Defining and Measuring Unmet Need to Guide Healthcare Funding: Identifying and Filling the Gaps

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Abstract

Budget allocations to Clinical Commissioning Groups include adjustments for *unmet need* for healthcare, but there is a lack of robust evidence to support this. This article describes a literature review with an objective to understand the available evidence regarding unmet need. We developed a conceptual framework for what constitutes ideal evidence that; defines unmet need for a given population, indicates how that need can be met by health care, establishes the barriers to meeting need and provides relevant proxies based on observable measures. Our search focused on recent and empirical UK data and conceptual papers. We found no one article which satisfied all requirements of ideal evidence; the literature was strongest in defining need but weakest in regard to establishing observable proxies of need capable of being used in budget allocations. Our review was limited by its timescale and a vast body of literature, which translated into a limited number of key words for the search. We conclude that further research to inform budget allocation is required and should focus on conditions or services where adverse health outcomes from unmet need are amenable to healthcare interventions and which affect a sizeable proportion of the population.
1. Introduction

1.1 Background
The central problem of how best to allocate resources for public services is addressed in a diverse number of ways, nationally and internationally. However, a common theme is the devolution of responsibility for providing or purchasing services to organisations or commissioners, usually at regional or local levels. This also entails the devolution of the resources or budget with which to organise or commission those services on behalf of defined populations. In healthcare, this is a common feature of almost every system in the world (Rice and Smith, 2001) and it is also prevalent in the police sector in many countries (Home Office, 2015); as well as underpinning the approach taken in other public services in England such that for primary care resources, personal social services for children and public health funding to Local Authorities (LAs).

In determining the size of the budget to be allocated to organisations to provide or commission public services for their populations, governments in many countries seek to ensure that resource levels reflect the population’s need for those services. In the English NHS, there is a particularly long history of allocating resources to commissioners based on the relative need for health care services of populations living in defined geographical areas. This paper addresses one important element of this assessment – the notion of unmet need.

In England, a substantial part of the budget for health care is channelled from the Department of Health through NHS England to Clinical Commissioning Groups (CCGs1) and in 2014/15 CCGs received £67bn (Department of Health, 2015). CCGs are responsible for commissioning many health care services for patients in their area, i.e. they purchase services from health care providers to cover the needs of their populations. There is an underlying equity goal reflected in the process to determine the ‘correct’ amount of resources allocated to CCGs. A weighted capitation formula is used in order to match, as far as possible, the resource received with the healthcare needs of the CCGs’ populations. Technical details of the way in which the formula has developed and is applied are available elsewhere (NHS England, 2014) but the main feature of relevance to this paper is the fact that since the mid-1970s the allocations have been population based (Mays, 1987).

The budget allocated to a specific CCG therefore depends on the size and characteristics (eg, age, health status) of its population and its location. Using these factors a weighted population is calculated for each CCG, which determines the target allocation of the budget between them.2 The calculation also includes an adjustment for unmet need based on all-cause mortality rates, but it is acknowledged that this adjustment is not based on robust evidence (NHS England, 2014). Understanding and addressing the evidence base in relation to unmet need is the subject of this paper, with a particular focus on the practical use of evidence for policy purposes.

1.2 Unmet and inappropriately met need in resource allocation
The complexity of the concept of healthcare need, and its contested nature, is reflected in a vast literature relating to the definition and operationalisation of need (Aday and Andersen, 1981, Allin et al., 2010, Daniels, 1982, Diwan and Moriarty, 1995). Need is not observable and, even if it were, the degree to which it can be met by the provision of healthcare resources will vary. Utilisation of

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2 Note that the actual allocation can differ from the target allocation, as actual allocations also consider the deviation between the current and the target allocation, for example, to avoid reducing drastically the allocation of one area.
healthcare services may be a proxy for how well needs are met, but if there is a mismatch between what is used by particular patient groups and what they need, then the RA formula based on utilisation, will not succeed in achieving its equity aim.

There is widespread policy concern regarding systematic under-utilisation of healthcare resources by particular groups, relative to their level of need. There are two ways in which need may diverge from utilisation: through ‘supply’ factors i.e. arising because adequate services are not made available; or due to ‘demand’ factors i.e. despite the availability of services, they are not accessed (which may in turn be due to factors related to the way in which services are provided or the way in which individuals seek out the services).

Whatever the underlying reason, the consequence is that such groups may have lower healthcare status or poorer outcomes because they are not in receipt of the appropriate level of services. It is also possible that there is systematic over-utilisation of healthcare resources by particular groups, relative to their level of need. Again, this may be due to supply or demand factors but the concerns here are more complex. There may be a risk of poorer outcomes in terms of health and wellbeing if people over-use services which they do not need, e.g. having unnecessary treatments with potential harmful side-effects. There is also a resource issue if such use implies fewer resources are available for other parts of the healthcare system.

Our study sought to review the literature in relation to unmet, or inappropriately met, healthcare needs in order to inform adjustments to the RA formula to reflect such needs. The term ‘inappropriately met’ is, for the purposes of this review, interpreted to designate over-use. However, in a broader context there is a possibility that needs are only partially met or met but with lower quality for some groups than others, which could also be designated as ‘inappropriately met’ but in this review we reserve that term for over-use, making it clear where studies refer to partially met needs or needs that are met with lower quality services. It became clear early in the implementation of our review that by far the greater focus in the literature is on unmet need. We did not find any references that quantified the concept of inappropriate over-use in regard to lowering the quality of healthcare for some groups. We found only a single reference dealing directly with the measurement of over-use, but the evidence it presented was not for the UK. Henceforth, this paper deals exclusively with unmet need as discussed above.

For the purposes of an allocation formula to determine the geographical distribution of resources, the central issue is not just whether variations in unmet needs exist, but how they are distributed across the country. If there is no evidence to suggest a systematic geographical variation, there may be little that adjustments to the RA formula can do to address the issue.


2. A framework for understanding unmet need

2.1 Introduction

Given the vast literature, a tight time-frame for the project (four months) and the fact that our ultimate aim was to locate evidence that could specifically be used for RA purposes, it was important to begin with a framework to guide the review process.

Our unit of analysis was a geographically defined population of individuals. Unmet need for health care can be reflected in a number of potentially observable characteristics of that population, ranging from measures of ill-health and disease prevalence to stated unmet needs adduced from surveys and agreement with statements such as ‘I need to see a doctor but cannot find one’ or ‘my GP has referred me to a specialist but I cannot get an appointment’. We term any such manifestation of unmet need for a population as expressed unmet need. The literature dealing with such measures is potentially vast since it also constitutes the basis for describing inequality of health within and across populations. We therefore set out a series of restrictions that allow us to focus on what is relevant to resource allocation.

For the purposes of resource allocation it is important to distinguish between expressed unmet need that can plausibly be met by increasing the provision of health care and that which cannot. We termed the former effective unmet health care need.

It is also important to distinguish the potential mechanisms for addressing effective unmet health care need. One mechanism is increasing the provision of health care (across all sectors) – a supply-side response. That mechanism is directly responsive to resource allocation and thus a natural focus for the literature search. The alternative mechanism involves facilitating individuals to access existing health care provision (e.g. via education campaigns or better information on services) – this is a demand-side focus and whilst we identify elements of the literature that address this, we regard that literature of less direct relevance to resource allocation decisions, albeit that we recognise that some types of demand can potentially be influenced by supply-side measures. Hence we have been especially concerned with identifying in the literature measures of supply-side responsive effective unmet health care need.

Practical resource allocation mechanisms require the specification of a formula that takes observable proxies of supply-side responsive effective unmet health care need and bases a budget calculation on these. We thus further considered from within the reviewed literature those contributions that identify relevant proxies. Proxies are practically useful if they are based on quantifiable measures at a relevant population level and if the evidence supporting their use is recent or can readily be updated. It is also important that proxies are not subject to manipulation by those who are receiving the resource, e.g. hospital waiting times can be affected by provider behaviour in order to represent unmet need. Hence we further refined our search to establish whether there are practically useful proxies of supply-side responsive effective unmet health care need.

In judging whether any practically useful proxies are directly relevant for a resource allocation formula the likely variation in those proxies across geographic areas/populations is important. If a proxy does not vary from area to area, including it in a formula would not directly change the allocation of resources across those areas/populations. However, there may be an indirect effect. Even if there is no variation across areas in the unmet need proxy, the shares received by areas may actually change because the allocation for an area is decided by the ratio of the total needs in that area to the total needs of all areas. Thus if a proxy for unmet need was added to the formula equally across all areas, it would in effect increase the constant term in the numerator and denominator of
the shares calculation and those areas with below average levels of other types of need measured in
the formula, will gain from the inclusion of the constant for unmet need. But from the perspective
of the literature review we focused on whether papers consider variation across areas at all.

