

Accepted Manuscript

Patients' perceptions and experiences of cardiovascular disease and diabetes prevention programmes: a systematic review and framework synthesis using the Theoretical Domains Framework

Rachel L. Shaw, Carol Holland, Helen M. Pattison, Richard Cooke

PII: S0277-9536(16)30115-0

DOI: [10.1016/j.socscimed.2016.03.015](https://doi.org/10.1016/j.socscimed.2016.03.015)

Reference: SSM 10561

To appear in: *Social Science & Medicine*

Received Date: 7 May 2015

Revised Date: 16 February 2016

Accepted Date: 11 March 2016

Please cite this article as: Shaw, R.L., Holland, C., Pattison, H.M., Cooke, R., Patients' perceptions and experiences of cardiovascular disease and diabetes prevention programmes: a systematic review and framework synthesis using the Theoretical Domains Framework, *Social Science & Medicine* (2016), doi: 10.1016/j.socscimed.2016.03.015.

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Patients' perceptions and experiences of cardiovascular disease and diabetes prevention programmes: a systematic review and framework synthesis using the Theoretical Domains Framework

Rachel L. Shaw^{*a}, Carol Holland^b, Helen M. Pattison^c & Richard Cooke^d

* Corresponding author

- a. Health Psychologist and Senior Lecturer. School of Life & Health Sciences, Aston University, Birmingham, B4 7ET, UK. Tel: +44(0)121 2044050; email: r.l.shaw@aston.ac.uk.
- b. Director of Aston Research Centre for Healthy Ageing (ARCHA) and Reader in Psychology. School of Life & Health Sciences, Aston University, Birmingham, B4 7ET, UK. Tel: +44(0)121 2044063; fax: +44(0)121 2044090; email: c.holland1@aston.ac.uk.
- c. Director of Research in Applied Health Sciences and Professor of Health Psychology. School of Life & Health Sciences, Aston University, Birmingham, B4 7ET, UK. Tel: +44(0)121 2044073; fax: +44(0)121 2044090; email: h.m.pattison@aston.ac.uk.
- d. Health Psychologist and Senior Lecturer in Psychology. School of Life & Health Sciences, Aston University, Birmingham, B4 7ET, UK. Tel: +44(0)121 2044072; fax: +44(0)121 2044090; email: r.cooke@aston.ac.uk.

1 **Patients' perceptions and experiences of cardiovascular disease and diabetes prevention**
2 **programmes: a systematic review and framework synthesis using the Theoretical**
3 **Domains Framework**

4
5 **Background:** This review provides a worked example of 'best fit' framework synthesis using
6 the Theoretical Domains Framework (TDF) of health psychology theories as an a priori
7 framework in the synthesis of qualitative evidence. Framework synthesis works best with
8 'policy urgent' questions. **Objective:** The review question selected was: what are patients'
9 experiences of prevention programmes for cardiovascular disease (CVD) and diabetes? The
10 significance of these conditions is clear: CVD claims more deaths worldwide than any other;
11 diabetes is a risk factor for CVD and leading cause of death. **Method:** A systematic review and
12 framework synthesis were conducted. This novel method for synthesizing qualitative evidence
13 aims to make health psychology theory accessible to implementation science and advance the
14 application of qualitative research findings in evidence-based healthcare. **Results:** Findings
15 from 14 original studies were coded deductively into the TDF and subsequently an inductive
16 thematic analysis was conducted. Synthesized findings produced six themes relating to:
17 knowledge, beliefs, cues to (in)action, social influences, role and identity, and context. A
18 conceptual model was generated illustrating combinations of factors that produce cues to
19 (in)action. This model demonstrated interrelationships between individual (beliefs and
20 knowledge) and societal (social influences, role and identity, context) factors. **Conclusion:**
21 Several intervention points were highlighted where factors could be manipulated to produce
22 favourable cues to action. However, a lack of transparency of behavioural components of
23 published interventions needs to be corrected and further evaluations of acceptability in
24 relation to patient experience are required. Further work is needed to test the

25 comprehensiveness of the TDF as an a priori framework for ‘policy urgent’ questions using
26 ‘best fit’ framework synthesis.

27 **Keywords:** Cardiovascular diseases; diabetes; health check; behaviour change intervention;
28 theoretical domains framework

29

ACCEPTED MANUSCRIPT

1 **Introduction**

2 Substantial advances in methodology for reviewing and synthesizing qualitative evidence
3 have been made (e.g. Pope, Mays & Popay, 2007; Shaw, 2010) and clear arguments exist for
4 including non-trial, context-sensitive evidence within reviews of effectiveness; this offers a
5 route for patient perspectives to be incorporated into good practice guidance if methods for
6 qualitative evidence synthesis are taken up (Kelly, Stewart, Morgan et al., 2009; Shaw,
7 Larkin & Flowers, 2014; SIGN, 2011). However, qualitative evidence synthesis can be labour
8 intensive and requires a high level of expertise in qualitative methodology. The recent
9 development of ‘best fit’ framework synthesis (Carroll, Booth & Cooper, 2011; Carroll,
10 Booth, Leaviss & Rick, 2013) offers an alternative systematic methodology based on
11 framework analysis (Ritchie & Spencer, 1994). It adopts an a priori theoretical framework to
12 guide data extraction and synthesis making it more efficient and accessible as an approach for
13 reviewing and synthesizing ‘policy-urgent’ questions without sacrificing theory.

14 This paper offers a novel application of framework synthesis using the Theoretical Domains
15 Framework (TDF; Cane, O’Conner & Michie, 2012; Michie, Johnson, Abraham et al., 2005).
16 The TDF was chosen as the theoretical framework for this review because it was developed
17 following a systematic review and synthesis of health psychology theories (Michie et al.,
18 2005), thus completing the initial step in ‘best fit’ framework synthesis (Booth & Carroll,
19 2015). The review identified 14 theoretical domains and 84 component constructs (Michie et
20 al., 2005). These were then validated (Cane et al., 2012) and have been used to explain
21 implementation problems, to develop theory-informed behaviour change interventions, and to
22 assess which theoretical domains are relevant to particular interventions (e.g. French et al.,
23 2012; Francis, Stockton, Eccles et al., 2009; McKenzie, O’Connor, Page et al., 2010). Using
24 the TDF as an a priori framework to guide the synthesis enabled insights from a wider range
25 of theoretical constructs than using one theory alone. This is the first review of which we are

26 aware that brings together the TDF with 'best fit' framework synthesis to offer a rigorous and
27 theoretically informed method for synthesizing qualitative research studies.

28 The 'policy urgent' review question selected was: What are patients' experiences of
29 prevention programmes for cardiovascular disease (CVD) and diabetes? These conditions
30 were selected because they feature in many public health programmes around the world (see
31 for example: Holland, Cooper, Shaw, Pattison & Cooke, 2013). One reason for both
32 conditions being the focus of prevention programmes is that they are related. CVD, including
33 coronary heart disease and stroke, account for more deaths globally than any other diseases
34 (WHO, 2011a); in 2008, 30% of deaths worldwide were attributed to CVD (WHO, 2011b).
35 Diabetes is a risk factor for CVD and the World Health Organisation (WHO) predicts
36 diabetes will be the seventh leading cause of death globally by 2030 (WHO, 2011a).
37 Furthermore the incidence of type 2 diabetes mellitus globally is rising, specifically in
38 younger age groups (Alberti, Zimmet, Shaw, Bloomgarden, Kaufman & Silink, 2004).
39 Lifestyle changes can reduce the risk and prevent further complications of CVD and diabetes
40 and evidence suggests that early detection may lead to better health outcomes (NICE, 2010;
41 WHO, 1999).

42 Previous reviews of prevention programmes have considered reduction in risk measurements
43 and cost-effectiveness or years of life added as outcomes (Ebrahim, Taylor, Ward et al.,
44 2011) but have not considered behavioural aspects. A recent review by Holland et al. (2013)
45 focused on behaviour change elements within coronary heart disease (CHD) and diabetes
46 prevention programmes and revealed mixed benefits. They found that feedback regarding risk
47 level, an evidence-based behaviour change technique (Michie, Ashford, Sniehotta et al.,
48 2011), prompts successful behaviour change (e.g. Robertson, Phillips & Mant, 1992).
49 Furthermore, those at higher risk have been shown to be more likely to change their
50 behaviour following dialogue (Craigie, Barton, Macleod et al., 2011; Koelewijn-van Loo, van

51 der Weijden, Ronda et al., 2010). Nevertheless, despite ongoing research in the field, it is not
52 clear why prevention programmes do not have more reliable effects on behaviour change. A
53 review of patient perspectives and experiences of such programmes may help to answer this
54 question.

55 **Method**

56 This review adopted the methodology endorsed by the PRISMA (Preferred Reporting Items
57 for Systematic Reviews and Meta-Analyses) Statement (Moher, Liberati, Tetzlaff & Altman,
58 2009) and followed the step-by-step procedure for 'best fit' framework synthesis (Booth &
59 Carroll, 2015).

60 *Study inclusion criteria and search strategy*

61 Inclusion criteria. Qualitative research studies reporting evaluations of existing early
62 detection or prevention or screening programmes for CVD or diabetes; in primary care or in
63 the community; for adults; including patients' perspectives; using qualitative methods; since
64 1990; in English. Search terms were adapted from Holland et al. (2013) and included the
65 qualitative methods filter (qualitative, findings, interview*; Grant, 2004) identified as an
66 efficient method for identifying qualitative research (within the restraints of limited subject
67 headings in bibliographic databases for qualitative methods; Shaw, Booth, Sutton et al.,
68 2004). Web of Knowledge and PubMed were searched and reference chaining of relevant
69 studies conducted. The full search strategy is included in Additional File 1.

70 *Quality assessment of studies*

71 Studies were appraised using prompts (Dixon-Woods, Shaw, Agarwal & Smith, 2004)
72 devised specifically to determine the quality of qualitative research which focus on
73 transparency, a key indicator of trustworthiness (Carroll, Booth & Lloyd-Jones, 2012;
74 Lincoln & Guba, 1985). A rating system, adapted from Dixon-Woods, Sutton, Shaw et al.

