Title

Strategies to improve adherence to skin self-examination and other self-management practices in people at high risk of melanoma: a scoping review of randomised clinical trials

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Word count: 3305

Date of revision: 10 December 2022

Key Points

Question

What evidence exists on adherence in trials of melanoma self-monitoring practices?

Findings

This scoping review of 18 trials found that the most common adherence strategies used targeted trial design (limiting eligibility, theory-based intervention) and participant support (educational materials). There were no strategies reported for supporting underserved groups to adhere, limited strategies targeting provider adherence, and underutilisation of patient behavioural support strategies such as reminders and motivational tools. Reporting on nonadherence was limited and rarely included in implementation recommendations.

Meaning

Clearer definition, measurement, reporting and discussion of intervention adherence in trial settings is needed to successfully guide implementation into practice.

Abstract

Importance:

Adherence, both in research trials and in clinical practice, is crucial to the success of interventions. There is limited guidance on strategies to increase adherence, and the measurement and reporting of adherence in trials of melanoma self-management practices.

Objective:

This scoping review aimed to describe (i) strategies to improve adherence to self-management practices in randomised clinical trials of people at high risk of melanoma and (ii) measurement and reporting of adherence data in these trials.

Evidence Review:

We searched four databases to July 2022. Eligible studies were randomised trials of self-monitoring interventions for early detection of melanoma in people at increased risk due to personal history (e.g., melanoma, transplant, dysplastic naevus syndrome), family history of melanoma or as determined by a risk assessment tool or clinical judgement.

Findings:

From 939 records screened, we identified 18 eligible trials using a range of adherence strategies but with sparse evidence on effectiveness of the strategies. Strategies were classified as: trial design (n=15); social and economic support (n=5); intervention design (n=18); intervention and condition support (n=10); and participant support (n=18). No strategies were reported for supporting underserved groups to adhere, and few trials targeted provider adherence (n=5). Behavioural support tools included reminders (n=8), priority setting guidance (n=5) and clinician feedback (n=5). Measurement of adherence was usually by participant report of skin self-examination practice, with some recent trials of digital interventions also directly measuring adherence to the intervention through website or

application analytic data. Reporting of adherence data was limited and fewer than half of all reports mentioned adherence in their discussion.

Conclusions and Relevance:

Using an adaptation of the World Health Organization framework for clinical adherence, we identified key concepts as well as gaps in the way adherence is approached in design, conduct and reporting of trials for skin self-examination and other self-management practices in people at high risk of melanoma. Our findings may usefully guide future trials and clinical practice. Evaluation of adherence strategies may be possible using a Study Within A Trial (SWAT) within host trials.

Keywords

Adherence, melanoma, randomised controlled trial, skin self-examination

Background

Clinical adherence, defined as the extent to which a person's behavior corresponds with agreed-upon recommendations from a healthcare provider, significantly influences treatment effectiveness.[1] According to the World Health Organization (WHO), multiple interacting factors determine a patient's adherence to treatment recommendations. These factors can be divided into five dimensions — social and economic, healthcare team and system-related, disease-related, therapy-related, and patient-related.[2] Optimizing adherence may require multiple strategies targeting different dimensions.

Within a randomised clinical trial (RCT) setting, the WHO definition of adherence may be adapted to refer to the extent to which the intervention is undertaken as specified in the trial protocol, and is dependent on the actions of both participants and health care providers.[3] Non-adherence lessens the contrast between randomised study groups which may result in underestimation of both the benefits and harms of the intervention, and in loss of statistical power.[4-6] Additionally, adherence data may provide information about the acceptability of the intervention to patients and healthcare providers, and on how to support adherence in clinical practice. However, adherence is often poorly measured in trials, with many of the measures used found to be low quality.[7] As with clinical adherence, factors determining adherence in trials occur in different dimensions, and multiple strategies are likely to be most effective.

