Unmet need in healthcare

Summary of a roundtable held at the Academy of Medical Sciences on 31 July 2017, held with support from the British Academy and NHS England

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The Academy of Medical Sciences

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Opinions expressed in this report do not necessarily represent the views of all participants at the event, the Academy of Medical Sciences or its Fellows, the British Academy or its Fellows or NHS England.

All web references were accessed in September 2017

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Executive summary

On 31 July 2017, the Academy of Medical Sciences, with support from the British Academy and NHS England, hosted a roundtable on unmet need in healthcare funding allocations formulae.

Participants from across the medical, social, economic and epidemiological sciences were brought together to discuss the opportunities for improving the assessment of unmet need – defined for the purpose of the meeting as those who have healthcare needs but do not or cannot access healthcare - for use in the funding allocations formulae.[1] They discussed improvements that could be made to the formulae by using existing data sets, as well as the potential for research to generate new data sets designed to assess unmet need.

The group addressed two questions around ways to improve the allocation formulae: firstly, is further research capable of reliably assessing unmet need for the purposes of resource allocation, and secondly, in the absence of a reliable direct assessment, can a more robust proxy measurement be developed?

Overall, there was agreement to both questions. In terms of directly measuring unmet need for resource allocation, the conclusion from the roundtable was that not just one study would be able to provide a measurement and instead a research agenda would be required, bringing together a range of methods.

The key proposal for further research were:

1. Shorter-term pieces and improvements to the current proxy:

- A comprehensive literature review should be carried out that includes papers from pre-2005, which were excluded from a previous literature review carried out by the Centre for Health Economics.[2]
- For a more robust proxy measurement, SMR<75, the current proxy measurement, could be further developed to stratify based on demographics such as age and geography (region or CCG), focussed on cause-specific mortality amenable to healthcare and supplemented with a measure of cause-specific morbidity.
- Studies of prison records could provide insight given the detailed, longitudinal data available on prisoner morbidity.
- Patient surveys or activity data combined with microsimulations and modelling of the prevalence of key conditions could present a mixed-methods opportunity to accurately

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[1] NHS England (2016). *Technical Guide to determination of revenue allocations to CCGs and commissioning areas for 2016-17 to 2020-21.* https://www.england.nhs.uk/wp-content/uploads/2016/04/1-allctins-16-17-tech-guid-formulae.pdf

[2] Centre for Health Economics (2017). *Defining and measuring unmet need to guide healthcare funding: identifying and filling the gaps.* https://www.york.ac.uk/media/che/documents/papers/researchpapers/CHERP141_need_healthcare_funding.pdf

assess unmet need on a local level. This is something that NHS England are currently investigating.

2. Longer term and more experimental work-streams:

- Existing data sources and metrics, such as the Health Survey for England, Hospital Episode Statistics, UK Biobank, the Millennium cohort study, the Understanding Society study and primary care data all have the potential to provide useful resources for estimating unmet need, if they could be linked in order to track individuals over time. They may need to be supplemented by additional studies of the most vulnerable groups who may not feature in the sampling frames of surveys or official statistics, such as homeless people.
- Alternatively, new sources of data could be used for examining unmet need, such as social media data and bespoke longitudinal cohorts.
- Audits of deaths in hospital amenable to healthcare and of frequent and return users of emergency departments could highlight areas of higher unmet need.
- Confidential inquiries into patient records at individual GP surgeries could allow access to data on cause-specific morbidity and mortality.

Introduction

Introduction to unmet healthcare need

Unmet need for healthcare can be seen as covering a spectrum of healthcare needs that are not optimally met. At one end there is "unexpressed demand" (people who have healthcare needs but who are not aware of them, or who choose not to seek healthcare). At the other end there is "expressed demand that is sub-optimally met". This can include people ineligible for treatment, or who have poorer quality treatment than would optimally be the case. For some individuals, their unmet need may be a combination of the two. The focus of this roundtable was on "unexpressed demand" to ensure that funding captures everyone who should be able to access services given their healthcare needs, and not just those that are already accessing services. Participants also agreed not to focus on the mechanics and technicality of implementation of new formulae or new measures.