75 (2007), was then used to categorise original studies. In the revised system only studies to be
76 included were appraised; no studies were excluded on grounds of quality.

77 *Data extraction and synthesis*

78 Data were extracted from the results sections of included studies directly into the *a priori*
79 framework, i.e. the TDF, using a deductive process. This included themes or categories of
80 findings presented by authors, primary data extracts, and author commentary about those
81 data. Subsequently, an inductive (data-driven) thematic analysis (Braun & Clarke, 2006) was
82 conducted in order to code any data that did not fit into the TDF to ensure nothing was
83 missed.

84 Concepts from the TDF and inductive thematic analysis were then clustered and synthesized
85 into a final set of themes representing the whole dataset. This involved interpretative work to
86 identify relationships between themes and mediating factors between individual-societal-
87 organisational based aspects within them. All stages of analysis were discussed within the
88 review team until consensus was reached.

89 *Sensitivity analysis*

90 It has been argued that the transparency of reporting of qualitative studies is crucial to their
91 utility in secondary analysis (Carroll et al., 2012). 'Thin' descriptions of people's views, with
92 inadequately reported research questions or methods, cannot be relied upon and so the
93 strength of secondary analyses rests on the quality of included studies (Harden, Garcia,
94 Oliver et al., 2004). A sensitivity analysis (Carroll et al., 2012) was conducted with and
95 without the poorer quality studies to determine the impact on coding against the TDF and the
96 generation of inductive themes. Further analysis was conducted to examine whether the
97 presence/absence of (a) the theoretical domains from the TDF and (b) the inductively
98 generated themes affected the final set of themes and conceptual model in order to ensure the

99 synthesis of findings was not skewed in favour of either the TDF or the inductive thematic
100 analysis.

101 **Results**

102 *Included studies*

103 Following removal of duplicates 585 potentially relevant records were identified. These were
104 screened at title and abstract level to leave 50 studies to be assessed for eligibility. After
105 further exclusions against inclusion criteria 42 studies were excluded, leaving eight included
106 studies. Reference chaining identified six additional studies, resulting in 14 studies judged
107 relevant for inclusion (see Figure 1 for the PRISMA flow diagram). Full details of studies are
108 available in Table 1. Six studies were conducted in the United Kingdom (UK), three studies
109 reported findings from one Danish study, two were based in the United States (US), one in
110 Australia, one in Sweden, and one in Thailand. Six studies described prevention programmes
111 for diabetes and pre-diabetes; five of which involved prevention programmes for CVD. Two
112 studies focused on the UK National Health Service (NHS) Health Check, a prevention
113 programme targeting cardiovascular disease, diabetes, stroke and kidney disease; one focused
114 on CHD and the other on CHD risk. Four studies collected data from healthcare professionals
115 as well as patients; the remaining ten included patients only. Individual interviews were the
116 dominant method of data collection ($n=12$) with some using focus groups ($n=3$) and one
117 study used both; analysis methods included Content Analysis ($n=1$), Framework Analysis
118 ($n=3$), Grounded Theory ($n=2$), Interpretative Phenomenological Analysis ($n=1$), Thematic
119 Analysis ($n=5$) and two were unstated.

120 **[INSERT FIGURE 1 ABOUT HERE]**

121 **[INSERT TABLE 1 ABOUT HERE]**

122

123 *Quality of included studies*

124 Studies were appraised and rated independently by the first and last author. Any differences
125 were discussed in full, and a rating agreed (see Table 2 for ratings). Overall, study quality
126 was good with good levels of transparency and detailed discussion of data included. Using an
127 adaptation of Dixon-Woods et al. (2007), *key papers* were those which fitted the review
128 question and met all quality criteria; *satisfactory* studies fitted the review question and met
129 most criteria. Studies categorised as *unsure* did not meet all the quality criteria and were
130 treated cautiously because we were unsure about their trustworthiness. Studies rated *poor* did
131 not include sufficient data extracts to judge whether conclusions were evidenced and some
132 omitted their method of analysis.

133 **[INSERT TABLE 2 ABOUT HERE]**

134

135 *Sensitivity analyses*

136 Sensitivity analyses confirmed that no final theme was reliant on a single original study and
137 excluding those of rated unsure did not affect the results; they acted to support higher quality
138 studies which reported ‘thick descriptions’ (Geertz, 1973) of findings. None of the studies
139 rated unsure was represented in the inductive thematic analysis because of the lack of data
140 included. One theme (Cue to (in)action; see below) was generated largely from the inductive
141 analysis alone but others were representative of both.

142 Findings from included studies supported the theoretical constructs included in the TDF
143 which demonstrated the utility of the framework (see Table 3 for full descriptions of
144 theoretical domains and constructs in the TDF and in which studies they were identified).
145 However, some elements of original findings were not addressed in the TDF which meant
146 additional themes were identified in the inductive thematic analysis. Furthermore, some

147 original studies cited theories *not* in the TDF, suggesting further development of the
148 framework may be necessary: the Common Sense Model of Illness Representations
149 (Leventhal, Nerenz, Steele, Taylor & Singer, 1984) and the Health Promotion Model (Pender,
150 1996) (see Table 4 for additional theoretical constructs and in which studies they were
151 identified). Related to illness representations, the thematic analysis highlighted the
152 physiological signs of illness which were related to people's confidence in their (in)ability to
153 identify CVD or diabetes through their bodily sensory perceptions, i.e., their impact on self-
154 efficacy (Bandura, 1977). Self-efficacy is described in the TDF as beliefs about an
155 individual's self-confidence, perceived behavioural control and empowerment regarding
156 behaviour.

157 **[INSERT TABLE 3 ABOUT HERE]**

158 **[INSERT TABLE 4 ABOUT HERE]**

160 *Framework synthesis*

161 Below, the final set of themes is presented followed by a summary of the conceptual model.

162 Knowledge.

163 This theme represents what is often considered the starting point for behaviour change;
164 knowing what the prevention programme entails and why it is important to reduce risk for
165 CVD and diabetes. Original studies reported a range of knowledge levels in their patients and
166 one paper reported low levels of knowledge among healthcare professionals
167 (Sranacharoenpong & Hanning, 2011).

168 In general, there was a lack of awareness of prevention programmes for CVD and diabetes
169 prior to being invited to attend one (Burgess, Wright, Forster et al., 2014; Chipchase,
170 Waterall & Hill, 2013; Harkins, Shaw, Gillies, Sloan et al., 2010). However, a common

171 conceptualisation of prevention programmes once they have been introduced is that they are
172 like a general health check.

173 My perception of reading through things was that it was going to be a good overhaul.
174 You know, overall body check for everything, so I don't think it was as in-depth as I
175 thought it was going to be. (Rachel; participant; Chipchase et al., 2014, p.24)

176 Although perceived as a *general* health check there was an expectation that the tests would be
177 tailored to individuals.

178 I thought it was more particular to me, you know trying to sort out just how bad I was
179 whatever, didn't realise it was a separate little screening as opposed to just for myself.
180 (Patient 43; participant; Goyder, Carlisle, Lawton & Peters, 2009, p. 88)

181 That the programme was a public health intervention aimed at the whole population seemed
182 to undermine patients' perceptions of its importance to them as individuals; "a separate little
183 screening". Not knowing what the tests involved was also likely to dissuade patients from
184 attending.

185 Lack of awareness emerged as a general theme across both those who accepted and
186 those who declined the health check. It may be that lack of clarity and understanding of
187 what the health check involved had discouraged attendance. (authors; Burgess et al.,
188 2014, p. 4)

189 I didn't know what it was about, I didn't know if they'd have me on a treadmill or
190 anything like that and I wasn't wanting that. (Respondent 1, Group 1; participant;
191 Harkins et al., 2010, p. 5)

192 As well as indicating limited knowledge about the tests themselves, included studies revealed
193 poor knowledge about CVD and diabetes (Goyder et al., 2009; Harkins et al., 2010; Lanza,

194 Albright, Zucker & Martin, 2044; Sranacharoenpong & Hanning, 2011; Williams, Mason &
195 Wold, 2001). Some participants perceived screening as an opportunity to provide information
196 and thereby improve knowledge about risk factors and disease prevention among patients
197 (Goyder et al., 2009) and healthcare staff (Sranacharoenpong & Hanning, 2011).

198 Beliefs.

199 This theme demonstrates the complexity of beliefs and how they play out in people's
200 perceptions of lifestyle related diseases, risks and their own capacity to make lifestyle
201 changes. The original studies revealed a range of beliefs about different aspects of prevention
202 programmes which sometimes interacted with knowledge levels. Sometimes beliefs can
203 change with increased knowledge; equally, one's knowledge may be stunted by a belief that
204 acts as a barrier to information provision. Sometimes this meant that patients did not believe
205 test results which indicated an elevated risk.

206 I don't know what they found to make them think I am at risk in the future...what
207 would make them believe that I will develop diabetes. I don't know why. (N13;
208 participant; Troughton, Jarvis, Skinner et al., 2008, p. 90)

209 Others actively avoided obtaining new knowledge specific to their own risk in response to
210 their belief that getting high risk results from the tests would elicit negative feelings,
211 something to be avoided.

212 Negative beliefs about the consequences of having a health check included potentially
213 being given bad news or being 'told off'. Non-attendance was sometimes linked to a
214 belief that it might be better not to know that one might have an undiagnosed condition
215 or be at risk of developing one. (authors; Burgess et al., 2014, p. 8)

216 Patients' beliefs about capabilities were cited in relation to their perceived ability to make
217 lifestyle changes if they were found to be at risk of CVD or diabetes. These reflected internal

218 beliefs about their “self-motivation and self-concept” and were split into negative beliefs
219 about themselves, e.g. “lack of self-discipline” and “no willpower to exercise” and positive
220 beliefs about themselves being “able to do more” and “looking better” as a result of
221 beginning to make lifestyle changes which encouraged them to continue (Ray, 2001). The
222 link to self-efficacy is clear; one needs to feel able to make a change and be encouraged by
223 initial steps toward change for it to be initiated.