Adherence is particularly challenging for self-management interventions (whether in clinical practice or in trials). These complex behavioural change interventions often require significant participant commitment and effort to sustain. One such self-management practice is skin self-examination (SSE) for the early detection of new or recurrent melanoma in people at high risk,[8] with the rationale for this intervention illustrated in Figure 1. The top section shows a simplified natural history of a progressive melanoma from risk factors (surrogate outcomes) though to death (patient relevant health outcome). Below is the SSE intervention pathway that aims to interrupt the natural history through SSE facilitated early

detection and treatment. As few high-risk people routinely undertake SSE frequently or thoroughly,[9, 10] interventions to support SSE are needed. Adherence to SSE can be defined and measured at different points in the pathway: use of a SSE support intervention, adherence to recommended total body SSE practice (frequency and thoroughness), and adherence with SSE prompted clinical review and management.

We recently commenced the MEL-SELF RCT of patient-led melanoma surveillance that includes SSE in the intervention.[11] To inform the trial and clinical practice, we undertook a scoping review to identify strategies to improve adherence to SSE and other self-monitoring practices in RCTs of people at high risk of melanoma. We aimed to describe the types of adherence strategies used based on the WHO dimensions of adherence,[2] how adherence was defined, measured and reported, and any evaluation undertaken. The scoping review research question is presented according to the Population, Concept, and Context structure (eTable 1).

Methods

A detailed description of the pre-specified study protocol is provided on the Open Science Framework, and we provide a summary of the Methods here (the protocol includes the current review, and another focusing on recruitment, response, and retention in RCTs of melanoma early detection).[12] The review was conducted according to Joanna Briggs Institute methodology[13] and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist.[14] (eMethods 1)

Search strategy

We searched MEDLINE (OVID), EMBASE (OVID), CENTRAL (OVID), and CINAHL (EBSCO) from inception to 1st July 2022 (eFigure 1). We also screened records in the Studies Within A Trial (SWAT) repository,[15] reference lists and forward citations of included articles, and additional references provided by a content expert who was part of the study

team (KJLB).

Eligibility criteria

Eligible studies were randomised trials of self-monitoring interventions for early detection of melanoma in people at increased risk due to personal history (e.g., melanoma, transplant, dysplastic naevus syndrome), family history, or as determined by a risk assessment tool or clinical judgement (eTable 1). There were no restrictions by year of publication or language.

Study selection

Two reviewers independently screened titles and abstracts (DA and DD), and full text (DA and KBr) using a flowchart to guide decision making (eFigure 2). Disagreements were resolved through discussion or through involvement of a third reviewer (KJLB). Multiple reports from one trial could contribute to data extraction, but the trial was only included as one entry. Data were extracted primarily from the most recent report and earlier reports were scanned for additional relevant information.

Data extraction

A data extraction tool was developed and piloted, and data extracted by one reviewer (DA), with a convenience sample (n=5, 28%) cross-checked by a second reviewer (KJLB). Extracted data included characteristics of the intervention and steps taken to ensure provider adherence to the treatment protocol (guided by the Template for Intervention Description and Replication Framework checklist[16]); definition of adherence as mapped to the pathway illustrated in Figure 1, methods used to measure adherence; strategies to improve adherence; and key study results. Adherence strategies were classified according to the WHO adherence dimension targeted (which could be more than one): social and economic factors, therapy-related factors, disease-related factors, patient-related factors, and health care system-related factors. We took a broad approach to identifying adherence strategies and included all adherence strategies whether or not they were labelled as such by the trialists, in order to find potential strategies to improve SSE in both research and clinical practice.

Results

Search results

We screened the titles and abstracts of 938 articles identified through our database searches, resulting in 76 full texts to screen (eFigure 3: Preferred Reporting Items for Systematic Reviews and Meta-Analyses), of which 54 were excluded (for reasons, see eTable 2). Searches of references, forward citations and the SWAT repository[15] did not identify additional references. One additional study was identified through recommendation from the content expert. We included 18 studies reported across 24 papers.

Included studies

Studies were from the USA,[17-30] the United Kingdom[31, 32] and Australia[10, 33] and ranged in size from 40 to 724 participants and in duration from 3 to 24 months (eTable 3). They included people with personal history of melanoma,[10, 17, 23, 27-31] patients attending high risk melanoma clinics,[24-26] first degree relatives of people with melanoma,[18, 19, 22] primary care patients assessed as high risk,[20, 21, 32] and previous melanoma trial participants.[33] All interventions aimed to improve SSE practice.

