

review title

Self-management education programmes by lay leaders for people with chronic conditions (Foster et al 2007)

focus of the review

The aim of this Cochrane review was to assess the effectiveness of lay-led self-management education programmes for people with chronic conditions. Interventions of included studies had the following characteristics:

- Trained lay people delivered the majority of the content
- Disease self-management was the primary issue addressed
- Programmes had an educational aim and were structured
- People with chronic conditions were the target
- Formats for delivery varied—face-to-face, groups/individually, other interactive media
- Person with the chronic illness was the primary focus

key results of the review

This review shows that, lay-led self-management interventions, compared with usual care, for people with chronic conditions:

- May in the short term improve participants' self-efficacy to manage symptoms, as well as self-rated health and use of cognitive symptom management techniques. They may also reduce health distress.
- May in the short term improve measures of pain, disability, fatigue, depression and anxiety. (Review authors state that although there were effects in favour of the intervention for these five outcomes they were extremely small and likely to be trivial).

This review does not show, for people with chronic conditions:

- The effects of lay-led self-management interventions, compared with professional-led interventions, on health and treatment outcomes, behavioural outcomes, consumer knowledge, involvement and evaluation of care.
- The effects of lay-led self-management interventions, compared with usual care or professionally-led interventions, on health service use outcomes (including doctor visits and time in hospital), clinical outcomes, psychological wellbeing overall or health-related quality of life.
- On consumer-oriented and other outcomes (professional and health services outcomes) beyond 6 months.

this bulletin summarises a Cochrane systematic review

this page highlights key aspects of the review

pages 5-8 summarise the review

the evidence table on pages 6-9 contains more detail of the review

this evidence bulletin is provided by The Cochrane Consumers & Communication Review Group

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summary of
the review

Background to the review

Health systems are shifting to models of care that are inclusive of patient involvement in management of their own health condition. Lay-led self-management education programmes for people with chronic disease are considered an effective way to promote increased patient involvement. Such education programmes are an attempt to provide cost-effective care for the growing number of people with chronic disease.

Self-management education programmes, designed to enable active patient involvement in management of their own condition, are generally well-defined and have a pre-determined structure. They are distinct from simple patient education, skills training or less formalised peer support interventions.

While interpretations of the term 'lay-led' may vary between programmes, lay leaders are all trained and accredited and follow a self-management philosophy rather than a medical approach. There are key differences between lay-led (or peer-led) education and professionally-led education: lay leaders commonly have a chronic disease; lay-led education may be less formal and facilitate more helpful discussion for participants; and lay-leaders may provide important and sensitive interpretations of health advice for specific cultural groups or interpretations that reflect particular health beliefs.

National programmes developed in the UK and Canada have attracted considerable public support and publicity, and consumers recognise that such programmes have the potential to provide them with a voice and better health outcomes. There are uncertainties, however, about the effectiveness of lay-led self-management education programmes in different populations, in different health care settings, compared with professionally-led education programmes, and about the best modes of delivery.

Studies included in the review

Seventeen studies were included in the review; sixteen were randomised controlled trials; one was a cluster randomised

controlled trial; and 7442 participants were included.

Ten studies were conducted in North America, four took place in the United Kingdom, and one each in China, Australia and the Netherlands. Thirteen studies took place in the community, three in primary care and one in a hospital outpatient department.

Studies in this review involved adults with chronic conditions including arthritis, diabetes, hypertension, heart disease, chronic lung disease, mental health and neurological conditions, HIV infection and chronic pain. There were no studies of children and adolescents.

Overall 70% of the 7442 recruited participants were female. The mean age of the study participants ranged from 44 to 79 years. In eleven studies over 90% of participants were white. Five studies were directed at participants from other cultural groups including: Hispanic; Chinese; Bangladeshi; and Vietnamese, Greek and Italian.

In eight studies the majority of participants had 13 or more years of education, in two studies participants had on average 11 to 12 years of education and in five studies participants had on average less than 10 years of education.

Focus of interventions

Interventions were lay-led self-management education programmes targeting people with chronic conditions. All studies compared interventions delivered by lay leaders with usual care. Three studies also assessed the effects of a professionally-led intervention group in a third study arm. All lay leaders were trained and in three of the studies at least one of the leaders had the same chronic condition as the participants.

