

Social Values Related to the Development of Health and Care Guidance

Literature review for NICE by its Research Support Unit

Report by David Gough, Caroline Kenny, Carol Vigurs, Claire Stansfield, Rachel Rosen and Ben Taylor

As part of the Research Support Unit for the National Institute for Health and Care Excellence

EPPI-Centre
Social Science Research Unit
Institute of Education
University of London

EPPI-Centre report • August 2014

Acknowledgements

This review was commissioned by the Research and Development team of NICE as part of its Research Support Unit. Many thanks to the following for their extremely helpful comments on the draft version of this report: (i) Dr Sarah Garner, Moni Choudhury and colleagues at NICE; and (ii) Research Support Unit partners Dr José Luis Fernandez, London School of Economics. Professor David Jones, University of Leicester, Professor Jane Noyes, University of Bangor, and James Thomas, EPPI-Centre, Institute of Education, University of London.

Please cite this report as: Gough D, Kenny C, Vigurs C, Stansfield C, Rosen R, Taylor T (2014). *Social Values Related to the Development of Health and Care Guidance: Literature review for NICE by its Research Support Unit*. Report of the Research Support Unit for the National Institute for Health and Care Excellence. London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London.
ISBN: 978-1-907345-71-5

SOCIAL VALUES RELATED TO HEALTH AND CARE GUIDANCE

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EXECUTIVE SUMMARY

The National Institute for Health and Care Excellence develops guidance for the allocation of resources for services in clinical and public health and social care. It has a policy of social values underpinning this work that was last updated in 2008.

This report is of a review of the literature on social values to help inform the further updating of this policy. The review involved a semi iterative search for literature that was then screened for ideas relevant to health and care guidance. These ideas and the main issues they raise are reported under eight major social value categories. Twenty one themes arising from the review are also provided. The literature raises many issues about the nature of social values that can be applied to guidance development. It needs to be emphasized that not all of these issues should necessarily be applied to guidance development. They are simply issues that have been raised in the literature and this review provides an opportunity for them to be considered. Many of the ideas that have been proposed are in tension with each other and could not all be achieved. It should also be emphasized that many of the issues raise considerable practical challenges in terms of methods, data and financial and timeliness.

The review does not assume that any of these issues or ideas could or should necessarily be part of NICE's policy on social values in guidance production. The review simply provides a list of ideas, issues and themes from the literature for consideration.

The main issues listed under the eight major social value categories are:

SV1: Utility and efficiency (Effectiveness and cost effectiveness)

Issue 1: Whether a consequentialist cost effectiveness approach is warranted.

Issue 2: Whether a social value of rights to health and welfare outcomes should be adopted.

Issue 3: Whether there should be a broader conception of the interventions in cost effectiveness evaluations.

Issue 4: Whether there should be a broader conception of outcomes in cost effectiveness interventions.

SV2: Justice and Equity

Issue 5: The extent that all possible weightings by group, situation and outcome (as for examples in the lists of ideas above) should be specified in guidance in terms of: (i) identifying factors that could be taken into account in particular types of circumstances; (ii) proposing specific balances between utility and such equity weightings; (iii) specification of how to manage tensions between different social values weightings in the same case; (iv) Whether any weightings should be applied specifically to reduce inequalities in society.

Issue 6: Whether all guidance production should include an assessment of both explicit and possible inadvertent social value weightings with, for example, a standard instrument or checklist to help make such assessments.

Issue 7: Whether to be more specific about how community and individual and group needs and guidance relate and whether community needs should also relate to global need.

Issue 8: Considering the social values of how to balance competing social values.

Issue 9: Considering developing social values for emergency and other special situations.

Issue 10: Considering the balance of social value and thus weighting for innovative services

Issue 11: Whether human values such as dignity, compassion, commitment and human relationships should become part of the guidance process.

SV3: Autonomy

Issue 12: The extent of explicit advice on the social values underpinning the tension between guidance and professional and client decision making (such as the goals of the guidance) and how these might be resolved.

SV4: Solidarity

Issue 13: Whether there should be explicit advice on the social values underpinning the tension between public outcomes and individual benefit and individual autonomy.

Issue 14: Whether to explicitly incorporate the value of solidarity in terms of social inequality and social values.

SV5: Participation

Issue 15: Whether to be more explicit and evidence informed about participation.

SV6: Sustainability

Issue 16: Considering sustainability issues in terms of the ability to provide ongoing guidance in its financial, political and broader societal contexts.

Guidance producers considering what processes they are able to manage not just now but in an ongoing sustainable way.

Issue 17: Considering sustainability issues in terms of the environmental and other impacts of the implementation of its guidance.

Issue 18: Considering sustainability issues in terms of the wellbeing of and costs for future generations.

SV7: Transparency and Accountability

Issue 19: Whether accountability and transparency is sufficiently and correctly specified in guidance processes.

SV8: Appropriate Methods of Guidance Development

Issue 20: Whether there should be formal processes for examining the social values being applied in the whole guidance development process and specific stages of: topic identification and clarification; evidence identification and analysis; calculation of metrics of cost effectiveness; guidance decisions; and implementation.

Issue 21: Considering the impact of lack of research data on, for example, harms, distributional effects, and implementation.

Issue 22: Considering the overall fitness of purpose and timeliness of guidance.

The main themes from this review are:

1. Increased sophistication in guidance development: It seems that the development of guidance as a formal accountable process of resource allocation has worked extremely well. The success at engaging with such complex and value laden issues is allowing the examination of even more difficult ideas about health and social care provision.
2. Boundaries of questions and boundaries of evidence: The starting point of resource allocation has been the assessment of effectiveness and cost effectiveness and so maximizing the outcome benefits of the investment in services. What started as relatively simple issue of one input and one output has become more complex with a concern for wider intervention effects and broader outcomes. The inclusion of public health and social care has further broadened this focus on breadth and complexity. This may also broaden the services: (i) that are not currently considered

for funding but that might have powerful impacts on well being in health and social care; (ii) who or what is considered part of the service provision and service recipient; and (iii) the breadth of outcomes considered.

3. Including all of society's social values?: The broadening of questions and outcomes beyond narrow focused calculations of cost effectiveness is bringing attention to wider social values related more generally to the health and social care services such as dignity, compassion and trust as well as further societal issues of the environment, culture, and global issues. This may be appropriate but engaging with such values is a considerably more challenging task than the original guidance development systems.
4. The balance between utility and equity?: The increased breadth of focus and inclusion of issues of equity leads to tensions between cost effectiveness and justice and equity values. This can involve providing weightings for particular groups and conditions and rights to a service rather than outcomes alone. This tension might be reduced through providing more specific frameworks for how these tensions could be managed but this begs the question of how such compromises will be reached and applied.
5. Corporate or societal social values?: The underlying question is who do the values belong to, who do the social values represent and how is this representation is obtained? The key here is participation and the social value of solidarity which reflects the mutuality of a shared system of resource allocation.
6. Guidance or rules?: As the guidance systems become more sophisticated and financial constraints becoming stronger then there may be less opportunity for professional and customer autonomy (through either direct or indirect constraints). Either 'one size fits all' or there may be variation based on predetermined criteria and less room for personal manoeuvre within these boundaries which makes the social values on which these are based and how they are agreed even more important.
7. Hidden social values?: The guidance development process may be based in explicit social values but these values may not be executed if there is missing data on harms or subgroup outcomes or there are problems with implementation. The extent of such hidden values is unknown but it is a question that can be asked.
8. Lack of research evidence?: If the research evidence is weak, then what are the processes by which other evidence is brought to bear and what is the effect of this?
9. Is social care different?: There is not much literature on social values of resource allocation in social care, but many of the issues identified by this review could apply to aspects of clinical medicine, public health and to social care. The extent that the issues are relevant may vary between and within these areas.
10. The guidance development process itself: The way in which the process involves social values, the extent that these are known and explicit, and the extent that the content of the guidance specifies values issues.

This review did not examine the implementation of guidance on service provision though this can have social value implications. If guidance is not fully implemented, then neither are the social values that the guidance contains.

1. INTRODUCTION

NICE and NICE Guidance

The National Institute for Health and Care Excellence (NICE) is a Non Departmental Public Body (NDPB) accountable to its sponsor department, the Department of Health, but operationally independent of government. NICE provides national guidance and advice to improve health and social care.

The role of NICE's guidance is to improve outcomes for people using the NHS and other public health and social care services. NICE achieves this by producing evidence-based guidance and advice for health, public health and social care practitioners.

Social Values

Social values are 'socially collective beliefs and systems of belief that operate as guiding principles in life' ... and the... 'means by which natural groups define the social order – what is acceptable and what is not acceptable' (Tsiroganni and Gaskell 2011: 442). Social values have a normative component in specifying what should be the case and these are legitimated as implicit or explicit shared values in society (Tsiroganni and Gaskell 2011). There is fairly broad agreement on the common features of social values. These include: '(a) concepts or beliefs, (b) about desirable end states or behaviors (c) that transcend specific situations, (d) guide selection or evaluation of behavior and events, and (e) are ordered by relative importance' (Schwartz and Bilsky 1987: 551 quoted in Witesman and Walters 2013: 4-5).

Social values are represented in many aspects of public life. The Committee on Standards in Public Life (2013), for example, lists public standards principles as:

1. Selflessness: Holders of public office should act solely in terms of the public interest.
2. Integrity: Holders of public office must avoid placing themselves under any obligation to people or organisations that might try inappropriately to influence them in their work. They should not act or take decisions in order to gain financial or other material benefits for themselves, their family, or their friends. They must declare and resolve any interests and relationships.
3. Objectivity: Holders of public office must act and take decisions impartially, fairly and on merit, using the best evidence and without discrimination or bias.
4. Accountability: Holders of public office are accountable to the public for their decisions and actions and must submit themselves to the scrutiny necessary to ensure this.
5. Openness: Holders of public office should act and take decisions in an open and transparent manner. Information should not be withheld from the public unless there are clear and lawful reasons for so doing.
6. Honesty: Holders of public office should be truthful.
7. Leadership: Holders of public office should exhibit these principles in their own behaviour. They should actively promote and robustly support the principles and be willing to challenge poor behaviour wherever it occurs.

Principles and values that guide the NHS

The National Health Service (NHS) Constitution (Department of Health 2013) lists a number of principles on which its work is based and the values underpinning these principles:

NHS Principles

1. The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.
2. Access to NHS services is based on clinical need, not an individual's ability to pay.
3. The NHS aspires to the highest standards of excellence and professionalism – in the provision of high quality care.
4. The NHS aspires to put patients at the heart of everything it does.
5. The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population.
6. The NHS is committed to providing best value for taxpayers' money and the most effective, fair and sustainable use of finite resources.
7. The NHS is accountable to the public, communities and patients that it serves.

NHS Values

1. Working together for patients.
2. Respect and dignity.
3. Commitment to quality of care.
4. Compassion.
5. Improving lives.
6. Everyone counts.

The NHS Constitution applies only to the NHS in England with the devolved administrations in Scotland, Wales and Northern Ireland being responsible for their own health policies. Although the core principles are generally shared across all parts of the United Kingdom, the devolution of health and care provision may lead to diverging operating values (Aylward 2011).

NICE and Social Values

NICE has also published statements on the principles that NICE should follow in its work; in particular, in designing and implementing the processes it uses to develop its guidance and in developing individual pieces of guidance. The most recent version of these principles, *Social Value Judgements: Principles for the Development of NICE Guidance* (NICE 2008), is currently under revision. This literature review was commissioned to inform this revision.

The remit of this project is restricted to those social values related to the production of health and care guidance. There are very many social values and virtually all of them could have some possible relevance to health and care guidance. This review only considers the social values which can easily be applied to health and care guidance.

2. REVIEW METHODS

Approach

The aim of this review is to identify and organise the variety of different viewpoints in the literature on social values in health and care guidance. The review is thus identifying and arranging issues and ideas (a configuring review) rather than adding up quantitative findings (an aggregative review)¹.

Inclusion criteria

The criteria for including studies in the review are: in the English language; and on social values that are potentially most relevant to the production of guidance in clinical health, public health or social care. This does not include the many values that might be relevant to the direct provision of health and social care services such as, for example, consent to treatment or values involved in working in child protection in social care.

Search strategy

The search strategy had four main components of a systematic search of bibliographic databases, a follow search of references of papers identified from these databases, documents known to the reviewers by other means and a rapid search for lists of social values more generally.