NHS England's current resource allocation formulae

In building the allocations formulae, NHS England uses data on past utilisation of healthcare and as a result only captures met need. If the geographical distribution of unmet need differs from that of met need, resources may be distributed inefficiently, leading to poorer outcomes for patients as funding wouldn't be directed to the benefit of patients with the greatest needs. The formulae undergo regular scrutiny by both NHS England and the Advisory Committee on Resource Allocation (ACRA), which consists of independent experts. Unmet need has been a topic of discussion by ACRA and its predecessors and in the wider community since the allocations formulae were first developed in the mid-1970s. Over the past four decades, a number of different proxies have been used to measure unmet need within the formulae, but these have been driven primarily by practical issues around data availability; robust evidence on the most appropriate way to adjust for unmet need has not been available.

NHS England currently uses a proxy in the formulae for unmet need and health inequalities based on early mortality - the standardised mortality ratio for those under age 75, SMR<75. This gives some indication of those who have not accessed healthcare until too late, if at all, but it is only a proxy; it should not be regarded as meaning that there is only an interest in differential mortality or only in those aged under 75 years. The proxy currently drives the distribution of up to £9bn of the circa £100bn of annual healthcare funding.[3]

In 2015, ACRA commissioned a literature review on unmet need from the Centre for Health Economics at the University of York.[4] The primary finding of the review was that there is not presently sufficient published research that would meet the requirements of providing evidence of unmet need to support resource allocation. However, the review also suggested

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[3] NHS England (2017). Fair shares – *A guide to NHS Allocations (infographics).* https://www.england.nhs.uk/wp-content/uploads/2017/07/nhs-allocations-infographics-v1-04.pdf

[4] Centre for Health Economics (2017). *Defining and measuring unmet need to guide healthcare funding: identifying and filling the gaps.* https://www.york.ac.uk/media/che/documents/papers/researchpapers/CHERP141_need_healthcare_funding.pdf

that further research in this area could be valuable, should it be sufficiently resourced so as not to duplicate smaller scale work already available.

Aim of this roundtable

The aim of this roundtable was to establish whether further research is capable of improving the allocations formulae to account for unmet need. For improvements to be made to the formulae there are two possibilities: a reliable assessment of unmet need or a more robust proxy measurement than SMR<75.

Discussion

The roundtable participants, drawn upon from a diverse range of disciplines, discussed the current limitations of the funding formulae and how these limitations might be alleviated by the use of new evidence sources for improving the formulae. Participants also discussed key questions that a research agenda could address to generate these evidence sources. For a full list of participants please see Annex I. For an agenda of the discussions, please see Annex II.

Social and service-based drivers of unmet need

Participants felt that defining unmet need, and the reasons for it, was important to guiding later discussions. Participants described that unmet need can be described as being either population driven or service driven. In the case of population-driven unmet need, individuals are not entering or accessing the healthcare system. Reasons for this could be a reluctance to seek help or a lack of awareness around the severity of a problem, among others. Participants suggested that in these cases policy should be focused at "population push" that aims to bring people into the health service. For service-driven unmet need, services are not reaching the target population, or they drop out of the system. This could be due to people being unaware of an available service, poor referral mechanisms or disconnected services. In these cases, "service pull" is required to pull people into the correct parts of the healthcare system, which in part relies on an efficient and coordinated healthcare system. Participants felt that these two sources of unmet need should be acknowledged and consideration should be given to how adjustment of the formulae would differentially affect these two factors.