Adherence strategies and categorization

Adherence strategies used in the included studies (eTable 4, eTable 5) were identified as: (i) a stand-alone intervention, (ii) a component of the intervention under investigation, or (iii) in the description of the study methods. For example, using reminders as an adherence strategy was variously described as a stand-alone,[25] intervention component,[10] or in the methods.[17] Many strategies simultaneously targeted several of the five WHO dimensions of adherence (adapted for the trial context, Table 1). Overall, 15 used trial design,[10, 17, 18, 22-33] 5 social and economic support,[10, 17, 18, 23, 31] 18 intervention design, 10 intervention support,[10, 20, 23, 25, 27-32] and 18 participant support (including the provision of knowledge and skills and support for behavioural change). Reporting of adherence strategies was rarely sufficiently detailed to allow replication. Figure 3 summarizes the adherence strategies in each of the categories.

Trial design and conduct

Fourteen trials limited eligibility criteria to participants likely to be able to adhere to the intervention. Participants were excluded if they had visual impairment, cognitive impairment, comorbidities, or no internet or smartphone access.[10, 17, 18, 23-33] In Manahan 2018, participants completed a screening questionnaire to confirm acceptance of teledermatology before enrolment.[33] No trials used an active run-in phase to assess potential participants ability to adhere to the intervention.

Five studies reported assessment of provider adherence with intervention delivery. In Manne 2010,[22] tailored telephone counselling calls which included review of SSE guidelines, participant risk factors, current SSE practice, barriers and motivators were rated for fidelity and counsellors were regularly given feedback regarding content and duration of the calls. Fidelity of intervention delivery in Robinson 2007,[27] Robinson 2010,[28] and Robinson 2016[29] was evaluated using a 16-item observer checklist, with results published separately.[34] In Walter 2020,[32] the study coordinator observed 10% of consultations using a checklist to score fidelity. Four trials reported training staff to deliver the intervention, thus providing support for the intervention to be delivered as planned.[27, 29, 30, 32] Training methods included PowerPoint presentations, provision of a written script or manual, role playing and individual feedback. In two trials the intervention was fully automated, so did not require trial staff support.[23, 24]

Social and economic support

Five trials used strategies that provided social support to participants. Research staff in two trials facilitated urgent clinical appointments,[10, 31] another two trials provided information on how to access care,[17, 18] and one trial enabled calendar scheduling to make a doctor's appointment.[24] Two trials of an internet-based education tool to improve communication about melanoma risk within families included a chat room for communication between participants.[17, 18] No study reported strategies to provide economic support for direct and

downstream costs to individual participants related to trial participation. There were also no strategies targeting health inequities, such as providing tailored support for people with socio-economic disadvantage, low health literacy, non-English speakers, or who are older.

Intervention design

All trials used intervention design to increase adherence. Thirteen trials reported using theories of health behavior change in the intervention design, including Social Cognitive Theory, Theory of Planned Behavior, and the Health Belief Model.[19-31] Two trials reported public and patient involvement in the study design and materials,[10, 32] and one trial reported co-design of the intervention with potential recipients.[31] Seven trials reported pre-trial user testing to establish acceptability and refine the intervention.[17, 18, 23, 24, 29, 32, 33] For example, Manne 2021 conducted user testing (n=15) which led to refinement of their mySmartSkin intervention with reduced text, rewording, improved navigation, and increased use of patient vignettes.[23]

Intervention support

Ten trials provided direct support to use the intervention. This included a research assistant or nurse practitioner to support the initial download and set-up of apps and/or devices[23, 25, 32] or ongoing technology support for task completion,[10, 31] practical support such as an 'enabling kit' including a magnifier and ruler to look for and check the size of their moles,[20, 27-30] and a skin check partner to assist with examining hard to reach body areas.[10, 23, 25, 27-30]