1. A systematic search of bibliographic databases in health and social care: the date range for the bibliographic databases was deliberately narrow and limited to publications from 2011. This strategy was undertaken for two reasons. Firstly, the piloting of the database searching located very many non relevant studies so was not efficient. Secondly, it was thought that most issues would be likely to either be directly discussed or to have been referred to in publications within the last few years (and thus be found through strategy 2). The two databases searched were Medline for health literature and Social Care Online for social care literature. The search on Medline was limited by English language, social values and decision making. The search on the smaller Social Care Online was of social values. The full search strategy of the bibliographic databases is listed in Appendix 1.
2. Search of the reference lists of included studies from the bibliographic database search (in 1 above) for potentially relevant studies.
3. Documents known to the reviewers or given to them by colleagues in NICE, by project partners and others.
4. A rapid search for papers on social values identified through 'hand searching' for papers identified through searching for 'social values' in Google Scholar. This was a supplementary strategy to identify papers not in health and social care bibliographic databases.

¹ Gough D, Oliver S, Thomas J (2013) *Learning from Research: Systematic Reviews for Informing Policy Decisions: A Quick Guide*. A paper for the Alliance for Useful Evidence. London: Nesta.
<http://www.alliance4usefulevidence.org/assets/Alliance-FUE-reviews-booklet-3.pdf>

Screening and coding

All papers were entered into specialist review software called EPPI-Reviewer 4. The papers were screened to determine whether they met the inclusion criteria.

As the aim of the review was to identify and organise ideas (issues related to social values and guidance) rather than aggregate findings, it was not necessary to identify and report every paper that discussed a relevant issue. The priority was to identify all issues and then provide a reference to the paper in which it is referenced rather than listing every paper (or what might be considered the most important or famous paper) on the issue (a 'saturation' approach).

Papers that did meet the criteria were scored on the extent that they were likely to provide additional information on social values relevant to NICE health and social care guidance on a five point scale of: None; Little; Some; Somewhat; or Significant likelihood. This was a pragmatic strategy to focus effort on the papers most likely to provide useful information for the review.

The most relevant papers (scored as Grade 4 or 5: Somewhat or Significant likelihood of relevance) were then fully coded by: the social value being discussed; and how the value was being applied. The references for these papers are listed at the end of the report. Two hundred and fifty papers were double coded by more than one reviewer. There was full agreement on Grade 4 and 5 coding between two of the reviewers and 80% agreement between another two reviewers. The 20% disagreement was due to one reviewer being more inclusive with only 3 papers being disagreements where the other reviewer included the studies as Grade 4 or 5.

The initial search identified 1264 potentially relevant papers. The references sections of included papers were examined for possible relevant papers and this 'follow on' searching identified a 655 further papers (thus a total of 1919 potentially relevant studies) which were then themselves screened for inclusion resulting in a total of 775 included papers. The flow of papers from identification through the search strategy through to inclusion and coding is shown in Figure 1.

Categorizing social values relevant to health and care guidance

The 775 included papers discussed many social values. These social values were divided into two groups, those that were particularly relevant to health and care guidance and discussed in the report (listed in Appendix 2) and those less relevant and excluded (listed in Appendix 3). Many of the social values excluded could have some relevance for guidance development but a pragmatic line had to be drawn as to which social values were more immediately relevant to guidance (just as was necessary for grading papers in the search and screening process described above).

Many of the included social values are closely related or are even overlapping in their meaning and in the issues they may raise for guidance and it is therefore helpful to group them into categories in a way that reflects these similarities.

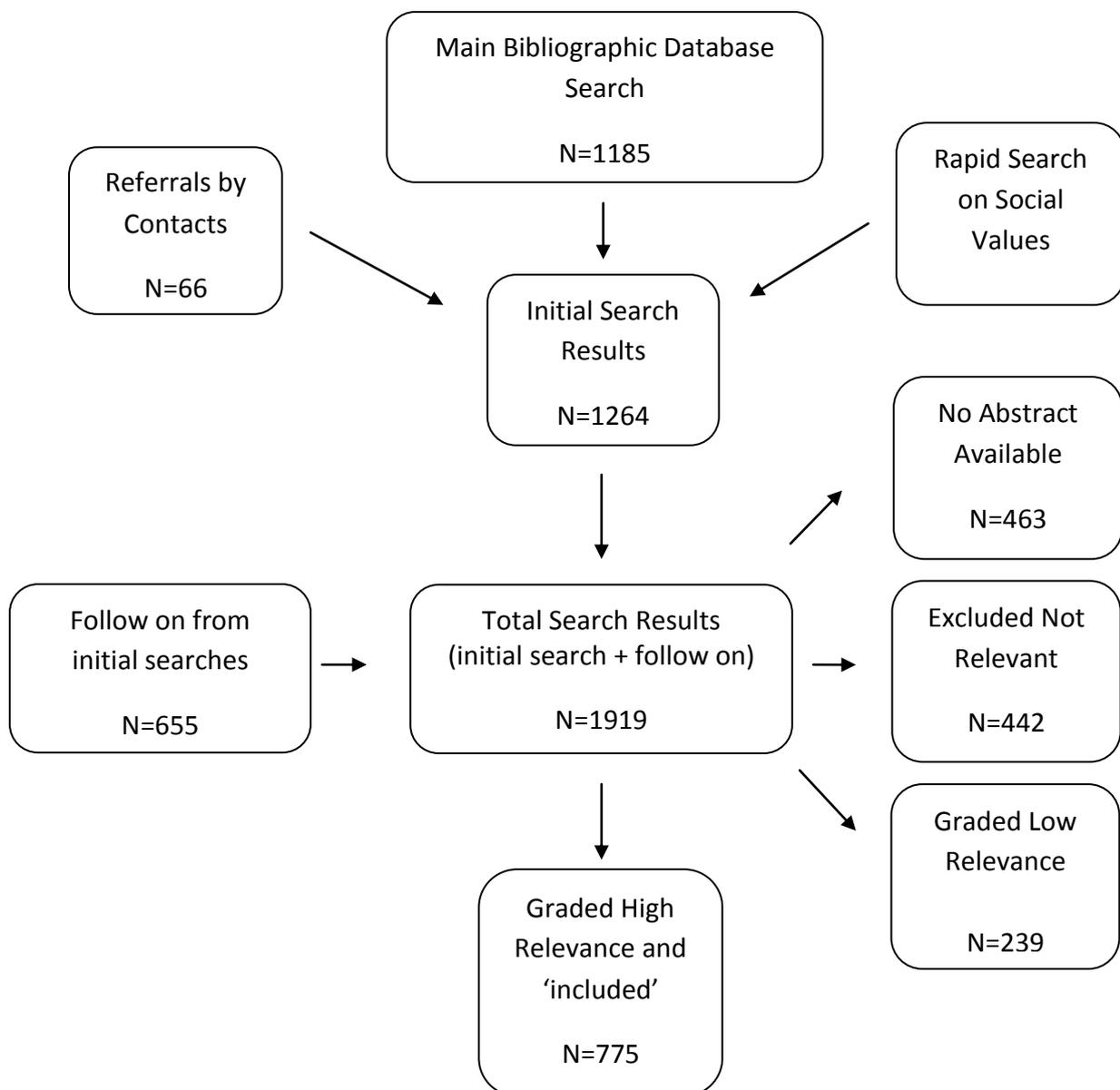
There are many classifications for social values in personal life (Schwartz 1992), public life, and the professional values of social workers (Gamble 2012), but these are not sufficiently focused on issues relevant for health and care guidance to be useful in this review.

There are also several classification systems developed specifically for health care guidance (Orr et al. 2011; Clarke & Weale 2012; Norheim et al. 2013). The organising system set out in Clarke and

Weale (2012) has arisen out of recent debates on values and health guidance in the UK and provided the easiest fit with the social values identified for this report though some further categories were added (described below). We were unable to identify a similar framework within social care. Those classifications that we did find within this field took the form of lists of social values of social care professional staff rather than frameworks for values of service organisation and resource allocation.

Figure 1: Flow of 'included' papers from identification to coding

Please note: these figures are not all mutually exclusive as the total search results include initial and 'follow on' search results and the 'included' studies arise from both the initial and 'follow on' searches.



Both the NICE 2008 Social Values Judgement document (NICE 2008) and Clarke & Weale (2012) make a distinction between substantive, or content, values on the one hand, and process values on the other hand. Content, or substance, values are understood as the substantive principles or ethical expertise (in other words the reasons and criteria) upon which decisions are made. Process values refer to the way in which those decisions are made and thus how the content or substantive issues are achieved (Clarke & Weale 2012). Process values are seen as essential because “disagreement on content is inevitable ... hence we need fair procedures” (Clarke 2012). The distinction between content and process values is not used in this report as several of the values categories usually considered to be of process such as Accountability and Participation have a substantive meaning for NICE guidance; they are values in themselves rather than simply being a means of achieving substantive values. Guidance is itself a process and so process issues are in a sense a substantive for such guidance.

Clarke and Weale propose a total of eight values categories (shown as ‘C&W’ in the list below). For clarity we have combined Justice and Equity as well as Transparency and Accountability as many of the social value discussions in the literature cross these boundaries. We have added extra categories to Clarke and Weale’s list (indicated as ‘Added’ in the list below) of Solidarity, Sustainability and Appropriate Methods of Guidance Development. These additions were to categorise further social values that we identified in the literature review. The categorisation is thus built on an existing framework with pragmatic adjustments to provide a clear overview of the types of social values identified and the issues raised about these social values in the literature. The aim is not to provide an absolute classification system but to assist the presentation of the many complex overlapping social issues identified.

The list of the resulting eight social values categories are listed below. It should be noted that some social values may be relevant to more than one category.

Social Value Category 1. Utility and Efficiency (Effectiveness and Cost Effectiveness) (C&W combined categories)

Social Value Category 2. Justice and Equity (Added plus C&W categories)

Social Value Category 3. Autonomy (C&W category)

Social Value Category 4. Solidarity (C&W category)

Social Value Category 5. Participation (C&W category)

Social Value Category 6. Sustainability (Added category)

Social Value Category 7. Transparency and Accountability (C&W combined categories)

Social Value Category 8. Appropriate Methods of Guidance Development (Added category)

Analysis

As each included paper had been coded according to the social values discussed, it was possible to search the EPPI-Reviewer system to identify the relevant papers and the ideas that had been raised about that value in relation to health and care guidance. The main ideas identified in these papers were then collated under each of the large social values categories as the basis for a listing and discussion of ideas as provided in Section 3. These ideas were then used as the basis for creating a summary list of issues and overall themes.

The process of identifying the most relevant papers, coding these papers, listing the most relevant issues and summarizing issues for NICE to consider involved formal processes but also much interpretation. This is a pragmatic exercise for coping with a topic without clear boundaries and where the aim is to identify important issues in the literature rather than to list every paper discussing every issue. This report provides a high level overview of these ideas and main issues many of which are major areas of study and debate.

Variations from protocol

Presentation

The protocol made a conceptual distinction between identifying social issues, examining its relevance to NICE guidance, and interaction across values. In practice it was found that these issues occurred together and so this review work was combined, except for undertaking a separate rapid search for lists of social values (see Search Strategy).

Additional coding framework

The large number of social values identified meant that it was helpful to apply a framework to group the included social values into categories and subcategories for analysis and discussion.

Change to search strategy and inclusion criteria

The large number of papers that discuss social values meant that it was necessary to limit the bibliographic database search (but not the inclusion criteria) to publications since 1st January 2011 but to follow up references to earlier discussions from the references from these recent papers. 1192 potential papers were identified by the narrow bibliographic database search and a further 676 were identified through follow hand searching of these papers. There were no inclusion criteria for date of publication of papers.

There was no separate search for media discussions of social value issues. The breadth of the search strategy and the breadth and number of papers identified led the review authors to conclude that that a separate media search was unlikely to include ideas beyond those already found by other aspects of the search strategy.

3. SOCIAL VALUES AND ISSUES IDENTIFIED

This section of this report presents the ideas and summary issues identified in the literature. These are discussed under the following headings for each of the eight categories of social value (listed earlier).

- Nature of Social Value – a brief summary and list of the more specific relevant social values included in this category.
- Relevance to NICE 2008 – a brief summary of how these social values are discussed in the 2008 Social Values Judgment document.
- Ideas identified in the literature - a list of ideas that have been identified with brief comments grouped in some cases under further sub-headings.
- Summary of main issues – that could be considered in development of social values policy though not all of them would necessarily be desirable or easy to achieve.