The 17 studies included in this review were grouped by type of intervention:

- Arthritis Self-Management Programme (ASMP): studies recruiting participants with arthritis (4 studies) and osteoarthritis (1 study);
- Chronic Disease Self-Management Program (CDSMP) or its variation The Expert Patient Programme (EPP): studies recruiting participants with variable conditions including hypertension, heart disease, chronic lung

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- disease, stroke, diabetes, mental health and neurological conditions (7 studies);
- Other disease-specific lay-led educational interventions: studies recruiting participants with diabetes (2 studies), HIV infection (1 study), chronic low back pain (1 study) and heart failure (1 study).

Description of interventions, outcomes

The ASMP and CDSMP, or its variation the EPP, included a structured course of six weekly sessions, each of approximately 2.5 hours, led by at least one trained and accredited lay leader. Session content included: information on goal setting and problem solving; lifestyle changes around diet, exercise, and sleep; identifying resources; symptom management; dealing with anger, fear and frustration; and communication with health professionals. The lay facilitator acted as a positive role model. Participants were also given an educational manual or booklet or videocassette covering the course content.

For disease-specific interventions, the course varied in structure from four to seven weekly sessions, each approximately 1.5 to 3 hours. Participants also received literature about their condition, and in 3 studies an additional videotape. In one study a physician led 25% of the classes.

Primary outcomes of included studies incorporated four major categories:

- Clinical outcomes; health status (eg self-rated health status and health-related quality of life, pain, disability, psychological wellbeing);
- Health behaviour (eg adherence, cognitive symptom management);
- Healthcare use (eg hospital admissions, doctor visits); and,
- Self-efficacy to self-care.

Secondary outcomes included:

- Knowledge of the condition;
- Social roles/ activities, perceived social support;
- Course attendance;
- Communication with physician;
- Costs of delivering the programme, cost effectiveness;

- Effects on carers/ family members; and,
- Adverse outcomes.

What the review shows: summary of key findings

Findings from studies that implemented structured lay-led self-management education programmes versus usual care or no intervention

Health status

There is sufficient evidence from trials that compared with usual care, lay-led programmes were associated with improvements in both **pain** (11 trials, 4683 participants) and **disability** (8 trials, 3491 participants) at 6 month follow-up, but there is insufficient evidence to decide between lay-led programmes and usual care for either outcome at 12 months.

There is sufficient evidence from trials that compared with usual care, lay-led programmes were associated with reduced **fatigue** (7 trials, 3251 participants).

There is sufficient evidence from trials that compared with usual care, lay-led programmes were associated with improvements in both **depression** (6 trials, 2613 participants) and **anxiety** (3 trials, 1573 participants).

There is sufficient evidence from trials that compared with usual care, lay-led programmes were associated with improvements in **health distress** (6 trials, 3061 participants) and general self-reported **health status** (6 trials, 3061 participants).

Health behaviour

There is sufficient evidence from trials that compared with usual care, lay-led programmes were associated with higher frequency of **aerobic exercise** (7 trials, 3040 participants) and frequency of practicing **cognitive symptom management** techniques (4 trials, 2628 participants).

Self-efficacy

There is sufficient evidence from trials that compared with usual care, lay-led programmes were associated with improvements in **self-efficacy to manage symptoms** (10 trials, 3682 participants).

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Communication

There is sufficient evidence from trials that compared with usual care, lay-led programmes were associated with improved **communication** with health professionals (7 trials, 3643 participants).

Findings from the studies that implemented structured lay-led self-management education programmes versus professionally-led programmes

Health behaviour

There is some evidence from trials that compared with a professionally-led programme, a lay-led programme was associated with more frequent practice of **relaxation techniques** (1 trial, 86 participants).

What the review does not show

Findings from the studies that implemented structured lay-led self-management education programmes versus usual care or no intervention

Other clinical and health status outcomes

There is insufficient evidence from trials to decide between lay-led programmes and usual care with respect to **psychological wellbeing**, health-related **quality of life**, **shortness of breath** or **clinical measures** (eg glycosylated haemoglobin levels).