Hence our ultimate goal was to determine whether the literature provides guidance regarding
regionally varying practically useful proxies of supply-side responsive effective unmet health care
need. We further distinguished between evidence that was quantitative (deriving from published
statistics or other quantitative data bases) or qualitative (deriving from surveys or otherwise self-
reported by individuals).

2.2 From expressed to effective unmet need

In order to establish an effective search of the literature it was necessary to clarify both the
relevant search terms and their context. As discussed above the purpose of our search and review
is to determine whether there is evidence to inform resource allocation decisions in the NHS.

Resource allocation directs budgets to the purchasers of health care and thus an important first
distinction is between unmet need in one sense that often occurs in the literature – as being
synonymous with poor health – and unmet need for health care. Often evidence of poor
population health is taken to be evidence of unmet need.

Many forms of poor health are amenable to health care interventions, in which case the
distinction is blurred, but some aspects of poor health are the result of unhealthy behaviours and
lifestyles, or unwillingness or inability to consume health care that is readily available. For these
aspects of poor health we might say there is unmet need for greater health, but not necessarily
unmet need for more health care, albeit that we recognise that demand for health care is a derived
demand from demand for health. But at a practical level we as far as possible focused our search
and review on the literature that identifies unmet health care need.

Some examples help to illustrate instances where ‘unmet need’ is subject to measurement and
analysis, but where that need is not unmet health care need. One example in the literature is
where research is concerned with a medical condition, giving rise to poor health, for which there
is no health care intervention available. In such instances researchers are concerned primarily
with making the case for the development of new (or better) health care interventions, not with
increasing the availability of existing ones. A second example can be found in empirical proxies for
unmet need. The most extreme poor health outcome is death, and thus it is natural to consider
excess mortality as a proxy for poor health and thus unmet need. Deaths due to causes such as
acute myocardial infarction (AMI) or complications from long term health conditions might indeed
be regarded as indicative of unmet health care need, but excess mortality due to road traffic
accidents is less clearly so. It may be that some of this excess mortality reflects poor emergency
hospital care, but it is perhaps more likely that it reflects either risky behaviours of the population or
a failure of infrastructure or road safety awareness. In which case this particular cause of excess
mortality does not proxy unmet health care need.

The above suggests caution is required in simply searching the literature for occurrences of unmet
need and our experience is that a number of authors tend to interchange health and health care
quite readily. In short, there are many research articles that reference unmet need that are simply
not relevant to the concept of unmet health care need, nor are useful for guiding resource allocation
for health care.

Hence in our review we focus on articles where unmet need can be addressed by increased health
care provision. We exclude articles where the unmet need is in respect of health care interventions
that do not currently exist, or where the concern is that a particular health condition has not been recognised.

2.3 Supply- and demand-side causes

Having established that our focus is on unmet health care need it is important to distinguish between mechanisms that might address that need.

Resource allocation operates through matching resources for the provision of health care to health care needs. In conventional economics terminology this is a supply-side approach. It is predicated on the idea that a greater availability of health care will result in a greater utilisation of that care. An alternative view is that unmet need is a consequence of individuals either not realising that they have poor health or not recognising that their poor health is amenable to health care interventions or being reluctant to seek advice or treatment – or a combination of these. Economists relate these issues under the term demand-side factors.

The relevance of a measure of unmet need for informing resource allocation therefore depends in part upon whether that need is viewed as stemming from the supply-side or the demand-side. We note that this issue has been raised and discussed in ACRA meetings and workshops under the distinction between ‘Population Focus’ (demand-side) and ‘Challenge to Providers’ (supply-side) (Bentley, 2014a, Bentley, 2014b).

Whereas unmet need on the supply-side is an obvious target for revising resource allocations, unmet need on the demand-side may or may not be responsive to spending by health care providers. It may, for example, require public information campaigns and a broad spectrum of public health interventions rather than simply an increase in health care provision. In which case, it will be important to alert purchasers of care of the nature of unmet need and equally as important to ensure that any extra resources are targeted in a way that addresses these unmet needs on the demand-side.

Hence in our review we categorised the literature according to whether it deals with supply-side or demand-side unmet need for health care. In instances where there are elements of both, or where we could not determine the supply- or demand-side focus we make note of that.

2.4 Useful evidence of unmet need for resource allocation

A large part of the literature is concerned with how unmet need can be characterised and with establishing the relationship between need, access and especially inequalities in health; across geographic areas, across different socio-economic, gender, or ethnic groups.

As set out in Section 1 our brief was to consider relevant empirical evidence that might inform resource allocation decisions. Hence our focus is on the subset of the literature in which unmet need is measured and related to factors that might be included into a resource allocation formula.

Empirical evidence can take many forms and each has advantages and limitations. Surveys of individuals, for example, can uncover aspects of their unmet needs that cannot be elicited by simply observing their health status which is reflected either in relation to the existence of some medical condition or in a relatively crude summary measure (poor, good or excellent health). Surveys are, however, expensive to conduct and thus often limited in their coverage. By contrast population based statistics which may be derived from administrative records offer extensive coverage, but relatively little details in respect of ‘need’ (unmet or otherwise).
Common to both forms of empirical evidence is the risk that it becomes out-dated. Population health and health care needs are dynamic phenomena. New diseases arise, treatments for existing medical conditions evolve, and populations grow or shrink and change in composition. So a concern with any evidence that might be used in resource allocation is how recent it is or how readily it can be updated.

A resource allocation formula will only alter the distribution of resources directly if the underlying data on which it is based displays variation across the geographic areas and populations that the formula is applied to. We therefore also need to consider how likely it is that any measure of unmet need displays the relevant variation.

Hence in our review we categorise evidence as being either quantitative (deriving from published statistics or other quantitative databases) or qualitative (deriving from surveys or otherwise self-reported by individuals). We further examine the literature to determine the extent of the populations being covered and whether these are extensive enough to be useful in the context of resource allocation. We look for indications of whether there will be variation in a measure across regions. We consider how recent the empirical evidence being reported is – evidence often considerably pre-dates the publication of a research article, although if readily updateable, the latter may be less problematic.
3. Searching the literature

The search strategy was devised in collaboration with an information specialist (Kath Wright) from the Centre for Reviews and Dissemination and was designed to be efficient within the very limited period of time available. We started with several iterative searches to test the impact of search terms and to inform the choice of key words. Key words were devised on the basis of known key papers and scrutiny of the results of the iterative test searches using a range of synonyms for the key issues of interest, i.e. unmet need for healthcare. The final search strategies combined terms for unmet need (and its synonyms) with terms for inequity of provision or access.

We carried out two sets of database searches. The first set of searches (using EconLIT, Embase, HMIC and MEDLINE databases) was intended to retrieve general papers about unmet healthcare need and identified 596 records; the second set of searches (using the same databases) focused on unmet need in relation to specific disease areas specified by NHS England as being of specific interest (cardiovascular, respiratory, cancer, digestive, hip and knee replacement, mental health, screening) and identified 483 records.

We identified two types of papers: (1) conceptual/methodological papers; and (2) empirical papers. For the first group we did not impose geographical or temporal restrictions as it was possible that older and non-UK papers could contain relevant conceptual thinking; but for the second we excluded non-UK papers and focused the search on the last ten years because our focus was on RA in the UK. The titles of the papers were initially screened using exclusion criteria which were devised to enable the review to focus on the key objective of identifying literature that can inform RA formulae, rather than on identifying all papers of potential interest in relation to unmet need. In addition, some practical measures were required in order to make the review manageable within the study period (e.g. we did not include books or chapters in books).

The exclusion criteria are detailed below.

1. Empirical papers
   - related to health needs of non-patient groups (e.g. carers)
   - related to needs for a new treatment
   - very small population area
   - pre-2005
   - based on non-UK data
   - commentary, opinion or think-pieces
   - non-English language
   - books and chapters.

2. Conceptual papers
   Generally we applied the same criteria as (1) but we included non-UK, pre-2005 and commentary/opinion papers.

The initial screening was focused on the results in terms of the titles of papers, details of the journal and date of publication. This was undertaken by at least two of three researchers (MJA, MC, MG) and those where at least one person did not exclude a paper, were initially included.

In a full systematic review, a further structured screening of all abstracts would have taken place as a second stage, but this was not applicable or achievable for this review in the light of resource and timing constraints. Instead, where at least one of the screeners had a specific query on which their decision to include or exclude depended (e.g. was it a UK study? What population did it cover?), the
abstract and/or full paper was retrieved in order to establish the answer and inform the final decision.

Details of those subsequently excluded are given in the diagram below and the full search strategies are reproduced in Appendix A.3. The results of the searches were downloaded into EndNote bibliographic software to enable deduplication of records.

Figure 1. Description of the review

Figure 1 shows how many papers were found initially and how many were discarded at different stages. From a starting point of 1079 papers, 24 were duplicates found in both search results, leaving 1055 to be screened. 817 of these were excluded based on the screening of the title and 82 based on the year of publication. There were 156 remaining identified for detailed review and of these, 121 were excluded (e.g. not relevant, non-UK populations covered, lack of empirical data); leaving 35 papers to be reviewed in detail.