224 Some beliefs acted as barriers to prevention programmes. One was a belief in a connection
225 between the mind and illness (Nielsen, Dyhr, Lauritzen & Malterud, 2009). For the patient in
226 this study a prevention programme was not necessary because she believed that a strong and
227 positive mind would protect her against lifestyle related conditions. For her, this rationalised
228 abstinence from the prevention programme and any health behaviour change.

229 [Patients] discussed the mind as a powerful tool to maintain good health. The mind can
230 make you ill, cure you, keep you well or kill you. A woman stated that someone who
231 feels well, is not so likely to catch a disease. It is important to avoid stress and be
232 positive. This makes you stronger and gives you a chance of a better and longer life.
233 (authors; Nielsen et al., 2004, p. 30)

234 A second belief that acted as a barrier to prevention programmes was a national sense of
235 pride in health that was closely associated to perceptions of citizenship. In the Danish studies,
236 being a good citizen was linked to the ability to work and poor health perceived as a
237 weakness which would bring into question one’s ability to work. Thus, accessing healthcare
238 services was perceived as a weakness which would prohibit participation in prevention
239 programmes.

240 The traditional strong connection between health and work influenced both attitudes
241 and feelings. One informant described her mother saying; “She never complained, even

242 if she was in pain. She struggled for a long time and was extremely enduring and I am
243 proud of that". This *pride* in being strong was still there today. (authors and participant;
244 Emmelin, Weinhall, Stenlund, Wall & Dahlgren, 2007, p. 8)

245 Although the authors observed a change among the younger generation, the legacy of this
246 underlying societal belief of illness as a weakness remained a powerful influence. This is an
247 example of how societal beliefs can impact on individuals' decision-making and readiness to
248 engage in prevention programmes.

249 Cue to (in)action.

250 The focus of the prevention programmes in the included studies was twofold: to identify risk
251 levels; and to foster positive health behaviour change and thereby prevent the risk of CVD or
252 diabetes from increasing further. The first part was reported in terms of CVD risk scores or
253 the detection of pre-diabetes; the second part was not always clearly described but involved
254 advice about nutrition, physical activity, and smoking cessation. This theme demonstrates
255 that sometimes the prevention programme was perceived as a cue to action, i.e. to make
256 lifestyle changes, but sometimes it was perceived as reinforcement of good health which did
257 not require action. In the Danish Ebeltoft Project (reported in: Nielsen et al., 2009; Nielsen,
258 Dyhr, Lauritzen & Malterud, 2005; Nielsen, Dyhr, Lauritzen & Malterud, 2004) it was clear
259 that patients' beliefs that they were in good health had been confirmed following a test result
260 which indicated a low or medium risk profile.

261 The screening confirmed the participants' feeling of being in good health and they put
262 emphasis on this acquired peace of mind. Participants used the results to eliminate
263 worries and confirm their lifestyle up to now [...] though others remarked on the risk of
264 becoming over-complacent. (authors; Nielsen et al., 2009, p.113-4)

265 That this reinforcement of good health acted as a cue to inaction reveals a belief that
266 preventative action, i.e. changes in lifestyle, was only necessary if risk was already elevated.
267 This belief undermines the essence of prevention programmes; preventative action can
268 always be taken even in the absence of risk. There was an awareness of this however in the
269 concern about over-complacency; clearly some participants were aware that their risk profile
270 may change over time and that taking preventative action may be required further down the
271 line. Of greater concern, was that the same kind of reaction was observed by those in higher
272 risk categories (Nielsen et al., 2005). If an elevated CVD risk score was identified but other
273 tests proved normal (e.g. lung capacity), those normal results tended to overshadow the fact
274 that they were a member of a high risk group.

275 It was great to get the “all-clear” on a whole lot of things I’d been wondering about. I
276 wasn’t in quite such bad shape as I’d thought. (J3-1; participant; Nielsen et al., 2005, p.
277 236)

278 These findings demonstrate a tendency toward unrealistic optimism which cued patients
279 toward inaction. Further consolidation of this perceived confirmation of good health came
280 from patients’ fundamental belief that illness was always symptomatic (Burgess et al., 2014;
281 Harkins et al., 2010).

282 I just didn’t feel I needed it (screening) I just didn’t feel...ill. (Respondent 4, Group 2;
283 participant; Harkins et al., 2010, p. 5)

284 There was a clear belief that signs of CVD or diabetes would be felt in the body as
285 symptoms; this expectation to feel the illness or to feel it coming was found to influence
286 participants’ perceptions of whether they were at risk and their decisions about the necessity
287 of lifestyle change. Thus, the lack of embodied symptoms was often perceived as a cue to
288 inaction (Burgess et al., 2014) illustrating the significance of the physiological or the ‘felt

289 sense' (Gendlin, 1996) of illness within the body and patients' perceptions of their illness
290 (Leventhal et al., 1984).

291 Social Influences.

292 This theme describes the impact of social influences—cultural, economic, political, social—
293 on patients' decisions to engage in prevention programmes and any subsequent lifestyle
294 changes. One study explicitly drew upon social networks to test different methods of
295 invitation (Harkins et al., 2010): the first was a social media campaign which depended on
296 'glossy' information leaflets sent to postal addresses requesting that local residents phone the
297 GP surgery to make an appointment; the second a community development project which
298 employed community outreach workers to invite local residents by word of mouth to a drop-
299 in clinic. There was resistance to being accessed by post for a number of reasons (including
300 letters being perceived as junk mail, frequent changes of address, escaping debt or benefit
301 fraud). In contrast, positive responses to face to face interactions with the outreach workers
302 were reported.

303 Meeting the woman (community outreach worker) she was great, I wouldn't have
304 bothered otherwise. (Respondent 3, Group 2; participant; Harkins et al., 2010, p. 4)

305 Other ways that social networks influenced patients was in their knowledge of CVD and/or
306 diabetes. Some were influenced by their friends' experience of having diabetes, which to
307 them did not appear to be serious (Eborall, Davies, Kinmouth, Griffin & Lawton, 2007).
308 Among those declining screening in the Ebeltoft project (Nielsen et al., 2009, 2005, 2004)
309 social comparisons provided legitimacy to a fatalist view which justified a passive approach
310 to health.

311 Several informants gave the example of people who had become ill or died young
312 despite giving up smoking, alcohol or unhealthy food. They told stories about people

313 who had been drinking, smoking and eating whatever they liked and yet enjoyed good
314 health and lived to a ripe old age. Thus, the informants questioned whether too many
315 restrictions were a good thing, hinting that they might be unhealthy or spoil one's
316 happiness. (authors; Nielsen et al., 2004, p.30)

317 This position relates to beliefs about health but also whether health – or preventative
318 behaviour to reduce risk - is prioritised when set in the context of quality of life. Enjoyment
319 of risky behaviours or the threat to happiness created by knowing one's risk in these cases
320 outweighed the benefits of engaging in a prevention programme. The example described
321 above of the pride associated with good health and the close link between health and ability
322 to work demonstrates how social influences can impact on individuals' decision-making
323 processes and health behaviours (Emmelin et al., 2007). In these cases, public health
324 campaigns must also seek to change perceptions of health if prevention programmes are
325 going to be taken up and make a difference in disease incidence on a national level.

326 Role and identity.

327 Factors related to social influence, and context, were aspects of role and identity attributed by
328 patients to themselves and healthcare professionals. This theme describes how for some
329 patients identity was a key factor that influenced their readiness to take up a healthier
330 lifestyle. The extract below demonstrates how a person's belief about their quality of life can
331 reflect their identity, in this case as a smoker/ex-smoker, and prevent them from taking
332 preventative action because the costs outweigh the benefits.

333 My life was better when I smoked, took five minutes off to sit and relax...I couldn't sit
334 still [when I gave up smoking], I couldn't relax enough to drink a cup of coffee with
335 my wife. I've really thought about this a lot; we only live once, I've almost made up my

336 mind that I'm going to take a gamble and smoke rather than torment myself. (J3-14;
337 participant; Nielsen et al., 2005, p. 236)

338 For this participant, the sense of wellbeing from engaging in a risky behaviour was perceived
339 as more important than denying such pleasures in order to reduce risk. There was a sense in
340 some accounts that population-level prevention programmes were badly received because
341 they challenged participants' sense of autonomy.

342 They [participants] stressed the importance of autonomy and the individual's
343 incontestable right to determine his [*sic*] own lifestyle himself [*sic*] and even to enjoy
344 risky habits. (authors; Nielsen et al., 2004, p. 30)

345 Some expressed trust toward healthcare professionals and readily accepted the need to rely on
346 the healthcare system to identify risk levels because they were unable to measure their own
347 blood pressure, blood glucose or cholesterol (Goyder et al., 2009; Nielsen et al., 2004).
348 Others reacted negatively toward being invited to a prevention programme and receiving
349 reminders if they did not attend. This was coupled with a rebellion against being told what to
350 do by the state.

351 Receiving more than one invitation made some feel that the authorities were being
352 over-officious. They also underlined the risk of giving people a guilty conscience and
353 the negative effects on one's quality of life. The informants neither wanted nor needed
354 the doctor to ask them to cut down on smoking or lose weight unless they had asked for
355 advice. Telling them to do so might simply irritate them and make them more reluctant
356 to try. (authors; Nielsen et al., 2004, p. 30)

357 This emphasizes the challenge of getting the balance right between information provision and
358 encouragement to make lifestyle changes and the sensitivities people feel about their health
359 which is bound up with their sense of identity. This means that having one's health criticised

360 may be perceived as an assault on the self. These emotional responses related to the role of
361 the healthcare system and the individual in prevention programmes were summarised in one
362 paper which categorised the different positions taken up by participants (Emmelin et al.,
363 2007). Some participants were reported to perceive the programme as a “disappointment”
364 because they felt they did not belong to the risk groups identified which meant their high
365 expectations of the programme were not met. Others felt the programme as an “insult”.

