruent interventions. Overall, the implementation of this protocol is expected to help advance the knowledge on how health literacy can improve health, well-being, and provide further understanding of its role as both a determinant and a response to reduce health inequalities among migrant communities and promote social integration.

ETHICS STATEMENT

Ethical approval for the HLQ survey was obtained from the NOVA Medical School Ethics Committee. The participation in this study is voluntary. Informed consent is obtained from all participants. Anonymity and data confidentiality are guaranteed.

AUTHOR CONTRIBUTIONS

SD, ACF, and RHO contributed to the conceptualization of the project. SD, ACF, AGa, MJM, and ACM contributed to the design of the protocol. SD and AGa drafted the manuscript. All authors contributed to the Health Literacy Questionnaire study, reviewed the manuscript drafts, and approved the final draft of the manuscript.

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SUPPLEMENTARY MATERIAL

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Scientific Cooperation and the Co-production of Scientific Outcomes for Physical Activity Promotion: Results From a Transdisciplinary Research Consortium

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Background: To tackle complex societal challenges such as the high prevalence of physical inactivity, research funding is increasingly channeled toward cross-disciplinary research consortia. This study focused on exchange and cooperation (E&C) among the scientists of a 5-year transdisciplinary research initiative in Germany. Researchers' perceptions of E&C were combined with numbers of collaborative products during the project's life to make the developments of E&C and the quality of collaborative products visible.

Methods: We applied a mixed-methods design including a qualitative content analysis of pre-interviews, focus-group interviews, and documents as well as a quantitative analysis of research (scientific publications, books, conference participations) and training outcomes (supervised bachelor's, master's, and Ph.D. theses). Inductive and deductive approaches were combined to analyze factors of collaborative readiness and to identify perceptions of E&C among project teams. Based on Hall et al.'s "Conceptual Model for Evaluation of Collaborative Initiatives," the project period was separated into phases of "collaborative readiness," "collaborative capacity," and "collaborative products."

Results: Our findings revealed a discrepancy between the objectively assessed concepts of collaborative readiness and researchers' reported perceptions of E&C during the early project stage. A set of E&C hindering factors identified during the initial project phase remained present until the final project stage. Further, E&C among scientists increased over time, as reflected by researchers' perceptions. Reports of scientists also showed that outcomes were co-produced at the final project stage for the first time, while knowledge integration had not yet been achieved. Generally, the number of collaborative products (particularly scientific publications) also substantially increased over time. E&C was supported and promoted by the efforts of the coordinating sub-project.

Conclusion: Scientific E&C is a learning process and needs time to develop. A participatory research approach taking into account the perspectives on and requirements for E&C during the project's design might lay the ground for suitable, supportive, and transparent conditions for effective and successful E&C. Despite their time- and resource-consuming nature, cross-disciplinary research initiatives provide a fertile context in which to generate new solutions for pressing societal issues given that long-term funding and the establishment of an overarching coordination organ is assured.

Keywords: cooperation of science teams, The Science of Team Science, transdisciplinary research consortium, physical activity promotion, collaborative readiness, collaborative products

INTRODUCTION

Complex societal problems such as climate change as well as health issues such as tobacco use or physical inactivity are increasingly addressed through the cooperation and knowledge integration of different scientific disciplines (1–3). Although cross-disciplinary (e.g., inter-, multi-, or transdisciplinary) exchange and cooperation (E&C) is a promising basis for scientific and societal advancements (4), it is complex and entails challenges at the individual, team, conceptual, institutional, and coordination levels (5, 6). Specifically, coordination, collaborative problem-solving, and the production of outcomes in initiatives with researchers located at different universities require time to develop (7–10).

In the context of academia, E&C is characterized by very specific conditions, such as the importance of a sound reputation or the competition for jobs, grants, and publication opportunities (11). Bozeman and Boardman have defined scientific collaboration as the "social processes whereby human beings pool their experience, knowledge and social skills with the objective of producing new knowledge, including knowledge as embedded in technology" (12). It has been shown that researchers were motivated to participate in research collaborations due to access to expertise and resources, recognition and reward, higher productivity, and the learning of new skills (13, 14). In contrast, the risks of collaboration in research include the critical assignment of credits and high coordination costs (13).

For cross-disciplinary E&C resulting in knowledge integration, several requirements have been identified in the literature. New methods and concepts need to be developed systematically and appropriate communication tools and institutional arrangements established (15). In the context of higher education, personal motivation and creativity, social capital (supportive social networks), and a knowledge-creating culture as well as access to information resources have been reported as important facilitation factors (16).

However, funding agencies are skeptical about the effectiveness and the added value of large cross-disciplinary initiatives when compared to less resource-intensive uni-disciplinary research (2). A discourse that may help to address these concerns is The Science of Team Science (TSTS), which has produced different approaches and models to assess and evaluate the functioning and effectiveness of cross-disciplinary teams. In their integrative literature review, Tigges et al. (17) provide an overview of existing teams science models and their measures of collaboration quality (e.g., team interactions and processes during collaboration) and collaboration outcomes (publications and citations). For instance, Stokols et al. (8) have suggested a conceptual framework to evaluate transdisciplinary research assessing large-scale scientific collaboration, scientific integration, health impacts, professional validation, and communication, differentiating between immediate, intermediate, and long-term markers. Wooten et al. (18) assessed team maturation and scientific progress in multidisciplinary teams using a mixed-methods design. Another approach to evaluate whether cross-disciplinary research initiatives effectively enhance research collaboration and long-term health impacts is Hall et al.'s (19) "Conceptual Model for Evaluation of Collaborative Initiatives." It evaluates research collaboration processes and outcomes, differentiating between three phases of (a) collaborative readiness, (b) collaborative capacity, and (c) collaborative products.

