

REPORT

2018

OVERVIEW OF SYSTEMATIC REVIEWS:

Adapted health information and patient education for persons with immigrant or minority ethnic background

Title	Adapted health information and patient education for persons with immigrant or minority ethnic background: an overview of systematic reviews
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Key messages

Health care services should be equitable for all. Some immigrant and minority ethnic groups struggle to use these services or adhere to self-treatment in an optimal way. Adapted health information and patient education may benefit these groups. This overview of systematic reviews summarises the effect of such adaptations.

We found high quality systematic reviews about diabetes education, asthma education and cancer screening information. These showed that adapted health information and patient education for immigrant and minority ethnic groups could entail a broad range of interventions of varying intensity. In some studies, the participants received a single culturally adapted education session. Other studies followed up the participants many times, giving them extra care and adapted resources over many months and years.

Most studies were with minority ethnic groups in the USA. Although the US health care system is different from the Norwegian, we consider these results relevant to immigrant and minority ethnic groups in Norway experiencing similar barriers and challenges in using the health care services. Based on the summarised evidence, the anticipated effects of adapted interventions compared to usual care are:

- Adapted diabetes education somewhat improves long-term blood sugar levels in patients. The evidence mainly comes from studies with highly intense interventions.
- Adapted asthma education may give some fewer severe asthmatic exacerbations among children, but the effect is unclear among adults. The evidence comes from studies with interventions of relatively low intensity.
- Adapted interventions to promote cancer screening probably increase the number of women attending mammography. The evidence comes from interventions that often involved lay health workers and took place outside the health care sector.

Title:

Adapted health information and patient education for persons with immigrant or minority ethnic background: an overview of systematic reviews

Type of publication:
Overview of systematic reviews

A review of a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise relevant research, and to collect and analyse data from the studies that are included in the review. Statistical methods (meta-analysis) may or may not be used to analyse and summarise the results of the included studies.

Doesn't answer everything:

- Excludes studies that fall outside of the inclusion criteria
- No health economic evaluation
- No recommendations

Publisher:

The Norwegian Institute of Public Health has completed this review based on a request from the Norwegian Centre for Migration and Minority Health (NAKMI)

Updated:

Last search for studies: May 2018.

Internal review:

Signe Flottorp and Atle Fretheim, The Norwegian Institute of Public Health

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Walaa Abuelmagd, University of Oslo
Hanne Sørberg Finbråten, Inland Norway University of Applied Sciences

Executive summary

Background

Health care services should be equitable for all. Some immigrant and minority ethnic groups use health care services to a lesser extent, in a different way or have lower compliance with recommend self-treatment than the general population. Limited access to adapted health information and patient education is one possible reason for these patterns. This report gives an overview of summarized evidence on the effect of adapted health information and patient education for immigrants or minority ethnic groups.

Method

This report is an overview of systematic reviews published in 2012 or later. Inclusion criteria were reviews assessing the effects of any adapted health information or patient education compared to usual care or non-adapted information and education. The reviews could include studies with populations of foreign origin, national minorities/minority ethnic groups or indigenous people believed to have specific health problems, limited health literacy skills, language problems or challenges related to optimal use of health care services in their resident country. We searched four electronic literature databases in May 2018. Two researchers independently screened 2689 titles and abstracts, and made final decisions on inclusion based on 55 full text assessments. Eligible systematic reviews were quality assessed and we only report results from high quality reviews. We used the review authors' analyses and, if available, their assessment of confidence in the evidence of effect for each outcome using the GRADE methodology. Using GRADE, we express our confidence that the estimated effect is close to the anticipated effect of the intervention (the "true effect") as high, moderate, low or very low for each outcome.

Results

We assessed the methodological quality of 22 systematic reviews that considered the effect of adapted health information or patient education in relation to six health issues or diagnoses: Adapted diabetes education (9 reviews); Adapted asthma education (3 reviews); Adapted information promoting cancer screening (5 reviews); Adapted information/education for diabetes prevention (1 review); Adapted information promoting smoking cessation (1 review); Other types of adapted health information/patient education (3 reviews). Systematic reviews with similar research questions will include the same studies and have overlapping data and findings. We therefore selected one systematic review presenting the evidence best within each health issues or diagnoses.

Thirteen systematic reviews were considered to be of high methodological quality, but these only investigated the three first categories: adapted diabetes education, asthma education and information promoting cancer screening. We present results from one high quality systematic review for each of these categories. Systematic reviews concerning the three next categories were of moderate methodological quality. Notably, these review authors presented results only using statistical significance and direction of effect, without information on the effect size and its uncertainty. For these topics, we present available studies, but no results. The majority of the studies in these systematic reviews were conducted in the USA, most commonly with African Americans and people of Latin American origin. Other studies were from several European countries, Canada, Australia, New Zealand and a few Asian countries, and included a variety of immigrant and minority ethnic groups. All study populations were adults, apart from studies on asthma education, which involved both children and adult patients.

The studies on adapted diabetes education typically entailed a much more intense follow up of the intervention groups than the control groups. Often the participants received several individual or group education sessions, counselling, and telephone follow-up over an average period of 8 months. It is unclear if all the programs had culturally adapted content, and which used another language suiting the participants or bilingual health care personnel. Most studies compared adapted diabetes education to standard diabetes care. The patients had relatively poor blood glucose control before the study. In total, 6536 participants (28 studies) contributed to findings. Based on the summarised evidence, adapted diabetes education somewhat improves long-term blood sugar levels in patients compared to usual care after six months (HbA1c values 0.5% lower, 95% confidence interval (CI) 0.7% to 0.4%, high confidence in the estimated effect); with still somewhat lower HbA1c values after 12 months and possibly after 24 months. It can possibly give patients more knowledge about diabetes and nutrition and higher self-efficacy scores (low confidence in the estimated effect).

The studies on adapted asthma education had interventions of low intensity, varying from only one education session up to three sessions. The interventions seemed to have involved culturally adapted content, but few details were presented. About half of the interventions provided written material using a language suiting the participants or used bilingual health care personnel. The control groups received either conventional asthma education or standard care. In total, 837 participants (7 studies) contributed to the findings. Based on the summarised evidence, adapted asthma education may give some fewer severe asthmatic exacerbations compared to usual care among children (Relative risk 0.48, 95% CI 0.24 to 0.95, low confidence in the estimated effect). The data is too limited to consider likely effect for adults with asthma.

Of the four systematic reviews of high methodological quality, we present results from one concerning adapted information about mammography for Hispanic women in the USA. The interventions in these studies generally used lay health workers from the same culture to deliver educational sessions, outreach to women on arenas outside the health sector and mobile screening units offering free screening. The control group received no specific interventions. In total, 2343 participants (5 studies) contributed to the findings. Based on the summarised evidence, adapted interventions to promote cancer screening probably increase the number of women attending mammography af-

ter 6-12 months (Odds ratio 1.67, 95% CI 1.24 to 2.26, moderate confidence in the estimated effect). The three other high quality systematic reviews on this topic concerned adapted information on screening for different types of cancers (cervix, colorectal and prostate), interventions targeting other minority ethnic groups (minorities in the USA) and men. The results indicate from little or no difference to a moderately higher adherence to cancer screening programs, when participants receive adapted information.

The systematic reviews on adapted health information for diabetes prevention, smoking cessation and some other health concerns were all of moderate methodological quality. The reviews did not summarise the pooled effects of these interventions. We still chose to give a brief presentation of the reviews in this report to indicate the considerable number of primary studies available on these topics.

Discussion

Most of the studies in the included reviews concerned African American and people of Latin American origin with low socioeconomic status in the USA. A high proportion of these participants have likely no or poor health insurance. There are fewer studies of adapted interventions for other immigrant and minority ethnic groups and from countries with other health care systems. However, the defined study population in this overview relates to patient groups “under-using” or having specific challenges regarding use of the health care services. We therefore consider the results relevant to immigrant and minority ethnic groups experiencing similar barriers and challenges in using the health care services, but not all immigrants and minority ethnic groups per se.

The terms “adapted health information” and “adapted patient education” comprises a wide range of activities and intensities of interventions. The interventions in these reviews were generally complex, often including a substantial increase in the number of interactions the participants had with the health care services. Common activities were individual or group education sessions, extra counselling, or telephone support, and not only linguistic or direct cultural adaptations.

The included systematic reviews gave limited descriptions of what the cultural adaptations entailed. In particular, the reviews give little insights into the use of learning aids (for instance pictures, movies, and comics) and if the interventions adapted the messages to deeper cultural characteristics of the target population. Many studies had intervention components that are not strictly adhering to cultural needs, but rather financial, structural, social or educational barriers to accessing appropriate health care. Examples are providing free access to mammography services or giving health information in people’s homes or on arenas outside the health care sector. Since many of the interventions were intense with several different components given together, we do not know which elements are most influential or necessary for achieving the effects.

Conclusion

It seems that intense interventions with adapted health information and patient education can improve health measures somewhat among vulnerable immigrant or minority ethnic groups.

Hovedbudskap (norsk)

Helsetjenesten bør være likeverdig for alle. Noen innvandrere og minoritetsetniske grupper strever med å bruke disse tjenestene eller følge opp egenbehandling på en optimal måte. Tilpasset helseinformasjon og pasientopplæring kan være ønskelig for disse gruppene. Denne oversikten over systematiske oversikter oppsummerer effekten av slike tilpasninger.

Vi fant systematiske oversikter av høy metodisk kvalitet om tilpasset diabetesopplæring, astmaopplæring og informasjon om kreft-screening. Disse oversiktene viste at tilpasset helseinformasjon og pasientopplæring for innvandrere og minoritetsetniske grupper kan innebære et spekter av tiltak med ulik intensitet. I noen studier fikk deltakerne opplæring med kulturelt tilpasset innhold bare én gang. Andre studier fulgte opp deltakerne mange ganger med ekstra omsorg og tilpassede ressurser over mange måneder og år.

Flest studier inkluderte minoritetsetniske grupper i USA. Selv om helsesystemet i USA er annerledes enn det norske, vurderte vi at resultatene er relevante for innvandrere og minoritetsetniske grupper i Norge som opplever liknende barrierer eller utfordringer knyttet til å bruke helsetjenestene. Basert på den oppsumerte kunnskapen er forventede effekter av tilpassede tiltak sammenliknet med vanlig omsorg følgende:

- Tilpasset diabetesopplæring forbedrer langtidsblodsukkeret noe blant pasienter. Kunnskapen kommer hovedsakelig fra studier med svært intense tiltak.
- Tilpasset astmaopplæring gir muligens noe færre astmaanfall hos barn, men effekten er uklar blant voksne. Kunnskapen kommer fra studier med tiltak av relativt lav intensitet.
- Tilpasset informasjon om kreft-screening øker muligens antall kvinner som møter til mammografi. Kunnskapen kommer fra studier som ofte involverte legfolk for å utføre opplæringen og oppsøkende tjenester utenfor helsesektoren.

Tittel:

Tilpasset helseinformasjon og pasientopplæring for personer med innvandrere eller minoritetsetnisk bakgrunn: en oversikt over systematiske oversikter

Publikasjonstype:

Oversikt over systematiske oversikter

En systematisk oversikt er resultatet av å

- innhente
- kritisk vurdere og
- sammenfatte

relevante forskningsresultater ved hjelp av forhåndsdefinerte og eksplisitte metoder.

Svarer ikke på alt:

- Ingen studier utenfor de eksplisitte inklusjonskriteriene
- Ingen helseøkonomisk evaluering
- Ingen anbefalinger

Hvem står bak denne publikasjonen?

Folkehelseinstituttet har gjennomført oppdraget etter forespørsel fra Nasjonalt kompetansesenter for migrasjons- og minoritetshelse (NAKMI)

Når ble litteratursøket utført?

Søk etter studier ble avsluttet mai 2018.

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Sammendrag (norsk)

Innledning

Helsetjenesten bør være likeverdig for alle. Enkelte innvandrere- og minoritetsetniske grupper bruker helsetjenestene i mindre grad, på en annen måte eller etterlever i mindre grad anbefalt egenbehandling enn resten av befolkningen. Begrenset tilgang til tilpasset helseinformasjon og pasientopplæring kan være én mulig årsak til disse mønstrene. Denne rapporten gir en oversikt over oppsummert kunnskap om effekten av tilpasset helseinformasjon og pasientopplæring for innvandrere eller personer med minoritetsetnisk bakgrunn.

Metode

Rapporten er en oversikt over systematiske oversikter publisert i 2012 eller senere. Inkluderingskriterier var oversikter som vurderte effekten av tilpasset helseinformasjon eller pasientopplæring sammenliknet med enten vanlig behandling eller ikke-tilpasset informasjon og opplæring. Oversiktene kunne omfatte studier av populasjoner av utenlandsk opprinnelse, nasjonale minoriteter eller urfolk som antas å ha spesifikke helseutfordringer, lav helsekompetanse (health literacy), språkproblemer eller utfordringer knyttet til optimal bruk av helsetjenestene i landet de bor i. Vi søkte fire elektroniske litteraturlister i mai 2018. To personer gikk uavhengig av hverandre gjennom 2689 titler og sammendrag, og tok endelige beslutninger om inkludering basert på 55 fulltekstvurderinger. Relevante systematiske oversikter ble kvalitetsvurdert. Kun resultater fra oversikter av høy kvalitet er rapportert. Vi brukte forfatterens analyser og, hvis tilgjengelig, deres vurdering av tillit dokumentasjonen av effekt for hvert utfall ved hjelp av GRADE-tilnærmingen. I GRADE-tilnærmingen uttrykker vi vår tiltro til at estimert effekt ligger nær den antatte effekten av intervensjonen (den "sanne effekten") som høy, middels, lav eller svært lav for hvert utfall.

Resultat

Vi vurderte den metodiske kvaliteten til 22 systematiske oversikter som omhandlet effekten av tilpasset helseinformasjon eller pasientopplæring for seks helsespørsmål eller diagnoser: Tilpasset diabetesopplæring (9 oversikter); Tilpasset astmaopplæring (3 oversikter); Tilpasset informasjon om kreft screening (5 oversikter); Tilpasset informasjon/opplæring for forebygging av diabetes (1 oversikt); Tilpasset informasjon om røykeslutt (1 oversikt); Andre typer tilpasset helseinformasjon/pasientopplæring (3 oversikter). Systematiske oversikter med lignende forskningsspørsmål vil omfatte de samme studiene og ha overlappende data og funn. Vi valgte derfor én systematisk oversikt som beskriver kunnskapen best for hvert helsespørsmål eller diagnose.

Tretten systematiske oversikter ble vurdert til å være av høy metodisk kvalitet, men disse undersøkte bare de tre første kategoriene: tilpasset diabetesopplæring, astmaopplæring og informasjon om kreft-screening. Vi presenterer resultater fra én systematisk oversikt av høy kvalitet innenfor hver av disse kategoriene. Systematiske oversikter som handlet om de tre neste kategoriene var av moderat metodisk kvalitet. Disse oversiktsfatterne presenterte resultater bare ved hjelp av statistisk signifikans og retning for effekten, uten informasjon om effektstørrelse og usikkerhet. For disse kategoriene presenterer vi tilgjengelige studier, men ingen resultater. Flertallet av studiene i disse systematiske oversiktene ble gjennomført i USA, oftest med afroamerikanere og grupper av latinamerikansk opprinnelse. Andre studier var fra flere europeiske land, Canada, Australia, New Zealand og noen få asiatiske land, og inkluderte en rekke ulike innvandrers- og minoritetsetniske grupper. Alle studiepopulasjonene var voksne, bortsett fra studier om astmaopplæring, som involverte både barn og voksne pasienter.

Studiene om tilpasset diabetesopplæring innebar vanligvis en mye mer intens oppfølging av intervensjonsgruppene enn kontrollgruppene. Ofte mottok deltakerne opplæring flere ganger individuelt eller i gruppe, samt rådgivning og telefonoppfølging over gjennomsnittlig en 8-måneders periode. Det er uklart om alle tiltakene hadde kulturelt tilpasset innhold, og hvilke som brukte et annet språk tilpasset deltakernes behov eller tospråklig helsepersonell. De fleste studiene sammenlignet tilpasset diabetesopplæring med standard diabetesomsorg. Pasientene hadde relativt dårlig blodsukkerkontroll før studien. Totalt bidro 6536 deltakere (28 studier) til funnene. Basert på den oppsummerte kunnskapen gir tilpasset diabetesopplæring noe lavere langtidsblodsukker blant pasienter sammenliknet med standard diabetesomsorg etter seks måneder (HbA1c verdier 0,5 % lavere, 95 % konfidensintervall (KI) 0,7 % til 0,4 %, høy tiltro til estimert effekt); fortsatt noe lavere HbA1c verdier etter 12 måneder og muligens også etter 24 måneder. Det kan muligens gi mer kunnskap om diabetes og kosthold og høyere skår på opplevd egenmestring enn vanlig omsorg (lav tiltro til estimert effekt).

Studiene om tilpasset astmaopplæring hadde intervensjoner av lav intensitet, som varierte fra én gang med opplæring opp til tre ganger. Intervensjonene ser ut til å ha hatt kulturelt tilpasset innhold, men få detaljer ble presentert. Omtrent halvparten av intervensjonene sørget for skriftlig materiale med et språk som passet for deltakerne eller tospråklig helsepersonell. Kontrollgruppene mottok enten konvensjonell opplæring eller standardomsorg. Totalt bidro 837 deltakere (7 studier) til funnene. Basert på den oppsummerte kunnskapen gir tilpasset astmaopplæring noe færre alvorlige astmaanfall hos barn (Relativ risiko 0,48, 95 % KI 0,24 til 0,95, lav tiltro til estimert effekt). Dataene er for begrenset til å vurdere sannsynlig effekt blant voksne med astma.

