

**ADDITIONAL FILE 2**

**Table 2. Full study characteristics of included studies.**

† Denotes where excerpts are taken verbatim from study.

Study	Country of conduct	Title	Multi-centre/ single centre	Sample Size	Field/Topic	Ethnic/Minority populations	Number of patients/community representatives engaged in research	Methods of Engagement <sup>†</sup>			
								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
Pearson, 2014 [33]	USA	Capacity building from the inside out: Development and evaluation of a CITI ethics certification training module for American Indian and Alaska native community researchers	Multi-centre	44	Human subject training module	American Indian and Alaska Native	4	Not reported	Not reported	During our first expert panel review with the AI/AN community members, we reviewed all three modules and community members discussed preference and importance of each module.	Not reported

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											Members prioritized the assessing risk and benefit module as they believed this was where researchers often made the biggest mistakes. Also they stated this was where community researchers

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											are often referred to in reviewing research protocols. The Community Panel provided the first level of review. They made recommendations for changes that would meet the needs of local AI/AN



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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												investigator s and the panel reviewed the core element matrix and then reviewed the module section by section. Changes to the original module were made. In the final, fifth step we sent the final version

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								<i>Develop ment of research question</i>	<i>Selec ting outco me</i>	<i>Other activities</i>	<i>Dissemin ation and Implemen tation of results</i>
											out to all panel members for their review. Only minor editorial comments were suggested.
Mitchell, 2013 [24]	UK	The development and pilot testing of	Multi-centre	37	chronic obstructive	Not reported	24	The pulmonary rehabilit	Not reported	The pulmonary rehabilitation team,	Not reported

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
		the Self-management Programme of Activity, Coping and Education for Chronic Obstructive Pulmonary Disease (SPACE for COPD)			pulmonary disease			ation team, patients, and health care professionals with expertise in particular topics were involved in the initial development of the	patients, and health care professionals with expertise in particular topics were involved in the initial development of the content and this was further refined through collaboration with		

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
								content and this was further refined through collaboration with professionals and patients. Once a draft manual was developed, FGs were conducted to review the manual content and determine preferences for the delivery of such a program based	professional s and patients. Once a draft manual was developed, FGs were conducted to review the manual content and determine preferences for the delivery of such a program based		



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
								conducted to review the manual content and determine preferences for the delivery of such a program based around a manual to			around a manual to support self-management. The FG schedule was structured to ensure new topics could arise; minor revisions were made to it after the first two FGs.	

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								support self-management.						
								The FG schedule was structured to ensure new topics could arise; minor revisions were made to it after the first						

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
								two FGs.			
Halanych, 2012 [36]	USA	Recruitment of a rural, southern, predominantly African-American population into a diabetes self-management trial	Multiple sites	384	diabetes self-management	African-American	Not reported	Prior to developing and submitting the study proposal for funding, study investigators carried out community	Not reported	Study investigators solicited input on study design as well as advice on recruitment approaches	Not reported

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results	
								engage ment				
								activities by partnerin g with an ongoing commun ity				
								coalition establish ed for cancer preventi on improve ment.				

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
								Coalition meetings had consistently included calls for diabetes programs, prompting this proposal, and when the study team received				

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results		
								notice of funding, they collaborated with					
								this coalition to hold a discussion group with community					
								members. With this discussion					

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
								group, study investigators	solicited input on study design as well as advice on recruitment			approaches

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
Bogart, L.M., 2013 [21]	USA	A Randomized Controlled Trial of Students for Nutrition and eXercise: A Community-Based Participatory Research Study	Multiple sites	2997	Nutrition and Exercise	Not reported	Not reported	Not reported	Not reported	Consistent with CBPR principles [18], school district administrators served on the study leadership team and were integral and equal partners in all research phases, including intervention	Consistent with CBPR principles [18], school district administrators served on the study leadership team and were integral and equal partners in all research phases,





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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
									adolescent obesity prevention (e.g., from LAUSD administration, parent groups, Los Angeles County's health department, youth-serving organizations, and research institutions) provided		contributed to community partnership investment and led to ongoing efforts toward wide-scale program dissemination. For example, the use of CBPR during the

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
										critical input and direction in regular in-person meetings.	intervention development and pilot testing phases contributed to the long-term sustainability of some of the environmental aspects of SNaX, through