Participant support

All trials provided education about melanoma and the benefits of SSE in addition to information explaining how to conduct the intervention. This was as written materials,[10, 19-23, 26-30, 32, 33] videos,[10, 23, 24, 26, 31] internet-based[17, 18, 23, 24] tablet/ smartphone applications (apps),[10, 25, 29, 31, 32], or as in-person training (to individuals, participant and skin check partner dyads, or groups).[26-32] Seven trials included individually tailored information based on participant responses to baseline questions related to risk factors, SSE practices, melanoma

knowledge and prevention behaviours.[17-23] Five interventions included quizzes to check learning[23, 24, 27-29] and two internet-based interventions included game-like activities.[23, 24] Eight studies reported using reminders for intervention activities.[10, 17, 18, 23-25, 31, 32] The mode, number, and frequency of reminders varied from trial to trial and reported details were often limited. Options included offering a choice of SMS or email,[10, 31] email prompts every three months,[17, 18] monthly in-app notifications,[32] and calendar scheduling.[24] No trials reported the use of incentives (financial or otherwise) to encourage adherence.

Five studies used reinforcement of knowledge and feedback on skills as adherence strategies. This was done using follow up telephone calls,[19, 22] feedback on SSE technique and a question and answer session at a return visit,[26] and checks by the trial dermatologist at 4-monthly clinics.[29, 30] Twelve studies provided monitoring tools to support participant adherence, using printed or online body maps[21, 23, 24, 27-30] to track changes in mole size/shape/colour, diaries[26] and in-app monitoring.[10, 25, 31, 32] Five studies used motivational tools including action plans,[23, 24] priority setting and confidence building exercises,[23, 28] and personalised telephone counselling which addressed participant barriers and motivators for conducting SSE.[19, 22]

Evaluations of adherence strategies

There were few evaluations of adherence strategies. Fidelity of intervention delivery was assessed in three trials[27-29], with results published separately.[34] Robinson 2007 compared dyadic learning with solo learning (i.e., patient together with partner vs. alone) and found that participants in the dyadic group were significantly more likely to undertake SSE.[27] Glanz 2010 and 2015 evaluated type of education support provided and found improvements in SSE frequency for receipt of tailored materials (mailed personalised skin cancer risk, prevention, and detection information) compared to generic materials.[20, 21] In contrast Manne 2010 found similar increases in SSE for tailored and generic materials (intervention same as Glanz studies plus telephone counselling).[22]

Measurement and reporting of adherence

Measurement of adherence to SSE facilitated early detection and treatment of melanoma may occur at: the point of the support intervention, the point of SSE, or the point of SSE-prompted clinician review (Figure 1). Methods of measurement of adherence for interventions to support SSE included survey or phone calls to assess receipt and use of mailed materials (e.g. number of mailings received, number of materials read, and whether materials were kept),[20-22, 30] recording attendance at educational interventions, training, or follow up clinical assessments; participation of skin check partners,[10, 29] and qualitative interviews (Figure 3).[10] Studies of digital technology used objective measures including website analytics (frequency and number of pages accessed), digital image submission, and app use.[10, 17, 18, 23-25, 31] Participant-reported measures of SSE behaviours were used in 17 trials, including frequency and thoroughness of SSE,[10, 17-19, 23, 24, 26-31] frequency alone,[22, 25] recency of SSE,[20, 21] and body areas examined.[33] Adherence to SSE-prompted clinician review was measured by image submission for teledermatology review[10, 31] and attendance at clinician review.[31, 32]

Reporting of adherence was often poor. Although fourteen (78%) of trial reports provided Consolidated Standards of Reporting of Trials (CONSORT) flow diagrams,[35] only seven reported the number of participants who received the allocated intervention,[10, 18, 25, 27, 31-33] and none reported adherence data. Of the eight trials that used internet or app-based interventions, five reported analytics.[10, 17, 23, 24, 31] Eight reports referred to adherence or participant engagement with the intervention in the Discussion[10, 18, 21-24, 32, 33] and none of the trials' main reports included adherence considerations in their recommendations. In a separate publication, Murchie 2022 reported adherence to monthly SSE over 12 months and identified three trajectories: consistent, high adherence; declining adherence; and early nonadherence. People with early nonadherence were less likely to intend to perform SSE as recommended and were more likely to be depressed than people who were at least initially adherent.[36] People whose adherence dropped off over time had lower self-efficacy and less-

developed action plans.