Av de fire oversiktene om kreft-screening med høy metodisk kvalitet presenterer vi resultater fra én som omhandlet tilpasset informasjon om mammografi for latinamerikanske kvinner i USA. Intervensjonene i disse studiene hadde generelt brukt lekfolk fra samme kultur til å gi opplæring, oppsøkende virksomhet på arenaer utenfor helsesektoren og mobile enheter som ga gratis screening. Kontrollgruppen mottok ingen spesifikke tiltak. Totalt bidro 2343 deltakere (5 studier) til funnene. Basert på den oppsummerte kunnskapen øker trolig tilpasset informasjon antall kvinner som møter til mammografiundersøkelse etter 6-12 måneder (Odds ratio 1,67, 95% KI 1,24 til 2,26, middels tiltro til estimert effekt). De tre andre systematiske oversiktene av høy kvalitet på

dette temaet omhandlet tilpasset informasjon om screening for andre kreftformer (livmorhals, tykktarm og prostata), intervensjoner rettet mot andre minoritetsetniske grupper (minoriteter i USA) og for menn. Resultatene viser fra liten til ingen forskjell til moderat høyere oppmøte til kreft-screening når deltakerne får tilpasset informasjon.

De systematiske oversiktene om tilpasset helseinformasjon for diabetesforebygging, røykeslutt og noen andre helsespørsmål var alle av moderat metodisk kvalitet. Oversiktene oppsummerte ikke de samlede effektene av disse intervensjonene. Vi valgte likevel å gi en kort presentasjon av oversiktene i denne rapporten for å indikere det betydelige antallet primærstudier som er tilgjengelige for disse temaene.

Diskusjon

De fleste av disse studiene innbefattet afroamerikanere og grupper av latinamerikansk opprinnelse med lav sosioøkonomisk status i USA. En høy andel av disse studiedeltakerne har trolig ingen eller utilstrekkelig helseforsikring. Det er færre studier om tilpassede intervensjoner for andre innvandrere- eller minoritetsetniske grupper og fra land med andre helsesystemer. Den definerte studiepopulasjonen i denne oversikten er imidlertid pasientgrupper som "under-bruker" eller har spesifikke utfordringer knyttet til bruk av helsetjenester. Vi anser derfor resultatene som relevante for innvandrere- og minoritetsetniske grupper som opplever lignende barrierer og utfordringer knyttet til å bruke helsetjenestene, men ikke alle innvandrere og minoritetsetniske grupper per se.

Uttrykkene "tilpasset helseinformasjon" og "tilpasset opplæring" omfatter et bredt spekter av aktiviteter og intervensjoner av varierende intensitet. Intervensjonene i disse oversiktene var generelt komplekse, ofte med en betydelig økning i antall interaksjoner deltakerne hadde med helsetjenesten. Vanlige aktiviteter var undervisning individuelt eller i gruppe, ekstra rådgivning eller telefonstøtte, og ikke bare språklige eller direkte kulturelle tilpasninger.

De inkluderte systematiske oversiktene ga begrensede beskrivelser av hva de tilpassede tiltakene innebar. Spesielt gir oversiktene lite innsikt i bruken av læringshjelpemidler (for eksempel bilder, filmer og tegneserier), og om tiltakene innebar at budskapene ble tilpasset til dypere kulturelle faktorer for målpopulasjonen. Mange studier hadde intervensjonskomponenter som strengt tatt ikke relaterer seg til kulturelle behov, men snarere økonomiske, strukturelle, sosiale eller utdanningsrelaterte barrierer for å oppnå tjenlige tjenester. Eksempler er gratis tilgang til mammografi eller å tilby helseinformasjonen i folks hjem eller på arenaer utenfor helsesektoren. Siden mange av intervensjonene var intense med mange ulike komponenter gitt samlet, vet vi ikke hvilke elementer som er mest betydningsfulle eller nødvendige for å oppnå effektene.

Konklusjon

Det ser ut til at intense intervensjoner med tilpasset helseinformasjon og pasientopplæring kan forbedre helseutfall i noen grad blant utsatte innvandrere eller minoritetsetniske grupper.

Preface

This report has been prepared following a proposal from the former Norwegian Centre for Migration and Minority Health (NAKMI) on a systematic overview of effects of adapted health information and patient education for persons with immigrant or minority ethnic backgrounds.

The project team consisted of:

- Annhild Mosdøl, Senior researcher, Norwegian Institute of Public Health
- Gunn E. Vist, Senior researcher, Norwegian Institute of Public Health
- Gyri Hval Straumann, Research librarian, Norwegian Institute of Public Health
- Ragnhild Storstein Spilker, Senior advisor, Unit for Migration and Health, Norwegian Institute of Public Health
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We thank Signe Flottorp and Atle Fretheim for being internal reviewers, and Walaa Abuelmagd and Hanne Sjøberg Finbråten for being external reviewer for this report. Inger Dagsvold and Walaa Abuelmagd were external reviewers for the research protocol.

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Background

Equitable health care services for all population groups

The Norwegian population is generally in good health, but most measures of health and disease vary with socioeconomic factors such as income, education and occupation (1). The overall prevalence of health problems is somewhat lower among immigrants compared to the general population, but disease patterns vary significantly between immigrant groups (1, 2). Obesity, diabetes, and some cardiovascular diseases are, for instance, more prevalent among persons of South-East Asian origin (1, 3, 4), while the risk of many types of cancers are lower (5). Self-rated health is somewhat lower and mental health problems higher among immigrants (2). Particularly refugees have a higher prevalence of mental illness due to trauma and a vulnerable life situation (6-8). Genetic variations can only partially explain such differences in disease patterns between ethnic groups (9). Differences in cultural factors (e.g. practices and customs) may influence health status, but social, economic and structural determinants of health appear to be associated with health inequities within and between ethnic groups as well (10-12).

It is challenging to provide equitable and appropriate health care services for all population groups. A thorough literature review from the USA reveals that patients with immigrant or minority ethnic¹ backgrounds do not have equal access to health care compared to the majority (“White”) ethnic group, even when adjusting for socio-demographic differences such as education and income (13). Norwegian health care services are generally available to all, but data indicate that some immigrant groups use these to a lesser extent or in a different way than the majority population (2, 14-17). Immigrants may use fewer preventive services, consult the health services at a later stage of disease development, and come later into treatment with a risk of poorer prognosis.

One explanation for these findings is that language barriers (18-20) and limited availability of adapted health information and patient education hamper appropriate user behaviour and access to care (21, 22). Immigrants can have limited knowledge about how

¹ We use the term “minority ethnic” rather than “ethnic minority” in this report. The term “minority ethnic” has been suggested to acknowledge that ethnicity is a characteristic of all individuals and groups, majorities and minorities alike. The term “ethnic minority” may suggest that the minority arose from its “possession” of ethnicity itself (<https://www.universities-scotland.ac.uk/raceequalitytoolkit/terminology.htm>).

the health care services are organised and their rights and duties as patients (23). Health professionals have generally little knowledge of what different population groups know and do not know about health and illnesses, and how they can adapt and organize health information and patient education to immigrant groups (24, 25). Studies find that health professionals may feel bewildered and hesitant in dealing with immigrant patients (13, 26, 27). Possible barriers from their side are stereotypical perceptions, a lack of confidence and knowledge, and fear of acting inappropriately (28).

The health care services, like all other public services, have a responsibility to facilitate good communication and adapted information. In Norway, the Act relating to Patients' Rights² states: "*Information shall be adapted to the qualifications of the individual recipient, such as age, maturity, experience and cultural and linguistic background. The information shall be provided in a considerate manner. As far as possible, health personnel shall ensure that the patient has understood the contents and significance of the information.*" (29). Patient education is an important management component in treatment guidelines for many diseases; particularly chronic diseases where correct handling of medication, preventive life-style changes and other self-care practises are vital components to prevent further disease progress. Internationally, the Ottawa Charter from 1986 states that health promotion is a process that enables people to improve and maintain their health, and providing equal opportunities and resources to develop personal skills through information, health education and knowledge of mastering techniques are important pillars (30).

When people's starting point is different, a goal of equal opportunities requires differentiated services to suit dissimilar needs. An intensified focus on adapted strategies to inform and educate immigrant or minority ethnic patients is therefore timely.

Health literacy as a determinant

Obtaining and understanding health information is essential to make informed health decisions, and to prevent or manage disease. Such abilities are influenced by a person's health literacy level (31, 32). Early definitions of health literacy considered adequate literacy and numeracy skills and familiarity with medical terminology and jargon as crucial components (33). These basic competencies are referred to by Nutbeam as functional or fundamental health literacy (31). Modern health care also have shared decision-making as an explicit goal, where the patient and health professionals make decisions together related to treatment options (29). This requires ability to participate in dialogues and knowledge about health issues and own rights (34), defined by Nutbeam as interactive health literacy (31). Relevant competencies also includes critical thinking and the ability to appraise different health information sources, such as advice from friends and family, through the media or from health care personnel (35); Nutbeam's

² LOV-1999-07-02-63. Lov om pasientrettigheter (pasientrettighetsloven).

third level critical health literacy. Knowledge about how the health services are organized and how to navigate in this system is also essential to get optimal treatment and employ good self-care (34, 36). Sørensen and colleagues, who regard health literacy as a multidimensional concept, have developed a more comprehensive model of health literacy with the following definition:

“Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.” (33)

Literature reviews on the association between health literacy and relevant health outcomes show that individuals with low health literacy levels tend to have poorer health, use preventive health care services less (for instance vaccination), use drugs incorrectly more often, and use different health care services inappropriately (37, 38). Based on studies from several countries, low health literacy appear to be relatively common in the general population (38, 39). Immigrants tend to be among the population groups with low health literacy scores (39-41). Limited health literacy skills have been indicated as a possible explanatory factor for refraining from seeking appropriate health care among refugees (42). However, it is important to acknowledge that there will be variations in health literacy levels both within and between groups.

Adapted health information and patient education

In this report, we summarize the effect of adapted patient education and health information provided as part of health care services.

The term *health information* is used in this report as advice and guidance provided by health care professionals and others promoting good health, preventing illness or ensuring proper follow-up of drug use and self-care. *Education* can be understood as teaching with the intention to induce learning by promoting knowledge, skills and attitudes. Health education can address a health issue or a diagnosis, medical treatments or recommended self-care behaviours. In this report, we include information or education given directly to an individual, as well as given in a group setting. However, public health interventions, such as campaigns, or system-based interventions, fall outside of this description. Questions about the effect of targeted mass media campaigns and system-level health care interventions are explored in two other systematic reviews from the Norwegian Institute of Public Health (43, 44).

Adapted information and education may have many forms and may include:

- Linguistic adaptation so that the information meets the target group at the right functional level, including using the patients' preferred language/native language.
- Adapted to cultural or religious beliefs and values, life circumstances and history.
- Adapted didactic method (e.g. theoretical approaches, different degree of participation, individual or group-based teaching).
- Adapted format of information and training material (e.g. graphics)

- Adapted type of communication (e.g. text, audio or image).
- Adapted amount and intensity (e.g. how often and how much information is given).

Within the theoretical field of health communication, it is common to distinguish between targeted communication and tailored communication. Kreuter and Wray (45) describes *targeted health communication* as communication "intended to reach some population subgroup based on characteristics presumed to be shared by the group's members". A targeted approach coincides with the term audience segmentation in social marketing theory, that is, the identification of meaningful differences among population groups that affect their responses to the promoted action. This approach is only relevant if the targeted population is sufficiently homogeneous (45, 46). A targeted approach should also carefully consider ethical aspects to avoid stereotyping and stigmatising. *Tailored health communication*, on the other hand, is adapted to the specific characteristics of an individual based on individual level factors related to the health or behavioural outcome of interest (45). Another concept, *culturally adapted interventions*, involve, according to Bernal and colleagues (47), changes that "consider language, culture, and context in such a way that it is compatible with the client's cultural patterns, meanings, and values". Cultural adaptation strategies have been categorised by Resnicow and colleagues (48) into surface adjustments and deep structural-level adjustments. *Surface-level adjustments* involve changing factors such as language, graphics, food and clothing to match the target audience. *Deep structural-level adjustments* are changes that reflect the cultural, social, historical, environmental, and psychological forces behind behaviours in the target population. We expected that relevant interventions could relate to one concept or several of concepts, but that it could be difficult to differentiate between different types of adapted interventions.

Definition of the study population

In this report, we include research on adapted interventions for both immigrants and minority ethnic groups. Although these groups may have different needs, all such studies may provide relevant information on the impact of adapted interventions per se.

The terms immigrants and minority ethnic groups are defined differently in different countries and contexts. Statistics Norway identifies immigrants as follows: "Persons born abroad by two foreign-born parents. Immigrants have at one point immigrated to Norway." (49) This definition is wide and narrow at the same time. It is wide because it includes any nationality and any length of time as residents in the country. It is also narrow, as it does not include children born in Norway of two foreign-born parents.

There is no international consensus on how ethnicity is defined, but the researcher Raj Bhopal has summarized important elements found in different definitions:

"The concept of ethnicity implies, according to most accounts, one or more of the following: shared origins or social background; shared culture and traditions which are distinctive, maintained between generations, and lead to a sense of identity and groupness; a common language or religious tradition" (9).

Bhopal points out that these definitions use social and cultural factors instead of biological (physical appearances or genetic differences) to define population groups. Minority

ethnic groups are sometimes divided into indigenous peoples (groups associated with an area from before current state borders were established) (50), national minorities (groups with long-term ties to the country)(51), and immigrants. In Norway, indigenous peoples and national minorities are recognized as own cultural groups (52, 53), but affiliation to these groups are not registered.

Since we did not want to limit the number of studies unnecessarily, no specific definitions of immigrants and minority ethnic groups was used. The study population for this report was defined pragmatically: Groups of people of foreign origin, national minorities/minority ethnic groups or indigenous people who in the identified studies are believed to have specific health problems, limited health literacy skills, language problems or challenges related to optimal use of health care services in their resident country. This definition also include children born in a country of two foreign-born parents.

Mandate and aim

The former Norwegian Centre for Migration and Minority Health, now Unit for Migration and Health, Norwegian Institute of Public Health, commissioned this report. They plan to develop a guide for health care professionals and others who work with immigrants on how to provide appropriate health information and patient education to immigrant groups. This report will inform the development of that guide.

Phase one of the project was a systematic literature search to identify the scope of published systematic reviews and primary studies on adapted health information and patient education for immigrants and/or minority ethnic groups. The systematic literature search, published as a memo in April 2017 (54), identified 96 potentially relevant literature reviews within a broader topic area.

This report is phase two of the project. The aim was to prepare an overview of high quality systematic reviews published in 2012 or later on the effect of adapted health information and patient education for immigrants or persons with minority ethnic backgrounds.

Methods

The methods in this report follows the procedures for overviews of systematic reviews given in the handbook used at the Division for Health Services, Norwegian Institute of Public Health (55). As this project is part two of a larger project, the methods builds on the previously completed memo (54) .

Inclusion and exclusion criteria

Study design: Systematic reviews published in 2012 or later, judged to be of high methodological quality.

- Population:** Groups of people of foreign origin, national minorities/minority ethnic groups or indigenous people who in the identified studies are believed to have specific health problems, limited health literacy skills, language problems or challenges related to optimal use of health care services in their resident country.
- Intervention:** Any adapted health information or patient education provided as personal follow-up to patients under the organisational structure of the health service.
- Control:** Not adapted health information or patient education. Usual care.
- Outcome:** Relevant outcomes included, but was not limited to:
- Health outcomes
 - Knowledge and understanding
 - Self-efficacy
 - Compliance with recommended treatment
 - Participation in health decisions
 - Use of health services
 - Costs
- Language :** Any language.

We excluded systematic reviews that only included:

- Measures directed at health care professionals (e.g. health care professionals only)
- System-based measures (e.g. mass media campaigns)
- Organizational measures (e.g. different treatment team configurations)

Publications were systematic reviews if they had described or presented 1) a systematic literature search, 2) clear criteria for relevant studies to include, and 3) quality assessment of the included studies (56).

Literature search

The literature search for this report is based on the search performed in 2017 (54) and updated in May 2018. A research librarian (GSH) performed the literature search (Appendix 1) and another librarian peer reviewed the search. We searched in:

- Cochrane Library (CDSR, DARE, HTA)
- MEDLINE
- PsycINFO
- Embase

In addition, we checked against the previously identified systematic reviews (54). Two researchers (AM, GEV) independently assessed the publications according to the inclusion criteria, first from title and abstract, and then relevant populations in full text. In cases of disagreement, we consulted a third person.

Assessment of methodological quality and overlap between reviews

We assessed the quality of included reviews based on a checklist for systematic reviews (55). Pairs of two people (AM, AA, GEV) considered each publication independently of each other based on nine checklist questions and decided on the methodological quality through discussions until consensus (see Appendix 3 for quality assessment of all the reviews).

Further, we sorted the systematic reviews according to themes based on which health issues or diagnoses the intervention addressed. This was done to consider whether the included reviews had overlapping scope and content. Within each of the identified themes, the reviews were sorted according to the date of the literature search. We present results within each theme from the high quality review with the newest literature search. However, if the high quality review with the newest literature search was restricted to specific ethnic groups or countries, we considered another recent high quality review with a wider study population. Appendix 4 contains documentation on themes, overlap and final selection of reviews contributing to the results.

Data extraction and analyses

AM retrieved information from the systematic reviews and GEV checked its accuracy. We only extracted information from the systematic review itself, including any supplementary tables or appendixes. None of the included primary studies was retrieved to provide additional information about interventions or results.

From the systematic reviews providing results in our review, we obtained information about the study populations in the included primary studies, characteristics of the interventions and control groups, duration of interventions and follow-up times, and information about who provided the intervention. In addition, we used the available information to assess the following: the likely intervention “dose” (i.e. the number of times participants in the intervention group were offered an activity, teaching sessions, counselling or similarly); individual or group teaching sessions; linguistic adaptation; content adaptation of the intervention; whether studies approached participants on arenas outside the health sector; and use of lay persons in the intervention.

Presented results are based on outcomes and analyses found in the systematic reviews. The effect estimates were risk ratio (RR), odds ratio (OR), standardised mean difference (SMD) or other relevant measures presented in the included systematic reviews, with 95% confidence intervals (CI) or other relevant measures of dispersion. If results from meta-analyses were presented both using fixed and random models, we reported results from the random effect model.