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												fruits. Furthermore, a Community board advisory member shared with a state-elected official our pilot study finding that key school leaders said that free

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												drinking water could not be made available with the school meal and helped to draft legislation , informed by our formative work. . In addition, the school district is presently

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												committed to wide-scale, ongoing dissemination of the program and is working with the research team to develop a sustainable model to implement SNaX across

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
											the district.
Kaholokula, J.K., 2012 [31]	USA	A Family and Community Focused Lifestyle Program Prevents Weight Regain in Pacific Islanders: A Pilot Randomized	Multiple sites	144	Obesity	Pacific Islanders, such as Native Hawaiians, Samoans, Chuukese, and Filipinos	Not reported	Not reported	Not Reported	Guiding the design of our pilot RCT was a CBPR approach in which the POP's community partners worked side-by-side with the academic partners in designing	"As shared earlier, the community partners identified the research topic and provided input into how the CBPR partnership would



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		Controlled Trial										the PLP O and in determining the study design as described in detail by Nacapoy et al. (2008) and by Mau et al. (2010). "We employed a CBPR approach whereby community members served as	be structured and how the study would be designed and implemented. They also own their own data and determine how the information is disseminated in their respective

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
									co-researchers	communities. "	
									(with co-equal decision making) in all aspects of designing and testing the intervention ; in delivering the intervention s via community-peer educators		

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												within their respective communities; and in having community researchers collect baseline and outcome data based on standardized protocol"
												From Nacapoey "Through a

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											series of meetings facilitated by the Community and Academic Co-Directors, the community-academic partnership negotiated a mutually acceptable research design and protocol that

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												engaged the community partners as well as maintained scientific rigor. The PILI `Ohana Project partners struggled with the scientific perspective and experimental design issues, such as

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												using a randomized controlled trial (RCT) protocol, in which participants are randomly assigned to either the intervention being evaluated or to a control group. From the community perspective,

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											intervention needed to ensure that no participant was denied or delayed in receiving a possibly effective intervention . In balancing these 2 perspectives, the partners agreed upon a RCT design that

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												ensured all participants would receive an active intervention while still being able to scientifically test the efficacy of the weight loss maintenance intervention ....To build the communitie



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												s' capacity to engage in research and deliver community-based interventions, it was collectively decided that all the interventions would be delivered, and all data maintained, by community-peer educators

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											and staff from each of the 5 community sites"
											"In this CBPR partnership, the community partners were completely and equally (e.g., individual budget management) involved

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											in all aspects of the research project, which a paucity of projects is able to do in practice. As shared earlier, the community partners identified the research topic and provided input into

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											how the CBPR partnership would be structured and how the study would be designed and implemented. They also own their own data and determine how the information is disseminate

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
								d in their respective communities. The active involvement of communities for which the research findings are to benefit is vital to developing effective and sustainable community engaged			

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
										interventions to eliminate health disparities."	
Cunningham, S., 2015 [34]	UK	Bronchiolitis of Infancy Discharge Study  (BIDS): a multicentre, parallel-group, double-blind, randomised controlled,	Multiple sites	615	Bronchiolitis	Not reported	Not reported	Not reported	Not reported	In the study set-up stages we engaged with a parent representative to guide protocol development. Unfortunately, that link was lost early in the	Not reported

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
		equivalence trial with economic evaluation										study and we were unable to engage appropriate patient and public involvement , possibly as acute bronchiolitis is a relatively short-duration illness for many and is often not given a labelled

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												diagnosis in primary care. In our prestudy feasibility assessment , we were fortunate to be able to meet the parents of children during an admission to hospital with acute bronchiolitis , to gauge their



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								Development of research question	Selecting outcome	Other activities	Dissemination and implementation of results	
												perspective on our proposed trial at a similar time point as that in which we would be engaging with parents of children enrolled to the study. Parents were more positive than we had expected

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											and the discussions gave valuable guidance for study exclusions, parent information sheets and appropriate use of language when conveying potential risks and benefits of the study.