This study reports on the E&C of science teams in Capital4Health (C4H), a transdisciplinary research consortium funded by the German Federal Ministry of Research (2015–2020), which aims to increase capabilities for active lifestyles across the lifespan. The consortium is based in Bavaria, Germany and is composed of research institutions as well as policy and professional partners. Following an interactive knowledge-to-action approach (20), partners seek to co-produce sustainable measures to promote physical activity in different settings. Settings include daycare centers, schools and universities, apprenticeship and vocational education, communities, and senior housing, and each are addressed by a dedicated sub-project.

The consortium has a specific focus on fostering E&C between the teams of scientists from five sub-projects, supporting them in jointly generating innovative solutions to the problem of physical inactivity and going beyond established discipline-specific approaches. Two cross-cutting projects support this process by providing theoretical input, supporting evaluation, and fostering consortium-wide interaction. Concrete interventions to foster E&C between projects have included expert workshops, annual meetings of the entire consortium with an international scientific advisory board, a network of all young researchers in C4H, semi-annual meetings of a transdisciplinary steering committee and all principal investigators (PIs) to coordinate consortium strategies, ongoing support by e-mail and phone, and regular group interviews with all project teams.

This study used a mixed-methods approach based on Hall et al.'s (19) three-stage model to analyze 5 years of E&C (2015–2020) in the C4H consortium. Given that (a) the capacity to cooperate needs to be developed during the collaboration process (21), that (b) collaborative outcomes are to be expected at the end of a project (8), and that (c) especially multi-university research projects benefit from intensive coordination efforts (22), we based our analysis on the following assumptions: (1) perceptions of E&C would increase over the project's life, (2) the number of collaborative products would increase toward the end of the project's life, and (3) the coordinating sub-project would qualify as an important support mechanism for E&C in this multi-university research consortium. From our perspective, gaining further insight regarding these assumptions and the temporal development of E&C during the lifetime of the project can provide insights into how to create conditions that are conducive to E&C (23) in health promotion in general and in physical activity promotion in particular. This might be of interest to both funding agencies and scientists embarking on cross-disciplinary collaborative projects.

METHODS

Theoretical Framework

As mentioned above, we used Hall et al.'s (19) conceptual framework to guide our analysis. As suggested by the authors (19), we divided the project span into phases of collaborative readiness, collaborative capacity, and collaborative products.

Collaborative readiness refers to a broad range of circumstances that influence effective cooperation among teams in the initial project phase and that are crucial for a successful project (19, 24). Hall et al. (19) suggest assessing collaborative readiness through environmental, intra- and interpersonal measures including institutional resources or support (24), the local proximity of investigators (2, 19, 24), the diversity of scientific disciplines (24), and research orientation (19). Also, programmatic goal setting, the duration of the program, the research orientation of scientists and their leadership skills, the number of participating scientists (25), the presence of brokers (2), and researchers' prior collaboration on past projects have been identified as readiness factors (2, 24).

Collaborative capacity addresses the above-mentioned circumstances in the intermediate or later project phases (19). At this stage, factors such as team functioning and cognitive (e.g., a shared mental model), motivational (e.g., knowledge sharing), and behavioral team processes (e.g., trust, face-to-face communication) (2, 13) as well as credit for co-authorship, institutional work culture, and power relations (26) inevitably influence effective cooperation and exchange among researchers. Further, collaborative capacity is not a given for scientists but needs to be learned over time during the collaboration process (21).

Finally, *collaborative products* such as research, training or policy, and health outcomes are to be expected toward the end of a research project (19). The literature on research outcomes—also labeled knowledge outcomes (22)—shows that they are often assessed through co-authored publication metrics, conference or workshop presentations (22), or the social network analysis of co-authored publications (2, 13, 27–30). Chen (28) analyzes academic social networks (project-based, learning-based, and institution-based) and their respective collaboration mechanisms influencing cooperative research outcomes. Others (31, 32) have combined research team outcomes with data about research participants' perceptions, an approach that is also increasingly encouraged in the literature (27, 33–35). Co-produced publication metrics were criticized as merely a partial indicator of collaboration (34) as they tell little about cooperation dynamics and processes over time (19). Examples of training outcomes include successfully supervised graduate students' theses or dissertations (7) or industry jobs that graduate students have received (22). Policy and health outcomes refer to established collaborations with political or healthcare institutions (22), among others.

Based on empirical findings showing that publication metrics tend to underestimate collaborative processes and should be combined with the subjective views of collaborating researchers (31, 32), we complemented the original model with perceptions of E&C among researchers as well as with the number of collaborative products across all project phases (collaborative readiness, collaborative capacity, and collaborative products) to make the developmental and integrative processes of E&C visible.

Data Collection

To collect data on these different aspects of E&C in the C4H consortium, we used a mixed-methods design based on (a) semi-structured individual interviews with the consortium's PIs at the start of the project (pre-interviews), (b) semi-structured reflexive focus-group interviews throughout the project's lifetime, and (c) document analysis of relevant project documents and scientific outcomes.