It was suggested that in the cases of "service pull", the use of incentives, such as the Quality and Outcomes Framework (QOF) and the Commissioning for Quality and Innovation (CQUIN), or similar, may allow allocations adjustments to positively affect service variability. Similarly, money could be "ear-marked" for therapy or service areas of higher unmet need to ensure the funding contributed to improving these areas.[5,6] However, participants warned that ring-fencing funding in this way could lead to consternation and that the process would need to be clear and transparent about what the aims of the funding would be.

The current limitations of the funding formulae with respect to unmet need

Whilst the focus of the meeting was on those who do not or cannot access the healthcare system, participants warned of the potential for inappropriate allocation of funding to negatively influence quality of care. They noted that the current formulae, by design, do not prescribe where any additional funding is spent, which means the allocations may not be addressing the unmet need they are intended to reduce.

Furthermore, participants noted that there are certain services that do not fall under the remit of NHS England, and as such are not part of the funding formulae, but have significant

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[5] NHS England (2016). *Quality and Outcomes Framework (QOF) - 2015-16.* http://www.content.digital.nhs.uk/catalogue/PUB22266

[6] https://www.england.nhs.uk/nhs-standard-contract/cquin/

implications for met and unmet needs. These include social care, public health prevention and sexual health, which fall under local authority jurisdiction. Adjustment of funding allocations based on unmet need which could be met by these services is therefore not possible as the funding formulae do not impact these services.

Participants felt that strong primary care was a key driver in producing better outcomes at a lower cost, and that evidence has shown that better upstream primary care provision reduces costs downstream in secondary and tertiary care. Therefore investment in primary care "generalists" rather than specialist care could improve services to reduce unmet need, as well as lower costs. Whilst outside of the focus of the meeting, it was felt that research could be carried out to investigate the structural effect of investment in primary care.

Possible sources of evidence for improving the proxy

Participants felt that age alone was not a good measure of unmet need; in socially deprived areas, people suffer from more health problems (including multimorbidity) at a younger age (quoted as 10-15 years earlier) than in more affluent areas.[7] As such, they felt that new sources of evidence were necessary to improve the proxy so that it better reflects the differences in unmet need across different demographics.

Disability-Free Life Expectancy (DFLE) statistics, published by the Office for National Statistics (ONS), could be used as a source for estimating unmet need.[8] These data, whilst estimates, are readily available and cover every region. However, DFLE statistics are calculated using subjective self-reports of health status collected in national population surveys, which are then combined with data on mortality. As a result they may not capture populations which have not self-reported, and as such may not be an accurate representation of unmet need in circumstances where people aren't accessing healthcare or are less engaged with the healthcare system. DFLE was previously used in funding formulae until it was removed in the 2013 Fundamental Review of Allocations Policy due to ACRA's concerns about its robustness.[9] However, participants were enthusiastic about the potential to utilise DFLE for unmet need.

Participants felt that the registers and statistics produced by the ONS were not currently sufficient for direct use in the allocations formulae, but could be adapted to include new information such as the severity of cases at the beginning of care, rather than just incidence. This could provide better measurements of both multimorbidity and unmet need as it would differentiate between those who present early with a mild case, compared to those who "self-manage" their condition until it is too severe, at which point they present. These may be measures of deprivation and unmet need.

Local-authority-provided services, such as social care, may be rich sources of data for estimating unmet need and these data could be fed back into NHS England for use in funding allocations, or used to improve models that are applied to NHS-provided services. Participants felt that the existing data on social care was very poor but could be an important component

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[7] Barnett *et al.* (2012). *Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study.* The Lancet **380(9836),** 37–43

[8] https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/datasets/disabilityfreelifeexpectancydfleandlifeexpectancyleatage65byregionengland

[9] https://www.england.nhs.uk/2013/08/rev-all-wrkshp/

if the data sets were of sufficient scale and quality. Similarly, it was felt that the quality or utilisation of social care services does not necessarily correlate with social deprivation. This was attributed to the "inverse care law" - a principle that states that high quality or high utilisation of services such as social care may in fact correlate to a lower level of need and unmet need. Whether this is true needs to be explored more thoroughly and could lead to difficulties in using this data to influence the models.