Judgements about certainty of the evidence

We assessed our confidence in the evidence of effect for each outcomes using the GRADE methodology (the Grading of Recommendations Assessment, Development and Evaluation) (57). If the systematic review authors already had completed a GRADE assessment, we reviewed their grading and judgements. Using GRADE, we describe our trust in the effect estimates as high, moderate, low or very low for each outcome.

Table 1: GRADE Working Group grades of evidence, symbols used and their interpretation to describe our confidence in the pooled estimate of effect.

Category	Symbol	Interpretation
High confidence	⊕⊕⊕⊕	We are very confident that the true effect lies close to that of the estimate of the effect.
Moderate confidence	⊕⊕⊕○	We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low confidence	⊕⊕○○	Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect.
Very low confidence	⊕○○○	We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect.

The grading represents our confidence in the evidence of effect based on the available studies. The GRADE-methodology has five criteria for possible downgrading of the quality of the documentation: study limitations, inconsistency between studies, indirectness of evidence, imprecision and reporting bias. In addition, observational studies can be considered for upgrading by the following three criteria: strong associations,

dose response effects and control for confounding factors. The assessments and the reasons for the judgements are presented in summary of findings tables.

Ethics

Considerations about ethical issues are not part of this assignment. However, we acknowledge that there can be ethical challenges related to giving adapted health information or patient education (e.g. risk of stereotyping and stigmatising) as well as ethical challenges if health information or patient education are not adapted to population groups in need of such measures.

Results

Results of the literature search

The search obtained 2689 references in the selected databases (Figure 1). We excluded 2634 of these based on the title or summary. Fifty-five references were retrieved in full text. Thirty-three of these did not fulfil the inclusion criteria, mainly because they were not systematic reviews or concerned other types of interventions (Appendix 2).

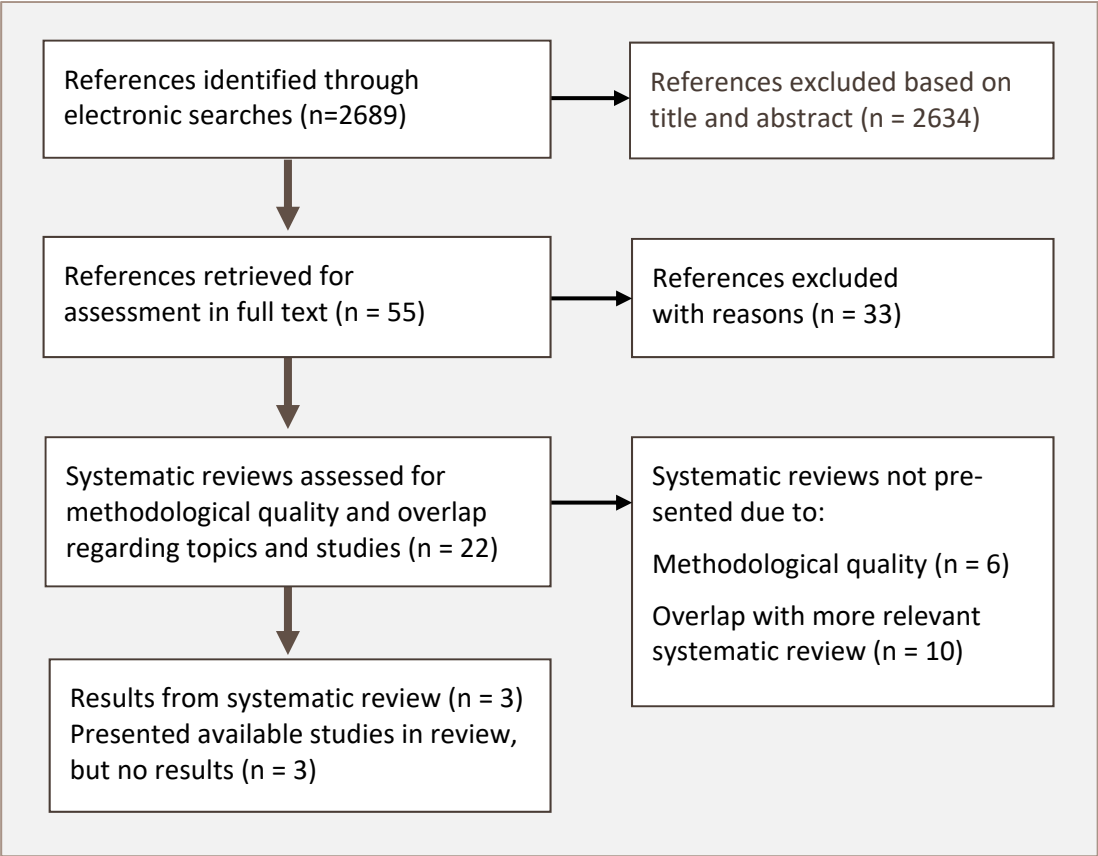


Figure 1: Flow chart for search results and handling of references.

Assessment of quality and overlap between systematic reviews

We assessed the methodological quality of 22 systematic reviews (58-79) (summarised in Appendix 3). These considered the effect of adapted health information or patient education in relation to six health issues or diagnoses:

- Adapted diabetes education (9 reviews)

- Adapted asthma education (3 reviews)
- Adapted information promoting cancer screening (5 reviews)
- Adapted information/education for diabetes prevention (1 review)
- Adapted information promoting smoking cessation (1 review)
- Other types of adapted health information/patient education (3 reviews)

We considered that nine systematic reviews had moderate methodological quality (58, 60, 62, 64, 65, 67, 69, 78, 80), and the other thirteen had high methodological quality.

Systematic reviews that have the same or a similar research question will – if conducted thoroughly and about the same time – include the same studies. For instance, the nine systematic reviews on adapted diabetes education included many of the same primary studies and therefore have overlapping data and findings. Thus, for the three first health issues or diagnoses, we present results from one systematic review of high methodological quality with the newest search date and widest population search. However, among the reviews on adapted information promoting cancer screening, four reviews had high methodological quality. All four were somewhat restricted to specific ethnic groups, concerned different cancer types or only one gender. We decided to present results from the newest systematic review on cancer screening (71), and briefly comment on the results of the remaining three systematic reviews on adapted health information promoting cancer screening.

Within the three last categories, we only found systematic reviews of moderate methodological quality. For these, we present the available primary studies, but do not report findings as these are inappropriately summarised in the reviews. Appendix 4 contains justification for selection of systematic reviews.

Adapted diabetes education

Among the nine systematic reviews on adapted education for diabetes patients, we present results from Attridge and colleagues, published in 2014 (59). The authors searched for interventions considered to be "culturally appropriate (or adapted) health education" for patients with diabetes, defined as:

«Culturally appropriate health education is defined here as education that is tailored to the cultural or religious beliefs and linguistic skills of the community being approached, taking into account likely literacy skills [...]. It could include adapting established health education to innovative delivery methods, such as using community-based health advocates, delivering the information to same-gender groups or adapting dietary advice to fit the likely diet of a particular community.» (p.8 (59))

Eligible studies were randomized, controlled studies of adults (> 16 years) belonging to a minority ethnic community in a middle or high-income country who had confirmed diabetes mellitus type 2. The literature search was from July 2013. The review included 33 studies with in total 7453 participants, but only 28 studies had relevant data for the analyses (6536 participants). Appendix 5 contains a reference list and detailed presentation of study populations, duration of studies, intervention and control treatments, and additional extracted information for each included study in the review.

Most of the studies were conducted in USA (27 studies), and otherwise in the UK, the Netherlands and Canada (Table 2, next page). Almost half of the North American studies targeted African Americans and the remainder mostly Latin American groups. The European studies targeted Asian immigrant groups.

Table 2: Country and study population included in Attridge 2014.

Country	Study population ¹ (number of studies)
USA	African American (10) Latin American origin (12) Both African American and Latin American origin (2) East Asian immigrants (1) Native Americans, American Polynesian (2)
UK	South Asian immigrants (4)
The Netherlands	Southeast Asian origin/immigrants (1)
Canada	Latin American immigrants (1)

¹ Study population as described by review authors.

Attridge and colleagues commented that the participants often had low socioeconomic status and that study authors discussed high prevalence of diabetes, poor dietary habits, insufficient physical activity levels and communication barriers as common challenges to provide good care for these groups. The study populations appear to have had relatively poor blood glucose control. Average values for glycated haemoglobin (HbA1c) – a measure of long-term blood sugar – in the control groups ranged from 7.8% to 12.2% in various studies (see Table 3). In Norway, the treatment target for HbA1c for most patients with type 2 diabetes is around 7% (81).

The interventions varied considerably in the included studies (Appendix 5):

- The studies lasted from 3 to 36 months (last follow up). Median duration was 6 months and the mean 8 months.
- The least intensive intervention was one teaching session only, while most interventions provided regular follow-up regularly over time – the longest two years.
- Eleven studies offered group interventions, 13 studies offered one-on-one education or counselling, and 9 studies offered a combination of both. One intervention had multimedia content only.
- Nurses (in 16 studies) and dieticians (in 12 studies) frequently provided the intervention. Sixteen studies used link workers or community health workers, while four studies used lay workers to deliver the intervention – in addition to health care workers or alone.

About half of the studies based the intervention on previous qualitative work, experience with the study population or involvement of user representatives. Some theoretical models used were empowerment theory, trans-theoretical model for behavioural change, and social-cognitive theory. Attridge and colleagues summarise only sparingly in what way and to what extent these interventions were culturally, linguistically or otherwise adapted. Based on our extracted information, we assume the participants had a different preferred language than the majority population in almost half of the

studies. About one third of the studies approached participants on arenas outside the health sector. We also estimated the number of times participants in the intervention groups were offered an activity (intervention “dose”), e.g. individual or group education sessions, counselling, telephone contact or similarly. In all but two studies, participants in the intervention groups were offered at least 3-4 extra activities compared to the control groups. In about half of the studies, the difference in dose was at least 10 additional activities; in four studies at least 30 additional activities (Appendix 5).

The control groups were given either conventional diabetes education or usual diabetes care. The review authors discussed that usual care may vary widely between countries, but chose to present this as one comparison. Half of the studies offered no intervention apart from usual care for the control group, while several studies offered some minimal “non-culturally adapted” intervention such as leaflets, newsletters or telephone calls to maintain interest in further data collection. Two studies compared the intervention to a non-culturally adapted intervention of similar intensity, i.e. generic diabetes education.

Attridge and colleagues presented effect estimates on three primary and 41 secondary outcomes at 3, 6, 12 and 24 months. We present results for the three primary outcomes (HbA1c, health-related quality of life, and adverse event/outcomes of the intervention), and two secondary outcomes (knowledge and self-efficacy scores) (Table 3). The authors used GRADE to assess their confidence in evidence of effect. We considered their judgements appropriate. Our GRADE assessment is based on the assumption that the effect sizes are relevant for patients from immigrants or minority ethnic groups with poorly controlled diabetes mellitus type 2.

The documentation in Table 3 shows effects of adapted diabetes education for patients belonging to a minority ethnic community compared to usual care or conventional education.

Table 3: Effects of adapted diabetes education compared to usual care.

Outcome, follow-up	Anticipated absolute effects		Relative effect (95% CI)	No. of participants (Studies)	Quality of evidence (GRADE)
	Assumed risk with usual care/conventional education	Risk with adapted diabetes education (95% CI)			
Long term blood sugar level (HbA1c, percent glycated haemoglobin)					
HbA1c, 6 months	Mean in control groups ranged from 7.8% to 12.2%	0.5% lower (0.7% to 0.4%)	-	1972 (14 RCTs)	⊕⊕⊕⊕ HIGH
HbA1c, 12 months	Mean in control groups ranged from 7.6% to 11.6%	0.2% lower (0.3% to 0.04%)	-	1966 (9 RCTs)	⊕⊕⊕⊕ HIGH
HbA1c, 24 months	Mean in control groups ranged from 7.2% to 7.6%	0.3% lower (0.6% to 0.1%)	-	2268 (4 RCTs)	⊕⊕⊕○ MODERATE ¹
Diabetes and nutrition knowledge, Self-efficacy and quality of life (self-reported scores)					
Knowledge, 6 months	Different scales used	SMD 0.50 (95% CI 0.33 to 0.68)	-	994 (9 RCTs)	⊕⊕○○ LOW ²
Self-efficacy, 6 months	Different scales used	SMD 0.49 (95% CI 0.18 to 0.80)	-	1 546 (9 studies)	⊕⊕○○ LOW ²
Health-related quality of life, all follow ups	Review authors report no statistically significant effects based on 3 of 7 studies with this outcome.		-	224 (3 studies)	⊕⊕○○ LOW ²
Adverse event or outcomes of the intervention					
Any adverse events/outcomes	Four studies reported on possible adverse events/outcomes, but did not register any considered relevant.		-	Unclear (4 studies)	-

1. Downgraded by one level because of high heterogeneity, *P* 61%

2. Downgraded by two levels because of inconsistency and risk of performance and detection bias.

CI: Confidence interval; RCT: Randomised, controlled study; SMD: Standardised mean difference.

Based on the summarised evidence, patients receiving adapted diabetes education have:

- somewhat lower HbA1c values after six months
- still somewhat lower HbA1c values after 12 months and possibly also after 24 months.
- possibly more knowledge about diabetes and nutrition.
- possibly higher self-efficacy scores.

Few studies looked for possible adverse events or outcomes of the intervention. These did not register any relevant incidents.

Adapted asthma education

Among the three systematic reviews on adapted asthma education, we present results from McCallum and colleagues, published in 2017 (72). The authors searched for interventions considered to be “culture-oriented asthma programmes”, defined as:

“An education programme is defined as a programme which transfers information about asthma in any form, including but not limited to, adapting the programme to the culture-values, language, and/or using educators who come from the same culture, inclusion of beliefs and practices, culturally appropriate role models, involvement of local community health workers to support clinical teams etc.” (p.6 (72))

Eligible studies were randomized, controlled studies of children or adults from a minority ethnic group according to the country’s own definition who had physician-diagnosed asthma. The literature search was from June 2016. The review included seven studies with total 837 participants. Appendix 6 contains a reference list and detailed presentation of study populations, duration of studies, intervention and control treatments, and additional extracted information for each included study.

Table 4: Country and study population included in McCallum 2017 (72).

Country	Study population ¹ (number of studies)
USA	African American (1) Latin American (1) Both African American and Latin American (1)
Australia	Aboriginals (1)
Canada	Immigrants with first language other than English (1)
India	Indian (1)
UK	Asian descent (1)

1 Study population as described by review authors.

The studies were conducted in USA, Australia, Canada, India and UK (Table 4). The studies targeted both minority ethnic and immigrant groups. It is unclear whether the study from India concerned a minority ethnic group, but it involved adapting a patient education program from English to an Indian language and sub-culture. Two studies included adults only, four studies only children and one study included both older children and adults. The definition of asthma varied between the studies.

The review authors commented that culture-specific programs were defined differently for each study and varied in content:

- The studies lasted from 4 to 12 months (last follow up).
- The interventions varied in intensity from one session (3 studies) up to three sessions delivered over 6 months.
- Six studies gave the participants individual education or counselling (in child studies with family members). One intervention had multimedia content only.

- Different health professionals provided the asthma education in most of the studies. In three studies, these were persons with bilingual skills or from the same cultural group as the study population.

The review authors present few details regarding the theoretical and practical aspects of the cultural adaptations done. Based on our extracted information, we assume participants had a different preferred language than the majority population in four of the seven studies. One study approached the participants outside the health sector and offered home visits and telephone calls. The estimated difference in intervention “dose” between the intervention group and the control group varied from no extra activities in the studies (one study comparing two different cultural formats) up to three extra activities (Appendix 6).

The control groups were either provided with conventional training or standard asthma care. In most studies, this involved giving some resources, such as standard information or leaflets. However, one study compared giving three standard education modules (control group) with giving three education modules adapted to the socioeconomic or cultural context of ethnic minorities (intervention group). One study compared one standard education module with additional three educational sessions led by trained, Indigenous health care workers.

McCallum and colleagues present effects on four primary and seven secondary outcomes after 6 to 24 months. All primary outcomes were related to asthmatic exacerbations and need for treatment. We present findings for these (Table 5), but for any no secondary outcomes, as the amount of data was limited. The review authors had not extracted data about adverse outcomes of the intervention. The authors used GRADE to assess their confidence in evidence of effect. We considered their judgements appropriate.

The documentation in Table 5 shows effects of adapted asthma education for patients belonging to a minority ethnic group compared to usual care or conventional education.

Table 5: Effects of adapted asthma education compared to usual care.

Outcome, follow up	Anticipated absolute effects		Relative effect (95% CI)	No. of participants (Studies)	Quality of evidence (GRADE)
	Assumed risk with usual care/conventional education	Risk with adapted asthma education (95% CI)			
Population: Children or adults from a minority ethnic group in their country with asthma.					
Countries: USA, Australia, Canada, India and UK.					
Intervention: Adapted asthma education for patients belonging to a minority ethnic group.					
Comparison: Usual care or standard education for asthma patients.					
Studies with children: Asthmatic exacerbations (different severity and definitions)					
Severe exacerbations (hospitalisation), 6-12 months	434 per 1000	545 per 1000 (336 to 737)	OR 1.55 (0.6 to 3.66)	88 (1 RCT)	⊕⊕○○ LOW ¹
	-	-	RR 0.48 (0.24 to 0.95)	305 (2 RCTs)	
No. of exacerbations, 12 months	-	Exacerbation rate 0.18 MD higher (0.25 lower to 0.62 higher)	-	110 (2 RCTs)	⊕⊕○○ LOW ¹
Studies with adults: Asthmatic exacerbations (different severity and definitions)					
No. with ≥ one exacerbation, 12 months	559 per 1000	504 per 1000 (388 to 615)	OR 0.80 (0.50 to 1.26)	294 (1 RCT)	⊕○○○ VERY LOW ²
No. requiring oral corticosteroids, 12 months	203 per 1000	198 per 1000 (123 to 306)	OR 0.97 (0.55 to 1.73)	294 (1 RCT)	⊕○○○ VERY LOW ²
Severe exacerbations (hospitalisation), 12 months	63 per 1,000	53 per 1000 (20 to 130)	OR 0.83 (0.31 to 2.22)	294 (1 RCT)	⊕○○○ VERY LOW ²
Adverse event/outcomes of the intervention					
Any adverse events/outcomes	No data had been extracted from the primary studies.				
¹ Downgraded by two levels due to risk of bias in the studies and imprecision. ² Downgraded by three levels due to high risk of bias and imprecision in the only study providing relevant data.					

