# Self Assessment of Health and Social Care Needs by Older People: A multi-method systematic review of practices, accuracy, effectiveness and experience

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)

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# **Executive summary**

#### **Background**

This review considers the evidence base for 'self-assessment' by older people in managing and identifying health and social care needs.

Self-assessment is widely advocated in policy and practice developments for older people.

The National Service Framework for Older People specifically emphasises person centred care, the key themes of which are proper assessment of potentially complex needs, integration of assessment, sharing of information between services and with clients and active involvement of older people in both health promotion and assessments.

The single-assessment process is a key tool to achieve these goals and self-assessment is identified as having an important role.

Despite the widespread discussion there is little agreement on the precise meaning of the term. Although occasionally used to simply refer to self-report self-assessment is defined here as comprising at least self-report, self-completion or direction of the process and self as the potential beneficiary of the assessment.

In addition to these three elements, self-assessment can be self-initiated, self-interpreted and prompt self-care actions.

Self-assessment raises complex questions about accuracy, effectiveness and the experience for users.

This review addresses these complex issues through a number of approaches. These are;

- a survey of the scope of approaches toward self-assessment based upon a comprehensive review of literature and a survey of practice
- a systematic review of studies of accuracy comparing the results of self-assessments with appropriate gold standard assessments
- a systematic review of controlled trials of effectiveness of selfassessment
- a review of qualitative evidence of self-assessment focussing on the experience and acceptability of self-assessment from the perspective of both the older person and professionals.

#### Scope

Self-assessment has been used across a wide variety of domains and for a number of purposes ranging from targeted screening for specific medical disorders through to approaches designed to help individual decision-making in relation to major life events such as changing accommodation.

Self-assessments can be categorised according to their content in relation to health and social care and according to the extent to which they focussed on single or multiple problems.

In the majority of focussed health related assessments, self-assessment substituted for professional assessment, and in most cases is simply a mode of administering a screening test without having face-to-face contact. Most self-assessments in focussed health are professionally initiated questionnaires, focusing on internal factors. In most cases the questionnaire is professionally interpreted and it is the professional who is prompted to act.

Although fewer in number, there is more variety in the general health assessments identified. Examples include paper and pencil questionnaires, self-assessment algorithms and web-based systems with feedback. There is much more autonomy in the use of the assessments, with some examples being entirely user directed from initiation to action. Frequently the goal is to improve management of healthcare in general and to mediate relationships with professionals.

Despite the limited numbers of examples of self-assessment in the social care / life skills domain there is more variety and many of the examples identified are substantively different from any face-to-face assessment. Self-assessments in this domain are more likely to be user initiated and interpreted and to aid decision making on behalf of the user. One reason for this is that they cover issues that would not routinely be addressed by a professional assessment e.g. driving ability, moving home, life strengths.

Most examples of comprehensive assessment were related to the UK's Single Assessment Process. While there has been considerable innovation in terms of user involvement in development and in modes of delivering comprehensive assessments, few examples of self-assessment were identified.

As with medical screening the value of an assessment lies not simply in its ability to gather information but what happens afterwards. In this regard it is clear that even the most innovative self-assessments require appropriate action by professionals and are not designed to impact upon the person themselves directly.

Although the paper and pencil questionnaire remains ubiquitous there are examples of the use of computers and the Internet in the assessment process and it would seem likely that this will become

increasingly prevalent offering a possible mechanism to disseminate self-assessment questionnaires and increase initiation of assessment by users themselves. However, the development of such methods for older people may be inhibited by a (misguided) perception that they lack the requisite skills.

#### Accuracy

Twenty-six studies were identified which met the review criteria. The majority of those were in the domain of focussed health and sample sizes were often modest.

This suggests that self-assessment tool development is not well advanced. There were also a small number of general health assessments, however no evaluations of the accuracy of comprehensive or life and social skills were found.

The accuracy of the self-assessment tools was considerably varied with some assessments performing well. The tools that were found to be more accurate tended to be in areas where the reference standard was well developed e.g. mental health, and where there is closer overlap between the content of the self-assessment and the diagnostic criteria.

Several tools have at least modest accuracy in identifying older people with depression. These self-assessments generally have higher sensitivity than specificity, suggesting that their value may be in screening but there is a risk of high numbers of false positives.

Other areas of focussed health care where potentially useful self-assessment tools exist include screening for osteoporosis and screening for mobility problems. In both cases tools exist which have high sensitivity and moderate specificity. This means that although a high proportion of people with problems will be identified, this is at the expense of a high false positive rate. The potential costs of this need to be taken into consideration when developing a screening programme.

Health care areas where the accuracy of self-assessment tools remains unclear include dental health, nutrition and hearing.

Visual self-assessment has been shown in a single large study to have high specificity but low sensitivity, making it unsuitable as a screening tool.

Although the predominant proposed use of most of the self-assessment tools is as a screening tool the majority, including the general health assessments, show modest sensitivity and specificity, and thus the self-assessments will fail to identify many older people who may have problems.

#### **Effectiveness**

Nine studies of the effectiveness of self–assessment based programmes were identified. Most of these related to studies of general health approaches with studies examining over 75 health checks, self-care books and a system which gives feedback to both client and care provider (Dartmouth COOP).

There is no direct evidence from which to directly evaluate the effectiveness of focused self-assessment based screening programmes for older people, either related to non screening or other approaches to screening.

Unless self-assessment introduces additional action on behalf of the client it would seem unlikely to lead to different outcomes from non-self-assessment based approaches, since professional interpretation and action is the norm.

Thus self-assessment is probably effective under the same circumstances as other screening programmes: where it is accurate and resources exist to follow up and deliver effective treatment.

The results of studies to evaluate the effectiveness of selfassessment on reducing drug reactions or interactions are positive but there is no evidence of clients' actual behaviour change.

Approaches such as those based on the Dartmouth COOP system, which provide feedback to both client and practitioner, seem most beneficial.

It is likely that benefits will be maximised if this information is used explicitly during face-to-face consultations.

Where assessments are targeted at those over 75, a strategy that regards non-response as an adverse assessment may maximise benefit.

There is a large evidence base for self-care approaches including algorithms but it is weak and inconclusive.

Although the evidence is promising, self-care does not necessarily lessen the demand for health care.

No evidence was found that related to the effectiveness of comprehensive assessment.

#### **Experience of self-assessment**

Evidence of how older people experience self-assessment is weak due to the small number of studies that address this issue.

Although generally willing to complete self-assessment screening questionnaires, there is little evidence on whether or not older people perceive the activity to be useful or will initiate any action in response to the self-assessment.

Older people express a preference for professional assessment for some issues e.g. hearing, however for other more sensitive issues there is tentative evidence of a preference for self-assessment.

The limited evidence suggests that the more general the assessment and less focussed on a specific problem requiring diagnosis, the more acceptable self-assessment is.

The perception of the purpose of self-assessment is important.

Self-assessments that emanate from respected and known sources, such as family practitioners, seem to result in high participation

An opportunity to complete the assessment with the potential for professional input as needed/wanted is important, rather than being 'left to get on with it'. Supported self-assessment can be a positive experience for older people.

The length and complexity of a questionnaire does not necessarily have a negative impact on the experience of self-assessment if it is easy to use and the items correspond to issues considered by older people as being important to them.

There is some evidence that older people are satisfied with a user-initiated and user-interpreted self-assessment.

There is a large gap in current knowledge on how older people experience comprehensive assessment, within which self-assessment is increasingly incorporated.

#### Recommendations for further research

Although there is evidence for the accuracy of self-assessments, particularly in the field of focussed health, this area is under researched.

In terms of focussed health, more studies on the accuracy of selfassessments of functional status in practice as opposed to for research purposes are required.

Where self-assessment is intended to impact upon health behaviour more evidence is required to determine actual behavioural change.

Self-care approaches seem promising but again further research is required particularly in the UK context and, specifically in relation to developments such as NHS direct

With the widespread implementation of the Single Assessment Process there is a need to explore older people's experiences of the self-assessed component of comprehensive assessment as a matter of urgency.

Further research should directly investigate the experience of selfassessment rather than resort to making inferences based on assumptions from indirect sources, notably response rates.

Evidence of how the process and content of assessment affects the experience of self-assessment would be of value in the design and implementation of self-assessment with older people.

Exploring other factors that may impact on older people's experience of self-assessment e.g. the characteristics of the person completing the self-assessment and the timing of the assessment is also important.

Exploration of the extent to which, and in what circumstances older people are comfortable with self-assessment as a substitution for professional assessment, in part or as a whole, would be beneficial.

#### **Recommendations for practice**

Wherever self-assessment is employed as part of an interaction with services, professionals need to demonstrate that they value the information provided

Systems that incorporate both feedback and self care information for users as well as delivering assessment information to professionals are best supported by evidence

Where initiated by professionals the use of self-assessment in practice demands professional expertise and involvement in order to maximise benefits and avoid a perception of neglect.

Results of self-assessments for health conditions are not definitive: they can serve to provide focus in an individual's assessment but cannot fully replace it.

From the weak evidence available it appears that older people are comfortable with self-assessment, including user-initiated and user-interpreted assessments,

Many people may prefer to have a degree of professional support with the process.

The use of self-assessment for identifying health and social needs may be a more positive and helpful exercise for older people if directly supported by a known health professional.

The use of computer-based questionnaires may be a positive development for older people but format, ease of use and access is crucial.

The design content and layout of self-assessment material is crucial and active involvement of potential users in the process may be beneficial.

#### **Recommendations for policy**

Knowledge about the use of self-assessment among older people is underdeveloped despite long standing guidance reinforcing the

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importance of user's views in assessment, patient involvement in care and person centred care.

The varieties of practices identified indicates that there is considerable scope to advance policy directives regarding self-assessment further within the confines of patient acceptability.

Benefits should not be assumed and in particular the use of selfassessment should not be equated with user involvement and partnership. Generally more clarity is required when advocating self-assessment

The majority of self-assessments that have been developed are designed to be initiated, interpreted and acted upon by professionals, not the older people themselves.

These are potentially useful but the partnership is embedded in how the assessment is used, not the assessment itself.

The small number of self-assessments included in this review that were directed by older people were considered to be useful and acceptable.

User involvement in the development of assessments is potentially valuable but professional expertise in terms of the performance of specific test should not be neglected

# Section 1 Introduction

This review considers the use of self-assessment instruments and techniques by older people in diagnosis, problem identification and management for health and social care. It explores the scope and evidence-base for 'self-assessment' as a mechanism for promoting accurate, comprehensive, assessment; effective health and social care; and active user involvement for older people.

Self-assessment for health and social care needs has been used over a considerable period of time and for purposes as diverse as case finding for depression to assessment of housing options. Although self-assessment has usually involved the use of short scales and questionnaires it can involve the use of physiological tests (such as testing urine for glucose) or complex computerised decision support systems.

Although it has often been explored as a simple means for extending the 'reach' of professional assessments (for example mass screening) and ensuring 'appropriate' use of health services (for example self-care algorithms) it is increasingly being advocated as a means of actively involving and empowering the users of services. In particular in the UK, the advent of the Single Assessment Process (SAP) as part of the National Service Framework for Older People (DoH, 2001b) has led to considerable interest in self-assessment as a means for active user involvement.

#### 1.1 Context

The involvement of service users as active participants in health care is a stated aim of many current developments within health and social care and self-assessment has been identified as a key mechanism. Guidance issued by the Department of Health has, for 15 years or more, referred to the importance of the service user's views in assessment including (for example) the original community care guidance issued in 1990 (DHSS, 1990b) and in 1991 (DHSS, 1990a). More recently this has been re-emphasised in guidance issued to both local authorities social services and the NHS (HSC 2002/001, LAC 2002/1: (DoH, 2002a).

The concept of the expert patient and the promotion of self-care amongst people with long-term conditions are also highlighted as central to current NHS development. Although not labelled as such, self-assessment is an important component of these person-focused initiatives, which encourage self-diagnosis, self-monitoring and self-management. (DoH, 2005).

For older people specifically, person centred care is identified as a standard in the National Service Framework for Older People (DoH, 2001b). This has many facets but the key themes of person centred care are proper assessment of potentially complex needs, integration of assessment, sharing of information between services and with clients and active involvement of older people in health promotion and assessments. Government policy continues to emphasise the role of self-management and self-care (DoH, 2001a, 2005)

The SAP is one of the major innovations proposed to achieve the goal of person centred care. It aims to make sure older people's needs are assessed thoroughly and accurately and to avoid procedures being needlessly duplicated by different agencies. At the core of the SAP is the development of common assessment procedures and records that reflect the persons' needs from a broad perspective.

User involvement and self-assessment are envisaged as forming an element of this process (DoH, 2001b). Detailed guidelines (DoH, 2002a) and a list of tools and scales that might contribute to the process were identified at the time that this review commenced (DoH, 2002b). The list was subsequently expanded and updated (DoH, 2004a) and a number of tools given accreditation (DoH, 2004b) but authorities remain free to develop their own approach based on the principles outlined and are encouraged to consider the use of existing validated scales when developing their approach.

The ambitions for self-assessment embodied in the NSF in particular are wide. Self-assessment used as part of the single assessment process or in other, perhaps narrower contexts, must provide accurate information in a form that has the potential to impact positively on care management and ultimately the outcome of care. Additionally if it is to be a tool for user involvement it must, as a minimum be perceived as acceptable and furthermore actually engender perceptions and activities of involvement among users.

Whereas user involvement in general has been relatively well studied, self-assessment as a specific mechanism has not. However, there is evidence that professionals and older people have conflicting understanding of current assessment practice, with the professional agenda dominating and sometimes obstructing the older persons attempt to communicate problems and potential solutions (Richards, 2000). Many scales and tools exist which might be completed by potential service users but evidence regarding a tool when completed by a professional or under close supervision may not apply when undertaken by the older person him/herself. Furthermore, accurate assessment may not result in more effective care. Feelings of empowerment and engagement engendered in specific groups with specific conditions may not be reproduced for older people with differing challenges and cultural perspectives. If

self-assessment is to contribute to the process as envisaged it is important to determine whether the anticipated benefits do in fact result from it.

In order to inform these developments this review aims to identify the scope (i.e. in what ways has self-assessment been used?), accuracy, effectiveness and experience of self-assessments by older people. Specifically the review aims to determine the evidence base for self-assessment instruments and practices in making health and social care decisions about diagnoses, needs, problems and care management for individual older people.

#### 1.2 The 'self' in self-assessment

Despite widespread use of the term 'self-assessment' and interest in the concept no clear single definition of the term emerges from the literature. Much of the literature on 'self-assessment' simply refers to the ability of individual self report to accurately reflect and predict present or future health status, with no direct utility for the individual and with no application in practice (In the context of this review practice refers to both professional practice and to the use of an assessment by an older person to manage their own needs, which need not necessarily involve a professional practitioner). It has been observed that self-assessment can be used to refer to little more than the acknowledged and widely accepted good practice of professionals considering (potential) service users' views of their own needs (ICES, 2002b). In many cases self-assessment is used to refer to a client's response to an evaluative question about health status or need asked by a practitioner. In these terms selfassessment applies to all self-reports of health status or specific symptoms (for example pain severity). In other cases the use of the term is broader in that it appears to refer to the introduction of a more client centred approach to care planning for groups who had simply not been involved or consulted in the past. This was most strongly illustrated during the course of this review in some of the material that was offered as potential examples of self-assessment. For example, much of the material in the field of learning disability and mental health is based on a change in practice where clients were offered choice or asked about preferences.

Self-assessment as used in this review involves practices that have as a minimum self-report, self-completion and self as the potential beneficiary. The recognition of the significance of a patient's history as part of the diagnostic process in medicine long ago established self-report as crucial. But this definition of self-assessment; equating it with self-report alone; is too broad to be useful since it does little to distinguish self-assessment from history taking. Clearly though, self-assessment must consist of self-report.

The use of self-administered questionnaires to prospectively identify risk across a number of domains, including functional decline, is well

established. It might be argued that responding verbally to a questionnaire presented at an interview involves the same level of self-reflection/self-examination, and the same cognitive processes, as completing the same questionnaire in writing at home. However, the presence of another may influence response (Lyons *et al.*, 1999) and certainly will affect the dynamics of the process. However, the predominant use of such questionnaires has been in epidemiological studies and surveys designed to determine need in a given community (Angel *et al.*, 2001). In such cases there is no implied or intended direct use of the information by, or for, the individual making the assessment. Thus it is not the 'self' that is assessed but a wider group. Thus although self-administration or completion of the process is again essential, it is not a sufficient definition.

The use of self-administered questionnaires to 'case-find' specific disorders, usually in general practice, is also well established (Iliffe et al., 1999). In this case the recipient completes answers to specified screening questions. Although the process is largely directed by professionals, the assessment itself can be completed by the individual away from the practice environment, and consists entirely of self-report data. So case finding may involve self-assessment when it is both self-report and self-completed, and crucially is intended to assess the needs of the person who completes it, with the intention that they should be the beneficiaries.

More recently self-assessment questionnaires have been used to facilitate appropriate communication between clients and health care practitioners with the aim of improving care management (Wasson *et al.*, 1999a). These constitute self-assessment in much the same way as case finding, even though the intended outcome is different. Such goals come closer to the aims stated in the NSF of active user involvement.

The self-directed elements of the process can extend further. Selfassessments may be initiated by the user them self, rather than prompted by a professional. In most examples of case finding the interpretation of assessment findings and initiation of action is carried out by a professional. However, in the case of a number of self-care interventions (Fries, 2001) the intent is (in part at least) to reduce the reliance on professionals, and assessments are initiated, and actions completed, by the person who self-assesses, with no professional involvement. Some self-assessments may thus be construed as interventions in themselves. Self-care programmes could be classified in this way, as could assessments that identify specific actions to prevent or delay problems. An example of this type is home safety assessment which has been used extensively in the USA and includes environmental self-assessment for falls risk and other accidents in the home (Newton, 1999). A further example is the Self Assessment Rapid Access (SARA) system that is being

piloted in the UK for provision of equipment to maintain independence (ICES, 2002a).

Further than self-initiation, self-interpretation and self-action, the development of the assessment itself could also have elements of 'self', if not at the individual level, at least in terms of users being involved in designing the process. However, these elements are not incorporated into the *definition* used here, although these may be key variables, which impact upon the process. Self-assessment must incorporate self-report, self-completion and the self as beneficiary as a minimum. But the elements of self-direction may be far wider. Conversely, although self-assessment raises the potential for users to take control of the process, a professionally designed and defined questionnaire might provide less flexibility and opportunity for self-expression than an interview because of the fixed format.

#### 1.3 Scope of the review.

Thus, for the purpose of this review 'self-assessment' refers to an assessment that is completed by the subject of the assessment without the immediate involvement of professionals, or a professionally employed layperson. Usually this includes completing any relevant documentation. This may range from structured questionnaires distributed by, and returned to, professionals for interpretation, to systems that define need from the older person's perspective in order to facilitate planning and action by the person themselves.

Although this generally involves completion of relevant documentation in the absence of others, the interpretation of 'completion' is broader than this and refers to the management of the immediate assessment process. In some cases, for example web based systems, there may be no documentation. A third party may be engaged as an agent of an impaired client (for example) to complete the assessment for them. However, the respondent here must be the client him/herself. Assessments undertaken by carers for example, reflecting their view of the client's need, or those undertaken by lay people in lieu of professionals, are not 'self' assessment.

Although any assessment process conducted in the presence of a care professional, or layperson acting on behalf of a professional, cannot generally be considered to be self-assessment, it is at least conceivable that a client – professional consultation could take on similar characteristics to a client self-assessment undertaken with the help of a third party agent. However, under such circumstances some objective markers of the altered status of the professional must exist.

Self-assessments (for example previously completed questionnaires) may be introduced into a professionally led-interview and such practices are within the scope of this review. On the other hand, other modifications to consultations which aim to make them more 'client centred', are beyond the scope of this review, although they have been reviewed elsewhere (Lewin *et al.*, 2004b).

Since the focus of this review is on the use of self-assessment in the identification of problems and management of care by and for individuals, this review will only consider self-assessments which are deployed in practice and which are intended or believed to change the behaviour of the individual or care providers with regard to the care of the individual being assessed. Some important aspects of self-assessment are not considered as a part of the systematic review.

Many studies have been undertaken using self-assessment surveys in order to identify need and to plan services (or make recommendations for such services) for populations of specific communities. Indeed, as discussed below, some such studies clearly establish the link between self-report of Global Self-Rated Health (GSRH) and eventual health outcome. However, a core principle of evidence-based practice is that theoretical linkages frequently fail to deliver anticipated benefits.

Consequently, despite the compelling evidence that self-assessment accurately predicts health needs in general this review does not consider such evidence unless the assessment is studied when utilised in the management of individual care. The literature as a whole is not included because in itself assessing health status as part of a survey does not lead to an action. Most research in the area does little but allude to how the information could be used to target services at an individual level. However, the literature on global self-assessment of health for older people does provide an important underpinning that establishes the potential validity of self-report data, in particular in relation to health states, and so it is considered briefly below.

In a similar vein, literature relating to the behaviour of older people when undertaking surveys or questionnaires in general is not considered because again the key issue is the impact that such factors have upon the utility of the approach *in practice*. However, an important limitation does arise from this decision. Most systematic reviews focus upon practices for which there is evidence and thus do not describe extant practice which has not been researched. This review aims to present a broader picture by considering papers and reports that simply describe practice in addition to considering evidence. Thus the review will identify practices about which questions could be asked, in addition to examining the evidence from evaluative studies.

Where particular groups have not been included in self-assessment they will, of necessity, remain largely unconsidered in this review. Thus the reader must consider the extent to which the approaches described might be generalised to groups such as the frail older people, or those with substantial cognitive or sensory impairment. Therefore this literature will be briefly discussed below since it establishes issues that may pertain to assessment of older people in particular and various sub-groups of them.

Finally, this review does not address the increasingly widespread use of self-assessment in the management of specific long-term disorders, typically involving self-management by the client. A prime example of this would be self-monitoring of blood glucose for diabetics. Such approaches are best considered as interventions to treat or manage the condition, and are rarely constructed in a manner that self-assessment is a component that could be isolated alone. They are thus more usefully considered in the context of the package of treatment for the condition as a whole.

Such an undertaking for all possible conditions is beyond the resources available, or requested, at the outset of this review. Such reviews do exist, or are being undertaken, for disorders such as diabetes (Norris *et al.*, 2002); asthma (Warsi *et al.*, 2004) and Chronic Obstructive Pulmonary Disease (COPD) (Monninkhof *et al.*, 2003) where self-management has been widely practiced. However, it is worth noting that even in some cases where the practice is ubiquitous, as it is for type 2 diabetes, the evidence of benefit from self-assessment specifically can be surprisingly sparse (Holmes *et al.*, 2002) even though the rationale is compelling.

# 1.4 Self report and health outcomes

Self-assessment for health and social care can relate to a wide range of phenomena (as will be seen in the following sections). Personal preferences and desires must, by their nature, be in essence a self-report and there is no external criterion by which they may be judged. Self-assessment approaches may be used to elicit them but the key issue is the successful communication of something already known by one person to another. Validity here can only be judged by successful communication as perceived by the person being assessed, satisfaction with the process and improved management of care.

However, assessment of health status and function has historically been viewed as a matter of professional assessment which could, in whole or part, be determined by reference to physiological parameters and assessment of function. However, in many cases such individual assessment is not possible and interest developed in the use of self-report data to gain an overall index of health (so called global health), generally in the context of large-scale surveys.

GSRH is frequently assessed by use of a single question, sometimes with a scale. Many health status measures, such as the MOS 36-item short-form health survey (SF36) (Ware *et al.*, 1992) or Nottingham Health Profile (Hunt *et al.*, 1980), some of which also examine function (identified here as a distinct concept), contain single or multiple items to measure GSRH. These measures are generally administered as a paper and pencil questionnaire, often distributed to participants by post.

Items asking about GSRH typically include a simple question with a response scale e.g. 'How do you rate your health, in general?' with responses measured by Likert scales or visual analogue. GSRH can be used as a measure of health in its own right or as a predictor of future events e.g. mortality, morbidity or use of health care services. GSRH is commonly used as an outcome measure in health services research, often as a component of quality of life measurement. Although this area falls outside the scope of the current review, the use of GSRH as a predictor of future health-related events has potential application for the care of individuals. Some general health self-assessments reviewed later incorporate such items. The relationship between self rated health and health related events will be briefly summarised here based upon a systematic review of global self-rated health (Bjorner et al., 1996).

#### 1.4.1 Self rated health and mortality

Bjoner et al's review identified 28 studies with GSRH as a predictor of mortality. These provide good evidence for a strong association between GSRH and mortality. Sixteen of the reviewed studies involved samples of people over 60, 6 included people under the age of 60 as well as older people, and 6 studies involved only people under 60. The majority of the work reviewed was conducted in the USA, although studies from the UK, Scandinavia, Japan, Israel and Europe were also included. Sample sizes ranged from 150 to 11000 individuals at baseline, with 20 samples of over 1000. Follow-up periods range from 2 to 20 years (mean=8.5 years).

Where simple comparisons have been made there is a clear trend showing increased risk of death in groups reporting poor GSRH. Most commonly this trend is seen as a stepwise gradient with increasing risk of mortality in groups with decreasing GSRH.

In more complex analyses, researchers have controlled for potential confounding variables such as medically assessed health, age, functional ability, socio-economic status and gender. The majority of these analyses reveal stronger associations between GSRH and mortality after taking confounding factors into account. In a few cases the control negated the association for the whole sample or for sub-groups but the findings are not consistent in terms of which covariates made the association disappear, or about the sub-groups in which the association disappeared.

More than half of the studies reviewed controlled for medical health, either by asking the individual to report medical conditions or through a medical examination. Controlling for medical health does not remove the association between GSRH and mortality. GSRH is not simply a summary statement of medical health or if it is it identifies factors that are not identified through a typical history or examination.

Although no pooled estimate of the increase of risk was possible, substantial differences in mortality were found consistently in those with worst health suffering a 2 to 5 or more fold increase in risk when compared to those with the best health. More recent studies and overviews (Benyamini *et al.*, 1999; Heistaro *et al.*, 2001; Idler *et al.*, 1997) have largely served to confirm these conclusions. It appears that GSRH is an independent predictor of mortality. Thus it appears that self-report of health is not simply a proxy for medical assessment but contains additional information about the individuals' ultimate health status.

#### 1.4.2 Self rated health and morbidity

Although less work has been undertaken with GSRH as a predictor of morbidity a number of studies have showed strong associations between GSRH and current morbidity (Bjorner *et al.*, 1996). Across the body of research functional ability, number of medical diagnoses and physical and mental symptoms were consistently strong correlates of GSRH. Three prospective studies investigated GSRH as a predictor of non-fatal morbidity. This work suggest some association between GSRH and future medical health (as evaluated by a medical doctor), functional ability, increased blood sugar in patients with diabetes and increased blood pressure in patients with hypertension (Bjorner *et al.*, 1996).

One of the earliest studies in this area (Maddox *et al.*, 1973) identified the ability of both doctors and patient's global rating of health to predict morbidity in a longitudinal cohort study of older people (n=270, age at inception 60+) over 15 years. Physician rating and self-rating correlated highly. Incongruity between the two was more likely to be as a result of patients rating their health better than physicians did rather than as result of them considering themselves less healthy than their doctor did. Overall self-rating is a *better* predictor of subsequent physician rating (medical health) than vice versa.

Two further studies considered by Bjorner et al looked at GSRH and use of health care. Research conducted in the US found that GSRH was a strong predictor of hospitalisation and nursing home placement. After controlling for age, gender and education the relative risk for hospitalisation was 2.1 and for nursing home placement 3.4 when older people with poor GSRH were compared with those with good GSRH. In a large Japanese study, GSRH was

found to be a strong predictor for health care use. The relative risk of health care use when comparing persons with fair/poor GSRH to persons with excellent/good GSRH was 2.4 for mental health problems, 2.1 for vascular diseases, 2.1 for endocrine diseases and 2.05 for all diseases taken together. Additionally a number of studies report strong associations between GSRH and disease specific mortality in coronary heart disease and cancer.

The authors of the review concluded that there is a 'very great need' for further research in this field. Although we have not formally reviewed this topic ourselves, and this source is now somewhat dated, when selecting material for the present review we did not form the opinion that the deficit has been significantly rectified and it is of note that all the more recent research that we found (Benyamini *et al.*, 1999; Heistaro *et al.*, 2001; Idler *et al.*, 1997) is concerned with mortality. Nonetheless, it is clear that even broad questions about health obtained from structured postal surveys delivers valid information about future and current health care needs which may be additional to that gained through professional assessment.

#### 1.5 Older people and questionnaires/surveys

The aspirations of the single assessment process to include self-assessment makes examination of self-assessment for older people specifically an important question, since they will be the main group in receipt of such assessments. Similarly, initiatives such as SARA for assistive equipment, while not specific to older people, have great potential to benefit them. While evidence from surveys of health confirms the potential for obtaining valid and valuable information, such literature also calls attention to a number of issues that may differentiate older people from the population at large in terms of their ability and willingness to participate in self-assessments.

A number of studies have shown a relationship between age and response to postal surveys, with older people generally being less likely to respond (Picavet, 2001; Rupp  $et\ al.$ , 2002). However, non-response rates vary. While those over 65 are less likely to respond than those aged 45-64, analysis of findings from a large European survey of musculoskeletal problems (Picavet, 2001) suggests that although age is clearly significant there may be no overall trend for age (Chi squared test for linear trend calculated from data in paper (Stats Direct 1.9) 3.53 (df 1) p=0.06). Younger people (age 44 or less) are also less likely to respond.

However, among people over 75, those who do not respond to such surveys are more cognitively and functionally impaired and have higher 1 year mortality than responders (Hebert *et al.*, 1996b). Studies of people with rheumatoid arthritis, however, suggest that those with specific problems related to the survey may be more

likely to respond (Rupp *et al.*, 2002), suggesting that the nature of what is to be assessed will also affect response rates and the impact of age related factors.

There is inconsistent evidence on response to postal compared to face-to-face surveys and although several studies suggest that older people are less likely to respond to questionnaires than face-to-face interviews (Hebert *et al.*, 1996b) results are by no means consistent. A number of studies show high response rates with several showing higher response to questionnaires (e.g.Hebert *et al.*, 1996b).

However, these findings largely arise from surveys where there would be no direct benefit for participants and non-participants alike. There is similar evidence suggesting that participants in intervention studies are younger than non-participants but contradictory evidence regarding health status. Some studies show non responders as having better health while others show them to have worse health (Minder et al., 2002). It does seem that the pattern of non-response (and hence differences between participants and non participants) is related to the degree of involvement required and the precise risk factors targeted (Minder et al., 2002). This difference may be accounted for by the existence of a variety of sub-groups of non-responders, including those who perceive themselves too well to benefit and those who consider themselves to ill. Differences in overall risk estimates for the relationship between health and non response between studies may be explained by different proportions of each group in the populations studied (Minder et al., 2002).

There is some evidence of systematic differences among older people in the nature of self-report information. Among people over 65 there is more agreement between records and self reported utilisation for those who assess their health to be very good than those whose self-assessment is lower, although this finding does apply to all elements of utilisation (Raina *et al.*, 2002). Self-report of hospital utilisation for those between 65 and 74 is more likely to agree with records than for those aged over 75 (Raina *et al.*, 2002) although this finding is not supported by self reported contact with General Practitioner or other practitioners where no age relationship was found.

There is evidence of systematic differences in responses to face-to-face interviews and self-assessment questionnaires. Some studies have found considerable discrepancies between the results of different approaches (Doll *et al.*, 1991; Hebert *et al.*, 1996b). Agreement on socio-demographic characteristics is high but there is considerable disagreement in answers to questions about symptoms, disability, social support and life events. While there is some suggestion of systematic under reporting of problems in face

to face interview (Doll et al., 1991) Hebert and colleagues (1996b) found no consistent pattern to the differences.

These findings do not clearly indicate that self-assessment is unsuitable for any subgroup of older people (other than those who simply cannot complete it due to impairment) but do suggest that there may be particular issues relating to the utility of the approach in this group. Data from surveys highlights the potential for accurate information from self-assessment and possible enhancement of that information. However, it also highlights possible sub-groups of older people for whom the approach may be unsuitable because of response bias or non-participation. While the data here relates only to self-assessment questionnaires and primarily to the use of surveys for research purposes, the importance of examining the evidence for the use of self-assessment in managing care for older people is highlighted.

### 1.6 Review approach

It is clear that self-assessment is a potentially valuable approach with considerable current interest in its application to health and social care. Benefits may accrue in terms of improved accuracy, proactive identification of unidentified need, primary or secondary prevention of disorders and enablement/empowerment in relation to health and social care. However, benefits cannot be assumed. In the context of developments related to the NSF, it is timely and important to examine the existing literature on self-assessment.

A review of this topic requires an adaptation of 'classic' systematic review approaches. The scoping search indicated that while there is a wide-ranging literature there is relatively limited evaluative research in this area. Evaluations have examined a limited range of the practices identified.

In order to ensure that the results of this review are able to reflect the full scope of practice, and are not simply limited to a skewed sample of interventions that have been rigorously evaluated, we undertook a mixed method review that included the following components;

- survey of scope of approaches toward self-assessment based upon a comprehensive review of literature and a survey of practice

In this section, any assessment that addressed problems prevalent in older people was considered. No specific limitations were applied on the type of material considered other than it must refer to a self-assessment deployed in *practice* as opposed to research on the link between self-assessment data and some outcome.

- systematic review of studies of accuracy comparing the results of self-assessments with appropriate gold standard assessments

Here questions of the accuracy of self-assessments, relative to recognised gold standards (primarily for diagnosis and screening) are addressed. Here, and in later sections, studies included are limited to those in which a substantial proportion of participants were older people and which met recognised quality criteria for the study design (Deeks, 2001).

However, the use of a gold standard to judge accuracy, and indeed external validation of the accuracy of self-assessment, is not appropriate for many aspects of self-assessment. Whereas presence or absence of a disorder, or even a functional deficit might be objectively verified, other issues of need and perception cannot. However, the impact of the process on the person and their use of services can be meaningfully assessed. These are considered in the final two review sections.

- systematic review of studies of controlled trials of effectiveness of self-assessment

This section examines studies that explore the effect of self-assessment on health status, function, experience, satisfaction and service use. It is limited to controlled trials in which the impact of self-assessment on older people (mean age 65+) is compared with the impact of a standard approach to care or an alternative (non-self) assessment approach. Study quality is again assessed by recognised criteria for evaluating studies of the effect of changes to professional practice/organisation of care (Alderson et al., 2003).

Finally, because not all aspects of the experience can be measured, a final section addresses questions of the experience of the assessment from a qualitative perspective.

- review of qualitative evidence of self-assessment focussing on the experience and acceptability of self-assessment from the perspective of both person and professionals

Because literature was scant no a-priori quality criteria were utilised for studies included in this section. Instead evidence was graded according to the likelihood of it giving a valid representation of the experience.

These sections are presented as separate reviews in subsequent sections.

# Section 2 Review Methods

In order to address the multiple questions that arise, the review was undertaken in four parts. These are a descriptive review of the scope of self-assessment practices (Scope); a systematic review of studies of accuracy comparing the results of self-assessments with appropriate gold standard assessments (Accuracy); a systematic review of studies of controlled trials of effectiveness of self-assessment (Effectiveness) and a systematic review of qualitative evidence focusing on the experience and acceptability of self-assessment from the perspective of both person and professionals (Experience). This chapter gives an outline of the methods and approaches used.

## 2.1 Search strategy

Nineteen databases were searched in the fields of health care, social sciences and education: Medline, Embase, AgeInfo, Ageline, ASSIA, BEI, BNI, CancerLit, CareData, CHID, CINAHL, ERIC, HealthPromis, IBSS, PsychInfo, Social Services Abstracts, Social Sciences Citation Index, Papers First, Web Resources.

Table 2.1 gives the terms used for the core search (combined as indicated). Terms for older people were used to limit searches with large numbers of hits (i.e. Embase and Medline). For other databases, where the number of hits was far fewer, and facilities for searching more limited, terms for self-assessment were used without this limit. References were stored and managed using bibliographic software (Endnote).

Table 2.1 Core search strategy

		Administer\$		
		or		
		Assess\$		
self		or		Aged*
or		case finding		or
patient		or		Elder\$
or		Complet\$	AND	or
client	Adjacent	or		Geriatrics*
or	to	directed		or
user		or		older
or		identified need		or
lay		or		Senior\$
		rated		
		or		
		screen\$		
OR				
Self-assessment (psychology)*				

<sup>\*</sup> MESH Index term used – all terms were 'exploded' to cover sub categories

#### \$Term truncated

More focused supplemental searching was conducted for each of the systematic review sections in order to widen retrieval. For the accuracy review, searches of Medline, Embase, PsycINFO and CINAHL were repeated using database specific filters to identify studies addressing the diagnostic accuracy of self-assessment (Deeks, 2001; Greenhalgh et al., 2000) with terms such as 'sensitivity', 'specificity' and 'diagnosis' (mapped to keywords and index terms as available). For the effectiveness review the core search was adapted to include generic terms for topics that had vielded a large number of self-assessment items (e.g. 'self care') or for areas where self -assessment could be deployed (e.g. 'geriatric assessment') but limited to exclude items that related to educational self-assessments or non research papers such as editorials (Table 2.2). The adapted strategy was run on Medline, Cinahl, Embase, PsycINFO and HMIC. For the experience review a further search of Medline, Embase, Cinahl and PsycINFO was conducted with terms for experience (AND experience, satisfaction, perception) used to filter results. In essence these searches were more specific replications of the original search (allowing closer scrutiny of a smaller number of items most of which would have been retrieved by the original searches) thus improving the

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reliability of study identification from databases which yielded high numbers of hits. Secondary references were followed up and authors contacted where required for clarification of some aspects of research. Searching was completed in March 2004.

Table 2.2 Supplemental search strategy for the effectiveness review

		Administer\$		ategy for the effe		
		or				
		Assess\$				
self		or				
or		case finding				
patient		or				
Or		Complet\$				
client		or				
or	Adjacent	directed				
user	to	or				
or		identified need		aged*		Editorial**
lay		or		or		Or
		rated		frail elderly*		Comment**
		or		or		Or
		screen\$	AND	Elder\$	NOT	letter**
		or		or		or
		Geriatric assessment*		geriatrics*		(education*
Or	Or			or		not
Self-assessment (psychology)*			geriatric Nursing*		(health education*	
Or				or		or needs
self-assess	ment			older person\$		assessment*))
Or			or			
Self evaluation*			older person\$			
Or			or			
Self care*			older people			
Or						
Self help						
Or						
Self management						

<sup>\*\*</sup> Publication type

<sup>\$</sup> Truncated key word

# 2.2 Identification of self-assessment practice and unpublished material

As part of the process of the review we attempted to identify examples of self-assessment used in practice in the UK and particularly in the context of the development of the single assessment process. The original intention had been to follow up examples of effective practice identified within the research literature but the rapid changes engendered by the introduction of the SAP and the scant evidence for effectiveness found made this endeavour fruitless.

In addition to using the published literature the Institute of Applied Health and Social Policy's database of inclusive practice and network of practitioners and users was searched for potential examples. From this search we identified a number of individuals (generally people responsible for implementing the SAP) whose work was described (by themselves or others) as involving the development of self-assessment. From this search we have developed brief case studies, largely based on self-report by practitioners. We also identified a reference group of older people who were involved in developing the SAP in one locality. The views of this group, which emerged during discussions about the project and self-assessment, are presented as a separate case study.

These are offered as examples of progress toward implementing self-assessment in the single assessment programmes. Some are not identified as self-assessment by those involved but are included here, as others have identified them as examples. Thus we believe they are informative.

In addition members of the research team used prior knowledge, expertise and personal contacts to identify further examples of self-assessment. Extensive but by no means comprehensive searches of the World Wide Web were conducted to identify web-based self-assessments. This process was continuous through the course of the project.

#### 2.3 Selection of items for review

#### 2.3.1 Scope

For the scope review items that satisfied any of the following criteria were identified as being potentially relevant and retrieved for review if the self-assessment was described in a population of older people or the self-assessment addressed an issue pertinent to older people e.g. hearing loss. Both research and non-research articles were included:

- description of a self-assessment practice
- details of the development of a self-assessment practice

- comparison of self-assessment with an alternative mode of assessment e.g., telephone interview or face-to-face interview
- review of self-assessment practice and
- description or evaluation of a programme or intervention that included at least one self-assessed component.

All potentially relevant items identified by the Medline were retrieved and assessed. Those that clearly did not constitute a self-assessment, or were targeted specifically at a younger population, were discarded. Remaining papers were read and summarised by a member of the research team using a structured data extraction form (see appendix 4). These were then examined by three members of the research team, who agreed final inclusion by consensus.

At this point a database was developed using FileMaker Pro to facilitate storage, classification and analysis of extracted data. Each database file resembled the data extraction sheet, with data entry aided through the use of drop-down menus. Once inclusion criteria had been finally agreed, single researchers undertook searching, retrieval and description. Wherever there was an element of doubt over inclusion, a second member of the research team was consulted and a consensus reached. Data extracted from included articles was entered directly onto the database (The database was available via a local area network and on the World Wide Web for periods of the project. Unfortunately, technical problems mean that at the time of writing it is not accessible. The majority of the content of this databases is reproduced in the tables in appendices of this report).

Since the aim of this section of the review was descriptive, item retrieval was stopped when brief review of remaining titles and abstracts suggested that novel information would not result from retrieval of further papers. This informal assessment of data 'saturation' by two reviewers meant that no items uniquely identified in BNI, CINAHL, CancerLit and PsycINFO being presented in the scope review. However, given the overlap in coverage between databases in our assessment it is unlikely that significant aspects of practice are omitted.

The case studies are also included in this section as they are informative on the integration of self-assessment in the single assessment process.

#### 2.3.2 Accuracy

For the accuracy review studies that compared the result of self-assessment with a 'gold standard' reference test were considered. To be included the self-assessment and gold standard must be conducted independently on the same individual and blinded so that

each assessment is undertaken and interpreted without knowledge of the results of the other. The study sample must be a consecutive (or random) sample of patients recruited from a relevant population so the study sample represents the group of people with whom the self-assessment will be used in practice. Only studies that included a large proportion of older people (50 per cent or more 60 + or mean age 65+) were considered. Inclusion was assessed independently by two reviewers and disagreement resolved by discussion and consultation with a third reviewer where relevant. All studies that met the criteria were included in the review with no restriction on language or date of publication.

#### 2.3.3 Effectiveness

For the effectiveness review all controlled trials (including individual and cluster randomised trials) controlled before and after studies and interrupted time series designs that compared self-assessment to usual approaches to service provision, no provision or alternative approaches to assessment were considered. Only studies that included a large proportion of older people (50 per cent or more 60 + or mean age 65+) were included. Where self-assessment formed part of a package of care or intervention, studies were included if self-assessment formed a substantial component of care (for example self-care programmes, which involve distribution of selfassessment algorithms and other health information materials) and where the only universal aspect of assessment was the selfassessment. Where additional assessment or feedback was triggered by self-assessment findings these studies were included provided outcomes were reported for all participants in the programme not just those identified as requiring further intervention through self-assessment. Inclusion was assessed independently by two reviewers and disagreement resolved by discussion and consultation with a third reviewer where relevant. All studies that met the criteria were included in the review with no restriction on language or date of publication

#### 2.3.4 Experience

For the experience review, evidence that reported on the experience of self-assessment by users and practitioners was considered. Evidence was considered if it came from a research study where participants reported upon their own experience of self-assessment, or if it was a direct quotation from a person relating their own experience of self-assessment. Inclusion was assessed independently by two reviewers and disagreement resolved by discussion and consultation with a third reviewer where relevant. All studies that met the criteria were included in the review with no restriction on language or date of publication.

#### 2.4 Results

The numbers of items identified in the core searches are presented in Table 2.3. An additional 87 items were provided by members of the research steering group (n=31), through follow-up of secondary references (n=26), author searches (n=4), references from government web sites (n=7), Internet searching using Google (n=4), and hand searches of library collections (n=11). 135 papers were identified as potentially relevant for the accuracy review (core + additional searches) of which 26 met the criteria and were included in the review. 57 potentially relevant papers were identified (core + additional searches) for the effectiveness review of which 20 were rejected on the basis of further scrutiny (abstract). 37 were retrieved for more detailed consideration and nine were adjudged to be eligible for inclusion. 53 studies were as potentially relevant to the experience review (core + additional searches). Of the 53 papers assessed, 37 were found to include claims relating to the experience of self-assessment that were unsupported by relevant data and 16 offered some supporting evidence for the claims.