For the pre-interviews and the focus-group interviews, we developed interview guidelines (IG1, IG2) that were both compatible with the Hall framework but broad enough to allow for adaptation during different phases of the project (e.g., initial contacts with external partners in the early project stage or workshops on a potential new funding phase toward the end). In line with Hall et al. (19) and due to data availability, we chose the research orientation of PIs, local distances between sub-projects, and diversity of scientific perspectives as measures of collaborative readiness. Firstly, to assess research orientation, we analyzed qualitative telephone pre-interviews with the sub-project PIs conducted in 2016 by a former member of the coordinating project. The interview guideline (IG1) included questions on previous experience in cooperating with scientific partners (IG1_Q1), difficulties experienced during these cooperative endeavors (IG1_Q2), potential success factors (IG1_Q3), and personal motivation to participate in the research consortium (IG1_Q4). Five pre-interviews were conducted between May and June of 2016, lasting ∼30–45 min each.

In addition, a total of 23 semi-structured focus-group interviews were conducted by the first author (SF) or her predecessors between 2015 and 2020, and all interviewers were adequately trained in interviewing techniques. Due to Covid-19 induced difficulties, the last planned focus-group interview in 2020 was transformed into a semi-structured individual interview as only one of the invited focus-group participants was able to participate. The interview guideline addressed questions on the current status of the sub-project (IG2_Q1), expectations regarding the further project work (IG2_Q2), cooperation with project partners (IG2_Q3), and cooperation within the research consortium (IG2_Q4). The interviews took the form of semi-structured reflexive focus-group interviews conducted with the scientific sub-project teams on a semi-annual and later on an annual basis either face-to-face at the lead University of the respective sub-projects or *via* web conference in 2020 (due to the COVID-19 pandemic). The number of focus-group participants varied over time and ranged from two to six researchers. Focus-group interviews lasted ∼30–90 min each, the individual interview about 90 min.

All (pre- and focus-group) interviews were audio-recorded and transcribed. Identification elements (person names, places, institutions or factory names) were anonymized, and participants signed consent forms before participating in the interviews. Transcripts of all interviews were transferred to the qualitative analysis software MAXQDA (version 20). Final transcripts were not returned to participants for correction or comment, and participants were not asked to provide feedback on the findings. The interview quotes used in this article were translated from German to English by the first author and verified by the second author. This work adheres to the COREQ criteria for reporting qualitative results (36).

Document Analysis

While researchers' subjective views on cooperation, as reflected in interviews, provide a grasp on the dynamics and processes of cooperation (19, 31), the analysis of research outputs, such as co-authored publications, is considered an objective measure of cooperation that can be applied validly and reliably across research settings (19). Although such products are expected toward the end of a project, we aimed at analyzing research products across all project phases. The first author collected the number of published scientific articles or books and both published or unpublished conference abstracts from a shared electronic storage folder used by all sub-projects and the common C4H website and sub-projects' University homepages. We further analyzed the number of training outcomes, such as finished bachelor's, master's, or doctoral theses supervised by researchers of the consortium. The first author sent a small survey *via* e-mail to all sub-projects, asking them to complete a list with all completed works (for bachelor's, master's, or doctoral theses) during the entire project of C4H (2015–2020). Additionally, and with regard to collaborative readiness measures, the C4H grant proposal was included and provided important basic information on the participating teams and disciplines.

Data Analysis

We used content analysis (37) to explore the research orientation among the participating PIs as reported in the pre-interviews. This method involved a deductive definition of the main categories based on the interview guideline (IG1) and concepts of inter-, multi-, and transdisciplinary research. The first author (SF) repeatedly read all the interview material and generated codes and anchor examples based on the pre-defined categories. Subsequently, the second author (MT) reviewed the codes and categories. Finally, the category system was applied to the rest of the material. Discrepancies were discussed between SF and MT until consensus was reached.

We analyzed all interview questions (IG1_Q1 to IG1_Q4), collecting quotes indicating a PI's prior experience in cooperation with academic, practice, and policy partners. Inspired by Rosenfield (38), we considered a PI to be oriented toward inter-/multidisciplinarity if the researcher reported having had experience in cooperation with academic partners from other scientific disciplines prior to participation in C4H. Following Bergmann et al. (39), a transdisciplinary research orientation was assumed if the PI reported to have had experience in cooperation with academic, policy, and practice partners including the co-creation of solutions prior to participation in C4H. During the analysis, a third intermediate category was identified, namely experience in cooperation with policy and practice partners (research-practice-partnership orientation).

The focus-group interviews were first categorized into one of Hall et al.'s respective project phases based on the year in which they were conducted, as follows: collaborative readiness (interviews conducted in 2015–2016), collaborative capacity (interviews conducted in 2017–2019), and research outputs (interviews conducted in 2020). We used content analysis (37) of all interview questions (IG2_1 to IG2_3), performing an inductive coding approach to collect quotes illustrating perceptions of E&C among and between sub-projects. Quotes were extracted and coded by the first author (SF), who also classified the categories and sub-categories and developed a codebook. The second author (MT) revised the work, and divergences were discussed until agreement was reached.