Discussion

Multiple strategies to support adherence were used in most of the trials of melanoma self-monitoring. Trials commonly limited eligibility to people who spoke English, and who were more likely to adhere. Although a few trials provided some social support, none provided economic support to offset additional costs, and no efforts were made to ensure materials were health literacy sensitive. This may have unintentionally limited diversity in trial populations, contributing to underrepresentation of groups such as those with socioeconomic disadvantage. Co-design with community members of underserved groups may identify ways to improve trial process to increase diversity of trial populations and applicability of evidence generated.[37, 38] Although all trials used intervention design as a strategy, very few used co-design methods for the intervention or trial design, and a minority of trials incorporated end-user testing of the intervention pre-trial. All trials provided participant support in the form of educational materials, with information often delivered in more than one mode, but only a minority used behavioural or motivational strategies (reminders, clinician reinforcement and feedback, priority setting exercises and/or action plans). Reporting of adherence strategies was rarely sufficient to allow replication, and evaluations of individual strategies were rare.

This is the first review on adherence to SSE and other melanoma self-management interventions in a trial setting. Previous reviews have focused on effectiveness of SSE interventions on early detection,[39] how SSE is defined and measured,[40] or the prevalence and correlates of SSE behaviours among adult melanoma survivors.[41] A major strength is the rigor of our review process with two authors involved in each step of study selection. In addition, we were able to define different levels of adherence to SSE facilitated early detection of melanoma using the causal pathway illustrated in Figure 1. By restricting our focus to trials conducted in a clinical setting of people at high-risk of melanoma, we identified evidence relevant to optimizing adherence to SSE in both future trials and in practice. A

limitation is that many trials used multiple adherence strategies with few evaluated in isolation, making it difficult to determine which elements were effective and necessary. Adherence strategies are often components of complex interventions (e.g., in Ackermann 2022, reminders were one component of patient-led surveillance) and are not evaluated separately to the whole intervention package. The findings in this study are specific to adherence to self-management practices and may not generalize to pharmaceutical treatment of dermatological diseases.

There is currently limited practical guidance for the best practices to maximise adherence to SSE in research or practice. Assessment of adherence to an intervention in a trial may provide valuable insights on the ease with which it can be translated into routine clinical practice. Trialists may consider developing a comprehensive adherence plan as part of the study protocol including strategies for dealing with non-adherence and may find our adaptation of the WHO adherence framework helpful for this. However, care is needed to ensure strategies are achievable in everyday routine care.[42] In trials of complex interventions such as SSE for the early detection of melanoma, simple causal diagrams like Figure 1 may be helpful to define the specific targets of adherence strategies. Specific adherence items in reporting guidelines may improve measurement and reporting of adherence (CONSORT)[35] and implementation into practice (TIDIER).[16] The increasing use of digital technologies producing usage logs provides an opportunity to use objective methods to track adherence to interventions. This type of data may provide a more comprehensive picture of adherence behavior and help explain variability in intervention effectiveness. Opportunities to apply technology to adherence monitoring and management are ever-increasing, necessitating further research to maximise their potential.

The clinical implications of this research are presented in Box 1. Screening patients for early nonadherence and declining adherence and consequent implementation of strategies to support behavior change and improve self-efficacy may be beneficial.[36] Research is needed to identify adherence interventions which are low cost and can be easily integrated into the

workflow of routine clinical practice, including automated digital interventions. Interventions that require the active participation of healthcare professionals or large administrative support may be difficult to implement in busy clinical contexts. Evaluation of individual components of a complex intervention may be undertaken using a Study Within A Trial (SWAT) within the host RCT: a "*self-contained study that has been embedded within a host trial with the aim of evaluating or exploring alternative ways of delivering or organizing a particular trial process*".[43] The SWAT may directly benefit adherence in the host trial, provide results generalizable to other trials (combined with other SWAT results in a meta-analysis),[44] and may also guide post-trial clinical implementation. In addition, future research to identify specific adherence strategies for populations who are underrepresented in dermatology trials would be valuable. Such strategies are likely to support all participants to adhere but will be especially important for underserved groups to help address current health inequities.