Table 2.3: Core search results

Database	No. of hits	Potentially useful	Scrutinised in detail
AgeInfo	511	69	20
AgeLine	279	44	11
ASSIA	387	15	7
BEI	501	3	3
CareData	754	102	26
CHID	747	22	4
Embase	5209	117	32
ERIC	1007	28	14
HealthPromis	89	31	5
IBSS	379	10	2
Medline	3687	399	112
PapersFirst	190	2	2
Social Services Abstracts	373	6	6
SSCI	864	60	25
Web Resources	22	1	1
CINAHL/BNI/ PsychInfo/CancerLit*	9255	-	-

The number of items reviewed is dependent in part upon the order in which the databases were searched. Medline was searched first, followed by Embase. As a large number of duplicates were identified this resulted in a large number of items that had been identified as potentially relevant being discarded prior to review

\* BNI, CINAHL, CancerLit and PsycINFO were searched together with duplicates removed. A total of 9455 hits were made. No items were retrieved for the scope review as saturation had occurred

# Section 3 The Scope of Self Assessment

#### 3.1 Introduction

The aim of this review is to describe and classify the different types of self-assessment that have been used in practice and are relevant to older people, either because they have been used in a group of older people or because they relate to problems prevalent in older people. It is not intended to be exhaustive in terms of including every example of self-assessment, but it does aim to cover the complete range of self-assessment practices and provide a typology to encompass this.

The typology was developed as part of the review process based on key themes and issues identified relating to the content and process of self-assessment. Four broad classifications were identified based on the content / topic of the self-assessment. The categories used for this review group approaches based on their content on two dimensions: health – social care (or, more properly, 'other' needs) and general – condition specific content / outcomes (Figure 3.1 Assessments classified as 'focussed health care' were those that assessed specific health issues and focused on single problems. The term 'general health care' is used here to refer to assessments covering a range of health care issues. This range may be very broad, as in self-help books covering upwards of 60 health problems, or more limited as is the case with case-finding questionnaires used in UK general practice.

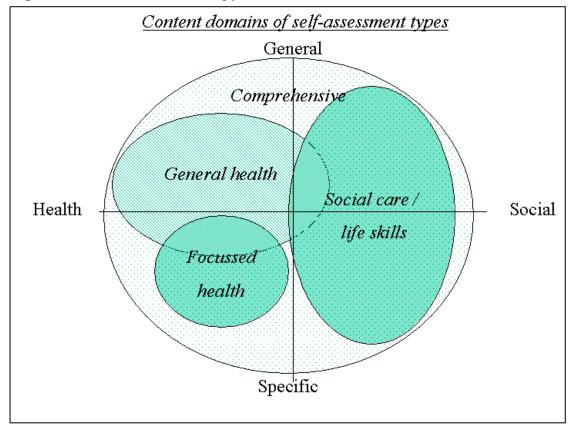


Figure 3.1 self-assessment types

A third group of assessments were classified as 'Social Care and Life Skills'. Like focussed health, these assessments dealt with specific problems, although in a wider domain of problems other than bodily or psychological health (encompassing social care needs and problems as diverse as housing and driving). The nature of the issues concerned meant that the assessments could cover a broad range of topics but nonetheless remained focused on fairly specific issues. As there were few examples, we did not identify separate categories to differentiate specific from general assessments in this area. Finally 'comprehensive assessments' covered a wide range of problems across health and social care domains. This is the 'model' for the SAP. These assessments could be constructed from a number of more narrowly focused assessments but crucially were not focused on single topics and covered a wide range of problems in both the health and social care domains.

In most cases, self-assessment is accompanied by a structured tool, usually a questionnaire. Any given self-assessment can further be described in terms of the process of use. The initiation of the assessment can be can be prompted by either the user themselves, or, as is often the case, another (usually a professional care provider). The interpretation can similarly be done by the user or by a third party, again usually a professional. The immediate action

can be prompted by the user (for example, to contact a professional) or by the professional (who might be prompted to undertake further assessment or contact). Finally, the process may be one that, if not self-assessed, would ordinarily be performed by a professional. In this sense it substitutes for a professional assessment in some way. Alternatively, the assessment may be over and above what would ordinarily be encompassed by professional assessment (and is thus additional to professional assessment).

Clearly there is overlap. Comprehensive assessments are a composite of assessments from the other categories. Social care and life skills assessments may include brief assessments of the impact of health states and thus the distinction from comprehensive assessments is more a matter of the overall balance and aim. Similarly general health assessments may incorporate items about social support and a range of specific health problems. The distinction from both social care and comprehensive assessments is based on balance and a focus on health problems and services. Just as comprehensive assessments are a composite of other assessments, general health assessments may simply be a composite of a number of focussed health assessments. Consequently, the review presents a discussion of focused health assessments first, followed by general health and social care / life skills before identifying evidence or examples of comprehensive assessments.

Self-assessments within each of the broad domains identified above are thus described in terms of the process under the following headings;

- initiation
- interpretation
- action and
- substitution.

The process issues define the degree to which the self-assessment is truly a reflection of 'self'. An assessment which substitutes for professional assessment, is initiated by the person themselves, interpreted by the person and where it is the person who is prompted to act could be said to be self-directed self-assessment.

The nature and precise topics of assessments vary considerably in terms of the structure or format of the instrument or approach, the specific topics covered and the extent to which the content concerns matters internal to the individual (such as health or function) or external (focusing on, for example, circumstances and environment). Finally, the process may have a role in either identifying immediate problems ('diagnostic') for which corrective

action might be taken, or predicting the likelihood of future problems, which might be avoided through certain actions ('predictive').

Self-assessments within each of the broad domains identified above are thus described in terms of content under the following headings;

- structure/format
- issues/topics covered
- external/environmental vs. internal/personal issues and
- predictive vs. diagnostic.

There may be instances where a 'kernel' of self-assessment can be embedded in a professionally led interview. For example, the use of simple visual screening questions embedded in a multidimensional professional interview, and items prompting the user to provide his/her views and opinions in comprehensive assessments undertaken as part of the SAP. Although strictly speaking these fall outside the scope of self-assessment as defined here, they are mentioned where they inform the broader discussion.

### 3.2 Focussed Health Care

Within the domain of focused health care there are five specific fields of health care where a substantial body of literature pertaining to self-assessment has been identified: mental health, hearing loss, nutrition, mobility and function, and oral health. Consequently, many of the examples in the following sub-sections relate to these areas. Where additional examples have been identified these are included but, in terms of volume of published literature, these five areas dominate this domain.

## 3.2.1 Initiation

Even where the assessment is interpreted and acted upon by the older person, assessments in this domain are almost always initiated by professionals e.g. dental screening (Bush *et al.*, 1996a), or trained lay people acting as 'agents' of health professionals e.g. assessment of nutritional behaviour (Lach *et al.*, 1994).

A US programme to provide older adults with information to help them improve their diet and promote enjoyable, healthy eating provides an innovative example of the latter (Lach *et al.*, 1994). Known as the Personal Eating Plan (PEP), this programme represented a partnership between the Nabisco Foods Group and an educational organisation for older adults, the Older Adult Service and Information System (OASIS). The programme consisted of a

PEP questionnaire to assist the older person identify for themselves nutritional needs in six key areas;

- higher nutrient eating
- lower calorie eating
- lower fat consumption
- eating more fibre
- eating less sodium and
- increased calcium intake.

The person is also given an information booklet and guide to healthy eating, a meal planner, recipes and free samples provided by Nabisco. Trained volunteers at stands in supermarkets, hospitals and OASIS community centres ran the programme. While participation in this programme is at the request of trained volunteers the completion of the questionnaire, interpretation of its findings and subsequent action is undertaken solely by the older person with no further input from others.

Three self-assessments were found which were initiated by the older person themselves, both in the field of diet and nutrition. The DETERMINE Nutrition Checklist is targeted at older people (White et al., 1992). The ten-item checklist includes questions relating to medical health, alcohol consumption, oral health, financial hardship, consumption of fresh fruit and vegetables and milk products, and physical ability to shop and cook. A simple weighted scoring system is used to assess nutritional risk and direct the older person to the appropriate action e.g. for a moderate score the person is advised where to find advice about healthy eating. A more extensive nutritional self-assessment manual, 'The Diet', contains nine sections focusing on food choice, exercise, meal planning and nutritional content of food (Bassler et al., 1987). For each of these sections the user undertakes a beliefs assessment to determine their current beliefs about an area and a self-assessment to enable the user to compare their current habits with guidelines. Although this self-assessment is not intended solely for older people, its focus on diet as part of a person's lifestyle, and the recognition of the need to assess current nutritional habits and beliefs, means it could be valuable for use by older people.

By contrast to these, breast self-examination (BSE) represents an example of physical self-assessment which women are encouraged to perform regularly on their own initiative. However, little of the literature addresses older women although a description of an intervention to teach BSE to women and promote regular self-assessment was found (Grady, 1988).

# 3.2.2 Interpretation

Completed self-assessments can be interpreted either by the user, a second person (usually a professional) or by both. The majority of self-assessments identified in this domain were professionally interpreted and used to prompt professional action. Focused health issues covered by these assessments include: mental health (including dementia) (Ball, et al. 2001a; Burns, et al. 2002; Collins, et al. 1996; Drachman, et al. 1996; Gallagher 1987; Gilewski, et al. 1988; Horn, et al. 1989; Thompson, et al. 1988), hearing, (Bennet, et al. 1997; Bentler, et al. 2000; Kaplan, et al. 1997; McCarthy 1997; Schow, et al. 1990a; Schow, et al. 1990c; Smeeth, et al. 2002; Weinstein, et al. 1983; Yueh, et al. 2003a) vision (Smeeth et al., 2000; Smeeth et al., 1998a), oral health (Dolan et al., 1998; Pitiphat et al., 2002), nutrition (Patterson et al., 2002), melanoma (Jackson et al., 1998) and coronary heart disease (Cameron et al., 1997). While covering disparate clinical areas, what these selfassessments have in common is a self-assessment process under the control of professionals. The professional rather than the older person undertaking the assessment owns the assessment, and the main aim of the self-assessment is to inform clinical decisionmaking by the professional.

A substantial body of literature exists reporting the use of self-assessment scales in the field of hearing loss (Bennet, et al. 1997; Bentler, et al. 2000; Kaplan, et al. 1997; McCarthy 1997; Schow, et al. 1990a; Schow, et al. 1990c; Smeeth, et al. 2002; Weinstein, et al. 1983; Yueh, et al. 2003a) Most are primarily intended for managing established disease. The Hearing Handicap Inventory for the Elderly – Screening version (HHIE-S) has been cited as demonstrating excellent accuracy in screening for functional hearing loss (Yueh et al., 2003a). This ten-item inventory asks the person to reflect upon the social and emotional impact of hearing loss, for example;

- do you feel that any difficulty with hearing limits or hampers your personal or social life?

In addition to such brief scales, a number of in-depth self-assessment questionnaires also exist for screening for hearing loss and its impact on the individual e.g. the Communication Scale for Older Adults (CSOA, 72 items); the Hearing Performance Inventory (HPI, 158 items) and the Communication Profile for the Hearing Impaired (CPHI, 145 items) (Bentler et al., 2000). These scales are fairly similar in their construction, containing sub-scales that examine communication strategies, understanding speech, social impact of hearing loss and personal adjustment to hearing loss. Each questionnaire presents items alongside a Likert response scale that is scored and interpreted by the clinician.

In other areas of health care, self-assessments represent simple screening tools, as in the case of many mental health self-assessments (Ball, et al.2001a; Drachman, et al. 1996; Gallgher 1987; Horn, et al 1989). Other examples include screening tools for testosterone deficiency (Smith *et al.*, 2000a), oral health problems (Bush *et al.*, 1996a) and coronary artery disease (Cameron *et al.*, 1997; Pirie *et al.*, 1983). These too are interpreted by the professional, who is prompted to act if any suspicious findings are detected. In a number of cases the questionnaire is scored by a nurse or doctor and those found to be at high risk are asked to see a clinician for further examination and skin care advice (Jackson *et al.*, 1998). For example, a four-item self-completion questionnaire used for screening for contains items such as;

- does your skin have any large moles with irregular edge or colour?
- how many times in your life have you had bad sunburn?

Although older people are not a prime risk group for this condition, a similar approach to screening for lesions could be adopted for this group. Similar simple, short self-completion questionnaires have also been used to screen for colorectal cancer (Farrands et al., 1984) and coronary heart disease (Jackson et al., 1998),

Five examples of user-interpreted tools were identified. The PEP program for nutrition (described above) is one such example. The other examples of user-interpreted assessments are all intended as self-screening where the user is helped to identify problems or risk factors and prompted to contact a professional for further diagnosis and treatment if necessary. In the field of oral health a short questionnaire can be used to enable older people to self-screen for dental problems. An example of one such questionnaire (Bush *et al.*, 1996a) comprises six simple items such as 'do you have a dry mouth?' and 'do you have any difficulty eating?' A person giving a positive response to any item is directed to seek advice from a dentist.

An eight-item self-completion questionnaire used to screen for testosterone deficiency asks men if they have any of the risk factors associated with this condition e.g. diabetes, allergy, asthma, sleeplessness, low dominance (personality trait) (Smith et al., 2000a). The user is advised how to score the questionnaire and encouraged to contact a medical practitioner if the score is above a given value. A similar six-item scale has been developed to help users identify whether they are at risk of coronary heart disease (Pirie et al., 1983). Again people are asked to report current medical conditions, for example, the presence of high blood pressure and weight, plus an assessment of intake of cholesterol-rich foods (described in terms of number of whole eggs and amount of red meat eaten each week), and number of cigarettes smoked

daily. This schedule has a weighted self-scoring system and includes advice to contact a medical practitioner if the score obtained is above a designated cut-off value.

BSE also requires a degree of user interpretation. Having been taught how to perform the self-assessment the person is also advised to seek professional help if a possible problem is suspected. While BSE is not targeted solely at older women, women over 50 years of age are more likely to regularly perform BSE than women under 50, with the highest rates of compliance being found in women aged between 60 and 80 (Grady, 1988).

# 3.2.3 Acting on the assessment

Only one example of self-assessment identified in the domain of focused health is entirely intended to prompt the older person to take action for themselves, the PEP program (Lach *et al.*, 1994). Here the program includes advice and guidelines on healthy eating that enables the person to decide for themselves how to alter their eating habits in order to improve their nutritional intake. For other self-assessments that fall into this category, the older person is only prompted to act in so far as they are directed to contact a professional, thus shifting control and decision-making responsibility away from the older person themselves e.g. coronary heart disease risk (Pirie *et al.*, 1983), testosterone deficiency (Smith *et al.*, 2000a) and BSE (Grady, 1988).

Most commonly self-assessments are used to prompt professional action with examples in the fields of hearing loss, nutrition, cancer screening and function and mobility (Farrands, et al. 1984; Finley, et al. 1999; Gaines, et al. 2002; Little, et al. 1999; Schow, et al. 1990c). All the mental health assessments identified are intended for interpretation by a professional who is then prompted to take appropriate action. Self-assessments here fall into two main categories – assessment for depression and/or anxiety and assessment of cognitive ability/dementia. Both fields of mental health assessment employ questionnaires in order to identify people who show signs of mental health problems. A number of these scales have been developed specifically for use with older people, or make claims for validity with this group, although, as later sections will demonstrate, these claims are rarely based on comparison against a gold standard for diagnosis.

The Beck Depression Inventory (BDI- Beck *et al.*, 1972) and Geriatric Depression Scale (BDI, based on the generic Stanford Mood Assessment Scale Yesavage *et al.*, 1982) have been recommended as self-assessment scales for depression screening in older people (Gallagher, 1987) It has also been reported that the GDS can be used to detect depression in older people suffering from mild dementia (Yesavage, 1988). Both are typical of the approach

used, consisting of a short questionnaire, with those at risk being identified based on a cut off score, generally a number of items checked with 'adverse' symptoms. Professionals identify those at risk and undertake further detailed assessment of make onward referral. Examples of items from the GDS are listed below;

- are you basically satisfied with your life?
- do you think that most people are better off than you are?

It is worth noting that increasingly these, and other similar questionnaires, can be found on the Internet, with automated scoring and recommendation. Thus, although designed to be initiated, interpreted and acted upon by professionals there is a potential for a very different pattern of use, even though a web based version of the GDI is very clearly marked 'to be completed by a trained clinician'. (Ashville, et al.no date) (http://www.stanford.edu/~yesavage/Testing.htm accessed: April 2005)

#### 3.2.4 Substitution

Almost all self-assessments in focused health care are used in addition to professional assessment, either as a screening tool (e.g. Grady 1988; Little, et al. 1999; Pirie, et al. 1983; Schow, et al. 1990c; Smeeth, et al. 2000) and/or to provide additional information to help the clinician provide more appropriate care (Pincus, et al. 1989; Schow, et al. 1990a; Wolfe, et al. 1991). The self-assessment is used to identify which individuals require further professional advice and support, and in some cases it also provides detailed information that enables the professional to provide appropriate, individualised care e.g. in the fields of hearing (Schow et al., 1990a; Yueh et al., 2003a) and nutrition (Little et al., 1999). In each of these areas there remains a degree of uncertainty over whether the self-assessment alone is adequate as a screening tool or whether it should be used in conjunction with other clinical measures. In the field of mental health, professional opinion generally asserts that self-assessment should always be used in conjunction with interview-based medical examination (Thompson et al., 1988).

Examples were found of self-assessments in focused health care where the assessment may substitute for professional assessment. These assessments are in the areas of BSE (Grady, 1988), where regular self examination may replace irregular examination by a physician, and nutrition (Lach *et al.*, 1994) where self-assessment can be more comprehensive than could be encompassed in a short clinical consultation. Additionally, many of the mental health screening questionnaires can be used as self-administered questionnaires or as verbally administered questions. If the former

is employed this can be said to substitute for a process that would otherwise involve a professional.

#### 3.2.5 Structure/format

The majority of the self-assessments identified are presented as simple questionnaires, generally short, with some taking a very brief format. The physical examination involved in breast examination or self-assessment for skin lesions clearly differ, as does the use of a 'manual' for nutritional assessment (Bassler *et al.*, 1987). There are some examples of posting out simple tests such as urine dipstick (Davies *et al.*, 1991). The use of computers and the World Wide Web introduces novel formats, although in essence these still deliver similar questionnaires (e.g. Ashville *et al.*, no date). Occasionally graphical elements such as visual analogue scales are used to rate severity, or the person may be asked to mark on a diagram the location of a symptom have been describing, for example 'chest pain' (Cameron *et al.*, 1997).

A number of scales have been developed to assess cognitive decline in older people, including some that are primarily questionnaire based but include specific assessment tasks. For example, the Early Assessment Self Inventory (EASI) comprises 35 items intended to examine orientation to time and place, ability to name common objects, remote memory (e.g. current and former prime minister), but also includes visual construction (e.g. copying line drawings), recent memory and arithmetic calculation (Horn et al., 1989). A more recently developed cognitive assessment tool, the Cognitive Assessment Screening Test (CAST), has been used to detect dementia in a population of previously unscreened older people (Drachman et al., 1996). The CAST comprises three sections. Part A contains ten simple items e.g. person's name and address, today's date, copying a picture of a flower; Part B has five more difficult questions e.g. adding four numbers, completing a bank cheque; and Part C is a self-assessment of the person's own perceptions of their cognitive decline.

Some of the more novel approaches to the format of assessments highlight possible limitations in the use of the approach for older people. A single-item tool for the detection of depression, the Yale Single Item Assessment (Watkins *et al.*, 2001) simply asks 'Do you often feel sad or depressed?'. Developed for use with people following stroke this simple 'tool' provides an example of a self-assessment developed for people who are unable to read, write or speak. Given the need for verbal administration of the question it is unlikely to be used in a manner that meets the definition of self-assessment identified here, but it is included because it addresses an important problem, namely, how to elicit self-report information from a person with severely impaired communication abilities.

Another innovative development to allow self-assessment in a group with impaired communication is currently being developed at Northwick Park Hospital, London. Known as the Depression Intensity Scale Circles (DISC) this tool comprises a visual scale for use by people with perceptual/language processing problems e.g. following head trauma or stroke (Turner-Stokes, 2005 (in press)). The scale comprises six circles. The first is a simple circle, the other five each contain a grey spot of increasing size, with the last one being completely filled in (Figure 3.2). The empty circle represents no depression and the others represent an increasing amount of depression. The person is asked to point to, or otherwise indicate, which symbol best represents the level of depression they are experiencing. As with the YSIA, it is difficult to define a process as simple as this as self-assessment but it does provide a valuable contribution to the field of self-assessment as an example of how people can be helped to express themselves despite severe communication difficulties.

The Depression Intensity Scale Circles (DISCs) Instructions for administration Most severe depression This is a scale to measure depression Please point to each of the circles in turn to make sure that you can see them all. [Continue only if satisfactorily accomplished] The grey circles show how depressed you feel. [Indicate the clear circle at the bottom] The bottom circle shows no depression. [Indicate the fully shaded circle at the top] · The top circle shows depression as bad as it can be. [Pointing at each circle in ascending order] As you go from the bottom circle to the top, you can see that depression is becoming more and more · Which of these circles shows how depressed you feel No Depression To the administrator: In your opinion was the person able to understand this scale? The DISCs is displayed on a laminated card. Yes D No D Each circle is 2 cm in diameter. The scale measures 15 cm from the centre of the Comment bottom circle to the centre of the top circle. A pictorial version also available.

Figure 3. 2 (reproduced with permission of the author)

### 3.2.6 Issues/topics covered

Topics covered by self-assessments in focussed health care fall into two main categories: condition specific and functional. Condition specific assessments tend to focus on possible symptoms and may also include disease risk factors. Examples of self-assessments based solely on symptomology include examples such as a screen for colorectal cancer (Farrands et al., 1984), coronary heart disease (Cameron et al., 1997) and mobility problems (Wilcock, 1979). Usually these are brief questionnaires that ask the person to identify presence or severity of listed physical symptoms. The questionnaires are interpreted by a professional and the person asked to attend for further assessment and diagnostic testing if the number of reported problems suggests the presence of disease. Similarly, the majority of psychological assessments ultimately aim to identify symptoms and worries as opposed to risk factors. In the case of physical examination and testing, a single finding (e.g. breast lump for BSE) or measurement (e.g. glycosuria) is generally used to identify potential problems.

Many focussed health assessments include questions about disease risk factors as well as symptomology. Examples of this type have been described earlier from the fields of coronary heart disease

(Pirie et al., 1983), nutritional inadequacy (Little et al., 1999) (Patterson et al., 2002), testosterone deficiency (Smith et al., 2000a) and melanoma (Jackson et al., 1998). Tools used to assess nutritional status can include either questions about dietary intake, items concerning factors which might impact upon food intake e.g. sufficient money to buy food, ability to go shopping, or aspects of diet that might put the person at risk of health problems.

Functional health assessments have been used to assess the physical capabilities of seemingly healthy older people (Fillenbaum. 1985; Granger, et al. 1994; Jannink-Nijlant, et al. 1999a; Myers, et al.) and the capabilities of those suffering from illness or disability (Pincus et al., 1983; Yohannes et al., 2002). While tools designed for use with different target populations have been developed independently, they reflect very similar potential problems and hence have similar content. Questions in this field of work centre around everyday activities known as activities of daily living (ADL) e.g. washing oneself, getting dressed, eating a meal, and instrumental activities of daily living (IADL) e.g. preparing a meal, going shopping or using the telephone

Although self-assessments in the domain of focussed health care are usually problem-centred, this is not always the case. For example, self-assessments can also be useful in identifying a person's strengths. In the field of psychotherapy this can provide a useful basis upon which to build a therapeutic intervention identifying (for example) coping strategies and external resources such as family and friends (McQuaide et al., 1997).

### 3.2.7 Internal vs. External factors

The vast majority of self-assessments related to focussed health care involve internal or personal issues as opposed to environmental factors. As demonstrated by the self-assessments reviewed earlier, the focus is mostly upon physical signs and symptoms psychological signs and symptoms, cognitive performance and/or the ability to perform everyday tasks.

While no assessments of purely external factors were found in this category, a few mixed assessments, including both internal and environmental issues, were noted. All examples come from the field of nutrition where the external items assessed include lack of money (Kita et al., 1996; Patterson et al., 2002) and inadequate cooking and/or food storage facilities (Kita et al., 1996).

## 3.2.8 Predictive vs. diagnostic

Self-assessments can be used to aid in the identification and diagnosis of current disease or problems, or to predict possible future health problems. Assessments which comprise items related

to current signs and symptoms fall into the former category, for example those used to screen for testosterone deficiency (Smith *et al.*, 2000a) and coronary heart disease (Cameron *et al.*, 1997) along with self-assessments of hearing (Bentler, *et al.* 2000; Schow, *et al.* 1990a; Yueh, *et al.* 2003a Schow, *et al.* 1990c) and oral health (Bush *et al.*, 1996a; Pitiphat *et al.*, 2002).

A number of self-assessments can be used both as diagnostic and predictive tests. Tools used to screen for cognitive problems<sup>1</sup>, melanoma (Jackson *et al.*, 1998), oral health problems (Bush *et al.*, 1996a; Pitiphat *et al.*, 2002), nutritional status (Kita *et al.*, 1996; Little *et al.*, 1999) and functional capabilities (Drachman, *et al.* 1996; Horn, *et al.* 1989; Vecchi, *et al.* 1999) provide examples of this type. These self-assessment schedules are used both to detect current problems and to enable the practitioner to identify those individuals who are at risk of developing further problems in the future. For functional assessment this includes assessments used to identify older people at risk of falling e.g. (Pathy *et al.*, 1992a). None of the assessments reviewed aimed to specifically help the user identify and act to avoid/postpone potential problems, although the PEP (Lach *et al.*, 1994) described earlier in this review does go some way toward this.

Only one focussed health self-assessment schedule identified was intended as a purely predictive assessment, a tool to identify people at risk of developing coronary heart disease (Pirie *et al.*, 1983).

A small number of self-report tools were identified which were meant neither as predictive nor diagnostic tests but rather as a means of increasing patients' involvement in mental health care. Although not specific there is certainly potential for their use in older people. The Behaviour and Symptom Identification Scale (BASIS-32) is one such tool (Elsen et al., 2000). Developed for use with hospitalised patients with mental health problems, this 32-item schedule asks patients to rate on a five point Likert scale the difficulty they have experienced for each item over the preceding week. Items are presented in five domains: relation to self and others, depression and anxiety, daily living skills, impulsive and addictive behaviour and psychosis. Patients' views of their difficulties are used by the professional team to build a therapeutic relationship with the person and to inform treatment planning. A similar example is the Maynard Personal Assessment Rating (MPAR), a 150 item self-report instrument designed for use in a 'partial hospitalisation' setting to identify strengths and problematic behaviours (Maynard, 1982)

Also worthy of note here is work which involved patients with mental illness in the development of a new self-assessment tool designed to measure changes in behaviour and self-concept in people with mental illness in intermediate care (Prager *et al.*, 1980). A panel of 12 patients reviewed an existing self-assessment schedule and concluded that 'it measured the wrong things'. They were then asked to develop a new instrument resulting in a new 170-item assessment tool with Likert-type response scales. Items cover predominantly covert areas such as situational determinants of anxiety, depressive symptomology and social-emotional self-perception including self-esteem and self-reliance. It is disappointing that only one such example was found in the literature, and this from 24 years ago. It appears that progress in involving users in such development is progressing at a very slow pace.

# 3.2.9 Section summary - focussed health care

There are large numbers of self-assessment instruments focussing on specific health conditions

Most predict current need, some predict future need, while a few highlight health resources available to the individual

The focus of the assessments is almost exclusively on internal factors

The use of the assessment is typically prompted by professionals, and interpretation and action is also generally undertaken by professionals

The use of the world wide web raises the potential for self-initiation and action but the format of the instruments is largely unchanged

Although the assessment is generally in addition to professional assessments the model is typically to extend the professional reach beyond traditional consultations (case finding / screening).

The content is generally similar to a professionally led interview / assessment.

Most assessments are questionnaire based, although there are examples of self-assessment using physical examination and tests.

### 3.3 General health care

The term general health care is used here to refer to assessments covering a range of health care issues. This range may be very broad, as in self-help books covering upwards of 60 health problems, or more limited, as is the case with case-finding questionnaires used in UK general practice. In general these case-finding questionnaires were designed to help target more costly,

comprehensive assessments and were often administered as postal questionnaires. Although the GP contract introduced in 1990, which specified the offer of an assessment in the patients home for those over 75 as part of the 'over 75 health check' shifted attention from such activity (Iliffe et al., 1999), the Department of Health guidance on assessment tools and scales for the SAP includes a short section on case-finding (DoH, 2002b). The Medical Research Council trial of assessment and management of older people in the community (Smeeth et al., 2001b) uses face to face or postal self-assessment to target detailed screening assessments in the context of a trial to determine if this is more effective than universal screening.

#### 3.3.1 Initiation

In contrast to the field of focussed health care, a number of self-assessments of general health were identified which are intended to be initiated by the user. These are most frequently in the form of self-help books which are intended as a resource for the person to turn to for information and advice regarding diagnosis of symptoms and, depending upon the likely severity of the problem, options for self-treatment. Where more serious problems are suspected the user is advised to visit their medical practitioner. An early example of this type of book, 'How to be Your Own Doctor (Sometimes)' encourages people to become 'activated patients', learning to diagnose problems and self-medicate where possible (Sehnert, 1975).

Emphasis is also given to communicating effectively and working in partnership with the family doctor. The book provides a comprehensive list of common ailments with a description of their signs and symptoms, appropriate self-treatment and what to look out for that would necessitate a medical consultation. Also included are two additional self-assessment schedules, a DIY quiz for coping and the Medical Age Score. The former is a 20-item questionnaire with yes/no responses. Six or more positive responses indicate the respondent is not coping well and the person is advised to visit their 'doctor, minister or psychiatrist' for advice and support. This scale is designed to stimulate the person to think about self-help and preventative medicine to improve their general health (Sehnert, 1975). Although this self-help book could be used by older people it is not targeted at older people specifically.

A similar self-help book 'Take Care of Yourself: A Consumer's Guide to Medical Care' contains algorithms to help the person diagnose 63 common medical problems, again with guidance on how to self-treat or advice to seek medical help if any more serious signs or symptoms are present (Vickery *et al.*, 1981). Another very similar book entitled 'Aging Well' (Fries, 1991) is, as the name suggests, targeted specifically at older people. The book comprises a series of

algorithm-based self-help guides aimed to help the user identify and rectify common problems. The reader is encouraged to take personal responsibility for health and health care, with an emphasis on relying less on doctors. Guidance is given for diagnosing and finding solutions for problems in a range of areas including physical and functional health problems. In the UK specifically the NHS direct self help guide (Banks, 2000), which exists in a number of formats including printed and web versions, contains similar self help algorithms for identifying appropriate actions in a number of conditions.

# 3.3.2 Interpretation

The majority of work undertaken in the UK regarding self-assessment and the general health care of older people has been focussed on case-finding in general practice. This usually involves a two-stage case-finding strategy where a self-completion screening questionnaire is sent to older people first in order to identify those most at risk and therefore most likely to benefit from receipt of health and/or social service input. This sub-group is then followed-up with a comprehensive assessment undertaken by a professional (Taylor et al., 1983; Williamson, 1987).

One of the most widely reported tools used to carry out the first stage of case-finding is the Woodside Screening and Assessment Programme (Barber *et al.*, 1980). This nine-item questionnaire developed in Glasgow asks for simple yes/no responses to the following questions;

- do you live on your own?
- are you in the position of having no relative whom you can rely on for help?
- do you need regular help with housework or shopping?
- are there days when you are unable to prepare a hot meal for yourself?
- are you confined in your home due to ill health?
- is there any difficulty or concern over your health you still have to see about?
- do you have any problem with your eyes or eyesight?
- do you have any difficulty with your hearing? and
- have you been in hospital during the past year?

If an older person (someone aged 70 or over) responds positively to any of the items, a follow-up visit is deemed necessary. Modified versions of the nine-item Woodside questionnaire have been used in other case-finding programmes in the UK (Cameron, et al.

1987; Porter 1987; Taine, et al. 1990b). A similar postal questionnaire has been developed in the UK by Bowns et al (1991a). This 18-item tool presented simple questions with yes/no responses covering social support, disability, recent stresses and mood state.

Brief case-finding questionnaires similar to the Woodside screening tool have also been developed in the USA (Cameron et al., 1987), as have more extensive instruments such as the 'Self-evaluation of life function (self) scale' (Linn et al., 1984) (Maly et al., 1997) a 54-item self-assessment scale to measure physical, emotional and social function in older people. While the items included in the short assessment scales developed in the UK were based upon clinical judgement and experience, this US tool was based upon findings from two large-scale studies of older people and their needs, although its use in clinical practice is not reported.

A combination of the self-help and case finding approaches are used in the 'personal health record' (Barber, 1988). Following an initial screening letter older people with identified problems are visited at home by a health visitor. The older person is given a personal health record that includes sections regarding health and lifestyle, plus information and advice about local health care services, entitlements and benefits. Although initially completed by the health visitor, this booklet also contains questions for self-assessment at three or six monthly intervals and advice to contact a health care professional if any problem is suspected. Although initiated by a professional, the self-assessed component of the personal health record requires ongoing commitment from the user. Findings are interpreted by the user, who is prompted to contact a professional if potential problems are detected.

## 3.3.3 Acting on the assessment

Use of self-help guides prompt the user to act, either by undertaking self-treatment or seeking medical advice. This is in contrast to self-assessed case finding / screening in UK primary health care where it is usually the professional who is prompted to act, having initiated and interpreted the self-assessment.

A number of variations on the 'Dartmouth COOP Clinical Improvement system' (Jenkinson *et al.*, 2002), which incorporates a number of self-assessments, have been reported. Wasson et al (1999b) used a comprehensive postal questionnaire based on this tool that prompted the user to take action following a self-assessed screen for health problems. The questionnaire also incorporates the MEDS assessment for medication use (Wasson *et al.*, 1992) and provides an assessment of how well the older person feels identified problems are being dealt with by their physician. Issues covered by the questionnaire include: physical function, emotional status, pain,

activities of daily living (ADL), social support, social activities, medications taken, use of cigarettes and alcohol, history of immunization and difficulties driving a car. On completion, the questionnaire is returned for scoring by a third party but, unusually, the interpretation/ recommendations are returned directly to the user. Responses are used to generate a customised letter that directs the user to relevant sections of an 80 page information and advice booklet for older people. A summarised version of the letter is also sent to the person's physician, although in some implementations of the system, for example the web based version (http://www.howsyourhealth.org/), this is optional. Here the self-assessment is initiated and interpreted by a professional but it is the older person themselves who is prompted to act.

#### 3.3.4 Substitution

Self-help books are intended to substitute for professional assessment wherever it is safe to do so. Indeed one of the prime aims of such guides is to enable the user to take responsibility for their own health care and (explicitly) reduce the burden placed upon medical practitioners (Sehnert, 1975; Vickery *et al.*, 1981). Most of the postal questionnaires used in general health care are intended as first level screening tools to identify those older people who would benefit from an additional, more comprehensive, professional assessment. These questionnaires are probably best considered as additional to professional assessment in so far as screening was not ubiquitous at the time they were developed. The approach remains prevalent as an element of practice where such mass screening is attempted (Barber, *et al.* 1980; Cameron, *et al.* 1997; Porter 1987; Taine, *et al.* 1990b), but does not necessarily replace an alternative approach.

#### 3.3.5 Structure/format

Most of the self-assessments of general health have incorporated elements of paper and pencil tests, namely questionnaires of varying lengths and degrees of complexity, although the use of self-assessment algorithms does not involve completing a form. Many of these self-assessment tools for general health can be presented in electronic format and some examples have already been noted. This presentation potentially makes them more attractive and user-friendly by the use of photographs, interactive charts and intelligent navigation e.g. the British Medical Association Family Health Encyclopaedia (Anonymous, 2001a). Alternatively automated 'scoring' can give immediate and direct feedback on the results of assessments that otherwise require 'professional' interpretation (e.g. Wasson et al., 1992)

While the format of electronic versions could facilitate use by older people, it is probable that, in the UK at least, access via a computer would pose a barrier to many older people, especially those over 75. In order for many older people to use these self-assessments, assistance and encouragement would need to be provided to enable them to access and complete the questionnaire. However, it is equally certain that as the current more technologically oriented population ages, this situation will change rapidly with over 40 per cent of those over 55 using the internet to access health information in a 12 month period in the early part of this century (anonymous, 2003: - research by Datamonitor).

The Dartmouth COOP Charts, use simple diagrams next to each response category to make the charts more user-friendly (Jenkinson et al., 2002). For example, in the assessment of mood (Figure 3.3) the diagrams represent simple facial expressions ranging from a smiling face through to a sad face with a down-turned mouth, which the designers claim aid comprehension.

Figure 3.3 Example of Dartmouth COOP chart.

# **FEELINGS**

During the past 4 weeks . . .

How much have you been bothered by emotional problems such as feeling anxious, depressed, imitable or downhearted and blue?

Not at all	8	1
Slightly	(®)	2
Moderately	(S)	3
Quite a bit	(R)	4
Extremely	(8)	5

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## 3.3.6 Issues/topics covered

Comprehensive general health assessments and self-help books cover a wide range of topics including mental health, functional ability, mobility, sensory impairment, living arrangements, social contacts, service use and medications. While items relating to social contacts and social activity may be included, the focus of these assessment tools is predominantly health-related issues.

Of the brief postal questionnaires used for case-finding in primary health care in the UK the Woodside Screening and Assessment Programme (Barber et al., 1980) is the most frequently cited, often forming the basis from which other tools are developed (Taine et al., 1990b). As the Woodside questionnaire does not contain any items relating to mental health, many of the UK self-assessment screening tools used for general health assessment also have this omission. Given that mental health problems are prevalent in older people this is a major limitation. However, some primary health care self-assessment questionnaires do include mental health items. Examples include Bowns et al. (1991a) and the COOP assessment (Figure 3.3) both of which contain items on mood.

#### 3.3.7 Internal vs. external factors

Self help algorithms tend to relate to specific health problems and are thus exclusively focussed on physical problems. However, some of the content of the self help books in which they are presented extends to address external factors such as supportive resources and finance. The latest edition of Aging well (Living Well. Taking Care of Yourself in Middle and Later Years - Fries, 2001) contains information on finances, life planning and home safety that also has elements of self-assessment which might even extend the range of this guide beyond the 'health' sphere. These passages tend to be largely narrative and do not directly support a formal selfassessment. Case finding instruments tend to have a focus upon internal factors. Even where issues that might be related to external factors are alluded to, as in instrumental activities of daily living, the impact of external factors is not made explicit (e.g. do you need regular help with housework or shopping? - from the Woodside SAP). Many of the assessments also incorporate items that relate specifically to sources of support and help (e.g. are you in the position of having no relative whom you can rely on for help? - also from the Woodside SAP).

Assessments based on the Dartmouth COOP system (e.g. Wasson et al., 1999a) encompass consideration of personal social and financial resources related to health care as well as items relating to the persons relationship with their care providers and the extent to which they are aware of problems. This is in keeping with one of the stated aims of the COOP system, namely improving the quality of communication between client and professionals.

### 3.3.8 Predictive vs. diagnostic

The majority of the assessments considered in this section are diagnostic in the sense that they relate to identification of latent need (case finding) or identifying appropriate actions in the face of particular symptoms (self-help algorithms). Systems based on, or similar to, the Dartmouth COOP assessments are mixed in that they focus on generic symptoms which may indicate current unmet need / undiagnosed problems (e.g. pain), but there is also an element of preventative care and identification of future problems where issues such as advanced directives, vaccinations (influenza) and specific screening (e.g. bowel cancer) are assessed. Thus these assessments are both diagnostic and predictive. There are also elements of identification of current resources in terms of appropriate use of the health care team, although the focus of the assessment is on deficits. Elements of the self-care books also cover similar preventative aspects and are thus predictive, although the preventative elements (e.g. diet, cardiovascular risk) are not

covered by formal assessments in the texts considered (e.g. Fries, 2001).

# 3.3.9 Section summary – general health care

Although fewer in number, there is more variety in the general health assessments identified

There are examples of paper and pencil questionnaires, self-assessment algorithms and web-based systems with feedback.

In common with focussed health, most general health assessments identify current need, some predict future need while a few highlight health resources available to the individual

The assessments tend to consider both internal and external factors

There is much more autonomy in the use of the assessments with some examples being entirely user directed from initiation to action

The aim of the assessments is broader, commensurate with the broader content

Frequently the goal is to improve management of healthcare in general and to mediate relationships with professionals

For some examples there is an explicit goal of substituting for professional assessment by avoiding 'unnecessary' consultations

## 3.4 Social care and life skills

In contrast to the widespread use of self-assessment in health care, only a few examples of self-assessment were discovered that focussed on the domain of social care and life skills. This would seem to suggest that self-assessment is infrequently used in this field, which tends to be dominated by interview-based assessment. It may be that the data sources used (primarily professional literature) is a source of bias since examples of self-assessment are to be found in the popular media. However, even here the focus is more clearly on health than other issues. The more highly developed databases of literature in health care (e.g. Medline) may also be a partial explanation but the coverage of databases was wide and encompassed databases most likely to report social care literature (e.g. AgeInfo, Ageline, ASSIA, CareData, CHID and HMIC). In health and social care practice in the UK social assessment is now undertaken under the auspices of comprehensive assessment within the SAP. Nonetheless the dearth of material is striking. Self-care guides are potential vehicles for such tools (although they would then be classified as comprehensive assessments here as they encompass both health and social care) but it is surprising that, as noted above, none of

the examples identified in this review do in fact use self-assessment for these aspects of their content (e.g. Fries, 2001).

# 3.5 Initiation of the self-assessment

Generally assessments found in this area were more likely to be initiated by the user. Two examples were found in the field of housing which could potentially be user-initiated, the Housing Options for Older People (HOOP) project (Russell, 2000) and the Canada Mortgage and Housing Corporation's (CMHC) selfassessment guide for home adaptations (Canada Mortgage and Housing Corporation, 2004). The latter is an interactive web-site (Canada Mortgage and Housing Corporation 2004 (www.cmhcschl.gc.ca/en/burema/repi/masein accessed: 20.3.2004) designed to help older people decide whether they need any home adaptations and, if so, which ones would be appropriate. Although this self-assessment might be initiated by the older person themselves, it might also be used at the suggestion of another person e.g. a representative from the CMHC. The assessment addresses problems related to moving about and using facilities in the home (e.g. kitchen and bathroom). If the person identifies that they have difficulty in a particular area suggestions for actions are made. For example, if an older person has identified that they experience difficulty using the stairs the suggestions to help overcome the problem include: improve lighting, install handrails on either side, extend existing handrails one tread's length at the top and bottom of the stairs, replace worn stair covering, install toilet on main floor, relocate bedroom to main floor.

## 3.5.1 Interpretation of completed self-assessment

HOOP is a UK joint project jointly developed by the Housing Corporation, the Elderly Accommodation Council, the School for Policy Studies and the University of the West of England (Russell, 2000). The HOOP self-assessment form is designed to help older people who are trying to decide whether or not to move home. The questionnaire can be completed wholly as a self-assessment or be worked through with an interviewer, or a combination of both. The HOOP questionnaire contains items which help the older person think through issues related to moving house, suitability of current housing and concerns about the future. Like the CMHC questionnaire the HOOP instrument is also available in a web-based format.

# 3.5.2 Acting on the assessment

Both examples noted so far primarily prompt the user of the assessment to act. The HOOP questionnaire contains links to specific advice dependant upon the respondent's answers. A further

example of this was a self-assessment of driving ability using diaries (Kiernan *et al.*, 1999b). When using the diary the person is asked to record mileage and to note the degree of difficulty encountered on four driving elements;

- maintaining a steady speed on the open road
- driving slower than the rest of the traffic
- keeping a steady lane position and
- keeping in your lane e.g. not crossing the centre line

In addition, the person is also asked to indicate for each trip how many times a dangerous event occurred. The authors claim that the self-monitoring diary could be used to facilitate the evaluation of driving performance and bring about a change in driving behaviour so as to improve driving performance and reduce the risk of serious accidents occurring, although use in practice outside the context of the study was not reported.

By contrast a self-assessment instrument for identifying the user's perspective of their housing environment developed for use by occupational therapists (Fange *et al.*, 1999) is a process that is initiated by professionals who also interpret the outcome in a similar way to many of self-assessments of focussed health reviewed earlier. This 16-item instrument asks the user to rate their physical housing environment on the following areas: accessibility, suitability, occupational performance (facilitation of self-maintenance, leisure and hobbies, rest and relaxation), safety, privacy, flexibility and social contacts. The completed schedule is interpreted by the occupational therapist in order to enhance his/her understanding of the user's perspective and thus enable them to provide appropriate, individualised care.