The first author (SF) analyzed the grant proposal and extracted the University locations, university departments, and research areas of the research teams. She also compiled the numbers of published journal articles, books, degree-qualifying works, and conference abstracts according to the phase (collaborative readiness, collaborative capacity, research outputs) in which they were produced. The second author (MT) reviewed the analysis, and divergences were discussed until agreement was reached.

In the final step, data from all three data sources were compiled and, where possible, triangulated (40) to provide a comprehensive overview of E&C in the different project phases of C4H. **Table 1** provides an overview of how evidence from the pre-interviews, the focus-group interviews, and the document analysis was used to inform the results reported below for collaborative readiness, collaborative capacity, and collaborative products, respectively. Data summaries were initially collated by the first author (SF), double-checked by the second author (MT), and finalized in discussions with the other co-authors.

Participants

Participants consisted of members of the C4H project research teams, including PIs (males, $N = 5$; females, $N = 3$—all University professors) and research associates at the postdoctoral or early researcher levels. A consistent number of research associates and their genders and ranks cannot be ascertained due to staff fluctuation throughout the lifetime of the projects. A total of $N = 5$ sub-projects was included in the analysis. Since the coordinating sub-project conducted the reflexive interviews

TABLE 1 | Mixed-methods design applied in this study.

Data sources and methods	**Project phases based on Hall et al. (19)**		
	Collaborative readiness	**Collaborative capacity**	**Collaborative products**
		Measures	
Qualitative content analysis of pre-interviews ($N = 5$; IG1) conducted in 2016 with five participating PIs (deductive approach)	Research orientation of PIs		
Qualitative content analysis of semi-structured reflexive focus-group/individual interviews ($N = 23/N = 1$; IG2) conducted between 2015 and 2020 with 5 sub-project research teams (inductive approach)	Perception of E&C among the sub-projects in 2015–2016	Perception of E&C among the sub-projects in 2017–2019	Perception of E&C among the sub-projects in 2020
Qualitative content analysis of grant proposal for the first funding phase (2013)	Diversity of scientific disciplines Local distance between sub-project teams		
Quantitative analysis (count) of the number of publications (scientific articles, books, conference presentation) retrieved from University websites, shared electronic storage, and the C4H-website	Number of publications in 2015–2016	Number of publications in 2017–2019	Number of publications in 2020
Quantitative analysis (count) of survey on the number of degree-qualifying works (bachelor's, master's, and doctoral)	Number of degree-qualifying works in 2015–2016	Number of degree-qualifying works in 2017–2019	Number of degree-qualifying works in 2020

analyzed in this study, it was excluded from all analysis. Also, the evaluating sub-project was omitted because it did not take part in the reflexive interviews.

RESULTS

The qualitative content analysis of the pre-interviews resulted in $N = 10$ codings falling into the aforementioned main categories of "inter-, multidisciplinary research orientation," "research-practice-partnership orientation," and "transdisciplinary research orientation." With regard to the analysis of the focus-group interviews, we identified a total of $N = 152$ codings. The identified main- and sub-categories are shown in **Table 2**. The main categories include "general perceptions of E&C among the sub-projects," "perceived challenges to E&C among the sub-projects," "perceived facilitators for E&C among the sub-projects," "E&C with the coordinating project," "E&C with the evaluating project," and "E&C with the Young Researchers Network." In 2020, additional categories addressing E&C among the PIs (see **Table 2**) were identified. In the following, the results of the analyzed interviews as well as of the collaborative products are presented according to the project phase in which the data were collected. Results dealing with E&C with the coordinating and evaluating sub-projects as well as with the Young Researchers Network are reported for the entire project phase to make reading more coherent. Quotations from the interviews are provided to illustrate the main findings. Participants are identified by research team and year.

Phase of Collaborative Readiness (2015–2016)

Research Orientation

Concerning their research orientation, all five PIs reported an inter-, multidisciplinary research orientation [experience in cooperation with academic partners from other scientific disciplines ($N = 5$)] and a research-practice-partnership orientation [experience in cooperation with practice and/or policy partners ($N = 5$)]. None of the interviewed PIs reported to have experience in cooperation with academic, practice, and policy partners including the co-production of new solutions (transdisciplinary research orientation).

Local Distance Between the Sub-projects

Research teams were located in seven different cities in Germany, with six of them in the State of Bavaria and one in Hesse. Three sub-projects were located within the same University department, and one PI was involved in two sub-projects at different sites. In sum, distances of maximally 324 km were to overcome for meetings, and the time zone was the same for all involved sub-projects.

Diversity Between Scientific Perspectives

The majority of researchers were affiliated with departments of sport sciences. However, specializations differed, including sports medicine ($N = 1$), physical education ($N = 2$), sport/rehabilitation science ($N = 1$), and public health and physical activity ($N = 2$). Other researchers were from the fields of health sciences ($N = 1$) and medical sociology ($N = 1$).

Perceptions of E&C During the Collaborative Readiness Phase (2015–2016)

At the start of the project (2015–2016), the majority of participants reported perceiving no or little cooperation with sub-projects other than the coordinating or evaluating project, as illustrated by the following quote: "[...]but we actually do not notice anything [regarding any of] the other projects" (Participant, team 1; 2015).

TABLE 2 | Category system for pre-interviews and semi-structured focus-group interviews.