Note that even though our criteria for empirical papers was to review those published after 2005, we only excluded based on year of publication those published before 2000, and screened those falling during this period (based on the title), in order to make sure we did not exclude any major paper of relevance that was published close to the limit of our time frame.

The report focuses on reporting the empirical literature that fits the criteria of being potentially useful for the purposes of RA. However, the outputs from the review also include: (1) an EndNote library containing the results of the literature search that were found by looking for key terms in the title only; and (2) an EndNote library that contains the results found by looking for the key terms in title and abstract and for the following specific diseases: cardiovascular, respiratory, cancer, digestive, hip and knee replacement, mental health, screening. These are available from the authors on request.
4. Results and discussion

Comments for each of the papers included in our results can be found in Appendix A.1, indicating whether they comply with any of the requirements (A-D) deemed relevant for RA (see below):

Those that were considered relevant and refer to empirical evidence for the UK are summarised in Appendix A.2, in a table which includes the details of the data, methods and results from each of them.

In assessing whether the literature can usefully inform RA, we draw on our overall conceptual framework. It is convenient to consider what might constitute the holy grail of evidence on unmet need which could be used to inform RA. Our framework suggests that this should:

A. Provide robust evidence of unmet need within a given population of individuals and have elicited that information in ways that are potentially reproducible for different populations and/or specific health conditions or domains of health service.

B. Provide clear evidence of how (indeed if) that unmet need can be met by health care.

C. Establish whether the barriers to meeting that unmet need are on the supply-side (inadequate provision of services) or the demand-side (not accessing available services) or a combination of the two.

D. Provide a means of proxying the relevant notions of unmet need through observable measures of the affected population that are robustly correlated with need, measurable at the appropriate geographic/population area for RA, readily updateable, not subject to manipulation, and exhibit sufficient variability over geographic areas.

We can state immediately that none of the literature we reviewed satisfies all four of these sets of requirements A-D for ‘ideal’ evidence for use in RA. Furthermore no one study or article simultaneously addresses more than two of the requirements A-D. Hence our first conclusion is that there is not presently published evidence that would meet the requirements of providing evidence of unmet need to support RA.

Where then is the evidence strongest and where is it weakest?

In terms of weaknesses it is not surprising that the set of requirements D is the most problematic. These requirements are quite specific to the needs of RA and published research has a large number of foci that seldom include the concerns of determining the allocation of budgets. Most of the research is more concerned with understanding the functioning of existing health care systems and delivery mechanism, and other than making a case for ‘more resources’ seldom if ever deals with the funding mechanism.

Nevertheless some of the literature deals with modelling of unmet need in terms of observables and we regard this as a good starting place for further research that could then satisfy requirements outlined in D. Of particular note in this regard are (Nacul et al., 2007), (Judge et al., 2009), (Williams and Drinkwater, 2009) and (Bebbington et al., 2003).

Arguably the literature is strongest in terms of satisfying requirements detailed in A. There is a vast literature concerned with defining, measuring and analysing unmet need across different populations, disease categories and according to different socio-economic, ethnic, gender and cultural sub-groups. However as our framework and discussion above make clear this definition and measurement is far too broad to meet the requirements of RA and so it is unfortunately the case that the literature is strongest where it is probably the least useful. Some of the insights to be gained
from this general approach are most readily accessible in papers such as (Aspinall and London Health Observatory. Department of Health, 2004) which discusses disparities in health across ethnic groups, (Purandare et al., 2004) which uses a survey of care home managers to identify unmet need among older people in care homes in the UK, and (Joska, 2005) which focuses on mental health and supports the idea that treatment (clinical) populations are not necessarily capturing unmet need. The study by (Sheringham et al., 2009) provides an indication of how commercial data sets might be brought to bear on this issue and offers some novel potential proxies of unmet need based on deprivation.

In terms of our conceptual framework, and especially the issues that give rise to requirements B and C we find a considerable degree of support in the literature – but very little resolution. On the distinction between unmet need as it is usually measured and unmet need relevant to RA two very useful references are (Burt et al., 2010) which uses the ratio between need and access in palliative care for lung cancer as a metric of unmet need and finds that observable population characteristics are associated with need, but not associated with unmet need, and (Judge et al., 2010) which also uses need and provision, of knee and hip replacements, and finds that there is systematic variation in the unmet need measure according to population/area characteristics. These two papers illustrate that measuring disease prevalence alone is not sufficient to inform RA.

Our discussion of demand- and supply-side factors resonates with a lot of the literature and again argues for caution in moving from observing unmet health care need to increasing service provision. A quite strong sense emerges from the literature – that a lot of unmet need really has to do with the demand-side. It is difficult to pin down the root causes of this but there is a strong element of the role of patient expectations and cultural factors. In other words, for at least some domains of health care it would seem that unmet need could be met by better engaging with patients rather than increasing services per se, although of course better engagement may involve new approaches to service delivery. There are many examples of this in the literature, such as: (Dixon-Woods et al., 2006) which proposes an interpretive review of the literature concerning access of health care by vulnerable groups; (McColl, 2006) which focuses on the unmet need in mental health of asylum seekers and finds that the demand-side has an important role to play; (Austin et al., 2009) which also suggests a demand-side focus for unmet need in a specific type of cancer screening among ethnic groups; (Orton et al., 2013) which uses a survey to analyse uptake of a screening programme and is helpful in confirming the role of demand-side factors and the fact that it is not simply a deficit of services that leads to unmet need; and the previously described (Burt et al., 2010).
5. Limitations

The main limitations of this review are linked to the remit of the research commissioned i.e., the practical assessment in a short timescale of an unmanageably vast body of literature. Thus we were able to choose only a limited number of key words for searching the literature, which may have excluded some studies that focused on services received by specific groups but did not use our key words such as access, equity of access or unmet needs. Second, although the search included the grey literature this was restricted to the core databases searched rather than websites. Last, the focus of our efforts were on identifying relevant literature rather than critiquing methods in depth.
6. Implications for resource allocation in healthcare: future research

The review found that there is little published empirical, UK-based evidence from the last ten years that can usefully inform RA in relation to unmet need issues. It also revealed the challenge of undertaking research that can meet the brief of informing the RA formula in this context. Policymakers considering options for filling the gaps in relation to information on unmet need should consider a range of issues when determining the scope and focus of any future research on unmet need. There are three broad domains to consider: survey data, primary research, and data linkages.

6.1 Surveys

Large scale general surveys of self-assessed need are probably of limited use in isolation for the purposes of RA. The measures of self-assessed need and often also of health service use, can be poor and the sample size may not enable estimates to be made at the relevant population level. However, recent developments suggest there may be more promising avenues to pursue. The large household survey ‘Understanding Society’ has begun to gather information on health from sub samples of respondents in novel ways (https://www.understandingsociety.ac.uk/about/health/health-assessments) combining a range of biomedical measures (including blood pressure, lung function, blood samples and others), biomarker data (indicators of diabetes, liver function, etc.), and genetics data. In principle, such data can indicate ‘need’ and if this can then be linked to the medications and services received by individuals (also part of the survey), i.e., utilisation, it may be possible to interpret any gaps in services received as at least suggestive of unmet need. Similar developments have been in train in relation to the English Longitudinal Survey of Ageing (ELSA) which also includes some objective, nurse led health status measures and where respondents have been asked for permission to allow researchers to link their data with administrative data on health service use (e.g. HES data) (http://www.elsa-project.ac.uk/). ELSA includes only those over the age of 50 years so there is an issue of representativeness. Other surveys (e.g. Millennium Cohort) have also sought similar permissions from respondents for data linkage (see http://www.natcen.ac.uk/media/205504/data-linkage-review.pdf).

6.2 Primary research

Methodologically robust primary research that is capable of informing RA is likely to be resource intensive. Whilst such research may be valuable, it is important to resource it adequately or there is danger of re-producing studies that are similar to many of those reviewed which, although producing interesting results are not sufficiently reliable or robust to be used for RA. Rather than launching large scale and resource intensive primary research studies, interrogating data at local level may provide useful insights as a prelude to such research, indicating where the focus of research efforts should be. Using the CCG/LA areas, geographical variation in availability and uptake of services may be described at a level that is most relevant for RA, along with some measures of needs derived from local or national data sources. The gaps are then suggestive of the presence of unmet need. Moreover, interrogating the data at different points in the care pathway (e.g. diagnostic versus treatments), can shed light on where the ‘blockages’ to meeting needs may occur. It may then be possible to delve deeper into the explanations for such variation. However, even then it is no small feat to determine the degree to which such variations are warranted or unwarranted from a needs perspective; and also whether additional healthcare resources would actually allow the needs to be met. Another approach based on area level analysis is the research that has been undertaken on ‘programme budgeting’ in the NHS, which analyses the relationship between outcomes – age standardised years of life lost (SYLL) - and NHS expenditure (Martin et al., 2008, Martin et al., 2012). Using this approach the idea would be to take for example, the ‘big four'
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programme budgeting areas (cancer, circulatory disease, respiratory disease, cardiovascular disease), and estimate SYLL from the relationship between outcomes (SYLL) and expenditure, conditional on need. For each CCG it would be feasible to derive a predicted SYLL based around what is achievable on average across the country. The difference between the actual and predicted SYLLs could be interpreted as a crude measure of unmet need. This is very likely to be the best proxy to use at present with current data. Of course, the degree to which health care provision can have an impact on this ‘gap’ is another question.