Conclusion

Supporting adherence to self-management strategies is a complex problem influenced by multiple interacting factors. Using an adaptation of the WHO framework for clinical adherence, we identified key concepts as well as gaps in the way adherence is approached in design, conduct and reporting of trials for self-management of melanoma risk. Our findings may support improvements in the design, evaluation, and reporting of adherence strategies for use in research and practice.

Article Information

Author contributions: Deonna Ackermann had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Conflict of interest disclosures: The authors declare no conflicts of interest.

Funding/Support: This research project is funded by a National Health and Medical Research Council (NHMRC) Project grant (1163054) and a University of Sydney Research Accelerator (SOAR) Prize. KB is supported by an NHMRC Investigator Grant (1174523). JH

368 is supported by a Cancer Institute NSW Early Career Fellowship (2020/ECF1158). DA is
369 supported by an NHMRC Postgraduate Scholarship (2014163).

370 **Role of the Funder/Sponsor:** The sponsors had no role in the design and conduct of the
371 study; collection, management, analysis, and interpretation of the data; preparation, review,
372 or approval of the manuscript; and decision to submit the manuscript for publication.
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532 **Box 1: Clinical implications**

● Adherence to SSE may follow one of three trajectories: consistently high adherence – initial high adherence is sustained over time; declining adherence – initial high adherence is not sustained over time; and early nonadherence – initial low adherence remains low over time.

● Screening patients for their intention to conduct SSE and for possible depression may be helpful to identify those likely to need additional support and/or treatment for them to initiate SSE.

● Strategies to improve self-efficacy may increase the likelihood that SSE (once initiated) is sustained. These may include provision of training, involvement of a skin check partner, motivational materials, and clinician feedback on technique.

● Strategies to improve planning for SSE may also increase the likelihood that SSE is sustained. These may include calendar scheduling and reminders.

● Strategies that can be integrated into routine workflows may have greater uptake in clinical practice. This may include strategies that are brief, easily implemented, and that can be tailored to individual patients and diverse clinical settings. Fully automated digital interventions to support SSE adherence are an example of such an intervention.

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535 **Table 1: Strategies to promote adherence to self-management interventions used in**

536 **18 trials of people at increased risk of melanoma[1]**

Strategy category[2]	**Strategy details**		**Frequency (%)[3]**
Trial design and conduct n=15 (83)	Eligibility criteria limits		14 (78)
	Pre-testing potential participants for suitability		1 (6)
	Fidelity of intervention delivery		5 (28)
	Staff training		4 (22)
Social and Economic support n=5 (28)	Cost (direct and downstream) minimization for participants		0 (0)
	Facilitation of access to health care providers and services		5 (28)
	Provision of a social support network		2 (11)
	Targeted support for underserved populations	Culturally diverse materials: available in languages other than English, materials sensitive to cultural beliefs about illness and treatment	0 (0)
		Older adults	0 (0)
		Low health literacy	0 (0)
Intervention design n=18 (100)	Theory-based intervention design		13 (72)
	Patient public co-design		3 (17)
	Pre-trial user testing		8 (44)
Intervention support n=10 (56)	Technical support		4 (22)
	Practical support		5 (28)
	Skin check partner		7 (39)
Participant support n=18 (100)	Provision of knowledge and skills regarding the	Written materials	13 (72)
		Videos	5 (28)
		Internet-based	4 (22)
		App-based materials	5 (28)

	condition and intervention	Skills training: individual, dyad group	7 (39)
	Enhance understanding	Tailored/personalised materials	7 (39)
		Quizzes	5 (28)
		Game-like activities	2 (11)
	Behavior change support	Reminders: mode, number, frequency	8 (44)
		Incentives	0 (0)
		Reinforcement and feedback	5 (28)
		Self-monitoring materials	12 (67)
		Motivational materials - goal setting	5 (28)
		Counselling	2 (11)

[1]Adherence strategies within the included trials were identified in three ways: (i) stand-alone adherence interventions; (ii) defined components of complex interventions; or (iii) strategies described in the methods of the study.

[2]Adapted from the WHO dimensions of adherence.

