

CO-PRODUCING HEALTH ECONOMICS RESEARCH

Increasing seldom-heard groups' visibility in health economics research: guidance for civil society organisations.



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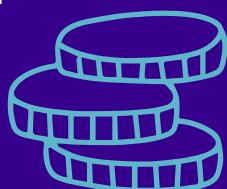
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CO-PRODUCING HEALTH ECONOMICS RESEARCH

Key messages

There is a strong tradition of making use of economic arguments to inform mental health (and wider) policy and practice in the UK. Economic research can provide information on what works best, for whom, in what context and at what cost.



People from seldom-heard groups, with lived experience, both of poor mental health and other disadvantage, may benefit greatly from more investment in measures to protect their mental health, yet they are rarely involved in co-producing economic research used to inform policy and practice choices.



Civil society organisations are well placed to act as the bridge between professional researchers and seldom-heard groups to facilitate co-design and co-production of health economic research. These organisations can also benefit from health economics evidence that shows the value of their services.



As part of the co-design and co-production of health economic research it is essential to identify, from the perspective of seldom-heard groups, the key interventions to implement and which key impacts to measure.



Civil society organisations that bring together professional researchers and seldom-heard groups should ensure that peer researchers are paid and have the same opportunities as professional researchers to be authors of research findings.

Civil society organisations should be compensated for their participation and/or facilitation of co-produced research. In addition to covering any of their own researcher time, this includes financial (and potentially technical support) for data collection, as well as engagement with, and/or training, of seldom-heard groups.



Civil society organisations working with seldom-heard lived experience groups can facilitate health economic research by putting in place monitoring systems for the services provided.

The information obtained can be used in future assessments of cost-effectiveness, and should include the resources used for service delivery, service uptake and sustained engagement rates, as well as information on different outcomes, such as those considered to be important to people with lived experience.



A database of civil society organisations that are willing to participate in research would help facilitate health economic research that is co-designed with seldom-heard groups.

Peer researchers and representatives of seldom-heard groups should be compensated for their role in the co-design and co-production of research.



Decision-maker / Funder

Missing research

- Marginalised groups
- LGBTQIA+
- Asylum seeker
- Later life
- Long-term conditions



Intervention that works



Researchers

- Train and build peer capacity
- Pay peer researchers
- Give opportunities for peer research
- Compensate NGOs / Associations

NGOs / Associations



How can the involvement of third sector organisations working with people from seldom-heard groups in co-producing health economic research be strengthened?

1. Introduction

In recent years conversations about mental health have become more common place. Many people have been willing to share their own lived experiences of poor mental health, helping to challenge negative attitudes and discrimination. Conversations about the collective experience that we all went through during the COVID-19 pandemic have also shown how important it is to look after our mental health. These conversations continue to keep mental health concerns visible with policymakers; new policy strategy documents have been developed, with commitments made by the UK and devolved administrations to do more to support mental health. Research findings have played a major role in these changes, including research looking at the economic impacts of poor mental health and how these can be reduced.

In 2022, we produced a report for the Mental Health Foundation highlighting the very high personal, societal and economic impacts of living with poor mental health. We estimated that these costs conservatively are more than £118 billion in the UK every year¹ and that there is a strong moral, health and economic case for investing more money into different evidence-based ways of preventing mental health conditions. However, much of the evidence for investing in prevention has focused on the general population. This is invaluable, but it can mean that the voices of some population groups whose mental health may be at higher risk than that of the general population are often not heard.

This document is primarily about how third sector organisations working with these groups can be more involved in health economic research related to mental health.

Language

In writing this document, it is important to acknowledge from the outset that the language used to describe different population groups is contested and that many different expressions could be used. Here we refer to individuals having lived experience either of mental health problems, or of being in 'seldom-heard' groups due to discrimination, prejudice and disadvantage and how these all interact. We have used this latter expression to reflect imbalances in power structures that mean that the views of various minority population groups may not even be heard, let alone considered, in policymaking.

Examples of seldom-heard groups include people with lived experience of being in the LGBTQ+ community, coming from ethnic and cultural minorities, having a chronic disability, residing in or having left the care system, having lived experience of seeking sanctuary or refuge or otherwise displaced, or being homeless. Lived experience can also take different forms: there will be the direct experience, for instance of having experienced challenges, but it can also refer to having a close relationship with someone who has experienced challenges.

We also define professional researchers as individuals who are primarily thought of as individuals paid to undertake various forms of research. Some professional researchers will have their own lived experience of poor mental health and may be members of seldom-heard groups. In addition, there will be peer researchers, who might also have a formal paid researcher role, helping to co-design and co-produce research. Their lived experience is the primary reason for their initial involvement in research.