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
Zgibor, J.C., 2016 [38]	USA	Partnership Building and Implementation of an Integrated Healthy-Aging Program	Multiple sites	462	Health aging	Blacks, other	NR	Not reported	Not reported	Both the AF and CAPH-PRC recruited instructors, integrated the content of the programs, and shared training costs. The CAPH-PRC was responsible for new site and participant	Not reported

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												recruitment and research-related tasks including data collection, data entry, and analysis, and the AF was responsible for facilitating engagement of existing sites and

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											training new instructors.
											A Research Advisory Board was formed consisting of two representatives from the AF and three representatives from CAPH-PRC. Bi-weekly meetings were held

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												with additional contact made as needed in order to address any program challenges. Although the study design and selection of measures was driven by the researchers, the AF had

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												considerable input into training and implementation. The CAPH-PRC provided all recruitment materials, instructor manuals, participant materials, training on human subject research, and a small

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
										stipend for instructors. A representative from the AF also sat on the Data Safety Monitoring Committee for the study.	
Man, M.S., 2015 [25]	UK	Improving recruitment to a study of telehealth management for long-term conditions	Multiple sites	2 trials embedded in study: Healthlines CVD (n	Patient information aids	Not reported	2	Not reported	Not reported	Study does not state how patients were engaged. However	Not reported



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**Table 2. Full study characteristics of included studies.**

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Study	Country of conduct	Title	Multi-centre/ single centre	Sample Size	Field/Topic	Ethnic/Minority populations	Number of patients/ community representatives engaged in research	Methods of Engagement <sup>†</sup>			
								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
		in primary care: two embedded, randomised controlled trials of optimised patient information materials		= 671); Healthlines Depression (n = 1364)							they do state "Judith Hogg and Ailsa Donnelly from PRIMER (the Primary Care Research in Manchester Engagement Resource) who contributed patient and public

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results	
											involvement to the work of the MRC-START Study team" (In acknowledgments)	Developing the recruitment intervention : "In MRC-START, a process involving

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											consumer feedback, expertise in writing for patients and graphic design is used to produce an optimised version of the patient information materials (patient information sheet and covering letter) for

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
										each host trial"	
Bauermeister, J.A., 2015 [30]	USA	Acceptability and Preliminary Efficacy of a Tailored Online HIV/STI Testing Intervention for Young Men who have Sex with Men: The Get	Multiple sites	130	HIV/STI Testing Intervention	The CAB (community advisory board) were also diverse with regards to race/ethnicity (three Whites, two Latinos, and two African American). The YAB:	The community advisory board includes consisted of seven community organization. The youth advisory board consisted of eight members	Not reported	Not reported	"We thank our CAB and YAB for their contributions during the development and implementation of the intervention . "All study procedures were approved	Not reported

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results	
		Connected! Program				four African American, two White, one Middle Eastern, and one Mixed Race (African American/ White).			by Community Advisory Board (CAB) and Youth Advisory Board (YAB).			The CAB met with the Get Connected! research team four times, providing constructive

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								Develop ment of research question	Selec ting outcome	Other activities	Dissemin ation and Implemen tation of results
											feedback on most aspects of the study's progression , including the developme nt of the provider checklist, which was used to evaluate the HIV/STI testing sites, and the online

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											tailored website.
											They were invaluable in helping to assemble critical questions for study participants to ask providers upon getting tested as well as developing the “STI

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results	
												facts” portion of the website.
												The YAB met with the Get Connected! research team six times throughout the study, providing critical feedback at each stage of the



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												project. As members of the study's target population, their insights were crucial to the success of the study. In collaboration with a graphic designer, the YAB members designed

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results					
																the logo and recruitment materials (e.g., palm cards) for Get Connected! They critiqued each iteration of the website design and gave extensive feedback on both the content presented

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
											on each page of the site and the language used in the survey items. YAB members also assisted with study participant recruitment.	
												As the content for the intervention

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results		
													and control conditions (including imagery and messaging) was developed, focus groups consisting of YAB and CAB members evaluated this content for its acceptability and relevance

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results	
								to the target population.				
Huppelshoven, A, G. 2015 [39]	Netherlands	Improving patient-centredness in partnership with female patients: a cluster RCT in fertility care	Multiple sites	730	Patient-centered fertility care	Not reported	Not reported	Not reported	audit and feedback procedure and in the outcome measurements	"The Dutch Patient Association 'Freya' was involved in the design of the intervention . "	Not reported	"This randomized study on the improve



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											audit and feedback procedure and in the outcome measurements. Moreover, patients played an important role in the execution of the intervention, as former patients of the participating clinics (i.e.