366 They expressed ambivalence towards the programme even if they may have applauded
367 it at the start. Their participation was more based on feelings than on their own health
368 problems. However, they may have had the targeted risk factors but felt that they could
369 not meet the demands from the programme. They felt criticised and worried over not
370 being able to do something about it. In this group there was also a greater suspicion
371 about the collective ambition of the programme. (authors; Emmelin et al., 2007, p. 9)

372 The embedded emotion in these reactions implies that prevention programmes were not
373 always evaluated rationally. There was also an underlying sense of moralisation, as
374 demonstrated above with the belief that health is something good, an indicator of citizenship
375 or “civic responsibility” (Burgess et al., 2014, p. 6). This notion of ‘doing good’ was also
376 observed in the perceived role of healthcare professionals who were described or described
377 themselves as educators or facilitators (Goyder et al., 2009).

378 Context.

379 This final theme brings together the impact of social influences and role and identity to focus
380 on the context of interactions between healthcare professionals and patients within prevention
381 programmes. This includes micro-contextual factors such as whether interactions were face-
382 to-face up to macro-contextual factors such as whether the programme received
383 governmental support. It was clear that patients valued face-to-face interactions or

384 conversations on the telephone (Goyder et al., 2009; Harkins et al., 2010; Lanza et al., 2007;
385 Sraranchaoenpong & Hanning, 2011; Troughton et al., 2008). This enabled patients to ask
386 questions and gave healthcare professionals the opportunity to explain to patients the process
387 and benefits of knowing their risk level. As stated above, letters and written information were
388 often ignored, negating their utility in this context but there was little imagination about how
389 else to communicate with the public about such programmes and about the risks of CVD and
390 diabetes (Goyder et al., 2009; Harkins et al., 2010; Troughton et al., 2008).

391 The benefits of face-to-face interactions were also highlighted in the comparison between
392 social media based invitations and community based verbal invitations (Harkins et al., 2010).
393 Setting these conversations in a community context rather than in a healthcare setting was
394 preferable to some because it prevented a feeling of “getting lectured to” (Respondent 3,
395 Williams et al., 2001) with the intention of boosting attendance and breaking down the barrier
396 of asking people to make a special trip to a clinic for the tests. Whether such time intensive
397 resources were available was related to the level of organisational commitment to the
398 programme. In almost all studies there was a clear indication of support both in terms of
399 financial investment and infrastructure. Furthermore, some participants appreciated the
400 community spirit and enjoyed feeling part of something larger (Emmelin et al., 2007; Nielsen
401 et al., 2004; Nielsen et al., 2009). A striking exception to this was the lack of organisational
402 and governmental commitment evident in the Thai study (Sraranchaoenpong & Hanning,
403 2011) which raised significant questions regarding the sustainability of the programme.

404 The conceptual model.

405 The themes reported above were combined to create a conceptual model of patients’
406 perceptions and experiences of prevention programmes (represented in Figure 2). This
407 conceptual model of prevention programmes brings together what were identified as active
408 components in the prevention programmes evaluated in the original studies. Synthesizing this

409 evidence with theoretical constructs from the a priori framework and other health psychology
410 theories cited in the original studies has informed the development of this model particularly
411 with respect to the relationships between the themes generated.

412 The diagram depicts *social influences* feeding into *knowledge* and *beliefs*. Social influences
413 included social constructions of health in terms of citizenship which influenced patients'
414 sense of identity in relation to judgements about risky behaviours and quality of life.

415 Similarly, some patients' sense of autonomy led them to rebel against a population level
416 prevention programme designed to help them manage their health, because they felt that was
417 their own responsibility. *Knowledge* and *beliefs* were often described as interconnected and
418 sometimes interdependent, hence the two-way arrow. Knowledge can be targeted through
419 educational programmes, but we know that knowledge alone does not predict behaviour.

420 Indeed, most health psychology theories of behaviour—Theory of Planned Behaviour (Ajzen,
421 1991), Protection Motivation Theory (Rogers, 1983), the Health Action Process Approach
422 (Schwarzer, 1992)—argue that knowledge informs beliefs, which in turn, influence more
423 proximal predictors of behaviour such as self-efficacy and intentions. Furthermore, the
424 synthesis suggested that *beliefs* could manifest as barriers to education confirming that
425 changes in beliefs may be required for prevention programmes to be successful.

426 On the right hand side of the diagram is *context*. Some patients conceptualized healthcare
427 professionals as educators and associated them with a formal consultation in which
428 information and advice were provided to increase patients' knowledge and understanding of
429 CVD and/or diabetes. Setting the prevention programme within a community context altered
430 the *role* played by community workers or healthcare professionals involved in delivering the
431 intervention; face-to-face contact in a non-health setting deformed the programme and
432 facilitated access.

433 Together, *social influences, knowledge and beliefs, context, and role and identity* fed into
434 *cues to (in)action*. The nature of participants' beliefs and their level of understanding of risk
435 factors and CVD or diabetes influenced their readiness to act. Likewise, the setting, the role
436 adopted by healthcare professionals, the perceived role of the programme itself, individuals'
437 sense of identity, and societal factors worked together to influence readiness to engage in
438 prevention programmes and associated behaviour change. Each interconnected theme on the
439 right hand side manifested as either a barrier or facilitator of action and competed with the
440 factors on the left to produce a cue to action or inaction. Together, they were all related to
441 social influences, which cuts across the model as a foundational factor. There was limited
442 evidence to suggest prioritisation of any one factor over another which is why they are
443 presented as equivalent in this model. Nevertheless, the evidence suggests that the
444 significance of each factor is not fixed and that different combinations of factors will play out
445 differently on different occasions.

446 **[INSERT FIGURE 2 ABOUT HERE]**

447

448 **Discussion**

449 The conceptual model generated from themes identified in included studies illustrates the
450 complex interactions at play between the individual and their social context and between
451 healthcare professionals and organisational structures. These complex factors combine to
452 generate a cue to action or inaction. There are number of entry points within this model
453 where healthcare interventions could manipulate factors affecting (in)action. For these entry
454 points to work as active ingredients they need to be targeted within a supportive context, i.e.
455 through government policy and funding at both national and local levels. An initial entry
456 point might be through *knowledge* and information provision. There is an urgent need to
457 move away from written materials and to invest in resources to facilitate face-to-face

458 healthcare professional-patient interactions through *role and identity*. Secondly, a move
459 toward focusing more strongly on smaller communities may work to produce productive
460 *social influences*. Although prevention programmes are often delivered at the population
461 level, there is a need to make them more accessible for the local community which may
462 involve taking them out of the healthcare setting and putting them into workplaces or
463 community centres with additional support available by telephone. Indeed, prevention
464 programmes delivered in primary care or in the community may need to be accompanied by
465 large scale public health messages focusing on lifestyle related to specific behaviours that
466 help to reduce CVD and diabetes risk, e.g. stop smoking, eat well, engage in physical
467 activity. There would then be a foundation on which to build better understanding in
468 individual consultations when tests are conducted.

469 In terms of the content of the programmes evaluated as potential *cues for (in)action*, there
470 was a marked absence of discussion of goals in the included studies; healthcare professionals
471 gave advice about nutrition and physical activity but it was not clear from the way they were
472 reported whether efforts were made to tailor this advice to the individual or indeed to engage
473 in goal-setting. These findings resonate with empirical work published following the
474 completion of this review (Shaw, Pattison, Holland & Cooke, 2015). The lack of tailored
475 advice identified was disappointing because there is evidence to demonstrate that making
476 specific plans to reach a goal is a successful behaviour change technique for promoting
477 adoption of healthy behaviours (Michie et al., 2011; Snihotta, Scholtz & Schwarzer, 2006).
478 Furthermore, there is a need to change people's *beliefs* about symptoms in relation to lifestyle
479 related conditions. The absence of symptoms, and feeling well, were common reasons for
480 non-engagement with programmes which justified *inaction* or confirmed participants'
481 perceptions that their current lifestyle did not need to be changed. This link between a 'felt
482 sense' of illness in the body is not included in the TDF but discussed in the original studies

483 with reference to Leventhal et al.'s (1984) Common Sense Model of Illness Representations
484 and physiological factors contributing to self-efficacy (Bandura, 1977). It is clear from these
485 qualitative studies that illness perceptions are a significant contributor to *beliefs* which then
486 help to formulate *cues to (in)action*, i.e. whether individuals take up invitations to prevention
487 programmes.

488 Of course taking action is not only the responsibility of the patient; the behaviour of
489 healthcare professionals is also important and should be considered a proximal determinant
490 for the quality of care that patients receive (French et al., 2012). Thus, in reviewing the
491 effectiveness of interventions, especially in terms of context and acceptability, it is necessary
492 to examine patient *and* healthcare professional perspectives regarding the reception and
493 delivery of interventions, their impact on patients' everyday lives, and the training and
494 support required to enable healthcare professionals to follow protocols faithfully and deliver
495 them competently (Bellg et al., 2004; Shaw et al., 2014). Unfortunately few studies included
496 accounts from healthcare professionals which means there is insufficient evidence on which
497 to draw conclusions about their role in CVD and diabetes prevention programmes.

498 Finally, these qualitative studies made clear that people's perceptions and reactions to
499 prevention programmes may not always be rational. This highlighted the need to strike a
500 careful balance between information provision and encouragement from healthcare
501 organisations to make lifestyle changes so as not to cause insult or prompt a rebellious denial.
502 Each element of the prevention programme needs to be carefully crafted to ensure it is
503 positively received. The best way to achieve this is to work together with patients and
504 families. Using rigorous qualitative research can be vital in formulating an intervention that
505 will be acceptable and feasible within a specific context (for an example of intervention
506 development using qualitative methods, see: Hudson, Duncan, Pattison & Shaw, 2015).