CI: Confidence interval; RCT: Randomised, controlled study; MD: Mean difference.

Based on the summarised evidence, patients receiving adapted asthma education have:

- possibly a small reduction or no difference in the number of severe asthmatic exacerbations requiring hospitalisation among children.
- possibly no difference in the overall number of exacerbations among children.

The data is too limited to consider likely effects among adults on the number of asthmatic exacerbations, number of patients requiring oral corticosteroids and number of severe exacerbations.

We have no available evidence on whether this intervention has adverse effects.

Adapted information promoting cancer screening

Among the four high quality systematic reviews on adapted information promoting cancer screening, we present results from the newest by Luque and colleagues, published in 2018 (71). Since this review only covers mammography screening among Latin-American women living in the USA, we comment on findings from the three other reviews regarding cancer screening towards the end of this chapter.

Luque and colleagues (71) searched for educational interventions to increase mammography screening among Hispanic women, but did not define this intervention any further. Eligible studies were randomized, controlled trials, case-control trials, quasi-experimental studies or prospective study with historical controls. The studies should aim to increase mammography screening among Hispanic women living in the USA. At least 50% of the study sample had to be Hispanic and, if the study targeted multiple population groups, with results presented separately for Hispanic participants. They only included studies conducted after 2003, when the American Cancer Society revised their screening guidelines. The literature search was from September 2017. The review included five studies with total 3578 participants, of which 2343 provided data for the main outcome. Three of the included studies were randomized, controlled trials, while two were cluster-randomised trials. Appendix 7 contains a reference list and detailed presentation of study population, duration of study, intervention and control treatment, and additional extracted information for each of the included studies.

By inclusion criteria, all studies were from the USA, targeting adult, Hispanic women. The majority of the participants were foreign-born (immigrants), predominantly from Mexico, and the remaining were US-born of Latin-American origin. Luque and colleagues stated that a high proportion of the participants had lower socioeconomic status and were without health insurance.

Key descriptions of the interventions were:

- The studies lasted from 8 to 24 months (last follow up).
- Three studies gave the participants two intervention sessions, while one study gave six sessions delivered over 6 weeks. In one study, it was unclear if the participants were exposed to the intervention more than once.
- Two studies gave the participants individual education; two studies gave group education, while one study combined the two. One study provided free access to mammography services delivered by a mobile unit in addition to health information.
- All five studies used a lay health worker, predominantly a “promotora”³. One of these studies also involved a peer cancer survivor.

³ A “promotora” is lay Hispanic/Latino community member who receives training to provide basic health education without being a professional health care worker.

Based on our extracted information, we assume that all participants were Spanish speaking and that these “promotora”-led interventions were linguistically adapted. All studies approached the participants on arenas outside the health sector. The control intervention was not specified for these studies, but we assume that all comparisons were against no specific intervention. The estimated difference in intervention “dose” between the intervention group and the control group was two to six extra activities in the intervention group compared no activities for the control group, apart from one study with unclear intervention dose (Appendix 8).

The effects of the interventions were measured as OR for mammography screening during the follow up period (from 6 to 12 months). The authors had not performed a GRADE assessment, so we assessed the confidence in evidence of effect based on the available information in the review (71).

The documentation in Table 6 shows effects of adapted health information promoting cancer screening compared to usual care (no intervention). The findings are based on studies of Hispanic women and mammography screening only.

Table 6: Effects of adapted health information promoting cancer screening compared to usual care (no intervention).

Population: Hispanic women living in the USA.					
Countries: USA.					
Intervention: Educational interventions to increase mammography screening among Hispanic women.					
Comparison: Usual care (no intervention).					
Outcome, follow up	Anticipated absolute effects		Relative effect (95% CI)	No. of participants (Studies)	Quality of evidence (GRADE)
	Assumed risk with usual care (no intervention)	Risk with adapted health information (95% CI)			
Completed mammography screening (registered or self-reports)					
Mammography screened, 6-12 months	441 per 1 000	562 per 1 000 (516 to 607)	OR 1.67 (1.24 to 2.26)	2343 (5 studies)	⊕⊕⊕○ MODERATE ¹
Adverse event/outcomes of the intervention					
Any adverse event/outcome	No data had been extracted from the primary studies.				
<i>1. Downgraded one level because of risk of bias, high attrition and self-reported outcome in some studies.</i>					

CI: Confidence interval; OR: Odds ratio.

Based on the summarised evidence, Hispanic women receiving adapted information about cancer screening:

- have probably moderately higher adherence to mammography screening programmes after 6-12 months

We have no available evidence on adverse effects of the intervention.

In addition to the review by Luque and colleagues (46), we identified three relevant systematic reviews of high methodological quality, all published in 2012 (70, 74, 77), what is briefly presented here.

The aim of Lu and colleagues (70) was to summarise studies assessing interventions to increase the uptake of breast and cervical cancer screening among Asian women. This definition included both women living in Asian countries and Asian immigrants/women of Asian origin in other countries. About half of the 37 included studies were conducted among Asian women living in USA, otherwise Asian women living in the UK, Canada, New Zealand or Australia, or in their home countries Taiwan, Thailand, Singapore, Hong Kong, India or Malaysia. This review included very diverse types of interventions, for example print based information or letters, home education, outreach workers, community-based education, cultural awareness training of health professionals, media campaigns or free/subsidised/mobile screening services, given either alone or in various combinations. Only 18 studies reported a valid outcome measurement. Findings ranged from no effect of the intervention to somewhat increased adherence to breast or cervical cancer screening. We have not assessed our confidence in the effect estimates using GRADE.

Naylor and colleagues (74) aimed to review the literature on intervention to improve the colorectal cancer care, including adapted information promoting screening, among racial or ethnic minorities, but included only studies from USA. Most of the studies addressed African Americans, otherwise Hispanics, Asian or other ethnic groups. This review divided the types of interventions into patient-level interventions (i.e. educational interventions of individual or in groups, media based information, multilingual interventions with print, lay worker or interpreter services); patient-navigator interventions (i.e. support to schedule appointments, reminders, assistance with transportation, translation services, or similar); or provider/system-level interventions (i.e. multi-modal interventions with different components including some addressing health care personnel or organisation of care and patient flows). The review authors concluded that the interventions increase colorectal screening rates in the order of about 10 to 15 percentage points. We have not assessed our confidence in the effect estimates.

Sajid and colleagues (77) reviewed the literature on interventions to improve decision-making and reduce racial and ethnic disparities in prostate cancer management. The relevant sub-section of this review concerned interventions to increase informed decision making about prostate cancer screening. Inclusion criteria were studies conducted in the USA involving at least 50% participants from a minority ethnic group, and relevant studies included predominantly African American men. The review authors divided these into studies of educational programs, printed materials/booklets, telephone/videotape/DVD interventions, web-based interventions or self-efficacy for decision-making interventions. In these studies, culturally adapted content of the information appeared to have a prominent role. The review authors indicate increased knowledge about prostate cancer screening among participants. We have not assessed our confidence in the effect estimates.

Adapted information or education for diabetes prevention

We identified only one systematic review on adapted information or education for diabetes prevention, published by Lagisetty and colleagues in 2017 (68). This review was assessed to be of moderate methodological quality (Appendix 3). Notably, the authors

presented results only using statistical significance (p-values) and direction of effect (increased or decreased), without information on the effect size or level of uncertainty. In order to give a trustworthy summary of the evidence, it would be necessary to retrieve and extract data from all the primary studies, which was beyond the scope of this overview of systematic reviews. Instead, we give a short presentation of the availability of relevant studies based on Lagisetty and colleagues' review (Appendix 8). The authors searched for "culturally targeted strategies", defined as:

«... the terms cultural targeting and tailoring include strategies that improve the health of a racial and ethnic population by taking into account their cultural practices, attitudes, and beliefs. The distinction between targeting (which is often thought as group level programming), and tailoring (which is thought of as individual level programming as these concepts often overlap in community-based interventions), is not made.» (s.55, (68)).

Eligible studies were randomized and quasi-randomized of adults from ethnic groups that differ from the dominant population in their resident country. The participants should be at risk to develop diabetes mellitus type 2. The literature search was from June 2016. The review included 35 studies (see Appendix 8 for reference list), mostly conducted in USA (26 studies) and otherwise in Canada and India (two studies each), and one respectively in the Netherlands, New Zealand, Norway and the UK (Table 7).

Table 7: Country and study population included in Lagisetty 2017.

Country	Study population ¹ (number of studies)
USA	African American (8) Latin American origin (8) Both African American and Latin American origin (3) East Asian origin/immigrants (2) Southeast Asian (1) Arab American (1) Native Americans, American Polynesian (3)
Canada	Native Americans (2)
India	Indian (2)
The Netherlands	Southeast Asian origin/immigrants (1)
New Zealand	Aboriginals (1)
Norway	South Asian immigrants (1)
UK	South Asian immigrants (1)

¹ Study population as described by review authors.

The review by Lagisetty and colleagues shows that there is a significant number of available primary studies on adapted health information or education for diabetes prevention.

Adapted information promoting smoking cessation

We only identified one systematic review on adapted health information promoting smoking cessation, published by Liu and colleagues in 2013 (69). This review was assessed to be of moderate methodological quality (Appendix 3). In this review as well, the authors presented results only using statistical significance and direction of effect, without information on the effect size or its level of uncertainty. We give a short overview of the studies in Liu and colleagues' review (Appendix 9).

The authors searched for interventions considered to be "adapted smoking cessation interventions for ethnic minority groups" defined as:

«Interventions for smoking cessation in ethnic minority groups should thus be adapted accordingly to take into account these unique patterns [preferred tobacco products and use] of risk and protective factors [...], as well as other culturally relevant dimensions such as values, beliefs and practices.» (p.766, (69))

The review included studies with any study design aiming to assess the effect of health promotion interventions on smoking cessation targeting children and non-pregnant adults of African-, Chinese- or South Asian-origin. The literature search was from April 2013. The review included 28 studies (see Appendix 9 for reference list). All the included studies were conducted in USA, of which 23 studies were adapted for African American groups and five for Chinese American groups.

The review by Liu and colleagues shows that there is a substantial number of primary studies on adapted health information promoting smoking cessation.

Other types of adapted health information and patient education

Three systematic reviews did not fall clearly into any of the other categories above (60, 62, 64). They were all considered to be of moderate methodological quality, all with some limitations in the way the results were presented. The three reviews focused on:

- interventions to improve cultural competency in health care for Indigenous peoples in Australia, New Zealand, Canada and the USA, of which a proportion of the studies were targeting the patients (contrary to health professionals) (60).
- adapted or modified self-management programs (no specific diagnoses) for minority ethnic and Indigenous populations (62).
- interventions directed at immigrant populations to improve health literacy, taking into account the role played by nurses (64).

Many of these studies addressed health issues already discussed through the other systematic reviews, i.e. diabetes education, asthma education, cancer screening, or tobacco cessation information. Some additional health issues found in these reviews were cardiovascular disease prevention or patient education (60, 62, 64), education for patients with respiratory infections (64), HIV/AIDS (64), arthritis (62) or chronic kidney disease (62), reproductive health information (64) and general health literacy skills (64).

Discussion

Key findings

A substantial number of primary studies have addressed the effect of adapted health information and patient education for immigrants or minority ethnic groups, summarized in several systematic reviews. The studies of adapted diabetes education generally had intense interventions, with substantially increased interaction with the health care services and additional resources. Long-term blood sugar levels improved somewhat among diabetes patients who received this. Studies of adapted asthma education had interventions of relatively low intensity. The effect of adapted education on risk of severe asthmatic exacerbations were limited or unclear. Studies on adapted interventions promoting cancer screening showed moderately higher attendance at mammography. These interventions often involved lay health workers and contact on arenas outside the health sector.

This overview of systematic reviews shows that there are many studies on adapted health information and patient education regarding several health issues or diagnoses, including diabetes prevention and smoking cessation. However, the available summarised evidence from reviews did not describe the combined effect sizes.

Interventions characterised as adapted health information and patient education were generally complex programs, often including a substantial increase in the number of interactions between the patients and the health services in the form of additional individual or group teaching sessions, extra counselling, telephone support and outreach, and not only linguistic or direct cultural adaptations. Thus, it not possible to pinpoint the most important active intervention components, nor their relative importance.

Confidence in the evidence of effect

We only present results from systematic reviews of high methodological quality in this report. Even if a systematic review is methodologically sound, the included primary studies may be of varying quality. A high quality systematic review should have a thorough literature search, clear inclusion criteria, quality assessment of the included studies and compiled additional information about strengths and weaknesses in their implementation (56).

The GRADE assessments varied from high confidence in the pooled effect estimate, to very low confidence in the effect estimate for different outcomes. To some extent, this variation corresponded with the quantity of available evidence, meaning evidence

based on many studies provided higher certainty while fewer studies provided lower certainty. Lower certainty could also be due to unclear or inadequate execution of the primary studies and small studies with few observations.

It is important to underline that low confidence in the evidence of effect does not mean that the intervention is ineffective. The intervention may have an effect, but the available evidence is too limited to estimate the effect sizes with a high degree of certainty.

Strengths and limitations

A strength of this report is the systematic and transparent methods used to identify the available evidence. We have only included high quality systematic reviews published in 2012 or later, so this report represents an overview of the latest summarized evidence for this topic area. Together with our previous memo (54), this can provide a basis for decisions about adapted health information and patient education for immigrants or minority ethnic groups. A limitation of an overview of systematic overviews is that the analyses are based on already summarized knowledge. Results will be limited to the evidence available in published systematic reviews, with the review authors' notion of relevant populations, intervention and control measures. We have not retrieved information or data from any of the primary studies directly. This means that the quality of our report relies on review authors having retrieved all relevant information in a sensible manner. Although we considered the included reviews to be of high methodological quality, there may be reporting errors or insufficient information to get an in-depth understanding of the evidence. A limitation to systematic reviews in general is that they may become outdated as soon as new studies are published.

How generalizable are the results?

The contexts and study populations in these systematic reviews varied considerably. Most of the included systematic reviews defined their study populations as including both immigrants and minority ethnic groups, although the health related challenges faced by different groups might vary. The highest number of studies involved African Americans. African American and several Latin American groups have a long history of residency in USA. For immigrants, the migration process in itself, with relocation across borders and settlement in a new country, can directly affect an individual's physical vulnerability to disease, mental health and social well-being. However, this is often dependent on specific circumstances related to the motivation for migration (for instance war and conflict versus other motivations) and the journey itself. Asylum seekers and refugees may therefore have different health challenges than other immigrant groups (82). Language problems and unfamiliarity with a new health care system are also more common challenges for immigrant groups compared to minority ethnic groups. The need for adaptation in general, and types of adaptations needed, may therefore be different for some immigrant groups. On the other hand, immigrants and minority ethnic groups alike – also those with long-term ties to a country – may have other cultural preferences than the majority ethnic population. Cultural differences can be related to various aspects, such as perceived commitment to care for relatives, preferences and

values for care options, food culture, religious or traditional beliefs and practices. Immigrants and minority ethnic groups may also differ from the majority ethnic population in their ability to navigate structures of the society.

More than half of the underlying studies in this overview of systematic review were from the USA, where the health services, although generally being of high quality, are persistently less accessible to the poor and other people who lack health insurance (13). Review authors McCullum and colleagues (72) comment that participants in the studies for USA generally lacked health insurance. Other review authors did not extract data on insurance status, but several remarked (59, 68, 69, 71) that most study populations had low socioeconomic status or marginal living conditions. The study populations may therefore be poorer and more socially vulnerable than most low socio-economic groups in Norway. The comparison group in most studies received as “usual care” or no intervention. Given the low socioeconomic status of many participants, usual care may therefore range from almost no follow-up for a chronic disease to regular follow-up by general practitioners.

Although these studies mostly come from contexts that are different from the Norwegian health care and welfare system, we still consider the findings transferable to our defined study population. The defined study population was “Groups of people of foreign origin [...] who are believed to have specific health problems, limited health literacy skills, language problems or challenges related to optimal use of health care services in their resident country.” Figure 2 illustrates the underlying assumption for this transferability.

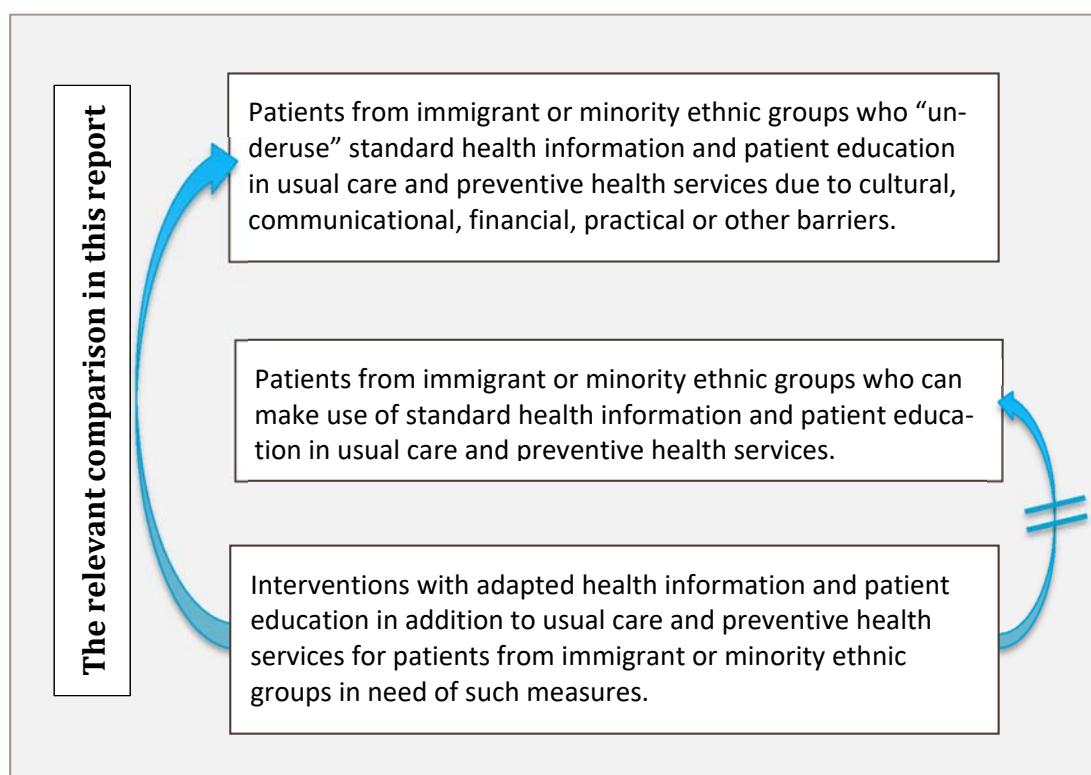


Figure 2: Illustration of how the comparison in this report can be interpreted.