### 3.5.3 Substitution

In general the assessments identified in this area are additional to professional assessment, covering issues not otherwise subject to professional assessment or adding an additional element to it. In the case of the HOOP assessment it is unlikely that a professional assessment would be available to help all older people to work through the issues of moving home, unless the situation was severe and urgent. As such, the HOOP questionnaire falls largely outside the scope of current professional assessment and thus is additional. The CMHC assessment provides advice that would often be delivered by health care professionals such as occupational therapists, although again the assessment is available to those who would not ordinarily receive such assessments. Even where professionals are involved it is unlikely to be used to specifically substitute for aspect of the assessment. Driving performance (Kiernan *et al.*, 1999b) is not usually subject to a formal

professional assessment, except where formal review of a license is concerned, and so this assessment is also additional to professional assessment

#### 3.5.4 Structure/format

Despite the small number of examples in the domain of social care and life skills, a number of different formats of self-assessment have been identified – paper and pencil questionnaires with simple response scales (Fange et al., 1999), more complex questionnaires involving summative scoring and prioritising (HOOP), a self-monitoring diary (Kiernan et al., 1999b) and electronic questionnaires (CMHC). The HOOP questionnaire is also available in a web based format (Elderly Accommodation Council no date (http://www.housingcare.org/adviceinfo/hoop/hoop.aspx accessed: 28/4/05) and the Canadian Automobile Association also provides a driving self-evaluation questionnaire on the web (Canadian Automobile Association no date

(http://www.national.caa.ca/DrivingSurvey/ accessed: 26/2/05)

## 3.5.5 Issues/topics covered

The topics covered in the social care/life skills domain have tended to be focussed on specific areas, namely housing (Canada Mortgage and Housing Corporation, 2004; Russell, 2000), driving performance (Kiernan *et al.*, 1999b), personal strengths (Kivnick *et al.*, 2001) and leisure interests (Kautzmann, 1984). Although this section would include broader assessments which focused solely on social care or life skills, none were identified, although the HOOP assessment does include items reflecting the potential for the impact of housing problems on the person's health and a general item on self-rated health. More comprehensive social assessments are included in the following section 'Comprehensive or Multidimensional Assessments'.

### 3.5.6 Internal vs. external factors

Most self-assessments in the domain of social care and life skills involve assessment of environmental factors e.g. physical housing environment (Canada Mortgage and Housing Corporation, 2004; Russell, 2000) and leisure interests (Kautzmann, 1984). However, an example was found with a very different, internal focus – the Life Strengths Interview Guide (Kivnick *et al.*, 2001). As the name suggests, this questionnaire is intended for use as a structured interview. It is included here because the tool is intended for use with frail, older people, a target group that contains people who would be unable to complete a paper and pencil instrument. However, the issues addressed could be incorporated into a self-

assessment for those able to undertake it. The ten-item version of the assessment tool includes items such as;

- what are you good at? What about yourself has always given you confidence or made you proud?
- what kinds of help/service/assistance do you give? and
- who are the people who are especially important to you?

The assessment is intended for use both by the older person and the professional (social worker) in order to utilise identified strengths in designing and implementing individual case plans. The authors claim this helps both parties to shift the emphasis away from the older person's problems and towards a strengths-focussed intervention (Kivnick *et al.*, 2001). The personal, reflective nature of this assessment tool sets it apart from the other tools described in this section, and emphasises the importance of self within the self-assessment.

# 3.5.7 Predictive vs. diagnostic

The CMHC assessment guide for home adaptations and the questionnaire developed for use by occupational therapists to assess physical housing environment (Fange *et al.*, 1999) have both predictive and diagnostic features. The CMHC home adaptations guide can be used to 'diagnose' areas in the home environment which would benefit from alteration, and to predict where future problems e.g. accidental falls, might occur. The physical housing assessment is also used to provide the occupational therapist with an insight into the user's perceptions concerning the accessibility and usability of their home, identifying actual problems and potential hazards.

The driving performance diary, by enabling the user to identify current problems with driving, also acts to predict why future accidents might occur. By highlighting poor driving habits, or lack of skills, it is hoped that driving behaviour will be improved, thus reducing the risk of accidents occurring (Kiernan *et al.*, 1999b).

Two of the self-assessment tools identified in this domain are intended to enable the user and the professional to identify areas of interest (Fange *et al.*, 1999) or strength (Kivnick *et al.*, 2001) upon which to focus therapeutic interventions, rather than as a predictive or diagnostic aid. Similarly the HOOP questionnaire does not have prediction or diagnosis as its aim, but is intended to facilitate decision-making.

# 3.5.8 Section summary – social care and life skills

Assessments identified cover a small number of diverse topics (housing, driving, life strengths and leisure)

Assessments tend to take a relatively narrow focus in terms of topic, although some take a very broad perspective on that topic

There are examples of both paper and pencil questionnaires and web-based systems with feedback.

Few focus solely on current need and several highlight health resources available to the individual

In common with general health, the assessments tend to consider both internal and external factors

There is much more autonomy in the use of the assessments compared with those identified in the fields of focussed and general health, although the process tends to be professionally initiated

The self-assessments typically cover issues that would not routinely be covered by a professional assessment, or provide an additional resource

# 3.6 Comprehensive assessments

The material identified in this section is dominated by systems developed for the SAP as part of the UK's NSF for Older People (NSF) for England and Wales (DoH, 2001b). The NSF has personcentred care and individualised assessment as one of its main focuses (Anonymous, 2001b). Standard two of the NSF SAP, integrated commissioning arrangements and integrated provision of services, as the means by which individualised care and the ability to exercise choice will be achieved. This involves providing information so that the service user and, where appropriate, their carer can be involved in decisions about their care.

At the commencement of this review implementation of the SAP was still in its relatively early stages. Our case studies were focussed on the SAP for this reason and illustrate this early stage of development. These are offered as examples of progress toward implementing self-assessment in the single assessment programmes. It is striking that many of the examples that were identified to us as examples of self-assessment were laudable examples of user involvement in developing processes, but were not actually self-assessment. One such example is a case management process (Box 3.1). Some of these examples were not identified as self-assessment by those involved, but are included here as others identified them as examples and those participating provided useful information on their perspectives on self-assessment (Box 3.2). Thus we believe they are informative.

Within the NSF, broad guidance was available relating to the content and process of tools, but there was no formal accreditation. A number of tools were being considered and tested. All covered a wide range of domains in health and social care. The majority of

these lend themselves to self-assessment in part, but were not primarily intended for use as a self-assessment at present. Examples considered here include the Cambridgeshire Assessment Tool (CAT, also known as the Common Assessment Tool see Box 3.5), EASY-Care (Philp.I, 2000) (Box 3.4) Camberwell Assessment of Need for the Elderly (CANE) (Hancock, 2003), Functional Assessment of the Care Environment (FACE Recording and Measurement systems, 2004) and Minimum Data Set – Home Care / RAI (MDS – RAI Challis et al., 1996). Of these, the paper version of the CAT and the CANE assessments did not receive accreditation in the process that commenced in 2003 (DoH, 2004b). Localities remain free to utilise locally developed tools. One such example was the only tool specifically intended for self-assessment as part of the SAP (The Knowsley Overview Assessment: Moss, 2003) which we identified (Box 3.3) Outside of the framework of the SAP we identified a comprehensive self-assessment tools for use by carers to assess their own needs (Nolan, 1995).

## Box 3.1 Case Study: Tower Hamlets case-management

The case-management programme in Tower Hamlets has been implemented as part of the London Older People's Programme. This joint initiative established between the Social Services Inspectorate and the NHS Directorate of Health and Social Care (London) is working to develop more responsive and co-ordinated services with the focus on person-centred care. The project is funded for 2 years. It aims to provide services that meet the needs of older people that have hitherto not been met despite lengthy contact with health and social services. The older people referred to the case-management programme usually have complex health and social care needs. It was identified as an example of self-assessment via the IAHSP database of inclusive practice and network of practitioners and users although it does not meet the criteria set out for this review. It is offered as an example of client centred assessment that does not involve formal self-assessment but which could be misclassified as such. The account is based upon the perceptions of practitioners.

#### **Process**

The assessment is initiated by the professional who contacts the older person to make a first appointment. There is no self-assessment. The assessment is conducted as a series of intensive interviews/discussions over an 8 – 10 week period. Much of this work depends upon building a relationship with the older person in order to encourage openness and honesty, and as such requires the investment of a lot of time and a firm commitment from both parties. The professional and the older person 'journey together' through the assessment process so that as needs are identified and possible options for meeting those needs are explored the older person is always the central focus of the assessment. While final interpretation of the assessment rests with the professional, it is hoped that, by working together through the assessment, the interpretation will be fully informed by the older person's viewpoint and priorities for action. A plan of action is agreed upon by both parties based upon the needs and priorities of the older person as defined by them.

The professional is prompted to act, usually by setting up services to try to meet the needs of the older person as they have defined them. The professional may also be required to suspend other services if they are not meeting the needs of the older person in a way that is perceived as beneficial by the older person. Case-management is carried out as an alternative to more traditional professional health and social care assessments where these have been unsuccessful in identifying needs and/or solving problems.

#### Content

During the series of interviews the older person is encouraged to talk about what they see as their needs, what their priorities are and how they would like them to be addressed. The case manager works to "unpick" what has gone before and start again by looking at the person's needs from their own perspective. Although the assessment is conducted as a face-to-face interview, its intention is to engage the older person in (verbal) self-assessment, placing them at the centre of the assessment and ensuring their story is told in their own words. This is carried out without imposing a professional agenda (i.e. asking a number of predetermined questions) or confining it within professionally defined boundaries e.g. within the limits of current service provision. The older person is encouraged to talk about any issues that impact upon their need/problem, both internal and environmental. The case-manager and the older person then try to identify what needs/problems can be addressed and how this might best be achieved in a way that suits the older person.

#### 3.6.1 Initiation

All the assessments identified were initiated by a professional. Within the SAP this can be any professional who comes into contact with the older person e.g. nurse, social worker or podiatrist. In the only true example of self-assessment identified, the Knowsley Overview Assessment, the assessment documentation was sent to clients for completion or consideration prior to a face-to-face assessment.

# 3.6.2 Interpretation

The comprehensive assessment schedules developed for the SAP vary in terms of the degree of self-assessment involved. However, all are intended for interpretation by a professional. Three of the assessment tools are designed for professional use rather than selfcompletion but do include an element of self-reflection - the CANE (Hancock, 2003), the Minimum Data Set for Home Care (MDS Home Care Morris et al., 1997) and the Minimum Data Set – Resident Assessment Instrument (MDS - RAIChallis et al., 1996). The MDS assessments represent one of the earlier comprehensive care assessments, originally developed in the US and later adapted for use in the UK. The guidelines for professionals and staff using the MDS instruments emphasise that the assessment approach is designed to facilitate discussion between the older person and their carers so that their preferences and priorities can be recognised and acted upon. The CANE questionnaire includes items in each section which ask how satisfied the older person is with the assistance/care they are receiving, with a space for recording user perspectives on their expectations, personal strengths and resources (Hancock, 2003). While this does not constitute self-assessment, there is an emphasis on acknowledging the older person's views and opinions and providing individualised care and services based on an understanding of the older person's perspective. However, other instruments in use or being developed reduce this reflective element in order to make the assessment more useable in practice.

#### **Box 3.2 The Tower Hamlets Single Assessment Process (SAP)**

Alongside the case-management programme, Tower Hamlets is also developing documentation for conducting Single Assessments in the more traditional interview format. Overview assessments were conducted initially using an early version of EASY-Care and a new Single Assessment tool is evolving based on this model.

The Older People's Reference Group, a voluntary group comprised of older people, is involved in developing this new tool and have been consulted on its language, clarity, ease of usage etc. Members of the group also agreed to participate in the pilot testing of the new assessment tool and to provide feedback on the experience of being assessed. The new tool comprises only closed questions, which makes it quicker and simpler to work through, and potentially easier to self-administer. However there is no opportunity for older people to express their needs in their own words. To date, self-assessment has not been considered as a viable option within the single assessment process in Tower Hamlets.

# 3.6.3 Acting on the assessment

All the comprehensive assessments reviewed provide information that is used to prompt the professional to act. Unlike the tools included in the previous sub-sections, alongside elements for professional assessment of health and social issues the FACE overview assessment for older people does include two selfassessed sections, one for use by the older person themselves and one for their carer. Entitled 'How are you?' the user self-assessment comprises four open-ended questions with a large blank space for recording responses. While this forms only a small part of a lengthy assessment tool it does represent full self-assessment where the person is given an opportunity to express their own needs and wishes in their own words and in a self-completion format. The carer's self-assessment is also a brief (nine-item), self-completion questionnaire with a combination of open-ended questions and fixed response questions with space provided for expansion if needed. Items include:

- do you have time for yourself? (yes/little/no)
- is care giving affecting your relationships with other people (e.g. friends or family)? (yes/little/no)

Responses to these questions alert the professional to the needs and potential needs of the carer, and provide an opportunity for discussion about support services and resources available. If the carer wishes a more comprehensive, professionally-led carer's assessment can be carried out (FACE Recording and Measurement systems, 2004).

## Box 3.3 Case study - Knowsley Social Services and PCT

'Go Integral' is a Knowsley PCT and social services initiative to integrate community health and social care services for adults, including older people. Implementation of the SAP for older people has been undertaken as part of this wider service plan for integration. The overview assessment for older people is undertaken wholly or partially as a self-assessment, depending upon the person's preference and ability.

#### **Process**

The overview assessments are initiated by professionals who mail the assessment form to the older person with a covering letter explaining the purpose of the form and encouraging them to complete as much of it as they feel able to, or want to, prior to a visit from a district nurse or social worker. The responses are interpreted by the professional, although this is often done in partnership with the older person to ensure the older person's perspective is fully understood. The self-assessment is carried out as part of the overview assessment

In some cases further information will be sought by the professional to supplement self-assessed details, in others the information provided stands alone as a substitute for professional assessment. In this way the professional's time is saved from collecting routine and straightforward data and the professional can work with the older person focussing on areas of need.

#### Content

The Knowsley Overview Assessment is a paper and pencil questionnaire. It comprises 45 items in ten domains as follows:

Service user's perspective (on their own difficulties and needs, expectations, strengths, abilities and motivation); carer support, relationships and social activity; clinical background; disease prevention; personal care and physical well-being; activities of daily living; senses; mental health; safety and security; Immediate environment and resources

The content of the Knowsley overview assessment is similar to that of the CAT (Box 3.4), and includes both internal and environmental topics. The questions are worded so as to address the older person directly in the first person, thus underlining its intention as a personalised assessment. For example, the opening question asks: 'What is your own view, in your own words, of your difficulties and needs?'

Whilst the majority of the assessment form is easy to understand, some sections use language that may be more familiar to professionals than to some older people for example 'Particular needs relating to race or culture' or 'Any help to speak for yourself (representation or independent advocacy and under the heading 'Personal care and physical well-being' the following two subcategories appear: 'Tissue viability, skin care inc. prevention of pressure sores' and 'Continence and other aspects of elimination'.

Thus whilst designed and used as a self-assessment some of the language used may limit the degree to which some older people can complete the form unaided. Usefully, each item includes space to record the identity of who provided the information i.e. the older person themselves, a carer, relative or professional. Thus it is possible to gauge how much of the assessment is directly representative of the older person's own views.

#### 3.6.4 Substitution

In most examples noted self-assessment is used in addition to professional assessment . While with the FACE assessment tool this represents an additional component of the overall assessment, there are examples where the majority of the comprehensive assessment can be undertaken by the older person themselves e.g., EASY-Care (Box 3.4) and CAT (Box 3.5) and the Knowsley Overview Assessment of Need (Box 3.3 Of these, the Knowsley Overview Assessment has been developed in close consultation with older people specifically as a self-completion questionnaire. In most cases the self-assessment forms a part of the overall assessment process. Explicit claims relating to savings of professional time were made regarding a self-assessment pilot of the CAT instrument using notebook computers (Box 3.5), suggesting the potential for professional substitution.

#### Box 3.4 Case study - Lewisham

Work to develop the SAP in Lewisham was also undertaken as part of the London Older People's Programme. Implementation of the SAP included a small pilot of self-assessment using the EASY-care assessment tool. The pilot study was undertaken to test the feasibility of conducting single assessment overviews as self-assessments in order to address the heavy burden placed on resources by carrying out assessments for all people aged 75 and over. The pilot involved 49 older people aged 75 and over living in sheltered housing in one area of Lewisham.

#### **Process**

The self-assessment process was initiated by a GP-attached district nurse who was responsible for providing assessment questionnaires for distribution by sheltered housing managers. The completed assessment forms were returned by post, or, in some cases, delivered by hand to the GP surgery. All forms were examined by the district nursing team in order to identify need, and to decide who should receive follow up visits. Follow-up visits were also made to older people when it was unclear from their self-assessment whether health or social services input might be beneficial. In this pilot study the self-assessment substituted for professional assessment by a health or social care professional.

#### Content

The paper and pencil version of the EASYcare 2002-2005 form was used (minus the section on memory which requires a trained assessor). This 93-item questionnaire is divided into nine sections. The assessment is comprehensive covering both environmental and internal issues in some detail. Environmental issues covered include the home (e.g. size and space, condition of accommodation, location) finance (e.g. advice about financial allowances or benefits) access (e.g. difficulty getting to public services) family and friends (e.g. is there anyone who would be able to help you in case of illness or emergency?) use of services (e.g. district nurse, delivered meals, attendance at a day centre). The self-assessment was used as a case-finding tool to identify current problems that required further follow-up by the community team e.g. district nurse, social worker, podiatrist.

#### 3.6.5 Structure/format of the self-assessment

As highlighted, self-assessments in this domain may employ openended questions with free space for detailed responses as well as the more usual closed question/fixed response format e.g. FACE (FACE Recording and Measurement systems, 2004). Two of the comprehensive assessment tools developed for the SAP are available both as a paper and pencil questionnaire and as an electronic version, FACE and EASY-Care. Uniquely, the CAT has been developed as an electronic assessment tool and is now available in that form alone. The CAT is an extensive tool covering 14 areas of health and social care (Box 3.5).

At present the CAT is being used as a professionally-led assessment, but it has been designed for use as a self-assessment and piloted as such. As noted for the Knowsley Overview Assessment, some of the language used is quite clinical and may not be readily understood by all potential users. A number of user-friendly features have been included in the questionnaire. For example, the screen shows a pro forma for each page of the questionnaire which is easy to understand and simple to follow. Answers are recorded using drop down menus of prescribed answers and text boxes. It is possible for assessors to hand write comments and additional information in text boxes using an electronic 'pen'. The CAT employs intelligent navigation i.e. questions are automatically 'skipped' if a previous answer indicates that it is inappropriate e.g. if a person is confined to bed, questions on how far they can walk outside are not presented.

A number of assessments that were previously available by other means are now being made available via the world wide web. A web based online assessment is available from Kent County Council, which points users to the need for full assessment or specific sources of help / support and identifies whether or not the person qualifies for Community Care Services or would benefit from a full assessment (Kent County Council No date (http://www.kent.gov.uk/selfassessment accessed: 27/04/05). Benefits claims, such as that for attendance allowance produced by the Department for Work and Pensions, also represents an example of a lengthy and complex self-assessment questionnaire where older people are likely to form a large proportion of those completing this claim form. Both include a detailed assessment of needs concerning mobility and ADL. However, in neither case does there appear to be a clear strategy for integrating the data gathered with data collected as part of the SAP, even though the potential is obvious.

Given that this questionnaire has been developed specifically as a self-assessment tool, some of the language used is rather clinical in nature.

The tool is used to facilitate identification of need and to direct professionals to provide appropriate support. By using a self-assessment approach it is hoped that the older person is placed at the centre of the SAP and that the services and support provided are appropriate and correctly targeted

## 3.6.6 Issues/topics covered

As would be expected of comprehensive assessments covering both health and social care, a wide range of topics are covered. One key component of most of the assessments in this domain is the inclusion of carers. Indeed, a number of self-assessment schedules exist which focus solely on carers' needs, these include the Carers' Assessment of Difficulty Index (CADI, Nolan *et al.*, 1992), Carers' Assessment of Managing Index (CAMI: Nolan, 1995), the Carers' Assessment of Satisfaction Index (CASI: Nolan *et al.*, 1998) and the Carers of Older People in Europe Index (COPE: Nolan *et al.*, 1999). The COPE Index is a 12-item comprehensive assessment of carers' needs. Items are rated on a four point scale in response to the statement 'I feel this statement is true of me' – always / mostly / sometimes / never, for example;

- the person I care for asks too much of me
- care giving places too many restrictions on my social life
- care giving causes me financial difficulties
- care giving has a negative effect on my financial health
- care giving has a negative effect on my physical health and
- I have a good relationship with the person I care for.

This brief schedule is intended as a first-stage assessment tool that can be used to identify carers who would benefit from further consideration of their support needs (Nolan *et al.*, 1999).

#### 3.6.7 Internal vs. external factors

Almost by definition, comprehensive self-assessments include both environmental and internal issues. The EASY-Care questionnaire underlines the need for the self-assessment to include 'environmental factors, relationships, recent life events and other external factors that precipitate or exacerbate needs'. While the assessment of individual items is important, it is often the interplay between items, and understanding how environmental factors influence personal issues, that enables appropriate service and/or care provision.

# 3.6.8 Predictive vs. diagnostic self-assessments

The main aim of comprehensive self-assessments is to identify needs and to provide information so that those needs can be appropriately met. In this respect the assessment tools can be said to be diagnostic. A predictive element may also be present where areas are identified where the older person is still coping, but only just. Thus future needs might be predicted, for example adaptations to assist mobility around the home, and action taken to ensure those needs can be met when they arise. However, there is little explicit discussion of this element.

The role played by self-assessments in recognising potential mental health problems before they become severe is also a very important one. In the case of carers the use of a self-assessment tool may provide a much-needed opportunity for a person to reveal the true burden of caring and prompt action to be taken which can alleviate that sense of burden e.g. additional home support or financial support.

## Box 3.5 Case study Cambridgeshire Assessment Tool (CAT)

#### Development

The CAT was piloted as a paper and pencil tool February – May 2001. Feedback from the pilot study made it clear that professionals wanted an electronic version of the assessment tool in order to meet the requirements of the SAP, namely avoidance of duplication, easy access to information for all individuals engaged in the assessment process and the ability to involve other agencies promptly as necessary.

Older people have been involved throughout the developmental stages of the CAT. Consultation with older people's groups (BGOP and COPAG) identified the following priorities: Quick responses to requests for information, avoidance of duplication of requests for information, fewer different professionals requesting similar information, improved communication between agencies, to feel in control of the assessment process, for older people to have a voice in the assessment proceedings and consideration of confidentiality without this blocking progress or hindering outcomes. Tool development has also involved social services, health services, housing services, voluntary organisations and the independent sector along with IT input from all these areas.

In response to findings from initial consultations the CAT has been developed as an electronic assessment tool, completed on tablet computer by the assessor. The electronic version has been developed in conjunction with Fujitsu and European Management Systems. Following pilot testing of the electronic version of the assessment tool (August 2002 – February 2003) the most recent version, CAT3, was launched in July 2003. The tool can be completed by a professional, a carer or as a self-assessment.

Use of the CAT as a self-assessment has been pilot tested with a sample of older people in a residential nursing home. The older people appeared to adapt fairly easily to using a computer-based questionnaire and few problems were encountered in using the assessment tool in this way (personal communication). Although further testing is required this does appear to be a promising development that would facilitate self-assessment of comprehensive health and social need. The use of the CAT as a self-assessment is described below.

#### Process

The self-assessments were initiated by health professionals. The older people encountered few problems completing the assessments or using the tablet computers. The use of an electronic pen on the tablet computer screen was felt to facilitate this. The completed assessments were interpreted by professionals who were then prompted to take action. Self-assessment was used as a substitution for professional assessment. Completion of the CAT overview assessment by a professional working with an older person takes between 1.5 and 2.5 hours. Self-assessment was described as shorter (no time specified) and represents a considerable saving of professionals' time.

#### Content

The use of an electronic format was not seen as a barrier by older people. Intelligent navigation through the questionnaire was perceived as a great benefit and allowed the questionnaire to be individualised, avoiding presentation of irrelevant questions and information. This very comprehensive assessment includes both environmental and internal issues. These include those listed above for the Knowsley Overview Assessment (Box 3.3) plus the following areas: assessor's view of cognitive ability; housing; and spiritual well-being

#### Personal fulfilment

The electronic CAT can be linked via the Internet to the web-sites of local service providers, self-help and voluntary groups and local information resources. Using this facility the assessment has the potential to be used by the older person, with or without input from a carer or professional, to predict future needs/problems and take preventative action.

## 3.6.9 Section summary - comprehensive assessment

Most examples considered were related to the UK's SAP

The content is, by definition, broad covering a variety of health, social care and well being issues

There were relatively few examples of instruments designed for self-assessment, although a number of examples were identified where their use was being piloted as self-assessment

Paper and pencil, handheld computers and web based assessments have all been used

There were some examples of older people being involved in the development of the process

Although we found examples of joint care planning this was not explicitly built into self-assessments, although computerised links to sources of advice could fulfil the function partially

There were explicit statements relating to the possibility of selfassessment increasing user involvement and participation not seen elsewhere

The process was largely mediated by professionals although statements relating to 'partnership' are inbuilt

## 3.7 Conclusion

Self-assessment has been used across a wide variety of domains, and for a number of purposes ranging from targeted screening for specific medical disorders through to approaches designed to help individual decision-making in relation to major life events such as changing accommodation. In many of the health related domains self-assessment is a simple substitution for professional assessments, and in most of these cases self-assessment is simply a mode of administering a screening test without having face-to-face contact. The content differs little, if at all, from a face-to-face assessment.

In the social care / life skills domain, despite the limited number of examples, there is considerably more variety, and it is clear that many of the examples identified are substantively different from any face to face assessment, or indeed cover issues and topics that would be unlikely to fall within the domain of professional assessment. In this area we have noted examples of assessments that are primarily designed to aid decision-making on behalf of the user and are both user initiated and interpreted. Clearly 'self-assessment' means many things to many people and the extent to which users are actively involved varies considerably.

In relation to comprehensive assessments we have observed considerable innovation in terms of both user involvement in development and in modes of delivering the assessment. However, as with medical screening, the value lies not simply in terms of the ability to gather information but what then happens to it. In this regard it is clear that even the most innovative self-assessments require appropriate action by professionals and are not designed to impact upon the person themselves directly. Further, although attempts at user involvement are explicitly stated, the claims of partnership in the process are clearly dependant upon the aspirations of service providers, which are mandated by policy, being translated into reality for the older people.

Although the paper and pencil questionnaire remains ubiquitous we have seen a number of examples of the use of computers (often by means of the World Wide Web) to 'host' the assessment process and it would seem likely that this will become increasingly prevalent, although it may be that the development of such methods for older people will be inhibited by a perception that they lack the requisite skills. It is certainly notable that despite the burgeoning number of web sites offering self-assessments related to conditions that affect older people (predominantly based in the US and offered by healthcare providers), there is relatively little reflection of this in the published literature, although we have identified a number of examples through other means.

It is perhaps unsurprising that the professional literature is dominated by examples of assessments that are in some way or another professionally initiated. Many of the examples identified could, if disseminated appropriately, be initiated by users themselves. Again, the World Wide Web represents a possible mechanism for doing this and we have found examples of screening questionnaires designed for paper / pencil completion being made available on the web. In terms of published examples, though, the most prominent is in the field of health in the form of 'self care books' in various forms. Where the book is sold commercially, initiation of assessments based upon it are clearly user defined. Wide dissemination as part of a programme puts the books in the hands of those who might not otherwise use it, but, nonetheless, after the initial prompt, use of the book in a specific circumstance must be in the hands of the users. Ultimately though, selfassessment always involves more choice on behalf of the user / client, since not responding to a postal questionnaire requires less of an act of will than not responding to questions on a face to face hasis

The context in which an assessment is undertaken is clearly key. A postal medical screening questionnaire may (or may not) represent a sufficient and efficient way of targeting resources in particular populations. The priorities tend to be professionally defined in terms

of prevalent conditions and issues deemed important, which may or may not be shared by the recipients of screening. However, little concern is given to issues such as empowerment of shared decision-making. Very similar material deployed in the form of a self-care programme puts information and decision making in the hands of the users to a much greater extent, even though it is clear that at least part of the motivation from participating health care providers, or insurers, may be to simply reduce their own responsibilities and liabilities. The extent to which self-assessment as an element of self-care is empowering may also depend upon the perspective and perceptions of the users and the reaction of professionals. In terms of comprehensive assessment the aspiration of user involvement and partnership is clearly stated, but in terms of this review has yet to be put to the test.

Ultimately whether self-assessment is a 'good' thing rests upon a number of factors. For many aspects of self-assessment there is an objective element of accuracy. This applies particularly where there is a degree of substitution for professional face-to-face assessment related to a focused medical problem. This question is addressed in chapter 3, a focused review of the accuracy of self-assessment. However, an accurate assessment does not necessarily deliver any benefit (from whichever perspective benefit is defined), and this question must be answered additionally and separately. The question of whether the use of self-assessment affects the process of care across a range of dimensions, ranging from resource use through to health outcomes as a result of improved care management (including participation and communication), is addressed in chapter 4, a focused review of the effectiveness of self-assessment. Further, for many issues, there is no external criterion by which to judge 'accuracy' except in so far as the user's perception is that they have successfully communicated need, or the assessment leads to improved care in some way. Finally, the experience of self-assessment is multidimensional and must be understood in order to fully evaluate its utility from any perspective. The answers to these questions will no doubt be influenced by mode of administration, topic and a host of other factors identified here. These issues relating to the experience of self-assessment are addressed in a focused review of evidence in chapter 5.

## 3.8 Implications and recommendations for research, practice and policy

#### 3.8.1 Research

The diversity of goals, topics and approaches to self-assessment highlights the need for research in this area

There can be no single and simple answers

### 3.8.2 Practice

There are numerous examples of self-assessment already in existence which either have been or could be used with older people

The diversity of examples identified here illustrates that the potential scope for self-assessment is vast.

The diversity of practice and definition illustrates the need for clarity about what is meant be 'self-assessment'.

The mechanisms for self-assessment range far beyond the simple use of paper and pencil questionnaire type formats

Computerised approaches, especially the world wide web, are becoming increasingly important

Practitioners should not dismiss this for older people but equally need to be mindful about issues of access and usability, just as with any other approach

## **3.8.3 Policy**

Policies supporting self-assessment are grounded in examples from practice

Policies which advocate self-assessment should be clear about definitions

In particular, assuming that self-assessment and user involvement are necessarily synonymous is unhelpful

The potential value of self-assessment is great but the method of implementation is likely to have considerable impact upon the extent to which self-assessment can actively involve users.

## Section 4 Accuracy of self-assessment

## 4.1 Introduction

This chapter considers studies that evaluate the accuracy of selfassessments as one of the criteria against which the usefulness and appropriateness of the approach will be judged. In order to judge accuracy comparison, some external reference standard must be made. For some aspects of self-assessment there can be no external reference. For example it is difficult to determine a criterion by which self-reported preference for an approach to care could be construed as 'inaccurate' even if later experience changed that preference. Thus, of necessity this review can only consider circumstances where a valid external reference standard can be determined. For medical diagnosis or prediction reference standards are generally easy to define in terms of appropriate methods for definitively diagnosing a disorder. Accuracy is judged by correct classification of people in terms of presence or absence of a problem (e.g. a diagnosis) or accurate prediction of risk, verified by event rates.

For other areas there are different criteria against which to judge the performance of an assessment. An example of this is general health screening tools where a number of issues are addressed. The criterion used is generally a full professional interview and problems identified in that are used to judge the self-assessment. A meaningful bottom line still exists since such screening questionnaires are often considered as alternatives for professional screens, designed to target further professional assessment at those most likely to have problems. Where the aim is not to improve on the professional assessment per se but rather to target it effectively or, potentially, substitute for it, errors in professional assessments are not immediately at issue, although the concept of accuracy becomes looser. The aim is to maintain or effectively extend the (presumed) benefits of professional assessment. For other aspects of assessment, for example life skills, the concept of a gold standard remains elusive since it is difficult to set aside a person's subjective assessment of their need because a professional disagrees and thus these assessments are not covered by this section, although for some of the issues identified (such as driving assessments for example), the possibility of external verification of accuracy remains.

## 4.2 Methods

## 4.2.1 Inclusion criteria

In order to ensure the validity of studies for review the following criteria, based on the guidelines given by Greenhalgh (Greenhalgh et al., 2000) and Deeks (2001), were applied to study selection. Studies, or systematic reviews of studies, that compared the result of self-assessment with a 'gold standard' reference test in a consecutive (or random) sample of people recruited from a population on whom the test would be used in practice were considered. Only studies that included a large proportion of older people (50 per cent or more 60 + or mean age 65+) were considered. For questions of diagnosis and screening, the gold standard test must be a full diagnostic assessment and not an alternative screening assessment. The self-assessment and gold standard must be conducted independently on the same individual and blinded, so that each assessment is undertaken and interpreted without knowledge of the results of the other. Inclusion was assessed independently by two reviewers and disagreement resolved by discussion and consultation with a third reviewer where relevant. All studies that met the criteria were included in the review with no restriction on language or date of publication. Quality of included studies was assessed using the same criteria.

## 4.2.2 Data extraction

There are several well-accepted statistics that demonstrate the diagnostic accuracy of an assessment. These are sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV), and the positive and negative likelihood ratios (+LR and – LR).

Likelihood ratios are particularly relevant in clinical practice with the positive likelihood ratio (+LR) corresponding with the concept of 'ruling-in disease' and the negative likelihood ratio (-LR) corresponding with the concept of 'ruling-out disease'. The positive likelihood ratio indicates how much more likely an adverse finding is in a person who actually has the problem than one without. Conversely, the negative likelihood ratio indicates how much less likely a negative result is in a person with the problem than one without. Likelihood ratios can be combined with estimates of population prevalence (or subjective pre-test estimates) in order to estimate the odds that a person has the problem based on their test result.

There are criteria with which to judge the pertinence of the likelihood ratios (Sackett *et al.*, 2000) which have been applied when judging evidence here;

Very positive = 10

Moderately positive = 3

Neutral = 1

Moderately negative = 0.3

Extremely negative = 0.1

Similarly, with high values of sensitivity, a negative result to a test effectively rules out the diagnosis or problem, particularly valuable in screening, although many of those who test positive may not have the problem depending upon the specificity. With extremely high values of specificity, a positive test result effectively rules in (or tends to confirm) the presence of the problem in an individual although a negative result does not necessarily rule it out (depending upon the sensitivity).

Where these values are not reported data from within the paper has been used to calculate these values. A single reviewer conducted data extraction with validation by a second.

## 4.3 Results

135 papers were identified as relevant for the review. Of these one hundred and nine did not meet the review criteria (see appendix table 9.9 for detail on notable excluded studies) and 26 papers were included. The papers included fit into only two of the four broad organisational domains identified in the 'scope' review: focused health and general health. Given the limitations noted above, this is largely unsurprising.

The majority of studies addressed self-assessment of focused health, with 21 papers falling into this category. Six evaluate the diagnostic accuracy of self-assessment of mental health disorders. Five papers address the diagnostic accuracy of self-assessments of nutrition: oral health (Buhlin *et al.*, 2002; Bush *et al.*, 1996a; Jones *et al.*, 2002), weight (Lawlor *et al.*, 2002) and general nutrition (Jackson *et al.*, 1990). Other conditions included are: osteoporosis (n=3: Adler *et al.*, 2003; Goemaere *et al.*, 1999; Lydick *et al.*, 1998), testosterone deficiency (Smith *et al.*, 2000b) and diabetes (Davies *et al.*, 1993), hearing (Lichtenstein *et al.*, 1988; Sever *et al.*, 1989; Yueh *et al.*, 2003b), vision (Davies *et al.*, 1999) and mobility (Jannink-Nijlant *et al.*, 1999a). Details of individual studies are presented in appendix tables 9.2-9.7.

There were a number of self-assessments of other conditions that did not meet the inclusion criteria. There were notable self-

assessments that were excluded (see Appendix table 9.9). For example, in their evaluation of the self-assessment of post-prandial glycosuria, Davies et al (1999) followed up only those participants who tested positive. Little et al (1999) compared two dietary assessments although both were self-assessed, and Ventry et al (1982) in their developmental study of the Hearing Handicap Inventory of the Elderly (HHIE), a frequently used self-assessment tool, administered the tool by interview.

Five papers included in the review were in the domain of general health (Barber *et al.*, 1980; Bowns *et al.*, 1991a; Brody *et al.*, 1997; Kerse *et al.*, 1994; Taine *et al.*, 1990b). Four of these assessments are self-completion case finding questionnaires designed to identify unmet need or a need for further assessment by a professional. There were a number of papers that were reviewed and excluded from this section because of the absence of an adequate standard criterion with which to compare the accuracy of self-assessment (Cousins, 1997; Dowrick, 1993; Linn *et al.*, 1984; Shelton *et al.*, 2000).

It is clear that there is overlap between focussed health assessments (since some of these self-assessments are composites of screening questions across several domains) and comprehensive care (since many enquire about aspects of function). However, these studies are classified as general health as the content of the assessment, or the criterion for accuracy is primarily health related (for example frailty as the outcome), or is an assessment conducted by health professionals. This issue will be discussed further in the next chapter.

## 4.4 Focused health care

## 4.4.1 Depression

Seven self-assessment tools for depression are evaluated in studies included in the review (Table 4.1). The Beck Depression Inventory (BDI), The Self-report Depression Scale (SDS), The Geriatric Depression Scale (GDS) The Centre for Epidemiological Studies Depression Scale (CES-D), SelfCARE(D), The Symptom Check List (SCL-90) and the Hospital Anxiety and Depression Scale (HADS). The sensitivity of these self-assessment tools ranges from 70-100 per cent and specificity from 53-98 per cent.

Positive likelihood ratios (+LR) range from 1.91 to 38.5 and negative likelihood ratios (-LR) from 0.05-0.37. These scores demonstrate a wide range of accuracy of self-assessment tools for depression as evaluated in the studies reviewed. However some tools show a more consistently accuracy than others. The BDI has been shown to have a moderate ability in correctly discriminating between older people with or without depression as demonstrated

by the +LR scores of between 2.37 and 5.67 and -LR scores of between 0.06 and 0.26. Likewise, the HADS scale has shown moderate ability in assessing both major (+LR 5.21, -LR 0.26) and minor (+LR 5.73, -LR 0.12) depression in older people.

Table 4.1 Summary of studies of depression self-assessment tools

Test	Study (cut off score)	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
BDI	Rapp et al., 1988 (10)	SADS	150	83 (77-89)	65 (57-73)	2.37	0.26
	Strik et al., 2001 Major depression(7/8)	SCID-1	199	81.8 (76.4- 87.2)	78.7 (73.0- 84.4)	3.84	0.23
	Strik et al., 2001 Major+ minor depression(7/8)	SCID-1	199	83.8 (78.7- 88.9)	71.7 (65.4- 80.0)	2.96	0.23
	Kongstvedt et al., 1991 Early onset depression cut off 10 cut off 16	SADS	20	95 (85- 100) 85 (69- 100)	85 (69- 100) 95 (85- 100)	6.34 17.0	0.06 0.16
	Kongstvedt et al., 1991 Late onset depression : cut off 10 cut off 16	SADS	20	85 (69- 100) 55 (33-77)	85 (69- 100) 95 (85- 100)	5.67 11.0	0.18 0.47
CES-D	All studies cited in Watson et al., 2003:		Not in report				
	Gerety et al., (1994)	SCID		74(55-86)	70(60-79)	2.47	0.37
	Beekman et al., (1997)	DIS		93(91-95)	73(69-77)	3.44	0.1
	Lewisohn et al., (1997)	RDC, DSM-IIIR		76(73-79)	77(74-80)	3.3	0.31
	Lyness et al., (1997)	SCID		92(87-97)	87(81-93)	7.08	0.09
	Papassotiropoulos et al., (1999)	CIDI		75(70-80)	74(67-81)	2.88	0.34
GDS	Rapp et al., 1988	SADS	150	70 (63-77)	89 (84-94)	6.36	0.34
	Kongstvedt et al.,	SADS	20				

Test	Study (cut off score)	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
	1991						
	Early onset depression						
	cut off 11			95 (85- 100)	95 (85- 100)	19	0.05
	cut off 14			95 (85- 100)	100	-	0.05
	Kongstvedt et al., 1991	SADS	20				
	Late onset depression	SADS	group				
	Late onset depression :						
	cut off 11			80 (62-98)	95 (85- 100)	16	0.21
	cut off 14			60 (39-81)	100	-	0.4
	Data from Watson et al 2003 all use cut off 15						
	D'Ath et al (1994)	GMS/ AGECAT		91(86-96)	72(66-78)	3.25	0.13
	Arthur et al (1999)	ICD-10		100(98- 100)	72(67-77)	3.57	-
	Hoyl et al (1999)	SCID		94(89-99)	82(73-91)	5.22	0.07
	Rait et al (1999)	GMS/AGECAT		92(64-100)	71(63-79)	3.17	0.11
	Abas et al (1998)	GMS/AGECAT		82(62-92)	82(62-92)	4.56	0.22
HADS	Strik et al., 2001 (3/4)	SCID-1	179				
	Major depression			90.0 (85.6- 94.4)	84.3 (79.0- 89.6)	5.73	0.12
	Major+ minor depression			78.1 (72.0- 84.2)	85.0 (79.9- 90.2)	5.21	0.26
SCL-90	Strik et al., 2001 (26/27)	SCID-1	199				
	Major depression			95.5 (92.6- 98.4)	74.0 (67.9- 80.1)	3.67	0.06
	Major+ minor depression			81.1 (75.7- 86.5)	83.5 (78.3- 88.7)	4.9	0.23
SDS	Rapp et al., 1988	SADS	150	83 (77-89)	65 (57-73)	2.37	0.26
SelfCARE(D)	All studies cited in Watson et al., 2003:		Not in report				

Test	Study (cut off score)	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
	Bird et al., 1987	Interview		77(67-87)	98(95- 101)	38.5	.23
	Upadhyaya & Stanley 1997	GMS/ AGECAT		95(90-100)	86(78-94)	6.79	.06
	Banerjee et al., 1998	GMS/ AGECAT		90(86-94)	53(46-60)	1.91	0.19

The GDS shows a moderate accuracy. In one study (Kongstvedt *et al.*, 1991) the GDS has a very high sensitivity (95 per cent) and specificity (95 per cent) for assessing early onset depression in older adults suggesting that a positive test result rules in a diagnosis of depression and a negative test rules out a diagnosis. In the same study the GDS had a high specificity for assessing late onset depression, although sensitivity was not so high (80 per cent), indicating that a positive GDS score is virtually definitive in the diagnosis of depression while a negative result only has moderate predictive ability. However, these findings are based on a sample size of 20 and thus are not strong evidence of the diagnostic accuracy of the GDS.

For adults one month after myocardial infarction (MI) (Strik *et al.*, 2001) the SCL-90 showed a moderate diagnostic ability for major and minor depression, although for major depression sensitivity was 95.5 per cent (-LR 0.061) and thus a negative SCL-90 result can rule out a diagnosis of major depression post MI.

Therefore, while there is a wide range of findings of the diagnostic accuracy of self-assessment scales for depression, the majority show at least a moderate degree of accuracy. Generally, sensitivity is better than specificity, making the tests useful screening instruments as they can rule out the problem in those who test negative. However, there are likely to be large numbers of false positives – the only positive likelihood ratios greater than 10 (extremely positive) emanated from a small study on the GDS and a single study on the SelfCARE(D). However, evidence on this latter instrument was contradictory and results from this one study inconsistent with others.

## 4.4.2 Dementia

Of the two studies (table 4.2) that evaluate the diagnostic accuracy of self-assessment of dementia and cognitive impairment, one tool performs particularly well in diagnosing a variety of dementias. The Dementia Diagnostic Screening Questionnaire (DDSQ) was tested

with 241 older people and gave +LR scores of 18.41 to 85.70 and -LR scores from 0.03 to 0.25. Specificity of the DDSQ for all types of dementia is above 95 per cent suggesting that a positive result is strongly indicative of dementia (Rogers et al., 1988). Negative likelihood ratios are only moderate for most forms of dementia indicating that a negative test cannot rule dementia out.

The Clock Completion Test (CCT) (Ball, 2001), which was designed to assess risk of Alzheimer's disease, has a +LR of 2.16 and a -LR of 0.48 (sensitivity 67 per cent, specificity 69 per cent). However, the authors concluded that the method of delivery i.e. postal survey was ineffective as non-responders were assessed to have a threefold greater prevalence of cognitive impairment. Moreover, the sample size of this study is small so strength of evidence is low. These studies provide weak evidence of the diagnostic accuracy of the tools. Although the DDSQ may be valuable, the impressive performance is based upon a high participation rate that might not be found in a practice setting given the target population.

Table 4.2 Summary of studies of dementia self-assessment tools

Test	Study	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
DDSQ	Rogers et al 1988	DSM-III	241				
		Dementia type:					
		Alzheimers		90.2 (86.4- 94.0)	95.1 (92.4- 97.8)	18.4	0.08
		Multi-infarct		82.4 (77.6- 87.2)	96.0 (93.5- 98.5)	20.6	0.14
		Parkinson's		75.0 (69.5- 80.5)	99.0 (97.7- 100)	75	0.25
		Wernicke-Korsakoff		85.7 (81.3- 90.1)	99.0 (97.4- 100)	85.7	0.14
		Huntington's		100 (-)	97.1 (95.0- 99.2)	34.5	0.03
		Norm pressure hydrocephalus		77.8 (72.5- 83.0)	97.1 (95.0- 99.2)	26.8	0.2
		Posttraumatic		90.0 (86.2-93.8)	98.1 (96.4-99.8)	47.4	0.1
ССТ	Ball et al 2001	NINCDRD criteria	53	67 (54-80)	69 (57-81)	2.16	0.48

### 4.4.3 Nutrition & oral health

Two studies addressed the accuracy of self-assessment of general nutrition (Jackson et al., 1990; Lawlor et al., 2002) (Table 4.3)

Lawlor et al found that self-reported and nurse-measured weight were highly correlated (Pearson's r=0.982) with a mean difference between the weight measurements of +0.97kg. However, the 95 per cent limits of agreement were -4.0kg to +6.0 kg demonstrating considerable potential inaccuracy of self-reported weight. Jackson et al 1990 found modest agreement between a self report questionnaire and a diet history interview, with weighted Kappa coefficients of 0.45 (fibre), 0.40 (fat) and 0.42 (calcium). Thus, there is little evidence of the accuracy of self-assessment of nutrition.