507 *Strengths and limitations of original studies*

508 Limitations of original studies included missing details of the behavioural components of
509 interventions and lack of transparency making it difficult to determine which aspects of the
510 interventions were successful. Nevertheless, the transparent reporting of the analysis of
511 primary data in high quality studies meant that data extracts were available providing a
512 greater depth of understanding.

513 *Strengths and limitations of the review*

514 This is the first synthesis of evidence relating to prevention programmes for CVD and
515 diabetes which uses the TDF as an a priori framework. This meant the synthesis was
516 informed both by a range of health psychology theories *and* empirical findings in the
517 included studies. This review is limited by the quality of original studies, though we note that
518 none of the 14 included studies was rated as poor, and it is limited in scope by its question.
519 Furthermore, additional work is required to test the use of the TDF and its coverage; several
520 theoretical constructs in included studies were not represented. This suggests further
521 development of the TDF is required for it to fully serve as an a priori framework that
522 comprehensively represents the breadth of existing health psychology theory. Thus, an update
523 of the systematic review of health psychology theories may be required before the TDF could
524 be packaged alongside 'best fit' framework synthesis as a methodological exemplar for
525 'policy urgent' systematic reviews in health psychology.

526 **Conclusion**

527 The conceptual model, developed from this synthesis, enhances the emphasis on the complex
528 interactions between individuals' beliefs, knowledge and identity, their social networks,
529 wider societal constructions of health and organisational factors. At the centre of the model
530 are the *cues to (in)action* which are created through different combinations of factors. More
531 research is needed to make explicit the behavioural components of prevention programmes

532 which focus on patients' and also healthcare professionals' perceptions and experiences to
533 discern which behavioural elements are active in which contexts. Furthermore, programmes
534 for the identification of risk and prevention of CVD and diabetes need to take account of the
535 person-in-context and therefore of the individual within the system. Thus, healthcare
536 providers need to take seriously patients' health beliefs and the context in which programmes
537 operate when identifying intervention points. Public health campaigns to improve knowledge
538 and change beliefs and behaviour need to be combined with practical steps to facilitate
539 equivalent access across socio-demographic boundaries.

540

541 **References**

- 542 Abraham, C., Kelly, M.P., West, R. & Michie, S. (2009). The UK national institute for health
543 and clinical excellence public health guidance on behaviour change: a brief
544 introduction. *Psychology, Health & Medicine*, 14, 1-8.
- 545 Alberti, G., Zimmet, P., Shaw, J., Bloomgarden, Z., Kaufman, F., Silink, M.; Consequences
546 Workshop Group (2004). Type 2 diabetes in the young: the evolving epidemic. The
547 International Diabetes Federation Consequences Workshop. *Diabetes Care*, 7, 1798-
548 1811.
- 549 Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human*
550 *Decision Processes*, 50, 179–211.
- 551 Bandura, A. (1977). Self-efficacy: Toward a Unifying Theory of Behavioral Change.
552 *Psychological Review*, 84(2), 191-215.
- 553 Bellg, A.J., Borrelli, B., Resnick, B., Hecht, J., Minicucci, D.S., Ory, M., Ogedegbe, G.,
554 Orwig, D., Ernst, D. & Czajkowski, S. (2004). Enhancing treatment fidelity in health
555 behaviour change studies: best practices and recommendations from the NIH
556 Behavior Change Consortium. *Health Psychology*, 23(4), 443-451.
- 557 Booth, A. & Carroll, C. (2015). How to build up the actionable knowledge base: the role of
558 ‘best fit’ framework synthesis for studies of improvement in healthcare. *BMJ Quality*
559 *& Safety*, 24(11), 700-708.
- 560 Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research*
561 *in Psychology*, 3(2), 77-101.

- 562 *Burgess, C., Wright, A.J., Forster, A.S., Dodhia, H., Miller, J., Fuller, F., Cajeat, E. &
563 Gulliford, M.C. (2014). Influences on individuals' decisions to take up the offer of a
564 health check: a qualitative study. *Health Expectations*. Available online; DOI:
565 10.1111/hex.12212.
- 566 Cane, J., O'Connor, D., & Michie, S. (2012). Validation of the theoretical domains
567 framework for use in behaviour change and implementation research. *Implementation
568 Science*, 7, 37. Available from
569 <http://www.implementationscience.com/content/7/1/37>.
- 570 Carroll, C., Booth, A., & Lloyd-Jones, M. (2012). Should we exclude inadequately reported
571 studies from qualitative systematic reviews? An evaluation of sensitivity analyses in
572 two case study reviews. *Qualitative Health Research*, 22(10), 1425-1434.
- 573 Carroll, C., Booth, A., Leaviss, J., & Rick, J. (2013). "Best fit" framework synthesis: refining
574 the method. *BMC Medical Research Methodology*, 13, 37. Available from:
575 <http://www.biomedcentral.com/1471-2238/13/37>.
- 576 *Chipchase, L., Waterall, J. & Hill, P. (2013). Understanding how the NHS Health Check
577 works in practice. *Practice Nursing*, 24(1), 24-29.
- 578 Craigie, A.M., Barton, K.L., Macleod, M., Williams, B., van Teijlingen, E., Belch, J.J.
579 Anderson, A.S.; HealthForce Team (2011). A feasibility study of a personalised
580 lifestyle programme (HealthForce) for individuals who have participated in
581 cardiovascular screening. *Preventative Medicine*, 52, 387-389.
- 582 Dixon-Woods, M., Shaw, R.L., Agarwal, S. & Smith, J.A. (2004). The problem of appraising
583 qualitative research. *Quality & Safety in Health Care*, 13, 223-225.

- 584 Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., Bonas, S., Booth,
585 A. & Jones, D. (2007). Appraising qualitative research for inclusion in systematic
586 reviews: a quantitative and qualitative comparison of three methods. *Journal of*
587 *Health Services Research & Policy*, 12(1), 42-47.
- 588 *Eborall, H., Davies, R., Kinmouth A-L., Griffin, S. & Lawton, J. (2007). Patients'
589 experiences of screening for type 2 diabetes: prospective qualitative study embedded
590 in the ADDITION (Cambridge) randomised controlled trial. *British Medical Journal*,
591 335, 490-493.
- 592 Ebrahim, S., Taylor, F., Ward, K., Beswick, A. Burke, M. & Davey Smith, G. (2011).
593 Multiple risk factor interventions for primary prevention of coronary heart disease.
594 *Cochrane Database Systematic Review*, 1, CD001561.
- 595 *Emmelin, M., Weinhall, L., Stenlund, H., Wall, S. & Dahlgren, L. (2007). To be seen,
596 confirmed and involved – a ten year follow-up of perceived health and cardiovascular
597 risk factors in a Swedish community intervention programme. *BMC Public Health*,
598 7,190. Available from: <http://www.biomedcentral.com/1471-2458/7/190>.
- 599 Francis, J., Stockton, C., Eccles, M.P., Johnston, M., Cuthbertson, B.H., Grimshaw, J.M.,
600 Hyde, C., Tinmouth, A. & Stanworth, S.J. (2009). Evidence-based selection of
601 theories for designing behaviour change interventions: using methods based on
602 theoretical construct domains to understand clinicians' blood transfusion behaviour.
603 *British Journal of Health Psychology*, 14, 625-646.
- 604 French, S.D., Green, S.E., O'Connor, D.A., McKenzie, J.E., Francis, J.J., Michie, S.,
605 Buchbinder, R., Schattner, P., Spike, N. & Grimshaw, J.M. (2012). Developing
606 theory-informed behaviour change interventions to implement evidence into practice:

- 607 a systematic approach using the Theoretical Domains Framework. *Implement Science*,
608 7, 38. Available from: <http://www.implementationscience.com/content/7/1/38>.
- 609 Geertz, C. (1973). *The Interpretation of Cultures: Selected Essays*. New York: Basic Books.
- 610 Gendlin, E.T. (1996). *Focusing-oriented psychotherapy. A manual of the experiential*
611 *method*. New York: Guilford.
- 612 *Goyder, E., Carlisle, J., Lawton, J. & Peters, J. (2009). Informed choice and diabetes
613 screening in primary care: qualitative study of patient and professional views in
614 deprived areas of England. *Primary Care Diabetes*, 3, 85-90.
- 615 Grant, M.J. (2004). How does your searching grow? A survey of search preferences and the
616 use of optimal search strategies in the identification of qualitative research. *Health*
617 *Information & Libraries Journal*, 21(1). 21-32.
- 618 Harden, A., Garcia, J., Oliver, S., Rees, R., Shepherd, J., Brunton, G. & Oakley, A. (2004).
619 Applying systematic review methods to studies of people's views: an example from
620 public health research *Journal of Epidemiology and Community Health*, 58, 794-800.
- 621 *Harkins, C., Shaw, R., Gillies, M., Sloan, H., MacIntyre, K., Scoular, A., Morrison, C.,
622 MacKay, F., Cunningham, H., Docherty, P., MacIntyre, P. & Findlay, I.N. (2010).
623 Overcoming barriers to engaging socio-economically disadvantaged populations in
624 CHD primary prevention: a qualitative study. *BMC Public Health*, 10, 391. Available
625 from: <http://www.biomedcentral.com/1471-2458/10/391>.
- 626 Holland, C., Cooper, Y., Shaw, R., Pattison, H. & Cooke, R. (2013). Effectiveness and uptake
627 of screening programmes for coronary heart disease and diabetes: a realist review of
628 design components in interventions. *BMJ Open*, 3(11), e003428 DOI:

- 629 10.1136/bmjopen-2013-003428. Available
630 from: <http://bmjopen.bmj.com/content/3/11/e003428.full>
- 631 Hudson, A.P., Duncan, H.P., Pattison, H.M., & Shaw, R.L. (2015). Developing an
632 intervention to equip nurses for acute life threatening events (ALTEs) in hospital: a
633 phenomenological approach to healthcare research. *Health Psychology, 34(4)*, 361-
634 370.
- 635 Kelly, M.P., Stewart, E., Morgan, A., Killoran, A., Fischer, A., Threlfall, A., & Bonnefoy, J.
636 (2009). A conceptual framework for public health: NICE's emerging approach. *Public*
637 *Health, 123*, e14-e20.
- 638 Koelewijn-van Loo, M.S., van der Weijden, T., Ronda, G., van Steenkiste, B., Winkens, B.,
639 Elwyn, G. & Grol, R. (2010). Improving lifestyle and risk perception through patient
640 involvement in nurse-led cardiovascular risk management: a cluster-randomised
641 controlled trial in primary care. *Preventative Medicine, 50*,35-44.
- 642 *Lanza, A., Albright, A., Zucker, H. & Martin, M. (2007). The Diabetes Detection Initiative:
643 a pilot program of selective screening. *American Journal of Health Behavior, 31(6)*,
644 632-342.
- 645 Leventhal, H., Nerenz, D.R., Steele, D.J., Taylor, S.E. & Singer, J.E. (1984). Illness
646 representations and coping with health threats. In A. Baum (Ed.) *Handbook of*
647 *psychology and health*. Hillsdale, NJ: Lawrence Erlbaum Associates; pp. 219-252.
- 648 Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- 649 McKenzie, J.E., O'Connor, D.A., Page, M.J., Mortimer, D., French, S.D., Walker, B.F.,
650 Keating, J.L., Grimshaw, J.M., Michie, S., Francis, J.J. & Green, S.E. (2010).