Project phase		**Collaborative readiness**	**Collaborative capacity**	**Research outcomes**
Interview	**Main category**	**Sub-categories**	**Sub-categories**	**Sub-categories**
Pre-interviews with PIs	Research orientation (deductive categories)	- Multi-/interdisciplinary: experienced in cooperation with academic partners from other academic disciplines prior to the participation in C4H - Research-practice partnership: experienced in cooperation with policy and/or practice partners prior to the participation in C4H - Transdisciplinary: experienced in cooperation with academic, practice, and policy partners including the co-creation of new solutions prior to the participation in C4H (transdisciplinary)	-	-
Semi-structured focus-group interviews with sub-project research teams	General perception of E&C among the sub-projects (inductive categories)	- None to little	- None or little - Increasing	- None or little - Increasing - Exchange without co-production/cooperation
	Perceived challenges to E&C among sub-projects (inductive categories)	- Lack of trust - Start-up phase of the project - No perceived benefit of E&C - Own project load - No planned occasions of E&C - E&C as time-consuming development process - No clearly communicated goal of increased E&C - Too project-specific problems - Limited resources - Perceived reluctance for E&C among other sub-projects	- Focus on own project work - E&C have not been taken into account in project design from beginning on - Limited resources - Unpopular topics - Own project load - Too project-specific problems - E&C as add-on business - No clearly communicated goal of increased E&C - Staff discontinuities - Perceived reluctance for E&C among other sub-projects	- Own project load - Too project-specific problems - No perceived benefit - Limited resources - Unclear roles (who is defining tasks and who is pursuing them?) - Perceived reluctance for E&C among other sub-projects
	Perceived facilitators for E&C among sub-projects (inductive categories)	- Involvement of project members in two sub-projects - Young Researchers Network - Coordinating project - Events (workshops, advisory board meeting) - Shared problems	- Shared problems - Shared interests - Coordinating project - Events (workshops, advisory board meeting) - Local proximity - Experience of prior collaboration - Young Researchers Network	- Perceived benefit - Shared interests - Events (advisory board meeting) - E&C as mandatory task - Young Researchers Network - Coordinating project
	General perception of E&C among PIs (inductive categories)			- Increasing - Valued (helpful, positive, feeling of connectedness)
	Perceived facilitators for E&C among PIs (inductive categories)			- Shared goals (third funding phase, publication) - Clear structure and time frame - Coordinating project

(Continued)

TABLE 2 | Continued

Project phase		Collaborative readiness	Collaborative capacity	Research outcomes
Interview	**Main category**	**Sub-categories**	**Sub-categories**	**Sub-categories**
	E&C between a sub-project and the coordinating project (inductive categories)	- Coordinating project as the only E&C partner - Coordinating project as contact person	- Coordination and evaluating project as most frequent E&C partners - Coordination project perceived as exchange facilitator - Coordination project perceived as expertise holder/driver - Facilitators for E&C: local proximity, structure and transparency, enough resources - Work for the coordinating project perceived as add-on business - Valued (helpful)	- Valued (central role of the project) - Coordinating project as most frequent E&C partner - Facilitators for E&C: structure and transparency, enough resources
	E&C between a sub-project and the evaluating project (inductive categories)	- Regular contact with evaluating project - Valued contact (add-on business; positive)	- Evaluating and coordination project as most frequent E&C partners - Valued contact (positive, helpful)	- Valued contact (positive)
	E&C among sub-projects in the context of the Young Researchers Network (inductive categories)	- Young Researchers Network as a safe discussion forum for junior researchers	- Driven by engaged person of Young Researchers Network - Shared goal (special issue)	- Shared goal (special issue) - Scheduled, regular exchange

One reason for little E&C was that the fulfillment of their own project tasks required all the resources of the sub-projects, especially during the start-up phase of the project. Also mentioned were lack of trust between researchers, the fact that E&C amid teams is a process that takes time to develop, and that proceeding in a structured way toward the clearly formulated goal of "E&C" was necessary. It was reported that researchers could not see a benefit to more aspects of E&C as becoming acquainted and building trust were more important at this stage of the project. Some teams were able to learn about other sub-projects through a cooperator involved in two different sub-projects. Generally, if E&C took place, it was facilitated through the coordinating project or the Young Researchers Network, which organized occasions to meet (e.g., workshops and advisory board meetings).

Number of Research and Training Outputs

At this project stage, a total of 23 research outcomes was identified, including four conference presentations in 2015, and 17 conferences presentations in 2016. With regard to training outcomes, two bachelor's theses were supervised in 2016 (see **Table 3**).

Phase of Collaborative Capacity (2017–2019)

Perceptions of E&C During the Collaborative Capacity Phase (2017–2019)

The reports of the participants suggested a tendency toward increased E&C among sub-projects compared to the beginning phase. Among the facilitators mentioned for E&C were local proximity or prior experience working together. Several participants described shared interests or problems as additional facilitators. However, the E&C did not go beyond exchange or lead to the co-creation of new materials, as indicated in the following words from an interview:

> "[...]Team 1 and team 5 are two sub-projects dealing with health literacy and...we are basically working [on parallel tracks] and have developed independently of each other the constructs of physical-activity-related health literacy (team 1) and sport-related health literacy (team 5)...Every now and then we talk about what is similar or perhaps different, but we work mostly in [a parallel way] [...]" (Participant, team 5; 2019).