Health care use

There is insufficient evidence from trials to decide between lay-led programmes and usual care with respect to **healthcare use**, including physician/GP visits, number of days or nights in hospital or emergency room visits.

Other outcomes

There is insufficient evidence from trials to decide between lay-led programmes and usual care with respect to **knowledge**, **social support**, **programme attendance** or **costs**.

No study reported the effects of lay-led programmes, compared with usual care, on outcomes for **carers**.

Harms and adverse effects

Authors note that none of the included

studies reported adverse outcomes or harms, and that no study reported that complaints had been received.

Findings from the studies that implemented structured lay-led self-management education programmes versus professionally-led programmes

Other outcomes

There is insufficient evidence from trials to decide between lay-led and professionally-led interventions with respect to **knowledge** or **locus of control** (for people with diabetes).

Harms and adverse effects

Authors note that none of the included studies reported adverse outcomes or harms and that no study reported that complaints had been received.

Conclusions

Authors conclude that, in the short term, lay-led self-management education programmes improve health status outcomes (eg pain and disability), improve two health behaviours (cognitive symptom management and self-reported frequency of aerobic exercise), and increase self-efficacy to manage symptoms. There is currently little evidence of an effect on clinical measures, and no evidence of an effect on healthcare use.

Authors discuss three issues that may affect the impact of these interventions: large numbers of participants with chronic disease may not have been reached with the recruitment method targeted to patient registers (ie targeting patient registers may have led to low or variable uptake); programmes may need to target participants with higher morbidity at the time of study entry; benefits for a range of participants, such as men, adolescents and children, cannot be determined from the current research as this is based mainly on women aged over 40 years. Authors state that taking these issues into consideration, widespread implementation of self-management education interventions may have the potential to improve health inequalities. However, if the aim is to reduce healthcare resource use there is currently insufficient evidence to warrant such widespread dissemination.

see the evidence
table and
key to results
on pages 6-9

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Recommendations from authors

Authors recommend that further well-designed and reported research is needed to evaluate the effects of lay-led self-management education programmes in several areas. In particular, research is needed on a range of standardised outcomes relevant to chronic disease management, including long term effects beyond 6 months.

Additional outcomes that should be assessed include biological/clinical markers of disease control (such as cholesterol levels, glycaemic control); clearly defined measures of healthcare use and self-efficacy; and cost-effectiveness.

Authors recommend that the effects of disease-specific interventions be assessed in

rigorous studies; and that intervention components be systematically varied and evaluated to establish the most effective lay-led educational interventions for chronic disease-self-management. This should include assessment of professionally-led intervention components.

Authors also recommend that the effects of lay-led self-management education programmes be assessed in a broader range of participants, specifically including men, children and adolescents, and targeting those with more severe morbidity.

Authors additionally recommend that complementary qualitative research be conducted to explore how participants experience the interventions and how uptake of the interventions might be improved.

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Monthly bulletins, forwarding, feedback from members

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organisation's website. Let us know when you do this so we can keep in touch with the reach of our knowledge transfer service.

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inviting feedback on bulletins

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EVIDENCE TABLE

This table is part of an overview of the review created by Dr Rebecca Ryan, at The Consumers & Communication Review Group. It contains detailed data extracted from the review, and was referred to in the creation of the summary on previous pages of this EVIDENCE bulletin. This table uses standardised wording developed by Dr Ryan. A key to this wording follows the table and should be used to interpret the data.

Review title: Self-management education programmes by lay leaders for people with chronic conditions

Authors: Foster G, Taylor SJC, Eldridge SE, Ramsay J, Griffiths CJ

Description of main features

Aim: To assess the effectiveness of lay-led self-management programmes for people with chronic conditions .

Study design:

RCT

Participants:

Included: Patients and/or their carers or representatives, of any age, presenting for one-to-one consultations with doctors or nurses in healthcare settings.

Excluded: People attending activities such as health promotion clinics, either as individuals or in group settings. Studies in which people consulted healthcare professionals other than doctors or nurses were excluded; as were studies of inpatients where a specific consultation was not able to be identified.