6.3 Data linkages

There may be potentially new data linkages that could help inform RA in relation to needs. The care.data programme (or its replacement), which seeks to extract data from primary care records, if eventually rolled out nationally and if linked with other data (e.g. on supply-side variables), could provide useful information (http://www.england.nhs.uk/ourwork/tsd/care-data/). Also, Scotland has been at the forefront of linking health related data from different sources for many years and their existing practice could be reviewed in order to determine whether similar approaches might inform RA in England. There are ambitious plans for further data linkage in Scotland which would be useful to observe as they develop (http://www.gov.scot/Topics/Statistics/datalinkageframework).

6.4 Conclusion

Whether through expanding surveys, undertaking primary research or using data linkage, research to inform RA should focus on:

- Conditions or services where adverse health outcomes as a result of unmet or inappropriately met need are amenable to healthcare interventions
- Conditions for which cost-effective interventions exist
- Conditions which affect a sizeable proportion of the population rather than very ‘niche’ services.

Such research, as we have seen, can be either quantitative or qualitative. Quantitative studies generally aim to describe the gap between some measure of ‘need’ and the degree to which such needs are met, using similar sets of explanatory variables (e.g. socio-economic status, gender, ethnicity, age group), whereas qualitative studies focus on delving deeper into explanations of the causes of the gaps – whether due to supply or demand side factors. Both approaches are potentially relevant for RA.

In summary, although adjusting budget allocation to reflect ‘need’ is a relatively common aim across the public sector, especially in healthcare systems, the challenge of making adjustments for unmet need is substantial. Our review of the literature undertaken within a framework that defines specifically the nature of the information that is required for RA formulae, concludes that there is little useable evidence available, but we identify some potentially promising lines for future research if this policy aim is to be achieved.
References

Aday, L. A. & Andersen, R. M. 1981. Equity of access to medical care: a conceptual and empirical overview. Medical Care, 19, 4-27.


Kovandzic, M. 2011. Access to primary mental health care for hard-to-reach groups: From 'silent suffering' to 'making it work'. *Social Science and Medicine, 72*.


A. Appendices

A.1. Paper by paper commentaries

We can summarise our framework as indicating that, in order to be of real use in RA formulae it is necessary first to:

A. elicit evidence of unmet need from disparity of outcome/reports, then
B. establish how much can be attributed to unmet healthcare need, then
C. establish whether that is supply or demand side driven, and then
D. link that to observable correlates which are capable (and usefully vary) of being included in formula.

These letters are used as a point of reference to map papers. We highlight in grey the papers that we think are the most important to refer to (for varying reasons)


This paper starts with the idea of disparities in health across ethnic groups. Its focus is really on equity, but it offers some potential pointers for resource allocation in that if ethnicity were strongly correlated with unmet need it would suggest investigating how ethnicity (which particular groups, or subgroups) might be included in RA formulae. But what this paper then really indicates is that there is little concrete evidence linking poor health outcomes to unmet need for these groups – they claim the underlying data in this domain is poor – for example HES does not always have valid ethnic codes. The potential correlation and confounding of ethnicity and socio-economic status (which is already in RA formulae) is also noted. Finally the issues that we raise under the demand-side vs supply-side distinction are discussed, but again lack of evidence precludes their measurement.

So overall a paper that suggests an approach that might be taken, but which indicates the present lack of evidence with which to pursue it. It informs about A but does not get very far beyond that. It does not make the link from A to B and suggests evidence is lacking to do that.


This paper usefully illustrates the nexus between ‘access’ and ‘need’. Considering a small geographic area it founds a large disparity between provision of care (a surgical intervention for lung cancer) and the prevalence of that disease. However it does not claim to analyse the reasons for that need. And it is based on a very small area study (Norfolk, Suffolk and Cambridge) so it is not clear that even for this one procedure the results would generalise.

Overall a very useful illustration of the practical measurement and evidence of unmet need for health care at a local level – it covers both A and B. But it does not (cannot) provide insight into whether that need would be met with more resources for health care or whether it depends on
demand-side barriers, and the evidence is very limited both in terms of scope (a single intervention), scale (only a small number of treatments) and geographic extent.


This paper illustrates a survey based approach to establishing unmet need and the potential for proxying unmet need by characteristics some of which are already included in RA formulae. In terms of our overall framework, this paper therefore has elements of A, B and C. One point it confirms is that unmet need may already be proxied by measures of population that are included in RA.

Overall this deals with only a single treatment (hip replacement) and offers only survey evidence. Furthermore it is hard to see it providing any new avenues to investigate for proxying unmet need.


This paper is another survey based approach and so is concerned with directly measuring unmet need. The novelty is to capture a large population in a relatively small survey by targeting care home managers.

Overall a potentially useful paper for illustrating how to directly elicit unmet need, but it does not proceed beyond A. It is measurement without attribution and there is no association between reported unmet need and observable proxies.


The focus here is mental health and this is a useful article for establishing the measurement of unmet need for mental health services. The article is a review and includes a lot of non-UK studies. The article captures a number of the elements of our conceptual framework and discussed (in relation to published studies) the problems in measuring unmet need especially the conflicting measures that arise from studying populations as compared with groups being treated. A key idea here is that, in this domain at least there is support for the idea that treatment (clinical) populations are not necessarily capturing unmet need.

Overall a very useful article in regard to confirming our conceptual framework but one that suggests it is very unlikely that there is published research in the area of mental health that will fulfil the requirements of an RA formula. In terms of our framework, this establishes A, indicates that there are substantial problems in moving to B or C in the area of mental health; and points to likely inadequacies in respect to D.

- Kessler, D., *Social class and access to specialist palliative care services*. Palliative Medicine, 2005. 19(2).

This article concerns how the type of health care service that is accessed varies with social class. So this potentially relates to the quality of health care varying according to social class. Beyond this however it does not really address the issues of unmet need that are central to our review. In this particular domain (palliative care) it is suggested that the issues may be demand-side focused rather than supply-side.
Overall this is useful for highlighting the problem of associating inequality of access with unmet need, but otherwise does not provide evidence relevant for RA.


The commentary on this is really the same as for (Aspinall and London Health Observatory. Department of Health, 2004).

Overall another confirmation of the fact that inequality of access is not sufficient for establishing unmet need that can be addressed through more health care resources. If there is an emerging theme from this strand of literature (the inequality of access across ethnicity) it is that the demand-side seems very important. That argues that ethnicity may not be an appropriate proxy for unmet need in an RA context. As in (Aspinall and London Health Observatory. Department of Health, 2004) this informs regarding A but does not offer much more of practical significance to RA.


A review of the literature on inequity of access – with a twist. Rather in the same way as we have undertaken a review with a conceptual framework this article proposes an interpretive review of the literature concerning access of health care by vulnerable groups. There is rather little drawing a link between access and need but there is a focus on why access will vary across groups. Rather than distinguish supply-side and demand-side these authors stress the interaction of supply and demand – negotiation between patients and health service providers.

Overall an interesting conceptual approach which further emphasises the difficulty in moving from variation in access to inference about unmet need and from that to supply-side sensitive unmet need. In terms of our framework this can be viewed as articulating the difficulty in establishing C.


A study that establishes that certain population groups may be the focus of unmet needs for particular health care. In this instance the group is asylum seekers and the service is mental health care. A limited study comprising a small group in a specific location, so not easily generalizable. Also not obvious whether the status of asylum seeking correlates with other characteristics.

Overall this is a study which illustrates the tendency to examine health care needs of certain groups. It further confirms the need for care in moving from unmet need to establishing a case for more resources. In this instance (and once again) it would seem that the demand-side has an important role to play. The services may be there but individuals do not use them. Think of this as another focus on C that emphasises the demand-side.


This study was picked up because of the disease area and it makes reference to unmet need. Its focus is really on establishing mental health disease prevalence in relation to treatment. Other than
noting the distinction between failing to receive treatment and unmet need and the difficulty of distinguishing between lack of provision and unwillingness to access a service it does not offer any new evidence relevant to RA.

Overall not sufficiently aligned with goals of our review to consider further. It deals with C alone.


As (Torres et al., 2006) – study of mental health disease prevalence and incidence of treatment.