This chapter reviews a very broad range of ideas and issues many of which involve complex and contested philosophical and economic concepts. The complexity of these cannot be explained in detail and are instead summarized as high level issues which is likely to oversimplify sophisticated conceptual distinctions. The aim of the review is to provide a high level overview of issues that could be considered in guidance development rather than the explication of the detail of all those issues.

SV CATEGORY 1: UTILITY AND EFFICIENCY (EFFECTIVENESS AND COST EFFECTIVENESS)

Nature of the social value(s)

If resources for health and social care are limited then one way to distribute these resources is on the basis of the outcomes of the service in terms of: (i) there being evidence that the service was effective in that it was successful in achieving its aims; (ii) that the service was cost effective in achieving those aims.

The aim is for the services to maximize the benefits (outcomes) from a limited budget and so have maximum use (or utility) and maximum efficiency in use of the services. The aim is 'to ensure that the most health [and social care] benefits are obtained from the available resources' ...where 'opportunity costs are the central concern' 'such that the benefits provided by a treatment for one set of patients must be more than the benefits foregone by not providing a treatment to another set of patients' and 'By using estimates of health benefits and economic costs that are equivalent across treatments, cost-effectiveness evaluation can, in principle, compare the relative worth of healthcare interventions even if those interventions are quite different.' (Clark and Weale 2013:305). These quotes are from health but can also apply to the allocation of resources in social care.

Such approaches to the allocation of resources are based upon utilitarian theories of distributive justice. According to Amartya Sen (1979: 463-489) utilitarianism has three components: First is an account of what is good, otherwise described as welfarism and extra welfarism in the literature. According to welfarism, it is individuals' well-being (individuals' ability to 'do' and 'be' the things that are important in life) which is the predominant account of the good used in health care (Sen 1982: 28, 227). Extra welfarism is broader in that it can also include broader outcomes and these may not necessarily be defined by the individuals affected (Brouwer et al. 2008). The second component of utilitarianism is that actions should be selected according to the consequences (consequentialism).

The third component of utilitarianism is referred to as 'sum-ranking' and involves adding up individuals' well-being to evaluate consequences (Sen and Williams 1982:4).

The social values included within this category are: Belief in ability to change; Capable; Clinical and public health effectiveness; Cost effectiveness; Distributive justice: Utilitarianism; Effectiveness; Efficiency; Happiness; Productivity; Reduce use/waste; Value-based decision-making; Well-being.

Utility and efficiency (Effectiveness and cost effectiveness): Relevance to NICE 2008

The principles within NICE's current social values document (2008) are largely about the judgements that NICE and its advisory bodies should apply when making decisions about the effectiveness and cost effectiveness of interventions, especially where such decisions affect the allocation of NHS resources. This category of effectiveness and cost effectiveness is of particular relevance to section 4 of the 2008 NICE Social Value Judgements document (NICE 2008: 16). Decisions about whether and how to recommend the use of particular interventions are based upon two criteria:

- Clinical and public health effectiveness: "NICE should not recommend an intervention (that is, a treatment, procedure, action or programme) if there is no evidence, or not enough evidence, on which to make a clear decision. But NICE's advisory bodies may recommend the use of the intervention within a research programme if this will provide more information about its effectiveness, safety or cost" (Principle 1) (NICE 2008: 16).
- Cost effectiveness: "Those developing clinical guidelines, technology appraisals or public health guidance must take into account the relative costs and benefits of interventions (their 'cost effectiveness') when deciding whether or not to recommend them" (Principle 2) (NICE 2008: 17).

Assessing cost effectiveness: NICE assesses the cost effectiveness of an intervention by comparing its cost against the gain in health outcome (benefit) it is expected to provide. The main health outcome measure that NICE uses is the quality-adjusted life year (QALY). A QALY is a unit that combines both quantity (length) of life and a generic measure of the health-related quality of life into a single measure of health gain. NICE uses the QALY as an outcome measure because it takes into account not only the increased life expectancy from an intervention, but also the quality of the increased life. In addition to recognising that much of healthcare is concerned with improving people's quality of life, it also reflects the value judgement that mere survival is an insufficient measure of benefit; and that the expected quality of life years gained also needs to be considered. Balancing life years gained and quality involves social value judgements, some of which may be very difficult to make. The QALY also provides a 'common currency' which allows different interventions to be compared for different conditions. This allows NICE to make its decisions consistently, transparently and fairly. In some instances (for example, in some public health assessments) cost-effectiveness is assessed in terms of cost-reductions if assumptions can be made that the outcomes would not be worse.

The current Social Values Judgements policy (NICE 2008) was written before NICE had responsibility for social care guidance. The NICE methods manual for social care explains that assessing cost effectiveness and measuring outcomes is complex in this area. For that reason QALYs are not used and broader approaches are used both for assessing costs and for assessing quality of life.

Effectiveness and cost effectiveness: Ideas identified in the literature

Criticisms of the consequentialist nature of value of cost effectiveness

Although cost effectiveness can be considered a rational way to distribute health and social care resources, some argue that this focuses too much on the efficiency in terms of consequences of service provision rather than on other ideas such as equality of access to services (critiques of cost effectiveness are also considered under SV2 on justice and equity).

1. Rights to health and well being: arguments in the literature questioning whether services should be organised on the basis of right to level of health or well being rather than on the basis of efficiency (Wolff 2012; Gamble 2012). The right to health can be seen as an outcome (so consequentialist) but it does not assume efficiency or a way to distribute scarce resources. Also, the right to health might be linked to the right to access to service, which is considering the presenting problem rather than the consequences of any service received (the issue of lack of fairness in services is considered in SV2 on justice and equity). Several areas of social policy are conceptualised in terms of rights, particularly in terms of rights to the avoidance of negative experiences. This right cannot of course be guaranteed but an opportunity for services to maximize such outcomes could be a relevant value.
2. Equality of access to services: arguments questioning the consequentialist social value of efficiency in outcomes rather than basing the distribution of resources on equal access to services; for example in access to vaccines (McLachlan 2011). There are similar arguments for the sharing rather than efficient use of resources such as arguments for an individual good Samaritan basis of distribution of service resources (Frangenberg 2011) or other shared system of resource allocation (Ruger 2011).
3. Universalism is not a universal value: arguments that this is a Western idea, not a multicultural idea (Bellomonte 2012). Even if utility is a shared value the specific values (preferences) within such resource allocation systems may not be shared.

Criticisms of the methods and focus of the utilitarian cost effectiveness system

Even if the concept of cost effectiveness is accepted there are many methodological challenges that interact with different views about the values that should be built into any cost effectiveness calculations (Sassi et al. 2001, Pennington 2013). QALYs, for example, reflect societal preferences over health states associated with different combinations of length of life and measures of quality of life; whether it is preferable to have a short good quality or a longer poorer quality of life. Cost effectiveness systems may also have differential distributional effects on different individuals and groups within society. Also as quality of life is measured with generic measures it may be that some condition-specific problems cannot be shown to improve whatever the intervention.

The cost effectiveness efficiency model may focus in practice on narrow and short term questions and outcomes, though it may be more efficient to have broader questions and longer term outcomes. Cost effectiveness may be based on 'Utilitarian approaches [that] legitimise only one value (the pre-selected utility on offer), and may overlook benefits such as non-discrimination or social justice that, while harder to measure, are important to society' (Rae 2011). In other words, economic evaluations in cost effectiveness systems can in theory but in practice may not map the full longitudinal consequences on outcomes and costs of interventions.

Broader social interventions might also have greater impacts on health, with for example, income, employment and housing impacting more than any health or social service. If questions increased in breadth then they might move towards being social policies rather than practices as a means for major social change. Again, this is not a criticism of the principles behind the cost-effectiveness approach per se, but of the way it may be operationalised in a relatively narrow way. Welfare

economists would ideally want to see the approach applied not just within one practice or policy but across all public services at the same time, hence equalising marginal returns across areas.

A broad approach is possible within social care though policy level evaluations are not normally a focus for NICE guidance (NICE 2014a). A broad approach is also often taken by public health that may focus on universal rather than targeted interventions and population as well as individual level outcomes. The links between population and individual focused services are becoming clearer with NICE pathways linking all related NICE guidance on an issue.

4. The effects of unrelated health and social care: questioning whether cost effectiveness should include the costs of non directly related factors, and thus be more accurate (Van Baal 2013). So, in addition to ideas of breadth of interventions, is the breadth of outcomes.
5. The nature of the outcomes being achieved: assessment of utility depends on what outcomes are considered important and social stigmas about certain conditions may influence judgments on priority setting (Nordenfelt, 1995). The outcome for assessing cost effective distribution of resources has traditionally been health but it could be well being (Dolan 2013) or social justice (Gamble 2012; Hölscher 2012). The normative approach could also be framed more positively as a capability (Parkhurst 2012) with capable identified as an instrumental value of competency and effectiveness (Tsiroganni and Gaskell 2011).
6. Time period over which outcomes are considered: broader questions could more often be considered over longer time periods with many more interacting variables and be better for society and for the future and future generations (Graham 2010) and the conservation of resources (*See also SV6 on sustainability*). Over time there may be improved productivity arising from patient health and from technology improvements (Henshall & Schuller 2013).
7. Beneficiaries versus contributors over time: questioning who benefits and who pays for an intervention. Some guidance may be cost effective yet the burden and the benefit may not fall on the same people; for example, vaccination may create individual risk but benefit the population as a whole including those who are not vaccinated (Vietri 2012). This issue thus relates to the tension between community or public health outcomes and individual outcomes (Wardrope 2012) in assessing cost effectiveness.
8. Beneficiaries beyond direct service users: one can also consider whose burden or quality of life is judged – just the person with the illness, or that of her family too. Ill-health can have a detrimental effect on family-members, harming their quality of life as well as the sufferer for whom they may be caring (Hoedemaekers and Dekkers, 2003, Clark & Weale 2012, Fritsch et al. 2013; Henshall & Schuller 2013; Reamy et al. 2011). For example, the impact on caregivers' health related quality of life (HRQL) in multiple sclerosis (Acaster 2013). Non professional carers can also be providing support and so be: resources; co-workers with professional services; and co-clients (Twigg 1989).
9. Particular outcomes used to justify interventions: for example, is the aim of 'best interests' in the mandatory treatment of children against parental wishes is really the 'avoidance of harm' (Diekema 2011). This issue concerns the clarification of outcome measures as in item 8 above. Social value of best interest is discussed further within SV on justice and equity below.

Effectiveness and cost effectiveness: Summary of issues for consideration

Issue 1: Whether a consequentialist cost effectiveness approach is warranted

Should services be allocated on the basis of utilitarian consequentialist social value of distributive justice of cost effectiveness? This cost effectiveness strategy is an overt pillar of NICE's position on social values though it is subject to weightings of other social values to achieve equity. This raises issues of both the balance between efficiency and equity and the degree of specification of that balance (see SV2 on equity).

Issue 2: Whether a social value of rights to health and welfare outcomes should be adopted

Should there be the right to health and welfare? This right may be trumped in some situations by other rights or factors such as resource constraints. It would not, of course, be possible to guarantee positive outcomes and to avoid outcomes such as death but it would provide a benchmark of what is being strived for and what harms are being avoided by the services provided. In some countries there is a right to health in law and this has been used as a lever in the courts in other countries to increase resources (though not necessarily resulting in an equitable distribution of resources) (Wilson 2014).

Issue 3: Whether there should be a broader conception of the interventions in cost effectiveness evaluations.

In clinical medicine the intervention may be a very specific treatment such as a pharmaceutical agent. However, (as already mentioned under other issue headings) the service could be a much broader group of very different services that combine together to assist the client of the service or the population more generally or be beyond what is typically considered for guidance. Guidance could, for example, be developed on such things as wheelchairs, guide dogs, disabled facilities, grants, or national policies.

Issue 4: Whether there should be a broader conception of outcomes in cost effectiveness interventions.

There are several aspects to outcomes: (i) breadth of measure from health, to capability and well being (Dolan 2013); (ii) level of outcome from individual to population; (iii) time period over which the outcomes are considered ranging from immediate post treatment to long term deferred effects; and (iv) the methodological challenges of broader approaches in terms of data availability and that increased extrapolations and assumptions that may introduce more uncertainty into the decision making process.