Two papers assessed the accuracy of D-E-N-T-A-L (Table 4.3), a self-administered oral health questionnaire (Bush et al.; Jones et al.). Accuracy of D-E-N-T-A-L among community dwelling older people varied between the two studies: Bush et al 1996 found that it had more than moderate accuracy (+LR 8.2, -LR 0.2), whereas Jones et al 2002 in a much larger study found that it had failed to reach Sackett et al's (2000) criteria for moderate diagnostic accuracy (+LR 1.58 and -LR 0.34 for identifying dental need, +LR 2.11 and -LR 0.45 for identifying severe periodontal need). Overall, the evidence suggests that D-E-N-T-A-L has less than moderate diagnostic accuracy. A third study compared findings from a selfcompleted postal questionnaire on dental health with dental examination (Buhlin et al., 2002). Only 16.2 per cent of older people knew how many teeth they had. Sensitivity of assessment of bleeding gums was 42 per cent, and for the presence of gingival pockets was 55 per cent. No instructions about how to perform a self-examination were sent with the questionnaire. This study provides very little evidence of the accuracy of oral self-assessment.

Table 4.3 Summary of studies of nutrition and dental self-assessment tools

Test	Study	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
Self-assessed weight	Lawlor et al 2002	Nurse- measured weight	1310	Mean difference +0.97kg, 95% limits of agreement – 4.0kg to +6.0 kg	NA	NA	NA
Questionnaire of foods eaten each week	Jackson et al 1990	Diet history interview	80	NA	NA	NA	NA
D-E-N-T-A-L	Bush et al 1996	Dental examination	165	82 (76-88)	90 (85-95)	8.20	0.20
D-E-N-T-A-L	Jones et al 2002	Dental examination:	438				
		Dental need		84 (81-87)	47 (42-52)	1.58	0.38
		Severe periodontal need		80 (76-84)	62 (57-67)	2.11	0.45
Dental questionnaire	Buhlin et al 2002	Dental examination:	148				
		Bleeding gums		42 (34-50)	NA	NA	NA
		Gingival pockets		55 (47-63)			

## 4.4.4 Osteoporosis

Three studies assessed the accuracy of self-assessment of osteoporosis (Table 4.4) The Osteoporosis self-assessment tool (Adler *et al.*) was found to be sensitive for identifying older men with osteoporosis (sensitivity 93 per cent, specificity 66 per cent, +LR 2.7, LR - 0.11), although overall performance only approached moderate accuracy for both positive and negative test results. The questionnaire used by Goemaere et al (1999) showed lower accuracy in identifying postmenopausal osteoporosis. Accuracy of diagnosis when compared to bone mineral density of the hip was: sensitivity 75 per cent and specificity 63 per cent, +LR 2.03 and -LR 0.40, indicating a less than moderate diagnostic accuracy. Lydick *et al* (1998) developed the Simple Calculated Osteoporosis Risk Estimation (SCORE) for use with postmenopausal women. SCORE was also found to be sensitive for identifying osteoporosis (sensitivity 91 per cent, specificity 40 per cent, +LR 1.52, -LR

0.23). Overall evidence supports the use of OST but performance is moderate to weak.

Table 4.4 Summary of studies of osteoporosis self-assessment tools

Study	Test	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
Adler et al., 2003	OST	BMD	181	93 (89-97)	66 (59-73)	2.74	0.11
Goemaere et al., 1999	Osteoporosis questionnaire designed for study	BMD Lumbar Femoral neck Hip	300	62 (57-67) 65 (57-67) 75 (70-80)	62 (57-67) 62 (57-67) 63 (58-68)	1.63 1.71 2.03	0.61 0.56 0.40
Lydick et al., 1998	SCORE	BMD	207	91 (81-96)	40 (30-52)	1.52	0.23

#### 4.4.5 Endocrine disorders

Smith et al (2000b), compared a self-completed questionnaire with a biochemical standard measure (Table 4.5) for testosterone deficiency. The questionnaire was not found to be particularly accurate (sensitivity 75.8 per cent. specificity 49.4 per cent, +LR 1.5, -LR 0.50). In contrast to this, Davies et al (1993) found that self-testing for post-prandial glycosuria at home was reasonably accurate in identifying those who may have diabetes (Table 4.5) but overall performance was moderate to weak (sensitivity 89 per cent, specificity 67 per cent, +LR 2.7, -LR 0.16).

Table 4.5 Summary of studies of endocrinological self-assessment tools

Test	Study	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
Testosterone deficiency questionnaire designed for study	Smith et al 2000	Serum testosterone	304	75.8 (71.0- 80.6)	49.4 (43.8- 55.0)	1.5	0.50
Glucosuria home urine test	Davies 1993	Glucose tolerance test	821	89 (87-91)	67 (64-70)	2.70	0.16

## 4.4.6 Hearing and vision

Three papers assess the diagnostic accuracy of the Hearing Handicap Inventory for the Elderly-Screening (HHIE-S), a self-completed questionnaire to detect perceived social and emotional problems related to hearing loss (Lichtenstein *et al.*, 1988; Sever *et* 

al., 1989; Yueh et al., 2003b). Using a cut-off score of ≤10 the sensitivity of the HHIE-S ranged from 81 per cent to 63 per cent. Specificity ranged from 67-75 per cent. Positive likelihood ratios ranged from 2.52 to 1.8, indicating moderate to weak accuracy (Table 4.6).

Using a HHIE-S cut-off score of 8, sensitivity of the HHIE-S was 0.72 and specificity was 0.77 (+LR 3.13, -LR 0.36), which shows scores moderate accuracy for positive likelihood. If the HHIE-S cut-off score is increased to ≤24, the +LR ranges from 3.5 to 5.37 and the ability to rule out hearing loss increases (specificity 88 per cent), although the ability to accurately identify those with hearing loss deceases (sensitivity 42 per cent). Thus, the HHIE-S at the usual cut-off score does show moderate accuracy compared to pure-tone audiometry. It is worth noting that the main aim of the assessment is to identify the emotional and social problems of hearing loss, which may not correlate well with actual hearing loss.

One study (Table 4.6) assesses the accuracy of a vision self-assessment (Smeeth *et al.*, 2000). This assessment was part of a brief postal screening questionnaire that covers a range of healthcare issues. However, only the vision assessment is included in the review as the other self-assessments were not compared to accepted gold standard reference measures. The sensitivity of the vision questionnaire items was 40.2 per cent and specificity was 94.2 per cent (+LR 6.93, -LR 0.63) indicating that the assessment can usefully identify people with a visual problem, but the test cannot rule out the problem in those with a negative result.

Table 4.6 Summary of studies of hearing and vision self-assessment tools

Test	Study	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
HHIE-S	Studies cited in Yueh et al., 2003:	Pure tone audiometry					
HHIE-S cut off =10	McBride et al., 1994		185	0.63	0.75	2.52	0.49
HHIE-S cut off =10	Mulrow et al., 1990		238	0.75	0.67	2.27	0.37
HHIE-S cut off =26	McBride et al., 1994		185	0.42	0.88	3.5	0.66
HHIE-S cut off score =10	Sever, 1989	Pure tone audiometry	59	81 (71-91)	73 (62-84)	3	0.26
HHIE-S cut off	Lichtenstein,	Pure tone	178	72 (65-79)	77 (71-83)	3.13	0.36
score 8	1988	audiometry – 5 hearing loss		66 (59-73)	79 (73-85)	3.14	0.43
		criteria		53 (46-60)	84 (79-89)	3.31	0.56
				62 (55-69)	72 (65-79)	2.21	0.53
				63 (56-70)	72 (65-79)	2.25	0.51
Visual items on a health issues questionnaire	Smeeth,et al 2000	Distance visual acuity	32990	40.2 (34.8- 46.0)	94.2 (92.8- 95.3)	6.93	0.63

## 4.4.7 Mobility

Only one self-assessment addressed an aspect of functional ability(Jannink-Nijlant *et al.*, 1999a). The Mobility Control Subscale (MC scale) of the short version of the Sickness Impact Profile (SIP68) had a sensitivity of 91 per cent and specificity of 59 per cent (+LR 2.22, -LR 0.15) suggesting that this self-assessment tool was moderate to weakly accurate at ruling out mobility disorders (Table 4.7).

Table 4.7 Summary of studies of a functional mobility self-assessment tool

Study	Test	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
Jannink- Nijlant, 1999	Mobility Control Subscale of the SIP68	Lower extremity function – Guralnik's protocol	81	91 (85-97)	59 (48-70)	2.22	0.15

## 4.4.8 Section summary

There is considerable variation in the diagnostic accuracy of the various self-assessment tools reviewed.

Generally, the more successful tools are in conditions that have been subject to more research to establish diagnostic criteria e.g. mental health and where there is closer overlap between the content of the assessment and the diagnostic criteria (which ultimately rely entirely on self report data).

Several tools have at least moderate accuracy in identifying older people with depression

The evidence generally relates to full scales (usually ten items or more) and not brief screens of 1-3 items.

Self-assessments for depression generally have higher sensitivity than specificity, suggesting that their value may be to rule out depression.

A single study suggests that the DDSQ has very high specificity and may be a valuable screening tool for dementia.

Nutritional self-assessment is not well supported by evidence. Despite impressive correlation in two studies, one of good size and quality, an individual's self-assessment can be substantially incorrect.

Dental self-assessment has shown moderate sensitivity but evidence for specificity varies. Value of the use of the D-E-N-T-A-L instrument for screening is unclear.

Self-assessment for osteoporosis shows variable levels of sensitivity (moderate to good) but consistently modest specificity. Careful selection of an assessment tool with good sensitivity would be required before using it for screening purposes.

Self-assessed hearing impairment using the HHIES shows moderate to poor accuracy, with specificity better than sensitivity. The potential as a screening instrument seems limited.

Visual self-assessment has been shown in a single large study to have high specificity but low sensitivity, making it unsuitable as a screening tool.

A single small study showed that mobility-self-assessment using the SIP items had good sensitivity but poor specificity and as such maybe useful as a first level screening tool where a large number of false positives is acceptable.

## 4.5 General health care

Five studies were identified in the domain of general health (Table 4.8). The self-assessments in four of the studies included in the review are self-completion questionnaires designed to identify unmet need (Bowns *et al.*, 1991a) or a need for further assessment by a professional (Barber *et al.*, 1980; Kerse *et al.*, 1994; Taine *et al.*, 1990b). All were administered by postal survey (see appendix table 9.8). The sensitivity of these comprehensive self-assessments tools is consistently higher than their specificity (78-95 per cent vs. 23-68 per cent respectively).

One tool, the Woodside Questionnaire (Barber *et al.*, 1980) had a particularly high sensitivity (95 per cent, -LR 0.074) and therefore a negative test can effectively rule out the need for further assessment, although it is only moderately accurate in identifying those who do need further assessment which will result in false positives (+LR 2.97). However, a larger study on a modified version (Taine *et al.*, 1990b) showed much poorer performance (+LR1.53, -LR 0.45) raising questions about this widely used instrument. Another similar tool (Kerse *et al.*, 1994) performed even more poorly.. A general health self-assessment developed by Bowns et al (1991) has good sensitivity (87-90 per cent, +LR 2.3 to 1.8, -LR 0.27 to 0.24) demonstrating a moderate ability to identify all those who do have unmet needs but again at the risk of false positives, and so its use for screening in a low risk population would result in unnecessary follow up.

The fifth study in the area of general health evaluated a self-assessment administered via postal survey that was designed to identify the risk of frailty in the coming year (Brody *et al.*, 1997). Although the assessment is detailed and comprehensive it was tested against the criteria of the need for institutional care, a more focussed concept. This tool showed a different accuracy profile compared with the other four comprehensive self-assessments in that sensitivity was low at 50.7 to 54.6 per cent and specificity was very high at 97.8 to 97.9 per cent (+LR 23.05 to 26.0, -LR 0.46 to 0.50). Therefore, the self-assessment can effectively identify older people who are likely to become frail within a year, although a negative test does not rule out the possibility. Those who test positive do will need further assessment and follow up as they are almost certainly at risk.

Table 4.8 Summary of studies of general health self-assessment tools

Study	Test	Comparison	N	Sensitivity % (95% CI)	Specificity % (95% CI)	+LR	-LR
Barber et al 1980	Woodside Questionnaire	Comprehensive Geriatric Assessment	83	95 (90-100)	68 (58-78)	2.97	0.074
Bowns et al 1991	Case finding questionnaire						
	0.90 probability of predicted need	Detailed interview with district nurse/health visitor	1105	83 (81-85)	64 (61-67)	2.31	0.27
	'at risk' response to any item		1105	88 (86-90)	51 (48-54)	1.8	0.24
Taine et al 1990	Modified Barber 1980 questionnaire	Assessment by registered nurse	594	85 (82-88)	23 (20-26)	1.1	0.65
Kerse et al 1994	Questionnaire designed to identity unmet needs of older people	Comprehensive medical assessment	64	78 (68-88)	49 (37-61)	1.53	0.45
Brody et al 1997	HSF	Assessment of					
	4 frailty variables	need of institutional care	5810	50.7 (49.4- 52.0)	97.8 (97.4- 98.2)	23.05	0.5
	13 frailty variables		5810	54.6 (53.3- 55.9)	97.9 (97.5- 98.3)	26	0.46

In the area of general health assessment, some of the self-assessment tools reviewed here have the potential to be useful in identifying older people with the need for further professional assessment, although they are less discriminatory in identifying those who do not. However, given the contrasting results from some similar instruments the picture is unclear as to exactly how useful the approach is.

## 4.6 Social care and life skills

None of the papers included in the review were in the scoping domain of social care and life skills. Two papers were reviewed and

excluded. West et al (2003) addressed vision and driving restriction in older adults. Here the self-assessment of driving restriction was the outcome measure and there was no comparison standard measure. Fletcher et al (1992) used self-assessment to measure occupational self-efficacy, however, there was no occupational utility to the assessment that was purely a research tool (see appendix table 9.9).

## 4.7 Comprehensive care

No examples of assessments of accuracy of comprehensive self-assessment were found. As noted earlier, this may be a product of the focus of this aspect of the review since the criterion of 'accuracy' cannot be applied to some aspects of self report. Two papers were considered but excluded from this section (Saliba *et al.*, 2001; Walters *et al.*, 2000), both on the basis that the assessment questionnaire was administered by interview. A third paper (Maly *et al.*, 1997) was excluded as only subjects assessed as being at risk received a follow-up assessment.

## 4.8 Summary

The majority of self-assessments reviewed were in an area of focussed health assessment. A small number were general health assessments intended for case finding or screening. No evaluations of the accuracy of self-assessments in the domains of comprehensive or life and social skills were found. The majority of the self-assessments were questionnaire based. The exception was a home urine testing kit. Although the self-assessments were all self-completed, typically the assessments were initiated, scored and interpreted by professionals. Furthermore, it was the professionals who prompted any further action.

The accuracy of the self-assessment tools was considerably varied with some assessments performing exceptionally well. Self-assessment tools in mental health generally performed with moderate accuracy. One computer based self-assessment tool (DDSQ) for dementia performed particularly well to identify older people with different types of dementia although evidence from another dementia assessment suggests that response rates might be a considerable issue with those most at risk least likely to respond.

There was little evidence but self-assessment of weight and general nutrition did not show good accuracy. The evidence for the accuracy of D-E-N-T-A-L, an oral health self-assessment is mixed, with one study finding that it had moderate accuracy whereas a larger study found its accuracy to be lower. Self-assessments of osteoporosis were generally found to be moderate to weakly accurate but

sensitivity was better than specificity again raising the issue of numbers of false positives. A self-assessment of testosterone deficiency was not found to be very accurate although in diabetes, another endocrine disorder, self-assessment was moderately accurate using a urine test.

The HHIE-S was found to have moderate diagnostic accuracy of hearing impairment. Although only based on one very large study, the results of a self-assessment of vision was found to highly specific but as sensitivity was poor many people with problems did not test positive. There was only one functional self-assessment tool included in the review and that was found to be moderate to weakly accurate in identifying those with mobility disorders although it was not very specific.

General health self-assessment tools were varied in their ability to identify those with unmet need. Two of the four studies (Barber et al 1980, Bowns et al 1991) showed a good ability to identify all those with unmet needs but were not very specific, which would result in a high false positive rate. Interestingly, one tool behaved differently with very high specificity and a very high likelihood ratio for a positive test. This tool could be used to target services on at risk individuals as the risk among those who test positive is indeed very high. However, it would not be useful at identifying all those with such need and thus represents a poor screening instrument.

Overall surprisingly few studies of the accuracy self-assessments were identified suggesting that self-assessment tool development is not well advanced. Those self-assessments in the review cover several clinical conditions. This review demonstrates that the selfassessment by older people can have moderate to good diagnostic ability in a number of areas. However, there are a very small number of studies and thus drawing broader conclusions about the accuracy of self-assessment per se is not warranted. It is notable that although the predominant proposed use for most of these instruments as self-assessments is for screening many of the assessments showed modest specificity. In particular this is true of all the general health assessments all of which are designed to screen. The implication of this is that many people who do not have problems will receive further assessment thus reducing the value of the screen. Conversely a number of the instruments are specific but not sensitive, which makes a positive test result valuable in confirming a problem in an individual but means that many people with problems will be missed by the screen.

## 4.9 Implications and recommendations for research, practice and policy

### 4.9.1 Research

Although there is evidence for the accuracy of self-assessments, particularly in the field of focussed health, this area is under researched.

Studies are notably lacking on the accuracy of self-assessments of functional status in practice rather than for research purposes.

#### 4.9.2 Practice

There are numerous examples of self-assessment already in existence that either have been or could be used with older people

Practitioners selecting such instruments should pay attention to evidence on the performance of these tools, accuracy should not be assumed.

The performance of tools where there is reasonable evidence for accuracy is generally such that might make them useful for screening or case finding.

The role of such assessments in individualised assessments should be considered closely. An individual self-assessment rarely functions to both rule a problem in or out.

Knowledge of the test performance allows a practitioner to assess the need to conduct further assessment depending on the particular result.

Self-assessments can usefully be used to tailor further assessments to the main issues for an individual.

## **4.9.3 Policy**

Current recommendations for the instruments used in the single assessment process consider validity of instruments.

Further explanation of performance characteristics should accompany guidance for use of self-assessment tools since few assessments are simply 'accurate' but rather perform well for certain purposes.

Policy advocating self-assessment should highlight the need for specific evidence for self-assessment instruments.

# Section 5 Effectiveness of self-assessment methods

## 5.1 Introduction

This section of the review examines evidence for the effectiveness of self-assessment. The previous chapters have demonstrated the diverse range of self-assessment practices and the sparse evidence for the accuracy of such approaches compared to reference standards. However the accuracy of an assessment is not the ultimate test of its value. Accuracy is not a criterion that can meaningfully be applied to some self-assessments and furthermore, accurate assessment may not result in more effective care. Further questions of accuracy become secondary when viewed in the context of evidence of a beneficial impact upon the process of care. The potential benefits of self-assessment cover a wide scope. Selfassessment may lead to improved health outcomes because the technique allows a more appropriate or timely assessment of need than other approaches and thus clients receive more appropriate care. Similarly outcomes across a wide range of social and life domains could be improved by identifying problems and potential solutions. Minimal user involvement is a necessary component of self-assessment but there are clear aspirations for some assessments of much more active involvement in care, as desired outcome in itself and again one that could lead to improved outcomes. Other aspirations noted previously in this review include better communication between client and services, satisfaction and (from a service perspective) more appropriate and efficient use of resources.

## 5.2 Method

The methodological criteria of the Cochrane Collaboration Effective Practice and Organisation of Care Group (Alderson *et al.*, 2003) were used to critically appraise studies. Study designs considered were all controlled trials including random and quasi-random studies, cluster randomised controlled trials and controlled before and after studies in which a process of care involving self-assessment was compared to a process which did not involve it (including where there was an alternative assessment approach or where the comparison was usual organisation of care services). Only studies that included a large proportion of older people (50 per cent or more 60 + or mean age 65+) were considered. Outcomes considered were patient rated measures of well-being (e.g. quality

of life), health status, function, experience/satisfaction, measures of service uptake/ utilisation and costs. Relevant systematic reviews, which presented studies which met these criteria, were also considered.

The prime mode of synthesis is qualitative and narrative since interventions and outcomes are heterogeneous. Where outcomes from studies were reported using continuous measures such as health status, standard effect sizes (d) and confidence intervals have been calculated where possible using Stats Direct V1.92 meta-analysis function. Where necessary estimates have been made for parameters such as standard deviations based on published p values or confidence intervals. Where contact details could be ascertained authors of studies were contacted for clarification and additional data although no additional data was provided.

## 5.3 Results

57 potentially relevant papers were identified of which 20 were rejected on the basis of further scrutiny (abstract) and 37 were retrieved for more detailed consideration. Two independent raters determined eligibility of these 37 studies. Nine were adjudged to be eligible for review. Disagreements were resolved by discussion and a consensus reached. Agreement prior to discussion yielded 97 per cent agreement (kappa .93). A single reviewer conducted data extraction, with validation by a second reviewer.

## 5.4 Focussed health

Although a substantial proportion of material identified for consideration in this passage of the review was categorised as relating to focused health, none met the review criteria (see appendix table 9.10) although a number of studies considered later incorporate assessments related to a multiple specific focused health problems but reported on generic (not disease specific) outcomes. These are reported in the section on general health. The excluded studies are however somewhat informative.

One review was identified (Goldberg, 1999; Goldberg et al., 1997) which addressed evidence for screening and case finding in older adults. This made clear the potential scope of self-assessment as a number of recommendations for screening (albeit often based on relatively weak evidence) relate to areas that have been subjected to self-assessments identified elsewhere in this review. These include diabetes, osteoporosis, faecal occult blood, hearing impairment and visual problems. However no studies of effectiveness using self-assessment tools with older people were identified and not all recommendations were based on evidence of effect.

Of the possible studies of effect considered for this section two did not report data on older people (Beich *et al.*, 2003; Lewis *et al.*, 1996; Meland *et al.*, 1997) or, in the case of a study of self-assessment of faecal occult blood using home testing (Verne *et al.*, 1993) did not report any clinical or client outcomes for a group of older people (although uptake data reflecting acceptability are reported in the next section). A study which examined environmental hazard assessment in the prevention of falls (Stevens *et al.*, 2001) reported only on professionally conducted assessments using a home visit.

One large cluster randomised controlled trial in the UK (Smeeth *et al.*, 2003) reported the effectiveness of visual assessment from the MRC trial of assessment and management of older people. One arm of this trial used a two stage (targeted) screening process, which involved self-assessment by means of self-report postal questionnaire. Although there seemed to be little systematic difference in results of different approaches to administering the screening questionnaire in terms of problem identification (this study is considered as a diagnostic accuracy study in the relevant section of this review) no detail is available on the relative effectiveness of different approaches to screening or targeted screening based on self-assessment alone compared to universal assessment.

Another cluster randomised controlled trial (Eekhof *et al.*, 2000) in the Netherlands used self-assessment screening questions to assess hearing disorders, visual problems, urinary incontinence and mobility problems. However, the mode of administration was not described and it was clear that alternate criteria to self-report responses were available and used to target interventions. For example a hearing disorder was defined as difficulty following a conversation (self-report) or a whispered voice test (not self-assessed).

A systematic review of effectiveness of visual screening (Smeeth *et al.*, 1998b, 2004) concluded that there was no evidence of effect but did not include any studies where self-assessment was used. A systematic review of the effectiveness of screening for depression (Pignone *et al.*, 2003) included only one study on older people but self-assessment was not used in this study. The same was true of a systematic review of screening for alcohol problems (Beich *et al.*, 2003). These reviews concluded that screening for depression was effective only if systems to ensure follow up and treatment were in place (Pignone *et al.*, 2003) and that there was no evidence for the effectiveness of screening for alcohol problems (Beich *et al.*, 2003).

Thus there is no evidence to judge the relative effectiveness of self-assessment as defined for this review but unless self-assessment introduced additional action on behalf of the client it would seem

unlikely to lead to different outcomes, since professional interpretation and action is the norm.

## 5.5 General health and life-skills

There are a number of continua, albeit sparsely populated with examples that intersect here, with boundaries between categories somewhat arbitrary. The categories used for this review groups approaches based on their location on two dimensions: health – social care (with studies here toward the 'health' end) and general – condition specific outcomes (with studies here located toward the general end). We include the separate category of life skills in this section for convenience (as there is only one study) but also due to the link to the drug assessments reviewed here. Although the review team generally showed a high level of agreement about classification it is clear that other classification schemes could be derived and applied.

21 papers were identified for consideration for review in the area of general health of which nine were given detailed consideration as relevant studies of effectiveness (see appendix table 9.11). Some assessments had characteristics that were akin to focused health assessments (above) in that they were concerned with specific issues although not specific disorders. Both were self-assessment programmes relating to self medication (Neafsey *et al.*, 2001; Wasson *et al.*, 1992). They are classified here as general health, because they are not disease specific but do relate to health and healthcare, although one, a computerised interactive package on over the counter medication (Neafsey *et al.*, 2001) might also be classified with 'life skills' assessments. Only one study categorised as 'life-skills' – specifically self-assessment of driving (Kiernan *et al.*, 1999a) – was identified and given detailed consideration (below).

The second example considered under general health was interventions designed to promote 'patient centeredness' of consultations in health care. A single Cochrane systematic review which reported on 17 studies was identified and considered (Lewin et al., 2004a). It concluded that there was strong evidence that such interventions impacted upon the patient centeredness of the consultation although this was generally defined in terms of specific provider behaviours that were targeted for change. There was some evidence of improved patient satisfaction. Few studies reported on health outcome or behaviour of clients and evidence about impact on these dimensions was mixed. Although the scope of the review could encompass self-assessment practices, all the interventions reported focussed on training health care providers (most exclusively so) and so the review as a whole could not inform on

either self-assessment or older people. Individual studies were identified and considered separately.

One study designed to promote patient centeredness contained elements of self-assessment for older people (Kane *et al.*, 1999) but the extent of self-assessment depended upon the success of the intervention in changing provider behaviour, which was unclear. At least one of the studies included elsewhere in this section of the review had a stated intent of improving patient provider interaction (Wasson *et al.*, 1999b) and thus had much in common with interventions to promote patient cantered consultations.

Other interventions considered here encompass a large number of specific assessments (such as over 75 health checks and broad ranging screening programmes) some as part of a broader ranging package of care (for example self-assessment algorithms as part of a 'self-care' programme (Fries et al., 1993b; Fries et al., 1994a; Vickery et al., 1988). On one hand they clearly overlap with the focused health self-assessments and the distinction is primarily made in terms of the broad aims of the programme and the generic rather than focussed measures of impact that are relevant. On the other hand the distinction from comprehensive assessments is generally based on the focus on health in these studies (either resource use, behaviours or patient outcomes) even though in some cases social factors form part of the assessment (Wasson et al., 1999b). For studies to be classified as comprehensive an explicit goal in managing and coordinating care or services across a range of health and social domains was required as was the inclusion of outcomes relating to constructs and services other than health (below).

## 5.5.1 Medication usage

Two studies examined interventions related to medication usage in older people. One aimed at enabling action on behalf of the patient, the other utilised self-assessment data to alert professionals. One study (Neafsey et al., 2001) examined a Personal Education Package (PEP) that aimed to provide knowledge about drug interactions for commonly used over the counter (OTC) medicines. The package was delivered via touch screen notebook computers. Aspects of design layout and content were tailored to the perceived needs and preferences of older people with input from a focus group of older people who evaluated the design formatively. The package included interactive self-assessment knowledge quizzes. By contrast the MEDS (Monitoring in Elderly of Drug Related Symptoms) questionnaire (Wasson et al., 1992) was given to patients to complete prior to a medical consultation. A nurse scored the questionnaire, identifying those considered at risk (i.e. possibly experiencing an adverse drug reaction).

Both interventions were studied by RCTs of modest quality (Table 5.1), In both cases sample sizes were small, in one case (Wasson *et al.*, 1992) because the cluster is used as the unit of analysis with no account taken (apparently) of the number of individuals in each cluster. Allocation concealment is not described in either study. Follow up was acceptable in both cases (80 per cent+) but for the PEP only an immediate follow up was presented.

Table 5.1 Design features of medication use studies

	Design (allocation concealment, blinding, control)?	N (t,c)	Sample	Pre-test Group difference?	Follow up (%)	Outcomes	1 or more reliable / objective outcomes?
(Neafsey et al., 2001)	RCT (concealment of allocation unclear) comparing PEP (?single session but unclear?) with waiting list volunteers	60 (30, 30)	Community dwelling people taking calcium supplements of H2 agonists. Age over 60 (mean age t 68.8, C 73). 88% female Screened for cognitive, functional and visual problems and reading ability.	No	100% (immediate)	Knowledge test Self efficacy Satisfaction (all participants)	Yes – objective test of knowledge reliable instrument (alpha 0.94) to measure self efficacy
(Wasson et al., 1992)	Cluster RCT(concealment of allocation unclear) in primary care practices (matched for speciality and size) comparing usual care with providing feedback from the MEDS (monitoring in Elderly of Drug Related Symptoms) questionnaire during the	29 cluster (15,14) 477 People 564)	Primary care physician (group / solo practice) patients over 65 receiving one or more medications from a list of eligible common drugs. 52%>75, 68% F	More T patients took digoxin and had degenerative arthritis	83% (1 year)	Self reported MEDS score. Change in medication use Audit of possible drug interactions	MEDS is reliable (test retest r=0.88) change in medication use was patient self report (reliability / validity not assessed)

concultation			
I consultation			

The use of the PEP resulted in increased self-efficacy for avoiding drug/alcohol interactions and increased knowledge (p=0.01, Table 5.2). No comparative data was presented on satisfaction, user opinion or behaviour change. Satisfaction was reported to be high (mean agreement 4.46 out of 5) and although only 25 per cent of respondents identified 'easy to use' as a 'like' few dislikes were identified. Users reported intention to change behaviour (mean agreement 4.2 out of 5) but in the absence of follow up the significance of this is questionable.

Table 5.2 Main results from Neafsey et al., 2001

Outcome	PEP		Control		P*	Effect size (d) (95% CI)**
	Mean	SD	Mean	SD		
Self efficacy	3.14	.9	1.76	.99	<0.001	1.44 (0.87-2.01)
Knowledge	71.7	19.1	36.2	16.5	<0.001	1.96 (1.35-2.58)

<sup>\*</sup> As reported in paper unless indicated

The use of MEDS questionnaire over one year was associated with a decrease in severe symptoms over one year compared to an 8 per cent increase for controls but this was not significant (standardised effect d, 0.18, 95 per cent CI .91 to 0.55 (calculated using Stats Direct) reported Wilcoxon p value 0.064). There appeared to be a trend to increasing benefit associated with higher medication use. The difference was reported as significant when patients taking two or more medications were considered (19 per cent difference between groups, p=0.031) and the apparent benefit increased as groups with higher medication use were considered, increasing to a 40 per cent difference between groups for those taking five or more medications (p=0.015). However there was no difference in overall medication use, with both groups showing an increase in number of medications (0.6 in the meds group, 0.3 control) but no significant difference (standardised effect d, -0.19, 95 per cent CI .92 to 0.54 (calculated using Stats Direct) reported Wilcoxon p value 0.25) and there was no difference in the number of potentially major drug interactions noted (12 in each group).

<sup>\*\*</sup> Calculated using Stats Direct

### 5.5.2 Life skills

This category is broad and encompasses most assessments where the potential outcome is not directly health related, whether narrow or broad in focus. Previous sections of the review have described specific but diverse practices assessing housing needs (Russell, 2000)and potential leisure activities for those with functional impairment (Kautzmann, 1984). However, assessment of the effect (indeed any evaluation) of these approaches is sparse. A single study examining the effect of a self-assessment driving diary was identified for consideration in this section (Kiernan *et al.*, 1999b).

The study was a single group before and after trial comparing self reported driving behaviour at the beginning and end of a period of 30 days completing the diaries (checklist of adverse incidents). 47 older people (mean age 71.3, 57 per cent female) took part. The number of subjects reporting dangerous driving events declined from 36 per cent to 6 per cent (p<0.05). While it is unlikely that this decline can be attributable to events other than the diary (even if it is a product of a generic mechanism for drawing attention to behaviour) the absence of a control group and any objective measure of performance renders conclusions about changes in actual driving behaviour impossible.

There is no evidence regarding the impact of most life skills assessments. For the specific area of driving ability it is possible to conclude that completion of a driving diary for a period of 30 days leads to a decline in self-report of adverse driving events but there is no evidence for impact on actual behaviours.

#### 5.5.3 'Health checks'

In the UK an offer of home based annual assessment for people aged 75 or over became a contracted part of the service offered by general practitioners in 1990. Since it is mandated by contract, controlled trials of delivering that specific service by selfassessment (compared to no assessment) are not possible in the UK although older studies on similar interventions exist and non-UK based studies are possible. However studies have examined the use of self-assessment to target more detailed screening (compared to universal screening), for example the MRC trial of the assessment and management of older people in the community (which was considered in relation to vision screening above, but from which full data is not available at time of writing), and comparisons between face to face and postal (self-completion) methods. However, despite the widespread interest and use of postal screening only three eligible studies were identified which allowed for the independent assessment of the contribution of selfassessment (see Table 5.3).

Table 5.3 Design features of health check studies

	Design (allocation concealment, blinding, control)?	N (t,c)	Sample	Pre-test Group differences?	Follow up (%)	Outcome(s)	1 or more reliable / objective outcomes?
(Johansen, 1994)	RCT (concealment unclear) of geriatric screening – postal questionnaire vs. clinic-based consultation	198 (99,99)	Aged 70 or over, community dwelling. No other detail given.	Unclear	100% (intention to treat)	Costs Resource use	Yes
(Pathy et al., 1992b)	RCT (concealment unclear) of postal screening questionnaire to target health visiting interventions vs. usual health visitor care	725 (369,356)	Community dwelling mean age 73.4, 60% female	No	100% (use of hospital services), 73% of living pts completed health status questionnaires at ?3 year?*	Mortality, Institution- alisation Health status Resource use	Utilisation data collected blind. Self report health status used reliable valid methods
(Smeeth et al., 2001b)	Cluster RCT (Practices), concealed allocation, comparing three methods of screening postal (self- assessment) vs. lay interview (C1) vs. nurse interview (C2)	106 practices (36 T, 35 (C1), 35 (C2) 42278 individuals (15407,13229, 13642)	Mean age 78, 64% female community dwelling	No	100% (outcome response)	Response	Yes

<sup>\*</sup> Trial ran for three years exact period of follow up is unclear

Two studies (Johansen, 1994; Smeeth *et al.*, 2001b) compared self completion postal questionnaires with invitation to a consultation. A third (Pathy *et al.*, 1992b) examined the use of a postal screening questionnaire covering general health and a range of functional and specific health topics to target health visitor interventions. Although important study features could not be determined for two studies (Johansen, 1994; Pathy *et al.*, 1992b) both appeared to be of reasonable quality although one (Johansen, 1994) was small and of limited scope. The third study (Smeeth *et al.*, 2001b) was very large and of high quality but the only outcome available was response rates (Table 5.3).

Two studies reported response rates to different methods of screening. For one small study (Johansen, 1994) postal questionnaires yielded a higher response rate (9.1 per cent) but this was not significant (p=.198, 95 per cent CI 22.9 to -4.8) and overall response rate in the rural community was low (53 per cent). The MRC study (Smeeth et al., 2001b) also showed a higher response rate to postal screening than to an invitation to face to face screening in the context of a higher overall response rate of 78 per cent. Postal screening yielded a response rate 8.5 per cent higher than the face-to-face methods (p<0.001 95 per cent CI 12.7 to 4.4). A higher rate of incomplete answers for postal screening (3.2 per cent, 95 per cent CI 2.7 per cent to 3.6 per cent) did not undermine this advantage. Costs of administering screening through postal versus face to face measures were assessed by one study (Johansen, 1994). Direct costs to providers of postal screening were assessed as being approximately equal to that of face to face screening (7368 Vs 7408 Norwegian Kroner) although detail of resource use was not given.

A single study (Pathy *et al.*, 1992b) compared the effects of a self-assessment based health check programme with no screening. Results generally favoured the health check group (Table 5.4) with statistically significant benefits in terms of self rated health, days in hospital (for the 65-74 age group only) and mortality. Difference in Health status (measured by the Nottingham Health profile) was reported as not significant (no data given) (Table 5.4). There was no overall increase in contact with the GP although there was a clear trend across all resource use measures (GP contact, home help, meals on wheels, chiropody) to increased use in the intervention group.

Table 5.4 Main results for health check vs. no health check (Pathy et al., 1992b)

Outcome	Screening			Control			p (reported)	Effect size (d) (95% CI)	
Interval	N	Mean	SD	N	Mean	SD			
Health status (NHP)	223	NA	NA	196	NA	NA	>0.05	NA	
Self rated health	223	6.9	2.7	196	6.4	2.9	p<0.05*	0.18 (.37 to01)	
Mean days in hospital (65-74)	115	10.5	23.3**	117	15.1	23.3	P<0.01	0.20 (.45 to06)	
Mean days in hospital (75+)	147	14.1	31.1***	15.1	14.2	31.1	p>0.05	0.00 (.53 to53)	
GP consultations	273	20.7	NA	252	20.4	NA	p>0.05	NA	
Binary	N	n	%	N	n	%	р		
Mortality	369	67	18%	356	86	24%	0.05	OR 0.7 (0.49 to 1)	
Institutional care	369	20	5.4%	356	28	7.9%	0.19****	OR 0.7 (0.37 to 1.22)	

<sup>\*</sup> Reported as significant in paper but t-test from published values gives p=0.07 but published figures only given to 1 dp and the result is sensitive to rounding

### 5.5.4 Self care books

Nine studies were identified that examined so-called 'self care' programmes that centred around the use of a self care book (most commonly one of the 'Take Care of Yourself' series (Fries, 2001)). These books contain general health advice and specific self-assessment algorithms that are intended to guide users to self-care strategies or appropriate access to professional health advice. The algorithms are similar to those used in the UK for a number of NHS direct related services such as the NHS direct Healthcare Guide which is available as a book and web site (Banks, 2000). Some programmes additionally incorporate supportive services such as the availability of telephone advice and tailored feedback based on self-assessment of health / lifestyle risks.

<sup>\*\*</sup> Estimated from 95% CI in paper

<sup>\*\*\*</sup> Estimated from 95% CI in paper

<sup>\*\*\*\*</sup>Calculated from data

Table 5.5 Design features of self care studies

	Design (allocation concealment, blinding, control)?	N (t,c)	Sample	Pre-test Group differences?	Follow up (%)	Outcome(s)	1 or more reliable / objective outcomes?
(Fries et al., 1993b)	Cluster ('health clubs) randomized controlled trial (blinding not described) comparing no intervention to questionnaire only for year 1 (t1) and book+ questionnaire and feedback (t 2)	Clubs 11(t1)*, 11(t2),11(c)  Individuals 1887 1892 1907**	Retired personnel from one US employer mean age 68.6 (t1, t2) 52% F.(over 75% aged 65+)	No	Intention to treat (claims data) 82% (2 years) Self report data (t1, t2) 47% (1 year) 38% to 2 years. Participants self report 84% 1 year, 69% 2 year	Health habits Resource use	Self reported health risk had modest evidence for reliability (r=.79). Claims data used to validate self reported costs
(Fries et al., 1994a)	RCT with randomly selected controls followed up on claims data with others sent programme materials	Retirees 11853, 921 Seniors 26641, 921	Members of the Public Employees Retirement System + others administered by Blue Shield in one US state. Retirees mean age 63.6, seniors mean age 73.5	Unclear	Intention to treat (claims data) 88%, self-report data 22%. Participants self report 81%.***	Health habits Resource use	Self reported health risk had modest evidence for reliability (r=.79). Claims data used to validate self reported costs
(Vickery et al., 1988)	Randomised controlled trial on households (n=1009) comparing those invited to receive intervention with a no intervention	households 560, 449	Medicare eligible therefore 60+	Yes	64.8% (utilization) 42% (self- report)	Resource use	Utilisation data was obtained from records.

group

- \*T1 forms control group for 1 year follow up study on self-report. Population impact / RCT only assessed on claims data. I year self report Control comes from those enrolling on programme probably valid comparison
- \*\* All members of the groups. Separate figures not available for numbers of members over 65
- \*\*\*Population impact / RCT only assessed on claims data. I year self report Control comes from those enrolling on programme – probably valid comparison

Three studies met the criteria for consideration for this review. All three used the self care book 'Take care of yourself' (Vickery et al., 1981) and two (Fries et al., 1993a; Fries et al., 1994b in Leigh et al 1992 and Fries et al 1993a) additionally used texts specifically adapted to the needs of older people (Fries, 1991). In two studies (Fries et al., 1993a; Fries et al., 1994b) users received automatically generated feedback tailored on their responses to health habit questionnaires. In the other, users completed a self-scored risk appraisal related to lifestyle factors (Vickery et al., 1988). The major outcomes considered were use of healthcare resources and change in lifestyle factors.

Although large, the quality of these studies was poor (Table 5.1), primarily due to the fact that in all three randomisation occurred prior to recruitment into the study, thus for self report data the benefits of randomisation was lost, since active participants / responders formed a small proportion of the target population. However, for 2/3 studies (Fries et al., 1993a; Fries et al., 1994b) claims data was available for a high (80 per cent+) proportion of the eligible population allowing the impact on the population to be studied on an intention to treat basis. In two studies (Fries et al., 1993a; Fries et al., 1994b) a potentially suitable control group for self-report data was obtained through use of responders from a randomly allocated second wave of recruitment to the programme. Although members of these two groups are not truly randomly allocated, since those who choose to respond to the invitation are such a small proportion of those invited to participate (47 per cent in one study, 22 per cent in another) the selection process is similar for both groups. However it is unclear if there was a difference between these groups at pre-test in one of these studies (Fries et al., 1994a). Self-report data was obtained from 42 per cent of participants in the third study (Vickery et al., 1988) but responders in the control group were not commencing participation in the full programme and some significant differences from participants were identified.

Self reported health / lifestyle behaviours were reported in two studies (Fries et al., 1993a; Fries et al., 1994b). For one of these

(Fries et al., 1994a), statistical analysis was provided based on changes for those enrolled in the programme only. As there was no control for this comparison it is not included here. Thus the only available comparison is a static group comparison. Although all studies used self reported resource use these are not reported here due to the availability of claims data which is based on randomised comparisons within the population studied with good follow up for 2/3 studies (Fries et al 1993a, 1994b).

Table 5.6 Main results for self care studies

Outcome	Self care						р	Effect size (d) (95% CI)
	n	Mean	SD	n	Mean	SD		
General Health								
(Fries et al., 1993b)*	919	.2	1.01**	867	3	1.01	0.008	2.77 (2.90 to 2.64)
Health Habits								
(Fries et al., 1993b)***	919	8	.76+	867	1.4	.76	0.001	2.89 (3.02-2.76)
(Fries et al., 1994a) Retirees ++	1940	16.5	N/A	199	18.7	N/A	N/A	N/A
(Fries et al., 1994a) Seniors +++	6524	15.6	N/A	247	16.4	N/A	N/A	N/A
Resource use (claims)								
(Fries et al., 1993b)#	1606	- \$102	\$3166	3106	\$45	\$2341	0.1	0.05 (0.11—0.00) (\$-307 to \$13)##
(Fries et al., 1994a) Retirees	8316	\$293	\$7934	768	\$1034	\$18743	0.04	0.08 (.15 to 0.01) (-\$1432 to - \$50)###
(Fries et al., 1994a) Seniors	25416	\$107	\$1275	879	\$61	\$1097	0.29>	-0.03 (0.03 to 0.1) (-\$39 to \$131) >>
Resources use (change in visits)								
(Vickery et al., 1988)	363	.404	4.61	291	1.112	5.22	0.07	0.144 (0.3 to 0.001)

<sup>\*</sup> Difference from baseline - negative = improvement

<sup>\*\*</sup> Estimated from 95% CI in paper

<sup>\*\*\*</sup> Difference from baseline – negative = improvement

<sup>+</sup> Estimated from 95% CI in paper

<sup>++</sup> Lower score = lower health risk +++ Lower score = lower health risk

<sup>#</sup> I year claims data change: T1 vs (T2 + C)

<sup>##</sup> Assumes equal variances – assuming unequal variances leads to wider CI

<sup>###</sup> Assumes equal variances – assuming unequal variances leads to wider CI which is not significant

Calculated from data in paper >>Assumes equal variances – assuming unequal variances leads to wider CI

Generally results are favourable to the self-care programmes but there are few significant differences (Table 5.6). Although one study (Fries et al., 1993b) shows a significant improvement and large effect sizes for both health habits (=0.001) and general health (p=0.008) the response rate for these variables was less than 50 per cent. The pattern of results in a second study (Fries et al., 1994a) is favourable but between group comparisons can only be made between active participants in the programme and responders to a post test only questionnaire from the randomly selected controls. Overall response was less than 25 per cent and comparisons not corrected for pre test differences.