Thus, we consider these results transferable to immigrant or minority ethnic groups “under-using” or having specific challenges regarding use of the health care services, not all immigrants and minority ethnic groups per se.

Attridge and colleagues (59) state that «culturally appropriate health education is taken to mean any type of health education that has been specifically tailored to the *cultural needs of a target minority group ...*». The other cited systematic reviews have similar definitions (68, 69, 71, 72). However, “under-use” or inefficient use of the health care services may arise from several factors. Many of the included studies in this overview had intervention components that are not strictly adhering to “cultural needs”. Examples are making health information more accessible by providing it in people’s homes or on arenas outside the health care sector, or providing free access to mammography services by mobile unit. Financial barriers is apparent for uninsured patients in the USA, but also in welfare states like Norway out-of-pocket fees or travel costs may hinder optimal use of services. People with low socioeconomic status may find it difficult to attend patient education courses due to for instance shift work or lack of child-care. Researchers in the field of clinical epidemiology have warned that cultural factors may be exaggerated as explanations for ethnic inequalities in health instead of raising attention to socioeconomic differentials (for instance education, income, wealth, housing conditions) and social disadvantage, including experiences of racism (10, 83).

The outcomes reported in this review have different characteristics and are of variable nature. Most of the reported outcomes are risk factors or risk markers for disease, such as HbA1c for diabetes patients. While such outcomes may be viewed as “surrogates”, i.e. not measuring clinically important outcomes such as morbidity, they serve as objective measures of effect in these interventions.

Implications for practice

The evidence in this overview of systematic reviews summarizes the available research and indicates how much confidence we have in the estimates of effects. Different types of knowledge must be integrated in order to offer evidence-based health care services. These are:

- Best available research evidence.
- Experience-based knowledge.
- User knowledge and user involvement.
- Knowledge about the context.

Experience-based knowledge from health professionals can be skills and assessment, communication and relationships developed through clinical experience. User knowledge and user involvement may consist of knowledge, experiences, values, wishes and needs of users, patients or relatives. The context includes factors related to the geographic location, available resources, national legislation and guidelines.

The evidence in this report covers health issues relevant to the Norwegian context and, at least partly, relevant population groups. An important finding is that the terms “adapted health information” and “adapted patient education” conceal many different

adaptation strategies. Some interventions contained many activities and appear as complex programs for major lifestyle changes. Other interventions include community campaigns or used outreach on arenas outside the health care sector. In many of the reviews, it is unclear how the interventions have been “culturally adapted”.

These factors makes it difficult to conclude whether an effect is related to specific adaptations or whether the combined efforts and overall intensity of the interventions are essential, as also pointed out by some review authors (69, 70). The intervention intensity seems to be an important factor in itself. In particular adapted diabetes education, involved a substantial increase in the time and resources given to the participants.

Some implications for practice are:

- Intense interventions with adapted health information and patient education seem to give measurable effects on selected health outcomes among vulnerable immigrant or minority ethnic groups.
- Since most of the studies in these systematic reviews contain a package of activities, the effect of single activities cannot be anticipated based on these systematic reviews, nor can we assume that some of the components are more important than other elements.
- The research evidence regarding this subject still needs improvement. When planning new interventions, decision makers and clinicians should evaluate the program and document their findings to contribute to the knowledge base.
- Adapted health information and patient education may increase the costs of care substantially. Aspects of cost-effectiveness must be discussed both a local and national level.

Need for further research

It would be beneficial with further research regarding the following topics/factors:

- Studies done in countries with different health care systems and models of access to care, including more studies from Norway and other welfare states.
- Primary studies and systematic reviews with adapted interventions for newly arrived immigrants assessed separately from studies of long-term resident immigrants and minority ethnic groups.
- Studies comparing different types of adaptations to identify the most effective and crucial components.
- Studies that take into account and investigates the importance of cultural adaptation relative to factors related to socioeconomic factors, marginalisation and low health literacy levels among immigrant and minority ethnic groups.

Conclusion

It seems that intense interventions with adapted health information and patient education can improve health outcomes among vulnerable immigrant or minority ethnic groups. The evidence is most extensive for adapted diabetes education. The available studies have generally focused on complex and often intense interventions. We do not know which elements are most influential or necessary for achieving the effects.

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Appendixes

Appendix 1: Search strategy

Embase 1974 to 2018 April 26

27. April 2018

- 1 minority health/ (603)
- 2 exp "ethnic and racial groups"/ (121904)
- 3 exp "ethnic or racial aspects"/ (226167)
- 4 exp migration/ (42621)
- 5 refugee/ (10239)
- 6 (refugee* or immigrant* or (asyl* adj1 seek*) or foreign* or ethnic* or minorit* or racial* or (multi adj cultural*) or multicultural* or (newly adj arrived) or ((family or families) adj2 reuni*) or resettl*).ti,ab. (355464)
- 7 1 or 2 or 3 or 4 or 5 or 6 (591803)
- 8 health education/ (91636)
- 9 consumer health information/ (3416)
- 10 dental health education/ (5610)
- 11 patient education/ (103432)
- 12 health education/ (91636)
- 13 breast feeding education/ (2048)
- 14 childbirth education/ (339)
- 15 diabetes education/ (2733)
- 16 hiv education/ (679)
- 17 nutrition education/ (4174)
- 18 patient education/ (103432)
- 19 medical information/ (65906)
- 20 health literacy/ (7407)
- 21 ((language* or cultural*) adj5 (adapt* or accomodat* or approp* or target* or tailor*) adj5 (educat* or teach* or train* or inform* or communicat*)).ti,ab. (1831)
- 22 (health adj (inform* or communicat* or literacy or literate)).ti,ab,kw. (33673)
- 23 ((health or medic* or patient*) adj3 (educat* or teach* or train*)).ti,ab,kw. (233833)
- 24 or/8-23 (467408)
- 25 7 and 24 (26094)
- 26 limit 25 to "reviews (best balance of sensitivity and specificity)" (3612)
- 27 limit 26 to yr="2012 -Current" (1238)

Database: Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) <1946 to Present>

27. april 2018

- 1 Minority Groups/ (12411)
- 2 Minority Health/ (635)
- 3 "Emigrants and Immigrants"/ (9777)

- 4 Refugees/ (8553)
- 5 cultural diversity/ (10536)
- 6 exp Human Migration/ (25028)
- 7 (refugee* or immigrant* or (asyl* adj1 seek*) or foreign* or ethnic* or minorit* or racial* or (multi adj cultural*) or multicultural* or (newly adj arrived) or ((family or families) adj2 reuni*) or resettl*).ti,ab. (280109)
- 8 or/1-7 (310210)
- 9 health education/ (57544)
- 10 consumer health information/ (3117)
- 11 health education, dental/ (5946)
- 12 health fairs/ (463)
- 13 patient education as topic/ (79442)
- 14 sex education/ (8416)
- 15 teach-back communication/ (19)
- 16 "Early Intervention (Education)"/ (2530)
- 17 Health Communication/ (1514)
- 18 Health Literacy/ (3871)
- 19 ((language* or cultural*) adj5 (adapt* or accomodat* or approp* or target* or tailor*) adj5 (educat* or teach* or train* or inform* or communicat*)).ti,ab. (1505)
- 20 (health adj (inform* or communicat* or literacy or literate)).ti,ab,kf. (27971)
- 21 ((health or medic* or patient*) adj3 (educat* or teach* or train*)).ti,ab,kf. (181076)
- 22 or/9-21 (325151)
- 23 8 and 22 (13074)
- 24 limit 23 to (yr="2012 -Current" and "reviews (best balance of sensitivity and specificity)") (558)

Database: PsycINFO <1806 to April Week 3 2018>

27. April 2018

- 1 minority groups/ (13676)
- 2 exp "racial and ethnic groups"/ (117275)
- 3 immigration/ (20044)
- 4 exp human migration/ (10792)
- 5 (refugee* or immigrant* or (asyl* adj1 seek*) or foreign* or ethnic* or minorit* or racial* or (multi adj cultural*) or multicultural* or (newly adj arrived) or ((family or families) adj2 reuni*) or resettl*).ti,ab. (180238)
- 6 or/1-5 (258657)
- 7 exp health education/ (17269)
- 8 client education/ (3652)
- 9 health literacy/ (2348)
- 10 ((language* or cultural*) adj5 (adapt* or accomodat* or approp* or target* or tailor*) adj5 (educat* or teach* or train* or inform* or communicat*)).ti,ab. (1449)
- 11 (health adj (inform* or communicat* or literacy or literate)).tw. (10250)
- 12 ((health or medic* or patient*) adj3 (educat* or teach* or train*)).tw. (56595)
- 13 or/7-12 (78055)
- 14 6 and 13 (7849)
- 15 limit 14 to ("reviews (maximizes sensitivity)" and yr="2012 -Current") (1453)

Database: CDSR, DARE, HTA

27. April 2018

124 hits

- #1 MeSH descriptor: [Minority Groups] explode all trees
- #2 MeSH descriptor: [Minority Health] explode all trees

- #3 MeSH descriptor: [Minority Health] explode all trees
- #4 MeSH descriptor: [Emigrants and Immigrants] explode all trees
- #5 MeSH descriptor: [Refugees] explode all trees
- #6 MeSH descriptor: [Cultural Diversity] explode all trees
- #7 MeSH descriptor: [Human Migration] explode all trees
- #8 (refugee* or immigrant* or (asyl* near/1 seek*) or foreign* or ethnic* or minorit* or racial* or (multi next cultural*) or multicultural* or (newly next arrived) or ((family or families) near/2 reuni*) or resettl*) Publication Year from 2012 to 2018, in Other Reviews and Technology Assessments
- #9 (refugee* or immigrant* or (asyl* near/1 seek*) or foreign* or ethnic* or minorit* or racial* or (multi next cultural*) or multicultural* or (newly next arrived) or ((family or families) near/2 reuni*) or resettl*):ti,ab,kw Publication Year from 2012 to 2018
- #10 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 Publication Year from 2012 to 2018, in Other Reviews and Technology Assessments
- #11 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #9 Publication Year from 2012 to 2018
- #12 MeSH descriptor: [Health Education] explode all trees
- #13 MeSH descriptor: [Early Intervention (Education)] explode all trees
- #14 MeSH descriptor: [Health Communication] explode all trees
- #15 MeSH descriptor: [Health Literacy] explode all trees
- #16 ((language* or cultural*) near/5 (adapt* or accomodat* or approp* or target* or tailor*) adj5 (educat* or teach* or train* or inform* or communicat*))
- #17 (health next (inform* or communicat* or literacy or literate))
- #18 ((health or medic* or patient*) near/3 (educat* or teach* or train*))
- #19 ((language* or cultural*) near/5 (adapt* or accomodat* or approp* or target* or tailor*) adj5 (educat* or teach* or train* or inform* or communicat*))):ti,ab,kw
- #20 (health next (inform* or communicat* or literacy or literate)):ti,ab,kw
- #21 ((health or medic* or patient*) near/3 (educat* or teach* or train*))):ti,ab,kw
- #22 #12 or #13 or #14 or #15 or #16 or #17 or #18 Publication Year from 2012 to 2018, in Other Reviews and Technology Assessments
- #23 #12 or #13 or #14 or #15 or #19 or #20 or #21 Publication Year from 2012 to 2018
- #24 #10 and #22 Publication Year from 2012 to 2018, in Other Reviews and Technology Assessments
- #25 #11 and #23 Publication Year from 2012 to 2018
- #26 #24 or #25

Appendix 2: Excluded studies

Studies excluded after full text assessment, with reason for exclusion.

Reference	Reason for exclusion
Adedoyin ACA. A systematic review of evidence-based cancer education media interventions to improve cancer screening behaviors among African Americans in the United States. Dissertation Abstracts International Section A: Humanities and Social Sciences. 2014;75: No-Specified.	Other intervention (primarily mass media).
Belice PJ, Becker EA. Effective education parameters for trigger remediation in underserved children with asthma: A systematic review. <i>Journal of Asthma</i> . 2017;54(2):186-201.	Other intervention (not adapted).
Bender MS., Choi J, Won G Y, Fukuoka Y. Randomized controlled trial lifestyle interventions for Asian Americans: A systematic review. <i>Preventive Medicine</i> . 2014;67: 171-81.	Other intervention (various lifestyle measures).
Bennett GG, Steinberg DM, Stoute C, Lanpher M, Lane I, Askew S, et al. Electronic health (eHealth) interventions for weight management among racial/ethnic minority adults: A systematic review. <i>Obesity Reviews</i> . 2014;15:146-58.	Other intervention (primarily mass media).
Burlew AK, Copeland VC, Ahuama-Jonas C, Calsyn DA. Does cultural adaptation have a role in substance abuse treatment? <i>Social Work in Public Health</i> . 2013;28(3):440-60.	Not a systematic review of effect.
Chapman D J, Perez-Escamilla R. Breastfeeding among minority women: Moving from risk factors to interventions. <i>Advances in Nutrition</i> . 2012;3:95-104.	Other intervention (various measures to increase breast-feeding).
Clarke AR, Glick S, Blanchard A, Whitaker AK. Interventions to improve minority health and reduce racial and ethnic disparities in care for cervical cancer: A systematic review. <i>Journal of General Internal Medicine</i> . 2012;27:S233.	Conference abstract. Later published as Glick 2012.
Daniel-Ulloa J, Ulibarri M, Baquero B, Sleeth C, Harig H, Rhodes SD. Behavioral HIV Prevention Interventions Among Latinas in the US: A Systematic Review of the Evidence. <i>Journal of immigrant and minority health</i> . 2016;18(6):1498-521.	Other intervention (various measures for HIV prevention).
El-Haddad N, Faruqi N, Spooner C, Denney-Wilson E, Harris M. Improving health literacy for weight management in overweight or obese non-English speaking migrants in primary health care: A systematic review of quantitative and qualitative data. <i>Obesity Research and Clinical Practice</i> . 2014;8:29.	Conference abstract. Relevant, full publication not found.
Fitzgerald EM. Evidence-Based Tobacco Cessation Strategies with Pregnant Latina Women. <i>Nursing Clinics of North America</i> . 2012;47(1):45-54.	Not a systematic review of effect.
Geng ZZ, Gupta S. Interventions to increase colorectal cancer screening among underserved populations: A systematic review. <i>Gastroenterology</i> . 2013;1:S576.	Conference abstract. Full publication not found.
Gonzalez LS, Berry DC, Davison JA. Diabetes self-management education interventions and glycemic control among hispanics: a literature review. <i>Hispanic health care international: the official journal of the National Association of Hispanic Nurses</i> . 2013;11(4):157-66.	Not a systematic review (no quality assessment of included studies).

Heitkemper EM, Mamykina L, Travers J, Smaldone A. Do health information technology self-management interventions improve glycemic control in medically underserved adults with diabetes? A systematic review and meta-analysis. <i>Journal of the American Medical Informatics Association</i> . 2017;24(5):1024-35.	Other intervention (primarily tele/digital/media-based).
Heo HH, Braun KL. Culturally tailored interventions of chronic disease targeting Korean Americans: a systematic review. <i>Ethnicity & Health</i> . 2014;19:64-85.	Not a systematic review (no quality assessment of included studies). Little focus on effects.
Holub CK, Elder JP, Arredondo EM, Barquera S, Eisenberg CM, Sanchez Romero LM, et al. Obesity control in Latin American and U.S. Latinos: A systematic review. <i>American Journal of Preventive Medicine</i> . 2013;44(5):529-37.	Other intervention (various measures for obesity prevention).
Hu D, Juarez DT, M Yeboah M, Castillo TP. Interventions to increase medication adherence in African-American and Latino populations: a literature review. <i>Hawai'i Journal of Medicine & Public Health</i> . 2014;73: 11-8.	Not a systematic review (no quality assessment of included studies). Unclear if interventions are adapted. Little focus on effects.
Huang Y, Shen F. Effects of cultural tailoring on persuasion in cancer communication: A meta-analysis. <i>Journal of Communication</i> 2016;66:694-715.	Not a systematic review. Analyses of moderating factors.
Kruk A, Kavookjian J. Culturally tailored motivational interviewing interventions in hispanic populations: A systematic review. <i>Journal of the American Pharmacists Association</i> 2012;52:209.	Conference abstract. Relevant, full publication not found.
Lagisetty PA, Priyadarshini S, Terrell S, Landgraf J, Chopra V, Heisler M. Culturally targeted strategies for diabetes prevention in minority populations: A systematic review and framework. <i>Journal of General Internal Medicine</i> 2016;1:S171.	Conference abstract. Later published as Lagisetty 2017.
Leske., Harris MG, Charlson FJ, Ferrari A J, Baxter AJ, Logan JM, Toombs M, Whiteford H. Systematic review of interventions for Indigenous adults with mental and substance use disorders in Australia, Canada, New Zealand and the United States. <i>Australian and New Zealand Journal of Psychiatry</i> . 2016;50:1040-54.	Other intervention (various measures for persons with mental and substance use disorders).
Lofton S, Julion WA, McNaughton DB, Bergren MD, Keim KS. A systematic review of literature on culturally adapted obesity prevention interventions for African American youth. <i>The Journal of School Nursing</i> . 2016;32:32-46.	Other intervention (various measures for obesity prevention).
Lood Q, Haggblom-Kronlof G, Dahlin-Ivanoff S. Health promotion programme design and efficacy in relation to ageing persons with culturally and linguistically diverse backgrounds: a systematic literature review and meta-analysis. <i>BMC Health Services Research</i> . 2015;15:560.	Other intervention (various lifestyle measures).
Louisias M, Phipatanakul W. Managing Asthma in Low-Income, Underrepresented Minority, and Other Disadvantaged Pediatric Populations: Closing the Gap. <i>Current Allergy and Asthma Reports</i> . 2017;17(68).	Not a systematic review (no description of literature search, inclusion criteria and quality assessment of studies).