Overall not sufficiently aligned with goals of our review to consider further. It deals with C alone.


This is a study that illustrates an approach that might be useful in moving towards evidence-based proxies for RA. It establishes models for predicting COPD – this establishes need. It is a strong evidence-based approach. A next step could be to relate the estimated need against service provision. Our framework however is useful precisely because it indicates how much further work would be required; establishing whether lack of service provision or unwillingness to access is the cause, and testing whether some of the elements of the model exhibit sufficient variation across geographic areas to be practical proxies of unmet need amenable to greater health care provision.

Overall – a recommended paper as providing an indication of an approach that might be useful (if considerably developed) in RA. How do we interpret the development required? This paper is strong on A and pointing the direction of travel for B but its approach would need to be developed in respect of C and D.


A paper in the same general spirit as (Aspinall and London Health Observatory. Department of Health, 2004) and (Szczepura, 2005) with similar implications for RA. Inequity of access across ethnicity is not necessarily unmet need.

Overall – informative of C and again suggesting a demand-side focus for unmet need in ethnic groups.


This paper is similar in its contribution to (Nacul et al., 2007) except that it concerns need for hip and knee replacement. A novel element here is combining health survey data with census data to model need in small-areas. To recap, this approach identifies the prevalence of a need (for joint replacement) modelled as a function of population characteristics. However, the ‘need’ is not assessed as unmet or met and we could view such a study as a building block for identifying unmet
need in the context of RA. There would need to be a considerable super-structure on top of these foundations to act as an evidence base for RA formula – as our framework suggests this would need to establish demand and supply side explanations and consider the practicalities of using the models proxies in any RA formula.

Overall as in (Nacul et al., 2007) a recommended paper as providing an indication of an approach that might be useful (if considerably developed) in RA. The paper is strong on A and pointing the direction of travel for B but its approach would need to be developed in respect of C and D.


In comparison with (Nacul et al., 2007) and (Judge et al., 2009) this study is concerned with country level variation – in this case the ‘need’ is that for radiotherapy services. The study does draw attention to the necessity of moving from need to unmet need by comparing service provision with the identified need – and finding variation in the treatment deficit that is correlated with some population characteristics. Thus there is more of an emphasis on B in this approach, so it might be used to illustrate how (Nacul et al., 2007) and (Judge et al., 2009) could be extended to be of more relevance to RA. However the geographic area of analysis in this study precludes any direct use in RA – and there is little consideration of issues C and D within our framework.

Overall – another study that is valuable in suggesting how relevant original research might be developed, but not directly applicable to RA.


A study focused on the relationship between need and access – palliative care for lung cancer. It is this ratio that often serves as a metric of unmet need. In this study there is attention on what correlates with this ratio. Interestingly this study finds that observable population characteristics whilst associated with need, are NOT associated with unmet need, i.e. service provision is in some way matching to need. In terms of our framework this is a potentially important example of why A alone is not enough – we can measure disease incidence and note that it correlates with observable characteristics, but this does not mean there is unmet need that correlates with those characteristics.

Overall – a very important illustration of the importance of considering our restriction B – and a warning that many apparently relevant studies (identifying variation in health outcome) might not identify unmet need.


See above for (Burt et al., 2010) on the ratio of need to access. This study examines that for hip and knee replacement. They found in this domain that there is systematic variation in the unmet need measure according to population/area characteristics. Importantly, this is not the same as the variation in need. So in this case there is less *unmet* need for women than men, for deprived relative to not and mixed results for urban/rural split. However, referring to other commentaries
above there is not much attention to supply-vs demand-side drivers. So this is a study that has A and B but stops short of C.

Overall – a complement to (Burt et al., 2010) in establishing that need and unmet need may not correlate with need. And worth noting that this still is far short of the sort of evidence that our framework indicates would be necessary for RA.

- Miranda-Castillo, C., et al., Unmet needs, quality of life and support networks of people with dementia living at home. Health & Quality of Life Outcomes, 2010. 8: p. 132. (Miranda-Castillo et al., 2010)

A study eliciting unmet need by direct survey methods but concerns a very small sample relies on patient reports and does not distinguish potential causes of unmet need.

Overall – captured by our search but of little relevance to our brief.


A health inequality paper studying the relationship between diagnosis (of intellectual disability) and access to health care. Not directly applicable to our brief as no substantive discussion of need or unmet need. Finds no substantive evidence of health inequalities in respect of adults with intellectual disabilities.

Overall – possibly notable in as much as suggests mental health is not like other health care in regards to inequity (and one might therefore infer not like other health care in respect of unmet need) but otherwise of little relevance.

- Kovandzic, M., Access to primary mental health care for hard-to-reach groups: From ‘silent suffering’ to ‘making it work’. Social Science and Medicine, 2011. 72(5). (Kovandzic, 2011)

A similar focus to (Cooper et al., 2011) but more directly relevant to C. This is another study which indicates that demand-side factors are very important in the domain of mental health care.

Overall – further support for the idea that there may be substantial demand-side explanations of unmet need (and therefore caution needed in jumping form measuring unmet need to building it into RA). In terms of our framework a topic C paper.


Looks at variation in self-reported unmet need for severe mental illness care need ethnicity measures. Find White British have more unmet need in general.

Overall – main issues are discussed in the context of (Aspinall and London Health Observatory. Department of Health, 2004) above. This study is not of much relevance to our brief. It concerns only A.
Defining and measuring unmet need to guide healthcare funding: identifying and filling the gaps


Not relevant for our review. It is concerned with a particular treatment and whether clinical guidance is being followed.

Overall – off-topic.


Concerned with the uptake of a screening programme and based on questionnaire. This is another study that is helpful in confirming the role of demand-side factors and the fact that it is not simply a deficit of services that leads to unmet need. As most surveys, it is based on small numbers and only considers one small area, therefore not easily generalizable for RA purposes.

Overall – another study that emphasises C in our framework, but not extensive enough to be of value for RA.


Focus is on a tool (usually termed ‘instrument’?) for measuring met and unmet needs of a particular group of patients – in this instance those with complex neurological deficit. This seems to be more about the mix of services that patients received than about the overall level of provision and so seems marginal for RA. It does however illustrate one of a range of methods that can be used to elicit unmet need (i.e. illustrates the range of approach that are or can be taken for A).

Overall – a further illustration of the mixture of methods available for A, but as we have emphasised establishing the extent of unmet need falls a good deal short of using such a measure in RA.


This is a study focused on inequity of provision across predominantly ethnic groups. It is a very small scale study and does not address the identification of unmet need.

Overall – not central to our brief.


A study that utilises a patient survey to examine the nature of the health care that individuals report they need but are not receiving. For this small group of patients the results indicate that more social care, rather than medical treatment, is required. This fits under the heading of B in our framework and illustrates that poor outcome, or ‘illness’ alone might not establish unmet need for health care.
Overall the evidence here is too limited to be of use in resource allocation, but the study usefully illustrates the issues that our framework encompasses under B.


An example of the use of routine data to examine inequality in health care – this is focused on mental health care in Scotland. Another study that shows the abundance of research on inequalities in health care provision but does not link this to the needs or the populations under study. Therefore, a study of little value in informing about unmet need.

Overall – provides more context in terms of A regarding mental health care. Otherwise not central to our brief.


This is a multi-country study which does feature the UK, but at an aggregate level, and therefore not directly relevant to our brief. The measure of unmet need is survey based. The findings are that there tends to be greater unmet need where there is reliance on hospital-based over community-based care. This offers some insight into B – the suggestion is that unmet need in this domain might be more addressed by social care than health care.

Overall – rather peripheral but offers some insight into the need to take care in associating unmet need, with unmet need for health care. In this case the unmet need appears to be for more community-based support.


(Comments based on abstract, paper needed to be paid for to view and was deemed marginal).

This study uses a direct instrument approach to assess unmet need in the domain of mental health care. The study is very small (79 participants) and limited to two hospitals in London. Therefore not generalizable for purposes of RA.

Overall – of value as an illustration of the direct elicitation of unmet need (A). Makes no attempt to attribute unmet need to demand or supply-side factors.


A study illustrating the use of national survey data to identify need and relate this to access to services, with a view to understanding any correlates of unmet need. The domain is mental health care. The potential proxies for unmet health care need are sex, age, marital status and employment status – so this study is illustrative of approaches that might prove valuable in RA. However there is no consideration of the reasons why need is not being met or whether increased resources would address unmet need.
Overall and important study illustrating the nexus between A and D, but essentially omitting B and C.


A recent study that uses a follow up survey of NHS Direct to assess the utilisation of this service and its variation across socio-economic groups. No clear measures of unmet need and so a study that falls into the general realm of variation in health care and is not central to our brief. Notable however in providing an illustration of how important mechanisms for health care access are. In this case, if there were unmet need it might correlate with access to a telephone – so it is not more health care that would be required but rather more communications infrastructure.