Utilisation data from three studies was available on an intention to treat basis. Data was reported separately for two groups (retirees and seniors) for one of the trials, giving four sets of comparisons in total. In one study (Fries et al., 1993b) resource use (claims) reduced for the self care groups and increased for controls but the difference was not significant (p=0.1). In the remaining studies both groups increased resource use over the course of the study. In two groups (Fries et al., 1994a; Vickery et al., 1988) the increase was lower for the self care group than for controls while for a third (Fries et al., 1994a) a small difference favoured controls. Although one study reported a significant benefit for the self care-group, (Fries et al., 1994a) the analysis appears to have inappropriately assumed equal variances between groups. If this assumption is not made the contrast is not significant (p=.28). Effect size metaanalysis was not statistically significant (random effects P = 0.1626). Pooled effect size and confidence interval are not reported as this analysis is intended to confirm the qualitative judgement of the lack of evidence.

#### 5.5.5 Dartmouth COOP clinical improvement system

A final group of interventions identified here relate to delivery of aspects of the Dartmouth Primary Care Cooperative Information Project (COOP) clinical improvement system to defined populations. Two studies were identified for consideration of which one is included. The approach differs from the self care programmes identified above in that users are invited to complete selfassessments across a range of domains (function, emotional status, pain, daily activities and social support) plus a number of focussed questions on general health, common health problems (e.g. incontinence) medications (using items from MEDS described earlier) and preventative care (e.g. influenza vaccine). Tailored feedback in terms of health information is triggered by responses. Feedback may also be given to care providers although in some implementations such feedback is optional (Wasson et al., 2001). This also sets this approach apart from the over 75 health checks with which it also has much in common. Although it was not for the

included study the approach is notable as it is available and has been evaluated (although not for older people) as part of a programme delivered via the World Wide Web (<a href="http://www.howsyourhealth.com">http://www.howsyourhealth.com</a>) which is significant considering a burgeoning number of self-assessments available on the web.

The single study selected for review (Wasson et al., 1999b) is a cluster randomised controlled trial (allocation concealment unclear) comparing 11 intervention primary care practices with 11 control (usual care). The quality is higher than for studies of self-care but is still modest. Further, it does not include a population-based intention to treat analysis using routinely collected data for all those in the relevant population. 3051 patients over 70 consented to participate. Mean age was 78 years with 65 per cent female. It is implicit (but unclear) that consent and baseline data collection was conducted prior to randomisation. Patients in intervention practices were sent tailored heath information and feedback including reference to specific sections of a self-help health manual. Their survey results were summarised and passed to physicians. Although overall follow up is low (54 per cent) attrition is accounted for over the 15 month follow up and is equal and for similar reasons in each group. If patients admitted to nursing homes or died are removed from the sample (this can be assumed to be non treatment related attrition) follow up is 65 per cent. However the intervention group was a mean of two years younger than controls p<0.001) had 4 per cent more women (p=0.02) and had a higher educational level (p=0.02).

Over the course of the study patient rated quality of healthcare provision improved relative to the mean for 8/11 intervention practices, but only 1/11 control (p=0.003). Patient assessment of care was significantly better for the intervention group (p<0.05 exact p not reported, data in chart only) for 6/22 areas included in the self-assessment and the more favourable assessment was in favour of the intervention for 18/22 areas (p<0.01 by sign test). No significant differences in health status were reported although functional limitations showed a near significant (p=0.06) improvement (data not available in paper to estimate confidence intervals or p values of other differences). Recall of feedback (93 per cent) and use of patient education materials (74 per cent) was high but only 23 per cent of intervention patients recalled providers discussing the results of assessments with them.

## 5.6 Comprehensive assessment

Three studies were identified for consideration as comprehensive self-assessments but none were included (see appendix table 9.12 for detail). Thus no evidence is available to determine the effectiveness of self-assessment within a comprehensive

assessment approach such as the single assessment process. However many of the approaches discussed earlier could be components of a single assessment process and the COOP charts utilised in one study above (Wasson *et al.*, 1999b) could form a substantial component of such an assessment which has been administered using face to face, postal and internet based methods, although comparative data are not available and only postal self-assessment has been considered here.

#### 5.7 Conclusions

Despite widespread use of self report data in screening/case finding and authoritative recommendations for screening in a number of conditions where self-assessment approaches have been used there is no evidence from which to determine the effect of self-assessment based screening programmes either relative to no screening or other approaches to screening. However, where accurate self-assessment methods exist evidence of effectiveness may generalise from other methods provided that adequate follow up and effective treatment is available (for example in the case of depression).

Self-assessment to reduce adverse drug reactions or interactions has been investigated using feedback to users/clients and to providers. Although in both cases the results of the studies were positive there was no evidence of actual behaviour change when clients received feedback. Evidence for providing feedback to care providers was limited by primary study quality and lack of clear evidence that provider behaviour changed. Given the significance of this issue for older people more research is warranted. There was no evidence of effect for any life skills assessments although self-report of adverse driving events reduced while using a self-assessment diary in one small study.

Although the evidence for the benefits of self-assessment based health checks is limited to a single study, the results here are consistent with reviews on health checks using mechanisms other than self-assessment (Byles, 2000). Evidence from studies comparing different approaches to screening is limited but suggest that response rates to postal self-assessments is higher than for invitation to face to face assessment and that this benefit is not undermined by missing data. A notable feature of the one study was that all non-responders to the postal questionnaire were identified as at risk as if they had self-reported adverse findings and assessed face to face. This may maximise the ensuing benefits and represent an efficient strategy.

Despite the larger body of research with good sample sizes examining self-care programmes, evidence of benefit in terms of health behaviours is limited by study weaknesses. Evidence for impact on resource use/cost is variable but generally positive. More

evidence is required. Evidence from a single study of moderate quality suggests that self-assessment and tailored advice to both the older person and their provider improves perceived helpfulness of care but there is no evidence of benefit in terms of health status. Although a stated goal was improved patient provider interaction the success in this regard was limited.

No evidence was found that related to comprehensive assessments although the evidence from more narrowly focused assessments may apply to similar assessments as components of the comprehensive assessment. However response rates may be dramatically affected by the format and length of assessments and so benefits and acceptability should not be assumed if an entire assessment is presented in a self-assessment format. However the Dartmouth COOP system appears to be a promising basis upon which comprehensive assessments could be developed.

# 5.8 Implications and recommendations for research, practice and policy

#### 5.8.1 Research

More evidence is required to establish the benefits of selfassessment based screening and case finding.

It seems likely that evidence may generalise from other approaches to screening and case finding where there is an accurate assessment method and adequate treatment and follow up is available

Where self-assessment is intended to impact upon health behaviour more evidence is required to determine actual behaviour change

Self-care approaches seem promising but again further research is required

#### 5.8.2 Practice

Benefit from self-assessment in terms of health can only be achieved by follow up of the assessment findings

There is some evidence that the use of self-assessment approaches can improve the quality of interaction between client and professionals

Approaches such as those based on the Dartmouth COOP system, which provide feedback to both client and practitioner seem most beneficial

It is likely that benefits will be maximised if the information is used *explicitly* during face to face consultations

Where assessments are targeted at those over 75 a strategy that regards non-response as an adverse assessment finding may maximise benefit.

#### **5.8.3 Policy**

Much of the strongest evidence stems form the US health care where the relationship between patient and provider is mediated by a specific financial relationship

The culture of health care in the UK may differ and approaches should be adopted with caution

Self-care does not necessarily lessen demand for health care

# Section 6 The experience of self-assessment

The two previous chapters have addressed measurable criteria of accuracy and effect. The evidence base identified was sparse. There are aspects of the self-assessment that simply cannot be assessed in terms of the measurable attributes considered here. It is important to know how older people experience self-assessment for a number of reasons. It is unlikely that self-assessment will engender user involvement if it is not seen as desirable and is perceived as an imposition by the older person. Unless selfassessment is acceptable it will be difficult to collect valid information using this method. Older people may, for example, choose not to complete forms or will give them to someone else to fill in. If people do not participate the potential benefits highlighted in terms of health status cannot be realised. From the point of view of service providers, unless it is accepted by professionals the selfassessments of older people may impede rather than engender partnership. This section of the report presents the literature that describes older peoples' and professionals' experience of selfassessment.

The evidence is drawn from four areas of literature;

- satisfaction with services/care
- acceptability of self-assessment
- professional's views of self-assessment and
- older people's expressed views of self-assessment.

Few papers included direct references to older people's experience or views of self-assessment, therefore, occasionally, inferences have been drawn from other sources of evidence.

#### 6.1 Methods

#### 6.1.1 Inclusion criteria

No a priori methodological criteria were applied to study selection at the initial stage. All papers that discussed or reported aspects of experience were considered. Papers were judged for strength of evidence using a grading system based upon the critical appraisal guidelines given by Greenhalgh and Donald (Greenhalgh et al., 2000) and the grading system used by the Joanna Briggs Institute (JBI) for qualitative evidence (Joanna Briggs Institute, no date). The specific assessment criteria applied are shown in Table 6.1.

#### Table 6.1 Assessment and grading of evidence of experience

Is the evidence from a research study on experience? Yes / No / Can't tell?

No / Can't tell Grade Unsupported

If supported by client quote grade Unsupported +

If not grade Unsupported -

Was the method of sampling appropriate? Yes / No / Can't Tell

Was the sample size adequate (power / saturation) Yes / No / Can't Tell?

Was the data collected appropriate to the question of experience? Yes / No / Can't tell?

Are the conclusions about experience convincingly based on the findings? Yes /  $\mbox{No}$ 

If Yes to all grade Credible +

If Yes to 5 AND some of 2-4 grade Credible

If yes to 5 only grade Credible -

If No grade unsupported +

If several studies support a finding with credible evidence grade unequivocal overall

Evidence graded as 'unsupported' is essentially opinion that is not supported by appropriate research (even where the opinion may be offered in a research paper but not based on relevant data on experience). Unsupported opinion is classified as U(-) or U(+) where that opinion appears to come directly from clients (essentially if direct quotation is offered). Evidence graded 'credible' is derived from a formal study of experience and is additionally classified as C– where the research is weak or C+ where it is strong. Finally the JBI grading of unequivocal is applied where it is supported by several credible studies.

A specific criterion was applied with regard to the classification of inferences about experience made based on response rates. Since there was no direct study of experience these were classified as U(-). There are obvious limitations in using response rate as an indication of the acceptability of self-assessment. An extensive review of best practice in the use of questionnaires in surveys of health service patients and staff identify numerous factors that affect response rate. These include pre-notification contacts, the nature of the covering letter, saliency of the survey to the potential respondent and fundamentally the ability of the person to complete the questionnaire (McColl et al., 2001).

Furthermore, response rate may reflect the professionals' view of acceptability that if someone completes an assessment or questionnaire it must be acceptable to them. However, the users' view of acceptability may be different. They may complete a questionnaire that is not acceptable to them simply because their doctor has asked them to. Conversely, they may not complete a

questionnaire they consider acceptable because they do not get around to it or forget or (as noted previously), they have made a self-assessment that it is not relevant to them. Overall the pattern of non-response is related to the degree of involvement required and the precise risk factors targeted The existence of a variety of sub-groups of non-responders, including those who perceive themselves too well to benefit and those who consider themselves to ill has already been hypothesised (Minder et al., 2002). Therefore, response to a specific self-assessment has no simple relationship to acceptability and can indicate different things in different individuals and in different circumstances. However, in the absence of other data to assess the experience or acceptability of self-assessment, response rate does give some indication, although weak and difficult to interpret.

Literature will be presented for the four fields identified for the review: focussed health care; general health care; social care and life skills; and comprehensive care. Findings are presented using the typology developed to describe the scope of self-assessment under the broad headings of process and content to reflect upon different aspects of experience.

### 6.1.2 Findings

A total of 53 studies were identified that included reference to an element of older people's experience of self-assessment. Of the 54 papers assessed, 37 were found to include claims relating to the experience of self-assessment that were unsupported by relevant data (U-). The most common reason for a paper to be graded as unsupported was where claims for acceptability of the self-assessment were based solely on response rate (n=26). Other reasons for papers being graded as unsupported included: acceptability inferred from reported usage of self-help guides (n=3); negative experience inferred from under-reporting of sensitive issues e.g. alcohol intake (n=5); authors claim of acceptability with no supporting evidence (n=3); experience inferred from nature of the topic of the self-assessment (n=2). See appendix tables 9.13-9.28.

Seventeen papers were graded at levels above U+ or above. These are used as the prime sources for the review. A brief summary of the remaining 37 unsupported papers will also be presented in the relevant sections in order to include any potentially important contribution that may help to inform an understanding of older people's experience of self-assessment.

#### 6.2 Focussed health care

Much of the research in focussed health involving self-assessment is carried out as part of a clinical examination e.g. in the field of

hearing loss, rheumatoid arthritis, oral health and mental health, with very little attention being paid to the user's experience of the self-assessment. Although 21 papers were identified which mentioned acceptability or the experience of self-assessment, just eight of these were graded as having some supporting evidence (see appendix tables 9.13 to 9.14).

Nine studies which make inferences concerning acceptability based upon questionnaire response rate only U(-). See appendix tables 9.15-9.16. In one of these examples, the fact that the questionnaire was initiated by a known professional appears to have enhanced the response rate further (Yohannes et al., 2002). Although the authors claim that a high response rate reflects a high degree of acceptability, as has been discussed above, this is not necessarily the case. Although response rates can be high six studies reported response rates of below 50 per cent, suggesting that despite the endorsement of a professional, self-assessment may not always be completed and returned by older people, with the inference that it may not have been acceptable to them.

Two studies describe high initial response rates to self-assessment questionnaires, with much lower response rates for uptake of follow-up (Cameron et al., 1997; Schow et al., 1990b). In both cases the first questionnaire was completed while in the waiting/reception area of a health clinic. The contrast between the initial response rate and the follow-up rate underlines the persuasive effect of asking someone to complete a self-assessment while waiting in a professional's office/clinic. High response rates in this situation cannot be said to reflect a high level of acceptability. A third example included a short mailed self-assessment questionnaire about potential symptoms of bowel cancer (Farrands et al., 1984). The response rate for the initial questionnaire was just 34 per cent. The recipients were also required to test two stool specimens for occult blood and return the results of these tests with the questionnaire. It is far more likely that the low response rate reflects people's disinclination to perform self-testing on stool samples rather than a reluctance to complete the questionnaire. This finding which is in accord with the views of diabetic patients on urine monitoring (Lawton et al., 2004).

There is some suggestion from research findings that self-assessment may be more acceptable than interviewer-administered questionnaires where sensitive issues are being investigated e.g. body weight (Lawlor et al., 2002) alcohol consumption (Rhodes et al., 1995; Wilcox et al., 2000). For example, when information concerning alcohol consumption is sought, self-assessment questionnaires tend to yield a higher, (and presumably more accurate), assessment of intake (Rhodes et al., 1995). It can be inferred that respondents find self-assessment less threatening or embarrassing and are, therefore, more inclined to be truthful.

However, by contrast, screening for memory loss may be unacceptable to a large proportion of a population of older people (Boustani et al., 2003). In a mailed survey of older people's views of screening and assessment, half the respondents reported that they would not be willing to participate in annual screening for memory loss. The authors concluded that this high proportion of decliners suggested this group of older people perceived a degree of harm in participating in this form of assessment.

#### 6.2.1 Process

None of the self-assessments identified in the field of focussed health were user-initiated. It might be assumed that self-assessment initiated by a professional would be perceived as having a high degree of credibility and would, therefore, be acceptable to older people. The low response rates reported by some studies in this area suggest this may not be so, although, as discussed previously, it is not possible to draw any firm conclusions based upon response rates alone.

A self-assessment programme designed to improve nutritional awareness and nutritional intake reported a good uptake and response rate to the initial self-assessments, and was evaluated positively (U+) by a sub-sample of respondents (Lach et al., 1994). This was the only example reviewed of focussed health assessments initiated by non-professionals and partially distributed in a commercial setting. It is not possible to know how these aspects of the assessment impacted upon the experience of the selfassessment as it was distributed as part of a package that included an information booklet, menus, meal planners and free samples (provided by the sponsor, Nabisco). It is probable that the programme owed much of its popularity to these promotional components. An evaluation of the programme received a poor response rate (35 per cent) with responders tending to be white, middle class, married women. Amongst this non-representative group the whole package was viewed very positively, although the questionnaire itself was not evaluated separately.

It is not possible to ascertain from the literature reviewed if older people's experience of self-assessment is affected by who interprets the assessment. Two user-interpreted self-assessments reviewed, the PEP programme (Lach et al., 1994) and D-E-N-T-A-L (Bush et al., 1996a) had good uptake and response rates and were viewed positively by recipients (U+). A study of breast self-examination (BSE) (Grady, 1988) reported much lower uptake of the initial training programme (49 per cent) and of these less than half the participants returned follow up cards confirming their continuation with BSE. Women over 50 were significantly more likely than those younger than 50 to confirm continued monthly examinations for the 2 years following a training session. This difference was even

greater when women over 60 were compared with those under 60. Attitude measures were completed by all participants in the programme to provide information as to why some women may be more likely to perform BSE than others (U+). The strongest predictor of continuation with BSE was found to be confidence in the ability to perform BSE. Given that BSE is a user-interpreted self-assessment it seems reasonable that women will only find the assessment worthwhile if they believe they will be successful in detecting any abnormalities. The credibility of a self-assessment, and the trust placed in its findings are likely to make an important contribution to how it is experienced.

In addition to the two examples of self-assessment where the user is prompted to act (Bush et al., 1996a; Grady, 1988; Lach et al., 1994) there were two where both the user and the professional are prompted to act (McQuaide et al., 1997; Patterson et al., 2002) (U+ / C). One of these self-assessments is used to identify personal strengths in clients involved in psychotherapy or counselling in order to help clients recognise and mobilise their available resources (inner and outer) and coping abilities (McQuaide et al., 1997). Three case studies are described (Classified as Credible evidence). In two of these examples the questionnaire triggered the hoped-for recognition of strengths and abilities and represented a positive experience for those completing it. In the third example the questionnaire had made the person feel dismissed and not listened to. It was apparent that it had not been appropriate to administer the questionnaire at that time, although the author stated that he was able to use it successfully at a later date.

This highlights an important point. The experience of self-assessment does not depend solely on the process and content of the assessment, but also on the characteristics of the person completing it and the timing of the assessment. This is particularly relevant for assessments involving older people, where the person may be feeling physically unwell, vulnerable or weak, or suffering from mental illness. In these cases the burden of self-assessment may be too great and therefore wholly inappropriate.

Two of the studies (both U+) examined self-assessment as a substitute for professional assessment (Grady, 1988; Lach et al., 1994). In both cases the self-assessment was user-interpreted and the user was prompted to take action, thus the responsibility for the assessment and action following the assessment was placed firmly with the user. In one of these studies involving a nutrition education programme for older people, the initial uptake was high and was evaluated positively (Lach et al., 1994). However, the response rate for the evaluation questionnaires was very low (35 per cent). Similarly, a low response rate (45 per cent) was reported for older women (over 50) required to confirm continued monthly performance of BSE (Grady, 1988). These findings may imply that

commitment to such programmes is not high, despite the high degree of user involvement and responsibility required. However, it is not possible to determine the number of older people who may be engaging in the self-assessment but not returning the documentation that confirms their participation to researchers. It may be that more active follow-up by researchers (e.g. telephone follow-up) may provide a more accurate reflection of self-assessment practice.

Most self-assessment is in this area is carried out in addition to professional assessment. Some focussed health self-assessments are conducted as part of a detailed professional assessment, either while the professional is present or in the waiting area prior to seeing him/her. The association of a self-assessment with a professional consultation has a positive influence on response rate. This is the case with self-assessments of hearing (Yueh et al., 2003b). These have a near 100 per cent response rate. This association may increase the credibility and perceived value of the assessment as discussed above.

However, the high response rate clearly does not reflect the older person's experience of the assessment, as there may be little or no perceived choice to complete it. The low uptake of follow-up in some instances suggests other factors need to be taken in to consideration e.g. the relevance of the subject of the assessment, the perceived usefulness of the self-assessment and the perceived effectiveness of treatment. While a few inferences may be drawn from the available literature, the lack of direct evidence pertaining to older people's views of self-assessment in focussed health care means it is not possible to determine how different aspects of the process of the assessment affect older people's experience of self-assessment.

#### 6.2.2 Content

Physical self-assessment, for example BSE, may cause embarrassment or anxiety in some older people who may feel uncomfortable performing the self-examination, or worried about the implications of any abnormalities detected. Evidence from a study comparing attitudes towards BSE of women under 50 with those over 50 found no significant difference between the two groups concerning embarrassment or fear (Grady, 1988) (U+) . No evidence was found for men's views towards physical self-assessment. Given that there is some evidence to suggest gender differences in self-assessment (Synodinos et al., 2000) this is an area worthy of further investigation.

There is some evidence to suggest that when older people are asked directly whether they prefer self-assessment or a clinical test, the majority express a preference for the latter. In a review of

literature pertaining to screening of hearing loss one item is included (U+) that sought older people's views of self-assessment compared with audiometric testing (Yueh et al., 2003b). In the study (McBride et al., 1994), 60 per cent of the 185 older people involved were found to prefer audiometry compared with just 13 per cent who expressed a preference for the self-completion questionnaire as a screening tool. Were the clinical test to be more unpleasant it might well be that self-assessment would be the preferred option.

It might be supposed that lengthy or more complex self-assessment questionnaires might be less acceptable to older people than short, easy-to-complete schedules. There is credible evidence (C) to suggest that older people will complete a self-assessment in order to help a health care professional even if they find the assessment challenging. Most older people did complete a self-assessment sent to people's homes prior to a home visit by an occupational therapist (Mayers, 1998) even though only half the respondents reported that they found the questions easy to complete and understand, and only 20 per cent found it useful. In this case, although the experience of self-assessment was a negative one for many of those concerned, they carried out for the benefit of the professional carer. In this way perhaps some self-assessments would become another one of the things older people 'put up with' in order to obtain the health care they require (rather like unpleasant preliminary investigations carried out to confirm medical diagnoses).

One of the more complex self-assessments identified was used to determine a person's risk of coronary heart disease (CHD, Paterson et al., 2002). In an evaluative study to determine the feasibility and usefulness of the new tool, 20 family physicians were asked to give a self-assessment workbook (entitled Heartcheck) to 40 patients, without a diagnosis of CHD, whom they felt would benefit from carrying out the assessment. Following completion of the self-assessment the participants met with their physician to discuss its findings and implications, including correction of misperceptions. Both physicians and patients were interviewed following use of the workbook to ascertain their views providing some credible evidence (C).

Most participants (78 per cent) had been able to complete the assessment unaided, felt they had learned something from carrying out the assessment (80 per cent) and reported that they would recommend its use (98 per cent). Concerns raised by at least two participants included: problems with the required arithmetic and difficulties understanding some of the terms used for example 'risk' and 'high blood pressure'.

Physicians felt that use of the booklet was feasible and not too time-consuming. Only one of the 20 physicians interviewed had not

found the book helpful and would not wish to use it if it became widely available. It should be noted, however, that this study sample was not made up solely of older people (age range: 31 to 63 years; mean 41.4 years). Although it seems likely from the high percentage of positive responses regarding use of the booklet that the older people included did endorse its use, this cannot be stated with any certainty.

Findings from this small-scale study suggest that the use of a booklet for self-assessment of CHD risk, or to correct misplaced anxiety, may be useful and acceptable to both patients and family physicians.

Response rates in topic areas such as alcohol consumption, memory loss and body weight seem to suggest that the assessment of sensitive issues may be experienced negatively by at least some older people (U-). In this case it might be assumed that self-assessment may be perceived as less embarrassing or anxiety provoking than interviewer-assessment. Unfortunately, within the field of focussed health, there is no direct evidence of experience upon which to base these assumptions.

It is not possible to conclude how predictive assessments might differ from diagnostic assessments in terms of older people's experience of self-assessment. Only one item related to predictive self-assessment (Patterson et al., 2002), the Heartcheck self-assessment workbook for CHD risk. Evaluation of patients' and doctors' views of the workbook suggested it was well-received by both groups, with both reporting that it was valuable in demonstrating lower levels of risk to some patients who had been concerned that they were at high risk of CHD (Credible).

#### 6.2.3 Section summary - focussed health care

Evidence of how older people experience self-assessment in focussed health care is weak due to the small number of studies (n=7) that address this issue.

None of the studies reviewed directly addressed how different aspects of the process of the assessment affected older people's experience of self-assessment.

Findings from one study suggested that the characteristics of the person completing the self-assessment, and the timing of the assessment, may be important factors in the experience of self-assessment.

Where older people are physically unwell, feeling vulnerable or suffering mental illness, self-assessment may be burdensome and inappropriate.

Several studies found that the format of a focussed health assessment influenced the experience of older people.

One study that suggested that older people may prefer a non-invasive clinical test to a self- completion questionnaire. However, there is also evidence that older people will complete an arduous self-assessment for the benefit of a professional carer, despite finding it difficult to complete and not useful.

There is evidence from one study of professionals positively evaluating the experience of self-assessment

#### 6.3 General health care

Twenty studies were identified in the field of general health care that reported older people's experience of self-assessment. Of these, 16 were graded as unsupported (U-) and only four were assessed as containing supporting evidence (U+ or above) (see appendix tables 9.17, 9.18). These are used as the prime sources although a brief summary of the weaker evidence (U-, tables 9.19, 9.20) will also be presented in order to include any potentially important contribution that may help to inform an understanding of older people's experience of self-assessment. Most of the weaker evidence (U-) comes from inferences made based on response rates.

In general response rates are high. A number of studies were conducted in the UK during the 1980s and early 1990s to test the feasibility of self-completion case-finding postal questionnaires in order to identify older people who would benefit from further input from primary health care services (Bowns, et al. 1991; Killingback, et al. 1987; Taine, et al. 1990; Wilcock 1979; Barber, 1980 Porter, 1987; Barber, 1988; Cameron and Wright, 1987; Pathy et al. 1992; Taylor et al, 1983). Nine were distributed as postal surveys, eight with covering letters from the GP, GP surgery or health visitor explaining the purpose of the questionnaire and encouraging the older person to complete and return it. The response rates for all of these studies were very high, ranging from 81per cent to 95 per cent. Although most authors also concluded that the selfassessments were acceptable to the older people involved, in eight of the ten papers this claim is unsupported by evidence (U-). For example, based on the high response rate obtained, the authors concluded that the original Woodside Screening Questionnaire was acceptable to older people (Barber et al., 1980) but views of the older people were not examined as part of the study.

The very high response rates associated with these case-finding studies in UK primary health care may be largely attributable to their association with, and endorsement by, GP and health visiting services. This contrasts with the findings from focussed health self-

assessments, where professional initiation does not seem to have such a strong positive influence on response rates. A large national UK cluster randomised trial compared three different methods of administering a screening questionnaire: post, interview by lay interviewer, and interview by nurse (Smeeth et al., 2001b) The 29item general health assessment was administered to 32, 990 people aged 75 and over drawn from 106 GP surgeries. The response rate was significantly higher for the postal survey than the two interview methods, although all were good (postal - 83.5 per cent; lay interviewer - 73.9 per cent; nurse interviewer - 75.9 per cent). This suggests that self-assessment of general health is acceptable, and may be preferred by some compared with interviewer assessment. Response rates fell for all groups with increasing age. In addition, the higher response rate for postal questionnaires was not evident in the older age groups, suggesting this method may be less acceptable amongst the very old. One non-UK study on health checks (Johansen, 1994) found that postal questionnaires yielded a higher response rate (9.1 per cent) but this was not significant but that overall response rate in the rural community was low (53 per

There is some evidence on response to self help books. Most (84 per cent) of respondents in one evaluative on self help books reported that they read at least some of the self-help book (Moore et al., 1980b). However respondents represented only a minority (22-48 per cent) of those offered the and so this may be a biased estimate (Fries et al., 1993a).

#### 6.3.1 Process

Credible evidence was found (C+) relating to the experience of the assessment of a user-initiated self-assessment (Terry et al., 2000). In an evaluation of an initiative designed to improve physicians' role in patient education, a self-help guide was found to be well-received by patients, most of whom were satisfied with the booklet and believed it to be a credible source of information Unfortunately, although overall satisfaction scores are reported, no further details are given to describe what aspects of the self-care guide were liked. Although the study included adults of all ages, a third were over the age of 60. Findings for this sub-group are not reported separately so it is not possible to tell whether there were any age-related differences in patients' views.

The other assessments reviewed in this sub-section were initiated and distributed by professionals. Acknowledging the inadequacies of response rate as a proxy for acceptability, the consistently high response rates for general health case-finding questionnaires distributed by GPs/GP surgeries suggest that these may be acceptable to the majority of older people. Sadly, there is little strong evidence to further support this claim. A five-item screening

tool based on the Woodside Screening Questionnaire has been tested in Edinburgh (Porter, 1987). The authors noted an 'enthusiastic' response from the older people involved in the study, stating that the birthday card scheme had proved 'very popular', with 'many' adding comments to their returned assessment forms. Thus the evidence for the popularity of the scheme is based upon a general impression drawn from an indeterminate number of unprompted positive comments, thus making difficult to judge how strong the support really was (U+).

The evaluative study described above (Terry et al., 2000) examining the use of a self-care guide found that while most patients were satisfied with the self-care book, those who had been given the book by their physician were significantly more satisfied with their care and communication with the physician than those who received the book in the post (C+). These findings suggest that supported use of a general health self-assessment can have a positive influence on the person's perception of the self-assessment and their experience of health care provision.

One further Credible example (C+) was found of a self-assessment interpreted by the user. The Personal Health Record was used by a UK general practice as an on-going health check for older people to prompt regular self-assessment and encourage the older person to seek further medical advice if appropriate (Barber, 1988). In a questionnaire survey to evaluate the acceptability and usefulness of the health record the vast majority of older people reported that they found the booklet easy to read and understand, and useful. Most respondents (86 per cent) felt that all older people should use the booklet and 81per cent indicated that they would be willing to complete the self-assessment checklist every six months. This finding further supports the assertion that general health self-assessments associated with a known health care professional are viewed positively by older people.

User-interpreted self-assessments that prompt the user to take action are generally used as a substitution for professional assessment. Self-assessments of this type require the user to take responsibility for decision-making and health-related behaviours, although this may simply involve seeking professional advice. This type of assessment contrasts with the professionally initiated self-assessments that inform professional decision-making and action. Although it is not possible to draw any firm conclusions, from the available evidence it appears both types of self-assessment may be acceptable to older people.

#### 6.3.2 Content

Little evidence was found regarding the structure and format of the assessment. Generally the information available was based on

response rates (U-). Most of the UK general practice case-finding postal questionnaires are short (ten items or fewer) and receive high response rates (U-). An example of a long (32-page) postal questionnaire identified from the literature (Minder et al., 2002) received a lower response rate of 51-58 per cent. Although the majority of older people who did respond reported that they found the questionnaire easy to understand and complete (U+), it is likely that this would not be the case for many of the non-responders. There is no evidence regarding web based formats.

The effects of questionnaire length and response format on response rates have been tested directly (Victor, 1988). Long (117-item) and short (47-item) versions of a postal questionnaire to assess the needs of older people (aged 65 and over) following discharge from hospital were compared. Both were found to have good response rates, which the authors suggest indicates a high level of acceptability (U-). Non-responders were noted to be older, more frail and include more women than the response group, suggesting that a self-assessed format may be less acceptable to these groups.

The issues covered by general health assessments are very similar. It appears that older people find self-assessments in this category acceptable, although this is based on inference from reports of usefulness and response rate rather than responses to direct questions relating to questionnaire content. Perhaps the less specific nature of the questions asked makes general health assessments less threatening than more focussed health assessments.

General health assessments tend to cover both environmental and internal issues e.g. living arrangements and social support as well as physical and mental abilities. Only 1 of the 4 reviewed papers contained questions relating to only internal issues (Terry et al., 2000). There is no evidence to suggest older people experience these self-assessments any differently from those containing both types of issues.

It is not possible to assert the effect, if any, of predictive versus diagnostic assessments on older people's experience of self-assessment. Most evidence in this area related to assessments that encompassed elements of both.

#### 6.3.3 Section summary – general health care

Evidence of how older people experience self-assessment in general health care is weak due to the small number of studies (n=4) that address this issue.

Two studies found that most patients were satisfied with a user-initiated and user- interpreted self-assessments

Acceptability of general health self-assessments is enhanced by support from a known health professional and, in turn, a self-assessment tool may enhance the patient/professional interaction.

Where self-assessment prompts the user to act appears to be acceptable to older people in the studies reviewed.

Although based on response rate, which has inherent limitations in assessing acceptability to patients, one study suggests length of self-assessment questionnaire does not have a major impact on acceptability.

#### 6.4 Social care and life skills

Of the eight papers identified in this field (appendix tables 9.21 to 9.24), just two were found to contain some evidence (U+ or above).

Three papers described the use of self-assessment instruments as part of a professional assessment (Kautzmann, 1984; Kivnick et al., 2001; Kosberg et al., 1986). In two of these three cases, the selfassessment was used either with individuals or with groups, with contrasting reports of the experience of the assessment. Use of a self-assessment tool to help disabled people identify potential leisure interests was described by the authors as being 'wellreceived' by participants, who were reported to be encouraged by an activity that focused on participation rather than limitations and restrictions (Kautzmann, 1984). In contrast, where a selfassessment tool was used to assist carers to recognise the cost of caring, the focus was entirely on the negative aspects of informal caring and the burdens it places on the individual. Not surprisingly, the authors report that some respondents experienced emotional difficulty when completing the questionnaire (Kosberg et al., 1986). Group discussion of the negative feelings aroused by completing the questionnaire is suggested as a way of dealing with those feelings. The implications of asking potentially vulnerable people to complete a self-assessment in circumstances where there may not be sufficient emotional or practical support available to meet identified needs, needs to be given careful consideration when planning the use of such assessment methods. However in all cases inferences were drawn by authors (U-) with no direct formal exploration of users' perceptions.

In both of the examples where evidence was available, the self-assessment was one that is initiated by professionals. In one case, the Housing Options for Older People (HOOP) project (Heywood et al., 1999), the self-assessment was initiated by lay volunteers or staff of charitable institutions, and the authors express an intention to make the tool accessible to users directly (e.g. via public libraries). The HOOP assessment is intended for user and

professional interpretation rather than solely professional interpretation (Heywood et al., 1999). This self-assessment is for use by an older person to help them make a decision about whether or not to move home. The interpretation of the assessment can be carried out by the user alone or with the help of another person (professional or non-professional), but the role of the other person is very much as a facilitator, helping the older person interpret the assessment findings for themselves, rather than telling them what their responses mean. Pilot testing of the HOOP tool suggested that older people were pleased that the process of completing the assessment had enabled them to clarify their own thoughts and priorities (U+).

The HOOP assessment tool stands out as providing a vehicle that enables older people to make their own decisions based upon their own wishes and perceptions of need (Heywood et al., 1999). Older people reported that working through the self-assessment had enabled them to take control of the decision-making process (U+). This was particularly useful for older people who were feeling pressurised into making a decision by family or friends.

The HOOP tool provides self-that is largely additional to that provided by services. An example was found of a carer self-assessment which substituted for professional assessment (Arksey et al., 2000). Carers reported that they preferred interviewer assessments compared with self-assessment, although self-assessment was seen as useful when used in conjunction with face-to-face assessment.

#### 6.4.1 Content of the self-assessment

Evidence from the pilot-testing of the HOOP questionnaire suggests that, despite it being rather long and complex, older people found it easy to use and understand (Heywood et al., 1999). It is reported that the categories used in the questionnaire corresponded well with issues older people regarded as significant and enabled them to consider in detail areas they felt were important. The scoring systems are reported as having been well understood (U+). It should be noted, however, that the HOOP questionnaire can be completed wholly or partially as a self-assessment, with assistance being provided as necessary/wished. No details are given describing how this is reflected amongst the participants of the pilot study. Further (in common with other assessments covered) there is no evaluation of the experience of using the web version of the assessment.

The reported ease of use might simply be a reflection of the fact that most of the older people involved had assistance in completing at least part of the questionnaire. However, as described above, this does not detract from the process of self-assessment as embodied

in this instrument i.e. encouraging the user to reflect on their own needs, wishes and priorities and come to a decision not influenced by others.

#### 6.4.2 Section summary – social care and life skills

Evidence of how older people experience self-assessment in social care and life skills is weak due to the small number of studies that address this issue.

One of the two studies reviewed found that self-assessment can be a positive experience for older people, helping them to make decisions about their social care needs.

Both studies suggested that support can contribute to making this experience a positive one and it is important that self-assessment for complex needs is not perceived as being unsupported..

The length and complexity of a questionnaire does not necessarily have a negative impact on the experience of self-assessment if it is easy to use and the items correspond to issues considered by older people as being important to them.

### 6.5 Comprehensive care

Of the six items identified for inclusion in this section, only four were judged to contain evidence relating to older people's experience of the assessment (U+ or above). For detail see appendix tables 9.25 to 9.28. Two of the examples come from pilot studies carried out in two of the case study sites identified as part of the scope review (see Box 3.4 – Lewisham and Box 3.5 – CAT) and a third comes from opinions expressed in a meeting between the research team and an older persons reference group on a site that was not undertaking self-assessment (Box 3.2 – Tower Hamlets) All these items are classified as U+ since they are not based on formal research report but do include direct report of older people's views. The final item is a qualitative study to explore older people's perceptions of their needs and how they would like them to be met, including older people's views of comprehensive assessment (Robertson, 1995) which is classed as credible (c) evidence.

The two unsupported (U-) papers in this domain demonstrate how mode of administration can influence response rate, (Berkman et al., 1999; Linn et al., 1984). In one study (Berkman et al., 1999) the self-assessment questionnaires were distributed by mail to older people with forthcoming appointments to see the physician. The questionnaires were all distributed with an explanatory letter from the physician requesting participation. However, the response rate for the mailed survey was only 38 per cent. It may be that the older people perceived little benefit in completing a self-assessment when

they were soon to see the physician for a face to face consultation. In contrast, in the second study (Linn et al., 1984) administration of the self-assessment followed an interview assessment. Although completed alone, the older person was informed that someone would return to collect the questionnaire. The sample included hospital in-patients, older people attending medical outpatients, and older people in residential care. The response rate for this study was 94 per cent. Rather than being attributable to a high level of acceptability of the self-assessment, this is more likely to be a reflection of the intensive recruitment and administration/collection of the self-assessment.

All the evidence regarding self-assessment in the field of comprehensive related to examples that were initiated by professionals. The possible effects of who initiated the assessment on the experience of self-assessment cannot be examined. The seemingly positive effect of initiation of general health assessments by a known professional has been discussed above.

The two case studies included pilot studies undertaken as part of the implementation of the SAP for older people in England. The work carried out in Lewisham was undertaken by two general practice nurses and tested the EASYCare overview assessment instrument as a self-assessment. Two groups of older people living in sheltered/warden-controlled accommodation received the questionnaire from their respective accommodation managers. Completed questionnaires were returned in a pre-paid mailed envelope or in person to the general practice concerned. All the self-assessments were completed and returned. Focus groups were held following completion of the assessments to ascertain older people's views.

It became apparent during the focus groups that the attitude of the accommodation managers towards the assessments had influenced the older people's perceptions of them. In one group where the manager was supportive of the assessment the older people were welcoming towards it and reported few difficulties with it. In the second group, where the manager had expressed a much more negative attitude towards the assessment, this negative attitude was also expressed by the older people, who were particularly suspicious of who was going to see the completed assessments and what the information might be used for. This small-scale pilot study, illustrates how mode of administration can impact upon older people's perceptions and experience of self-assessment.

The Cambridgeshire Assessment Tool (CAT) is an electronic tool, completed using a small tablet lap-top computer. The acceptability of the electronic version has been tested with a small sample  $(n\sim50)$  of older people living in very sheltered accommodation (Purdie, 2003). Despite misgivings of some of the professionals

involved in the assessment programme, the older people were able to complete the self-assessment with a professional present to call on for help if necessary, and found the electronic version acceptable. In addition, professionals reported that sitting alongside the older person while they completed the assessment enhanced a sense of partnership and a sharing of the assessment process (U+).

Older people's views of comprehensive assessment and self-assessment were sought by a qualitative study undertaken in Scotland (Robertson, 1995). The older people involved in the focus group interviews expressed a wish to be involved in the assessment process, for example requesting that assessment forms be left with them after an initial assessment for them to review and amend if necessary. However, the older people felt that they should not be responsible for completing the assessment forms, preferring that this be carried out by the assessor. The older people's reference group also expressed the importance of choice and identified the importance of a third part in preventing a carer or relative from 'taking over' (see Box 6.2). It would appear that, at least for some older people, the presence of a professional (or other lay helper perhaps) is preferred in order to assist them with form completion when carrying out lengthy comprehensive assessments.

#### **Box 6.2 The Tower Hamlets Single Assessment Process (SAP)**

The Older People's Reference Group, a voluntary group comprised of older people, is involved in developing the single assessment instrument and have been consulted on its language, clarity, ease of usage etc. Members of the group also agreed to participate in the pilot testing of the new assessment tool and to provide feedback on the experience of being assessed. To date, self-assessment has not been considered as a viable option within the single assessment process in Tower Hamlets. A member of the research team attended a meeting of the Older People's Reference Group and explored their views of self-assessment in relation to the SAP in an informal focus group. The points raised by the 12 older people present are summarised below:

The older person should be able to choose whether or not to undertake an assessment as a self-assessment or with the assistance of a professional or voluntary worker.

In some cases it might be appropriate to carry out part of the assessment as self-assessment whilst engaging the help of others for some sections. It was felt that certain issues benefit from discussion whilst others are best kept 'private'.

Concern was expressed that there is more scope for family members to "take over" the assessment if it is done without the presence of a third party.

Wording of questions is particularly important as a questionnaire is undertaken as self-assessment as the older person has no opportunity to clarify ambiguities and the person interpreting the assessment has no way of checking that the question has been understood.

Self-assessment is not always appropriate e.g. if a person is feeling unwell or distressed.

Some older people are not able to see and/or write well enough to complete a questionnaire themselves.

The older people felt very strongly that although self-assessment might represent a good option for some older people in certain situations there should always be an element of choice. Older people should not be forced into carrying out a self-assessment against their wishes.

Evidence is inconclusive. It appears from findings from the Lewisham piloting of the EASYcare self-assessment and the focus group work carried out in Scotland (Roberts, 1995) that some older people have misgivings about self-assessment being used as a substitution for professional assessment, preferring to perform the self-assessment as an adjunct to professional assessment. However, piloting of the CAT (Purdie, 2003) and findings from one of the focus groups in the pilot testing of the EASYCare tool suggest that if a comprehensive self-assessment is administered with appropriate information, it is acceptable as a substitution for professional assessment, at least to some older people.

The overview assessments that form part of the SAP are lengthy and fairly complex comprehensive assessments (e.g. EASYCare; CAT3; FACE). Unfortunately, there seems to have been little attention paid to user's views of completing these assessments,

either as self-assessments or interview-based assessments. The CAT represents the only electronic assessment tool that has sought older people's views on using the tool as a self-assessment. Although the sample of older people involved in the testing was quite small, the finding that older people reported this version acceptable and user-friendly is important given that it seems likely that more self-assessments will be electronically-based in the future. The intelligent navigation used by the electronic assessment tool, CAT, means that the older person is only presented with relevant questions, and does not see the overall length of the questionnaire. This may reduce the perceived burden of completing the questionnaire, making it more acceptable and easier to use.

The older people's reference group (Box 6.2) made a number of comments relating to the usability of questionnaires for self-assessment in particular the need for language to be unambiguous if self-completion is to be achieved and the need to take reading and writing abilities into account (including visual problems).

Little evidence could be found relating to older people's experience of comprehensive self-assessment with respect to the content of the assessment. Findings based upon item response rates from studies of the acceptability of focussed health and general health self-assessments reviewed above suggest that there are some issues which older people may find uncomfortable reporting verbally or on self-completion questionnaire e.g. urinary symptoms (Maly et al., 1997); memory loss (Boustani et al., 2003) These same feelings of embarrassment or anxiety may also occur when questions relating to these or other sensitive topics arise during a comprehensive assessment. The older people's reference group felt that certain issues benefit from discussion while others are best kept 'private' suggesting that acceptability may indeed be related to content (U+).

Due to the comprehensive nature of the self-assessments reviewed in this domain, each of the three examples include both environmental and internal issues. None of the reviewed material considered how assessments relating to these two areas might affect older people's experience of self-assessment.