- 651 Improving the care for people with acute low-back pain by allied health professionals
652 (the ALIGN trial): a cluster randomised trial protocol. *Implementation Science*, 5, 86.
- 653 Michie, S., Ashford, S., Sniehotta, F.F., Dombrowski, S.U., Bishop, A. & French, D.P.
654 (2011). A refined taxonomy of behaviour change techniques to help people change
655 their physical activity and healthy eating behaviours: the CALO-RE taxonomy.
656 *Psychology & Health*, 26(11), 1479-1498.
- 657 Michie, S., Johnston, M., Abraham. C., Lawton, R., Parker, D. & Walker, A., on behalf of the
658 'Psychological Theory' Group (2005). Making psychological theory useful for
659 implementing evidence based practice: a consensus approach. *Quality & Safety in*
660 *Health Care*, 14, 26-33.
- 661 Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G.; PRIMSA Group. (2009). Preferred
662 reporting items for systematic reviews and meta-analyses: the PRISMA statement.
663 *British Medical Journal*, 339, b2535-6.
- 664 National Cancer Research Institute (2012). *Impact of Patient, Carer and Public Involvement*
665 *in Cancer Research*. London: National Institute for Health Research. Available from:
666 <http://www.ncri.org.uk/wp-content/uploads/2013/07/2012-NCRI-PPI-report.pdf>.
- 667 NICE (2010). *Prevention of cardiovascular disease at population level*. NICE Public Health
668 Guidance 25. Available from:
669 <http://www.nice.org.uk/nicemedia/live/13024/49273/49273.pdf>.
- 670 *Nielsen, K-D.B., Dyhr, L., Lauritzen, T. & Malterud, K. (2004). "You can't prevent
671 anything anyway" A qualitative study of beliefs and attitudes about refusing health
672 screening in general practice. *Family Practice*, 21(1), 28-32.

- 673 *Nielsen, K-D.B., Dyhr, L., Lauritzen, T. & Malterud, K. (2005). Long-term impact of
674 elevated cardiovascular risk detected by screening: a qualitative interview study.
675 *Scandinavian Journal of Primary Health Care*, 23, 233-238.
- 676 *Nielsen, K-D.B., Dyhr, L., Lauritzen, T. & Malterud, K. (2009). “Couldn’t you have done
677 just as well without the screening?” A qualitative study of benefits from screening as
678 perceived by people without a high cardiovascular risk score. *Scandinavian Journal of*
679 *Primary Health Care*, 27, 111-116.
- 680 Patient-Centered Outcomes Research Institute (2014). Available from: <http://www.pcori.org>.
- 681 Pender, N.J. (1996). *Health promotion in nursing practice* (3rd Ed.). Stamford, CT: Appleton
682 & Lange.
- 683 Pope, C., Mays, N. & Popay, J. (2007). *Synthesizing qualitative and quantitative health*
684 *research: a guide to methods*. Maidenhead, UK: Open University Press.
- 685 *Ray, R. (2001). Self-reported heart health behaviour patterns in a rural context. *Australian*
686 *Journal of Rural Health*, 9, 60-64.
- 687 Ritchie, J. & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A.
688 Bryman & R.G. Burgess (Eds.) *Analysing qualitative data*. London: Routledge.
- 689 Robertson, I., Phillips, A. & Mant, D. (1992). Motivational effect of cholesterol measurement
690 in general practice health checks. *British Journal of General Practice*, 42,469-472.
- 691 Rogers, R.W. (1983). Cognitive and physiological processes in fear appeals and attitude
692 change: a revised theory of protection motivation. In J.T. Cacioppo and R.E. Petty
693 (Eds.) *Social Psychophysiology: A source book*. New York, Guildford.

- 694 Schwarzer, R. (1992). Self-efficacy in the adoption and maintenance of health behaviours:
695 Theoretical approaches and a new model. In R. Schwarzer (Ed.) *Self-efficacy:*
696 *Thought control of action* (pp.217-243).
- 697 Shaw, R.L. (2011). Identifying and synthesising qualitative literature. In D. Harper & A.
698 Thompson (Eds.) *Qualitative research methods in mental health and psychotherapy:*
699 *An introduction for students and practitioners*. Wiley Blackwell.
- 700 Shaw, R.L., Booth, A., Sutton, A.J., Miller, T., Smith, J.A., Young, B., Jones, D.R., Dixon-
701 Woods, M. (2004). Finding qualitative research: an evaluation of search strategies.
702 *BMC Medical Research Methodology*, 4, 5 Available from:
703 <http://www.biomedcentral.com/1471-2288/4/5>.
- 704 Shaw, R.L., Larkin, M. & Flowers, P. (2014). Expanding the evidence within evidence-based
705 healthcare: thinking about the context, acceptability and feasibility of interventions.
706 *Evidence Based Medicine*, 19, 201-203.
- 707 Shaw, R.L., Pattison, H.M., Holland, C. & Cooke, R. (2015). Be SMART: examining the
708 experience of implementing the NHS Health Check in UK primary care. *BMC Family*
709 *Practice*, 16 (1). Available from: [http://0-](http://0-www.biomedcentral.com.brum.beds.ac.uk/1471-2296/16/1/abstract)
710 [www.biomedcentral.com.brum.beds.ac.uk/1471-2296/16/1/abstract](http://0-www.biomedcentral.com.brum.beds.ac.uk/1471-2296/16/1/abstract).
- 711 SIGN (2011). *SIGN 50: A guideline developer's handbook* (revised edition November 2011).
712 Edinburgh: Health Improvement Scotland.
- 713 Sniehotta, F.F., Scholtz, U. & Schwarzer, R. (2006). Action plans and coping plans for
714 physical exercise: a longitudinal intervention study in cardiac rehabilitation. *British*
715 *Journal of Health Psychology*, 11, 23-37.

- 716 *Sranacharoenpong, K. & Hanning, R.M. (2011). Developing a diabetes prevention
717 education programme for community health-care workers in Thailand: formative
718 findings. *Primary Health Care Research & Development*, 12,357-369.
- 719 *Troughton, J., Jarvis, J., Skinner, C., Robertson, N., Khunti, K. & Davies, M. (2008).
720 Waiting for diabetes: perceptions of people with pre-diabetes: a qualitative study.
721 *Patient Education & Counseling*, 72, 88-93.
- 722 WHO (2009). *Definition, diagnosis and classification of diabetes mellitus and its*
723 *complications. WHO/NCD/NCS/99.2*. Geneva: WHO Department of
724 Noncommunicable Disease Surveillance.
- 725 WHO (2011a). *Global status report on noncommunicable diseases 2010*. Geneva: World
726 Health Organization.
- 727 WHO (2011b). *Global atlas on cardiovascular disease prevention and control*. Geneva:
728 World Health Organization.
- 729 *Williams, A., Mason, A. & Wold, J. (2001). Cultural sensitivity and day care workers:
730 examination of a worksite based cardiovascular disease prevention project. *American*
731 *Association of Occupational Health Nurses Journal*, 49(1), 35-43
- 732

Table 1. Description of the original studies included in this review.

| Paper | Author (Year) | Research Question/Aim | Sampling Method and Size (n) | Intervention | Location | Data Collection Method | Data Analysis Method | Quality Rating |
|--------------|-----------------------------|---|--|---|-----------------|-------------------------------|---|-----------------------|
| P1 | Burgess (2014) | To explore patterns of uptake; influences on decision to attend screening | Patients ($n=27$), Purposive | NHS Health Check | UK | Interviews | Framework analysis | Key Paper |
| P2 | Chipchase (2013) | To explore impact of NHS Health Check with patients | Patients ($n=10$), Random | NHS Health Check | UK | Interviews | Interpretative phenomenological analysis | Satisfactory |
| P3 | Eborall (2007) | To provide insight into factors contributing to anxiety; to explore expectations & reactions to screening experience | Patients & HCPs ($n=23$), Purposive | ADDITION trial Type 2 diabetes screening | UK | Interviews | Grounded theory | Key Paper |
| P4 | Emmelin (2007) ^a | To describe changes in self-rated health related to risk factors; to describe health related norms & attitudes toward CVD programme | Patients ($n=9$), Purposive | Cardiovascular risk factors screening | Sweden | Interviews | Grounded theory | Key Paper |
| P5 | Goyder (2009) | To examine perceptions of staff & patients involved in screening | Patients ($n=49$) & HCPs ($n=23$), Purposive | Diabetes screening | UK | Interviews | Framework analysis | Key Paper |
| P6 | Harkins (2010) | To explore perceived barriers & facilitators to engaging in CHD primary prevention programme | Patients ($n=13$) | CHD prevention programme | UK | Focus groups | Thematic analysis | Key Paper |
| P7 | Lanza (2007) ^a | To evaluate the Diabetes Detection Initiative | Patients ($n=20-32$) ^c , Purposive | Diabetes Detection Initiative | US | Discussion groups | Not stated | Unsure |
| P8 | Nielsen (2009) ^b | To explore individuals' responses to a low cardiovascular risk score | Patients ($n=22$), Purposive | Ebeltoft Project CVD | Denmark | Interviews | Thematic analysis using Malterud's principles | Satisfactory |