Overall, not central to our brief but interesting in regards to B and C. Unmet need might be demand-driven and might be a need for something other than health care.


A study which in itself is quite niche but has potentially important implications for how tools to reflect unmet need might be developed. The study uses a commercial sociodemographic classification system to relate unequal access to services to a number of proxies that are richer than those usually adopted (including some more detailed proxies of socio-economic status – assets and relative poverty). This is illustrative of the kind of dataset that might be of value in D.

Overall – although limited in terms of unmet need an interesting use of data that could inform D within our framework.


A further study addressing the relationship between ethnicity and access to health care. This study is based on a survey that is more directed to understanding perceptions of service delivery than to relating the delivery of services to ethnicity or measuring unmet need.

Overall not relevant to our brief.


This study provides further context for the link between health care and unmet need. Based on a small (363) sample of mental health patients it examines the variation in attendance by patients for treatment, according to their health and socio-demographic characteristics. Within our framework this is an A, C study. The results mirror a number of other studies in the mental health domain that emphasise the importance of demand-side factors is driving unmet need.

Overall a further study illustrating the importance of the issues included under C in our conceptual framework. As is usual for survey based studies there is not sufficiently robust evidence here for use in resource allocation.

This study provides a good example of the use of administrative data in the NHS combined with survey data to inform about equity of access. The linkage to unmet need is implicit. This study finds that there is no systematic variation of treatment for CHD according to socio-economic indicators age and sex. It is therefore a useful study to consider in conjunction with disparate studies that find strong evidence of outcome variation. In regards to our framework this indicates that variation in outcome alone cannot be taken as indicative unmet need that will be amenable to increased health care resources.

Overall: A recommended study both on account of its illustration of the use of administrative data and because it confirms that A alone does not evidence unmet need that can be addressed by greater resources.
### A.2. Details of UK empirical papers