Older people's attitudes towards screening and case-finding will influence their experience of self-assessment, and indeed whether or not they will want to complete the assessment. Comprehensive assessments are used to both predict and diagnose problems. For some older people diagnosis may represent a welcome recognition of a problem which has been causing anxiety or suffering. On the other hand some older people might cope better without the labelling or stigma which some diagnoses can bring e.g. of mild-moderate dementia (Aminzadeh et al., 2002; Boustani et al., 2003).

Similarly, it cannot be assumed that predicting future problems will always be welcomed by, or be beneficial to, the older person.

#### 6.5.1 Section summary – comprehensive care

Evidence of how older people experience self-assessment in comprehensive care is weak due to the small number of studies that address this issue.

From the studies reviewed self-assessment does seem acceptable to older people, although professional support e.g. in terms of reinforcing the value of the assessment or the actual presence of the professional when completing the assessment is important in making this experience a positive one.

The evidence to support self-assessment as a substitute for professional assessment rather than as an adjunct to professional assessment is inconclusive and requires further research.

Very little insight in older peoples experience of the content of selfassessment is gained from the studies reviewed although evidence form one study suggests that the use of an electronic format for self-assessments is acceptable and user-friendly.

There is a large gap in current knowledge of how older people experience comprehensive assessment within which self-assessment is increasingly incorporated.

As part of the SAP introduced in England and Wales, many older people will undergo self-assessment and therefore the importance of understanding the older person's experience of the assessment and the impact it will have on their life cannot be understated.

#### 6.6 Conclusions

As comprehensive assessments are introduced in England and Wales as part of the SAP, in order to ensure no harm is done, it is important that professionals understand the older person's experience of the assessment, and the impact it will have on their life. It appears from the literature reviewed that this represents a large gap in current knowledge.

The vast majority of assessments included in this review are designed to be initiated, interpreted and acted upon by professionals, not the older people themselves. The few assessments that were directed by older people were considered to be very useful and acceptable. Evidence of the acceptability of self-assessment as a substitute for professional assessment is inconclusive. Several studies suggest that older people find self-assessment very acceptable when they have direct support from a health professional.

Very few studies addressed whether the content of an assessment had an impact on the older person's experience of self-assessment. A long and complex questionnaire was not found to impact negatively on the users' experience of self-assessment if the questions asked were considered by the respondents to be important to them. Furthermore, electronic versions of questionnaires, where easy to use, were found in one study to be acceptable.

Older people are generally willing to complete screening questionnaires, although it does seem that response decreases with age and that the perceived legitimacy and authority of the source is significant. Both postal questionnaires and those given out in waiting areas obtain generally high response rates (although not universally) but self-initiated action following completing the questionnaire does not necessarily follow, nor does the perception that such activity is useful. The sparse evidence does not allow for firm conclusions on the reasons for variation. There is no evidence that assessments that are more clearly owned by the older person are (for example BSE) are more accepted. It is important to recognise that high response rates for questionnaires does not equate with high levels of acceptability.

Although for some issues older people express a preference for professional assessment (for example hearing) for other issues, generally sensitive ones, there is some indication (not from older people) that self-assessment is preferred to face to face interview. Comments from the case studies reviewed show that the perception of the purpose of the self-assessment is important. There is a subtle difference between being given the opportunity (and respect) to complete the assessment oneself and feeling 'left to get on with it'.

The importance of having access to resources for further support and information is highlighted. As identified in the review of effectiveness – self-assessment is unlikely to have an effect if the results are not acted upon. In terms of the user experience prompting action but having incomplete resources of sources of information (as in the example of housing self-assessment) may result in negative perceptions and have adverse consequences. The link between assessment and action is perhaps most important in assessments that are user initiated or interpreted but supported/distributed by providers.

While the format of the assessment seems obviously significant this review has shed little light upon it. The impact of length of instrument on response rate could not be determined for focused health although some evidence from general health showed some evidence for lower response to longer assessments, although evidence was not consistent. Qualitative evidence highlights the crucial importance of wording and the potential confusion of terms

that appear unproblematic such as 'risk'. Despite expectations (ours) there are examples of successful implantations of computer-based self-assessments. These are becoming increasingly common and more research is needed relating to the needs of older people.

# 6.7 Implications and recommendations for research, practice and policy

#### 6.7.1 Research

With the widespread implementation of the SAP there is a need to explore older people's experience of the self-assessed component of comprehensive assessment as a matter of urgency.

Further research should directly investigate the experience of selfassessment rather than resort to making inferences based on assumptions from indirect sources, notably response rates.

Evidence of how the process and content of assessment affects the experience of self-assessment would be of value in design and implementation of self-assessment with older people.

Exploring other factors that may impact on older people's experience of self-assessment e.g. the characteristics of the person completing the self-assessment and the timing of the assessment is also important.

Exploration of the extent to which, and in what circumstances older people are comfortable with self-assessment as a substitution for professional assessment, in part or as a whole, would be beneficial.

#### 6.7.2 Practice

The use of self-assessment in practice demands considerable consideration and professional involvement in order to maximise benefits and avoid a perception of neglect.

From the weak evidence available it appears that older people are comfortable with self-assessment, including user-initiated and user-interpreted assessments,

Many may prefer to have a degree of professional support with the process.

The use of self-assessment for identifying health and social needs may be a more positive and helpful exercise for older people if directly supported by a known health professional.

The use of computer-based questionnaires may be a positive development for older people but format and ease of use is likely to be crucial.

#### **6.7.3 Policy**

The use of self-assessment among older people is extremely underdeveloped despite long standing guidance reinforcing the importance of user's views in assessment, patient involvement in care and person centred care.

The majority of self-assessments that have been developed are designed to be initiated, interpreted and acted upon by professionals, not the older people themselves.

The small number of self-assessments included in this review that were directed by older people were considered to be very useful and acceptable.

There is considerable scope to advance policy directives further within the confines of patient acceptability.

Self-assessment is identified as an important component of self-care, and recent policy recommendations (DoH 2005) include the need to develop practitioners' skills in when and how to use approaches to support self-care, and to devise initiatives to develop partnerships between professionals and the public. This review reinforces these recommendations.

## Section 7 Conclusions

The interest in incorporating self-assessment into the SAP makes this review timely. Although it was concurrent with developments in the process and, in particular the accreditation of tools, the continued development and diversity of locality-based approaches does not undermine its utility. The more recent advocacy of self-care in UK health policy further emphasises the importance of self-assessment. Many of the media used and distributed by NHS direct incorporate elements of self-assessment and the variety of other self-assessments identified here indicate the importance of the topic. Since older people are a major consumer group for health and social care services (indeed for the SAP the predominant group), consideration of the appropriateness and potential benefits is clearly justified.

This review has succeeded in identifying multiple issues related to self-assessment but few questions are answered definitively. Because its scope is broad it is possible that focused searches on the specific sub topics identified might yield more evidence. This is the reason that where possible we have built our findings upon existing systematic reviews of those topics, identifying self-assessments within them. Consequently the picture of the evidence base we have presented here is unlikely to be a misrepresentation. There is relatively little research, little of it is good and it is of small volume in relation to the questions raised by self-assessment.

In this review we have taken a broad definition of self-assessment. The extent of 'self' in the approaches identified varied considerably. The range; from a narrowly focused self-completion questionnaire, which is returned to a doctor for action, to a broad ranging decision support system for making major life decisions without direct professional involvement; is vast. Ironically the former was more likely to be called self-assessment than the latter in papers we reviewed. The typology we have developed here should draw attention to the need to consider self-initiation, self-interpretation and self-action in addition to simple self-completion.

The majority of self-assessments that we identified were designed to be initiated, interpreted and acted upon by professionals, not the older people themselves. However, we have found a variety. Some of the most promising approaches give direct feedback and access to self help information even in the context of professionally initiated assessments. It seems unlikely that evidence will generalise widely across self-assessments that do not share similar characteristics, particularly in relation to user experience.

This review has demonstrated that the scope of self-assessment is also wide in terms of content and format. It has been used in many

ways and for many groups of people. Although paper and pencil based medical screening is probably the most commonly represented approach in the literature the variety of approaches used with older people is much wider than this. Further, there are approaches for which we have found no examples for older people but may have an application.

However what we have not found is a matching evidence base. Many aspects of self-assessment are under researched. Even in the field of medical screening, where the evidence base for a number of approaches is relatively large, there are substantial gaps and surprisingly little evidence for the effectiveness of self-assessment based screening for specific disorders or for more general health checks. However, provided that there is appropriate follow-up for adverse findings, such evidence as there is seems to be positive in relation to broad based health checks. Little comparative data is available but given the high response rates, postal screening may be preferable to other approaches and if non-responders are followed up by other methods this may be optimal.

There is more direct evidence for the accuracy of focussed health assessments than there is for their effectiveness. Few assessments showed good performance in terms of both sensitivity and specificity. Selection of instruments from screening and case finding demands consideration of both factors. Optimisation of both is not necessary provided that the number of false positives is not unmanageably high or the consequences of a missed case is not unacceptable. However it does raise issues in terms of the use of the instruments for individualised assessment as there is rarely a direct correspondence between the assessment result and a defined problem at an individual assessment. The results of self-assessments can focus further assessment (by ruling certain issue out ad others in) but no more.

A range of alternatives (or compliments) to the UK style health checks were identified. These alternatives have a more active user component incorporating self-care self-assessment algorithms or elements of interactive feedback to clients giving advice and focus in relation to accessing care services. However, the evidence base here, although directly based on self-assessment and some rather large studies, is currently weak. More research is needed. The approach seems acceptable to users so far as can be ascertained. The evidence obtained is exclusively from the US. Although in the UK the many modes of delivery for NHS direct resemble it, there is little self-assessment material tailored to the needs of older people and no comparable evaluations in this very different health care system.

Consideration needs to be given on how to promote such facilities as self care algorithms if they are developed for older people.

Currently they are available in local telephone directories but the content is general with considerable emphasis on younger families. Further work needs to be conducted to establish both the effectiveness and acceptability in the UK.

Self-assessment is potentially acceptable in a wide range of areas although consideration must be given to the perceptions noted here. That a self-assessment is seen as coming from a respected professional makes it more acceptable but if it is seen as an abrogation of responsibility by that professional the response is negative. The format and distribution of self-assessments is important.

We have seen a number of examples of older people being involved in the development of self-assessment although no evaluation of whether the results are more acceptable to other older people. Issues such as appropriate layout and wording apply to all self-assessments although the specific requirements of older people are unclear. Some obvious considerations such as use of larger text for a population where moderate visual impairment is prevalent should not be neglected. Similarly professional jargon should be avoided but whether language should differ in other ways for older people is unclear.

There are examples of innovation, in particular the use of the web and other computer interfaces, which seem promising, but remain largely unevaluated. However the continued popularity of self-care books should remind us of the importance of paper based resources and formats and the need to pay attention to their design.

Given the developments in the SAP in the UK the experience of selfassessment for older people in comprehensive assessments is in urgent need of further research as we found little direct evidence. However since the comprehensive assessments are overarching the evidence from more narrowly focussed assessments is informative since they may be components of the SAP.

The upcoming results of the MRC trial may also shed much light onto the appropriate method of administering over 75 health checks, which (should) integrate with the SAP. The examples such as CAT and the HOOP assessment here show that it might be possible to provide a vehicle that can be used by professionals to collect information that is of value to them (and hopefully ultimately of value to the older people) while at the same time directing older people to self help resources. The Dartmouth COOP model might also deliver this within a rather different system. How to achieve engagement and ownership remains unclear since the mechanism we have identified for engagement (legitimate authority) may mitigate against ownership by the older person. The Dartmouth COOP model again provides some guidance since its authority stems from the family doctor but it asks the client to reflect on whether or

not issues and problems raised in the assessment are known to services.

The issue of active user involvement, so central to the ambitions embodied in policy, is notable by its absence in much of what is discussed here. In relation to the SAP, the evidence regarding client preferences suggests that they are ambiguous. There is no clear preference and there are clearly pros and cons from the point of view of older people. Surprisingly, given research on perceptions of professional assessment, some of the evidence suggested that the role of the professional might in fact be to prevent a carer from dominating the assessment process. Although there is a role for self-assessment it must be skilfully managed and there should be an element of choice about self-assessment. The use of self-assessment to ensure active user involvement and partnership may require more, not less professional input.

Self-assessment is identified as an important component of self-care, and recent policy recommendations (DoH 2005) include the need to develop practitioners' skills in when and how to use approaches to support self-care, and to devise initiatives to develop partnerships between professionals and the public. This review reinforces these recommendations. The SAP has not been specifically identified as a vehicle for self-care but there is unrealized potential if utilized appropriately and with systems that provide user feedback and support.

Self-care programmes inherently involve more active participation by users if they choose to participate. This review did not consider specific condition management but did include evidence on more general self-care packages that closely resembles elements of NHS direct. As noted above there is considerable scope for developing this with specialist content and consideration of modes of delivery suited to older people. However we found no evidence in the UK that indicated the extent to which the potential is currently realized or whether further development would be of benefit to older people. For example we are not aware of any research on the use of the NHS guide in the telephone directory.

In terms of the NSF's aims in relation to comprehensive assessment, active involvement of service users and person centred care it is clear that self-assessment has a role in the former. Self-report of health status is an important predictor and self-report of specific information provided by self-completion means has advantages. Where self-report is known to be accurate in identifying problems self-assessment can be used to provide it. However user involvement and person centred care does not automatically follow. There is some evidence in terms of self-care examples that self-assessment does facilitate involvement. The evidence from the Dartmouth COOP system of self-assessments suggests that users

may be more engaged in care and thus have a more satisfying experience. However the evidence from this also suggests that this was not necessarily as a result of provider behaviour change and so the extent to which care was more 'person centred' is far from clear. Clearly providers need to be active participants and demonstrate that they value the users' self-assessments. The potential is clear but the evidence is largely absent.

# 7.1 Implications and recommendations for research, practice and policy

#### 7.1.1 Research

With the widespread implementation of the SAP there is a need to explore older people's experience of the self-assessed component of comprehensive assessment as a matter of urgency.

Further research should directly investigate the experience of selfassessment rather than resort to making inferences based on assumptions from indirect sources, notably response rates.

Evidence of how the process and content of assessment affects the experience of self-assessment would be of value in design and implementation of self-assessment with older people.

Exploring other factors that may impact on older people's experience of self-assessment e.g. the characteristics of the person completing the self-assessment and the timing of the assessment is also important.

Exploration of the extent to which, and in what circumstances older people are comfortable with self-assessment as a substitution for professional assessment, in part or as a whole, would be beneficial.

#### 7.1.2 Practice

Wherever self-assessment is employed as part of an interaction with services professionals need to demonstrate that they value the information provided

Systems that incorporate both feedback and self care information for users as well as delivering assessment information to professionals are best supported by evidence

Where initiated by professionals the use of self-assessment in practice demands professional expertise and involvement in order to maximise benefits and avoid a perception of neglect.

Results of self-assessments for health conditions are not definitive: they can serve to provide focus in an individual's assessment but can rarely fully replace it.

From the weak evidence available it appears that older people are comfortable with self-assessment, including user-initiated and user-interpreted assessments,

Many may prefer to have a degree of professional support with the process.

The use of self-assessment for identifying health and social needs may be a more positive and helpful exercise for older people if directly supported by a known health professional.

The use of computer-based questionnaires may be a positive development for older people but format, ease of use and access is crucial.

The design content and layout of self-assessment material is crucial and active involvement of potential users in the process may be beneficial.

### **7.1.3 Policy**

The use of self-assessment among older people is extremely underdeveloped despite long standing guidance reinforcing the importance of user's views in assessment, patient involvement in care and person centred care.

The use of self-assessment should not be equated with user involvement and partnership

The majority of self-assessments that have been developed are designed to be initiated, interpreted and acted upon by professionals, not the older people themselves.

These are potentially useful but the partnership is embedded in how the assessment is used, not the assessment itself.

The small number of self-assessments included in this review that were directed by older people were considered to be useful and acceptable.

There is considerable scope to advance policy directives further within the confines of patient acceptability.

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## Section 9 Appendices

### 9.1 Tables for studies of accuracy

Table 9.1 Instruments for assessing depression

Assessment tool	Reference	Brief description
Beck Depression Inventory (BDI)	Beck et al (1961) An inventory for measuring depression. Arch. Gen. Psychiatry 4: 561-571.	21 items of graded intensity; time frame: past week, including. Today.
Mood Assessment Scale (MAS); also known as the Geriatric Depression Scale (GDS)	Yesavage et al (1983)  Development & validation of a geriatric screening scale: A preliminary report.  J. Psychiatric Res. 17:37-49.	30 items withyes/no response format.
Brief Symptom Inventory (BSI)	Derogatis and Spencer (1982)  The Brief Symptom Inventory (BSI) – administration, scoring and procedures manual. Baltimore: Clinical Psychometric Research.	53 items ,responses for intensity of discomfort. 9 symptom dimensions including depression (6 items).
Minnesota Multiphasic Personality Inventory Depression Scale (MMPI-D)	Hathaway and McKinley (1951) The Minnesota Multiphasic Personality Inventory manual. New York: Psychological Corporation.	Depression scale has 60 items.
Bradburn Affect Balance Scale (ABS)	Bradburn (1969)  The Structure of Psychological Well-Being. Chicago: University of Chicago Press.	10 items with yes/no response format.
Zung Self-Rating Depression Scale (SDS)	Zung (1965)  A self-rating depression scale. Arch. Gen. Psychiatry 12: 63-70.	20 items, responses made on a frequency scale.

Table 9.2 Study details accuracy- mental health

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
(Rapp et al., 1988)  Journal of Consulting and Clinical Psychology 56(4): 509- 513	Evaluation of self-report scales to detect depression in older adults. Randomly selected consecutive older adults >65 years admitted to general and surgical units in a Veterans Administration Hospital, USA. n= 150 RR=48% mean age = 69.3 yrs (SD=5.2)	Beck Depression Inventory (BDI), a 21-item self-report questionnaire that measures depression severity.  Self-report depression Scale (SDS), a 20-item self-administered scale.  Geriatric Depression Scale (GDS), a 30-item scale. All assessments were initiated, interpreted and acted upon by professionals.	Diagnostic interview using the Schedule for Affective Disorders and Schizophrenia (SADS). Diagnoses were then assigned according to the Research Diagnostic Criteria. Interviews conducted by a 4 <sup>th</sup> year graduate student in clinical psychology blinded to questionnaire responses.	NB paper states that "there were no significant effects on the dependent measuresfor whether or participants had questionnaire items read to them"  The numbers of participants who completed the scales themselves is not reported.

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Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
(Strik et al., 2001) Psychosomatics 42(5): 423-428	Adults who had had their first Myocardial Infarction (MI)	All patients were asked to complete the 90-item Symptom Check List (SCL-90), the Hospital Anxiety and Depression Scale (HADS) and the Beck Depression Inventory (BDI) at home following the 1-month post-MI interview. Initiation, interpretation and	One-month post-MI patients were interviewed using the depression section of the Structured Clinical Interview for DSM-IV (SCID-I). Patients were diagnosed with major depression if they fulfilled at least one care criterion (depressed mood or loss of interest) and at least four additional criteria (total of five) with a duration of	
		further action by professionals.	at least 2 weeks. A diagnosis of minor depression was made where patients fulfilled one to three instead of four additional criteria.	

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
Behavior, Health and Aging 2(3): 133-148  see in of 33: no age with a second and age wit	An evaluation of the accuracy of self-report depression measures in older people. n=80 made up of 20 younger adults mean age 33.3 years, 20 older adults with mo psychiatric symptoms mean age 71.6 years, 20 older adults with early onset depression mean age 67.8 years and 20 older adults with late onset depression mean age 69.5 years.	Geriatric Depression Scale (GDS), a 30-item true/false scale. Cut-off scores of 11 and 14 were used.  Beck Depression Inventory (BDI).  Standard cut-off scores were used: 0-9=no depression, 10- 15 = probable mild depression and 16 or more = moderate to severe depression.  Symptom Checklist-90-R (SCL- 90-R) is a 90 item self- assessed tool designed to measure somatic symptoms e.g. phobic anxiety, paranoid ideation. All tools completed by the patient. Initiation, interpretation and further	Schedule for Affective Disorders and Schizophrenia structured interview (SADS) which yields a diagnosis based on the Research Diagnostic Criteria and includes all DSM-III-R criteria. This interview was administered by a doctoral level psychology student trained in its use and scoring. Self-report measures were completed after the diagnostic interview.	

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Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
(Watson et al., 2003)  Journal of Family Practice 52: 956-964	Systematic review to determine accuracy of depression screening tools for older adults in primary care. Search strategy targeted studies of older adults > 65 years.	The self-assessment tools included in the review were:  The Geriatric Depression Scale 15-item (GDS-15), the Center for Epidemiologic Studies  Depression scale (CES-D) (20 items) and the SelfCARE(D) (12 items).  That administration was by the patient was not specified.	Criterion standards accepted by the review were commonly accepted, structured or semi-structured diagnostic interviews or independent evaluations by psychiatrists based on DSM-IIIR, DSM-IV, ICD-10 or Research Diagnostic Criteria.	

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
(Rogers et al., 1988)  JAGS 36: 13-21  Veterans Administration Medical Center, USA	An evaluation of the validity of self-assessment scales with older adults with dementia. n=140 patients with 7 different diagnostic categories of dementia and n= 101 neurologically unimpaired	A 94-item computerised assessment questionnaire, the Dementia Diagnostic Screening Questionnaire (DDSQ) which can be completed by patients, close relatives or friends. In this study 94% were completed by the patient.  Initiation, interpretation and further action by professionals	A series of tests:  a) medical and neurological examination  b) Cognitive capacity Screening examination  c) Hachinski Ischemic index  d) regional cerebral bloodflow measurement using Xe inhalation method  Those assessed as having dementia also had a CT and/or nuclear MRI scan.  All final clinical diagnoses were based on guidelines established by the Diagnostic and Statistical Manual III (DSM-III)	

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
(Ball et al., 2001b)  JAGS 49: 798-802  A geriatric assessment clinic, USA.	Comparison of self-administered screening test with clinician evaluation.  Women over 65 years randomly selected from the Older Adult Services and Information Systems membership, a community -based educational program for older adults. n=53 who agreed to have the clinical examination RR=	A brief two page self-administered postal survey questionnaire which includes the Clock Completion Test (CCT). The questionnaire was designed to elicit general health information and assess risk factors for Alzheimer's disease (AD). Initiation, interpretation and further action by professionals.	Clinical assessment by a geriatrician experienced in the diagnosis of AD. This comprised of a thorough history, a focused standardised physical and neurological test battery that included the Short Blessed Test, CCT, Storandt Battery, Consortium to establish a Registry for Alzheimer's Disease (CERAD) Word List Memory – immediate and delayed recall, Trail making B, Stroop test, judgement Screen and the Geriatric Depression Scale-15. A second geriatrician reviewed this assessment and the two blinded to the survey result developed a diagnosis of DAT by National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Association criteria for probable AD.	However postal survey thought to be ineffective as non-responders had a threefold greater prevalence of cognitive impairment as measured by the SBT than survey respondents.  Performance of postal survey also compared to SBT as a criterion for a diagnosis of dementia. However authors conclude that the CCT performed better than the SBT therefore not an adequate standard there these results are not reported.

Table 9.3 Study details accuracy - nutrition and dental care

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
(Lawlor et al., 2002) Age and Ageing 31: 169-174	A UK national cross sectional survey of women aged 60-79 yrs to determine the accuracy of self-reported weight among older women n= 1310 (RR 48%)	A self-completed postal questionnaire which asked for weight in stones and pounds as well as details about health problems.	Weight measurement taken by a member of the study nursing team who had undergo intensive training using a Soenhle portable scale to the nearest 100g.  Measurement was taken within 6 weeks of return of the questionnaire with subjects dressed in a light dressing gown having fasted for 6 hours.	
(Jackson et al., 1990)  Journal of Epidemiology and  Community Health 44: 162-9	To compare the outcome of a diet history interview with a self completed questionnaire. n=80 (RR = 62%) of patients aged 59-74 at a health centre in UK. Half the sample was randomly assigned to receive the interview first.	Self-completion questionnaire based on that developed to investigate the nutritional determinants of ischaemic heart disease. 62 food groups or items were included and the subject asked to indicate how many times a week they eat each item.	Diet history interview asking subjects to describe their family's weekly intake of various food types and the content of main meals. Computerised McCance and Widdowson tables were used to convert the dietary information into estimated nutritional intakes	Neither technique provides an accurate estimate of intake.
(Bush et al., 1996b)  JAGS 44: 979-981  General medicine clinics in a university based practice, USA.	Cross sectional study to assess accuracy of D-E-N-T-A-L. Convenience sample of n = 165 adults over 65 years. RR not reported.	D-E-N-T-A-L is a six item self- administered questionnaire to detect dental disease requiring a visit to the dentist. Initiation, interpretation and further action	A visual clinical examination by a dental fellow with 30 years experience.	

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
		by professionals.		
(Jones et al., 2002)  JAGS 50: 163-168  USA	Cross sectional study of self-report oral health measures. Older community dwelling male veterans from four Department of Veteran Affairs (VA) clinics (n-232) (mean age 61.9 yrs) and the VA Dental Longitudinal Study (DLS) (n= 206) (mean age 70.3 years)	D-E-N-T-A-L is a six-item self-completion questionnaire initiated, scored and interpreted by professionals. Those scoring 2 or more are likely to need dental treatment.	Clinical dental examination by trained and calibrated examiners.	
(Buhlin et al., 2002)  Community Dent Oral Epidemiol 30: 431-7	Assesses the agreement between self-reported dental conditions and clinical findings in an adult population. 723 (81%) of adults aged 20-84 returned the postal questionnaire of which 148 were randomly selected to undergo a dental examination. 47/148 were aged 75-84 years.	Self-completed postal questionnaire addressing questions such as number of teeth, presence of removable dentures and fixed prosthetics, types of restorations and more specific periodontal parameters i.e. gingival pockets, gingival bleeding, tooth mobility and oral hygiene. No instructions were given about how to do the self-examination. Two versions of the questionnaire were used, one had 25 questions and the other	Clinical dental examination by an experienced dentist or dental hygienist not knowing that the patient had answered the questionnaire.	

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Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
		66. Initiation, interpretation and		
		further action by professionals.		

Table 9.4 Focussed health care accuracy – osteoporosis

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
(Adler et al., 2003)  Mayo Clinic Proceedings 78 (6): 723-7  Pulmonary and rheumatology clinics in a Veterans Affairs medical center in USA.	Data from 2 cross-sectional studies used to evaluate the accuracy of the Osteoporosis Self-assessment Tool (OST) to predict osteoporosis in men.  Male veterans n=181, RR not reported.  Mean age in study 64.3 years (range32-87)	OST risk index is derived from self-reported age and weight only. Assessment initiated by professionals.  Questionnaire filled out by patients, scored and interpreted by professionals who are prompted to act	Bone mineral density (spine, femoral neck, total hip) measured by dual energy x-ray absorptiometry (DXA). Osteoporosis defined as any T score of -2.5 or less. T-score cut-off of -2.0 denotes osteopenia	Authors recommend OST cut-off score of 4.  Study not designed specifically to test accuracy of OST.
(Goemaere et al., 1999)  Calcified Tissue International 65: 354-358  Two community academic study centers in USA.	Cross sectional study to assess the efficiency of a self-administered questionnaire to identify postmenopausal osteoporosis. Postmenopausal women aged 50-80 years consulting general practitioners for health problems unrelated to osteoporosis. n=300, RR not reported. Age 60.9 ± 7.5 years	18-item questionnaire to be filed out by patient although in this study a few needed assistance from a family member or hospital staff (number not stated). Initiation, scoring and interpretation carried out by professionals who are prompted to act.	Bone mineral density (spine, femoral neck, total hip) measured by dual energy x-ray absorptiometry (DXA). Osteoporosis defined as any T score of -2.5 or less.	
(Lydick et al., 1998)  American Journal of Managed	A study to develop and validate a questionnaire to facilitate identification of	The development cohort completed a self-administered questionnaire of approximately	Hip and posterior-anterior lumbar spine bone mineral density (BMD) measured using	

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Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
Care 4(1): 37-48	postmenopausal women likely	60 questions on factors possibly	dual x-ray absorptiometry. Low	
	to have low bone density. Tool	associated with osteoporosis.	BMD was defined as <2 SD or	
	development cohort n= 1279	As a result of regression	more below the mean bone at	
	(mean age = 61.5 SD 9.6). Tool	modeling, a shorter self -	the femoral neck in young,	
	validation cohort n=207 (mean	completed questionnaire of	healthy white women.	
	age 63.1, SD 9.5).	factors most predictive of low		
		bone density at the femoral		
		neck in postmenopausal women		
		was developed. A 6 item		
		scoring system – SCORE		
		(Simple Calculated		
		Osteoporosis Risk Estimation)		
		was devised. SCORE was		
		completed by professionals to		
		identify risk of osteoporosis.		

Table 9.5 Study details accuracy - endocrine disorders

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
(Smith et al., 2000b)  Clinical Endocrinology 53: 703-711  Primary health care clinic in USA.	Cross sectional study to develop and validate a screening instrument to identify testosterone deficiency. Men aged 40-79 years presenting for routine check ups, flu vaccines and minor medical problems. n= 304, RR=80%, Mean age not reported.	8 item questionnaire to detect testosterone deficiency. Assessment initiated by professionals. Instrument completed and scored by patient. Interpreted by professionals.	Serum testosterone level (< 12.1 nmol/l) determined by a brief mail survey of The Endocrine Society due to the absence of a recognised gold standard.	Two samples reported in paper, the survey data from the Massachusetts Male Ageing Study collected via home interview and the data from the clinic field study. Only finding from the latter sample are reported.
(Davies et al., 1993)  Quarterly Journal of Medicine 86: 677-84	Assessment of self-testing for post-prandial glycosuria in adults aged 16-75 years. 10348 (RR 75%) patients at five practices in Ipswich returned the postal screen results.  Another sample of 442 patients from Isle of Ely were included as a normal population control group.	A postal system for self-testing for glycosuria which includes a foil wrapped dipstick and instruction card. Patients were asked to test their urine one hour after a main meal. A random sample of patients at two practices were asked to test their urine before breakfast and one hour after breakfast. Subjects recorded the result on the results card. The test was initiated, interpreted by professionals who were prompted to act.	All patients in Ipswich recording glysosuria n=330 and 49 randomly selected negative patients were invited to have a modified 75g oral glucose tolerance test. All patients in the Isle of Ely underwent oral glucose tolerance tests.	

Table 9.6 Study details accuracy - Vision and hearing

Reference, setting.	Description of study	Description of self-assessment	Reference test
(Yueh et al., 2003b)  JAMA 289: 1976-1985	Review of evidence on screening and management of hearing loss for older adults in primary care. Two studies in the review suitable for inclusion.	Included in the review is the Hearing Handicap Inventory for the Elderly – Screening (HHIE-S) which is a 10 item self- administered questionnaire. Scores range from 0-40. Initiated, scored and interpreted by professionals.	Varies slightly in the 2 studies reviewed. Criteria for actual hearing loss was failure to hear a 40-dB tone at 1 or 2 kHz in both ears or 1 and 2 kHz in one ear, or 2kHz in both ears with audioscope
(Sever et al., 1989) Perceptual and Motor Skills 69(2): 511-514	Comparison of self-assessed HHIE-S with audiological testing in a general practice population. n=59 (RR not reported), mean age 69 years.	Hearing Handicap Inventory for the Elderly – Screening Version (HHIE-S) designed to detect perceived social and emotional problems related to hearing loss. Tool has 10 items and completed by the patient. Initiation, interpretation and further action by professionals.	Standard audiological evaluation that included puretone threshold testing, speech-reception thresholds and speech-recognition testing. All audiometric measurements were performed in a sound-attenuated test room using standard clinical audiometer. Two definitions of hearing loss were used:  1) The speech frequency pure-tone average (SF-PTA) where the average threshold for frequencies of 500,1000 and 2000 Hz was ≤ 25 dB Hearing Level (HL) in the better ear.  2) Ventry & Weinstein (1983) criteria where there was a loss of 40dB HL in either 1000 or 2000 in both ears or a 40dB HL threshold at 1000 and 2000 in one ear.
(Lichtenstein et al., 1988) Ear and Hearing 9(4): 208-211	The diagnostic accuracy of the Hearing Handicap Inventory for the Elderly – Screening Version (HHIE-S) was evaluated against 5 definitions of hearing loss in	Hearing Handicap Inventory for the Elderly – Screening Version (HHIE-S), a 10-item self-administered questionnaire designed to detect perceived emotional and social problems associated with impaired hearing.	Pure-tone audiometry performed in an acoustically treated room. The HHIE-S was compared to 5 definitions of hearing loss:  1. Ventry & Weinstein criteria (H&V) – loss of 40dB HL for either the 1000 or 2000 HZ signals in both ears or

Reference, setting.	Description of study	Description of self-assessment	Reference test
	178 older adults in primary care	Total score ranges from 0-40. Initiation,	a 40dB HL loss at 1000 and 2000 Hz in one ear.
	(mean age 74.2 years).  Response rate to screening questionnaire = 89%, and to further testing 59% of those who completed screening questionnaire.	interpretation and further action by professionals. In this study subjects who completed the HHIE-S as a postal survey were referred to a speech and hearing centre for further testing with the HHIE-S and audiometry. It is the HHIE-S completed at the speech and hearing centre that is compared to the reference standard measure.	<ol> <li>Speech frequency pure-tone average (SFPTA) – if average hearing loss at 500, 1000, and 2000 Hz was greater than or equal to 25 dB HL in the better ear.</li> <li>High frequency pure-tone average (HFPTA) - if average hearing loss at1000, 2000 and 4000 Hz was greater than or equal to 25 dB HL in the better ear.</li> <li>Speech reception threshold (SRT) – if the SRT was greater than or equal to 25 dB HL in the better ear.</li> <li>Speech recognition (SR) – where speech recognition score (NU 6) in quiet was less than 90% in the better ear.</li> </ol>
(Smeeth et al., 2001a) British Medical Journal 323: 1-7	Randomised comparison of three methods of administering a brief screening questionnaire to older people: by post, interview by lay interviewer, interview by nurse.  Conducted in 106 general practices in the UK, n = 32990 over 75 years. Practices were randomly assigned to targeted screening where only people found to have a pre-specified level of problems were invited to	A postal questionnaire consisting of a range of health related questions covering the areas specified in the 1990 contract. The questionnaire had 26 items plus questions about smoking, alcohol intake and physical activity.	Participants in the universal arm had a detailed assessment by a trained nurse which covered four of the domains included in the brief assessment:  Hearing – whispered voice test  Vision – distance visual acuity at 3m with a Glasgow acuity chart.  Depression – 15 item version of the Geriatric Depression Scale  Cognition – Mini Mental State Examination.

### Self-assessment of health and social care needs by older people

Reference, setting.	Description of study	Description of self-assessment	Reference test
	have a detailed assessment or		
	universal screening where all		
	participants were invited to have		Tests for hearing, depression and cognition are not
	detailed screening.		considered to be gold standard tests therefore only the
			findings for the vision assessment are included in the
			review.

Self-assessment of health and social care needs by older people

Table 9.7 Focussed health care – mobility disorders

Reference, setting.	Description of study	Description of self-assessment	Reference test
(Jannink-Nijlant et al., 1999b) Clinical Rehabilitation 13: 492-497 One general practice, Netherlands.	Comparative study of two scales for screening mobility disorders in adults >70 years living independently. n= 81, RR = 43%, mean age =74.1 yrs.	Mobility Control Subscale (MC scale) of the short version of the Sickness Impact Profile (SIP68) is a simple self-administered questionnaire for screening mobility disorders. Initiated, scored and interpreted by professionals.	Assessment of lower extremity function following Guralnik's protocol. Theses measures are standing balance, walking speed and ability to rise from a chair.

Table 9.8 Study details accuracy - general health

Reference, setting.	Description of study	Description of self-assessment	Reference test
(Barber et al., 1980)  Journal of the Royal College of General Practitioners 30: 49- 51	The study assesses whether a postal questionnaire adequately identifies patients in need of comprehensive geriatric assessment.  83 randomly selected patients from one general practice completed both assessments RR=81%	The self-completed postal questionnaire has 9 item with yes/no format.  A patient was considered to require assessment if he/she answered 'yes' to any of the questions or failed to return the questionnaire. Initiation, interpretation and further action by professionals.	A comprehensive geriatric assessment by a member of medical or nursing staff at the practice.
(Bowns et al., 1991b) British Journal of General Practice 41: 100-104	Validation of a case finding questionnaire to identify older adults with unmet need. A questionnaire was sent to patients over 75 years at three practices - A, B, C. RR = 91%	18-item postal questionnaire requiring yes/no answers covering social support, disability, recent stresses and mood state. Completed by patients. Initiation, interpretation and further action by professionals.	An interview (within three months of receipt of questionnaire) at home with a health visitor or district nurse trained for the purpose. The interview was a structured questionnaire that included standard items covering personal and domestic circumstances, activities of daily living and health status. Intellectual impairment was tested using a subscale of the Clifton assessment procedures for the older people and anxiety and depression assessed using the General Health Questionnaire 12.
(Taine et al., 1990a) The Cicely Northcote Trust: London	Postal survey of all patients over 75 years in one general practice n= 594 RR 94.4%. For validation study a random sample of patients scoring less than the cut-off point for further assessment were also assessed at home.	Modified version of Barber 1980 8-item tool. Self-completed questionnaire with follow-up health and functional assessment by a registered nurse for those scoring above 5. Initiation, interpretation and further action by professionals.	Follow up health and functional assessment by registered nurse.
(Kerse et al., 1994)	An evaluation of a postal questionnaire to	An 8-item postal questionnaire completed by	Comprehensive medical assessment by a doctor

New Zealand Medical Journal 107: 33-6	identify older adults in the community in need of geriatric assessment and intervention. n= 64 older adults (RR=88%) from 4 general practices in New Zealand (mean age 80 years).	the older person. Initiation, interpretation and further action by professionals.	blinded to questionnaire results. The assessment involved 7 validated geriatric evaluation tools. These are: A) Functional status measures (Katz's ADL scale, PGC IADL scale). B) social status measure (OARS social resources scale). C) Psychological function measures (MMSE, GHQ). D) Physical function measure (Reuben's physical performance test PPT). E) the use of formal and informal services  The criteria for a positive test indicative of unmet need or borderline coping are score of >4 on section B, a score of <24 on MMSE or >8 on GHQ, deficits in two or more ADL functions and 4 or more IADL functions, interviewer or subject view that needs not being met on section E.
(Brody et al., 1997) Gerontologist 37(2): 182-191	The study evaluated the use of the Health Status Form (HSF) to predict older adults at risk of frailty in the coming year. The design was a retrospective observational study of a population of 5810 home-based older adults who returned the 1990 HSF.	The HSF is an eight page questionnaire posted annually to members of the Social Health Maintenance Organization (HMO), a national Medicare demonstration. The HSF includes questions on health status, service utilization, health-related behaviour, sociodemographic characteristics and physical functioning. Stepwise logistic regression was used on data from two thirds of the population to determine HSF variables that were associated with subjects who experienced frailty – there were 13 variables. A reduced model of four variables was also constructed.	The predictive ability of the HSF to assess whether a patient was frail or not was evaluated by whether the patient was judged as being 'Nursing Home Certifiable' by Social HMO staff, received authorised long-term home-based care not customarily covered by Medicare or being admitted to a nursing home sometime during the 365 days after the patient returned the HSF. One of these three criteria was considered to determine frailty.

Table 9.9 Notable excluded studies on accuracy

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
Focussed health care – mental he	ealth			
(Rabbitt, Maylor et al. 1995)  Applied Cognitive Psychology 9  Special issue S127-S152	A non-systematic review of the use of self-assessment questionnaires in cognitive psychology of older adults. Addresses theoretical aspects of the validity of self-assessment tools.	No specific assessments described	NA	
(Montorio and Izal 1996) International Psychogeriatrics8(1): 103-112	A non-systematic review of the evidence for the use of the Geriatric Depression Scale (GDS)	Self-report assessment to identify depression in older adults.		Excluded from the review as the paper includes very few details of the review e.g. inclusion criteria for studies. There are also very few details of the studies included e.g. patient groups, how the GDS was administered, sample sizes.
(Burke, Houston et al. 1989) JAGS 37: 856-60	An evaluation of the performance of the GDS among older adults with dementia.  Over 2 years 283 patients who were seen in the geriatric assessment center in USA completed the GDS and were	Self-report assessment to identify depression in older adults.	For patients in the first year of the study, clinical psychiatric diagnosis was made on the basis of record review by two geropsychiatrists and DSM-III diagnoses and a clinical dementia rating (CDR) assigned.	Although the GDS was designed to be self-administered, if the patient was unable to he or she was assisted in completing it by a trained nurse. The proportion of subjects who were helped

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
	assessed by a geropsychiatrist		During the second year of the study all patients were seen by a geropsychiatrist.	and what this help consisted of is not described so the extent that the GDS was a self-assessment is not known. Therefore the study was excluded.
(Stones and Kozma 1989) Psychology and Aging 4(1): 113-118	Comparison of the psychometric properties of a multidimensional self-report battery for use with cognitively able older adults when administered by microcomputer or interviewer. n=160 older adults in institution and community settings	The SENOTS battery contains five scales with a total of 57 items with yes/no answers. The five scales are:  1) The Memorial University of Newfoundland Scale of Happiness (MUNSH) which measures depression /happiness  2) the Physical Symptoms Scale derived for the CARE Schedule  3) the Activity Limitations Scale derived for the CARE Schedule  4) the Activity Propensity Scale (an abbreviated form of the Memorial University of Newfoundland Activities Inventory (MUNAIS)  5) the Financial Hardship Scale.	No reference test included in the study	

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
		The battery was self administered by microcomputer.		
(Leon, Olfson et al. 1996)  Journal of General Internal Medicine 11(7):426-30  Primary care clinic of Kaiser Permanente, USA.  Subjects randomly assigned to an index group (n=500) or a cross-validation group (n=501) which was the group used to provide independent evaluation of the operating characteristics of the screen.  Mean age of sample n=1001 = 49.4 SD=12.8.	Validation of a screen to test for multiple mental disorders.  Adults aged 18 to 70 years (mean = 49.4 years, SD 12.8) who could read, write and speak English and who were scheduled for face to face contact with a primary care clinician.	A self administered 26 item questionnaire that comprise separate screens for each of 6 disorders (alcohol dependence, drug dependence, generalised anxiety, major depression, obsessive compulsive and panic disorders)	Structured diagnostic interview with a trained research nurse.  Items of the interview correspond directly to symptom criteria of DSM-IV	Subject group did not included many older adults.
(Allen et al., 2001)  Preventative Medicine 33: 428-433	A review of US research on AUDIT. Seven studies included. For use in primary care but specific age groups included in studies are not specified.	Alcohol Use Disorders Identification Test (AUDIT) is a 10 item self-report measure to screen for early-stage alcohol abuse. Can be administered orally, in writing or via questionnaire. Actual method used in each study is not	Diagnosis of a current alcohol problem established by a standardised interview measure i.e. structured clinical interview for DSM-III-R, Composite International Diagnostic Interview (CIDI), Diagnostic Interview Schedule Revised (C-	This is a non-systematic review which does not include studies with many older adults. The one included study with veteran male patients used a reference standard of heavy drinking i.e. >14 drinks/week or ≥5 drinks/day

Description of study	Description of self- assessment	Reference test	Comments
	specified.	DISR).	at least monthly.
The study assesses whether Early Assessment Self Invention (EASI) can screen for cognit impairment in older adults. (RR=58%) older people attending senior centers (not patients, mean age =74 yrs; and 19 (RR=40%) outpatient a memory disorders clinic (patients, mean age = 73.8	with a maximum score of 36 presented as two booklets. The tool includes items on orientation, confrontation naming, remote memory, visual construction, recent memory and arithmetic calculation. The tool is self completed pencil and	Neuropsychological measures administered individually by an examiner. These included the Mini Mental State Examination (MMSE), Enhanced Cued Recall Test (ECR), The Mattis Dementia Rating Scale (MDRS). Patients received the same measures and also additional neuropsychological tests and full diagnostic work-up. Diagnoses were made based on DSMIII and NINCDS criteria by the psychiatrist who had evaluated the patient and reviewed at case conference.	EASI demonstrated similar correlations with neuropsychological measures as the MMSE for both patient and non-patient samples. However no comparison was made between EASI scores and clinical diagnosis therefore this data provides little evidence of accuracy of EASI.
The study evaluates how sco on the Sandoz Clinical Assessment-Geriatric (SCAG and the Self-Assessment Sca Geriatric (SASG) compare to	completed behaviour scale for older people to identify mild to moderate symptoms of	The SCAG had been used for the previous eight years of the study to measure the symptoms of behavioural disturbances associated with older age and	Authors concluded that correlations are not high enough for the SASG to be used for diagnosis decisions.
and the Self-Assessment	Sca e to	Scale – moderate symptoms of dementia. Four major areas are	Scale – moderate symptoms of behavioural disturbances associated with older age and

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
	assesses mild to moderate symptoms of dementia. Subjects included all older candidates for research protocols in treatment for dementia n=52 (mean age = 66 years, range 55-83).	function, physical complaints and self-care. It was developed from the observer-rated SCAG.	widely used scale employed for such purpose. The SCAG is performed in an hour long clinical interview with the use of operational instructions. The interviewer was blind to SASG ratings.	
(Steinbauer, Cantor et al. 1998) Annals of Internal Medicine 129(5): 353-362	Cross-sectional study with adult patients, n=1333, randomly selected from appointment lists in a university-based family practice clinic, USA.  Mean age of patients included was 43.2 years, SD 15.7 years	Three self-report questionnaires:  1) Alcohol Use Disorders Identification Test (AUDIT)  2) The CAGE questionnaire which has 4 questions that address the consequences of drinking alcohol  3) The Self-Administered Alcoholism Screening Test (SAAST) which has 9 items	Patient interview incorporating the Alcohol Use Disorder and Associated Disabilities Interview Schedule (AUDADIS) was administered by trained lay interviewers.	The AUDIT and CAGE were administered by interviewers in this study.  Patient group did not include many older adults.
Focussed health care - nutrition				
(Little, Barnett et al. 1999)  Journal of Epidemiology and  Community Health 53: 165-172	An evaluation of the validity of dietary assessment in general practice. Two groups of patients were included: a high-risk group with risk factors of cardiovascular disease n=61 and	HEA1 developed by the Health Education Authority in Oxford which is a self-completed (or nurse completed) questionnaire asks subjects to estimate the number of portions of different	A seven day weighed record. Patients weighed all food and drinks consumed during seven days and provide manufacturers data for foods.	The gold standard reference test is also self-assessed so the comparison is not useful in this review.