| | | | | | | | | |
|------------|------------------------------|---|--|-------------------------------------|-----------|-----------------------------|---|--------------|
| P9 | Nielsen (2005) ^b | To explore individuals' responses to an elevated cardiovascular risk score | Patients ($n=14$), Stratified, Purposive | Ebeltoft Project CVD | Denmark | Interviews | Thematic analysis using Malterud's principles | Key Paper |
| P10 | Nielsen (2004) ^b | To explore non-participants' views on invitations to health screenings | Patients ($n=47$), Stratified, Purposive | Ebeltoft Project CVD | Denmark | Interviews | Thematic analysis using Malterud's principles | Satisfactory |
| P11 | Ray (2001) | To explore behavioural changes of those attending screening | Patients ($n=135$), Self-selected | Heart risk screening | Australia | Telephone interviews | Content analysis | Satisfactory |
| P12 | Sranacharoenpong (2011) | To investigate barriers to & support for community-based diabetes prevention programme | Patients & HCPs ($n=43$), Purposive | Diabetes prevention programme | Thailand | Interviews and focus groups | Thematic analysis | Key Paper |
| P13 | Troughton (2008) | To ascertain individuals' experience of screening | Patients & HCPs ($n=15$), Purposive | Pre-diabetes | UK | Interviews | Framework analysis | Key Paper |
| P14 | Williams (2001) ^a | To examine the impact of a culturally appropriate recruitment strategy to CVD screening | Patients ($n=66$) in work context | Healthier People Risk Appraisal CVD | US | Interviews | Not stated | Unsure |

Note. CVD – Cardiovascular disease. HCPs – Health care professionals. UK – United Kingdom. US – United States. ^a Mixed methods study – only the qualitative elements of these studies were included in this review. ^b These studies report results from the same study. ^c Exact sample size of qualitative element not stated.

^d Quality Rating: Key paper – meets all quality criteria and clearly fits with review question. Satisfactory – meets most quality criteria and fits well to review question. Unsure – mixed responses to quality criteria and lack of clarity regarding relevance to review question. Poor – does not meet quality criteria.

Table 2. Appraisal of original studies included in this review.

| Prompt | Reviewer | P1 | P2 | P3 | P4 | P5 | P6 | P7 | P8 | P9 | P10 | P11 | P12 | P13 | P14 |
|--|----------|-----------|------------|-----------|-----------|-----------|-----------|------------|------------|-----------|------------|------------|-----------|-----------|------------|
| 1. Are the research questions clear? | 1 | Y | N | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | Y |
| | 2 | Y | N | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | Y |
| 2. Are the research questions suited to qualitative inquiry? | 1 | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | Y |
| | 2 | Y | - | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | Y |
| 3. Is the sampling clearly described? | 1 | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| | 2 | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | N | Y | N |
| 4. Is the data collection clearly described? | 1 | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y |
| | 2 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 5. Is the analysis clearly described? | 1 | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | N |
| | 2 | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | Y | Y |
| 6. Is the sampling appropriate to the research question? | 1 | Y | Y | Y | Y | - | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| | 2 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | - |
| 7. Is the data collection appropriate to the research question? | 1 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| | 2 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| 8. Is the analysis appropriate to the research question? | 1 | Y | Y | Y | Y | Y | Y | - | Y | Y | Y | Y | Y | Y | - |
| | 2 | Y | Y | Y | Y | Y | Y | - | - | - | - | Y | Y | Y | Y |
| 9. Are the claims made supported by sufficient evidence? | 1 | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | N | Y | Y | N |
| | 2 | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | N | Y | Y | N |
| 10. Are the data, interpretations, and conclusions clearly integrated? | 1 | Y | Y | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | Y |
| | 2 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | N |
| 11. Does the paper make a useful contribution? | 1 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| | 2 | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | N |
| Overall Rating^a | 1 | KP | SAT | KP | KP | SAT | KP | UNS | SAT | KP | SAT | SAT | KP | KP | SAT |
| | 2 | KP | SAT | KP | KP | KP | KP | UNS | SAT | SAT | SAT | KP | KP | KP | Poor |
| Agreed Rating | | KP | SAT | KP | KP | KP | KP | UNS | SAT | KP | SAT | SAT | KP | KP | UNS |

Note. P – Papers that were coded for the particular dimension; see Table 1 for corresponding Author (Year). ^aQuality Rating: KP: Key paper – meets all quality criteria and clearly fits with review question; SAT: satisfactory – meets most quality criteria and fits well to review question; UNS: unsure – mixed responses to quality criteria and lack of clarity regarding relevance to review question; Poor – does not meet quality criteria.

Table 3. Coding of included studies against the *a priori* framework: Theoretical domains framework.

| DOMAINS and Constructs* | Studies (<i>k</i>) Coded For Domain | Analytic Observations |
|---|---|--|
| D1 KNOWLEDGE Knowledge; procedural knowledge; knowledge of task environment | <i>k</i>=13 P1, 2, 3, 4, 5, 6, 7, 8, 10, 11, 12, 13, 14 | Generally knowledge is poor If knowledge is good it doesn't always lead to behaviour change – it interacts with other mediating factors |
| D2 SKILLS Skills; skills development; competence; ability; interpersonal skills; practice; skill assessment | <i>k</i>=3 P2, 3, 12 | Healthcare professionals need to be trained & supported |
| D3 SOCIAL/PROFESSIONAL ROLE AND IDENTITY Professional identity; professional role; social identity; identity; professional boundaries; professional confidence; group identity; leadership; organisational commitment | <i>k</i>=7 P3, 4, 9, 10, 12, 13, 14 | Identity in relation to individuals & organisations are mediating factors |
| D4 BELIEFS ABOUT CAPABILITIES Self-confidence; perceived competence; self-efficacy; perceived behavioural control; beliefs; self-esteem; empowerment; professional confidence | <i>k</i>=6 P4, 8, 10, 11, 12, 13 | A mixture of terms are used including: self-efficacy, perceived behavioural control, confidence |
| D5 OPTIMISM Optimism; pessimism; unrealistic optimism; identity | <i>k</i>=4 P1,3,9,13 | Sometimes unrealistic optimism linked to inaction |
| D6 BELIEFS ABOUT CONSEQUENCES Beliefs; outcome expectancies; characteristics of outcome expectancies; anticipated regret; consequents | <i>k</i>=8 P1, 2, 3, 4, 5, 8, 10, 13 | Expectations of results influence decision-making |
| D7 REINFORCEMENT Rewards; incentives; punishment; consequents; reinforcement; contingences; sanctions | <i>k</i>=4 P4, 8, 11, 13 | Confirmation of (good) health status |
| D8 INTENTIONS | <i>k</i>=6 | |

| | | |
|---|--|---|
| Stability of intentions; stages of change model; transtheoretical change model and stages of change | P4, 8, 9, 10, 11, 13 | Talk of changes included but in no detail |
| D9 GOALS | k=3 | |
| Goals; goal priority; goal/target setting; goals (autonomous/controlled); action planning; implementation intention | P4,9,11 | Talk of changes made but not in language of behaviour change techniques |
| D10 MEMORY, ATTENTION AND DECISION PROCESSES | k=2 | |
| Memory; attention; attention control; decision making; cognitive overload/tiredness | P5, 8 | Decision-making |
| D11 ENVIRONMENTAL CONTEXT AND RESOURCES | k=13 | |
| Environmental stressors; resources/material resources; organisational culture/climate; salient events/critical incidents; person x environment interaction; barriers and facilitators | P1, 2, 3, 4, 5, 6, 9, 10, 11, 12, 13, 14 | Materials & resources; person x organisation interaction includes patient × healthcare professional interaction |
| D12 SOCIAL INFLUENCES | k=11 | |
| Social pressure; social norms; group conformity; social comparisons; group norms; social support; power; intergroup conflict; alienation; group identity; modelling | P2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 13 | Community/collective effort; social pressures; power issues relating to doctor-patient relationship |
| D13 EMOTION | k=7 | |
| Fear; anxiety; affect; stress; depression; positive/negative affect; burn-out | P4, 5, 6, 8, 9, 10, 11 | Positive/negative affect; some anxiety |
| D14 BEHAVIOURAL REGULATION | k=1 | |
| Self-monitoring; breaking habit; action planning | P11 | Self-reported changes |

Note. *All definitions are based on definitions from the American Psychological Association's Dictionary of Psychology; adapted from Cane et al. (2012).
P – Papers that were coded for the particular dimension; see Table 1 for corresponding Author (Year).