Participants discussed the need to use existing data sets routinely gathered in care to help identify underperforming areas, and allow the creation of performance indicators which can be used to judge the effectiveness of the funding formulae for their improvement. Multimorbidity was again mentioned as a great challenge in this area, as the burden imposed by it can be large but also diffuse and spread across services.

A better proxy for unmet need

Participants suggested that instead of SMR<75, a new, more comprehensive set of proxies could be developed that look at different age groups, acknowledging that health needs differs across age populations. This could go further by disaggregating SMR to look at cause-specific mortality across CCG areas, which would allow further stratification based on the individual needs of a CCG. Building upon this, cause-specific morbidity rates could be incorporated, and it was felt that this was achievable at an individual CCG level. Finally, it was suggested that confidential inquiries into individual GP surgeries or hospitals could allow access to data on cause-specific morbidity and mortality.

It was questioned if there was a way to distinguish between emergency admissions where the admission may have been avoidable (e.g. un-medicated heart attack or suicide attempt) from those which were unavoidable (e.g. accidents). If the type of emergency admission can be measured this could allow better assessment of inadequately met health care.

One criticism of this approach was that emergency admissions and mortality are not direct measures of the reasons for unmet need; either the person was not cared for (i.e. did not access healthcare) or received insufficient care (i.e. poor delivery). As a result these data cannot distinguish between "quantity" and "quality" of care.

Possible sources of evidence for directly measuring unmet need

One delegate suggested that the use of social media data, especially in the future, could be used to estimate local need. Ebola and flu (as led by Professor Andrew Hayward, UCL) were cited as examples where social media data was effectively used in the past to monitor real-time outbreaks of disease. However, it was mentioned that in the cases of Ebola and flu, an absolute calibration exists, i.e. a measurement of the number of cases, which allows evaluation of the model. This is not the case in unmet need and employing a proxy in place of such a measure to act as a calibration would have its limitations. As a consequence, social media may be limited in its usefulness to understand local variation in unmet need.

Participants suggested that GP workload could be an indicator of need, and it was noted that NHS England have been exploring the Clinical Practice Research Datalink as a possible basis for understanding primary medical care workload.[10]

It was also suggested that Hospital Episode Statistics (HES) could be linked to Health Survey for England (HSE) data to examine patterns of high and low need population groups.[11,12] It was also felt that hospital emergency admissions could be a reflection of unmet need and could be used to describe patterns of use.

Possible areas of research to directly measure unmet need

Building upon existing data sources

One delegate stressed that there is limited value in looking backwards at existing data or historical figures, due to a change in demographics and the health of the population. The delegate stressed that the biggest challenge is complex multimorbidity (mental, physical, and social co-morbidities). Currently, the fragmentation of specialist care services results in a discordant assessment of complex multimorbidity, and efforts should be directed to better assess and understand multimorbidity, which would be highly valuable to the funding formulae. It is thought that the presence of multimorbidity can, in cases where one or more of the morbidities is a result of insufficient care, be indicative of a higher unmet need. It is therefore expected that areas of higher multimorbidity may have a higher unmet need.

It was suggested that specific disease areas could be incorporated into analyses of unmet need, as data collection of acute presentations, which may correlate to unmet need, is now routine. The evidence for this correlation is not assured but research could reveal whether such data sets could be used as a proxy measurement for unmet need. One method would be to use modelled estimates of the expected prevalence of conditions (such as cardiovascular disease or hypertension) and then compare this to actual prevalence. The difference between these two may be a measure of the unmet need for these disease areas. NHS England are currently investigating this approach.