SV CATEGORY 2: JUSTICE AND EQUITY

Nature of the social value(s)

This category is concerned with providing services in a fair and appropriate manner based on services users' needs or some other way in which their characteristics lead them to merit receiving the service. It is based on the prior need rather than the later consequence of receiving the service (as in utility and efficiency cost effectiveness approaches). Two people might have similar presenting problems but might vary in the extent that they are able to benefit from the service; for example, a person having more limited potential for improvement in their situation. Such allocation of services raises the question of how this presenting problem should be defined and thus the basis for priority setting of services to different groups. Those defined as having the same presenting problem rather than potential outcome should be treated equally to achieve equity in fairness (justice).

The social values included within this category are: Acceptance; Achievement; Advocacy; Avoiding discrimination/ Diversity; Being present and available; Belief in ability to change; Beneficence; Benevolence, Empowerment; Best interests; Burden; Capacity to benefit; Compassion; Cultural/ context; Dignity; Distributive justice of Egalitarianism; Fair innings; Harm and safety; Human relationships; Innovation; Knowing and Being Known; Merit/Desert; Non-maleficence; Personal growth; Protecting minorities on race, disability, age, sex, gender, socioeconomic status, behaviour-dependent conditions; Protection of majority; Rare conditions; Reducing health inequalities, Fairness, Justice, Access; Responding to need; Right to health; Right to minimum quality of life; Rule of rescue; Social cohesion; Spirituality; Trust; Universalism.

Justice and Equity: Relevance to NICE 2008

There are two main areas within the 2008 Social Value Judgements document that are of relevance to this category. The first area relates to the concern for societal, or population level, outcomes. For example, the concern to address health inequalities and ensure that resources are distributed fairly within society is highlighted in principles 3 and 8 (NICE 2008: 18; 28). In addition, the 2008 document also displays a concern for the outcomes of future societies or generations in its decision not to adopt a 'rule of rescue' (NICE 2008: 20-21).

The second area of relevance is in the processes outlined in the 2008 document. This includes a commitment to eliminating unlawful discrimination: "The NHS aims to provide free, necessary and appropriate treatment to the whole UK population. Legislation on human rights, discrimination and equality requires that patients are not denied access, or have different or restricted access, to NHS care because of their race, disability, age, sex/gender, sexual orientation, religion, beliefs, or socioeconomic or other status" (NICE 2008: 23). Recommending that the use of an intervention is restricted to a particular group of people within the population (for example, people under or over a certain age, or women only), is allowed but only in certain circumstances for which there must be clear evidence about the increased effectiveness of the intervention in this subgroup, or other reasons relating to fairness for society as a whole, or a legal requirement to act in this way (NICE 2008: 25).

The 2008 edition of Social Value Judgements pre-dates the Equality Act 2010. The Act's requirements now govern NICE's approach to applying social value principles when considering legally protected groups.

Justice and Equity: Ideas identified in the literature

Arguments for equity weightings

Some of the literature is concerned with general arguments for priority setting for resource allocation on the basis of need (rather than the specific areas of need discussed in later sub-sections).

1. Justice and equity in provision based on need, than benefit of services: proposing that presenting needs are as important as efficacy and cost. The NHS Constitution states that 'Access to NHS services is based on clinical need, not on an individual's ability to pay' (Department of Health 2013) but cost effectiveness approaches focus on benefit rather than presenting need. The idea of restrictions on allocation of health resources may not be politically acceptable even if some such restrictions apply in practice.
2. The extent that there is a focus on individual and subpopulation issues: There may be equity weightings that lead to greater cost effectiveness (Eslava-Schmalbach et al. 2011) from, for example, beneficial gains in cost effective sub populations (Bærøe 2011) and broader social issues (Akinloye 2011). NICE's system of cost benefit analysis does allow differential QALYS for subpopulations if there is evidence of differential cost effectiveness but such data may not always be available (see also SV8 on the methods of guidance production) which may result in priority setting for the allocation of resources ignoring vulnerable groups (Field 2012).
3. Weighting as an expression of community social values: guidance could allow a range of values (Giordano 2011 on pain) agreed with communities (Ritvo 2013; Donaldson 2011) as to how certain groups or presenting conditions should be given higher or lower weightings in terms of resource allocation. NICE's 2008 policy and its practice has allowed some weightings for equity issues (Shah et al. 2013) but does not specify what these weights should be except for additional resource allocation for those at the end of life. However at the time of writing NICE is consulting on ending this and creating new 'modifiers' (weighting) of value based assessments on 'burden of illness' and 'wider' societal benefit (see items 12 and 31 below) (NICE 2014b). Studies of NICE

decision making is also providing descriptive as well as the normative accounts of weighting (Karin et al. 2013; Shah et al. 2013). Studies of the population are providing more information on people's preferences (Dolan & Tsuchiya 2012; Joansson et al. 2013, Ottersen et al. 2014) though not all show clear evidence to support weighting of QALYs (Baker et al. 2011, Donaldson et al. 2011, Lancsar et al. 2011).

4. Inequality within society: the tension between the needs of individuals and groups versus societal inequality (Alberti 2013, Rust 2012) and the social welfarist function where society accepts lower individual outcomes in order to achieve greater population equity. This also relates to: (i) weightings of sub-populations; (ii) public health population versus individual level interventions; (iii) social care as a form of social justice; (iv) and taking a global not just a societal perspective to health and well being (Gostin 2013 – see also SV4 on solidarity). Taking a global view would be good from a rights perspective but may be difficult to achieve due to disparity in resources between countries (as is shown, for example, by the values problems from professional staff leaving low income countries to work in high income countries).
5. Realization of potential: questioning 'whether the intervention is not very cost effective because it targets a disadvantaged group who has a low capacity to benefit due to conditions that are less treatable or difficult to prevent' (Norheim et al. 2013). These arguments have also been applied to disability (Nord et al. 2013).

Responding to human need

Some literature emphasizes the importance of responding to human need rather than focusing on the utility of different services.

6. Empowerment, advocacy and self advancement of individuals and groups: the value of advocacy is strong in terms of achieving social justice in social care but is also relevant to health. It includes the preservation and enhancement of the welfare of people with whom one is in frequent personal contact and responding to need, advocacy, friendliness, loyalty (Witesman & Walters 2013). The understanding of value of advocacy is in contrast to NICE existing value of independence (within procedural justice): 'advocacy versus neutrality. If a public organization is to champion a particular point of view, or make sure that a specific problem is always on the agenda, then it might be said to live up to the value of advocacy' (Jørgensen & Bozeman 2007).
7. Spirituality as a positive outcome or component of services: there are wider cultural and societal dimensions to being human, including the fight against injustice that lies at the heart of some services. 'Overcoming powerlessness will involve moving beyond the individualism and market-based solutions of personalisation theory. It will require the development and strengthening of collective organisations both amongst those who use services and amongst those who provide them' (Ferguson 2007: 401). The WHO Quality of Life Assessment (WHOQOL-100) defines spirituality as a broader concept that captures an individual's sense of peace, purpose and connection to others, as well as beliefs about the meaning of life. Resilience can be seen as a core part of spirituality (Holloway et al. 2010).
8. Achievement, self enhancement and personal growth: positive outcomes (Cieciuch & Schwartz 2012, Tsirogianni & Gaskell 2011) and related to self-enhancement, social status, power, hedonism and stimulation with excitement, novelty, and challenge in life (Cieciuch & Schwartz 2012; Witesman & Walters 2013; Tsirogianni & Gaskell 2011).
9. Knowing and being known, and being present and available: as components of service provision beyond outcomes. Being known providing a level of community and mutuality and accountability to ensure that others would not just be available, but trusted, when they were needed. Also, trust and knowing between long term colleagues that allow them to do their job well. Long term relationship, and team working and communication also helps to build care capacity (Pesut et al. 2011). Being present and available also overlaps with access; the affordability and availability of health and social care (Parkhill et al. 2013). Also, the importance

of trust between professional and customer (Bombard et al. 2011) and human relationships as an aspect of well-being (Gamble 2012).

10. Compassion: commitment to humane, kind, and compassionate treatment of people is essential to meet their physical, psychological, cognitive, and interpersonal needs (ACHA 2011). Caring treatment creates affirming relationships, reduces anxiety and avoidance, and encourages health-seeking behaviour. Respect and compassion demonstrate that the patient-doctor relationship is understood in different ways that aim to approach the patient with dignity (Altamirano-Bustamante et al. 2013). Also seen as sharing patients' physical and mental pains and sufferings (Shahriari et al. 2013).
11. Acceptance: 'values of acceptance, nonjudgment, self-determination, the inherent worth of every individual, and the basic belief that all people have internal resources and the potential to change' (Sowbel 2012).

Weighting for certain diseases, conditions and/or interventions

Some of the literature argues that priority setting for allocating services should be based on the nature of the presenting condition.

12. Severity having greater weight: questioning 'whether the intervention has special value because of the severity of the health condition (present and future health gap) that the intervention targets' (Norheim et al. 2013) including 'rule of rescue' from danger (Jecker 2013) and public's aversion to severe conditions (Richardson 2012). NICE allows for weighting in general and provides a higher QALY measure for end of life. This raises issues of how to compare low increases in quality of life over many years versus higher increases over fewer years (Nord et al. 2009). Currently NICE is consulting on proposals for use of measures of 'burden of illness' (shortfall in quality of life from having a condition) to modify (create extra weighting) in the calculation of how much resource to provide (the QALY calculation of cost effectiveness of an intervention). It is being proposed that this is based on the proportional number of good quality years lost through the condition (NICE 2014b, NICE Decision Support Unit 2013a). In other words, 'burden of illness' proposals provide an equity weight from the burden of illness (quality years lost) to raise the threshold for resource allocation beyond the standard cost effectiveness calculations). See also item 31 below on 'wider societal benefit'.
13. Severity having less weight: questioning whether it is an effective use of resource when a condition is severe and it maybe futile to try and improve it (Smith 2013; Finkler 2012; Stewart 2012; Maio 2011) or arguments that not equitable if recipients have already received many resources (Gandjour 2011). Arguments about futility are in tension with the rule of rescue for those in severe illness.
14. Emergencies and safety and security: questioning whether the balance of social values should differ during in special circumstances such as, for example, emergencies such as drug shortage (Gibson 2012), pandemic (Caro et al. 2011; Ytzak 2012; Hick et al. 2012), or other disaster.
15. Precautionary values: for example, in public health the concern not to have negative impact may limit action to prevent poor outcomes (Upshur 2012). In other words, it is not only about cost effectiveness but also opportunity costs and the dangers of inaction.
16. Past health loss or condition: questioning 'whether the intervention has special value because it targets a group that has suffered significant health loss in the past (e.g. chronic disability)' (Norheim et al. 2013).
17. Capacity to benefit: weighting resource allocation on the capacity to benefit beyond the immediate outcome of cost effectiveness (for example, in kidney disease) (Ladin et al. 2011). This relates also to proportionality where it is relative rather than absolute benefits that are considered and to timeframes and breadth of outcomes (as discussed in SV 1 on utility and efficiency).

18. Rare conditions: providing greater weights to conditions which have more expensive interventions because of their rarity and where it would be unfair to disadvantage people on the basis of cost effectiveness because of that extra cost.
19. Orphan drugs: providing greater weights to new interventions where the cost effectiveness is not yet known but maybe be high (Holland 2012) with different levels of guidance at different stages of development/ innovation process (Henshall & Schuller 2013). Such weighting may be necessary for innovation and for the well being of the next generation (so related also to timeframes in SV 1).
20. Social value priorities of those with particular conditions: for example those with disabilities may differ from the general population so should be assessed separately (Sinclair 2012) (as in weightings of community social values above).

Characteristics of social groups weighting

Some of the literature argues that priority setting for allocating resources should be based on the nature of the social group that someone is a member of such as age or social economic status.