A major challenge to promoting E&C was limited resources. Researchers appreciated learning about new approaches through interdisciplinary exchange with other sub-projects but perceived E&C as an "add-on" business. Further, the project design of putting sub-projects in diverse contexts and defining topics and goals for every sub-project was perceived as a barrier that prevented increased E&C as the sub-projects were primarily consumed by their own workloads. E&C was not considered a source of added value for the work of individual projects since the settings were too different.

Number of Research and Trainings Outputs

At the collaborative capacity stage, a total of 48 research and training outcomes was produced. In 2017, three scientific publications, two master theses, and 12 conference presentations

TABLE 3 | Co-produced publications, degree-qualifying works, and conference presentations between 2015 and 2020.

Year	Publications	Mentoring of degree-required works			Conference presentations	Total outcomes
		Bachelor's	Master's	Ph.D.		
2015					4	**4**
2016		2			17	**19**
2017	3		2		12	**17**
2018	1	1	1		13	**16**
2019	4	1	2	1	23	**31**
2020	11		1	1	1	**14**
Total	**19**	**4**	**6**	**2**	**70**	**101**

(a total of $N = 17$ products) were counted. In 2019, the total number of research and training products increased to 31 with four scientific publications, 23 conference presentations, and four degree-qualifying works (bachelor's, master's, and Ph.D.) (see **Table 3**).

Phase of Collaborative Products (2020)

Perceptions of E&C During Collaborative Products Phase (2020)

Toward the end of the project (2020), E&C was reported to occur in the form of several joint activities—the PIs worked collaboratively on a publication about the research consortium, they met to discuss options to apply for a third funding phase, and the young researchers jointly worked on the publication of a special issue for a relevant journal in the field of public health. The meetings of the PIs for the joint publication and discussions about ideas for a potential third funding phase were observed as highly positive and created feelings of connectedness with the consortium, a spirit of optimism, and motivation for closer E&C among the participants of the consortium. Through work on the publication, PIs discovered commonalities among the sub-projects, a common goal (the publication), the resulting benefits of the undertaking (e.g., producing the publication), and the increased visibility of the consortium. One researcher stated,

> "[...] we made a shared outline for the publication and realized that it is all quite fitting. There are many parallels between the projects... Somehow we are a consortium that is [having] similar experiences regarding similar topics, [sharing] similar ideas and perspectives." (Participant, team 2; 2020)

Also, the mandatory nature of E&C to produce the publication and the clear structure and time frame with regard to the publication were perceived as facilitating E&C. As evidenced here, E&C with the coordinating project and the Young Researchers Network, both pushing forward the expansion of publications in scientific journals, was seen as a benefit.

In addition, researchers still perceived the E&C among sub-projects to be facilitated through events organized by the coordinating project or the Young Researchers Network. However, problems of high workloads of the sub-projects, limited resources, staff discontinuities, and the assumed reluctance of other sub-projects to engage in E&C continued to be reported at this project stage.

Number of Research and Training Outputs

The number of conference presentations was low ($N = 1$) in 2020 due to the COVID-19 pandemic. However, the highest number of scientific publications ($N = 11$) was produced during this year (see **Table 3**). A number of two supervised training outcomes (master's and doctoral theses) was reported.

E&C Between the Sub-projects and the Coordinating Sub-project, the Evaluating Sub-project, and the Young Researchers Network

Across all three project phases, respondents addressed the E&C with the coordinating and the evaluating sub-projects as well as with the Young Research Network. The results are summarized in the following.

a) E&C Between a Sub-project and the Coordinating Sub-project

The coordinating project was determined to be the major contributor to E&C for all sub-projects across the time frame of the entire project. One participant described its central role as facilitator for the connection and the collective exchange between the sub-projects with the words

> "[...] imagining it as a picture, ... [the coordinating project] would perhaps be at the center surrounded by the sub-projects, each having a connection to [the coordinating project], and through [the coordinating project] we might have a meeting with each other" (Participant, team 2; 2015).

Moreover, the participation at events such as workshops and the advisory board meeting organized through the coordinating sub-project was perceived as a major enabling factor for E&C between the sub-projects. The coordinating sub-project was seen as an expert on theoretical concepts and therefore considered responsible for identifying the needs of the sub-projects and providing input on different relevant topics. While the project design of the first funding phase was criticized for not having transparently communicated that the sub-projects themselves would be the objects of the research of the coordinating sub-project, additional resources for cooperation in the second funding phase as well as more transparent communication by the coordinating project significantly improved the collaboration between the sub-projects and the coordinating project.

b) E&C Between a Sub-project and the Evaluating Sub-project

Following E&C with the coordinating project, E&C with the evaluating project was also conveyed frequently over the course of the project. It was understood by the participants to be particularly helpful, according to the following reflection:

> "That was a good and regular exchange. We sat down together. [The scientist from the evaluating project] once even joined us in a residential home. That was excellent. Because you got to know each other and she also saw... the setting. I had the feeling she was more able to complete [the protocols] than us. After that, we learned how to do it and we did it as [well]. That is why the exchange with [the evaluating sub-project] was very good." (Participant, team 4; 2018)

While researchers originally considered the tasks to be performed for the evaluating project to be inconvenient or extra work, they eventually found them to be useful for their own project work.

c) E&C Among Sub-projects in the Context of the Young Researchers Network

From the onset of the project, the Young Researchers Network was reported to be an important establishment, enabling exchange among novice researchers. Through workshops and common work on a special issue, the young scientists involved saw the Young Researchers Network on one hand as an organized structure for E&C and on the other hand as a space to express thoughts in a smaller setting. One such researcher posited,

> "I think it is a good structure, ... to try to get all junior researchers of all projects at one table... we all benefit from that" (Participant, team 5; 2020).