A mixed-methods approach

Participants suggested that a “bottom-up” approach that focused on the patient would be another way to assess unmet need. This would involve following patients throughout their care pathway, and finding out how the patient made their decisions about accessing or continuing with the healthcare system. This was contrasted to a “top-down” approach that would use large-scale modelling and simulations to predict these factors. It was felt that the bottom-up approach could incentivise CCGs to understand their own unique patient populations to develop locally specific policy changes. While outside of the focus of the meeting, it was also proposed that such policy changes could be “randomised” in situations where the best policy is not clear. Different CCGs could trial different local policies and compare data with those of their peers to establish the best policies for improving unmet need. Participants felt that such a method may be considered to be controversial, but that

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[10] https://www.cprd.com/home/
[11] http://content.digital.nhs.uk/hes
[12] http://content.digital.nhs.uk/healthsurveyengland

hospitals are now routinely investigating deaths to understand the patient journey up until that point.

Longitudinal studies

Participants suggested that measures to assess undiagnosed disease and uncoordinated self-care could be developed. In the case of uncoordinated self-care, emergency admissions for chronic conditions could be a measure of this. This is because people who effectively manage their chronic conditions may be demographically separate to those who do not. Longitudinal studies could link this to administrative data and track patients over time to describe the characteristics of people who meet their care effectively compared to those who do not.

However, participants stressed that existing longitudinal studies are relatively small, have high drop-out and attrition rates, and have cohorts from different time frames. It was also suggested that they are biased according to both health and socioeconomic status. It was mentioned that "understanding society", a longitudinal household study, has consent to link health data, but that retroactively changing consent for other longitudinal studies, or seeking new consent, would not be possible.[13] An additional source of data, the Health Surveys for England (HSE) and Scotland (HSS) was suggested as a potential contributor.[14] It was stated that these data include clinical screening, and that these data, which are cross-sectional and clustered to specific areas, could be linked to hospital episodes. To identify patterns, participants felt that there was a need to link studies or surveys of population health to prevalence of conditions or utilisation of service, for example linking multimorbidity to social deprivation.

Although HSE and UK Biobank were cited as potential sources of data, it was generally agreed that a broader study of health and measures of utilisation is required, and that inadequacies in surveying should be acknowledged, and if possible adjusted.[15] It was stated that death rates in the UK Biobank database are half the national average, demonstrating that such databases are not representative of populations. This may be because these studies miss certain vulnerable populations who may have unmet need such as homeless people or people living in care homes. This underrepresentation limits their usefulness and makes database linking more difficult, as biases may be different between data sets.

Patient surveys and sampling

Participants felt that patient-experience sampling could be extremely valuable, and could be done either nationally or locally. However, it was acknowledged that there were issues around collecting these data as well as deciding upon sampling techniques. Such sampling could track the history of a patient, as well as hospitalisations, emergency admissions and mortality.

It was suggested that research could focus specifically on conditions that aren't outpatient care sensitive, but are sensitive to no- or poor-quality care. These could be tenable, measurable conditions that could be screened for, such as late stage cancers or childhood infections indicative of non-immunisation. A set of conditions could be defined that represent illnesses or diseases that occur but were preventable given timely access to adequate care.

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[13] https://www.understandingsociety.ac.uk/
[14] http://content.digital.nhs.uk/healthsurveyengland
[15] http://www.ukbiobank.ac.uk/

It was also suggested that audits of deaths in hospital amenable to healthcare and of frequent and return users of emergency departments could add insight.

It was proposed that prison records may be able to contribute to the analysis. Prisoners are given a unique number, and their healthcare throughout their incarceration, including any morbidities or mortality, is recorded. These data could be linked with data from outside incarceration to see if there is a difference in met health needs inside of prison, where health problems are often addressed promptly, compared to outside of prison.

Ultimately, a survey of unmet need must ensure that it captures those who are not identified in other surveys, which will require a mixed-method approach. One approach proposed was to take everyone on the HES registers (i.e. has ever been admitted to hospital) and follow up their outcomes. In addition, it was stated that a lot of research has been undertaken into engaging and surveying difficult-to-access groups, and that this research could be incorporated into an assessment of unmet need, but that utilisation of services by vulnerable groups may still be an area where further research is required. It was noted that any research agenda should be supplemented by a more comprehensive literature review that includes articles from pre-2005.