Interventions:

Included: Any lay-led self-management education programme targeting people with chronic conditions. Programmes were included if they were structured and their aim was primarily educational, they primarily addressed disease self-management, and the majority of the content was delivered by lay people. Interventions were included if they incorporated elements of peer support, as long as the primary focus was education addressing disease self-management. Interventions incorporating a clinician-led component were also included, as long as the majority of the time was devoted to lay-led activities. Education could be delivered in various formats, including face-to-face education, delivered in groups or individually. Educational interventions delivered via other media, such as by post or electronically (eg phone or internet) were included where the activities included an iterative process of interaction between the participant and tutor. Interventions could include education for carers and/or family members, as long as the intervention was primarily focussed on the person with the chronic illness.

Excluded: Interventions that did not involve structured formal education, such as those providing information (literature) alone without iteration; and those described as self-management education but were not structured education programmes.

Comparison arms:

Structured lay-led self-management education programmes for chronic conditions versus usual care or no intervention

Structured lay-led self-management education programmes for chronic conditions versus professional-led programmes

Outcomes:

Included: Primary outcomes incorporated four major categories: clinical outcomes and health status (eg self-rated health status and health-related quality of life, pain, disability, psychological wellbeing); health behaviour (eg adherence, cognitive symptom management); healthcare use (eg hospital admissions, doctor visits); and self-efficacy to self-care.

Secondary outcomes included: knowledge of the condition, social roles/ activities and perceived social support, course attendance, communication with physician, costs of delivering the programme and cost effectiveness, effects on carers/ family members, and adverse outcomes.

Number of studies included: 17 (1 study is ongoing)

Types of studies included: RCT (16), cluster RCT (1)

Number of participants included: 7442

Meta-analysis performed: Yes; narrative data also provided where meta-analysis was not possible.

Review methods: Standard Cochrane Collaboration review methods were used, including the following: a priori research design provided; extensive searching; selection criteria were specified in advance and applied; list of included and excluded studies provided; quality criteria for assessment of included studies were reported and applied; methods of analysis were reported; conflict of interest stated.

Quality:

Included studies: Assessed via a component approach in terms of: method of randomisation; allocation concealment; blinding of outcome assessors and data analysts; baseline comparability of groups; follow-up; intention-to-treat analysis; validation of tools; and other sources of bias. Overall, trials were of variable quality: two studies were rated as high quality, three of intermediate quality, and for the remainder of included studies quality was unclear. Of the included studies, 7/17 reported adequate randomisation methods; 4/17 adequately concealed allocation; 6/17 adequately blinded outcome assessors, but blinding of data analysts was unclear for all studies; all studies demonstrated comparable groups at baseline; follow-up was variable but none reported follow-up of <65% (2/17 studies achieved follow-up of >90%, 8/17 achieved 81 to 90% follow-up, 3/17 achieved 70 to 80% follow-up, 4/17 achieved rates <69%). ITT analysis was dealt with in different ways: 2/17 studies substituted baseline data for missing data; 1/17 imputed missing values by entering data selected from the sample on a rational basis; 9/17 stated use of ITT analysis but only presented data for study completers; 1/17 reported ITT analysis for some data but not all data; 4/17 did not use ITT analysis. Selective reporting of outcomes may predispose this review to reporting bias: only 7/17 studies identified primary outcomes and many outcomes were reported by a small number of, or single, studies. Participant-expectation bias may also exist as participants could not be blinded to interventions group and outcome measures were self-reported. Use of wait-list control groups may also be prone to bias in these situations: however, this was explicitly assessed by authors in sensitivity analyses and no major changes to results were found.

*Review AMSTAR rating (out of possible 11): 11 - high quality review.

Comments: The review methods adequately met all items of the AMSTAR checklist with the exception of the item evaluating assessment of publication bias: the likelihood of publication bias was not explicitly addressed by the review.

Setting: Country: North America (10) studies), UK (4), China (1), Australia (1) and the Netherlands (1). Intervention: In the majority of studies (13), interventions were delivered in community settings; three studies delivered interventions in primary care and one in a hospital outpatient setting.

Recipient: Interventions directed to the consumer.