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<tr>
<th>Ref.</th>
<th>Condition</th>
<th>Data</th>
<th>Definition of (Unmet) Need</th>
<th>Methodology</th>
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<tbody>
<tr>
<td>(Asadi-Lari et al., 2003)</td>
<td>Coronary Heart Disease</td>
<td>Nottingham Health Needs Assessment (NHNA) [developed by the authors] applied to 242 patients admitted to the Acute Cardiac Unit, Nottingham</td>
<td>Self-reported need.</td>
<td>Correlation between health-related quality of life (HRQL) and indicators of need. Comparison of HRQL and HNA domains means in various help needs (e.g. company, looking after patients).</td>
<td>High correlation between physical needs and HNA physical score. More physical needs were detected in elderly and ischaemic patients compared with confirmed MI. No gender differences.</td>
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<tr>
<td>(Austin et al., 2009)</td>
<td>Colorectal cancer (CRC)</td>
<td>Interviews with participants from African-Caribbean, Gujarati Indian and Pakistani communities with white British participants included for comparison [n=53].</td>
<td>Lower participation in screening programme.</td>
<td>Focus groups were tape-recorded, transcribed verbatim and checked twice to ensure accuracy. Transcripts were examined using ‘Framework analysis’.</td>
<td>There was limited understanding of CRC in any group, and this was considered a barrier to participating in flexible sigmoidoscopy (FS) screening. The majority of reported barriers were shared by all participants, with fear of the results a commonly cited deterrent. Few ethnic-specific differences were raised as barriers to the test.</td>
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<tr>
<td>(Bansal et al., 2014)</td>
<td>Mental Health</td>
<td>Census 2001 + SMR04, Scotland. Sample: first hospitalisations between 1 May 2001 and 30 April 2008.</td>
<td>Differences in admission rates.</td>
<td>Poisson regression to calculate risk ratio of first admission adjusted for patient characteristics.</td>
<td>Different patterns of mental health hospitalisation by ethnic group. Lower risk of psychiatric hospitalisation and compulsory treatment in the Other White British (mostly English compared to the White Scottish. Mixed Background, African and Chinese groups were at higher risk of being detained under the 2003 Act compared to the White Scottish.</td>
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<td>(Battersby et al., 2004)</td>
<td>Non-small cell lung cancers (NSCLC)</td>
<td>NSCLC age-sex standardised incidence rates for PCTs in Norfolk, Suffolk, and Cambridgeshire, 1998 to 2000</td>
<td>Relation between incidence and procedures rates.</td>
<td>Process Control Charts, based on the actual proportion of patients that receive surgery and on a higher arbitrary proportion.</td>
<td>3 of 17 PCTs lie outside (2 below, 1 above) the control limits based on the actual proportion of patients receiving surgery. 6 PCTs fall below the lower control limit and no PCTs lie above the upper control limit when using a higher proportion.</td>
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<tr>
<td>(Bebbington et al., 2003)</td>
<td>Neurotic Disorders.</td>
<td>British National Survey of Psychiatric Morbidity [n&gt;10000].</td>
<td>Professional evaluation = contact with primary care physicians for psychiatric symptoms.</td>
<td>Logistic regression.</td>
<td>Contact with primary care due to mental health is more likely if the individual has more severe psychiatric symptoms, has difficulties in daily living activities, is female, has a physical illness, is not working, and is divorced/separated.</td>
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<tr>
<td>(Bien et al., 2013)</td>
<td>Disability (in older people)</td>
<td>EUROFAMCARE study, 2003-04: survey of family carers (FC) of older people (OP). Focus on cases where the OP has high levels of disability [n (UK) = 371].</td>
<td>Answer 'Yes' to question 'Would you like OP to have more help to meet this need?' This was a follow up question to 'Does OP have a need for help with any of these areas? Health needs, physical/personal needs, mobility needs, domestic needs'.</td>
<td>Test for significant relationship between mean number of unmet care needs and the mean number of health and, separately, social services, by country.</td>
<td>Unmet need prevalence is generally higher in Southern-Eastern countries than in the Northern-Western countries (incl. UK)</td>
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<td>(Bruce et al., 2012)</td>
<td>Severe Mental Illness</td>
<td>Interviews with male participants with severe mental illness, recruited from 10 inpatient wards across various hospital sites in South London between September 2008 and July 2010 [n=165].</td>
<td>Need defined using Camberwell Assessment of Need Short Assessment Schedule (CANSAS).</td>
<td>[1] Univariate analyses to identify group differences across socio-demographic and clinical variables. [2] For variables with significant group differences, identify groups that differed significantly using univariate logistic regressions and post-hoc ANOVA tests with Bonferroni corrections. [3] Do [1] and [2] for differences in mean number of needs and unmet needs across ethnic heritage groups. [4] Stepwise multiple linear regressions to control for any significant socio-demographic variables and examine the independent contributions of ethnicity and clinical factors in explaining the variance in reported unmet needs.</td>
<td>Significant differences between ethnic groups with respect to total number of self-reported needs and unmet needs.</td>
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<td>(Burt et al., 2010)</td>
<td>Lung Cancer</td>
<td>Cross-sectional survey of lung cancer patients attending chest or oncology outpatient clinics at four NHS Trusts in south London between June 2006 and April 2007 [n=252].</td>
<td>Need for specialist palliative care (SPC), using health-related quality of life (HRQL) as an indicator.</td>
<td>Multivariate analyses.</td>
<td>Use of SPC is related to metastatic disease, global quality of life, and treating clinic.</td>
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<td>(Cooper et al., 2011)</td>
<td>Intellectual Disabilities (IDs)</td>
<td>GP records and interviews with adults (≥ 16) with IDs in Greater Glasgow Health Board area + Census 2001 [n=1023].</td>
<td>Service utilization (consultation rates, health promotion services uptake and social supports).</td>
<td>(1) Assess potential for non-participation bias using logistic regression models for participation in relation to year of birth, gender and deprivation score. (2) Examine the distributions of measures of consultation rates, health promotion service uptake and social supports in relation to these factors. (3) Repeat regression analyses, adjusting for type of accommodation and ability level.</td>
<td>Health inequalities experienced by adults with IDs are not accounted for by the fact they are more likely to live in more deprived areas.</td>
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<tr>
<td>(Di Bona et al., 2014)</td>
<td>Mental Health</td>
<td>Cohort patient data collected as part of the independent evaluation of the two Improving Access to Psychological Therapy (IAPT) demonstration sites, Doncaster and Newham, matched with patient questionnaires [n=363].</td>
<td>Access to service.</td>
<td>Logistic regression to identify socio-demographic, clinical and service factors predictive of IAPT non-attendance.</td>
<td>Significant predictors of IAPT first session non-attendance by patients were: lower non-risk score on the Clinical Outcomes in Routine Evaluation-Outcome Measure (CORE-OM); more frequent thoughts of ‘being better off dead’ (derived from the CORE-OM); either a very recent onset of common mental health disorder (1 month or less) or a long term condition (more than 2 years); and site</td>
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<td>(Hawkins et al., 2013)</td>
<td>Coronary Disease</td>
<td>Myocardial Ischemia National Audit Project + General Practice Research Database.</td>
<td>Differences in treatment.</td>
<td>Age-adjusted descriptive comparisons.</td>
<td>No socioeconomic gradients in the treatment of coronary artery disease, but treatment levels still under national targets.</td>
</tr>
<tr>
<td>(Judge et al., 2009)</td>
<td>Hip and Knee Replacement Surgery</td>
<td>English Longitudinal Study of Ageing (ELSA) + 2001 Census</td>
<td>Dichotomous variable of whether or not the patient was in need of joint replacement.</td>
<td>[1] Multilevel Poisson regression to estimate rates of need for hip/knee replacement by age, sex, deprivation, rurality, and ethnic mix using ELSA. [2] Combine regression model with stratified census population counts to produce small-area predictions of need. [3] Uncertainty in the predictions was obtained by taking a Bayesian simulation-based approach using WinBUGS software.</td>
<td>Generally, need for joint replacement is lower in the South than in the North of England. Rates are also lower in a circle of affluent areas in England, Home Counties, areas that border or surround London. The geographic distribution of rates of need across districts of England is similar for both hip and knee replacement.</td>
</tr>
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<td>Ref.</td>
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<td>Definition of (Unmet) Need</td>
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<td>Results</td>
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<tr>
<td>(Judge et al., 2010)</td>
<td>Hip and Knee Replacement Surgery</td>
<td>English Longitudinal Study of Ageing (ELSA) + HES</td>
<td>Equity rate ratios comparing rates of provision relative to need by sociodemographic, hospital, and distance variables.</td>
<td>Multilevel (individuals in age-sex group i, in ward j, and in district k) Poisson regression to generate rates of provision of joint replacement. Simulation model compares the log of the rate ratio of provision relative to need in each group, producing equity rate ratios by sociodemographic, hospital, and distance variables.</td>
<td>For total hip and knee replacement there is an ‘n’ shaped curve by age. Men received 8% more hip replacements relative to need than women (31% for knee). People living in the most deprived areas received around 70% less provision relative to need compared with people in the least deprived areas for both hip and knee replacement.</td>
</tr>
<tr>
<td>(Kessler, 2005)</td>
<td>Palliative Care (Cancer)</td>
<td>Public Health Mortality - cancer deaths of adults (≥ 18) registered in the twelve electoral wards of South Bristol between September 1999 and November 2002 [n=960].</td>
<td>Inequality in access - associations between social class and place of death.</td>
<td>Logistic regression</td>
<td>Individuals with unskilled occupations were less likely to die in hospice, but no other social class difference in place of death was found.</td>
</tr>
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<td>(Knowles et al., 2006)</td>
<td>No specific condition.</td>
<td>Postal survey, with 16 questions on recent use of unplanned health care, in Preston/Chorley, Sheffield, Northumbria, and Newcastle and North Tyneside. [n=2222]</td>
<td>Access = Use of NHS Direct.</td>
<td>Logistic regression</td>
<td>Respondents were less likely to have used NHS Direct if they were male, aged 65 years or over, lacked access to a car or telephone, did not own their own home, had difficulty in using the telephone due to a hearing problem or because English was not their first language, or had left full-time education at a younger age.</td>
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<td>(McColl, 2006)</td>
<td>Mental Health</td>
<td>Data on patients known to be current or former asylum seekers in Community Mental Health Teams (CMHTs) in London, collected from clinicians and case notes [n=104].</td>
<td>Based on Camberwell Assessment of Need Short Appraisal Schedule (CANSAS) results.</td>
<td>Compare total and unmet needs of asylum seekers with those of three reference populations. The most prominent needs were social, but just over half had unmet needs related to psychotic symptoms.</td>
<td></td>
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<tr>
<td>(Milner et al., 2004)</td>
<td>Hip Replacement</td>
<td>Random samples from the age-sex registers of Wiltshire (7,900) and Sheffield (7,100) Health Authorities, stratified by disadvantage using the Townsend Index of Material Deprivation.</td>
<td>Need for the intervention was determined by an adapted version of the index of severity of osteoarthritis of the hip. Compare need to services used.</td>
<td>Multiple logistic regression</td>
<td>Unmet need for hip replacement in those aged over 65 is relatively common (3.4%).</td>
</tr>
<tr>
<td>(Nacul et al., 2007)</td>
<td>Chronic obstructive pulmonary disease (COPD)</td>
<td>Heath Survey for England 2001 [n=10749]</td>
<td>Undiagnosed cases = compare the model estimates with the recorded prevalence of COPD.</td>
<td>Logistic regression.</td>
<td>Around 600,000 or nearly half of the 1.3 million COPD cases in England remain undiagnosed (no details on the paper on how that difference is distributed among population groups).</td>
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<td>(Orton et al., 2013)</td>
<td>Diabetic Retinopathy (DR)</td>
<td>Postal questionnaires, stratified (by district of residence, gender and age) sample of patients who had been invited for screening between 1st and 31st May 2010 [n=435].</td>
<td>DR screening uptake.</td>
<td>Logistic regressions for nonresponse to invite associated with potential predictive variables. Multivariate models to identify predictors of non-attendance.</td>
<td>Overall the under 40 age group more likely to be non-responders than the over 80 age group but this effect was stronger in younger men than younger women and was stronger for people with type 1 diabetes than people with type 2 or unknown type of diabetes. Results show increasing odds of non-attendance with increasing deprivation.</td>
</tr>
<tr>
<td>(Purandare et al., 2004)</td>
<td>Mental Health</td>
<td>Postal survey of managers of care homes (1) that have as residents older people with functional or organic mental illness requiring 24 hour nursing supervision/or over 65s with learning disabilities and (2) are classified as nursing/residential/or dual [n=1689]</td>
<td>Perceived need vs. provision of old age psychiatrists (OPs).</td>
<td>Multiple logistic regression</td>
<td>Perceived inadequacy of service provision by OPs increases with the proportion of elderly residents that need psychiatric evaluation, infrequent visits by OPs, unavailability of geriatricians, lack of pharmacological advice and inability to refer patients directly to OPs.</td>
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<tr>
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<td>(Sheringham et al., 2009)</td>
<td>Chlamydia</td>
<td>National Chlamydia Screening Programme (NCSP) data for 2006-07 + ACORN’s dataset of geodemographic classifications at postcode level linked to IMD 2004.</td>
<td>Inequalities in service use.</td>
<td>Compare performance of ACORN and IMD2004 as deprivation measure (ACORN has more geographical resolution than IMD2004).</td>
<td>ACORN is a valid area-level deprivation measure, it agreed moderately well with IMD 2004 in its segmentation of the population. Regarding chlamydia positivity, ACORN and IMD2004 show similar gradients: the most ‘deprived’ (hard pressed) areas have higher positivity rates.</td>
</tr>
<tr>
<td>(Turner-Stokes et al., 2013)</td>
<td>Long-term neurological conditions (LTnC)</td>
<td>Questionnaires to patients discharged from specialist neurorehabilitation units within the London area over a 12-month period in 2010–2011 [n=211]</td>
<td>Using Needs and Provision Complexity Scale (NPCS), comparing ‘needs’ with ‘gets’ (levels of service provided). Met (or exceeded) Needs= NPCS-Gets ≥ NPCS Needs. Unmet Needs = NPCS-Gets &lt; NPCS Needs.</td>
<td>‘Needs’ and ‘Gets’ were compared using non-parametric techniques (Wilcoxon Signed Rank tests).</td>
<td>Needs for a personal enabler were significantly undermet, but the frequency of personal care for activities of daily living was provided at a level significantly above predicted need.</td>
</tr>
<tr>
<td>(Williams and Drinkwater, 2009)</td>
<td>Radiotherapy Services</td>
<td>Audit of radiotherapy waiting times conducted by the Royal College of Radiologists + administrative data.</td>
<td>Access to radiotherapy = proportion of cancer patients receiving appropriate radiotherapy at least once during the treatment of their malignancy.</td>
<td>Spearman’s rank coefficient to calculate correlation coefficients; this assumes a linear relationship.</td>
<td>Variation in radiotherapy services across the UK measured by waiting times, access rates and dose fractionation. Deprivation negatively influences radiotherapy access rates.</td>
</tr>
</tbody>
</table>
A.3. Literature search details

Unmet need: general searches of EconLIT, Embase, HMIC and MEDLINE databases

Database: Econlit <1886 to April 2015> via OVID 14th April 2015
Search Strategy:
--------------------------------------------------------------------------------
1   (unmet health need$ or unmet healthcare need$ or unmet health care need$ or unmet medical need$).ti. (1)
2   ((inequit$ or equit$ or equality or inequality) adj2 (access or provision or provid$ or service$)).ti. (68)
3   ((unmet or inadequate$ met or inappropriate$ met or insufficient$ met or underserved or under-served) adj2 (need$ or demand$)).ti. (35)
4   2 or 3 (103)
5   (healthcare or health care or health or medical).ti. (20064)
6   4 and 5 (22)
7   1 or 6 (22)
8   (insured or uninsured or insurance).ti. (12253)
9   7 not 8 (19)
--------------------------------------------------------------------------------