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
										both male and female patients) took part in the EOVs as consultants of the team."	
Tully, M., 2015, [26]	USA	Implementation of an Adjunct Strategy to Reduce Blood Pressure in Blacks with Uncontrolled	Multiple sites	83	Hypertension	African-Americans	Not reported	Not reported	Not reported	"The community health worker (CHW) then contacted the patients again	Not reported



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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results		
		Hypertension: a Pilot Project									to field questions about study participation and offer convenient meeting times. She followed up with reminder calls, sent bus tickets and remained available for questions.		"The CHW, a black

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												<p>woman, functioned as a lay leader for the intervention . This was a full time position with fringe benefits. She had no other responsibilities. The individual in this position did not have a college</p>

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												degree but had a long history in primary education before becoming an AHEC certified Community Health Worker. She was also certified through the Living Well with Chronic Diseases

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											program (10). During the intervention, she reinforced individual patient action plans with weekly telephone calls to each participant. She assessed goals, reminded patients about

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												<p>scheduled group sessions, and provided encouragement. She served as a confidant, a source of information, and facilitated communication between patients, social workers, and</p>

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											healthcare providers."
											"A Community Advisory Board was established to inform the recruitment process, to review the study's progress and barriers, and to provide guidance in

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											selecting and developing culturally sensitive educational materials and strategies related to health promotion and hypertension. The Board was comprised of representatives from

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												nonprofit organizations with a stake in Milwaukee's at-risk black community. Membership included one representative from each of the following: the American Heart Association, a



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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												neighborhood Health Alliance, the Wisconsin Primary Health Care Association, and a community representative who is a locally recognized chef and who personally has

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
										hypertension. The Board met a total of 11 times during the course of the study, more frequently in the planning phases and subsequently quarterly."	
Ormerod, A.D., 2015 [40]	UK	Comparison of the two most commonly	Multiple sites	121	Pyoderma gangrenosum	Not reported	Not reported	During the feasibility stage,	During the feasibility	Patients were involved in the design	Not reported

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
		used treatments for pyoderma gangrenosum: results of the STOP GAP randomised controlled trial						priority of the research question, choice of outcome measures, and methods of recruitment were informed by discussions with patients through	stage, priority of the research question, choice of outcome measures, and methods of recruitment were	and conduct of this research. During the feasibility stage, priority of the research question, choice of outcome measures, and methods of recruitment were informed by	

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
								a focus group session and two structured interviews.	informed by discussions with patients through a focus group session with patients through a focus group session and two structured interviews. During the trial, a patient joined the independent trial steering committee. Members of the UK Dermatolog		



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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											participants will be informed of the results through a dedicated website (www.stopgapatrial.co.uk) and will be sent details of the results in a study newsletter suitable for a non-specialist audience

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
Goodacre., 2015 [27]	UK	The PAndemic INfluenza Triage in the Emergency Department (PAINTED) pilot cohort study	Multiple sites	165	Influenza	Not reported	Not reported	Enid Hirst has agreed to be the patient/public representative for the project and has reviewed the proposal. She acted as patient and public represen	Not reported	Enid's role will include the following: 2. reviewing the poster and information leaflet 3. patient/public representation on the Steering Committee 4. lay input into reporting	Enid's role include lay input into reporting and dissemination of findings

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
							tative for our project in the 2009 pandemic and was an independent member of the study Steering Committee. Enid is a founder member		and dissemination of findings	5. liaison between the project and the Sheffield Emergency Care Forum.	Lynn Winspear, Enid Hirst and other members of SECF also



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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
								of the Sheffield Emergency Care Forum. This is a patient and public representative group with a specific interest in emergency care research		provided specific input into the project's lay summary and patient leaflets		

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
								. The Forum has reviewed this proposal and provided feedback. Enid will continue to provide a link between the project and the Forum.				