McConnell S. Culturally tailored postsecondary nutrition and health education curricula for indigenous populations. <i>International journal of circumpolar health</i> . 2013;72.	Other intervention (cultural adaptation of textbooks).
Miller TA. Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis. <i>Patient Education and Counseling</i> . 2016;99(7):1079-86.	Other intervention (not adapted).
Montag A, Clapp JD, Calac D, Gorman J, Chambers C. A review of evidence-based approaches for reduction of alcohol consumption in native women who are pregnant or of reproductive age. <i>American Journal of Drug and Alcohol Abuse</i> . 2012;38(5):436-43.	Other intervention (various measures to reduce alcohol consumption).
Mosnaim GS, Akkoyun E, Eng J, Shalowitz MU. Behavioral interventions to improve asthma outcomes: A systematic review of recent publications. <i>Current Opinion in Allergy and Clinical Immunology</i> . 2017;17(3):194-200.	Other intervention (not adapted education).
Nasir BF, Hides L, Kisely S, Ranmuthugala G, Nicholson GC, Black E, et al. The need for a culturally-tailored gatekeeper training intervention program in preventing suicide among Indigenous peoples: A systematic review. <i>BMC Psychiatry</i> . 2016;16. ArtID 357.	Other intervention (gatekeeper training for suicide prevention)
Pillay J, Armstrong MJ, Butalia S, Donovan LE, Sigal RJ, Vandermeer B, et al. Behavioral programs for type 2 diabetes mellitus: A systematic review and network meta-Analysis. <i>Annals of Internal Medicine</i> . 2015;163(11):848-60.	Other intervention (not adapted education).
Sarte AF, Fong M, Yung K, Ng L, Koehn S, Sohal P. Culturally appropriate pre-diabetes lifestyle intervention programs: A review of the literature. <i>Canadian Journal of Diabetes</i> . 2012;1:S33-S34.	Conference abstract. Relevant, full publication not found.
Sawrikar P, Katz I. Preventing child sexual abuse (CSA) in ethnic minority communities: A literature review and suggestions for practice in Australia. <i>Children and Youth Services Review</i> . 2018;85:174-86.	Other intervention (prevention of child sexual abuse).
Tovar A, Renzaho AMN, Guerrero AD, Mena N, Ayala GX. A Systematic Review of Obesity Prevention Intervention Studies among Immigrant Populations in the US. <i>Current Obesity Reports</i> . 2014;3:206-22.	Other intervention (various measures for obesity prevention).
Wong VSW, So WK. Effectiveness of colorectal cancer preventive measures among ethnic minorities-an integrative review. <i>Cancer Nursing</i> . 2015;1:S61.	Conference abstract. Relevant, full publication not found.

Appendix 3: Quality assessment of included systematic reviews

Quality assessment of included systematic reviews based on nine questions (see footnote) and overall assessment from checklist systematic reviews (55).

Reference	Question in checklist for systematic reviews									Overall assessment
	1	2	3	4	5	6	7	8	9	
Ahmed 2018 (58)	+	+	+	-	+	+	+	?	+	Moderate quality
Attridge 2014 (59)	+	+	+	+	+	+	+	+	+	High quality
Clifford 2015 (60)	+	+	+	+	+	+	+	-	?	Moderate quality
Creamer 2016 (61)	+	+	+	+	+	+	+	+	+	High quality
Ehrlich 2016 (62)	+	+	+	?	+	+	?	?	+	Moderate quality
Ferguson 2015 (63)	+	+	+	?	+	+	+	+	+	High quality
Fernandez-Gutierrez 2018 (64)	+	+	+	+	+	+	+	-	?	Moderate quality
Glick 2012 (65)	+	+	+	-	+	+	?	+	?	Moderate quality
Gucciardi 2013 (66)	+	+	+	+	+	+	+	+	+	High quality
Joo 2014 (67)	+	+	+	-	+	+	?	+	-	Moderate quality
Lagisetty 2017 (68)	+	+	+	+	+	+	+	-	?	Moderate quality
Liu 2013 (69)	+	+	+	+	+	+	+	-	?	Moderate quality
Lu 2012 (70)	+	+	+	+	+	+	+	+	+	High quality
Luque 2018 (71)	+	+	+	+	+	+	+	+	+	High quality
McCallum 2017 (72)	+	+	+	+	+	+	+	+	+	High quality
Nam 2012 (73)	+	+	+	?	+	+	+	+	+	High quality
Naylor 2012 (74)	+	+	+	+	+	+	?	+	+	High quality
Press 2012 (75)	+	+	+	+	+	+	+	+	+	High quality
Ricci-Cabello 2014 (76)	+	+	+	+	+	+	+	+	+	High quality
Sajid 2012 (77)	+	+	+	+	+	+	+	+	+	High quality
Walker 2013 (78)	+	+	+	+	-	?	?	+	+	Moderate quality
Zeh 2012 (79)	+	+	+	+	+	+	+	+	+	High quality

 Yes,
  unclear or
  no to the questions below:

1. Do the authors clearly describe what methods they used to find the primary studies?
2. Was a satisfactory literature search performed?
3. Do the authors describe the criteria used to determine which studies should be included (study design, participants, and relevant outcomes)?

4. Were measures taken to limit systematic biases when selecting studies (explicit selection criteria used, assessment made by several assessors independently)?
5. Are there clear criteria for assessing internal validity?
6. Is the validity of the studies assessed (either by inclusion of primary studies or in the analysis of primary studies) using relevant criteria?
7. Are the methods used when the results were summarized clearly described?
8. Are the results of the studies summarized appropriately?
9. Are the authors' conclusions supported by the data and/or analysis reported in the review?

Appendix 4: Judgement of overlap between relevant systematic reviews

The 22 systematic reviews that fulfilled the inclusion criteria for population and intervention are grouped into six topics. Within each topics, the reviews are ranked by date for the literature search. The table also contain information on the authors' inclusion criterion for study population. The six systematic reviews considered to be of moderate methodological quality are included in the table to give an overview of the systematic review evidence in each of the topic areas.

Judgement of overlap, in included systematic reviews, grouped according to the-matic content.

Reference	Intervention, as described by authors	Quality	Date of search	The authors' defined study population/search criteria ¹	Judgement of overlap ²
Adapted diabetes education					
Ferguson 2015 (63)	Diabetes self-management education in conjunction with primary care among Hispanics.	High	October 2013	Latin American patients (implicit in the USA). Only studies from USA included.	Later date of search than Attridge 2014, but narrow population.
Creamer 2016 (61)	Culturally appropriate health education for diabetes type 2.	High	July 2013	Persons > 16 years from an ethnic minority group living in a high- or middle-income country.	Shorter version of Attridge 2014.
Attridge 2014 (59)	<i>Culturally appropriate health education for diabetes type 2.</i>	High	July 2013	<i>Persons > 16 years from an ethnic minority group living in a high- or middle-income country.</i>	Results presented
Joo 2014 (67)	Culturally tailored diabetes interventions for Asian immigrants.	Moderate	Published ≤ year 2013	Asian migrants to USA. Only studies from USA.	Covered by Attridge 2014
Ricci-Cabello 2014 (76)	Educational programs promoting self-management of racial/ethnic groups with type 2 diabetes	High	October 2012	Ethnic minorities with higher diabetes risk than the majority population. Only studies from OECD countries.	Covered by Attridge 2014
Walker 2013 (78)	Behavioural interventions targeted at African Americans to improve glycaemic control.	Moderate	January 2012	Afro Americans. Adults > 18 years	Covered by Attridge 2014
Zeh 2012 (79)	Culturally competent interventions tailored to people with diabetes from ethnic minority groups.	High	September 2011	Ethnic minority groups.	Covered by Attridge 2014
Nam 2012 (73)	Culturally tailored diabetes education on glycaemic control	High	Published ≤ year 2009	Ethnic minority groups.	Covered by Attridge 2014

Gucciardi 2013 (66)	Diabetes self-management education for Black African/Caribbean and Hispanic/Latin American women.	High	Published ≤ year 2008	Afro Americans, Spanish/Latin or South Asian ethnicity (implicit in USA). Only studies from «industrial» countries.	Covered by Attridge 2014
Adapted asthma education					
<i>McCallum 2017 (72)</i>	<i>Culture-specific asthma education programmes.</i>	<i>High</i>	<i>June 2016</i>	<i>Children and adults from ethnic from ethnic minority groups</i>	<i>Results presented</i>
Ahmed 2018 (58)	Asthma self-management in South Asian and Black populations.	Moderate	February 2015	South Asian or Afro American patients or parents of children with the diagnosis.	Covered by McCallum 2017
Press 2012 (75)	Interventions to improve outcomes for minority adults with asthma.	High	Autumn 2010	Minorities, adults > 18 years	Covered by McCallum 2017
Adapted health information/education for prevention of diabetes					
<i>Lagisetty 2017 (68)</i>	<i>Culturally tailored diabetes prevention</i>	<i>Moderate</i>	<i>May 2016</i>	<i>Ethnic minority groups.</i>	<i>Available studies presented, but no results.</i>
Adapted health information promoting cancer screening					
<i>Luque 2018 (71)</i>	<i>Mammography Screening Educational Interventions</i>	<i>High</i>	<i>May 2003 - September 2017</i>	<i>Hispanic Women in USA.</i>	<i>Results presented.</i>
Glick 2012 (65)	Cervical cancer screening, diagnosis and treatment interventions.	Moderate	August 2010	Racial or ethnic minorities in USA.	Partly covered by other reviews.
Lu 2012 (70)	Interventions to increase breast and cervical cancer screening uptake.	High	January 2010.	Asian women.	Short presentation of results.
Naylor 2012 (74)	Interventions to improve care related to colorectal cancer.	High	September 2010.	Racial or ethnic minorities. Only studies from USA.	Short presentation of results.
Sajid 2012 (77)	Interventions to improve decision-making/reduce disparities in management of prostate cancer.	High	Published ≤ year 2010	Racial or ethnic minorities. Only studies from USA.	Short presentation of results.
Adapted health information promoting smoking cessation					
<i>Liu 2013 (69)</i>	<i>Adapted smoking cessation interventions for ethnic minority groups.</i>	<i>Moderate</i>	<i>April 2013</i>	<i>Children and non-pregnant adults of African, Chinese or South Asian decent living in "Western" countries.</i>	<i>Available studies presented, but no results.</i>
Other types of adapted health information/patient education					
Fernandez-Gutierrez 2018 (64)	Interventions to improve functional, interactive and critical dimensions of health literacy.	Moderate	October 2015	Immigrants.	Not included. Moderate quality. Heterogeneous interventions.

Ehrlich 2016 (62)	Culturally responsive self-management interventions to improve chronic illness health outcomes.	Moderate	Data not specified.	Ethnic minority groups.	Not included. Moderate quality. Largely covered by diagnoses above.
Clifford 2015 (60)	Interventions to improve cultural competency in health care for Indigenous peoples.	Moderate	July 2013	Indigenous population groups in Australia, New Zealand, Canada or USA. Only studies from these countries considered.	Not included. Moderate quality. Largely covered by diagnoses above.

1 Commented if the authors have searched for studies done in specific countries.

2 Based on judgement of overall methodological quality, date of literature search and population included.

Appendix 5: Background information for Attridge 2014

References to studies included in Attridge 2014 (59):

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Kim MT, Han H, Song H, Lee J, Kim J, Ryu JP, et al. A community-based, culturally tailored behavioral intervention for Korean Americans with type 2 diabetes. *The Diabetes Educator* 2009;35(6):986–94.

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Sixta CS, Ostwald S. Texas-Mexico border intervention by promotores for patients with type 2 diabetes. *The Diabetes Educator* 2008;34(2):299–309.

Skelly AH, Carlson JR, Leeman J, Holditch-Davis D, Soward ACM. Symptoms-focused management for African American women with type 2 diabetes: a pilot study. *Applied Nursing Research* 2005;18:213–20.

Skelly AH, Carlson J, Leeman J, Soward A, Burns D. Controlled trial of nursing interventions to improve health outcomes of older African American women with type 2 diabetes. *Nursing Research* 2009;58(6):410–8.

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Toobert DJ, Strycker LA, Barrera M, Osuna D, King DK, Glasgow RE. Long-term outcomes from a multiple risk factor diabetes self-management trial for Latinas: Viva Bien!. *Annals of Behavioral Medicine* 2011;41(3):310–23.

Vincent D, Pasvogel A, Barrera L. A feasibility study of a culturally tailored diabetes intervention for Mexican Americans. *Biological Research for Nursing* 2007;9:130–41.

Characteristics of the studies, participants, controls and interventions included in Attridge 2014 (59). All data based on information provided by review authors only from the text, tables and appendixes in the systematic review.

Reference id	Country, Group, No. of participants randomised, inclusion criteria age, sex	Duration of intervention (longest follow-up)	Control group treatment	Intervention group treatment		Additional extracted information ¹					
				Description of the intervention	Providers	Estimated "dose" ²	Specified language ³	Adaptations to group			
								Language	Lay workers	Place	Content
Agurs-Collins 1997	USA, African American, n = 64, > 55 years, both sexes	6 months (6 months)	One session on glycaemic control. Two letters on nutrition. Own clinical results.	Weekly nutrition group sessions with exercise training for 3 months, then biweekly problem-solving sessions 3 months. One individual counselling session.	Dietician and exercise physiotherapist, experienced with target group.	20	-				?
Anderson 2005	USA, African American, n = 239, -, both sexes	6 weeks (12 months)	Wait-listed ⁴	Weekly problem based group sessions for 6 weeks.	Diabetes nurse, dietician	6	-				?
Babamoto 2009	USA, Hispanic descent, n = 318, > 18 years, both sexes	6 months (6 months)	Usual care	Individual education sessions at home/clinic/ community and routinely supporting telephone calls over 10-weeks period, then sporadic calls over 14 weeks.	Nurse, bilingual community health worker	Unclear	Assumed Spanish	x		x	?
Baradaran 2006	UK, South Asian descent, n = 118, > 30 years, both sexes	3 months (6 months)	Usual care	Three group sessions over 3 months.	Dietician, podiatrist	3	-				?
Bellary 2008	UK, South Asian origin, n = 1486, -, both sexes	24 months (24 months)	Intervention protocol provided to control practices, but no additional resources.	«Enhanced care». Additional resource to included practices: nurse 4 h/week, bi-lingual link workers, and support from diabetes specialist nurse. Participants followed up bi-monthly. Translated educational resources. Follow up on treatment goals.	Nurse, diabetes nurse, link workers.	12	Punjabi, Urdu, Mirpuri	x			x
Brown 2002	USA, Mexican American n = 252, 35-70 years, both sexes	12 months (12 months)	Usual care	Weekly group sessions 3 months, then bi-weekly support sessions for 6 months and monthly support sessions for 3 months.	Nurse, dietician, link worker. All bi-lingual.	27	Assumed Spanish	x			?

Carter 2011	USA, African American, n = 74, > 18 years, both sexes.	9 months (9 months)	Usual care	Participants were provided equipment for self-monitoring of weight and blood pressure to measure weekly and glucose to measure 3 t/day. Three online education modules (text and video). Individual video conference with nurse every second week.	Diabetes nurse, multimedia program.	21	English			x	x
Crowley 2013	USA, African American, n = 359, > 18 years, both sexes.	12 months (12 months)	Usual care and written material.	Self-management education with focus on behavioural change. Supported medication management. Nurse provided modules via monthly telephone calls over 12 months.	Nurse.	12	English			x	x
D'Eramo Melkus 2010	USA, African American, n = 109, 21-65 years, women.	11 weeks (24 months)	Weekly group sessions with "culturally neutral usual diabetes education" for 10 weeks.	Weekly group sessions with diabetes self-management training, coping skills training and diabetes care intervention for 11 weeks. Culturally specific educational material and examples.	Nurse, diabetes educator, clinical psychologist/mental health nurse.	11	English		x		x
DePue 2013	USA, American Samoan, n = 268, > 19 years, both sexes.	12 months (12 months)	Usual care, wait-listed ⁴	Individual education tailored to person's self-goals and diabetes risk. Groups sessions for high-risk individuals. Varying frequency among participants, over course of one year, delivered at home, work or clinic.	Nurse, link worker	Varying – tailored to need	-			x	?
Gary 2009	USA, African American, n = 542, > 25 years, both sexes.	24 months (36 months)	Phone call reminders every 6-12 months on preventative diabetes care by lay health workers. Written information by mail.	Individualised, culturally tailored diabetes care programme. Minimum one control with nurse. Three contacts (including one home visit) by community health worker, providing clinical measurements with feedback, education and hands-on problem-solving help. More frequent controls and actions for high-risk participants.	Nurse and African American community health workers familiar with community.	Minimum 4	-			x	x
Gucciardi 2007	Canada, Portuguese speaking Canadians n = 87,	3 days (3 months)	Individual counselling: Initial assessment + additionally mean 1.83 visits.	Combined intervention with group sessions and individual counselling: Three group meetings, individual counselling initial assessment + additionally mean 2.08 visits.	Nurse, dietician, pharmacist, psychologist, physiotherapist.	Minimum 4	Portuguese	x			?
Hawthorne 1997	UK, Pakistani origin, n = 201, -, both sexes.	1 session (6 months)	Not stated.	One individual educational session. Use of flash card health education.	Trained link worker.	1	-				?