The meeting closed with offers of further support from delegates should this be useful to NHS England, or additional, more focussed workshops on the ideas and topics that had been raised.

Annex I - Participant list

Chair
Professor Graham Hart FMedSci, Dean, Faculty of Population Health Sciences, School of Life & Medical Sciences, University College London

Participants
Professor Melanie Bartley FBA, Emeritus Professor of Medical Sociology, University College London
Professor Christopher Bentley, Public Health Consultant and Committee Member, Advisory Committee on Resource Allocation
Professor Sheila Bird OBE FRSE FMedSci, Programme Leader, MRC Biostatistics Unit, University of Cambridge
Professor Richard Cookson, Professor and NIHR Senior Research Fellow, Centre for Health Economics, University of York
Professor Catherine Law CBE FMedSci, Professor of Public Health and Epidemiology, UCL Great Ormond Street Institute of Child Health
Professor Michael Murphy FBA, Professor of Demography, London School of Economics
Professor Jon Nicholl CBE FMedSci, Dean of the School of Health and Related Research (ScHARR), University of Sheffield
Professor Rosalind Raine, Professor of Health Care Evaluation, University College London
Professor Graham Watt FRSE FMedSci, Professor of General Practice, University of Glasgow

Secretariat
Mr Matthew Balmforth, Policy Intern, Academy of Medical Sciences
Ms Anna Everton, Senior Analytical Lead - Allocations Analysis and Insight for Finance, NHS England
Ms Barbara Limon, Interim Head of Policy (Public), British Academy
Dr Stephen Lorrimer, Head of Analysis and Insight for Finance & Head of Operational Research, NHS England
Mr James Squires, Policy Officer, Academy of Medical Sciences
Dr Naho Yamazaki, Head of Policy, Academy of Medical Sciences

Observers
Mr Oliver Ducker, Analyst, NHS England
Mr John Wilkinson, Department of Health

Annex II - Agenda

10.00-10.30	**Registration and refreshments**
10.30-10.45	**Welcome and introduction from the chair** **Professor Graham Hart FMedSci**, Dean, Faculty of Population Health Sciences, School of Life & Medical Sciences, University College London
10.45-11.00	**Overview of NHS England and ACRA's work on unmet need** **Stephen Lorrimer,** Head of Analysis and Insight for Finance & Head of Operational Research, NHS England
11.00-12.00	**Discussion: Can further research practically contribute to an assessment of unmet need for allocation of funding that would be better than the current proxy?** The aim of this session is to establish a general consensus of whether or not unmet health need for the allocation of funding can be assessed through further research. Participants are asked to consider the practicalities of unmet need research, including the existing resources, opportunities for new resources and major challenges that would need to be overcome. participants should consider whether there are realistic and robust opportunities for the short term delivery of assessing unmet health needs for funding allocation
12.00-13.00	**Discussion: What could the future funding formula look like and what needs to be done to get there?** Based on the consensus of the previous session, participants are asked to discuss the relevant outcome. **If participants agree that YES, research can address unmet need for use in funding allocations –** What research is necessary and can it answer the following questions? a. How much unmet need is there in the system? b. What population groups is it concentrated in? c. How is it distributed geographically? d. Is the geographical variation in 'unmet' need different to that of 'met' need, and therefore, how should our funding formula be adjusted? **If participants agree that NO, research cannot realistically or reasonably address unmet need for use in funding allocations –** Is there a more appropriate proxy than SMR<75 and if so what might it be and how can it be generated and validated? If SMR<75 remains the best option, are there opportunities for a more representative proxy in the future?
13.00	**Close and lunch**

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Registered Charity No. 1070618
Registered Company No. 3520281
Academy of Medical Sciences
41 Portland Place
London, W1B 1QH
+44(0)20 3141 3200

info@acmedsci.ac.uk