DISCUSSION

Given the criticism by funding agencies concerning the effectiveness of long-lasting and resource-consuming transdisciplinary research initiatives (2, 41), this study contributes some vital aspects to a better understanding of the development of cooperative processes and products among scientific teams in a physical-activity-promotion research consortium. Based on Hall et al. (19), we separated the study period into the phases of "collaborative readiness (2015–2016)," "collaborative capacity (2017–2019)," and "collaborative products (2020)." Factors of cooperative readiness were assessed and research and training outcomes as well as perceptions of E&C reported by the participating researchers themselves were analyzed for each project phase. Facilitators of and challenges to effective cooperation during the respective project phases were identified.

With regard to the assessment of researchers' collaborative readiness, all participating PIs reported having had prior experience in cooperative work but not in transdisciplinary cooperation. These results indicate a research orientation inclined toward scientific collaboration among all researchers (19). Moreover, all sub-projects except one were located within one German state and some of them even within the same University department. This local proximity may have fostered collaborative readiness due to the fact that intramural and domestic collaboration (42) as well as frequent face-to-face communication enhance research productivity. In addition, the reported scientific disciplines varied, and further research is needed to assess whether they were different enough to produce innovations and suppress groupthink (43). Our analysis showed that lack of trust, limited resources, lack of a clearly communicated goal of E&C, and the perceived reluctance for E&C among the other sub-projects were challenges in the early project phase, thus confirming previous results from the literature (2, 13, 23, 25).

The following finding resulting from the combined analysis of readiness measures and focus-group interviews merits highlighting: Although all analyzed aspects seemed to speak in favor of collaborative readiness among researchers from an outside-perspective, the researchers themselves reported to perceive little or no E&C among the sub-projects.

Later, during the phase of collaborative capacity, the awareness of E&C grew considerably, and although the co-creation of scientific knowledge had not yet been achieved, common interests and problems were identified. Perceived problems were, besides heavy individual workloads, limited resources, the complex project design, and diverse intervention settings as well as the perceived reluctance for E&C among the other sub-projects. Finally, by the end of the project (phase of collaborative products), the researchers reported increased E&C and perceived a benefit of E&C although they experienced exchange rather than cooperation. Both the PIs and the young researchers experienced the collaboration on joint scientific publications as an occasion for regular exchange and increasing identification of commonalities and a sense of unity.

In sum, our first assumption of increasing E&C over time could be verified by these results. Although the perceptions of E&C increased over time, the specific challenges to E&C identified in 2015/2016 were also reported in 2017/2018 and in 2020, specifically, limited resources, one's own project load, perceived reluctance among other sub-projects, and the diversity of settings. This supports the findings from the literature indicating that the level of collaborative readiness influences the success of the entire project (14, 19).

We found an increasing number of scientific publications and conference presentations over time, a finding that is in line with the literature (9) and confirms our second assumption. The co-production of publications was first reported in 2020. Several degree-qualifying works were supervised by the research consortium, and although mentoring has been reported as a motivating factor for collaboration (44), the researchers did not report having cooperated in the supervision of those theses. These findings confirm the literature suggesting that the number of publications (and research outputs more generally) provides limited information on the actual grade of cooperation (34) and even less on the knowledge integration among researchers (45). In sum, E&C in the research consortium seemed to be perceived as increasingly positive by the researchers toward the end of the project phase. Additionally, increased numbers of collaborative products coincided with perceptions of increased exchange even though the co-production of new integrated knowledge had not yet been achieved.

Concerning our third assumption, we found evidence that the coordinating project was a major cooperation partner and supporting factor for E&C among the sub-projects. Providing expertise on theoretical issues and more importantly organizing events to foster effective E&C among researchers, it was thought to provide essential support. This is confirmed by Cummings and Kiesler (22), who found a negative relationship between multi-university collaboration and project outcomes, which could be explained by insufficient coordination. Our findings further underscore the importance of a coordination unit that ensures structured exchange and organizes events for the enhancement of E&C in complex research initiatives. Also, other groups established by the research consortium (e.g., the Young Researchers Network and the evaluation project) proved to be useful for E&C once their potential benefits were recognized by the research teams.

Despite the inherent advantages of Hall et al.'s (19) model, it neither allowed us to assess the iterative collaborative processes necessary to achieve new stages of collaborative capacity nor to differentiate between different project goals emerging at different points in time. For this purpose, future research might benefit from using the four-phase model of Transdisciplinary Research (46), which includes iterative pathways and accounts for differences in goal setting, team types, and key processes across different project phases. Moreover, the project design of the C4H consortium is highly complex due to the diversity of its intervention settings. To adequately address this, future analyses of research consortia could greatly benefit from multi-team systems research (47). This approach conceptualizes science teams as networks pursuing shared superordinate goals in addition to their own team goals (48) and distinguishes between within- and between-team processes and properties at different levels of analysis (47).