Table 4. Inductive thematic analysis of included studies: Concepts not included in the Theoretical domains framework.

| | Themes | Studies (<i>k</i>) Coded For Themes | Analytic Observations |
|------------|--|--|--|
| T1 | Perceived/Experienced Symptoms | <i>k</i> =5 P1, 3, 6, 10, 13 | Cited reason for not screening/not taking action (T4) |
| T2 | Prioritisation of health/behaviour change in relation to quality of life | <i>k</i> =3 P2, 9, 12 | Cited reason for not taking action (T4) |
| T3 | Reassurance/confirmation of (good) health status | <i>k</i> =5 P1, 2, 4, 8, 13 | Knowledge of risk factors & relationship of lifestyle on CVD mediate this confirmation of good health (D1); relates to beliefs/expectations of consequences (D6) |
| T4 | Cue to (in)action | <i>k</i> =4 P3,4,9,10 | Either prompts action or not depending on interaction with T1,2,9; related to D7,13 |
| T5 | Moralising health | <i>k</i> =3 P3, 4, 8 | Good health perceived to equate to good person; relates to social influences (D12) |
| T6 | Mind-body/whole person approach to health | <i>k</i> =2 P4, 10 | Physical symptoms not experienced is perceived to equate to absence of illness; relates to D1 |
| T7 | (in)dependence from/on healthcare services | <i>k</i> =3 P8, 10, 13 | Caution against passivity/dependence on healthcare system; individual choice |
| T8 | Rebellion against public health strategies/authority/community approach | <i>k</i> =2 P6, 10 | Related to moralising health – reaction against notion of common good/authority |
| T9 | Perceived good health/lack of symptoms | <i>k</i> =4 P2, 6, 10, 11 | Cited reason for inaction (T4) |
| T10 | Longevity of risk factors/illness | <i>k</i> =1 P10 | Related to knowledge of risk factors over time (T1) |
| T11 | Perceived professional role and identity | <i>k</i> =7 P3, 4, 9, 10, 12, 13, 14 | Related to professional role and identity (D3) but focuses on patients' perceptions of professionals |

Note. *All definitions are based on definitions from the American Psychological Association's Dictionary of Psychology; adapted from Cane et al. (2012).
P – Papers that were coded for the particular dimension; see Table 1 for corresponding Author (Year).

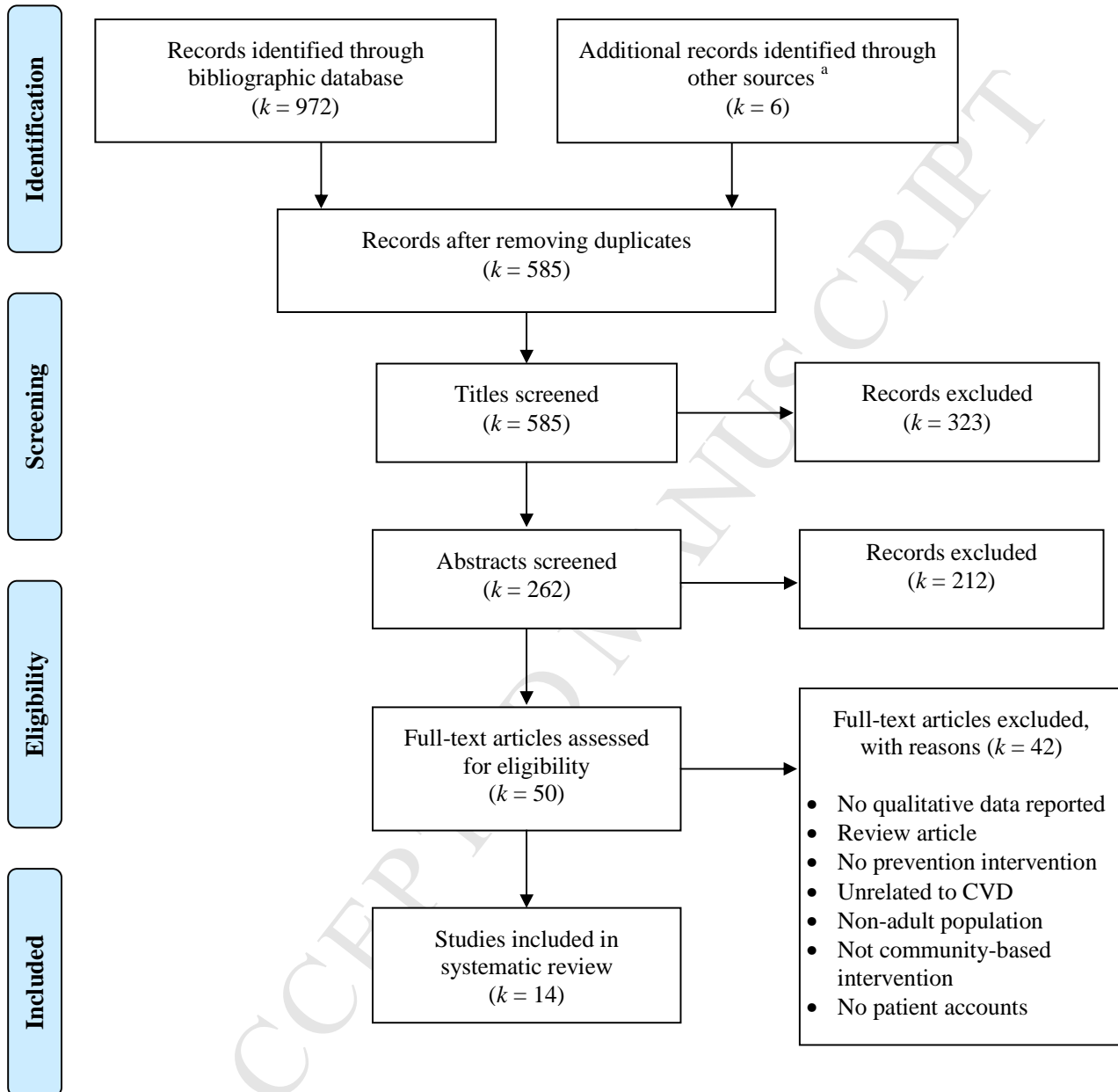


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram. ^a Other sources: Reference changing, contacting authors. CVD – Cardiovascular disease.

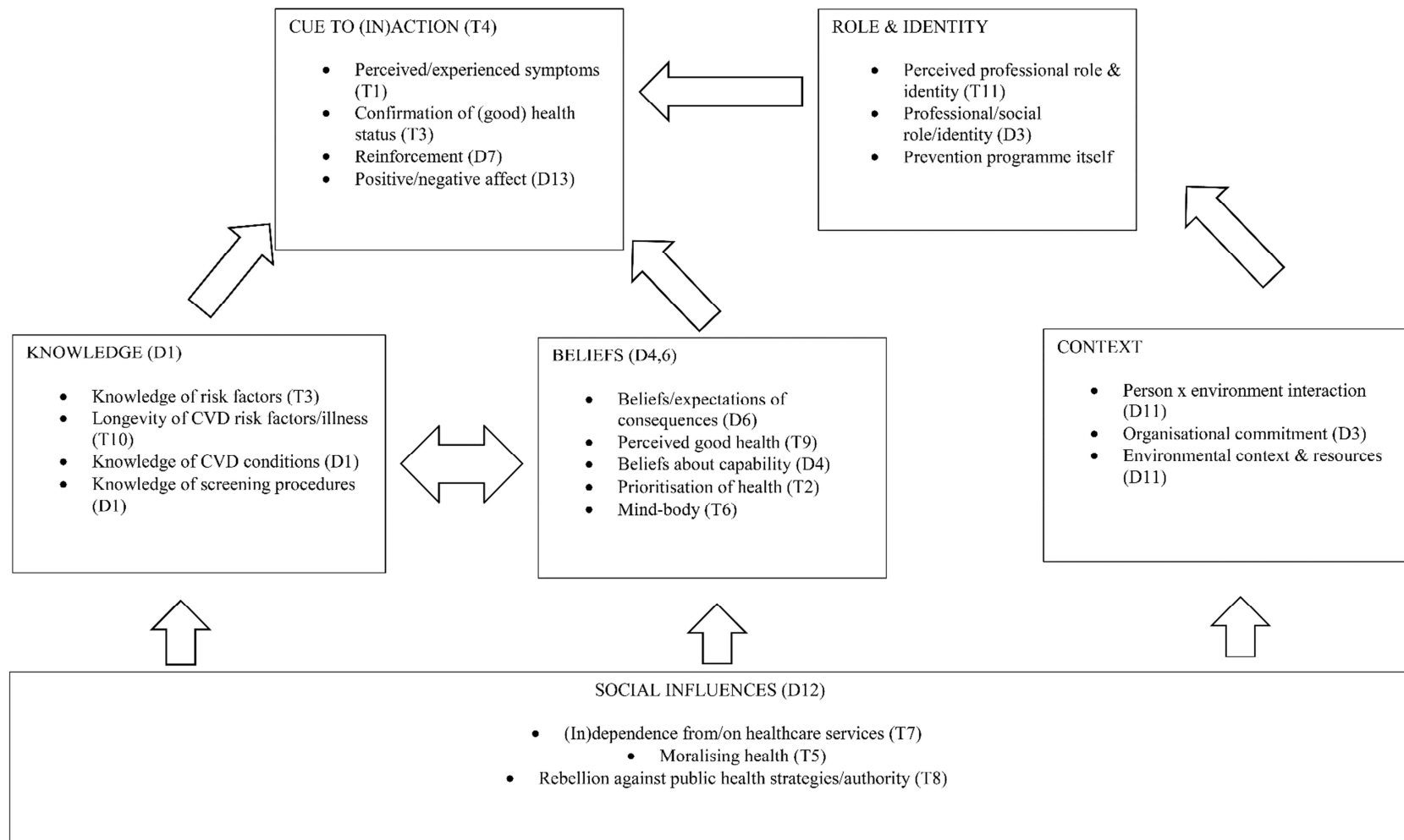


Figure 2. Conceptual model of patients' perceptions and experiences of prevention programmes. D – Domains; Theoretical domains and constructs in the theoretical domains framework (see Table 3 for details). T – Themes (identified through inductive thematic analysis); Theoretical constructs *not* included in the theoretical domains framework (see Table 4 for details). CVD – Cardiovascular disease.

Patients' perceptions and experiences of cardiovascular disease and diabetes prevention programmes: a systematic review and framework synthesis of qualitative evidence

Research highlights

- Framework synthesis offers robust review methodology for 'policy urgent' questions
- The Theoretical Domains Framework combines constructs; more development work on its comprehensiveness is needed
- Qualitative research studies tell us about patient acceptability of prevention programmes
- Organisation and social context create distinctive professional-patient interaction
- Knowledge and beliefs about risk & symptoms combine to create cues to (in)action