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
	a population group aged 18-80	food groups i.e. starchy foods,		
	years n=50. A range of dietary	fruit and vegetables, meat or		
	assessments were administered	equivalent, dairy and fatty/snack		
		foods eaten in a normal day.		
		HEA2 similar to HEA1 but		
		assesses food intake for an		
		average day or week.		
		HEA3 similar to HEA2 but		
		separates portion sizes and food		
		frequency.		
		EPIC which is a self-completed		
		food frequency questionnaire		
		The Post Graduate Nutrition		
		Centre (PGNC) self-completion		
		scoring sheets for fat and fibre		
		intake.		
(Patterson, Young et al. 2002)	Cross-sectional postal survey to	The Australian Nutrition	The authors state that there is	The reference standard used
Dublic Health Northing 5(4)	examine associations between	Screening Initiative (ANSI) is a	no gold standard for defining	does not allow adequate
Public Health Nutrition 5(1):	nutrition screening and the	12-item self-completed checklist	malnutrition in an	assessment of diagnostic
65-71	health of older women. The	for older people living in the	epidemiological setting.	accuracy.
	sample of 12939 women aged	community to determine their	Therefore greater than 6 visits	
	70-75 years (mean not	requirements for further	to a general practitioner and	
	reported) were derived from the	nutritional assessment. A	self-reported BNI outside the	The ANSI was not a specific
	older cohort of the Australian	moderate or high score is meant	acceptable range (20-24.9kgm <sup>-2</sup>	part of the ALSWH self-

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
	Longitudinal Study on Women's Health (ALSWH) (RR 37-40%) who completed a postal survey containing SF-36, questions about specific health problems e.g. diabetes, hypertension.	to guide people to speak to their health provider who then performs further assessment. The next and third stage of the initiative is diagnostic and involved biochemical assessment.	were used as surrogate measures of malnutrition.	completed questionnaire although a majority of the ANSI items were used with their exact wording. A couple of items were not the same.
Focussed health care – osteopor	osis			
(Richy, Gourlay et al. 2004)  Q J Med 97: 39-46	Epidemiological cross validation study comparing the performance of four osteoporosis risk indices in white ambulatory postmenopausal women in Belgium n=4035 seen at an outpatient osteoporosis centre.	The Osteoporosis Self- assessment Tool (OST) is based on self-reported age and weight.	Bone Mineral Density measurement.	OST was completed by researchers using data from a previous study which evaluated the performance of the Simple Calculated Osteoporosis Risk Estimation (SCORE). Therefore the OST scores obtained were not self-assessed by research subjects.
(Finley, Colburn et al. 1999)  Journal of Clinical  Rheumatology 5(4): 201-205	A comparison of a self-assessment tool of disease activity in rheumatoid arthritis (RA) with a consensus analysis of other measures.  100 consecutive patients with RA at a veterans administration	The Modified Health Assessment Questionnaire (MHAQ) is a 8 item instrument that assesses difficulty in the performance of activities of daily living asking patients to rank abilities on a scale of 1 (no difficulty) to 4	In the absence of an accepted reference test, consensus analysis was used to find the most suitable test to assess the severity of RA. This involves measuring the association between a given test and an	Management of a specific disorder. ESR was found to be the most effective test followed by the CRP and the MHAQ.

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
	(n=48) and university outpatient rheumatology unit (n= 52) RR=76%, Mean age = 57.79 yrs	(unable to do). The total score ranges from 8 to 32. Initiation, interpretation and further action by professionals.	average of tests (ranked data for comparability).  The following tests were included:  - average morning stiffness over past week (mins)  - pain level (VAS)  - Richie Index  - No. of swollen joints  - Blood tests inc. haemoglobin, haematocrit, Mean corpuscular volume (MCV), erythrocyte sedimentation rate (ESR), C-reactive protein (CRP)	For the 38 patients on Methotrexate alone the MHAQ performed virtually as well as ESR.
Focussed health care – cardiovas	scular disease and diabetes			
(Davies, Alban-Davies et al. 1991) British Medical Journal 303: 696-8	An evaluation of the accuracy of self- testing for postprandial glycosuria in one UK general practice area.	Self urine testing for glycosuria using a urine dipstick one hour after their main meal of the day and record on result card and return in the post.	75g oral glucose tolerance test (OGTT)	These data are included in Davies 1993 which is included in the review
(Davies, Ammari et al. 1999)	An evaluation of the accuracy of self- testing for postprandial	Self urine testing for glycosuria using a urine dipstick one hour	75g oral glucose tolerance test (OGTT)	None of the patients who did not have glycosuria were

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
Diabetic Medicine 16: 131-137	glycosuria in the UK Indo-Asian population n=9896 (RR=41.7%)	after their main meal of the day and record on result card and return in the post.		followed up with OGTT as a gold standard therefore diagnostic accuracy of the test not adequately assessed.
(Cameron, Jennings et al. 1997) Australian and New Zealand Journal of Public Health 21(5): 545-547	The usefulness of a questionnaire to identify unrecognised coronary heart disease (CHD) was tested.  Approximately 5000 (n=4070, RR=approximately 81%) questionnaires were distributed at large community based health and diet survey centres and a risk reduction in Australia. Those whose questionnaire responses were considered to indicate possible CHD were offered an exercise ECG. 229 accepted RR= 48.2%, mean age not reported, age range 45-69)	A 9-item self-completed questionnaire. Interpreted and acted upon by professionals.	Exercise ECG using a modified Bruce protocol.	The responses to the questionnaire were assessed and coded as 'known CHD', a response not suggestive of CHD - 'no further action' or a response consistent with CHD - 'for follow-up'. Therefore negative responses were not followed up and diagnostic accuracy not fully assessed.

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
Focussed health care – hearing o	lisorders			
(Ventry and Weinstein 1982) Ear and Hearing 3(3): 128-134	An evaluation of the HHIE in comparison to audiological examination. 100 adults aged 65-92 years (mean 75) were recruited from one of three speech and hearing centers in USA.	The Hearing Handicap Inventory for the Elderly (HHIE) is described as a self-assessment tool to assess the effects of hearing impairment on the emotional and social adjustment of older adults. There are two subscales: a 13 item subscale that explores the emotional consequences of hearing impairment and 1 12-item subscale that explores the social and situational effects.	Complete audiological evaluation.	An important study in the development of self-assessment hearing tests but in this study the HHIE is not used as a self-assessment.
Focussed health care – wound in	fection			
(Whitby, McLaws et al. 2002)  Journal of Hospital Infection 52: 155-160	Validation of patient self- assessment of a surgical-site infection (SSI) as part of a post –discharge surgical wound infection surveillance programme n=290, mean age 59.	A six item postal questionnaire includes questions about whether the wound has healed completely, the presence of redness, swelling, pain, yellow discharge, the occurrence of high fever, prescription of antibiotics. Criteria for diagnosis were:	Diagnosis of would infection by a research nurse	Study excluded as the purpose of the self-assessment is for surgical would infection surveillance rather than as a self-assessment with clinical utility for the patient.  Patient group is not specifically older adults.

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
		Presence or recall of yellow  displaying (with appearance of		
		discharge (with appearance of pus) alone or		
		2a. Presence or recall of fever and		
		b. Redness or swelling and/or		
		Recall by the patient of antibiotics prescribed by a		
		general practitioner for purported SSI		
Focussed health care – functiona	l independence			
(Yohannes, Greenwood et al. 2002)	Two single blind studies. One tests the test-retest reliability of	The Manchester Respiratory Activities of Daily Living	There is no reference test.	Diagnostic accuracy of the MRADL is not assessed. The
Age and Ageing 31: 355-358	the MRADL as a postal questionnaire (n=51, mean age	Questionnaire (MRADL) is a 21 item self-completed scale that		study compares different modes of administration of the
	74 years) which was sent twice with an interval of two weeks.	assesses respiratory disability in older adults in the community. It		same tool.
	The second study compares the	has four domains: functional		
	findings of face-to-face administration by a	ability in mobility, kitchen, domestic tasks and leisure		
	physiotherapist with postal survey.	activities.		
(Myers, Holliday et al. 1993)	A comparison of findings of self-	A 50-item instrumental activities	A set of 14 performance tasks	The paper does not give

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
Journal of Gerontology 48(5): M196-M206	assessment of functional ability with performance measures. Subjects were recruited from four urban seniors' apartment complexes in Canada n = 182 (mean age = 74.47, SD 7.67)	of daily living (IADL) questionnaire which was administered by postal survey but also by telephone interview and face-to-face interview.	including measures of motor capacity, manual ability, self-care ability, complex abilities.	proportions of subjects who complete the IADL as a self-assessment rather than as an interview assessment.  Only 99 of 183 participants completed one or more of the 14 performance measures.  Another paper (Myers 1992) which does not address diagnostic accuracy, gives additional details about the sample: 140 were contacted by mail or in person and 102 of these completed the IADL correctly. Seven received help to complete the questionnaire.
Focussed health care - oncology				
(Baulch, Larson et al. 1992) Oncology Nursing Forum 19(9): 1367-1372	The study uses a descriptive, correlational design to describe the relationship of visual acuity, tactile sensitivity and upper extremity to proficient Breast Self-examination (BSE) in women aged > 65 years. 32 women were recruited from 4	The visual, tactile and upper extremity mobility components of proficient BSE were assessed by subjects' ability to visually and tactilely detect abnormalities on a simulated breast model (SBM)	Visual acuity was measured with a standard Snellen hand-held visual acuity chart at 14 inches. Tactile sensitivity was measured by the static two-point discrimination test using a compass-type calliper on the finger pad of the 2 <sup>nd</sup> , 3 <sup>rd</sup> and 4 <sup>th</sup>	The study addresses the subjects ability to perform BSE rather than the accuracy of a self-assessment.

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
	retirement centers through an American Cancer Society (ACS) approved breast health program.	Subjects were given the		
Social care and life skills	1		T	
(Fletcher, Hansson et al. 1992)  Journal of Applied Gerontology 11(4): 489-501	Four studies were conducted to develop and validate a tool to assess occupational self-efficacy in older workers. Two studies addressed validity. One involved 166 employed adults (median age 54 years). The other involved 46 employed adults (median 53 years).	The Occupational Self-Efficacy Index (OSEI) is a 36 –item self completed tool that includes categories of job involvement, personal functioning and skills/experience. Respondents are asked to rate themselves on each item compared to other people they knew of their own age using a 5 point scale form 'worse than most' to 'better than most'.	A series of measurement questionnaires:  1) Global self-efficacy - General Self-efficacy Scale  2) Intrinsic job motivation  3) Job Stress  4) Personality  5) Previous job rewards	This study was not included in the review as it has been developed as a research tool and not as a tool to be used in older workers in their occupational setting.
(Schofield and Mishra 2003) Gerontologist 43(1): 110-120	The data for this postal survey was collected as part of the Australian Longitudinal Study on Women's Health (WHA). The	The Vulnerability to Abuse Screening Scale (VASS) is a 12- item self-completed scale that consists of four domains:	There was no gold standard reference test.	

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
	sample consisted of 10,421	vulnerability, dependence,	Determine a libert of an atmosp	
	women aged 73-78.	dejection and coercion.	Data was collected on stress	
			experience over the last 12	
			months, life events, social	
			support, dependence, health	
			related quality of life (SF-36),	
			acute and chronic illnesses, use	
			of health services, medication	
			use and body mass index.	
Comprehensive care				
(Walters, Hiffe et al. 2000)	The study addresses the	CANE is a structured multi-	The subjects' informal carers (a	CANE was administered by
	feasibility of the Camberwell	dimensional needs assessment	relative/friend/neighbour who	face-to-face interview.
Age and Ageing 29: 505-510	Assessment of Need for the	covering 24 patient-related	assisted them in their daily	
	Elderly (CANE) and to compare	domains and 2 carer-related	living on one or more occasions	
	the needs identified by patients,	domains. Examples of issues it	per week) and lead health	
	carers and professionals through	addresses are: self-care,	professional (the health	
	structured interviews.	physical illness, safety,	professional who was identified	
	Participants were randomly	managing money, psychological	by both the patient or carer and	
	recruited from patients over 75	distress. The nature and	their general practitioner as	
	years registered with 4 general	severity of problems in each	knowing them best) were	
	practices in inner city and	domain is asked about as is help	identified and interviewed.	
	suburban areas.	received and perceived need for	Identified met and unmet needs	
	SUDUI DAIT ALEAS.	•		
		help.	were compared between	
	+		patient, carer and professional.	
(Maly, Hirsch et al. 1997)	An evaluation of a screening	A 16 item self-completed	CGA	Excluded from the review as
	instrument for health and social	questionnaire including items on		none of the patients who were

## Self-assessment of health and social care needs by older people

Reference, setting.	Description of study	Description of self- assessment	Reference test	Comments
	problems prevalent in older people in the community to identify those in need of outpatient comprehensive geriatric assessment (CGA). Screening took place at senior center meal sites, n=821 and of the 555 who failed one or more criteria 150 had CGA (RR= 27%)	depression. Urinary incontinence, functional impairment and physical activities. Scored and interpreted by professionals.		assessed not to be at risk were followed by with CGA therefore the occurrence of false negatives is not known.

## 9.2 Studies considered for the effectiveness review

Table 9.10 Focussed health effectiveness: studies considered

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
(Goldberg, 1999; Goldberg et al., 1997)	General review of evidence on preventative care including screening / case finding. Review appears to be based on extensive searching uses explicit grading for evidence of recommendations on screening of older people (65+)	Professional	Varied	Professional	Professional	Additional	Review – non systematic	No- but provides useful background in terms of evidence for screening on a number of areas which could be self-assessed (e.g. diabetes, osteoporosis,) and summary of US and Canadian Task Force reviews (CTFPHC, no date; U.S. Preventive Services Task Force, no date)
(Eekhof et al., 2000)	Evaluation of routine screening in primary care for hearing, visual impairment, continence and		Random sample of cognitively intact people aged 75 and over from lists of general practitioners were	Professional	Professional	Additional	RCT (cluster) in 12 practices (1121 patients)	No. Method of administration for screening is not identified and although self-reporting questions are used most screening

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	mobility problems		screened. Mechanism of administration not specified but some data is self report some not					criteria are alternate self-report / professional assessment with no clear indication of how / when each was used.
Bowel Disease								
(Verne et al., 1993)	Examining the impact of self-administered / self interpreted faecal occult blood tests on compliance with screening	Professional	A symptomatic patients on general practice list (UK) aged 40-74 were posted a FOB kit with relevant instructions on completing and returning the test	Varied – some FOB tests were self interpreted / report	If self report patient (return to GP) otherwise professional	Additional	RCT comparing response to different tests on 1842 people aged 40-74 (569 aged 60+)	No. Provides overall compliance rats for 60+ age groups but no clinical outcome and no comparisons between approaches.
Cardiac								
(Meland et al., 1997)	Evaluates the impact of supporting patient selected behaviour change vs. usual behavioural advice	Professional	At risk patients recruited through Norwegian General Practice were asked to select behaviour changes	actions	Client	Substitution (in as much as client selects rather than Dr advises)	Cluster RCT on 22 practices, 100 clients aged 30 to 59 identified with risk factors at opportunistic screening	No, no older people studied.

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	u=in relation to CHD prevention		from a 'menu' of possibilities, progress reviewed in GP consultations					
Visual impairment / eye disease								
(Smeeth et al., 1998b), (Smeeth et al., 2004)	Systematic review of community screening for visual impairment in older people (65+). 5 RCTS. All used self-report measures of visual impairment.	Professional	In all cases the assessments were administered by a professional either in the home or clinic	Professional	Professionals (referral to others n=4) user (provided with further information about sources of help (n=1_	Additional to routine assessment	Systematic review of RCTs. 5 trials 3494 people	No – not self-assessment
(Smeeth et al., 2003)	Comparison of universal visual acuity screening with targeted screening based on response to a brief assessment including self	Professional	Unclear – three methods used in trial – face-to-face interview and postal questionnaire.	Professional	Professionals (detailed assessment / referral)	Additional to routine assessment	Cluster RCT 105 practices / 4340 participants	No - Comparison between self-assessment and other methods of assessment made.

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	reported visual problems for older (75+) people (controlled trial).							
Falls	(controlled trial)							
(Stevens et al., 2001)	Evaluates a falls prevention intervention including and environmental hazard assessment	Professional	Home visit by trained nurse to community dwelling older adults (70+) in Australian community	Professional	Person receiving the assessment is advised on environmental hazard reduction. Professionals supply equipment	Additional to usual assessment	Before and after study on 570 people examining impact on behaviour. Part of a RCT	No. The environmental assessment is conducted by a professional
Mental Health (Lewis et al., 1996)	Evaluates the impact of providing self-assessment data on mental health status (GHQ or PROQSY computerized	Professional	Patients asked to complete GHQ assessment prior to GP appointment. Consecutive attendees	Professional (GP)	Professional (GP)	Additional	RCT Patients (681) with high GHQ12 (only) randomly allocated to control, GHQ available at consultation or computerized assessment and further appointment after	No. Not older people (mean age 39.5 sd 14

Reference	Description of paper	the	Distribution, administration &	Interpretation of self-	Who is prompted to	Additional to professional	Design	Included?
		assessment	population	assessment	act	assessment?		
	assessment) to GP						consultation	
	at consultation							
(Beich et al., 2003)	Systematic review of screening and brief intervention for excessive alcohol use in general practice	Professional	includes 8 studies that screen using 'Health' or 'Lifestyle' questionnaires (unspecified in the review) but all were administered	Professional	Professional (brief intervention – generally advice + self help material)	Additional to routine assessment	Systematic review of 8 RCTs with 134393 screened and 3317 randomised (intervention vs. no intervention)	No – only one study on older people included – screening was not self - assessment.
			during a					
			consultation.					
(Pignone et al.,	Systematic review	Professional	The review	Professional	Professional	Additional to	Systematic review of 14	No. Only one study on
2003)	of screening for		includes screening	(feedback	(initiate	routine	RCTs 6383 people	older people, not using
	depression in		using a variety of	from	treatment or	assessment		self-assessment.
	adults. Included		instruments 7/14	screening	referral or			
	the effects of		of which were self-	provided to	simply assess			
	screening and		completion	health care	further)			
	feedback;		questionnaires. In	provider).				
	screening,		all cases the					
	feedback and		setting was					
	treatment advice		general practice					
	and screening as		and primary care.					
	part of a more							

## Self-assessment of health and social care needs by older people

Reference	Description of paper	the	aummistration &	Who is prompted to act	Additional to professional assessment?	Design	Included?
	integrated						
	programme to						
	improve						
	recognition and						
	management of						
	depression						

Table 9.11 General health and life skills effectiveness: studies considered

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
Medication usage								
(Neafsey et al., 2001)	Evaluation of the use of a touch screen notebook computer to deliver interactive educational software package (PEP) about self-medication (specifically drug interactions).	Professional invitation to participate.	distributed at senior centres (US) screened for functional	Self - There is no external interpretation on the automated feedback from the computer programme	Self	Additional	RCT on 60 older people (60+) comparing PEP with waiting list no intervention control examining knowledge, self efficacy and satisfaction	Yes although? balance of self-assessment vs. knowledge?
(Wasson et al., 1992)	Examines impact of use of a self completion questionnaire about common adverse drug reactions (MEDS) on function, compliance and cost of	Professional	Patients over 65 receiving one or more of 13 most common drug classes complete questionnaire prior to consultation with primary care physician (US)	Professional	Professional	Additional	Cluster RCT in 29 primary care practices (matched for speciality and size) comparing usual care with providing feedback from the MEDS questionnaire during the consultation	Yes

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	medication							
Social care / life skills								
(Kiernan et al., 1999a)	Examines the impact of self-assessment by means of a structured diary on driving performance	Professional	Volunteers recruited through a seniors centre (US)	No specific interpretation / feedback	There is a presumed mechanism that self monitoring feedback will alter driving performance	Additional	Single group before and after trial on 47 drivers mean age 71.3 years	Yes
(Neafsey et al., 2001)	See above – aimed to enhance patients ability to manage self medication with OTC products							
Modification of consultation								
(Kane et al., 1999)	Comparison of outcomes of a programme designed to	Professional	A values assessment instrument was administer during	Professional – designed to allow case managers to	Professional primarily but clients were encouraged to	Additional to standard professional assessment	Quasi experimental static group comparison with clients (n=158) of intervention site case	No. The extent to which this is 'self' assessment depends on the successful

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	support case managers in eliciting client values and preferences fro long term care clients		new client assessment / periodic reassessments of 'older' clients (mean age over 75) in a case management programme for long term care (USA)	take preference 'into account' client preference in care planning.	consider the implications of values and preferences for care decisions by means of a written brochure		managers (n=18) compared to clients (n=143) of case mangers (n=21)	implementation of the intervention, which is unclear.  Non-equivalent control group with no control for baseline values on outcome(s) assessed.
(Lewin et al., 2004a)	Systematic review of controlled trials of interventions to promote patient centred clinical consultations	Professional	Varied interventions targeted at changing practitioners (generally physicians in primary care) behaviour in the consultation, some of which included techniques aimed at eliciting the	Varied – essentially this is dependant on the success of the intervention	Professional and client	Neither – alters the form although some additional to traditional assessment is involved	17 studies (15 RCT, 2 CCT) with varying units of analysis (22-41 practices / 18-78 practitioners)	No – overall review not addressing self - assessment / older people independently. Relevant references have been identified and pursued.

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
			patient agenda					
(Wasson et al., 1999b)	See below – stated objective to improve patient provider interaction							
Health Checks								
(Byles, 2000)	Systematic review of 'health' assessment for older people (includes assessments with wider domains than simply health)	Professional	Generally recruited community dwelling people over 75 from GP lists (UK) or those in contact with primary care physician	Professional	Professional	Additional	Systematic review of 21 trials of effectiveness (20 individual pt RCT n=13549, 1 cluster n=22, 1651 pts)	No, Only two studies used pt-completed assessment – included separately.
(Johansen, 1994)	Examines 'cost effectiveness' of two methods of administering geriatric screening – postal questionnaire vs.	Professional	Inhabitants of coastal community aged 70 invited to participate – respondents were sent a postal questionnaire (or	Professional	Professional (detailed assessment)	Additional	RCT 198 invited to participate in screening	Yes

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	clinic-based consultation. No detail given on questionnaire		invited to clinic for C)					
(Newbury et al., 2001)	Examines the impact of a comprehensive home based assessment programme for older people	Professional	Random sample of patients agreed 75+ from lists of 6 GP practices in an urban setting (Australia) were invited to participate in programme. Those who accepted were volunteers were enrolled to a programme that involved a home based assessment covering a wide range of domains conducted by a	Professional	Professional - adverse findings communicated to GP	Additional	RCT on 100 eligible / consenting individuals aged over 75	No, not self-assessment

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
			nurse					
(Pathy et al., 1992b)	Evaluates use of a self completed postal screening questionnaire with selective follow up for targeting Health Visitor coordinated care to older people	Professional	Community dwelling older people (65+) on lists of 4 general practices in a UK City were posted an annual screening questionnaire and those with problems visited and further assessed	Professional	Professional (triggers further assessment)	Additional to	RCT 586 households (725 individuals) comparing screening with usual care (no routine screening)	Yes – partial – response to different screening methods available
(Tulloch et al., 1979)	The effectiveness of a programme of geriatric screening and surveillance for socio-economic, functional and health problems	Professional	All independent living patients over 70 on a GP list were invited to take part in a screening programme administered by a nurse	Professional	Professional	Additional	RCT on 295 participants comparing screening with usual (patient initiated) care	No. Although part of the screen was patient self completed all patients in the screening groups were offered face to face assessment
(Smeeth et al.,	Randomised	Professional	Community	Professional	Professional –	Substitutes	Cluster RCT (Practices)	Yes. (response rate only

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
2001b)	comparison of three methods of administering a screening questionnaire covering a range of health / functional issues to older people	(General Practice)	dwelling older people (75+) in UK patients of UK general practices with list sizes 200-700 eligible pts selected to be representative in terms of deprivation (Jarman scores)	or lay person	(detailed assessment triggered – one arm of the trial)	for alternative approaches to administering screening	with 2 (universal vs. targeted screening) X 2 (Primary care vs. geriatric management) (X3 mode of screening) with 106 practices and 32,990 people	reported)
Self care book								
(Fries et al., 1993c)	Overview of evidence on self care programmes							Not a systematic review
(Fries et al., 1993b)	Assesses the impact of a self care / health promotion programme comprising self completion health habit questionnaires	Professional (health behaviour) self (use of self care books although these were not solicited)	Retired personnel from one US employer received all communication about the intervention by post. Use of the intervention was	The person using the book must make determine the recommended actions + automated generation of	Client	Additional	Cluster ('health clubs) randomized controlled trial (n=33, 4712 individuals) comparing no intervention to questionnaire only and questionnaire and feedback (full intervention	Yes

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	and tailored feedback and self		supported by letters and	advice based on				
	care books (Take		newsletters	questionnaire				
	Care of Yourself		newsietters	responses.				
	and Aging Well)			. обранова				
(Fries et al.,	Assesses the	Professional	Members of the	The person	Client	Additional	RCT with random	Yes. Although largest
1994a)	impact of a self	(health	Public Employees	using the			controls (n=1487)	group (employees) are
	care / health	behaviour) self	Retirement	book must			followed up on claims	not older (mean age
	promotion	(use of self	System + others	make			data with others	50.9 years) two
	programme	care books	administered by	determine the			(n=29,486) sent	separate retiree groups
	comprising self	although these	Blue Shield in one	recommended			programme materials	(age 73.5, 63.6) are
	completion health	were not	US state received	actions +				reported.
	habit	solicited)	all	automated				
	questionnaires		communication	generation of				
	and tailored		about the	advice based				
	feedback and self		intervention by	on				
	care books (Take		post. Use of the	questionnaire				
	Care of Yourself		intervention was	responses.				
	and Aging Well)		supported by					
			letters and					
			newsletters					
(Moore et al.,	Assesses the	Subject of the	Books were	Self – the	Self – the	Mixed but	RCT on 785 families	No. Average age 29.5
1980b)	impact of a 'self	assessment or	delivered to	person using	person using	mostly	with 3 groups – control	
	care book' which	a family	randomly	the book	the book is	substitution	(no intervention), self	
	guides patients in	member	selected families	must make	given either a		care book only and self	

Reference	Description of	Initiation of the	Distribution,	Interpretation	Who is	Additional to	Design	Included?
Reference	paper	assessment	administration &	of self-	prompted to	professional	Design	moradou.
			population	assessment	act	assessment?		
	seeking	although	enrolled on an	determine the	self care		care book+ financial	
	appropriate care	participation	insurance plan	recommended	strategy or		incentive	
	for medical	and receipt of	(USA). All	actions	advice to			
	problems	the book was	participants were		attend for			
		unsolicited in	given an		professional			
		the first	explanatory letter		help			
		instance	and invitation to					
			an explanatory					
			seminar. Some					
			participants were					
			given a monetary					
			incentive to					
			manage problems					
			without the					
			physician visit (as					
			measured by					
			reduced visits)					
(Terry et al.,	Assesses the	Subject of the	Patients visiting	Self – the	Self – the	Mixed but	Controlled clinical trial	No. Less than 32% of
2000)	impact of delivery	assessment or	one of 4	person using	person using	mostly	(alternate week	respondents older than
	of a self care	a family	outpatient clinics	the book	the book is	substitution	allocations) on 2954	60 ???
	book on	member	(mixed inner city	must make	given either a		patients comparing no	
	satisfaction /	although the	/ suburban) for	determine the	self care		intervention, physician	
	therapeutic	book was given	family practice or	recommended	strategy or		delivered book and	
	relationship with	at the explicit	internal medicine	actions	advice to		postal delivery.	
	physician	prompting of	consultation		attend for			

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
		the primary	(USA). The self		professional			
		care physician	care book was		help			
			either given to					
			patient at a visit					
			and its use					
			described by the					
			physician or					
			distributed by					
			post with an					
			explanatory					
			letter`					
(Vickery et al.,	Assesses the	Subject of the	Invitation to	Self – the	Self – the	Mixed but	Randomised controlled	No. No indication of age
1989; Vickery et	impact of self-	assessment or	participate posted	person using	person using	mostly	trial (using Zellen's	of participants but
al., 1983)	help books (Take	a family	to all members of	the book	the book is	substitution	design) on 1625	clearly families of young
	Care of Yourself /	member	a HMO (US).	must	given either a		households (3051	children were involved
	Take Care of Your	although	Those accepting	determine the	self care		individuals) with 4	and there is no data
	Child/ Life plan	participation	were asked to	recommended	strategy or		groups (information	presented separately for
	for your health)	was prompted	consent and	actions –	advice to		only, information+	older people
	containing	in the first	those consenting	(although	attend for		telephone support, +	
	decision	instance	sent materials by	some	professional		telephone support and 1	
	algorithms + a		post. Some	telephone	help		to 1 counselling vs. no	
	self scored risk		groups had	advice /			intervention	
	appraisal +		additional	individual				
	ʻlifestyle'		telephone	counselling				
	brochures and a		support and	was also				

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	telephone		individual	available in				
	information		counselling based	2/4 groups)				
	service on		on self-assessed					
	utilisation of							
	services							
(Vickery et al.,	Assesses the	Professional	Invitation to	Self – the	Self – the	Mixed but	Randomised controlled	Yes but? Age of
1988)	impact of self-	initiation of	participate posted	person using	person using	mostly	trial on households	participants - not
	help books (Take	programme	to all Medicare	the book	the book is	substitution	(n=1009) comparing	specified although
	Care of Yourself /	(unsolicited)	eligible members	must	given either a		intervention with usual	'elderly' / over 60 is
	Life plan for your	but self-	of a HMO (US).	determine the	self care		care.	implied.
	health)	assessment	Those accepting	recommended	strategy or			
	containing	and action /	were sent all	actions -	advice to			
	decision	participation is	material by post.	although	attend for			
	algorithms + a	initiated by		some	professional			
	self scored risk	client with		telephone	help			
	appraisal +	'prompting' be		advice was				
	'lifestyle'	newsletters etc		also available				
	brochures and a							
	telephone							
	information							
	service on							
	utilisation of							
	services							
(Wagner et al.,	Assesses the	Books were	Various methods	Self – the	Self – the	Mixed but	Controlled before and	No. Less than 24% of
2001)	impact of	unsolicited but	of self-	person using	person using	mostly	after study with two	respondents older than

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	distributing a self	self-	assessment (see	the book	the book is	substitution	non equivalent control	65 ???
	care book	assessments	description)	must make	given either a		communities studying	
	(Healthwise	and	targeted at entire	determine the	self care		self reported change in	
	Handbook) to all	engagements	population of a	recommended	strategy or		a random sample of	
	households	in other	medium size	actions	advice to		households (n=5909)	
	combined with	activities were	town (US)		attend for			
	development of	user directed	(132,000		professional			
	help lines and				help			
	information							
	kiosks with							
	access points to							
	databases and							
	books across a							
	community. The							
	programme was							
	supported by							
	sponsored							
	workshops for							
	residents and							
	physicians and							
	advertising							
(Lorig et al., 1985)	Assesses the impact of self-	Subject of the assessment or	Books were distributed at a	Self – the person using	Self – the person using	Mixed but mostly	Quasi-experimental before and after trial	No, mean age of employees was 39. Less
	help books (Take	a family	20-minute	the book	the book is	substitution	with staggered	than 1% over 65.
	Care of Yourself /	member	introductory	must make	given either a		intervention time series	

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	Take Care of Your Child) containing decision algorithms on utilisation of	although participation and receipt of the book was unsolicited in	session (voluntary attendance) at the place of work. Use of the book	determine the recommended actions			at 22 workplaces (15,800 employees, 7,349 attendees, 5191 responders)	
	services	the first instance	was supported by posters and newsletters + 'payroll stuffers'.		help			
Dartmouth COOP Clinical Improvement system								
(Wasson et al., 2001)	Evaluation of web based self-assessment covering a wide range of health and social care issues, which generates tailored education and (optional) feedback to physicians	self initiated although implementation of the system was targeted and advertised within a	Web based – available to all from teenagers to older adults	Automated generation of advice and (optional) feedback to provider.	Self / professional (if automated feedback is generated)	Additional	Descriptive evaluation reporting pattern of use of and responses to the system for the first 2000 users	l = '

## Self-assessment of health and social care needs by older people

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
(Wasson et al., 1999b)	Evaluates use of patient self-assessment (includes COOP WONCA chards and MEDS) data to generate customised health advice	Professional	All patients over 70 years in US primary care practice sent a postal survey	Automated generation of advice and feedback to physician	Client and professional (non specific)	Additional	Cluster (primary care practice) randomised trial (n=22) involving 1651 patients over 69 comparing self-assessment and feedback with self-assessment but no feedback (no intervention)	Yes

Table 9.12 Comprehensive assessment effectiveness: studies considered

Reference	Description of paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
(McLachlan et al., 2001)	Assesses the impact of providing self-assessment data gathered via a computerised questionnaire to cancer physicians	Professional	Selected patients with cancer were recruited during attendance at ambulatory care clinic for 2nd or later appointment	Ambiguous but seems to be primarily professional although it is used as the basis of a 'discussion'.	Plan formulated by a 'coordination nurse' primarily for onward referral.	Additional	RCT with 450 patients (allocation 2T:1C) median age 61	No, confounding of self- assessment with co- ordination nurse + although comprehensive it concerns management of a specific condition.
(Fordyce et al., 1997)	Examines the impact of 'STAR' (Seniors assessment and referral team	Professional	Members of one HMO aged over 65 were mailed a self- administered screening questionnaire and invited to participate. STAR programme involved an assessment visit which reviewed self completed questionnaire	Professional	Professional	Additional	326 Randomly invited volunteer participants compared to 1000 matched controls who returned questionnaires but were not invited to participate	No, although self- assessment data is utilised all patients are given further face to face assessment so confounded
(Graves et al., 2003)	Describes implementation of a case management programme based on targeted	Professional	Community dwelling members of a Medicare HMO programme with COPD, CHD or diabetes aged	Professional	Plan formulated by a 'coordination nurse' primarily for	Additional	Presents results of assessments in terms of problem identification before and after programme implementation. Appears	No. Unclear if programme is self-assessment and unclear study design – authors contacted.

## Self-assessment of health and social care needs by older people

Reference	paper	Initiation of the assessment	Distribution, administration & population	Interpretation of self-assessment	Who is prompted to act	Additional to professional assessment?	Design	Included?
	interventions based on results of self-completed screening questionnaire		80+received the screen annually and were invited to participate in the case management programme		onward referral.		to derive from RCT of 3104 individuals but not reported ECM vs. usual care	

# 9.3 Studies considered for the experience of self-assessment

Table 9.13 Experience of process: focussed health care.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience	Grading
Bush L, Horenkamp N, Morley J & Spiro A (1996) (USA) (Bush et al., 1996a)	Description and evaluation of an oral health self- assessment tool.	Initiated by professionals	Distributed at university - based medical clinics	User interpreted	User prompted to contact professional	Additional to professional assessment	n=165 RR=100%	Appeared acceptable to a group of older people when their preliminary views were sought (Lane & Gallagher, 2003).	Unsupported +
			Age 65+					NB. No reference to experience of using the tool in original paper.	
Boustani M, Watson L, Fultz B, Perkins A & Druckenbrod R (2003)	Postal survey to ascertain older people's views of filling out an annual self-	The annual assessment would be initiated by professionals.	Postal distribution.  Older people living in	Professional interpretation	Professional prompted to act	Unclear, but infers additional to professional assessment	n=318 RR=64%	Just 49% respondents answered that they were willing to be screened regularly for dementia (Q: "Would you like to be screened on a regular	Unsupported +
(USA)	assessment for depression and dementia.		Continuous Care Retirement					basis for memory loss?") and only 40% responded that they would be	

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration &  Target population	Interpretation of self-assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience	Grading
			Communities.  Age 50+					willing to be screened regularly for depression.	
Grady E (1988) (USA) (Grady, 1988)	Description and evaluation of an education programme for breast self- examination.	Initiated by professionals	Taught as part of an education programme and monthly self-examination encouraged through the return of prepaid reply cards.	User interpreted	User prompted to contact professional	Substitution for professional assessment	Initial uptake: n=548 RR=49%  Follow up: Women <50: n=121 RR=37% Women=>50: n=82 RR=45%	Signif. higher response rates amongst older women suggest breast self-examination may be more acceptable, or perceived as more important, by this age group.	Unsupported +
Lach WL, Dwyer JT & Mann M (1994) (USA) (Lach et	Description and evaluation of a nutrition education	Initiated by trained volunteers	Distributed by volunteers in supermarkets, hospitals and	User interpreted	User prompted to act	Substitution for professional assessment	Programme: n>10,000 participants	Evaluation findings: 80% reported the programme materials to be "good" or "excellent" – this	Unsupported +

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience	Grading
al., 1994)	programme.		community centres. Adults age 55+				Questionnaire returns n=9,580  Evaluation: n=348 RR=35%	included a self- assessment questionnaire, information booklet, meal planner, recipes and free samples.	
Mayers C (1998) (UK) (Mayers, 1998)	Evaluation of a self-assessment questionnaire.	Initiated by professionals.	Postal with accompanying letter containing appointment for follow-up home visit by OT.  Adults requiring social services	Professional interpretation	Professional prompted to act	Additional to professional assessment	For evaluation questionnaire:  Client group: n=132  RR=49% (but dependent upon "their" professional entering the study)	Client group: 51% found self- assessment easy to complete and understand. 20% found it useful.  Professional group: 36% felt the self- assessment gave a comprehensive picture of problems and the client's perceptions of them.	Credible

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience	Grading
			support as well as input from OT (age not reported)				Professional group: n=45 RR=46%		
McQuaide S & Ehrenreich JH (1997) (USA) (McQuaide et al., 1997)	Theoretical background and description of a self-assessment instrument to identify strengths, plus case studies of its use.	Initiated by professionals	Administered by professional during consultation  Adults - not specific to older people	Professional and user interpreted	Professional and user prompted to act	Additional to professional assessment	Case study examples (n=3)	Case studies illustrate how the self-assessment of strengths can highlight positive characteristics and help clients to identify appropriate coping mechanisms.	Unsupported +
Paterson JM, Llewellyn-Thomas HA & CD Naylor (2002) (Canada) (Paterson et al., 2002)	Study to assess the feasibility and acceptability of a patient workbook for self-assessing	Initiated by professionals	Administered by professional during consultation Adults – not	Professional interpretation	Professional and user prompted to act	Additional to professional assessment	n=20 doctors RR not reported n=40 patients	95% doctors reported that the self-assessment booklet had been useful and they would use it in the future.  80% patients said they had learned from the	Credible

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience	Grading
	coronary risk.		specific to older people				RR not reported (age range 31- 63; mean age 41.4.)	self-assessment and 98% would recommend it to someone else.	
Yueh B, Shapiro N, MacLean CH & Shekelle PG (2003) (USA) (Yueh et al., 2003a)	Review of research in screening for hearing loss.	All screening tools reviewed initiated by professionals	All administered by professionals as part of hearing assessment Adults – not specific	All meant for professional interpretation		Additional to professional assessment	-	Authors report that there is evidence that older people prefer audioscope to questionnaire to measure hearing loss.	Unsupported +

Table 9.14 experience the content: focussed health care.

Reference (Country)	Structure/ Format	Issues/topics Covered	Environmental vs. internal/ personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience	Grading
Bush L, Horenkamp N, Morley J & Spiro A (1996) (USA)	6-item questionnaire Yes/no response format	Oral health	Internal	Diagnostic	Appeared acceptable to a group of older people when their preliminary views were sought (Lane & Gallagher, 2003).  NB. No reference to experience of using the tool in original paper.	Unsupported +
Boustani M, Watson L, Fultz B, Perkins A & Druckenbrod R (2003)	21-item questionnaire  Yes/no/not applicable response format for most questions	Socio-demographic details, medical status, willingness to take part in regular screening for depression and dementia.	Internal	Diagnostic	49% respondents answered that they were willing to be screened regularly for dementia (Q: "Would you like to be screened on a regular basis for memory loss?") and only 40% responded that they would be willing to be screened regularly for depression.	Unsupported +
Grady E (1988) (USA) (Grady, 1988)	Physical self- examination of breast	Breast lumps	Internal	Diagnostic	Signif. higher response rates amongst older women suggest breast self-examination may be more acceptable, or perceived as more important, by this age group.	Unsupported +
Lach WL, Dwyer JT & Mann M (1994)	Nutrition questionnaire as part of healthy eating programme	Healthy diet and nutrition. 6 domains: higher nutrient eating,	Environmental	Diagnostic	80% r(n=278) reported the programme materials to be "good" or "excellent" – this included a self-assessment questionnaire, information booklet, meal planner, recipes and free samples.	Unsupported +

Reference (Country)	Structure/ Format	Issues/topics Covered	Environmental vs. internal/ personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience	Grading
(USA)	including advice booklet, meal planner and recipes (number of items in questionnaire and response format not detailed)	lower calorie eating, lower fat eating, lower sodium eating, higher calcium eating.				
Mayers C (1998) (UK)	Lifestyle Questionnaire (no details given)	Activities of daily living & Instrumental activities of daily living	Internal & environmental	Identification of need	Client group: 51% found self-assessment easy to complete and understand. 20% found it useful.  Professional group: 36% felt the self-assessment gave a comprehensive picture of problems and the client's perceptions of them.	Credible
McQuaide S & Ehrenreich JH (1997) (USA)	38-item questionnaire 5 point semantic differential response scale	Mental health inc. depression, anxiety, self-esteem, coping difficulties and stress.	Internal	Diagnostic and identification of need	Case studies (n=3) illustrate how the self-assessment of strengths can highlight positive characteristics and help clients to identify appropriate coping mechanisms.	Unsupported +
Paterson JM, Llewellyn-	15 page booklet in 3 sections.	Risk of CHD	Internal & environmental	Predictive	95% doctors reported that the self-assessment booklet had been useful and they would use it in the future.	Credible

Reference (Country)	Structure/ Format	Issues/topics Covered	Environmental vs. internal/ personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience	Grading
Thomas HA & CD Naylor (2002) (Canada)	Section 1: defined CHD and concept of risk and described those eligible to use the workbook.  Section 2: presented each risk factor and table to translate risk into a score.  Section 3: Table for assessing relative risk.				80% patients said they had learned from the self-assessment and 98% would recommend it to someone else.	
Yueh B, Shapiro N, MacLean CH & Shekelle PG (2003) (USA)	Reviews 88 items	Hearing	Internal	Diagnostic	Some evidence that older people prefer audioscope to questionnaire to measure hearing loss.	Unsupported +

Table 9.15 Experience of content: focussed health care unsupported.

Reference (Country)	Structure/ Format	Issues/topics Covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
Cameron J, Jennings GL, Kay S et al (1997) (Australia)	9-item questionnaire  Mainly yes/no response format	Possible symptoms of coronary heart disease	Internal	Diagnostic	High response rate suggests questionnaire may be acceptable to this group BUT sample comprises people attending dietary assessment or coronary disease risk reduction centres. Of the 475 people offered follow-up, 229 (48%) accepted.
Elsen SV, Dickey B & Sederer LI (2000) (USA)	32-item 5 point semantic differential response scale	Mental health across 5 domains: relation to self & others, depression & anxiety, impulsive & addictive behaviour, daily living skills, psychosis.	Internal & interpersonal	Diagnostic	Patients' perceived involvement in treatment was significantly higher for the intervention group who had completed a self-report symptom and problem scale and whose psychiatrist reviewed and used this as a basis for designing a treatment programme.
Farrands PA & Hardcastle JD (1984) (UK)	5-item questionnaire  User asked to circle symptoms experienced in past 6 months.	Possible symptoms of bowel cancer.	Internal	Diagnostic	Low response rate probably due to the request for participants to test stool samples for occult blood rather than the questionnaire itself being unacceptable.
Lach WL, Dwyer JT & Mann M (1994) (USA)	Nutrition questionnaire as part of healthy eating programme including advice booklet, meal planner and recipes (number of items in	Healthy diet and nutrition. 6 domains: higher nutrient eating, lower calorie eating, lower fat eating, lower sodium eating, higher	Environmental	Diagnostic	80% r(n=278) reported the programme materials to be "good" or "excellent" – this included a self-assessment questionnaire, information booklet, meal planner, recipes and free samples.