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>		
								Her role will include the following:					
								1. reviewing the protocol and specifically advising on ethical issues and arrangements					

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results	
								for data protection and confidentiality				
Mohatt, G.V., 2014 [28]	USA	Feasibility of a Community Intervention for the Prevention of Suicide and Alcohol Abuse with Yup'ik Alaska Native Youth: The Elluam	Multiple sites	ET study-61 youth YA study-53 youth	Prevention of Suicide and Alcohol Abuse	Yup'ik ethnicity	Not reported	Not reported	Not reported	Planning, community development work, and development of prevention activity modules that would constitute the future	Not reported	

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
		Tungiinun and Yupiucimta Asvairtuum allerkaa Studies									intervention as implemented was conducted by community members with the assistance of local and university project staff over a one (YA) or two (ET) year time period prior to any module

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											delivery in the intervention activities.
											Community planning groups developed the interventions with representation from youth, parents, community leadership, Elders, and

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												university researchers through a process described in Rasmus et al. (this issue). This work, in the ET community, resulted in the Qungasvik (toolbox; Alakanuk Community Planning Group et al., 2008).

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												<p>Rather than offering a prescriptive manual of specific intervention activities, the Qungasvik was developed as a process manual for intervention . It provides a flexible format, selection from a</p>



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											range of activities at different levels (individual, family, community) , and basic outlines for prevention activities, all situated within a community development framework.

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
Koladouz, F., 2014 [29]	Canada	Impact of the Healthy Foods North nutrition intervention program on Inuit and Inuvialuit food consumption and preparation methods in Canadian Arctic communities	Multiple sites	332	Nutrition	Canadian Indigenous populations	Not reported	Not reported	Not reported	Community participatory research [24] was used to identify the themes of the interventions and have previously been described in detail [13]"	Not reported
										Ref[13]: "On the basis of dietary	

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												intake data (Sharma et al., 2009, 2010a), formative research (Gittelsohn et al., 2010) and using a community participatory process, a novel, integrated, multi-institutional chronic disease

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
										prevention programme called Healthy Foods North (HFN) was developed for Inuit and Inuvialuit in the Canadian Arctic"	
O'Callaghan, P., 2014 [32]	UK	A pilot study of a family focused, psychosocial	Multiple sites	159	Post-traumatic stress symptoms	Not reported	Not reported	Not reported	Not reported	The study protocol was approval by the ethical	Not reported

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
		intervention with war-exposed youth at risk of attack and abduction in north-eastern Democratic Republic of Congo									review board in the lead researcher's university and then by a 'Community Advisory Board', headed by a community pastor with a Masters in trauma interventions with youth victims of community





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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
										social interventions.	
Bowrey, D.J., 2014 [22]	UK	A randomised controlled trial of six weeks of home enteral nutrition versus standard care after oesophagectomy or total gastrectomy for cancer: report on a	Single site	54	Home enteral nutrition after esophagectomy or total gastrectomy for cancer	Not reported	Not reported	Not reported	Not reported	No specific details about how patients were involved in the full text. However, authors state in protocol "A trial management group has been setup	Not reported



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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
		pilot and feasibility study									including the investigators, representatives from the Leicester Clinical Trials Unit, and two former patients (one with their partner). This group will meet every six

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
											months for the duration of the study to review study progress"
Littlewood, E., 2015 [41]	UK	A randomised controlled trial of computerised cognitive behaviour therapy for the treatment of depression in primary care: the Randomise	Multiple sites	691	Depression Treatment	Mixed (white and black African), Mixed (white and black Caribbean), Any other mixed background, Asian or Asian	Not reported	Not reported	Not reported	The REEACT trial received patient and public participation input at the design, conduct, analysis and	Not reported

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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
		d Evaluation of the Effectiveness and Acceptability of Computerised Therapy (REEACT) trial				british-indian, Asian or British-Pakistani, Chinese, Other				interpretation stages. We received input from those with lived experience of depression in the design of all research materials. The REEACT trial received oversight via	

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											committee membership from members with lived experience of common mental health problems and a representative of a user-led self-help organisation. A user-led organisation

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											n (Anxiety UK and Self-Help Services via its Chief Executive) acted as co-applicant and collaborator on the REEACT trial.
McMilan, A., 2015. [42]	UK	A multicentre randomised controlled trial and economic evaluation	Multiple sites	278	Sleep Apnoea	Asian, other	2	Not reported	Not reported	Two patient representatives participated in the PREDICT	Frank Govan- raised awareness of the study to

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
		of continuous positive airway pressure for the treatment of obstructive sleep apnoea syndrome in older people: PREDICT						management; in particular, Mr Frank Govan from Oxford acted as the patient representative. He attended the TSC meetings and his feedback was very helpful in progressing the trial. For example,			the Sleep Apnoea Trust Association, which in turn, publicised the study with their members. Members of the Welsh Sleep Apnoea Society have also supported the PREDICT

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
									he raised awareness of the study to the Sleep Apnoea Trust Association, which in turn, publicised the study with their members. The protocol was discussed with Sleep Apnoea Trust		study by providing publicity for the trial.