Kattelmann 2009	USA, Native Americans, n = 114, 18-65 years, both sexes.	6 months (6 months)	Standardised dietary education by health care providers and wait-listed ⁴ .	Six group educational sessions with focus on Native Nutrition and physical activity, led by dietitian and tribal member. Subsequent group support session. Individual diet plans developed.	Dietitian and trained tribal member.	6	-		x		x
Keyserling 2002	USA, African-American n = 200, > 40 years, women.	12 months (12 months)	Mailed standard pamphlets on diabetes.	Four times individual counselling, two group sessions and monthly telephone calls over 6 months. One group session and monthly telephone calls next 6 months.	Dietician and link worker.	19	-				?
Khan 2011	USA, "Underserved people" (results for African American and Hispanics), n = 129, > 18 years, both sexes.	3 months (3 months)	Standard pamphlets on diabetes and standard care.	19 bilingual multimedia educational sessions on diabetes. Administered in waiting room before general education/standard care. Video-testimonials from members of same ethnic minority group.	Multimedia program.	19	English, Spanish	x		x	x
Kim 2009	USA, Korean American, n = 83, > 30 years, both sexes.	30 weeks (30 weeks)	Usual care, wait-listed ⁴	Weekly education sessions on diabetes knowledge and self-care for 6 weeks. Home glucose and blood pressure monitoring with tele-transmission with monthly telephone counselling by bilingual nurse for 24 weeks.	Bilingual nurse and nutritionist.	30	Assumed Korean	x		x	x
Lorig 2008	USA, Latinos n = 417, > 18 years, both sexes.	6 weeks (6 months)	Usual care.	Weekly group education sessions for 6 weeks. Participants' family and friends also attended the group sessions.	Diabetes educator, peer leaders (trained)	6	Spanish	x	x		x
Lujan 2007	USA, Mexican American n = 150, > 40 years, -	6 months (6 months)	Usual care: Individual sessions and leaflets.	Weekly group education sessions involving hands-on demonstrations and handouts for 8 weeks. Fortnightly telephone calls by promotor and inspirational faith-based health behaviour change postcards. Delivered by "promodora"	Promodoras (lay health workers)	Minimum 10	English, Spanish	x	x		x
Middelkoop 2001	The Netherlands, Asian Surinamese immigrants n = 113, -, both sexes.	6 months (6 months)	Wait-listed ⁴	Intensive guidance clinics, approximately 4-7 visits for the first 3 months, with less frequent subsequent visits.	Trained nurse and dietician.	Minimum 5	Unclear				x
O'Hare 2004	UK, South Asians n = 361, -, both sexes.	12 months (12 months)	Intervention protocol given to clinics without resources.	Extra weekly diabetes clinic at the primary care clinics. Language skilled link workers. Frequency of exposure unclear.	Diabetes/practice nurses, dietician, link workers	Unclear	Unclear				x

Osborn 2010	USA, Puerto Ricans n = 118, > 18 years, both sexes.	One session (3 months)	Usual care, including monthly diabetes support group and education delivered in Spanish (but not individually tailored).	Single educational session with subsequent personal feedback report. Culturally appropriate educational material and food examples. Culturally tailored, individualised meal plan booklet, handouts, brochure of familiar foods and recommended serving sizes. Usual care as for control group.	Bilingual medical assistant of Puerto Rican heritage.	1	Spanish				x
Philis-Tsimikas 2011	USA, Mexican American n = 207, 21-75 years, both sexes.	10 months (10 months)	Usual care.	Weekly interactive, group sessions on diabetes self-management (including cultural beliefs that may interfere with optimum self-management) for 8 weeks, then monthly support groups (unclear duration). Reminder calls before sessions.	Peer educator	Minimum 9	Unclear	?		x	x
Rosal 2005	USA, Puerto Ricans n = 25, > 18 years, both sexes.	6 months (12 months)	Usual care. Primary care physicians received participants' laboratory results during the trial.	Initial individual session, followed by two group sessions and two short individual sessions over 10-week period. Primary care physicians received participants' laboratory results during the trial.	Bilingual dietician, diabetes nurse and assistant.	5	English, Spanish	x			
Rosal 2011	USA, Latinos n = 252, > 18 years, both sexes.	12 months (12 months)	Usual care. Primary care physicians received participants' laboratory results at 4 and 12 months.	Weekly sessions for 12 weeks, then 8 monthly sessions. All sessions started with personalised counselling and cooking, then literacy and culturally appropriate group protocol and a meal.	Dietician or health educators, lay workers (trained)	20	English, Spanish	x	x		x
Rothschild 2013	USA, Mexican American n = 144, ≥ 18 years, both sexes.	24 months (24 months)	Usual care and mailed leaflets.	Participants received behavioural self-management training through 36 visits by community health worker over 2 years.	Community health worker from community.	36	-			?	
Samuel-Hodge 2009	USA, African Americans n = 201, > 20 years, both sexes.	8 months (12 months)	Two mailed pamphlets and three newsletters with general diabetes information.	Biweekly sessions 12 times, held in church. Each session individual counselling with dietician. Then group activity with prayer, educational component, physical activity segment and taste testing. Monthly telephone call from church diabetes adviser. Three postcards with encouragement, tailored to participants' treatment goals.	Dietician, church diabetes advisor (peer counsellor, trained)	12	English		x	x	x
Sixta 2008	USA, Mexican American n = 131, > 18 years, both sexes.	10 weeks (6 months)	Wait-listed ⁴	Weekly group self-management course over 10 weeks. Delivered by "promodora" in Spanish. Culturally sensitive.	Promodoras (lay health workers), nurse supervised.	10	Spanish	x	x		x

Skelly 2005	USA, African Americans n = 47, 50-85 years, women.	12 weeks (12 weeks)	Usual care. Telephone call and wait-listed ⁴	Biweekly home visits by nurse. Four modules, teaching and counselling intervention based on participant-nurse collaboration.	Nurse	6	-			x	
Skelly 2009	USA, African Americans n = 180, > 50 years, women.	2 months (9 months)	Four home visits by nurse delivering weight and diet program, also individualised and culturally tailored.	Four home visits by a nurse. Symptom-focused modules and counselling. Culturally adapted to individuals' coping strategies (e.g. spirituality and importance of family) and personal experiences as diabetic. Study material developed with advisory board of African American women.	Nurse	8	English			x	x
Spencer 2011	USA, African American or Hispanic n = 164, > 18 years, both sexes.	6 months (6 months)	Usual care, wait-listed ⁴	Community health workers promoted healthy lifestyle, self-management and patient-provider communication skills as 11 group education classes, two home visits and two phone call per month, one accompanied clinic visit, and facilitated referrals to other care services. Normal health care staff trained in cultural competency.	Community health workers (trained)	36	-		x	x	x
Toobert 2011	USA, Latinos n = 280, 30-75 years, women.	12 months (24 months)	Usual care.	Culturally adapted lifestyle program for diabetes delivered as 2.5-day retreat, followed by weekly meetings for 6 months and fortnightly meetings for 6 months.	"Bilingual staff"	Minimum 30	English, Spanish	x			x
Vincent 2007	USA, Mexican American n = 20, 18-75 years, both sexes.	8 weeks (3 months)	Usual care. Included short educational encounter with physician or nurse 2-4 times per year.	Eight weekly group sessions with teaching component, cooking demonstrations and group support. Support persons joined. Cultural modifications to teaching material. Delivered by "promodora" in Spanish.	Promodoras (lay health workers)	8	Spanish	x	x		x

1 Information in this table is based on data provided by the review authors in Characteristics of included studies-table, Additional tables 1, Appendix 2-4 and 9 (59). We extracted additional information based what could be found in all parts of the review, from the text, tables and appendixes in the systematic review.

2 Dose indicates our estimates of the number of times the participants in the intervention group have been offered an activity, individual or group teaching sessions, counselling or similarly. It is unknown to what extent the participants were reached by all the activities described (fidelity of the intervention).

3 If stated by the authors that the participants had a different mother tongue than the main language in the country.

4 Waiting list means that the control group received no follow-up or usual care during the trial, but was offered the intervention content after the trial was completed.

Appendix 6: Background information for McCallum 2017

References to studies included in McCallum 2017 (72):

Blixen CE, Hammel JP, Murphy D, Ault V. Feasibility of a nurse-run asthma education program for urban African-Americans: a pilot study. *Journal of Asthma* 2001;38(1):23–8.

Canino G, Vila D, Norman S, Acosta-Perez E, Ramirez R, Garcia P, et al. Reducing asthma health disparities in poor Puerto Rican children: The effectiveness of a culturally tailored family intervention. *Journal of Allergy and Clinical Immunology* 2008;121(3):665–70.

Grover C, Goel N, Armour C, van Asperen PP, Gaur SN, Moles RJ, et al. Medication education program for Indian children with asthma: A feasibility study. *Nigerian Journal of Clinical Practice* 2016;19(1):76–84.

La Roche M, Koinis-Mitchell D, Gualdron M. A culturally competent asthma management intervention: a randomized controlled pilot study. *Annals of Allergy, Asthma and Immunology* 2006;96:80–5.

Moudgil H, Marshall T, Honeybourne D. Asthma education and quality of life in the community: a randomised controlled study to evaluate the impact on white European and India subcontinent ethnic groups from socio-economically deprived areas in Birmingham, UK. *Thorax* 2000;55(3):177–83.

Poureslami, I. Nimmon L, Doyle-Waters M, Rootman I, Schulzer M, Kuramoto L, et al. Effectiveness of educational interventions on asthma self-management in Punjabi and Chinese asthma patients: a randomized controlled trial. *Journal of Asthma* 2012;49(5):542–51.

Valery PC, Masters IB, Taylor B, Laifoo Y, Chang AB. An education intervention for childhood asthma by Aboriginal and Torres Strait Islander health workers: a randomised controlled trial. *Medical Journal of Australia* 2010;192(10):574–9.

Characteristics of the studies, participants, controls and interventions included in McCullum 2017 (72). All data based on information provided by review authors only from the text, tables and appendixes in the systematic review.

Reference id	Country, Group, No. of participants randomised, inclusion criteria age, sex	Duration of intervention (longest follow-up)	Control group treatment	Intervention group treatment		Additional extracted information ¹					
				Description of the intervention	Providers	Estimated "dose" ²	Specified language ³	Adaptations to group			
								Language	Lay workers	Place	Content
Blixen 2001	USA, socially disadvantaged African American, n = 28, 18-50 years, both sexes	3 sessions (6 months)	Usual care ("generic" asthma programme)	Three individual asthma self-management educational sessions. Workbook modified to be culturally appropriate. Video on Metered Dose Inhaler technique and peak flow monitoring featuring well-known African-American asthma researcher.	Nurse educator	3	-				x
Canino 2008	USA, Poor Puerto Rican, n = 221, 5-12 years, both sexes	3 sessions (4 months)	Given five flyers with asthma information.	Eight asthma education modules delivered as two family home visits and follow-up telephone calls. Culturally adapted modules.	Not stated	Minimum 3	Spanish	x		x	x
Grover 2016	India, Indian residents whose first language was not English, n = 40, 7-12 years, both sexes	1 session + physician appointment (6 months)	Standard information pack for asthma.	One individual educational session with child and family. Culturally adapted asthma education program, including age appropriate, graphically appealing educational materials for child. Sent to physician for development of asthma action plan.	Pharmacists, asthma educators, physician	2	Not English	x			x
La Roche 2006	USA, African-American/Hispanic descent, n=22, 7-15 years, both sexes	3 sessions (12 months)	3 standard education modules (without focus on socio-economic or cultural context).	Three individual educational session with child and family. Program based on allocentric self-orientation and socio-economic context of ethnic minorities, emphasising relational and collaborative asthma management among children, families, physician and mental health specialist.	Hispanic and African-American educator/psychologist.	3	-				x
Moudgil 2000	UK, South Asian origin who's first language was not English, n = 689, 11-59 years, both sexes	1 session (12 months)	Usual care ("generic" asthma programme)	One individual educational session with an asthma educator fluent in participants' own dialect (English, Punjabi, Hindi, Urdu).	Bilingual asthma educator.	1	"Not English"	x			x

Poureslami 2012	Canada, Immigrants who's first langue was not English, n = 92, > 21 years, both sexes	1 session (6 months)	Given pictorial pamphlet on asthma.	Allocated to one of three groups with different formats of culturally and linguistically modified asthma education. Group 3 included in review: 3) Knowledge and community video.	Video.	1	Punjabi, Mandarin, Cantonese	x			x
Valery 2010	Australia, Aboriginal or Torres Strait Islander, n = 113, < 18 years, both sexes	3 sessions over 6 months (12 months)	Baseline education session (identical to intervention group)	Baseline + three individual education sessions over 6 months. Delivered by trained Indigenous Health Care Workers, using paediatric asthma and respiratory education adapted to Torres Strait culture.	Trained Indigenous Health Care Workers	3	-		x		x

1 Information in this table is based on data provided by the review authors in Characteristics of included studies-table and Additional tables (72). We extracted additional information based what could be found in all parts of the review, from the text, tables and appendixes in the systematic review.

2 Dose indicates our estimates of the number of times the participants in the intervention group have been offered an activity, individual og group teaching sessions, counselling or similarly.

It is unknown to what extent the participants were reached by all the activities described (fidelity of the intervention).

3 If stated by the authors that the participants had a different mother tongue than the main language in the country.

4 Waiting list means that the control group received no follow-up or usual care during the trial, but was offered the intervention content after the trial was completed.

Appendix 7: Background information for Luque 2018

References to studies included in Luque 2018 (71)

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Characteristics of the studies, participants, controls and interventions included in Luque 2018 (71). All data based on information provided by review authors only from the text, tables and appendixes in the systematic review.

Reference id	Country, Group, No. of participants randomised, inclusion criteria age, sex	Duration of intervention (longest follow-up)	Control group treatment	Intervention group treatment		Additional extracted information ¹					
				Description of the intervention	Providers	Estimated "dose" ²	Specified language ³	Adaptations to group			
								Language	Lay workers	Place	Content
Coronado 2016	USA, Mexican immigrants/descent, n = 539, 42-74 years, women	Unclear (12 months)	Usual care	Home visits and follow-up telephone calls by "promodora" using motivational interviewing program. Additional mammography services delivered by mobile unit (free access).	Promodoras (lay health workers)	2	Spanish	x	x	x	?
Elder 2017 #	USA, Mexican immigrants/descent, n = 436, mainly 40-65 years, women	6 weeks (12 months)	Usual care (no intervention)	Weekly educational group sessions in church by "promodora". Handouts on cancer prevention, different cancers, patient rights and responsibilities over 6 weeks. Promodora could accompany participants to screening appointments and provided information on clinics and services.	Promodoras (lay health workers).	6	Assumed Spanish	?	x	x	?
Fernandez 2009	USA, Hispanic descent, n = 264, ≥ 50 years, women	2 weeks (6 months)	Usual care (no intervention)	Individual education sessions at home by "promodora". Toolbox with bilingual breast and cervical cancer education material. Follow-up telephone call after 2 weeks.	Promodoras (lay health workers).	2	Assumed Spanish	x	x	x	x
Jandorf 2014 #	UK, Hispanic descent, n = 1986, ≥ 40 years, women	Unclear (8 months)	Usual care (no intervention)	Teams with a Hispanic breast cancer survivor and lay health advisor delivered group educational program in different community, faith-based or home-based locations. 180 educational sessions delivered in total.	Lay health workers and peers.	Unclear	Assumed Spanish	?	x	x	?
Nuño 2011	UK, Hispanic descent, n = 371, ≥ 50 years, women	12 months (24 months)	Usual care (no intervention)	One educational group sessions by "promodora" in participants' homes (3-12 women at each session), with refresher session one year later. Information on breast and cervical cancer, diet for cancer	Promodoras (lay health workers).	2	Spanish	x	x	x	x

				prevention, self-esteem and community resources available.							
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1 Information in this table is based on data provided by the review authors in tables 1 and 2 (71). We extracted additional information based what could be found in all parts of the review, from the text, tables and appendixes in the systematic review.

2 Dose indicates our estimates of the number of times the participants in the intervention group have been offered an activity, individual og group teaching sessions, counselling or similarly. It is unknown to what extent the participants were reached by all the activities described (fidelity of the intervention).

3 If stated by the authors that the participants had a different mother tongue than the main language in the country.

4 Waiting list means that the control group received no follow-up or usual care during the trail, but was offered the intervention content after the trail was completed.

Cluster-randomised controlled trials, otherwise individual-randomised controlled trials.

Appendix 8: Background information for Lagisetty 2017

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Project plan (in Norwegian)

Prosjektplan for Effekt av tilpasset helseinformasjon og opplæring for pasienter med innvandrers- eller minoritetsbakgrunn: en oversikt over systematiske oversikter

Prosjektkategori og oppdragsgiver

Produkt (programområde): Oversikt over systematiske oversikter

Oppdragsgiver/bestiller. Nasjonal kompetanseenhet for minoritetshelse
(med navn på kontaktperson for eksterne prosjekter): (NAKMI) ved prosjektkoordinator Ragnhild Storstein Spilker

Prosjektledelse og medarbeidere

Prosjektleder: Astrid Austvoll-Dahlgren/Annhild Mosdøl

Prosjektansvarlig Gunn E. Vist
(gruppeleder):

Interne medarbeidere: Annhild Mosdøl/Astrid Austvoll-Dahlgren
Gunn E. Vist
Kristoffer Yunpeng Ding

Eksterne medarbeidere: -

Plan for erstatning ved prosjektdeltakers fravær: Interne medarbeidere tar over etter avtale med prosjektansvarlig

Plan utarbeidet 26.05.2017

Kort beskrivelse/sammendrag

Å tilegne seg helseinformasjon er avgjørende for å kunne fatte informerte helsebeslutninger og er blant annet avhengig av en persons helsekompetanse («health literacy»). Studier indikerer at pasientgrupper med innvandrers- eller minoritetsbakgrunn ikke har lik tilgang til helsetjenester, selv når man justerer for sosiodemografiske forskjeller som utdanning og inntekt. Begrenset tilgang til tilpasset helseinformasjon og pasientopplæring er én mulig årsak. Formålet med denne rapporten er å lage en oversikt over systematiske oversikter som evaluerer effekt av tilpasset informasjon og opplæring for pasienter med innvandrers- eller minoritetsbakgrunn. Nasjonal kompetanseenhet for minoritetshelse (NAKMI) vil bruke rapporten som et kunnskapsgrunnlag til en faglig veileder for helsepersonell.