Returning to the criticism by funding agencies concerning consortium-based work, this study indeed found evidence for their long-lasting and resource-consuming nature. However, the findings might provide helpful information for funding agencies and researchers writing grant proposals for cross-disciplinary research initiatives.

The most important study finding is the discrepancy between the assessment of collaborative readiness resulting from the objective analysis and from the focus-group interviews. While local distances and the diversity of disciplines and research orientation are important readiness factors, the perceptions of researchers showed that their needs for consortium-based E&C (e.g., sufficient resources, lower project loads of sub-projects, less complex project design, and clearly communicated goals of increased E&C) were different and remained a topic during the entire project life. Given the long list of threats to and facilitators of collaborative readiness (14, 49), this warrants the question as to which factors should be assessed and evaluated before a project starts.

Further, our results showed that the researchers indeed learned to exchange and collaborate over time. The reported development of increasingly positive attitudes toward E&C and the onset of co-produced products at the final stage suggest that personal, temporal, and financial investments into the research consortium seem to pay off. Particularly, overarching organs such as the coordinating project or the Young Researchers Network proved to play indispensable roles in the promotion of E&C and need to be equipped with sufficient resources. After 5 years of consortium-based work, the researchers seemed to have acquired capabilities for effective and successful cooperation. If long-term research funding was provided, these conditions might be an optimal starting point to achieve knowledge-integration and future health impact over the long run.

Participatory research generally refers to the involvement of non-academic stakeholders, such as community members or partners from civil society and policy, into the research process (50, 51). While this study concentrated on E&C among interdisciplinary researchers, our results mirror existing findings on participatory processes in researcher–stakeholder partnerships (51): Both the capacity of E&C and mutual understanding increased over time, while continuing efforts were needed to establish and maintain effective partnerships and mutual trust between all participating actors. Additionally, our results show that diverse study contexts, varying priorities or conflicting interests among researchers challenged participatory processes. Similar results have been observed by Roura et al. (52) among different academic and non-academic stakeholders. Other factors seem to be more specific to the academic context, such as the pressure to publish study results, the need to apply for new funding sources and frequent staff fluctuation. Also, power dynamics have been identified as an important influence factor in participatory research (52), which might be of particular interest in the highly competitive academic setting in future studies. In sum, and restricted to the academic context, our results suggest that there are both general and academia-specific factors that will influence the success of participatory and co-creative processes within research consortia. They need to be considered from the stage of project design onward—by researchers and funding agencies alike.

There are several limitations of this study. Firstly, our study results do not contribute completely new knowledge to the field of team science and readiness. However, certain findings merit highlighting as we have discussed above. Secondly, the study results are only applicable to the specific context of the C4H consortium. Research initiatives in different contexts might require different evaluation approaches and measures. Also, the sample size was relatively low, and conclusions need to be drawn with caution and complemented by further research. Further, the analysis of the included journal publications was not based on a systematic search on the Web of Science as not all articles could be found there (e.g., German publications not registered in the international databases). Including such an analysis would have made it possible to consider questions of research impact and the number of citations of sub-projects within other sub-projects. Moreover, the analysis of journal article authorship is not an optimal measure of research co-production. Further research should combine qualitative data with additional, potentially more valid and reliable measures of scientific co-production. For instance, a network analysis of co-authored publications could supplement the empirical evidence on communication modes and frequencies. Due to staff fluctuations, we did not differentiate our analysis according to gender although research shows sex-related differences with regard to cooperation strategies (53) and impact of scientific outcomes (27). Lastly, the combination of qualitative and quantitative assessments of outcomes has the advantage of identifying the processes influencing scientific co-produced outputs, but the lack of reproducibility and problems of intrusion cannot be ignored (45).

CONCLUSION

This study analyzed the development of perceptions of E&C and of collaborative products in a consortium for physical activity promotion over an entire project cycle (5 years). The results show that a participatory research approach taking into account the perspectives on and requirements for scientific E&C even right from the stage of the project design might lay the ground for suitable, supporting, and transparent conditions for effective and successful E&C. Moreover, the unique individual and contextual conditions of each research initiative need to be considered, and it might be misleading to suggest one approach to measure collaborative readiness adaptable across contexts. This may help prevent or shorten long-lasting processes during which teams perceive E&C as challenging add-on business due to complex project designs, restricted resources, and unclear goals. To achieve the production of new solutions for pressing societal issues such as physical inactivity, time and personal efforts need to be invested to support researchers in their development of capabilities for E&C. Additionally, adequate financial and long-term funding of researchers including the establishment of a coordinating organ responsible for scanning researchers' needs and providing them with relevant information and E&C supportive skills are indispensable. Although cross-disciplinary research consortia are resource demanding, our results show that investments are important to support researchers during their learning process toward the co-production of new knowledge and societal impact.

DATA AVAILABILITY STATEMENT

To protect the confidentiality of the participants, audio data will not be made available. Other requests to access the data should be directed to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Ethical approval for research within CAPCOM was granted by the Ethical Committee of the Friedrich-Alexander University Erlangen-Nuremberg. The patients/participants provided their written informed consent to participate in this study.

AUTHOR CONTRIBUTIONS

SF collected, analyzed, and interpreted the data and drafted the manuscript. MT participated in the interpretation of the data, in the translation of quotes and interview guides, and helped in the drafting and revision of the manuscript. KA-O, KP, and PG critically reviewed and revised the manuscript. All authors read and approved the final manuscript.

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