21. Socioeconomic status: questioning 'whether the intervention will reduce disparities in health associated with unfair inequalities in wealth, income or level of education' (Norheim et al. 2013). Arguments that economic status is sometimes 'necessary information to realise the intended outcome' of services (Akinloye 2011; Bærøe & Bringedal 2011). This relates to social inequalities (discussed above).
22. Offenders: questioning whether guidance does or should have differential impact on offenders. This could occur if there was any data suggesting differential outcomes occurred for them as a group or if these outcomes were valued in any way differently. It has been argued, for example, that public health policies are enacted differently in prisons (Elger 2011).
23. Geographical location: questioning 'whether the intervention will reduce disparities in health associated with area of living' (Norheim et al. 2013) which relates to social inequalities (discussed above).
24. Gender: questioning 'whether the intervention will reduce gender-related disparities in health' (Norheim et al. 2013). This relates to the issue of there being evidence of cost effectiveness to support differential response for different social groups.
25. Race, ethnicity: questioning 'whether the intervention may disproportionately affect groups characterized by race, ethnicity, orientation religion, and sexual orientation' (Norheim et al. 2013).
26. Younger age positive bias: questioning whether services should be weighted against older people on the basis of having had a 'fair innings' of life. Questioning whether measures indirectly bias services to younger clients such as kidney transplants (Ladin et al. 2011). Some argue that NICE guidance favours the young as they are more likely to have years to live and thus QALYs available (Harris & Regmi 2012) though others argue that this has little effect in practice (Stevens et al. 2012). Some argue for favouring the young as the elderly have had a 'fair innings' but on the other hand services to the younger may result in greater expenditure over time. Also this value is opposite to the rule of rescue social value for those close to death.
27. Younger age negative bias: questioning whether the guidance system is discriminatory against children; for example, lack of research evidence; not considering deferred and long term benefits of services (Lev 2013); avoidance of harm rather than positive benefits; rules of rescue for older clients (Ungar 2013) with weightings for end of life (Caulden & Culyer 2010; Cookson 2013); that younger people are more likely to have more years to live and so have higher QALY ratings; and that children are not represented politically or in utility ratings.
28. Age and state for foetuses: arguments that foetus age is discriminatory as it does not reflect foetus state, so more appropriate to use gestational age equivalence as a measure (Wilkinson 2012). This equates with state not age being applied for judgements with elderly people.

29. Inadvertent discriminatory bias by considering only some groups for interventions: for example, sexually transmitted diseases interventions being more effective if directed at women and thus recommended in guidance and so the system reinforces less responsibility being taken by men (Rae 2011).
30. Discriminatory bias by lack of research on subpopulations who might be differentially affected by interventions (equity and systematic reviews, Waters et al. 2011; elderly, Diener et al. 2013) (which relates to SV8 on methods of guidance development).

Financial and social effects of ill health weightings

Some of the literature argues that priority setting for allocating resources should be based on the economic value of the recipients of services such as how economically useful they are to society.

31. Societal impact and economic productivity: suggestions that assessments of wider societal impact based on productivity and consumption should be considered in resource allocation for drugs in cases of serious illness so questioning 'whether the intervention has special value because it enhances welfare to the individual and society by protecting the target population's productivity' (Norheim et al. 2013). Currently NICE is consulting on proposals for use of measures of 'wider societal impact' (difference between the amount of resources a patient contributes to society and the amount they utilise). As there are technical and social value complications in measuring specific productivity, the proposal is to use societal shortfall' (loss of individual's capacity to engage with society as a result of having a certain condition). It is being proposed that this is based on loss of the absolute number of good quality years of life (similar to burden of illness in item 12 above) to modify (create extra weighting) in the calculation of how much resource to provide (the QALY calculation of cost effectiveness of an intervention) (NICE 2014b, NICE Decision Support Unit 2013b). In other words, this provides an equity weight from the 'wider societal impact' (quality years lost) to raise the threshold for resource allocation beyond the standard cost effectiveness calculations).
32. Care for others: questioning 'whether the intervention has special value because it enhances welfare by protecting the target population's ability to take care of others' (Norheim et al. 2013).
33. Catastrophic health expenditures: questioning 'whether the intervention has special value because it reduces catastrophic health expenditures on the target population' (Norheim et al. 2013). This relates to both public health issues and special circumstances as in emergency situations.

Justice and Equity: Summary of issues for consideration

Extra weightings beyond cost effectiveness

There is a wide-ranging discussion about whether cost effective calculations should be weighted to take account of social values relating to certain groups, situations or outcomes.

Issue 5: *The extent that all possible weightings by group, situation and outcome (as for examples in the lists of ideas above) should be specified in guidance in terms of: (i) identifying factors that could be taken into account in particular types of circumstances; (ii) proposing specific balances between utility and such equity weightings; (iii) specification of how to manage tensions between different social values weightings in the same case; (iv) Whether any weightings should be applied specifically to reduce inequalities in society.*

It would be difficult if not impossible for guidance to take into account all possible equity issues. It would, however, be possible to identify which equity issues were of highest priority, what weightings should be considered and how including whether these were technically achievable and financially sustainable.

Issue 6: *Whether all guidance production should include an assessment of both explicit and possible inadvertent social value weightings with, for example, a standard instrument or checklist to help make such assessments.*

Explicitness of social value judgements and whether standardized methods might enable greater clarity of deliberate and inadvertent use of values. Social weightings may be applied unknowingly due to other factors; for example, cost effectiveness based decisions reinforcing gender stereotypes or low cost benefit calculations for children as the health benefits are deferred or capacity to change as in disability. A standardized checklist might be applicable (see SV 8).

Issue 7: *Whether to be more specific about how community and individual and group needs and guidance relate and whether community needs should also relate to global need.*

A related factor is the extent that guidance is aiming to meet public health or community social outcomes rather than the well being of individuals or specific groups. A public or community level outcome may in practice be disadvantageous to particular individuals and groups and vice versa so there may be a problem in balancing social values of beneficence and maleficence.

Issue 8: *Balancing competing social values.*

A related aspect is the potential tension between social values; for example, the NICE policy of 2008 advocates a range of values but there may be situations where the values are in conflict. As social values are liable to change then consideration of several values together is likely to require regular reviews and development. (See also SV7 on transparency and accountability).

Issue 9: *Considering developing social values for emergency and other special situations.*

Another aspect is whether the normal bases of applying cost effectiveness and any weightings should be altered in special situations such as emergencies (such as a pandemic) or the need to avoid catastrophes. Social values are not static and vary over time and in different contexts so thought could be given to situations where the standard social values within routine decision making are temporarily replaced. It might be helpful to identify some values and decision making pathways for special situations.

Issue 10: *Considering the balance of social value and thus weighting for innovative services*

Innovation is necessary to develop more effective interventions for current and future populations. There are social values about the extent that: (i) cost effectiveness may be relatively conservative: (ii) health and care services can consider the future users as well as current users in deciding upon resource allocation. In addition, cost effectiveness may prevent innovation as new health and social care services may not have data to show effectiveness or may need developmental time and investment to show such effectiveness.

Issue 11: *Whether human values such as dignity, compassion, commitment and human relationships should become part of the guidance process.*

In the social care literature there is much discussion of such values yet they also apply to service provision in health.

'False' weightings beyond cost effectiveness

NICE's policy on discrimination states that everyone should be treated the same unless there is evidence that there is something about the group that means that the outcomes (cost effectiveness) will be different (NICE 2012). So it is not weighting for equity (as per SV2) but data for cost effectiveness (SV1). In other words, some of the arguments for providing weightings beyond cost effectiveness are based on a belief that the weighting is necessary to achieve cost effectiveness. In that case, it is not really a weighting but the availability of data as evidence to demonstrate such cost effectiveness. The seeking of and availability of data is thus a crucial aspect of applying social values

in relation to particular groups, situations or outcomes (see SV8 on guidance development methods).

SV CATEGORY 3: AUTONOMY

Nature of the social value(s)

The concept of autonomy has a varied set of meanings but it is 'often used to refer to the ability of individuals to be self-directing and to make decisions for themselves about important matters' (Clark & Weale 2012; p 310). The notion of autonomy goes hand in hand with that of responsibility; if one is to be self-directing and make important choices, those choices will be one's own and thus also one's own responsibility. This category focuses on decision-making at the level of individuals, both professionals and clients.

The social values included within this category are: Authority; Autonomy; Consent; Control; Control; Freedom/liberty; Hedonism (personal needs); Individual choice; Power; Professional choice. Self-determination/Informed consent; Protection of rights of individual; Responsibility.

Autonomy: Relevance to NICE 2008

The importance of the individual is emphasised in a number of areas in the 2008 Social Value Judgements document. NICE's social values policy subscribes to the widely accepted moral principle of respect for autonomy, though it recognises that this cannot be applied universally or regardless of other social values. In discussing possible exceptions to a commitment of autonomy, the 2008 document highlights issues around individuals' decision-making capacity and some public health measures which may be imposed on whole populations and therefore limit individual autonomy (NICE 2008: 8, 26-27). The 2008 document also states that respect for autonomy and individual choice should not mean that NHS users as a whole are disadvantaged by guidance recommending interventions that are not clinically and/or cost effective.

Autonomy: Ideas identified in the literature

1. Utilitarianism can reduce individual choice in service provision: the emphasis may be on control of expenditure and creating rules for the average case (Tannenbaum 2012). This may not be conducive to: individual professional or client decision making (Wilmot 2011; Bogdan-Lovis 2012; Swetz 2012); and shared decision making (Gupta 2011; Delany et al. 2013; Nowakowski 2012); professional – client ongoing relationships (Garbutt 2011); values based approaches (Altamirano-Bustamante 2013; Fulford 2011; Little et al. 2012; Parker 2013); person centred care (Miles 2013); and holistic approaches of complementary medicine (Flatt 2012). The tension is how to link cost effectiveness with professional autonomy in a resource limited system.
2. Professional competence and choice: giving professionals decision making power as 'an ethical model for responsibly managing the conceptual and clinical challenges of health care decision making for patients....under conditions of uncertainty that necessarily exist when evidence is low or very low.' (McCullough 2013).
3. Autonomy reduced by mandatory public health guidance and quality standards: what is good for the community may not be what is good, or wanted by, some individuals. These tensions may be greater when guidance is mandatory services to achieve required outcomes in, for example, obesity and public health (Chaloupka 2011; Purdy 2012).
4. The difficulties in practice for professionals to have autonomy due to indirect factors such as funding and for users of services to have real choice due to power and informational asymmetries (see SV7). In practice, resources for non guidance determined services may not be available if priority is given in budgets for services recommended by guidance (Scheunemann 2011). The extent that social and physical constraints apply may vary between clinical health,

public health and social care though there may be considerable overlap and the underlying factors may be similar.

Autonomy: Summary of issues for consideration

Issue 12: *The extent of explicit advice on the social values underpinning the tension between guidance and professional and client decision making (such as the goals of the guidance) and how these might be resolved.*

The literature on social values raises the issue of a tension between the social value of autonomy of clients and professional staff in decision making versus guidance and quality standards derived from such guidance on how such decisions are made. NICE's 2008 policy document makes clear that individual client decision making should be supported but that there were limits to what the government would offer as services in order to ensure cost effectiveness. Societal attitudes to these issues are changing over time within and between services. In health, medical professionals are more subject to organisational constraints and expected to engage with user views and needs. In social care, choice and empowerment of users are increasingly seen as a key value and key outcome for services. In social care there may be more scope for family non funded carers to take on and construct work roles than in health.

These tensions also relate to tensions between public health and individual based guidance (discussed in SV4 on solidarity). The issue is how should these tensions be managed and how can be reflected in guidance.

SV CATEGORY 4: SOLIDARITY

Nature of the social value(s)

Solidarity refers to the idea that individuals should commit themselves to the common good, that is 'the good of all and of each individual, because we are all really responsible for each other' (Coote 1989). The basis of solidarity is mutual obligation. This is mainly expressed through reciprocity, or exchange. Solidarity can be difficult to distinguish from 'altruism', but there is no reason to suppose that the motivation is unselfish. Concepts of solidarity also relate to a sense of community and that sharing of resources influences the nature and quality of that community (for example, giving not selling blood as discussed by Titmuss, 1970). This also fits with the Bismarckian welfare system of shared action.

Solidarity is often associated with the ability to access services notwithstanding the cost or the nature of the problem requiring a service and so relates to fairness and equity issues raised in SV2. The solidarity may be achieved through some sort of contractual system or a more general humanitarian commitment to provide (Clark & Weale 2012). Either way, there may be limits to what is provided or seen as reasonable to be provided and a societal level resource allocation system could also be a feature of solidarity.

The social values included in this category include: Altruism; Common good; Community; Solidarity.

Solidarity: Relevance to NICE 2008

There is relatively little explicit discussion of the social value of solidarity within the NICE 2008 document (Will 2012). Where this value is discussed is in the relationship between solidarity on the one hand and individual autonomy and choice on the other: "NICE recognizes the importance of individual choice and of respecting individuals' values, cultural attitudes and religious views. However, it recognized that it might sometimes be necessary to limit individual choice in the

interests of the population as a whole... Decisions about whether to recommend interventions should not be based on evidence of their relative costs and benefits alone. NICE must consider other factors when developing its guidance, including the need to distribute health resources in the fairest way within society as a whole (NICE 2008: 19, 22) (see also SV2 on inequality).