English:

To acquire health information is essential to make informed health decisions and is among other factors dependent on a person's health literacy skills. Studies indicate that patient groups with immigrant or minority backgrounds do not have equal access to health care, even after

adjusting for sociodemographic differences such as education and income. Limited access to tailored information and patient education is one possible factor explaining this inequity. The aim of this report is to conduct a review of systematic reviews evaluating effects of tailored information and patient education for patients with immigrant or minority background. The Norwegian Centre for Migration and Minority Health (NAKMI) will use the report as evidence in a forthcoming guideline for health professionals.

Mandat

Denne prosjektplanen er utarbeidet etter et forslag fra Nasjonalt kompetansesenter for migrasjons- og minoritetshelse (NAKMI). Prosjektplanen bygger på et systematisk litteratursøk med påfølgende sortering av mulige relevante publikasjoner. Dette notatet (1), som ble publisert i april 2017, var utgangspunkt for videre prioritering og spissing av problemstillingen i samråd med NAKMI. Det systematiske litteratursøket viste at det er utført et stort antall relevante litteraturoversikter. Vi fant 96 publikasjoner, kategorisert i tre grupper (1);

- 18 på overordnede tema (spenner over flere diagnoser eller typer av tilpassede tiltak)
- 40 på forebyggende informasjon- og opplæringstiltak (primærforebygging)
- 38 på informasjon og opplæringstiltak for pasienter i behandling

Det ble derfor besluttet at fase to av prosjektet skulle bestå av en oversikt over systematiske oversikter av høy kvalitet som har evaluert effekt av tilpasset informasjon og opplæring av pasienter med innvandrers- eller minoritetsbakgrunn.

Mål

Formålet med denne rapporten er å gi en oversikt over systematiske oversikter som evaluerer effekt av tilpasset informasjon og opplæring av pasienter med innvandrers- eller minoritetsbakgrunn.

Bakgrunn

Den norske befolkningen har totalt sett god helse, men de fleste mål på helse og sykdom varierer med sosioøkonomiske faktorer slik som inntekt, utdanning og yrke (2). Forekomsten av helseproblemer hos voksne innvandrere er generelt noe høyere enn i befolkningen forøvrig (2-4), selv om dette kan variere betydelig mellom ulike grupper (3). En omfattende litteraturstudie fra USA belyser at pasienter med innvandrers- eller minoritetsbakgrunn ikke har lik tilgang til helsetjenester som den majoritetsbefolkningen har, selv når man justerer for sosiodemografiske forskjeller som utdanning og inntekt (5). Selv om tilgang til helsetjenester er annerledes i Norge enn i USA, peker også norsk statistikk på at enkelte innvandrergupper bruker helsetjenester i mindre grad eller på en annen måte enn resten av befolkning (6, 7).

Det er flere mulige forklaringer på disse funnene. Personer med innvandrerbakgrunn kan ha en annen forståelse av helse eller mangelfull kunnskap om rettigheter og plikter knyttet til bruk av helsetjenester. Tilgang til tilpasset informasjon og opplæring av pasientene er én mulig årsak

(8-11). Helse- og omsorgstjenestene har generelt liten kunnskap om hva ulike grupper i befolkningen vet og ikke vet om helse og sykdom, og hvordan de kan tilpasse og tilrettelegge helseinformasjon og pasientopplæring til innvandrergupper (12). Forskning har vist at helsepersonell kan føle seg rådvill og nølende i møte med pasienter med innvandrerbakgrunn (5, 13, 14). Dette er forklart med at helsepersonell kan ha stereotypiske oppfatninger om pasienten, en generell usikkerhet, men også frykt for å opptre upassende.

Helse- og omsorgstjenestene har, som andre offentlige tjenester, gjennom sin aktivitetsplikt et ansvar for å legge til rette for god kommunikasjon og riktig tilpasset informasjon. I pasientrettighetslovens § 3-5 heter det at "Informasjonen skal være tilpasset mottakerens individuelle forutsetninger, som alder, modenhet, erfaring og kultur- og språkbakgrunn" (15). Dette er en stor utfordring for helsetjenesten, særlig med tanke på at enkelte innvandrergupper kan ha særskilt behov for helsetjenester. For eksempel har Rådet for psykisk helse etterlyst et systematisk minoritetsperspektiv i alle ledd av tjenesteapparatet. Spesielt flyktninger har langt høyere sannsynlighet for psykiske lidelser som følge av traume og en sårbar livssituasjon (16, 17). Med tanke på den siste tids økning av flyktninger i Europa, har denne problemstillingen fornyet aktualitet (18, 19). Den potensielle nytten av å støtte helsetjenesten i utvikling av nye ressurser for å informere og gi opplæring til pasienter med innvandrers- eller minoritetsbakgrunn er derfor stor.

Betydningen av god helsekompetanse

Å tilegne seg helseinformasjon er avgjørende for å kunne fatte informerte helsebeslutninger. Slik evne er blant annet avhengig av en persons helsekompetanse («health literacy») (20, 21). Det finnes mange definisjoner på hva helsekompetanse innebærer. Utgangspunktet for de fleste av disse definisjonene er tilstrekkelige lese- og regneferdigheter, og i mange tilfeller også kjennskap til medisinsk terminologi og faguttrykk (22). Dette er ofte omtalt som funksjonell helsekompetanse («functional or fundamental health literacy») (20). Det er dessuten et mål i dagens helsetjeneste at pasienten skal involveres i beslutninger om egen helse (15). Dette forutsetter kjennskap til rettigheter og evne til deltakelse (18). Relevant helsekompetanse omfatter også kritisk tenkning og evne til gjøre vurderinger av ulike kilder til helseinformasjon som vi møter i hverdagen, slik som råd fra familie og venner, gjennom media eller fra helsetjenesten (23). Videre er kjennskap til hvordan helsetjenesten er organisert samt kunnskap om muligheter og plikter avgjørende for å dra nytte av tilgjengelige tilbud i helsetjenesten og for å yte god egenomsorg (18, 19). Utdanningsnivå er en av flere faktor som kan påvirke en persons helsekompetanse.

Slik det finnes mange definisjoner av og innhold i begrepet helsekompetanse, finnes det også flere forskjellige verktøy for å måle denne typen ferdigheter i befolkningen (22, 25). De fleste verktøyene er avgrenset til å måle funksjonell helsekompetanse, selv om noen også måler kritisk tenkning (for eksempel evne til å kritisk vurdere helseinformasjon) og evne til deltakelse (22, 25). Det finnes flere litteraturoversikter som har sett på sammenhengen mellom

helsekompetanse og relevante helseutfall. Disse viser gjennomgående en tendens der det å ha lavere helsekompetanse er forbundet med dårligere helse, lavere bruk av forebyggende helsetjenester (som vaksinasjon), feil legemiddelbruk, og uhensiktsmessig bruk av helsetjenester (24, 25).

Fra internasjonale studier som har benyttet objektive måleinstrument i hele befolkningen vet vi at lav helsekompetanse er relativt vanlig (23, 25). En europeisk studie har også målt egenopplevelse av (altså selvrapportert) helsekompetanse. Her skårer pasienter med innvandrerbakgrunn lavere enn den generelle befolkningen (26). Det er imidlertid viktig å anerkjenne at det er stor variasjon både innen og mellom ulike innvandrer- og minoritetsgrupper når det gjelder forekomst av lav helsekompetanse (27).

Tilpasset informasjon og opplæring

I denne rapporten vil vi oppsummere forskning om effekt av tilpasset informasjon og opplæring gitt som personlig oppfølging til pasienter i regi av helsetjenesten.

Med *informasjon* menes råd og veiledning som er formidlet av helsepersonell og andre fagpersoner for å fremme god helse, forebygge sykdom eller for å sikre riktig oppfølging av legemiddelbruk og egenomsorg. *Opplæring* forstås her som undervisning med intensjon om å framkalle læring hos en annen ved å fremme kunnskap, ferdigheter og holdninger. Slik informasjon og opplæring kan omfatte informasjon om egen helsetilstand, rett legemiddelbruk og egenomsorg eller for eksempel informasjon om bruk av helsetjenester.

For denne rapporten definerer vi at *personlig oppfølging* også kan inkludere informasjon eller opplæring gitt til en gruppe (f.eks. gjennom deltakelse i kvinnegrupper eller pasientopplæring i grupper med bestemte diagnoser). Folkehelseiltak slik som kampanjer eller systembaserte tiltak faller imidlertid utenfor denne definisjonen. Spørsmål om effekt av tilpassede kampanjer og systembaserte tiltak besvares i to andre systematiske oversikter fra Folkehelseinstituttet (28, 29).

Tilpasning av informasjon og opplæring kan ha mange former, og kan omfatte:

- Språk, slik at informasjonen møter målgruppen på rett funksjonelt nivå (eller bruker pasientens eget språk/morsmål)
- Format på informasjons- og opplæringsmaterialet (f.eks. farger, grafikk og form)
- Type formidling (f.eks. tekst, lyd og bilde)
- Mengde og intensitet (hvor ofte og hvor mye informasjon/ opplæring blir gitt)
- Kultursensitivitet
- Valg av didaktisk metode (f.eks. individuell eller gruppebasert undervisning eller ulik grad av medvirkning)

Definisjon av studiepopulasjonen

I Norge definerer Statistisk sentralbyrå innvandrere slik: «Personer født i utlandet av to utenlandsfødte foreldre. Innvandrere har på et tidspunkt innvandret til Norge»(30). Denne definisjonen er bred og smal på samme tid. Den avgrenser ikke på nasjonalitet og omfatter personer som har oppholdt seg i landet kort og lang tid. Samtidig er den smal i den forstand at den ikke inkluderer barn av personer født i landet av to utenlandsfødte foreldre. I Norge er også urfolk og nasjonale minoriteter anerkjent som egne kulturelle grupper, men det føres ikke statistikk over hvem som har tilhørighet til disse.

Begrepene «innvandrer» og «minoritet» defineres forskjellig i ulike land og kontekster. Siden vi ønsker å inkludere all relevant forskning om tilpassede tiltak, både nasjonalt og internasjonalt, inkluderes ulike definisjoner av begrepene for ikke å avkorte antall studier unødig. Dette inkluderer også studier av tiltak tilpasset til minoritetsgrupper, siden dette kan være relevant informasjon om hvordan tilpassede tiltak virker. For formålet i denne rapporten vil vi derfor forstå begrepet *minoritet* slik: Grupper av mennesker med utenlandsk opprinnelse, nasjonale minoriteter eller urfolk, som i de identifiserte studiene kjennetegnes av å kunne ha utfordringer knyttet til språk, kjennskap til helsevesenet, samt rettigheter og plikter knyttet til tjenester og medvirkning i det landet de bor i. Denne definisjonen vil også inkludere barn av personer født i landet av to utenlandsfødte foreldre. Det er grunn til å tro at en viss andel i sistnevnte gruppe kan ha liknende utfordringer som sine foreldre.

Metoder og arbeidsform

Fremgangsmåten i denne rapporten vil være basert metodene for oversikter over systematiske oversikter som benyttes ved Område for helsetjenesten i Folkehelseinstituttet(19). For at en litteraturoversikt skal kjennetegnes som *systematisk* må den ha vært utført av minst to forfattere og som har tatt i bruk «systematiske og eksplisitte metoder for å identifisere, utvelge og kritisk vurdere relevant forskning, samt ved innsamling og analyse data fra studiene som er inkludert i oversikten»(31).

Siden denne prosjektplanen er en videreføring av en bred kartlegging av feltet i form av et litteratursøk med sortering (1), bygger metodene på det arbeidet som allerede er gjennomført.

Søkestrategi

Litteratursøket til denne rapporten ble gjennomført februar 2017 (1). Søket ble utarbeidet av en bibliotekar (GSH) og en annen bibliotekar fagfellevurderte dette. Vi søkte etter systematiske oversikter i:

- Cochrane Library (CDSR, DARE, HTA)
- MEDLINE
- PsycINFO
- Embase

I tillegg søkte vi etter planlagte systematiske oversikter i PROSPERO.

Utvelgelse av studier, vurdering av risiko for systematiske feil

To personer (AA, GEV, KY) vurderte uavhengig av hverandre litteraturoversikter identifisert i søket for inklusjon etter kriterier gitt i tabellen nedenfor. Ved uenighet konfererte vi med en tredje person.

Inklusjonskriterier	
Populasjon	Personer med innvandrer- eller minoritetsbakgrunn i det landet de er bosatt i og som antas å ha lav helsekompetanse
Tiltak	Tilpasset helseinformasjon eller opplæring (eksempelvis språk, format, type formidling, mengde og intensitet, kultursensitivitet eller didaktisk metode).
Sammenlikning	Ikke tilpasset helseinformasjon eller opplæring
Utfall	Relevante utfall omfatter, men er ikke begrenset til: -Helse -Kunnskap og forståelse -Mestring (self-efficacy) -Etterlevelse av anbefalt behandling -Deltakelse i helsebeslutninger -Bruk av helsetjenester -Kostnader
Studiedesign	Systematiske oversikter publisert 2012 eller senere, og som blir vurdert til å ha høy kvalitet
Språk	Ingen begrensninger

Vi ekskluderte systematiske oversikter som kun omfatter:

- tiltak rettet mot helsepersonell (eksempelvis kun opplæring av helsepersonell)
- systembaserte tiltak (eksempelvis massemediakampanjer)
- organiseringstiltak (eksempelvis ulike sammensetninger av behandlingsteam)

I videreføringen av dette prosjektet tar vi utgangspunkt i litteraturlisten fra notatet som ble publisert i april 2017 (1). Prosjektet bearbeider videre de publikasjonene som er relevante for den utvalgte problemstillingen fra NAKMI.

Vi vil vurdere kvaliteten på relevante publikasjoner basert på en sjekkliste for systematiske oversikter (19). Basert på sjekklisten kan kvaliteten på de systematiske oversiktene klassifiseres som av lav, middels eller høy. Kun systematiske oversikter vurdert til å være av høy kvalitet vil bli inkludert i de videre analysene. Resultatene vil bli oppsummert etter type tiltak (type tilpasning). Hvis det er overlapp i problemstillingen mellom de inkluderte systematiske oversiktene vil vi ta utgangspunkt i oversikten med det nyeste litteratursøket.

Dataekstraksjon og analyse

AA/AM vil hente ut data fra inkluderte systematiske oversiktene og GEV eller KY vil kvalitetssikre disse. Ved uenighet vil vi konferere med en tredje person. Vi vil basere analysen på informasjonen beskrevet i de systematiske oversiktene og vil følgelig ikke hente inn primærstudier. Vi vil sortere og presentere funnene fra de systematiske oversiktene separat og etter populasjon/ tiltak evaluert.

Vi vil vurdere tilliten til dokumentasjonen av effekt or hvert av utfallsmålene i hver systematisk oversikt ved hjelp av GRADE (32). Vi beskriver tilliten til dokumentasjon av effekt som høy, middels, lav eller svært lav for hvert utfall. Dersom de systematiske oversiktene allerede har vurdert tilliten til dokumentasjonen med GRADE, vil vi gjøre en vurdering av denne og formidle vår samlede vurdering.

Aktiviteter, milepæler og tidsplan

Oppgave	Ansvarlig	Startdato	Sluttdato
Skrive prosjektplan	AA/AM	26/05/2017	26/05/2017
Fagfellevurdering prosjektplan	AA/AM	29/05/2017	31/06/2017
Godkjenning prosjektplan	Ledergruppen	22/08/2017	30/08/2017
Velge ut systematiske oversikter	AA, GEV	29/05/2017	23/06/2017
Kvalitetsvurdering av systematiske oversikter	AA, AM, GEV, KYD	29/05/2017	30/08/2017
Hente ut data, sammenstille og GRADE-vurdere dokumentasjonen	AA, AM, GEV, KYD	01/06/2017	15/10/2017
Skrive ferdig rapport	AM	01/09/2017	31/10/2017
Fagfellevurdering rapport	AM	01/11/2017	05/12/2017
Godkjenne og publisere	Ledergruppen	06/12/2017	22/12/2017

Sluttdato (dato for publisering): 22/12/2017

Publikasjon/formidling

Prosjektet skal resultere i en rapport som vil bli publisert på Folkehelseinstituttets nettsider. Målgruppen for rapporten er helsepersonell og andre i helsetjenesten som jobber med å støtte pasienter med innvandrer- eller minoritetsbakgrunn i å ta informerte helsebeslutninger.

Risikoanalyse

Hvert elements risikofaktor er produktet av sannsynlighet og konsekvens. Vurderingen angis med graderingene liten, middels og stor.

RISIKOELEMENT	SANNSYNLIGHET	KONSEKVENNS	RISIKOFAKTOR
Omorganisering	Høy	Forlenger prosjektperioden	Middels
Ny prosjektleder fratrer stillingen	Lav	Annen forfatter tar over hovedansvaret	Lav
Andre prosjekter for prioritet først	Lav	Forlenger prosjektperioden	Lav

Tiltak for å begrense risikoelementenes sannsynlighet og konsekvens:

– Ingen kjente

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Indeksering for hjemmesiden

Health literacy, helsekompetanse, minoritetshelse, innvandrere, tilpasset, skreddersydd, helseinformasjon, pasientundervisning.

Relaterte prosjekter/publikasjoner

D'Eath M, Barry MM, Sixsmith J. Rapid Evidence Review of Interventions for Improving Health Literacy. Stockholm: ECDC; 2012

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