Reference (Country)	Structure/ Format	Issues/topics Covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
	questionnaire and response format not detailed)	calcium eating.			
Lawlor DA, Bedford C, Taylor M & Ebrahim S (2002) (UK)	One item of a "lengthy" questionnaire (number of items not given) asking for estimated weight in stones and pounds.	Weight	Internal	Diagnostic	Found that obese older people tended to underestimate their weight, and only 51% of the sample attended for weight to be measured, suggesting that self-assessment of weight may be uncomfortable for some older people.
Little P, Barnett J, Margetts B et al (1999) (UK)	Questionnaires asking user to calculate number of portions of different food groups eaten over a specified period. (No. of items and response format not detailed)	Dietary intake	Environmental	Diagnostic	Findings reported that some people found calculating the number of weekly portions of different food types difficult.
Maynard LB (1982) (USA)	150-item questionnaire with fixed response format	Coping difficulties, stress, behavioural problems	Internal	Diagnostic	Author reports that the assessment is "readily accepted" by patients and staff.
McLachlan SA, Allenby A, Matthews J et al (2001) (Australia)	Battery of 3 questionnaires:  1. 32-items, 4 point semantic differential response scale.	<ol> <li>Cancer patients         perceived need.</li> <li>Functioning in 5         domains: physical, role,         emotional, social,</li> </ol>	Internal & environmental	Diagnostic and identification of need	No signif. differences found between control and intervention groups with respect to identified cancer-related needs, quality of life measures, psychosocial functioning or satisfaction with care.

Reference (Country)	Structure/ Format	Issues/topics Covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
	<ol> <li>30-item, response format not reported</li> <li>13-items, 4 point semantic differential response scale.</li> </ol>	cognitive function.  3. Depression			
Prager E & Tanaka H (1980) (USA)	170-item questionnaire with Likert-type response format.	Mental health inc. anxiety, depressive symptomology, self- esteem and self- reliance.	Internal	Diagnostic	Although not tested, one of the reasons for developing a client-developed tool was to ensure the tool reflected the clients' perceptions and priorities thus making the assessment more meaningful and relevant.
Rhodes T, Girman CJ, Jacobsen SJ et al (1995) (USA)	Questionnaire (no. of items not detailed) 7 point scale of severity for each symptom.	Urinary symptoms	Internal	Diagnostic	Mean symptom scores obtained by oral interview were 1-2 points lower than those from self-administered questionnaire (p<0.01).
Schow RL, Reese L & Smedley TC (1990) (USA)	Questionnaire (no details given)	Hearing loss	Internal & environmental	Diagnostic	Very poor uptake of follow-up testing – 6 of the 123 people who "failed" the screening questionnaire (5%).
Toner J, Gurland B, Teresi J (1988) 43(5): 136-140 (USA)	20-item questionnaire with 4 point scale of severity for each symptom.	Depression	Internal	Diagnostic	Having first completed the interviewer-administered test, 57% (n=47) older people declined to complete the self-assessment tool. 15 of this group requesting that the questionnaire be read to them.

## Self-assessment of health and social care needs by older people

Reference (Country)	Structure/ Format	Issues/topics Covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
Wilcox S & King AC (2000) (USA)	Telephone interview included 3 items relating to alcohol consumption.  32-item self-assessment tool with one item relating to alcohol consumption.	Telephone interview:  Diet and physical activity.  Self-assessment:  Diet  Focus of this study – alcohol consumption	Internal	Diagnostic	The 2 alcohol consumption measures were signif. correlated. However, 13% older people reported a higher level of intake on the single item self-completion measure compared with 1.5% on the telephone interview.
Yohannes AM, Greenwood YA & Connolly MJ (2002) (UK)	21-item questionnaire 4-point semantic differential response scale	Activities of daily living & Instrumental activities of daily living	Internal	Diagnostic	High response rates suggest questionnaire may be acceptable. However, study was conducted with a sample of older people known to the researchers from a previous interview study.

Table 9.16 Experience of process: focussed health care unsupported.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience
Cameron J, Jennings GL, Kay S et al (1997) (Australia)	Describe use and report cost-effectiveness of questionnaire to identify previously unrecognised coronary heart disease.	Initiated by professionals	Distributed at large health centres, diet survey centres and risk reduction centre  Adults age 45 +	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=4047  RR ~ 80%  ("out of approx. 5000")	High response rate suggests questionnaire may be acceptable to this group BUT sample comprises people attending dietary assessment or coronary disease risk reduction centres. Of the 475 people offered follow-up, 229 (48%) accepted.
Elsen SV, Dickey B & Sederer LI (2000) (USA_	Study to investigate whether mentally ill inpatients who completed a self-report symptom and problem rating scale would feel more	Initiated by professionals	Distributed in a psychiatric hospital  Adults (age not reported)	Professional interpretation with patient.	To increase user - involvement	Additional to professional assessment. Reviewed by psychiatrist with patient to target treatment.	Whole study: n=109  Intervention group: n=23  RR=100%	Patients' perceived involvement in treatment was significantly higher for the intervention group who had completed a self-report symptom and problem scale and whose psychiatrist reviewed and used this as a basis for designing a treatment programme.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self-assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience
	involved in their care than those who hadn't.							
Farrands PA & Hardcastle JD (1984) (UK)	Description and evaluation of colorectal cancer screening by self- assessment questionnaire.	Initiated by professionals	Postal  Adults aged 45-74  years	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=527 RR=34%	Low response rate probably due to the request for participants to test stool samples for occult blood rather than the questionnaire itself being unacceptable.
Lawlor DA, Bedford C, Taylor M & Ebrahim S (2002) (UK)	Study to determine the accuracy of self-reported weight among older women.	Initiated by professionals	Postal questionnaire Women aged 60-79	Professional interpretation	Professional prompted to act	Substitution for professional assessment	Overall:  n=1636  RR=60%  Reported weight:  n=1549  RR=57%	Found that obese older people tended to underestimate their weight, and only 51% of the sample attended for weight to be measured, suggesting that self-assessment of weight may be uncomfortable for some older people.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience
Little P, Barnett J, Margetts B et al (1999) (UK)	Validation of a range of dietary assessment instruments, including simple self-assessment questionnaires, in general practice.	Initiated by professionals	Recruitment into study by nurse over the telephone.  Self-assessment tool distributed by practice nurse during consultation.  Adults aged 18-80.  Stratified sampling with upper stratum aged 65-80.	Professional interpretation.	Professional prompted to act	Additional to professional assessment	n=111 RR=40%	Findings reported that some people found calculating the number of weekly portions of different food types difficult.  Obese people were likely to underestimate their energy intake.
Maynard LB (1982) (USA)	To describe the conceptual basis, development and use of the Maynard Personal Assessment Rating	Initiated by professionals	Administered during first visit to transitional care setting (i.e. between hospital and home) prior to leaving hospital.  Adults with mental illness. Age not	Professional interpretation	Professional prompted to act	Additional to professional assessment	N/A	Author reports that the assessment is "readily accepted" by patients and staff.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience
			reported.					
McLachlan SA, Allenby A, Matthews J et al (2001) (Australia)	Study to determine whether patient assessed needs supplied to the physician during consultation improves targeting of psychosocial needs and hence care outcome and satisfaction	Initiated by professionals.	Invited to participate by research nurse at hospital outpatients clinic. Electronic questionnaire completed while waiting to see physician at outpatients clinic.  Adults with cancer.  Age range 18-92, median age 61.	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=450 RR=59%	No signif. differences found between control and intervention groups with respect to identified cancer-related needs, quality of life measures, psychosocial functioning or satisfaction with care.
Prager E & Tanaka H (1980) (USA)	Describes the development of a client-developed	Initiated by professionals	Administered by professional in intermediate care setting.	Professional and user interpreted	Professional and user prompted to act	Additional to professional assessment	N/A	Although not tested, one of the reasons for developing a client-developed tool was to ensure the tool reflected the clients'

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self-assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience
	measure for self-assessment of people with mental illness.		Adults with mental illness. Not specific to older people.					perceptions and priorities thus making the assessment more meaningful and relevant.
Rhodes T, Girman CJ, Jacobsen SJ et al (1995) (USA)	Study to assess the mode of questionnaire administration on reporting of urinary symptoms	Initiated by professionals	Compared self-administered questionnaires (completed at home with researcher present) with face-to-face interviews with telephone interviews.  Adults aged 40 to 79 years.	Professional interpretation	Professional prompted to act	Additional to professional assessment	Self-administered: n=471 RR=99% Interview: n=410 RR=87% Telephone interview: n=189 RR=95%	Mean symptom scores obtained by oral interview were 1-2 points lower than those from self-administered questionnaire (p<0.01).
Schow RL, Reese L & Smedley TC (1990) (USA)	Description and evaluation of a hearing	Initiated by professionals and dental	Administered in the waiting room of a dental surgery.	Professional interpretation (dentist)	User prompted to act	Additional to professional assessment	n=597	Very poor uptake of follow-up testing – 6 of the 123 people who "failed" the screening

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self-assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience
	loss screening programme.	surgery staff.	Adults – not specific to older people.				RR=69%	questionnaire (5%).
Toner J, Gurland B, Teresi J (1988) (USA)	Comparison of a self-completion tool and an interviewer-administered tool for assessing mental health and disability in older people.	Initiated by professionals.	Administered by professionals in a medical centre.  Older people aged 65+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=34 RR=43%	Having first completed the interviewer administered test, 57% (n=47) older people declined to complete the self-assessment tool, 15 of this group requesting that the questionnaire be read to them.
Wilcox S & King AC (2000) (USA)	Comparison of a telephone interview with a section on alcohol consumption with a self-	Initiated by professionals.	Telephone survey (not detailed by whom).  Self-completion tool administered at health centre.	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=134 for both questionnaires. RR not given	The 2 alcohol consumption measures were signif. correlated. However, 13% older people reported a higher level of intake on the single item self-completion measure compared with 1.5% on the telephone interview.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self-assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience
	completion dietary assessment tool with 1 item on alcohol consumption.		Older people aged 64+					
Yohannes AM, Greenwood YA & Connolly MJ (2002) (UK)	To test the reliability of a postal ADL questionnaire.	Initiated by professionals.	Postal  Older people age 60+	Professional interpretation	Professional prompted to act	Additional to professional assessment	1 <sup>st</sup> mailing: n=60 RR=86% 2nd mailing: n=51 RR=93%	High response rates suggest questionnaire may be acceptable. However, study was conducted with a sample of older people known to the researchers from a previous interview study.

Table 9.17 Experience of process: general health care.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for/additional to prof. assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience	Grading
Barber H. (1988) (UK)	To evaluate acceptability of regular self-assessment and personal health record for older people.	Initiated by professionals	Distributed during home visit by health visitor for self-completion every 6 months.  Older people aged 65+	User interpreted	User prompted to contact professional	Substitution for professional assessment	n=97 RR=75%	90% respondents reported that they found the booklet easy to read and understand. 91% indicated that they found the checklist of risk factors useful, 85% said they found the symptom checklist useful and 86% felt all older people should use the booklet.	Credible +
Porter AMD (1987) (UK)	To test the feasibility of a self-assessment screening questionnaire for use with older people.	Initiated by professionals	Postal with covering letter from GP surgery and birthday card from surgery staff.  Older people aged 65+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=133 RR= 84%	Authors noted an "enthusiastic" response from older people with "many" making unprompted positive comments about the scheme.	Unsupported +
Stuck AE, Elkuch P,	To test the feasibility of a self-	Initiated by professionals	Postal	Professional interpretation	Professional prompted to act	Additional to professional assessment	UK: n=348	Majority of people found the lengthy questionnaire easy to	Unsupported +

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for/additional to prof. assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience	Grading
Ander J et al (2002) (Switzerland, Germany, UK)	administered questionnaire for health risk appraisal in older people.						RR=58% Germany: n=149 RR=57% Switzerland: n=213 RR=51%	comprehend (UK 81%; Switzerland 97%; Germany 93%) and to complete (UK 83%; Switzerland 96%; Germany 91%).	
Terry PE & Healey ML (2000) (USA)	To examine whether increasing physicians' role in educating patients through use of a self-care book would improve patient satisfaction.	Initiated by professionals initially for later user- initiated use.	Group 1: Given book by physician during routine visit. Group 2: Postal distribution Group 3: No self-care book (controls)  Adults (32% over 60)	User interpretation	User prompted to act	Substitution for professional assessment	Total n=2140 RR=72%	Most patients were satisfied with the self-care book and believed it to be a credible source of information (overall satisfaction scores are given but not explained). Patients who had received the book from the physician were signif. more satisfied with their care and communication with their physician than controls.	Credible +

Table 9.18 Experience of content general health care.

Reference (Country)	Structure/ format	Issues/topics covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience	Grading
Barber H. (1988) (UK)	9-item questionnaire Yes/no response format	Social functioning and general health	Internal and environmental	Predictive and diagnostic	90% respondents reported that they found the booklet easy to read and understand. 91% indicated that they found the checklist of risk factors useful, 85% said they found the symptom checklist useful and 86% felt all older people should use the booklet.	Credible +
Porter AMD (1987) (UK) (Porter, 1987)	5-item questionnaire Yes/no response format	General health, hearing, presence of someone to call on in an emergency	Internal and environmental	Predictive and diagnostic	Authors noted an "enthusiastic" response from older people with "many" making unprompted positive comments about the scheme.	Unsupported +
Stuck AE, Elkuch P, Ander J et al (2002) (Switzerland, Germany, UK) (Stuck et al., 2002)	32-page questionnaire (no. of items not reported)  Response format not reported	Ongoing medical conditions; medication use; physical activity; general health; nutrition; eyesight; hearing; alcohol and tobacco use; mental health; social support.	Internal and environmental	Predictive and diagnostic	Majority of people found the lengthy questionnaire easy to comprehend (UK 81%; Switzerland 97%; Germany 93%) and to complete (UK 83%; Switzerland 96%; Germany 91%).	Unsupported +

## Self-assessment of health and social care needs by older people

Reference (Country)	Structure/ format	Issues/topics covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience	Grading
Terry PE & Healey ML (2000) (USA) (Terry et al., 2000)	Self-help guide including advice and information on over 100 health-related issues.	Includes home remedies for common minor ailments, advice for dealing with children's symptoms and information about when to call the physician.	Internal	Diagnostic	Most patients were satisfied with the self-care book and believed it to be a credible source of information (overall satisfaction scores are given but not explained). Patients who had received the book from the physician were signif. more satisfied with their care and communication with their physician than patients in the other 2 groups.	Credible +

Table 9.19 Experience of content: general health care: unsupported.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self-assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
Barber JH, Wallis JB & McKeating E (1980) (UK) (Barber et al., 1980)	To test the feasibility of a self-assessment screening questionnaire for use with older people.	Initiated by professionals	Postal, with covering letter from GP.  Older people aged 70+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=83 RR=81%	High response rate seen as an endorsement of the acceptability of the self-assessment.
Bowns I, Challis D, Tong M S (1991) (UK) (Bowns et al., 1991a)	To test the feasibility of a self-assessment screening questionnaire for use with older people.	Initiated by professionals	Postal, with covering letter from GP.  Older people aged 75+.	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=1460 RR=91%	High response rate seen as an endorsement of the acceptability of the self-assessment.
Cameron AW & Wright J (1987) (UK) (Cameron et al., 1987)		Initiated by professionals	Postal, with covering letter from GP.  Older people aged 75+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=335 RR=95%	High response rate suggests older people found the assessment acceptable.  Authors report comprehensibility and acceptability "checked" by health visitors but these

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
								findings are not reported.
Fries JF, Bloch DA, Harpington H et al (1993) (USA) (Fries, 1993)	Evaluation by RCT of the effectiveness of a health promotion program using a self-help manual.	Initiated by users	Postal  "Retirees"  Mean age 68	User interpreted	User prompted to act	Substitution for professional assessment	Intervention group:  n=931  RR=58% at yr 1  RR=47% at yr 2  Control group:  n=871  RR=58% at yr 1  RR=47% at yr 2	Response rates suggest this type of self-assessment is acceptable to some older people.  Amongst those returning follow-up questionnaires there was a significant difference between groups favouring the intervention group in: systolic blood pressure, pounds over ideal weight, high dietary fat, salt intake, seat belt use and health risk score.
Fries J (2001) (USA) (Fries, 2001)	A self-help manual for health including self-	Initiated by users	Available to purchase.	User interpreted	User prompted to act	Substitution for professional assessment	N/A	Book in its third edition with more than 500 000 copies sold suggests the
	assessment algorithms for		Describes target			122333		book is well-received by a number of older people.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
	common ailments.		population as people of pre-retirement age and older.					
Hebert R, Bravo G, Korner-Bitensky N et al (1996) (Canada) (Hebert et al., 1996a)	To develop and test a postal screening questionnaire for use in primary care.	Initiated by professionals	Postal, sent with a birthday card. Older people aged 75+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=842 RR=87%	High response rate suggests older people found the assessment acceptable.
Killingback P. & Sanderson C. (1987) (UK) (Killingback et al., 1987)	To test the feasibility of a self-assessment screening questionnaire for use with older people.	Initiated by professionals	Postal, accompanying letter included a date and time for follow-up visit by health visitor.  Older people aged 75+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=809 RR=91%	High response rate suggests older people found the assessment acceptable.
Maly RC, Hirsch SH & Reuben DB (1997)	To evaluate the clinical	Initiated by professionals	Administered at community	Professional interpretation	Professional prompted to	Additional to professional	n=150	Low sensitivity for detection of urinary

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
(USA) (Maly et al., 1997)	performance of a self-completion screening questionnaire for selecting older people for outpatient comprehensive assessment.		centres providing meals for older people.  Older people aged 64+ (mean age 76)		act	assessment	RR not given	incontinence suggests some older people were reluctant to report this on the self-completion questionnaire.
Moore SH, LoFerfo J & Inui AS (1980) (USA) (Moore et al., 1980a)	Study to assess effect of a self-care book on families visits to the physician.	Books distributed by researchers for later use initiated by user.	Distributed to families' homes by volunteers. Covering letter described the book as a gift from the community clinic and United Healthcare.  "Middle class families"	User interpretation	User prompted to act	Substitution for professional assessment	n=460 families received the book. Telephone survey of usage: RR=64%	Findings from telephone survey revealed:  Group 1 (no financial incentive) - most or all of the book was read by 49% of the families. 16% reported reading none of the book and 36% reported using the book for at least one specific problem.  Group 2 (with financial incentive) – 46%, 16% and 41% respectively.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
Pathy J, Bayer A, Harding K et al (1992) (UK) (Pathy et al., 1992a)	Randomised trial of case finding and surveillance of older people at home	Initiated by professionals	Postal, with covering letter from GP.  Older people aged 65+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=272 RR~74% (inferred from other data)	Good response rate suggests older people found the assessment acceptable.
Smeeth L, Fletcher AE, Stirling S et al (2001) (UK) (Smeeth et al., 2001b)	Cluster randomised trial to compare 3 methods of administering a brief postal questionnaire.	Initiated by professionals.	Comparison of 3 methods: post, interview by nurse and interview by lay interviewer.  Older people aged 75+.	Professional interpretation	Professional prompted to act	Substitution for professional assessment.	Postal questionnaire: n=7580 RR=84.3% Lay interview: n=4822 RR=75.1% Nurse interview: n=4325 RR=75.3%	High response rate and low percentage of missing values for self-completion questionnaire suggests this was an acceptable method for older people.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
Taine D, Cox PF & Shaw A (1990)  (UK) (Taine et al., 1990b)	To test the feasibility of a self-assessment screening questionnaire for use with older people.	Initiated by professionals	Postal with covering letter from GP.  Older people aged 75+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=564 RR=94%	High response rate suggests older people found the assessment acceptable.
Taylor R., Ford G. & Barber H. (1983)  (UK) (Taylor et al., 1983)	To test the feasibility of a self-assessment screening questionnaire for use with older people.	Initiated by professionals	Postal with covering letter from GP.  Older people aged 75+	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=619 RR=86%	High response rate suggests older people found the assessment acceptable.
Victor CR (1988) (UK) (Victor, 1988)	Study to compare long and short format questionnaires and different response formats in post-discharge survey.	Initiated by professionals	Postal following discharge from hospital.  Older people aged 65+	Professional interpretation	Professional prompted to act	Additional to professional assessment	Long version: n=522 RR=87% Short version: n=510 RR=85%	Both long and short questionnaires obtained equally high response rates and were concluded to be equally acceptable to sample of older people following discharge from hospital. Response format seems to make little

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
							Response formats – similar RRs (figures not given)	difference.
Wasson JH, Stukel TA, Weiss JE et al (1999) (USA) (Wasson et al., 1999b)	Stratified RCT to compare standard community-based physician care of older people with self-assessment screening questionnaire plus information and advice booklet.	Initiated by professionals	Postal plus customised mailed response letter directing people in intervention group to relevant sections of information and advice booklet.  Older people aged 70+	Professional interpretation	Professional and user prompted to act	Additional to professional assessment	n=1651 RR=73% in control group RR=75% in intervention group	In intervention group ratings of health care improved for 8 of the 11 practices. In control group ratings of health care improved for just 1 of the 11 practices – a signif. difference.  No difference in overall self-rated health between the 2 groups, although in the intervention group there were improvements in 18 of the 22 health assessments.
Wilcock G.K. (1979) (UK) (Wilcock, 1979)	To test the feasibility and usefulness of a	Initiated by professionals	Postal with covering letter from GP.	Professional interpretation	Professional prompted to act	Additional to professional assessment	n=454	High response rate suggests older people found the assessment

## Self-assessment of health and social care needs by older people

Reference (Country)	Description of paper	Initiation of the self- assessment	auministration &	Interpretation of self- assessment	prompted to	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
	self-assessment screening questionnaire for use with older		Older people aged 65+				RR=94%	acceptable.
	people.							

Table 9.20 Experience of content: general health care - unsupported.

Reference (Country)	Structure/ format	Issues/topics	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
Barber JH, Wallis JB & McKeating E (1980) (UK) (Barber et al., 1980)	9-item questionnaire Yes/no response format	Social functioning and general health	Internal and environmental	Predictive and diagnostic	High response rate seen as an endorsement of the acceptability of the self-assessment.
Bowns I, Challis D, Tong M S (1991) (UK) (Bowns et al., 1991a)	18-item questionnaire Yes/no response format	ADL; IADL; social support; mental health	Internal and environmental	Predictive and diagnostic	High response rate seen as an endorsement of the acceptability of the self-assessment. Authors report comprehensibility and acceptability "checked" by health visitors but these findings are not reported.
Cameron AW & Wright J (1987)  (UK) (Cameron et al., 1987)	7-item questionnaire  Mostly yes/no response format	Social support, ADL, general health	Internal and environmental	Predictive and diagnostic	High response rate suggests older people found the assessment acceptable.
Fries JF, Bloch DA, Harpington H et al (1993) (USA) (Fries et al., 1993a)	Self-help guide emphasising the importance of good health habits and containing algorithms for determining appropriate responses to	Details of self-help guide not included.	Internal and environmental	Diagnostic	Response rates suggest this type of self- assessment is acceptable to some older people. Amongst those returning follow-up questionnaires there was a significant difference between groups favouring the intervention group in: systolic blood pressure, pounds over ideal weight, high dietary

Reference (Country)	Structure/ format	Issues/topics covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
	common medical problems				fat, salt intake, seat belt use and health risk score.
Fries J (2001) (USA) (Fries, 2001)	Self-help guide emphasising the importance of good health habits and containing 45 algorithms for determining appropriate responses to common medical problems	Includes self- assessment algorithms for joint pain; chest pain; lower back pain; shortness of breath; constipation; abdominal pain; incontinence; fatigue; nausea and vomiting; problems with ADL.	Internal and environmental	Diagnostic	Book in its third edition with more than 500 000 copies sold suggests the book is well-received by a number of older people.
Hebert R, Bravo G, Korner-Bitensky N et al (1996) (Canada) (Hebert et al., 1996a)	21-item questionnaire Yes/no response format	ADL; IADL; social support; mental health, vision and hearing.	Internal and environmental	Predictive and diagnostic	High response rate suggests older people found the assessment acceptable.
Killingback P. & Sanderson C. (1987) (UK) (Killingback et	Short questionnaire (no. of items not given)  Likert scale response format (no. of response	Problems with eyes; ears; teeth; or feet. Living arrangements and help at home.	Internal and environmental	Predictive and diagnostic	High response rate suggests older people found the assessment acceptable.

Reference (Country)	Structure/ format	Issues/topics	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
al., 1987)	options not given)				
Maly RC, Hirsch SH & Reuben DB (1997) (USA) (Maly et al., 1997)	16-item questionnaire  Yes/no and 5-point Likert scale response formats	Depression; falls; urinary incontinence; functional impairment and social activities	Internal	Diagnostic	Low sensitivity for detection of urinary incontinence suggests some older people were reluctant to report this on the self-completion questionnaire.
Moore SH, LoFerfo J & Inui AS (1980) (USA) (Moore et al., 1980a)	Self-help guide emphasising the importance of good health habits and containing algorithms for determining appropriate responses to 63 common medical problems	Includes advice re e.g. smoking cessation and healthy eating. Algorithms for headaches; chest pain; sore throat; abdominal pain; lower back pain; joint pain and nausea and vomiting.	Internal and environmental	Diagnostic	Findings from telephone survey revealed:  Group 1 (no financial incentive) - most or all of the book was read by 49% of the families. 16% reported reading none of the book and 36% reported using the book for at least one specific problem.  Group 2 (with financial incentive) – 46%, 16% and 41% respectively.
Pathy J, Bayer A, Harding K & Dibble A (1992) (UK) (Pathy et al., 1992a)	30-item questionnaire  Response format not detailed	Living arrangements; recent health; present medication; physical handicap, mobility and falls; social activities; ADL and IADL; continence; eyesight	Internal and environmental	Predictive and diagnostic	Good response rate suggests older people found the assessment acceptable.

Reference (Country)	Structure/ format	Issues/topics	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
		and hearing; independence; mental health; present use and perceived need for services; changes in past year and present concerns.			
Smeeth L, Fletcher AE, Stirling S et al (2001) (UK) (Smeeth et al., 2001b)	29-item questionnaire with mostly 3-point Likert-type response format.	ADL; IADL; social support; mental health, vision, hearing, smoking, alcohol intake, physical activity.	Internal and environmental	Diagnostic	High response rate and low percentage of missing values for self-completion questionnaire suggests this was an acceptable method for older people.
Taine D, Cox PF & Shaw A (1990) (UK) (Taine et al., 1990b)	8-item questionnaire  Mostly yes/no response format	Living arrangements; functional ability; services used and vision/hearing.	Internal and environmental	Predictive and diagnostic	High response rate suggests older people found the assessment acceptable.
Taylor R., Ford G. & Barber H. (1983)	4-item questionnaire  Yes/no response format	General health; hearing	Internal	Diagnostic	High response rate suggests older people found the assessment acceptable.

Reference (Country)	Structure/ format	Issues/topics	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
(UK) (Taylor et al., 1983)					
Victor CR (1988) (UK) (Victor, 1988)	Long questionnaire - 117 items (12 pages)  Short questionnaire - 47 items (4 pages)  2 response formats for comparison:  Circle number and tick box	Physical disability; use of services; preparation for discharge from hospital; demographic characteristics; living arrangements.	Internal and environmental	Predictive and diagnostic	Both long and short questionnaires obtained equally high response rates and were concluded to be equally acceptable to sample of older people following discharge from hospital. Response format seems to make little difference.
Wasson JH, Stukel TA, Weiss JE et al (1999) (USA) (Wasson et al., 1999b)	30-item questionnaire  Not simple yes/no response format (no details given)	IADL; medications taken; "degree of bother from common geriatric symptoms".	Internal and environmental	Diagnostic	In intervention group ratings of health care improved for 8 of the 11 practices. In control group ratings of health care improved for just 1 of the 11 practices – a signif. difference.  No difference in overall self-rated health between the 2 groups, although in the intervention group there were improvements in 18 of the 22 health assessments.

Reference (Country)	Structure/ format	Issues/topics covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
Wilcock G.K. (1979) (UK) (Wilcock, 1979)	6-item questionnaire  Yes/no response format	Pain, stiffness and swelling in legs and feet.	Internal	Diagnostic	High response rate suggests older people found the assessment acceptable.

Table 9.21 Experience of process: social care and life skills.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ Administration & target population	Interpretation of self-assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience	Grading
Arksey H, Hepworth D & Qureshi H (2000) (UK)	Interview survey to investigate the impacts of the Carers Act both on local policy and practice and on carers themselves.	Carers' assessments:  Mostly initiated by professionals	Assessment forms distributed by professionals (no further details given).  Adult carers (age and age of cared for person not detailed)	Professional interpretation	Professional prompted to act.	Usually additional to professional assessment, but may be substitution for professional assessment.	Interview survey: n=51	Carers generally preferred face to face assessments compared with self- assessment, although the latter was seen as useful if used in conjunction with an interview.	Unsupported +
Heywood F Galvin J & Means R (1999) (UK)	Describes the HOOP assessment tool, its development and pilot	Initiated by lay volunteers / charity workers.	Mailed for self- completion at home prior to housing interview. Older people (not defined)	User and professional interpretation	Used to help user make housing- related decisions	Neither	Pilot testing: n=58 RR not reported	From pilot testing: Older people reported being pleased that their thoughts	Unsupported +

testing.				had been	
				clarified, felt	
			2 case	more able to	
			studies	take control of	
				the decision-	
				making	
				process,	
				questionnaire	
				seen as user-	
				friendly.	
				Enables	
				workers to	
				focus on	
				information	
				needs while	
				acknowledging	
				people's	
				emotional	
				needs.	

Table 9.22 Experience of process: social care and life skills.

Reference (Country)	Structure/ format	Issues/topics covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience	Grading
Arksey H, Hepworth D & Qureshi H (2000) (UK)	Not described.	Health and leisure interests; need for breaks or respite; main difficulties in current caring situation; further help which would be useful.	Internal and environmental	Predictive and diagnostic	Carers generally preferred face to face assessments compared with self-assessment, although the latter was seen as useful if used in conjunction with an interview.	Unsupported +
Heywood F, Pate A, Galvin J & Means R (1999) (UK)	Over 150 items  Complex response formats including 10-point rating scales, open responses and prioritisation chart.	Accommodation characteristics inc. size and space; condition of the property; comfort and design; location; managing; costs; security and safety; independence; well-being and quality of life; priorities; looking to the future.	Internal and environmental	Predictive and diagnostic	From pilot testing: Older people reported being pleased that their thoughts had been clarified, felt more able to take control of the decision-making process, questionnaire seen as user-friendly. Enables workers to focus on information needs while acknowledging people's emotional needs.	Unsupported +

Table 9.23 Experience of process: social care and life skills: unsupported.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ Administration & target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self-assessment or other indicator of experience
Audit Commission (2004) (UK)	Audit commission report including review of progress with assessments of carers of older people.	Initiated by professionals	Assessment forms distributed by professionals (no further details given).  Adult carers of older people	Professional interpretation	Professional prompted to act.	Additional to or substitution for professional assessment	Survey of carers: n~480 RR~40%	About half of carers reported that they had been asked if they needed help as a carer. At 2 of the 6 English sites surveyed this was carried out as a self-assessment. Carers appreciated being offered an assessment but report does not differentiate between self-assessment and interview assessment.
Berkman B, Chauncey S, Holmes W. et al (1999) (USA)	To test the use of a quality of life questionnaire as a screen predicting clients' needs for social work assessment.	Initiated by professionals	Distributed to people waiting to see their primary care physician, plus an additional mailed sample.	Professional interpretation	Professional prompted to act.	Additional to professional assessment	Waiting room administered: n=200 RR not known	Poor response rate suggests the assessment was not acceptable to many older people.

Guberman N, Nicholas E, Nolan M, et al (2003) (UK, Canada & Sweden)	Describes the impact of 3 tools developed to assess the situation of carers of adults who are ill, older people or have disabilities on professional practice of assessors.	Initiated by professionals	Older people aged 65+  UK self-completion assessment forms distributed by professionals.  Canada & Sweden: assessments carried out as interviews  Adults carers of people who are older people, ill or with disabilities	Professional interpretation	Professional prompted to act.	Additional to or substitution for professional assessment	n=113 RR=38% UK: n=37 Canada: n=168 Sweden: n=245 Response rates not detailed	Use of assessment tools with carers impacted positively on assessors and on practice. It appears that the use of carer assessment tools can lead to more appropriate interventions by alerting practitioners to previously unrecognised areas that are important to carers. No distinction made between use of self-completion tools and interviewer-administered assessments.
Kautzmann LN (1984) (USA)	Describes the development of an instrument for assessing the leisure interests	Initiated by professionals	Administered as part of a professional assessment interview, either	Professional interpretation	Professional and user prompted to act.	Additional to professional assessment	N/A	Author describes the self- assessment as being "well-received". People are reported to be encouraged by an activity

	of adults with rheumatoid arthritis or degenerative joint disease.		to an individual, small group or large group (up to 160).  Adults with rheumatoid arthritis					that focussed on participation rather than curtailment of activities.
Kivnick H.Q. & Murray S.V. (2001) (USA)	Describes a tool (for use as interview) to assess clients' strengths.	Initiated by professionals	Administered as part of a professional assessment interview.  "Frail", older people. Age not specified.	Professional interpretation	Professional prompted to act.	Additional to professional assessment	N/A	Positive experience inferred since the assessment focussed older person's and social worker's attention on strengths rather than problems i.e. shift to a positive focus.
Kosberg JI & Cairl RE (1986) (USA)	Describes the development, and potential use of the Cost of Care Index.	Initiated by professionals	Can be administered to individuals as part of a professional assessment	Professional interpretation	Professional prompted to act.	Additional to professional assessment	N/A	Some difficulties faced by carers when completing the tool are mentioned briefly e.g. discrepancies between written and verbal responses, a

		interview; or to			perceived need to "save
		groups during			face". Group discussion
		seminars.			of negative feelings
					aroused by the self-
					assessment is suggested
		Carers of older			as a way of recognising
		people			and dealing with those
					feelings.

Table 9.24 Experience of content: social care and life skills. unsupported.

Reference (Country)	Structure/ format	Issues/topics covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
Audit Commission (2004) (UK)	Not described.	Carer's assessments of need (no further details given).	Unclear	Unclear	About half of carers reported that they had been asked if they needed help as a carer. At 2 of the 6 English sites surveyed this was carried out as a self-assessment. Carers appreciated being offered an assessment but report does not differentiate between self-assessment and interview assessment.
Berkman B, Chauncey S, Holmes W. et al (USA)	57-item questionnaire.  Response format not described.	Limitations in physical activities; limitations in social activities; pain; mental health; vitality; general health perceptions; IADL; alcohol/drug misuse; vision.	Internal and environmental	Predictive and diagnostic	Poor response rate suggests the assessment was not acceptable to many older people.
Guberman N, Nicholas E, Nolan M, et al (2003) (UK, Canada & Sweden)	Carer's Needs Form: no. of items and response format not detailed.  CADI: 30-item questionnaire with tick boxes.  CASI:- 30-item questionnaire	Carer's Needs Form: basic details about the carer, the cared for and other commitments; level of care provided; impact of caring; desired outcomes.  CADI: carers views and experience of the caring	Internal and environmental	Identifies needs and wishes	Use of assessment tools with carers impacted positively on assessors and on practice. It appears that the use of carer assessment tools can lead to more appropriate interventions by alerting practitioners to previously unrecognised areas that are important to carers. No distinction made between use of self-completion tools and interviewer-administered assessments.

Reference (Country)	Structure/ format	Issues/topics covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
	CAMI: 38-item questionnaire	role with regards to difficulties encountered CASI: satisfaction with caring.  CAMI: management/ coping strategies of carer.			
Kautzmann LN (1984) (USA)	List of 63 leisure interests	For example: walking; bicycling; boating; model building; collecting specific items of interest; political activities; playing/learning to play a musical instrument; T'ai chi.	Internal and environmental	Predictive and diagnostic	Author describes the self-assessment as being "well-received". People are reported to be encouraged by an activity that focussed on participation rather than curtailment of activities.
Kivnick H.Q. & Murray S.V. (2001) (USA)	10-item questionnaire  Open response format	Clients' strengths, likes, coping strategies and important others.	Internal and environmental	Diagnostic	Positive experience inferred since the assessment focussed older person's and social worker's attention on strengths rather than problems i.e. shift to a positive focus.
Kosberg JI & Cairl RE (1986)	20-item questionnaire	Physical, emotional and financial burdens	Internal and environmental	Diagnostic	Some difficulties faced by carers when completing the tool are mentioned briefly e.g. discrepancies between

Reference (Country)	Structure/ format	Issues/topics covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
(UCA)		associated with caring			written and verbal responses, a perceived need to
(USA)	USA)				"save face". Group discussion of negative feelings
	Likert-type response scale				aroused by the self-assessment is suggested as a way
					of recognising and dealing with those feelings.

Table 9.25 Experience of process: comprehensive care.

Reference (Country)	Description of paper	Initiation of the self-assessment	Distribution/ administration & Target population	Interpretation of self- assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience	Grading
Cambridgeshire Assessment Tool (version2) (UK) (Purdie, 2003)	Small pilot study to test acceptability of electronic assessment tool as a self- assessment.	Initiated by professionals	Administered as overview assessment in person's home with professional present.  Older people living in very sheltered accommodation.	Professional interpretation	Professional prompted to act.	Additional to professional assessment	n~50 RR not known	Older people were able to use the tablet personal computer with few difficulties and found the assessment acceptable. Professionals reported that use of a self-completed format enhanced the sense of partnership between the older person and the professional.	Unsupported +
EASYCare – pilot of use as a self-assessment tool. Lewisham.  (Personal communication)  (UK) (communication,	Small pilot study to test feasibility and acceptability of EASYCare for use as a self- assessment tool.	Initiated by professionals	Distributed by managers of sheltered accommodation for self- completion in person's home.	Professional interpretation	Professional prompted to act.		n=34  RR=100%  Focus groups: 2 groups of	Findings from focus groups revealed mixed responses to the self-assessment. Older people on one site were happy to complete the assessment and found it acceptable. Older people on the other site reported that they felt uncomfortable completing the	Unsupported +

2003)		Older people living in sheltered accommodation.			~ 10 older people	assessment and were concerned what it would be used for.	
Robertson S (1995) (UK) (Robertson, 1995)	Describes qualitative research to explore older people's perceptions of their needs and how they would like them to be met. Includes older people's views of comprehensive assessment.	Overview assessment in person's home.	Professional interpretation	Professional prompted to act.	Oualitative research project: 4 focus groups (n=8, 9, 3 & 6). Each group met on 3 occasions.	Older people's views of assessment of needs: person being assessed should have information to enable them to fully understand the assessment process and available services; older person's views should be central; assessor should be skilled and sensitive; assessment forms should be available for older person to see; form should be left with older person to review afterwards and amend if necessary; older person should not be responsible for completing the form.	Credible

Table 9.26 Experience of content: comprehensive care.

Reference (Country)	Structure/ format	Issues/topics Covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience	Grading
Cambridgeshire Assessment Tool (version2) (UK) (Purdie, 2003)	Extensive, electronic assessment covering 14 areas of health and social care.  Uses intelligent navigation therefore the length of the questionnaire depends upon responses given.  Mostly tick box format using drop down menus. Space for free text also.	Carer support; relationships and social activity; clinical background; disease prevention; personal care; physical well-being; activities of daily living; senses; mental health; safety and security; immediate environment; resources; assessor's view of cognitive ability; housing; spiritual well- being; personal fulfillment.	Internal and environmental	Predictive and diagnostic	Older people were able to use the tablet personal computer with few difficulties and found the assessment acceptable.  Professionals reported that use of a self-completed format enhanced the sense of partnership between the older person and the professional.	Unsupported +
EASYCare – pilot of use as a self- assessment tool. Lewisham.	124-item questionnaire  Tick box responses	6 sections used in pilot study: User's perspective of current need; general health; mobility, ADL and	Internal and environmental	Predictive and diagnostic	Findings from focus groups revealed mixed responses to the self-assessment. Older people on one site were happy to complete the assessment and found it acceptable.	Unsupported +
(Personal	(yes/no, rating scales and Likert-type scales)	IADL; home circumstances, safety and			Older people on the other site reported that they felt uncomfortable completing the	

communication) (UK) (communication, 2003)	plus a large amount of space for free comment.	support; services received; healthy lifestyle e.g. smoking, alcohol use, exercise.			assessment and were concerned what it would be used for.	
Robertson S (1995) (UK) (Robertson, 1995)	Overview assessments (not detailed)	Comprehensive assessments (content not detailed)	Internal and environmental	Predictive and diagnostic	Older people's views of assessment of needs: person being assessed should have information to enable them to fully understand the assessment process and available services; older person's views should be central; assessor should be skilled and sensitive; assessment forms should be available for older person to see; form should be left with older person to review afterwards and amend if necessary; older person should not be responsible for completing the form.	Credible

Table 9.27 Experience of process: comprehensive care: unsupported.

Reference (Country)	Description of paper	Initiation of the self- assessment	Distribution/ administration & Target population	Interpretation of self-assessment	Who is prompted to act	Substitution for /additional to professional assessment	Sample size and response rate	Reported experience of self- assessment or other indicator of experience
Berkman B, Chauncey S, Holmes W. et al (1999) (USA)	To test the use of a quality of life questionnaire as a screen predicting clients' needs for social work assessment.	Initiated by professionals	Distributed to people waiting to see their primary care physician, plus an additional mailed sample.  Older people aged 65+	Professional interpretation	Professional prompted to act.	Additional to professional assessment	_	Poor response rate suggests the assessment was not acceptable to many older people.
Linn MW & Linn BS (1984) (USA)	Describes the development and usefulness of a comprehensive self-assessment scale	Initiated by professionals	Administered by research assistant. following interview to assess cognitive function and collect personal details. Older person left alone to complete self-	Professional interpretation	Professional prompted to act.	Substitution for or additional to professional assessment.	n=548 RR=94%	High response rate demonstrates that older people are able to complete the self-completion scale. Only 2% older people (n=11) declined to participate and 6 could not read the questionnaire. Such a small number of decliners calls into question the degree of

assessment but	perceived choice associated
checked by	with participation, and
research assistant	hence is probably not a
for missing items	reflection of the
which person then	acceptability of the self-
asked to	assessment.
complete.	
Older people aged	
60+	

Table 9.28 Experience of content: comprehensive care. unsupported.

Reference (Country)	Structure/ format	Issues/topics Covered	Environmental vs. internal/personal issues	Predictive vs. diagnostic	Reported experience of self-assessment or other indicator of experience
Berkman B, Chauncey S, Holmes W. et al (USA)	57-item questionnaire.  Response format not described.	Limitations in physical activities; limitations in social activities; pain; mental health; vitality; general health perceptions; IADL; alcohol/drug misuse; vision.	Internal and environmental	Predictive and diagnostic	Poor response rate suggests the assessment was not acceptable to many older people.
Linn MW & Linn BS (1984) (USA)	54-item questionnaire  Mostly circle response format with 4 point Likert-type scale.	General health; pain; ADL; IADL; current medical conditions; medication; social activities; mental health.	Internal and environmental	Predictive and diagnostic	High response rate demonstrates that many older people are able to complete the self-completion scale. Only 2% older people (n=11) declined to participate and 6 could not read the questionnaire. Such a small number of decliners calls into question the degree of perceived choice associated with participation, and hence is probably not a reflection of the acceptability of the self-assessment.

# 9.4 Data extraction form

Paper – Full reference:
Article Type – tick boxes that apply:
Topic: Background $\square$ , Overview of practices/research $\square$ , Practice description $\square$ , research $\square$
Age group: Not elderly specific $\square$ , includes elderly $\square$ , elderly specific $\square$
Specific self-assessment practice(s) described? Yes $\square$ , No $\square$
Assessment type: N/A $\square$ Condition specific $\square$ , functional/social $\square$ , general health $\square$ , other $\square$
Research – design: N/A ☐, RCT ☐, Cluster RCT ☐, Quasi random ☐, Non random control ☐, before and after ☐, diagnostic accuracy ☐, qualitative ☐, other ☐, don't know ☐
Review category: Background only $\square$ , Scope of practice $\square$ , Effectiveness $\square$ , Accuracy $\square$ , Experience $\square$ ,
Main aim:
Research - design including comparison/alternate practice if applicable (for non-research give a brief summary of paper)
Population including country:
Sample:
Main results:
Description of self-assessment practice where applicable:
References identified:

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