Solidarity: Ideas identified in the literature

Tensions between solidarity and individual social values

Some of the literature raises issues about the danger of solidarity impinging against the rights of certain sub-groups within society.

1. Solidarity for societal and public health services rather than individual level services and benefits. On the other hand, some argue that prioritising community rights can be at the expense of individual rights (Callahan 2012). Glaser (2003 quoted in Birgden and Cucolo 2011) warns that placing too much weight on the community's interests might breach the treatment rules of various ethical codes concerning beneficence (benefiting the client), non maleficence (do no harm), and autonomy (respecting self-determination). (See Sv3 on autonomy).
2. Solidarity and implications of this for how financial costs or priority setting of resources is shared (Hoedemaekers & Dekkers, 2003, Clark & Weale 2012).

Implications for equity

Some of the literature argues for the importance of solidarity as a means of righting social injustices within society.

3. Solidarity as understood within social work includes an obligation to explicitly challenge social conditions that contribute to social exclusion, stigmatisation or subjugation, and to work towards an inclusive society (The Policy Ethics and Human Rights Committee 2012). In this way, solidarity links to other social values such as health and social rights. This can have a particular resonance in social care which may be acting against societal injustices.

Implications sustainability and effectiveness

Some of the literature engages with the tensions between cost effectiveness as the basis for priority setting and the wish to show solidarity with peoples' needs.

4. Solidarity as a basis for the resource allocation system: 'The value of solidarity emphasises the mutual interdependence of human beings, their common neediness in the face of illness, and the obligation to support each other in paying for health care. This has direct implications for publicly financed systems: the effect of a decision to make a certain intervention the subject of a co-payment is to put that intervention beyond both the bounds of financial solidarity and health solidarity. The relevant intervention may be either so expensive (whether clinically effective or not) as to impose an unjustified burden on the pool of risk-sharers, or its benefits may be either sufficiently uncertain and/or trivial for it to be justified in terms of health solidarity' (Clark and Weale 2012). So the social value of solidarity has a consequence for wider community values and community functioning.
5. Solidarity in tension with cost effectiveness: 'Where humanitarian solidarity is valued particularly highly, medical need may be prioritized over all other considerations, including cost-effectiveness. This may lead to the undesirable situation where ineffective treatments aimed at serious conditions are always given higher priority than treatments for less serious conditions, no matter how effective these are. That is not to say, however, that exclusive attention to considerations of cost-effectiveness would be preferable since it would blind decision makers to issues of solidarity which, certainly in this country context, are highly salient' (Clark and Weale 2012). So there is a link between cost effectiveness, rule of rescue, futility and solidarity. As an

example, Birgden and Cucolo (2011) argue that in sex offender treatment, interventions are shaped more by requirements for solidarity rather than evidence of what works. So solidarity underpins cost effectiveness yet can also be in tension with it.

6. Solidarity in terms of fairness and justness in use of the needs and resources of society and the rest of the world (Gostin 2013; Friedman 2013, Ruger 2013) (so relates to SV6 on sustainability). The argument that services should either contribute to, or avoid detracting from, the healthiness and wellbeing of society (Parkhill et al. 2013).

Solidarity: Summary of issues for consideration

The main issue raised in the literature is the link and tension between solidarity and other social values. The absence of direct reference to solidarity in the 2008 policy is unclear.

Issue 13: *Whether there should be explicit advice on the social values underpinning the tension between public outcomes and individual benefit and individual autonomy.*

Public level guidance may benefit the majority most of the time but there may be tension between these values and outcomes and individual values and outcomes and the ability for self determination of these.

Issue 14: *Whether to explicitly incorporate the value of solidarity in terms of social inequality and social values.*

A policy on health and care guidance could state the role of solidarity and how it impacts upon other social values such as autonomy, cost effectiveness, clinical and health effectiveness and individual rights.

SV CATEGORY 5: PARTICIPATION

Nature of the social value(s)

The social values relate to engagement and influence of stakeholders in society in the guidance development process. As value judgments will inevitably vary between individuals and groups within society, participation allows members of society to have their views heard and to listen to the values and the reasoning of others.

The social values include: Civic engagement; Collaboration: Collective choice; Inclusiveness; Participation; Responsiveness; Shared decision-making; Stakeholder or shareholder value; Users: democracy and orientation; Well informed; Will of the people.

Participation: Relevance to NICE 2008

The NICE 2008 policy document Section 1.3 states: "Intended audiences for these principles. The principles are intended for three audiences: those involved in designing or revising the processes for developing NICE guidance; NICE's advisory bodies responsible for developing individual items of NICE guidance; NICE's stakeholders and the wider public, to enable them to understand the social values that underpin NICE guidance. The Institute's stakeholders include relevant professional bodies, patients and patient-carer organisations, health-related industries and the wider public health community."

"Key Principles

1. NICE's approach to patient and public involvement is based on two key principles:

- that lay people, and organisations representing their interests, have opportunities to contribute to developing NICE guidance, advice and quality standards, and support their implementation, and that, because of this contribution, our guidance and other products have a greater focus and relevance for the people most directly affected by our recommendations. “

NICE also has a formal policy for patient and public involvement from which these two key principles are taken (the current version is NICE 2013).

Participation: Ideas identified in the literature

1. Involving clients and public: methods of community engagement (Cluzeau et al. 2012; Kelso et al. 2012) including citizen’s council (Braconovic 2011; Bombard et al. 2011; Littlejohns and Rawlins 2009), avoid narrow focus of guidance (Porter 2011) and ensure that public values are involved (Jasanoff 2011), clarify differences between academia, professional practice and the community (Bombard et al. 2011; Guttman 2011; Stafinski 2011) and create mutuality (Pesut 2011). What degree of difference is acceptable between guidance, professional and community values and how do you work with differences within these? How does this participation relate to the extra welfarism of guidance development that may not differentiate individuals’ view of needs?
2. Variation in the values between and within groups of professional staff and their roles and responsibilities: for example, between and within clinical health, public health and social care.
3. Representation and participation: what is legitimate representation for appointments to priority setting bodies and public advisory committees to provide guidance to policy makers on social values and priority setting (Biron et al. 2012). In other words, what are the social values underpinning the particular use of methods of participation?
4. Whether social values should be differentiated by societal or client group as advocated for disability: ‘The narrow perspective of a patient who has a particular personal interest in the service which she receives may conflict with the broader, longer-term interest of a citizen who is a taxpayer, a voter, and a member of any number of communities: as such, they are interested in not only what happens to themselves but also to their families, neighbours and fellow citizens, both in the present and in the future’ (Clark & Weale 2012).
5. Assessing what service users consider to be important: ‘The published research available to a guideline development group may not have taken into account the range of outcomes that patients identify as important, or considered the range of interventions that may achieve those outcomes. For instance, COPD research studies may focus on lung function and disease progression which are less relevant to patients than symptoms, quality of life, and functional status. Research focused on surrogate outcomes may in turn drive the priorities of guideline developers, sometimes at the expense of outcomes or interventions that patients consider important’ (Kelson et al. 2012).
6. User orientation and democracy: that the individual ought to be involved in matters that affect them (user democracy, local governance, citizen involvement, the will of the people, listening to public opinion, responsiveness, dialogue, balance of interests, and self-fulfillment) (Jørgensen and Bozeman 2007) (see SV2 on children’s lack of representation); and that lack of such engagement is an authoritarian relationship rather than a channel for democratic input and based on the user’s/customer’s needs with services supplied on time, and with friendliness (Jørgensen and Bozeman 2007). Perspectives on these issues differ politically and culturally; for example between views on the role of the state in the UK and the USA (Callahan 2012). This also relates to the extent that technology transfer is seen as a technical issue with the privatizing of values debates (Jasanoff 2011). Some argue that a mismatch between these resource allocation systems and views of the public will be reflected in a limited ability of such systems to engage with the public (Wilmot 2013).

7. Collaboration: as ‘co-producers’ of outcomes, users of services should also, therefore, co-produce tools and guidance designed to promote and measure those outcomes’ (Roscoe et al. 2012) includes cooperation, collective choice, sharing of power and prestige, mutual benefit, citizen involvement, local governance, dialogue, democracy, will of the people, collective choice, listening to public opinion, user democracy, majority rule (Witesman & Walters 2013).
8. Well-informed users: the need to address informational asymmetries between providers and users of services particularly in assessment and decisions on services (treatment) which causes market failure where users have relatively little possibility of learning from experience or of testing the counterfactual of different treatment (Weisbrod 1978). Providers of services may act in a self interested way so how can this effect be minimized? It has been argued that evidence based medicine has shifted from a main focus on health outcomes to strengthened informed consent through sharing evidence and decision making with service users (Gupta 2011).

Participation: summary of issues for consideration

Issue 15: Whether to be more explicit and evidence informed about participation

User engagement is a research field in its own right and could be used to (i) examine how the guidance process reflects professional and community values; (ii) how different social values are examined and applied at different stages of guidance development and implementation; and to inform any changes in practice in guidance development.

SV CATEGORY 6: SUSTAINABILITY

Nature of the social value(s)

This category concerns those social values focusing upon the use of the World’s resources in the production and implementation of guidance. It can also concern the sustainability of the guidance system for future generations and the voice of those future generations in this.

One aspect of sustainability is about bequeathing a clean environment and plentiful resources to our descendants, instead of wilfully consuming and destroying what was created millions of years ago. However, sustainability has started to be used as a more generalized value: For example, organizations are sustainable if they do not wear out or use up material and nonmaterial resources such as the workforce, the good will of regulatory bodies, the production apparatus, and so forth. Sustainability has a host of related values branching off in different directions: (a) stability and continuity; (b) the common good and public interest; and (c) moral standards, ethical consciousness, and solidarity.

The voice of the future is a more specific value. The idea is that democracy is flawed because it is impossible to represent future generations in a politically elected assembly. As a result, other ways need to be found to redress the imbalance between the present and the future. Related values include fairness, moral standards, ethical consciousness, and protection of the rights of the individual (in this context, the rights of future generations) (Jørgensen and Bozeman 2007).

The social values include: Continuity and Future; Public interest; Stability; Sustainability; Voice of future.

Sustainability: Relevance to NICE 2008

Section 4.5 of the NICE 2008 policy document states: “NICE recognises that when it is making its decisions it should consider the needs of present and future patients of the NHS who are anonymous

and who do not necessarily have people to argue their case on their behalf. NICE considers that the principles provided in this document are appropriate to resolve the tension between the needs of an individual patient and the needs of present and future users of the NHS. The Institute has not therefore adopted an additional 'rule of rescue'".

NICE have also made statements in relation to sustainability in 2012 and 2014 reports by the NHS Sustainability Development Unit:

"NICE guidance is designed to help health and social care to get the best outcomes for patients. We recognise the importance of environmental sustainability and so we encourage research into the environmental impact of prevention and healthcare interventions which we will take into account in the development of our guidance in the future. With more consistent measures of environmental impact, we hope in future to produce guidance that will improve the quality of care and the health of current and future populations by taking into account the use of environmental as well as financial resources" David Haslam – Chair National Institute for Health and Care Excellence (Sustainable Development Unit 2014).

"NICE is committed to exploring methods for building sustainability into NICE guidance and to promoting sustainable growth in the life sciences industries. We warmly welcome this guidance. It represents an important extension of the scope and methods of carbon accounting. It's also a very practical support to industry efforts to reduce the carbon footprint of the drugs and medical devices that are so important to NHS patients." Sir Andrew Dillon CBE, CEO of the UK National Institute for Health and Care Excellence. (Sustainable Development Unit 2012).

Sustainability: Ideas identified in the literature

1. Fiscal sustainability: the long term financial sustainability of guidance decisions (Colombo et al. 2011; Parkhill et al. 2013).
2. Environmental sustainability: the effects on the environment of guidance decisions (Sustainability Development Unit 2011).
3. Appropriateness of economic approaches to assessing intergenerational inequities and the needs of current versus future users of services (Adam and Groves 2007; Broome 1994; Mulgan 2006; Sen 1982, Graham 2010, Van Baal 2013). Approaches to developing metrics that include future considerations (as in SV 1 on timelines of outcomes).
4. Future generation outcomes: consideration of what would be relevant outcomes for future guidance development (Sustainability Development Unit 2011).
5. Sustainability of the guidance development process (Sustainability Development Unit 2011) and stability and consistency in decision-making and thus also legitimacy (Docherty et al. 2012).