[3]Percentage is the number applicable out of the total number of studies (n = 18). Categories are not mutually exclusive and therefore do not add to 100%.

Figure 1: Causal pathway for how a skin self-examination intervention may impact the natural history of melanoma

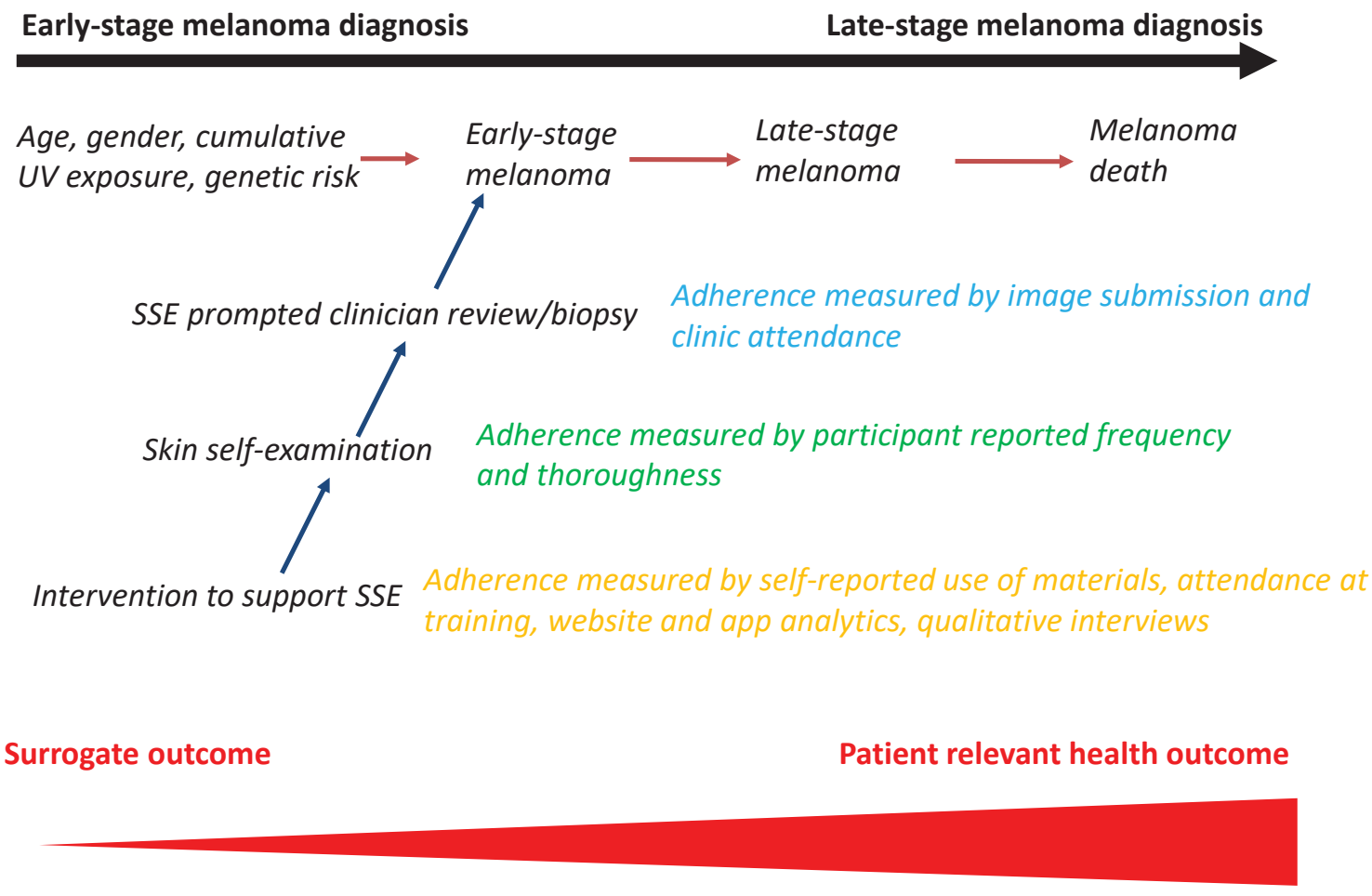

Figure 2: Strategies for improving adherence to self-management practices in 18 trials of people at increased risk of melanoma