Provider: Interventions were lay-led by definition. All studies compared interventions delivered by lay leaders with usual care. Three studies also assessed the effects of a professionally-led intervention group in a third study arm. All lay leaders were trained, and in three studies at least one of the lay leaders had the same chronic condition as study participants. In one study a physician led 25% of the classes.

Format: A number of intervention groups were found, but with similar underlying components: the Arthritis Self-Management Programme (ASMP) (5 studies, recruiting participants with arthritis (4 studies) and osteoarthritis of the knees or hips (1 study)); the Chronic Disease Self-Management Program (CDSMP) or its variation The Expert Patient Programme (EPP) (7 studies, recruiting participants with variable conditions including hypertension, heart disease, chronic lung disease, arthritis, stroke, diabetes, chronic pain, chronic back pain, chronic fatigue, mental health and neurological conditions); other disease-specific lay-led interventions (5 studies, recruiting participants with diabetes (2 studies), HIV infection (1 study), chronic low back pain (1 study) and heart failure (1 study)). The ASMP and CDSMP/EPP include a structured course of 6 weekly sessions, each of approximately 2.5 hours, led by at least one trained and accredited lay leaders. Session content includes information on goal setting, problem solving, lifestyle changes, symptom management and communication with health professionals. Participants also receive an educational booklet, manual or videotape that covers the course content. For disease-specific interventions, the course varied in structure from 4 to 7 weekly sessions, each approximately 1.5 to 3 hours. Participants also received literature about their condition, and in 3 studies an additional videotape.



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Intervention	Results of review
<p>Structured lay-led self-management education programmes versus usual care or no intervention</p>	<p><u>Primary outcomes:</u></p> <p>Sufficient evidence from trials: compared with usual care, lay-led programmes were associated with improvements in both pain (11 trials, 4683 participants) (SMD -0.10, 95% CI -0.17, -0.04) and disability (8 trials, 3491 participants) (SMD -0.15, 95% CI -0.25, -0.05) at 6 month follow-up, but insufficient evidence to decide between lay-led programmes and usual care for either outcome at 12 months.</p> <p>Sufficient evidence from trials: compared with usual care, lay-led programmes were associated with reduced fatigue (7 trials, 3251 participants) (SMD -0.16, 95% CI -0.23, -0.09).</p> <p>Sufficient evidence from trials: compared with usual care, lay-led programmes were associated with improvements in both depression (6 trials, 2613 participants) (SMD -0.16, 95% CI -0.24, -0.07) and anxiety (3 trials, 1573 participants) (SMD -0.14, 95% CI -0.25, -0.04).</p> <p>Sufficient evidence from trials: compared with usual care, lay-led programmes were associated with improvements in health distress (6 trials, 3061 participants) (SMD -0.25, 95% CI -0.34, -0.15) and general self-reported health status (6 trials, 3061 participants) (WMD -0.20, 95% CI -0.31, -0.10), although the latter outcome was associated with significant heterogeneity ($p < 0.01$).</p> <p>Sufficient evidence from trials: compared with usual care, lay-led programmes were associated with higher frequency of aerobic exercise (7 trials, 3040 participants) (SMD -0.20, 95% CI -0.27, -0.12) and frequency of practicing cognitive symptom management techniques (4 trials, 2628 participants) (WMD -0.55, 95% CI -0.85, -0.26), although there was significant heterogeneity in the latter outcome ($p < 0.001$).</p> <p>Sufficient evidence from trials: compared with usual care, lay-led programmes were associated with improvements in self-efficacy to manage symptoms (10 trials, 3682 participants) (SMD -0.30, 95% CI -0.41, -0.19), although there was significant heterogeneity for this outcome ($p = 0.01$).</p> <p>Insufficient evidence from trials: to decide between lay-led programmes and usual care with respect to psychological wellbeing, health-related quality of life, shortness of breath or clinical measures (HbA1c levels).</p> <p>Insufficient evidence from trials: to decide between lay-led programmes and usual care with respect to healthcare use, including physician/GP visits, number of days or nights in hospital or emergency room visits.</p> <p><u>Secondary outcomes:</u></p> <p>Sufficient evidence from trials: compared with usual care, lay-led programmes were associated with improved communication with health professionals (7 trials, 3643 participants) (SMD -0.15, 95% CI -0.25, -0.05), although there was significant heterogeneity in this outcome ($p = 0.05$).</p> <p>Insufficient evidence from trials: to decide between lay-led programmes and usual care with respect to knowledge, social support, programme attendance or costs.</p> <p>Insufficient evidence in relation to measurement: no study reported the effects of lay-led programmes, compared with usual care, on outcomes for carers.</p> <p><u>Harms and adverse effects:</u></p> <p>Insufficient evidence in relation to measurement: authors note that none of the included studies reported adverse outcomes or harms, and that no study reported that complaints had been received.</p>
<p>Structured lay-led self-management education programmes versus professionally-led programmes</p>	<p><u>Primary outcomes:</u></p> <p>Some evidence from trials: compared with a professionally-led programme, a lay-led programme was associated with more frequent practice of relaxation techniques (1 trial, 86 participants).</p> <p><u>Other outcomes:</u></p> <p>Insufficient evidence from trials: to decide between lay-led and professionally-led interventions with respect to knowledge or locus of control (diabetes).</p> <p><u>Harms and adverse effects:</u></p> <p>Insufficient evidence in relation to measurement: authors note that none of the included studies reported adverse outcomes or harms, and that no study reported that complaints had been received.</p>