Sustainability: Summary of issues for consideration

The literature raises issues of sustainability in terms of the impact of guidance development, the ability of guidance development to continue, the implementation of guidance and the extent that longer term outcomes are considered in guidance development (see also Category 1 on outcomes and timelines).

Issue 16: *Considering sustainability issues in terms of the ability to provide ongoing guidance in its financial, political and broader societal contexts.*

Guidance producers considering what processes they are able to manage not just now but in an ongoing sustainable way.

Issue 17: *Considering sustainability issues in terms of the environmental and other impacts of the implementation of its guidance.*

If this was a consideration then it would become a driver for relevant data on environmental impacts to become available and to influence decision making.

Issue 18: *Considering sustainability issues in terms of the wellbeing of and costs for future generations.* This relates to SV1 on the outcomes considered in cost effectiveness and the various needs of different sections of society (and future societies).

These are all issues which could be incorporated more explicitly into the guidance development process though the degree of this could be limited by available data as well as any policy imperatives.

SV CATEGORY 7: TRANSPARENCY AND ACCOUNTABILITY

Nature of the social value(s)

The social values are concerned with transparency for accountability in demonstrating reasonableness of decisions. 'Accountability exists when one party justifies and takes responsibility for its activities to another party. Being accountable in health priority setting means having the obligation to answer questions regarding decisions about which interventions are prioritised and why' (Clark and Weale 2012: 300).

The social values include: Accountability; Compromise; Decisiveness; Independence; Integrity; Legal obligations, Balance of interests; Procedural justice (publicity, relevance, challenge and revision, regulation); Reasonableness; Responding to comments & criticisms; Review; Safety; Soundness; Support for implementation; Thoroughness; Timeliness; Transparency.

Transparency and Accountability: Relevance to NICE 2008

The NICE 2008 policy document states:

Section 2.3: Procedural justice: Procedural justice provides for 'accountability for reasonableness'. For decision-makers to be 'accountable for their reasonableness,' the processes they use to make their decisions must have four characteristics [15]: publicity, relevance, challenge and revision, and regulation.

Section 3.1: Legal obligations: NICE is bound by its Establishment Order [16], any Directions from the Secretary of State for Health [17], and legislation on human rights, discrimination and equality. NICE is committed to promoting equality, eliminating unlawful discrimination, and actively considering the implications of its guidance for human rights. It therefore aims to comply fully with legislation on human rights, discrimination and equality.

- 3.2 Procedural principles: scientific rigour
- 3.2 Procedural principles: inclusiveness
- 3.2 Procedural principles: transparency
- 3.2 Procedural principles: independence
- 3.2 Procedural principles: challenge
- 3.2 Procedural principles: review
- 3.2 Procedural principles: support for implementation
- 3.2 Procedural principles: timeliness

These features relate to the procedural justice requirement for ‘accountability for reasonableness’ described in section 2.3 above and provide legitimacy to NICE guidance.

Section 5: ‘Responding to comments and criticism: Principle 6: NICE should consider and respond to comments it receives about its draft guidance, and make changes where appropriate. But NICE and its advisory bodies must use their own judgement to ensure that what it recommends is cost effective and takes account of the need to distribute health resources in the fairest way within society as a whole.’

Section 9: ‘Following the principles: The board of NICE considers that a statement of broad compliance with the principles should be included in all NICE guidance as well as in its process and methods manuals. In situations where guidance appears to depart from these principles, this should be stated and there should be a clear explanation.’

Transparency and Accountability: Ideas identified in the literature

1. Providing information on process versus it being communicated and understood: The disclosure of information does not ensure that it will be intelligible (O’Neill, 2002; see also Rid, 2009: 16). Transparency, communication, and intelligibility is required for accountability and to enable judgements of reasonableness.
2. Transparency of social values in guidance: the extent that social values are transparent in the guidance development and guidance implementation. The use of standard approaches to monitor and overtly plan and manage this (Saarni et al. 2011a, b; Golan 2011; Burls 2011) including HTA professionals’ values (Arellano et al. 2011).
3. The identification of social values in the community and the inclusion of these community social values in the guidance production process (e.g. Ahn et al. 2012; Hahm et al. 2012; Pesut et al. 2011). (This relates to SV1 on outcomes for cost effectiveness, SV2 on the basis of justice, SV5 on participation, to SV8 and the processes of guidance production.
4. Conflicts of interest (trust, transparency, fairness, accountability): the importance of systems and transparency for this; including the courts which both provide a means of challenge and a legitimatizing of the process (Syrett 2008).
5. Balancing of interests and compromise: the support of systems and actions that promote fairness and equality for individuals and groups without discrimination or favouritism (equal treatment, justice/social justice, equity, fairness, vertical equity, openness, democracy, and stability).
6. Compromise so that power is not misused and that plan is sufficiently satisfactory to everybody involved (reasonableness, fairness, and dialogue, robustness) (Jørgensen and Bozeman 2007).
7. Civic integrity: values of honesty, consistency, coherence, and reciprocity that result in a "high-trust" organizational culture and that ethical decisions result from thorough consideration being given to all legitimate values (Van Wart 1998).
8. Soundness and reasonableness: the degree to which a conclusion follows from the form and content of reasons offered in its support and the extent to which these reasons are true or probable (Bond et al. 2013; Schlander 2008).
9. Thoroughness: the degree to which all relevant ethical issues have been identified and discussed (Bond et al. 2011; also Burls et al. 2011).

Transparency and Accountability: Summary of issues for consideration

Issue 19: *Whether accountability and transparency is sufficiently and correctly specified in guidance processes.*

Transparency and accountability are often core aspects of utility based resource allocation systems. However, not all social values may be explicit or specified in practice and social values may also be

inadvertently hidden in the system. Greater specification could include formal processes of identifying what social values are being overtly or inadvertently employed at different parts of guidance development. It could also involve lack of data on effects of services or differential effects on subgroups hidden by aggregated data (as in the issues in SV8).

SV CATEGORY 8: APPROPRIATE METHODS OF GUIDANCE DEVELOPMENT

Nature of the social value(s)

Transparency and accountability (Category 7) are core aspects of the guidance development processes but within these processes are values about the process itself and values that may be hidden within the processes of guidance development.

Social values included in this category include: Coherence; Evidence-based decision making; Logicity; Neutrality and the relevance aspect within the value of procedural justice; Scientific rigour.

Appropriate Methods of Guidance Development: Relevance to NICE 2008

The NICE 2008 policy speaks to the values in the whole process of guidance development and specifically to methods of that process including scientific rigour and metrics for calculating cost effectiveness. The whole approach to guidance development contains the social value that it should be evidence informed and created due to transparent with procedural justice (see SV7) and rigorous methods.

Appropriate Methods of Guidance Development: Ideas identified in the literature

1. Transparency and fitness for purpose and methods in primary research, reviews of evidence, and guidance (Bond et al. 2011): for example, in statistical methods used (Gelfond 2011) or evaluations of multiple strategies of intervention with technically different assumptions (Eckerman 2011) and increasing sophistication in technical methods of analysis to assess the impacts of different intervention strategies including equity complexity (Waters et al. 2011) and context (Espallargues et al. 2011). Also practice standards and frameworks such as AGREE² to assess the methodological rigour and transparency in which a guideline is developed. The frequent lack of relevant studies to inform guidance has led to the suggestion that 'evidence searched' guidelines is a more accurate description than 'evidence based' guidelines (Knaapen 2013).
2. Transparency and fitness for purpose of social values in primary research, reviews of evidence, and guidance including: (i) ethics and ethical analysis (Bond et al. 2011, Burls et al. 2011, DeVries et al. 2011); (ii) quality and relevance appraisal of studies and their conclusions (Watine 2011); (iii) the lack of examination of, for example, subpopulation issues (as in SV2); and (iv) metrics of cost calculations: for example, differing ways of funding long term social care (Fernandez et al. 2010). So social values may be explicit in the main aspects of guidance development but not in the detail such as availability and choice of research used.
3. Relevance, fitness for purpose and timeliness of guidance: the emphasis on the technical aspects of guidance may detract attention from the aim to provide timely fit for purpose products.
4. Evidence of distributional effects of the guidance in practice (Sassi et al. 2001): transparency and fitness for purpose of implementation that impacts on whatever social values used: for example, the realities on the ground about who receives resource (Johansson et al. 2011; Omar 2013) and the fidelity of implementation and effects on cost effectiveness (as in statins, Grabowski 2012).

² <http://www.agreetrust.org>

Even if guidance is based on appropriate social values then this has little impact if implementation acts counter to this.

5. Harm and safety: the emphasis on effectiveness may lead to a lack of focus on harms. There are: many different types of safety issues; differences in the way an assessment of harm is undertaken; and can be resource intensive and time consuming. These can include: Identification and assessment of harms; quality of evidence for assessment of harms; summary of impact (outcomes) of harms; minimisation of harms; comparison with alternative technologies; and environmental safety. The estimates of harm can vary with the approach used (Lampe et al. 2008).
6. Social values as part of the content of guidance: guidance varies in the extent that ethical issues in direct service provision are addressed (Assasi et al. 2014; Knüppel et al. 2013; Stetch & Schildman 2011).

Appropriate Methods of Guidance Development: Summary of issues for consideration

Issue 20: *Whether there should be formal processes for examining the social values being applied in the whole guidance development process and specific stages of: topic identification and clarification; evidence identification and analysis; calculation of metrics of cost effectiveness; guidance decisions; and implementation.*

Issue 21: *Considering the impact of lack of research data on, for example, harms, distributional effects, and implementation.*

Issue 22: *Considering the overall fitness of purpose and timeliness of guidance.*

The main issues raised in the literature relate to the fitness for purpose of the guidance process, the social values implicit in each stage of the guidance process, and the way in which social values may be inadvertently hidden within the processes through lack of evidence.

4. OVERARCHING THEMES

The literature raises many issues about the nature of social values that can be applied to guidance development. It needs to be emphasized that not all of these issues should necessarily be applied to guidance development. They are simply issues that have been raised in the literature and this review provides an opportunity for them to be considered. Many of the ideas that have been proposed are in tension with each other and could not all be achieved. It should also be emphasized that many of the issues raise considerable practical challenges in terms of methods, data and financial and timeliness.

The literature has raised many issues. Some of the main themes include:

1. Increased sophistication in guidance development: It seems that the development of guidance as a formal accountable process of resource allocation has worked extremely well. The success at engaging with such complex and value laden issues is allowing the examination of even more difficult ideas about health and social care provision.
2. Boundaries of questions and boundaries of evidence: The starting point of resource allocation has been the assessment of effectiveness and cost effectiveness and so maximizing the outcome benefits of the investment in services. What started as relatively simple issue of one input and one output has become more complex with a concern for wider intervention effects and broader outcomes. The inclusion of public health and social care has further broadened this focus on breadth and complexity. This may also broaden the services: (i) that are not currently considered for funding but that might have powerful impacts on well being in health and social care; (ii) who or what is considered part of the service provision and service recipient; and (iii) the breadth of outcomes considered.
3. Including all of society's social values?: The broadening of questions and outcomes beyond narrow focused calculations of cost effectiveness is bringing attention to wider social values related more generally to the health and social care services such as dignity, compassion and trust as well as further societal issues of the environment, culture, and global issues. This may be appropriate but engaging with such values is a considerably more challenging task than the original guidance development systems.
4. The balance between utility and equity?: The increased breadth of focus and inclusion of issues of equity leads to tensions between cost effectiveness and justice and equity values. This can involve providing weightings for particular groups and conditions and rights to a service rather than outcomes alone. This tension might be reduced through providing more specific frameworks for how these tensions could be managed but this begs the question of how such compromises will be reached and applied.
5. Corporate or societal social values?: The underlying question is who do the values belong to, who do the social values represent and how is this representation is obtained? The key here is participation and the social value of solidarity which reflects the mutuality of a shared system of resource allocation.
6. Guidance or rules?: As the guidance systems become more sophisticated and financial constraints becoming stronger then there may be less opportunity for professional and customer autonomy (through either direct or indirect constraints). Either 'one size fits all' or there may be variation based on predetermined criteria and less room for personal manoeuvre

within these boundaries which makes the social values on which these are based and how they are agreed even more important.