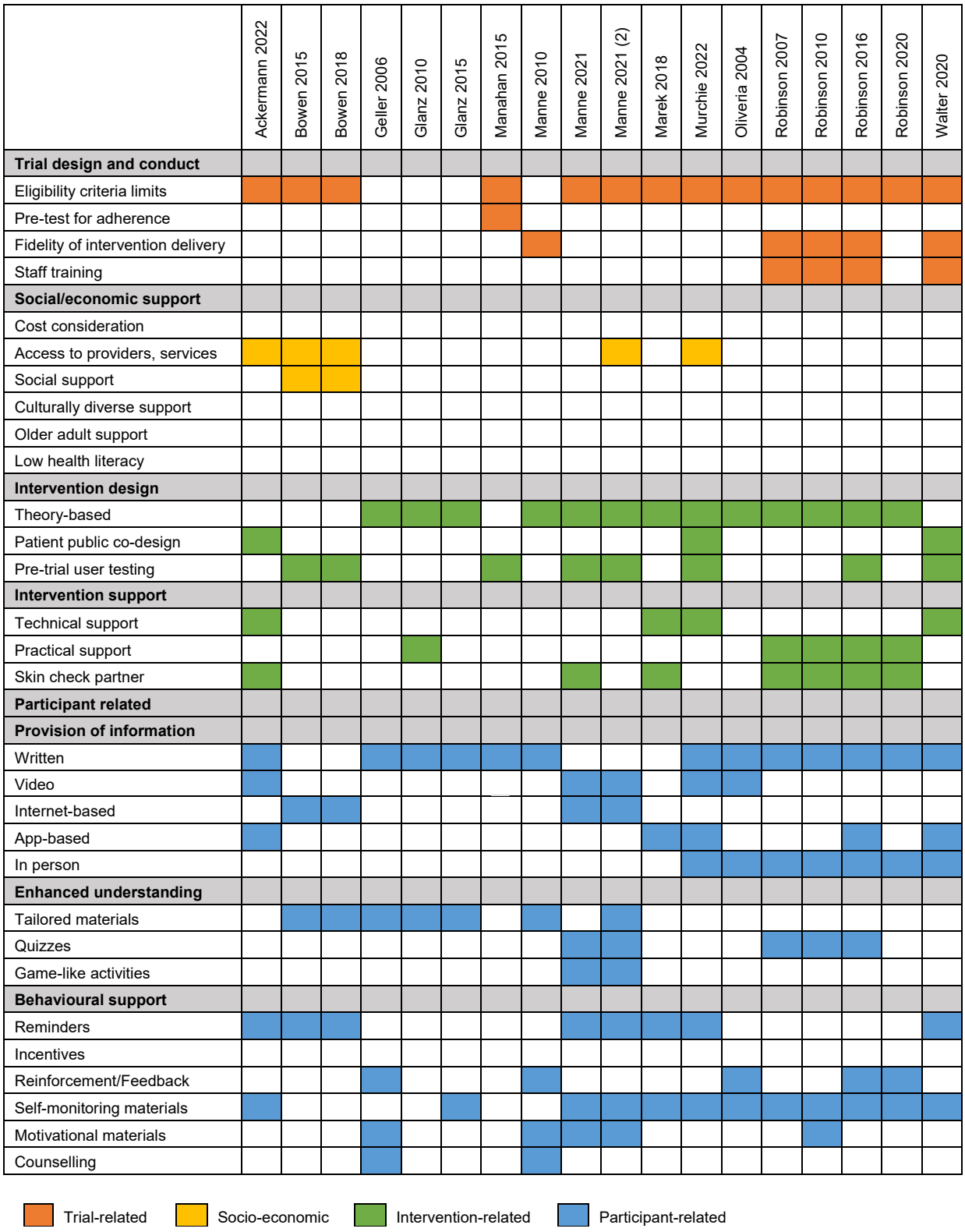

Figure 3: Adherence measurement in 18 trials of people at increased risk of melanoma