KEY TO RESULTS

The table on this page presents the standardised wording that should be used to interpret the data in the results section of the EVIDENCE table on the previous two pages.

SUMMARY STATEMENT	TRANSLATION
Sufficient evidence from trials	<p>Evidence to support conclusions about the effect of the intervention(s) in relation to a specific outcome(s). This includes evidence of an effect in terms of:</p> <ul style="list-style-type: none"> • benefit or • harm. <p>Statistically significant results are considered to represent sufficient evidence to support conclusions, but a judgement of 'sufficient evidence' is also based on the number of trials/ participants included in the analysis for a particular outcome.</p> <p>A grading of 'sufficient evidence' is often based on meta-analysis producing a statistically significant pooled result that is based on a large number of included trials/ participants.</p> <p>This judgement may also be made based on the number of trials and/or trial participants showing a statistically significant result - for example (in a narrative synthesis) a result where 12 studies of a total of 14 for a specific outcome showed a statistically significant effect of an intervention would be considered to represent 'sufficient evidence.'</p>
Some evidence from trials	<p>Less conclusive evidence to make a decision about the effects of a particular intervention(s) in relation to a specific outcome(s).</p> <p>This may be based on narrative syntheses of review results. In this case, the result is qualified according to the findings of the review - for example, 'some evidence (5 studies of 9) reported a positive effect of'</p> <p>{This would be based on a more equivocal set of results than those obtained for 'sufficient evidence' above. For example, while 12/14 statistically significant studies would be classed as 'sufficient evidence', 5/9 statistically significant studies is more equivocal and would be classes as 'some evidence.'}</p> <p>This may also be based on a statistically significant result obtained in a small number of trials; or a statistically significant result obtained from trials with a small number of participants.</p>
Insufficient evidence from trials	<p>Not enough evidence to support conclusions about the effects of the intervention(s) on the basis of the included studies. This should be interpreted as 'no evidence of effect', rather than 'evidence of no effect'.</p> <p>Statistically non-significant results are considered to represent insufficient evidence.</p> <p>Where the number of trials is small, and/or the number of participants included in the trials is small, 'insufficient evidence' might reflect underpowering of the included trials to be able to detect an effect of the intervention.</p> <p>Where the number of trials is large, and/or the number of participants included in these trials is large, 'insufficient evidence' may reflect underlying ineffectiveness of the intervention to affect the outcomes being examined.</p>
Insufficient evidence in relation to measurement	<p>Not enough evidence to support conclusions about the effects of the intervention due to a lack of reporting on the specified outcomes.</p> <p>This can be the result of :</p> <p>(i) the review electing not to report on a particular outcome, or set of outcomes, despite being reported by the included trials; or</p> <p>(ii) the review was not able to report on the outcome, as data for the outcome was not reported by the included trials. Note: used for reporting against outcomes only.</p>
N/A	<p>Not applicable to the outcome category of interest. Note: used for reporting against outcomes only.</p>