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											Association members at their annual meeting in 2012, and we were invited to present the results at their 2014 meeting ( <a href="http://www.sleep-apnoea-trust.org/user/image/sm52.pdf">www.sleep-apnoea-trust.org/user/image/sm52.pdf</a> ). Members of the Welsh Sleep Apnoea







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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												the rigours of participating in research studies with the TMG. These comments have been taken into account in designing subsequent trails. Mr Govern also voted at TSC meetings, and his

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											independent views were sought when discussing topics such as opening new trial sites, through to trial authorship. The patients who participated in PREDICT from the

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results	
												London centre were invited to an annual patient and public involvement event at the Royal Brompton Hospital (once their direct involvement in the trial was over) to provide feedback on their

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											experiences . This feedback was collated and has been used to improve the study facilities at the site, as well as trial logistics, for example increased time for travel between sites.

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
Gaucher, S., 2016, [43]	France	Assessment of a Standardized Pre-Operative Telephone Checklist Designed to Avoid Late Cancellation of Ambulatory Surgery: The AMBUPROG Multicenter Randomize	Multiple sites	4074	Ambulatory Surgery	Not reported	24	Not reported	Not reported	During the development of the intervention a checklist was created. "Given the reported effectiveness of checklists in reducing surgical complications and mortality [12], we developed a	Not reported

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
		d Controlled Trial								standardized pre-operative checklist that could be delivered to each patient via an automated phone system."	
Fraser, R., 2015 [44]	USA	PACES in epilepsy: Results of a self-management randomized	Single site	92	Epilepsy	Black, Latino, Asian, Other (unspecified)	50 surveys (165 returned)+ 2 focus groups of 10 patients + 22 adults	Not reported	Not reported	The survey was then refined by two focus groups of 10 adults with	Not reported



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
		controlled trial					with epilepsy from a local affiliate group				epilepsy, each at the University of Washington-Harborview Medical Center. The survey was then mailed to 250 adults with epilepsy who were being treated at either the UW-Harborview Medical

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											Center or the Swedish Medical Center, and a group of 22 adults with epilepsy in local affiliate support groups. The survey participants in the mailing were screened for marked



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												rate). There was very high response reliability (internal consistency) across all domains in the survey. A comprehensive description of the survey findings is available in Fraser et al., with

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results
											implications for the development of the PACES program"
Gimeno-Santos, E., 2015 [45]	Spain	The PROactive instruments to measure physical activity in patients with chronic obstructive pulmonary disease	Multiple sites	236	COPD	Not reported	Not reported	Not reported	Not reported	Within the framework of the European Union Innovative Medicines Initiative PROactive project (www.proactivecopd.com) our group first	Not reported

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
											conducted qualitative research and drafted a conceptual framework to set out the concept of physical activity from patients' experience and to provide the necessary basis to generate an item pool for two



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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>	
												was also approved by patient advisory boards and the advisory board provided advice to guide the whole process for the item reduction and validation of the tools. Dobbels F, de Jong C, Drost E, et



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								Development of research question	Selection outcome	Other activities	Dissemination and Implementation of results
											al. The PROactive innovative conceptual framework on physical activity. Eur Respir J 2014; 44: 1223–1233.
Kattelmann, K., 2014 [23]	USA	The Effects of Young Adults Eating and Active for Health (YEAH): A Theory-Based Web-	Single site	1639	Nutrition and exercise	African-American, Asian, Native Hawaiian/Pacific Islander, American Indian,	Not reported	Not reported	Not reported	The intervention was developed using the CBPR process of PRECEDE-PROCEED and was	Not reported

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								<i>Development of research question</i>	<i>Selecting outcome</i>	<i>Other activities</i>	<i>Dissemination and Implementation of results</i>
		Delivered Intervention				Hispanic, and other					delivered via the Web and e-mail. Greene GW, White AA, Hoerr SL, et al. Impact of an online healthful eating and physical activity program for college students. Am J Health Promot.

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								Development of research question	Selecting outcome	Other activities	Dissemination and Implementation of results

2012;27:E4  
7-E58.