7. Hidden social values?: The guidance development process may be based in explicit social values but these values may not be executed if there is missing data on harms or subgroup outcomes or there are problems with implementation. The extent of such hidden values is unknown but it is a question that can be asked.
8. Lack of research evidence?: If the research evidence is weak, then what are the processes by which other evidence is brought to bear and what is the effect of this?
9. Is social care different?: There is not much literature on social values of resource allocation in social care, but many of the issues identified by this review could apply to aspects of clinical medicine, public health and to social care. The extent that the issues are relevant may vary between and within these areas.
10. The guidance development process itself: The way in which the process involves social values, the extent that these are known and explicit, and the extent that the content of the guidance specifies values issues.

This review did not examine the implementation of guidance on service provision though this can have social value implications. If guidance is not fully implemented, then neither is the social values that the guidance contains.

APPENDICES

APPENDIX 1: Bibliographic searches

MEDLINE (EBSCO Host)

Boolean Searching

Search date: 8/10/2013

No. of records identified: 1131 minus 8 late identified duplicates = 1123

S62	S58 NOT S61	Limiters - Date of Publication: 20110101-20131231; English Language	1,131
S61	S60 NOT S59	Limiters - English Language	3,416,169
S60	MH "Animals+"	Limiters - English Language	13,708,998
S59	MH "Animals+" AND MH "Humans+"	Limiters - English Language	10,292,829
S58	S53 OR S56 OR S57	Limiters - English Language	7,283
S57	S40 OR S43 OR S44 OR S47 OR S49 OR S50 OR S51		1,840
S56	S54 AND S55		5,145
S55	S38 OR S39 OR S41 OR S42 OR S45 OR S46 OR S48 OR S52		120,969
S54	S36 OR S37		56,528
S53	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35		1,856
S52	MM "Health Planning" OR MM "Technology Assessment, Biomedical" OR MM "Evidence-Based Practice+" OR MM "Social Control Policies" OR MM "Health		44,135

	Priorities" OR MM "Resource Allocation"		
S51	(MM "Technology Assessment, Biomedical/ES")		58
S50	(MM "Evidence-Based Nursing/ES") OR (MM "Evidence-Based Medicine/ES") OR (MM "Evidence-Based Dentistry/ES") OR (MM "Evidence-Based Practice/ES")		208
S49	(MM "Health Planning/ES")		17
S48	(MM "Policy Making")		3,626
S47	(MM "Decision Making/ES")		1,312
S46	(MM "Guidelines as Topic")		7,608
S45	(MM "Public Policy")		14,462
S44	(MM "Social Control Policies/ES")		7
S43	(MM "Health Priorities/ES")		94
S42	(MM "Health Policy")		25,728
S41	(MM "Organizational Policy")		3,340
S40	(MM "Resource Allocation/ES")		206
S39	(MM "Advisory Committees")		2,188
S38	(MM "Decision Making")		25,915
S37	(MM "Ethical Analysis") OR (MM "Codes of Ethics") OR (MM "Principle-Based Ethics") OR (MM "Bioethical Issues") OR (MM "Bioethics") OR (MM "Ethics, Clinical") OR (MM "Ethics, Medical")		34,800
S36	(MM "Morals") OR (MM "Ethics") OR (MM "Moral Development") OR (MM "Social Values") OR (MM "Beneficence") OR (MM "Altruism") OR (MM "Social Justice") OR (MM "Personal Autonomy") OR (MM "Freedom")		24,626
S35	TI "protected values"		4
S34	TI "secular values"		1
S33	TI (bioethic* AND guidance)		0
S32	TI bioethic* AND values		24

S31	TI (ethical* AND (decision* OR guideline* OR (technolog* N2 health) OR (technolog* N2 assessment) OR "priority setting" OR agenda OR policy* OR "resource allocation"))	Limiters - Date of Publication: 20070101-20131231	459
S30	TI (ethics AND values)		145
S29	TI (ethical N1 values)		76
S28	TI (ethical N2 guidance)		38
S27	TI "Values Index"		0
S26	TI "ethical analysis" AND TI ((decision* OR (guideline N2 develop*) OR (technolog* N1 health) OR (technolog* N2 assessment) OR "priority setting" OR agenda OR policy* OR "resource allocation"))		23
S25	TI (ethics AND (decision* OR (guideline N2 develop*) OR (technolog* N1 health) OR (technolog* N2 assessment) OR "priority setting" OR "research agenda" OR policy* OR "resource allocation"))		667
S24	TI (bioethic* AND (decision* OR guideline* OR (technolog* N2 health) OR (technolog* N2 assessment) OR "priority setting" OR agenda OR policy* OR "resource allocation"))		195
S23	TI ("value# based" N3 (health OR medicine OR social))		77
S22	TI "Policy value#"	Limiters - Date of Publication: 20070101-20131231	0
S21	TI "Public value#"	Limiters - Date of Publication: 20070101-20131231	5
S20	TI "Public service value#"	Limiters - Date of Publication: 20070101-20131231	0
S19	TI "Stakeholder value#"	Limiters - Date of Publication: 20070101-20131231	1
S18	TI "value principle#"	Limiters - Date of Publication: 20070101-20131231	1

S17	TI "Socio-cultural value#"	Limiters - Date of Publication: 20070101-20131231	0
S16	TI "values measurement#"	Limiters - Date of Publication: 20070101-20131231	1
S15	TI "value consideration#"	Limiters - Date of Publication: 20070101-20131231	0
S14	TI "value judgment#"	Limiters - Date of Publication: 20070101-20131231	8
S13	TI "human values"	Limiters - Date of Publication: 20070101-20131231	11
S12	TI "ethical values"	Limiters - Date of Publication: 20070101-20131231	15
S11	TI (social N2 principle#)	Limiters - Date of Publication: 20070101-20131231	24
S10	TI "societal decision*"	Limiters - Date of Publication: 20070101-20131231	1
S9	TI (value# N2 instrument#)	Limiters - Date of Publication: 20070101-20131231	12
S8	TI (value# N2 framework#)	Limiters - Date of Publication: 20070101-20131231	18
S7	TI "framework values"	Limiters - Date of Publication: 20070101-20131231	0
S6	TI Social N3 ethics	Limiters - Date of Publication: 20070101-20131231	28
S5	TI Societal N3 ethics	Limiters - Date of Publication: 20070101-20131231	2
S4	TI Societal N3 values	Limiters - Date of Publication:	7

		20070101-20131231	
S3	TI (Social N3 values) NOT TI ("breeding values")	Limiters - Date of Publication: 20070101-20131231	43
S2	TI "societ* value#"	Limiters - Date of Publication: 20070101-20131231	11
S1	TI "social value#"	Limiters - Date of Publication: 20070101-20131231	72

Social Care online

Search date: 7/10/2013

No. of records identified: 61

Search string:

((freetext="social values" OR freetext="societal values" OR freetext="societal judgments" OR freetext="social judgment" OR freetext="social judgement" OR freetext="social judgements" OR freetext="social judgments" OR freetext="social morals" OR freetext="social moral" OR freetext="social principles" OR freetext="social ethics" OR freetext="societal ethics" OR freetext="ethical values" OR freetext="ethical analysis" OR freetext="Ethical values" OR freetext="Public values" OR freetext="Social ethics" OR freetext="Stakeholder values" OR freetext="Public service values" OR freetext="Public value mapping" OR freetext="social value mapping" OR freetext="Citizen's values" OR freetext="Human values" OR freetext="ethical values" OR freetext="Societal values" OR freetext="Personal values" OR freetext="Moral values" OR freetext="Policy values" OR freetext="society values" OR freetext="society's values" OR freetext="social value judgement" OR freetext="social value judgements" OR freetext="social value judgment" OR freetext="social value judgments"))

APPENDIX 2: Included social values

1. Acceptance
2. Access
3. Accountability
4. Achievement
5. Advocacy
6. Altruism
7. Authority
8. Autonomy
9. Avoiding discrimination
 - Race
 - Disability
 - Age
 - Sex/gender
 - Behaviour-dependent conditions
 - Socioeconomic status
10. Balance of interests
11. Being present and available
12. Belief in ability to change
13. Benevolence
14. Best interests e.g. surrogacy; who makes decisions on whose behalf and on what basis
15. Beneficence
16. Burden
17. Capable
18. Capacity to benefit
19. Challenge
20. Clinical and public health effectiveness
21. Civic engagement
22. Coherence
23. Collaboration
24. Collective choice
25. Compassion
26. Common good
27. Community
28. Compromise
29. Consent
30. Continuity
31. Control
32. Cost effectiveness
33. Cultural/context consideration
34. Decisiveness
35. Dignity
36. Distributive justice: Utilitarianism; Egalitarianism
37. Diversity
38. Effectiveness
39. Efficiency
40. Empowerment
41. Evidence-based decision making
42. Fair innings

- 43.Fairness
- 44.Freedom/liberty
- 45.Future looking
- 46.Happiness
- 47.Harm and safety
- 48.Hedonism
- 49.Human relationships
- 50.Inclusiveness
- 51.Independence
- 52.Individual choice
- 53.Innovation
- 54.Integrity
- 55.Justice/equity
- 56.Knowing and being known
- 57.Legal obligations
- 58.Logicality
- 59.Merit/Desert
- 60.Neutrality
- 61.Nonmaleficence
- 62.Participation
- 63.Personal growth
- 64.Power
- 65.Procedural justice: Publicity; Relevance; Challenge & revision; Regulation
- 66.Productivity
- 67.Professional choice
- 68.Protecting minorities
- 69.Protection of majority
- 70.Protection of rights of individual
- 71.Public interest
- 72.Quality care
- 73.Rare conditions
- 74.Reasonableness
- 75.Reduce use/waste
- 76.Reducing health inequalities
- 77.Responding to comments & criticisms
- 78.Responding to need
- 79.Responsibility
- 80.Responsiveness
- 81.Review
- 82.Right to a minimum quality of life
- 83.Right to health
- 84.Rule of rescue
- 85.Safety
- 86.Scientific rigour
- 87.Self-determination/Informed consent
- 88.Shared decision-making
- 89.Stakeholder or shareholder value
- 90.Social cohesion
- 91.Social recognition
- 92.Solidarity
- 93.Soundness

- 94.Spirituality
- 95.Stability
- 96.Stakeholder or shareholder value
- 97.Support for implementation
- 98.Sustainability
- 99.Timeliness
- 100.Thoroughness
- 101.Transparency
- 102.Trust
- 103.Universalism
- 104.Users: user democracy and orientation
- 105.Value-based decision-making
- 106.Value of human life/respect for death
- 107.Voice of future
- 108.Well-being
- 109.Well informed
- 110.Will of the people

APPENDIX 3: Identified but excluded social values

Only the social values seemingly most relevant to the provision of health and social care services have been included in this review. The social values listed here were identified in the literature review but were judged to be less central to the review and so were not prioritised for inclusion in the review. All of these social values could, of course, be potentially relevant in some way to health and care guidance.

1. Adaptability
2. Ambitious
3. Artistic
4. Character building
5. Clean
6. Client confidentiality
7. Competitiveness
8. Conformity
9. Conservation
10. Convenience
11. Courageous
12. Decency
13. Democracy
14. Dialogue
15. Education
16. Enthusiasm
17. Epistemology
18. Esthetic
19. Ethical consciousness
20. Excitement
21. Family and social
22. Forgiving
23. Friendliness
24. Good working environment
25. Helpful
26. Honesty
27. Honour
28. Imaginative
29. Impartiality/ (Professional) competence
30. Inner harmony
31. Intellectual
32. Local governance
33. Loving
34. Loyalty
35. Majority rule
36. Mature love
37. Moral standards
38. Non-judgement
39. Obedient
40. Obligation to provide information (without client consent)
41. Openness to change
42. Parsimony

43. Peace
44. Pleasure
45. Polite
46. Prestige
47. Privacy
48. Readiness
49. Reciprocity
50. Recreation
51. Respect
52. Salary
53. Salvation
54. Secrecy
55. Security
56. Self-control
57. Self enhancement
58. Self-respect
59. Self-transcendence
60. Stimulation
61. Therapeutic
62. Tradition
63. Wisdom

APPENDIX 4: REFERENCES OF PAPERS INFORMING THE ANALYSIS

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First produced in 2014 by:

Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre)
Social Science Research Unit
Institute of Education, University of London
18 Woburn Square
London WC1H 0NR

Tel: +44 (0)20 7612 6397

<http://eppi.ioe.ac.uk/>

<http://www.ioe.ac.uk/ssru/>

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telephone: +44 (0)20 7947 9556 email: info@ioe.ac.uk