Database: Embase <1974 to 2015> via OVID 14th April 2015
Search Strategy:
--------------------------------------------------------------------------------
1   (unmet health need$ or unmet healthcare need$ or unmet health care need$ or unmet medical need$).ti. (172)
2   ((inequit$ or equit$ or equality or inequality) adj2 (access or provision or provid$ or service$)).ti. (433)
3   ((unmet or inadequate$ met or inappropriate$ met or insufficient$ met or underserved or under-served) adj2 (need$ or demand$)).ti. (1861)
4   2 or 3 (2294)
5   (healthcare or health care or health or medical).ti. (785885)
6   4 and 5 (565)
7   1 or 6 (605)
8   limit 7 to english language (585)
9   (insured or uninsured or insurance).ti. (24214)
10  8 not 9 (565)
--------------------------------------------------------------------------------

Database: HMIC Health Management Information Consortium <1979 to March 2015> via OVID 14th April 2015
Search Strategy:
--------------------------------------------------------------------------------
1   (unmet health need$ or unmet healthcare need$ or unmet health care need$ or unmet medical need$).ti. (13)
2   ((inequit$ or equit$ or equality or inequality) adj2 (access or provision or provid$ or service$)).ti. (116)
3   ((unmet or inadequate$ met or inappropriate$ met or insufficient$ met or underserved or under-served) adj2 (need$ or demand$)).ti. (101)
4   2 or 3 (217)
5   (healthcare or health care or health or medical).ti. (80424)
6   4 and 5 (90)
7   1 or 6 (92)
8   (insured or uninsured or insurance).ti. (898)
--------------------------------------------------------------------------------
Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present> via OVID 13th April 2015

Search Strategy:
--------------------------------------------------------------------------------
1 (unmet health need$ or unmet healthcare need$ or unmet health care need$ or unmet medical need$).ti. (127)  
2 ((inequit$ or equit$ or equality or inequality) adj2 (access or provision or provid$ or service$)).ti. (372)  
3 ((unmet or inadequate$ met or inappropriate$ met or insufficient$ met or underserved or under-served) adj2 (need$ or demand$)).ti. (1326)  
4 2 or 3 (1698)  
5 (healthcare or health care or health or medical).ti. (682582)  
6 4 and 5 (456)  
7 1 or 6 (492)  
8 limit 7 to english language (474)  
9 (insured or uninsured or insurance).ti. (20735)  
10 8 not 9 (452)  

Unmet need: specific disease areas - searches of EconLIT, Embase, HMIC and MEDLINE databases

Database: Econlit <1886 to May 2015> via OVID 5th June 2015

Search Strategy:
--------------------------------------------------------------------------------
1 (unmet health need$ or unmet healthcare need$ or unmet health care need$ or unmet medical need$).ti,ab. (12)  
2 ((inequit$ or equit$ or equality or inequality) adj2 (access or provision or provid$ or service$)).ti,ab. (614)  
3 ((unmet or inadequate$ met or inappropriate$ met or insufficient$ met or underserved or under-served) adj2 (need$ or demand$)).ti,ab. (209)  
4 2 or 3 (823)  
5 (healthcare or health care or health or medical).ti,ab. (39338)  
6 4 and 5 (237)  
7 1 or 6 (239)  
8 ((cardiovascular or heart) adj2 disease$).ti,ab. (355)  
9 7 and 8 (3)  
10 ((respiratory or lung) adj2 disease$).ti,ab. (89)  
11 7 and 10 (0)  
12 (neoplasm$ or cancer$).ti,ab. (1122)  
13 7 and 12 (4)  
14 ((digestive or gastrointestinal) adj2 disease$).ti,ab. (19)  
15 7 and 14 (0)  
16 hip replace$.ti,ab. (21)  
17 7 and 16 (0)  
18 (mental health or mental illness$ or mental disorder$).ti,ab. (1348)  
19 7 and 18 (14)  
20 (diagnosis or diagnostic or screen$).ti. (1369)  
21 7 and 20 (0)  
22 9 or 11 or 13 or 15 or 17 or 19 or 21 (21)  
23 europe.gr. (240641)
Defining and measuring unmet need to guide healthcare funding: identifying and filling the gaps

24  22 and 23 (3)

Database: Embase <1974 to 2015 June 04> via OVID 5th June 2015
Search Strategy:

1  (unmet health need$ or unmet healthcare need$ or unmet health care need$ or unmet medical need$).ti,ab. (2392)
2  ((inequit$ or equit$ or equality or inequality) adj2 (access or provision or provid$ or service$)).ti,ab. (3305)
3  ((unmet or inadequate$ met or inappropriate$ met or insufficient$ met or underserved or under-served) adj2 (need$ or demand$)).ti,ab. (13218)
4  2 or 3 (16468)
5  (healthcare or health care or health or medical).ti,ab. (2518528)
6  4 and 5 (10005)
7  1 or 6 (10119)
8  exp Great Britain/ (350902)
9  7 and 8 (810)
10  *Cardiovascular Disease/ (76289)
11  9 and 10 (2)
12  exp *Respiratory Tract Disease/ (1121660)
13  9 and 12 (28)
14  exp *Neoplasm/ (2734450)
15  9 and 14 (71)
16  exp *Gastrointestinal Disease/ (48942)
17  9 and 16 (1)
18  Arthroplasty, Replacement, Hip/ (13370)
19  hip replace$.ti,ab. (12443)
20  18 or 19 (22719)
21  9 and 20 (3)
22  exp *Mental health/ (30302)
23  9 and 22 (11)
24  exp *diagnostic procedure/ or exp *screening/ (3188840)
25  9 and 24 (52)
26  11 or 13 or 15 or 17 or 21 or 23 or 25 (148)

Database: HMIC Health Management Information Consortium <1979 to March 2015> via OVID 5th June 2015
Search Strategy:

1  (unmet health need$ or unmet healthcare need$ or unmet health care need$ or unmet medical need$).ti,ab. (50)
2  ((inequit$ or equit$ or equality or inequality) adj2 (access or provision or provid$ or service$)).ti,ab. (775)
3  ((unmet or inadequate$ met or inappropriate$ met or insufficient$ met or underserved or under-served) adj2 (need$ or demand$)).ti,ab. (692)
4  2 or 3 (1455)
5  (healthcare or health care or health or medical).ti,ab. (157735)
6  4 and 5 (1110)
7  1 or 6 (1114)
8  ((cardiovascular or heart) adj2 disease$).ti,ab. (4644)
9  7 and 8 (26)
((respiratory or lung) adj2 disease$).ti,ab. (858)
7 and 10 (1)
(neoplasm$ or cancer$).ti,ab. (12533)
7 and 12 (61)
((digestive or gastrointestinal) adj2 disease$).ti,ab. (57)
7 and 14 (0)
hip replace$.ti,ab. (236)
7 and 16 (9)
(mental health or mental illness$ or mental disorder$).ti,ab. (18981)
7 and 18 (201)
(diagnosis or diagnostic or screen$).ti. (5507)
7 and 20 (14)
9 or 11 or 13 or 15 or 17 or 19 or 21 (286)

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present> via OVID 5th June 2015

Search Strategy:
--------------------------------------------------------------------------------
1 (unmet health need$ or unmet healthcare need$ or unmet health care need$ or unmet medical need$).ti,ab. (1540)
2 ((inequit$ or equit$ or equality or inequality) adj2 (access or provision or provid$ or service$)).ti,ab. (2655)
3 ((unmet or inadequate$ met or inappropriate$ met or insufficient$ met or underserved or under-served) adj2 (need$ or demand$)).ti,ab. (8979)
4 2 or 3 (11592)
5 (healthcare or health care or health or medical).ti,ab. (1890319)
6 4 and 5 (7212)
7 1 or 6 (7313)
8 exp Great Britain/ (308639)
9 7 and 8 (512)
10 *Cardiovascular Diseases/ (72083)
11 9 and 10 (2)
12 exp *Respiratory Tract Diseases/ (899051)
13 9 and 12 (13)
14 exp *Neoplasms/ (2334675)
15 9 and 14 (29)
16 exp *Digestive System Diseases/ (1195116)
17 9 and 16 (7)
18 Arthroplasty, Replacement, Hip/ (18107)
19 hip replace$.ti,ab. (9780)
20 18 or 19 (23619)
21 9 and 20 (5)
22 exp *Mental Disorders/ (817926)
23 9 and 22 (90)
24 exp **"diagnostic techniques and procedures"/ or exp *mass screening/ (2016924)
25 9 and 24 (25)
26 11 or 13 or 15 or 17 or 21 or 23 or 25 (156)