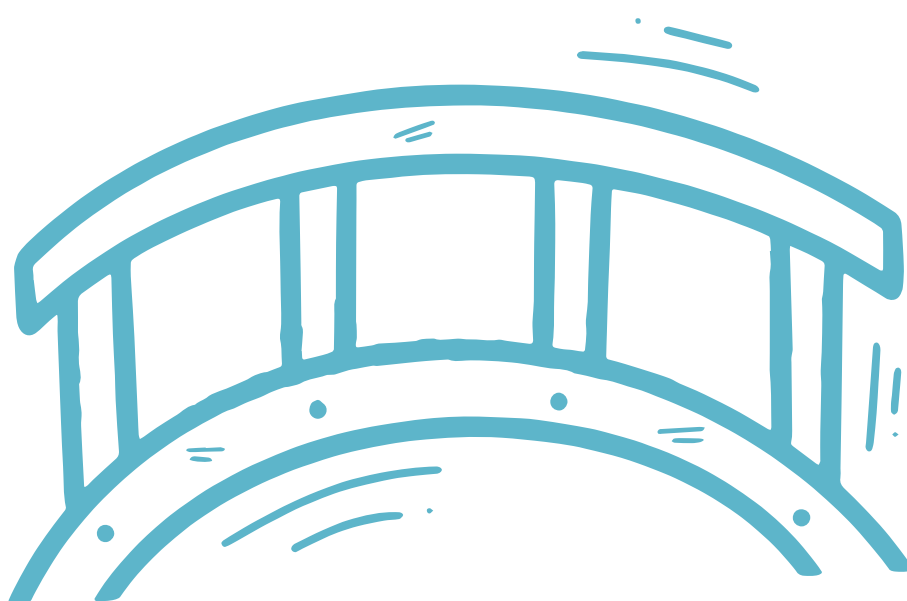
Aims

This brief document is written primarily for civil society (also sometimes known as third-sector, non-governmental, charitable, community or voluntary) organisations working with people with lived experience of higher risk of discrimination and prejudice, in addition to higher risk of poor mental health. It aims to help these groups engage more effectively in health economic research and policymaking, rather than being ignored. It provides a brief overview on the importance of the economic case for action for better mental health, in addition to determining, what works for whom and in what context. It has been informed by a workshop held with representatives of civil society organisations that support seldom-heard groups.

Unless seldom-heard groups have the opportunity to shape the design and impact of health economic research, health and social inequalities may widen further. For example, actions that do not appear cost-effective from a whole population perspective may in fact be highly cost effective if targeted at specific groups who may benefit more, such as children who are leaving foster care.

Civil society organisations can act as a bridge, bringing together seldom-heard groups, professional researchers and policymakers with the aim of co-designing and co-producing more meaningful research on the health and wider economic case for more investment in actions that support better mental health for these groups. The overarching principle should be that no research is undertaken without the direct involvement of the people being researched. This can be achieved by placing people from seldom-heard groups at the heart of the research and its findings.

Civil society organisations can themselves gain from being involved in health economics research. Not only can they potentially be partners in funding applications for research, but they can also use the evidence as support in funding applications for their services, especially if the findings show the value and impact of these services.



2. How can civil society organisations and people from the seldom-heard groups that they support use health economic evidence to inform policy and practice?

Box 1: Key messages

Civil society organisations can make use of information on five key economic questions to strengthen the case for action to promote and protect the mental health of seldom-heard population groups. This information can be co-produced with seldom-heard groups.

- 1** Identifying the costs/impacts of **not** taking action to protect mental health.
- 2** Identifying interventions/actions that seldom-heard groups feel best protect their mental health.
- 3** Estimating resources/costs for implementation of interventions to protect mental health.
- 4** Identifying outcomes and impacts considered most important to people in seldom-heard groups.
- 5** Estimating the value for money/ cost-effectiveness of interventions to protect mental health.

Economic arguments are NOT only about trying to save money. Box 1 highlights five key areas where economic evidence can help influence policy. This section briefly looks at each of these areas, and in section 3 we look at how this evidence can be co-generated by civil society organisations and seldom-heard groups.

2.1 Identifying the costs and other impacts of not taking action to protect mental health

Policymakers are not always aware of the consequences of not taking action to support mental health. Not taking action is not a cost-free decision. It may lead to poorer health and other adverse outcomes, as well as future higher use of health, social care and other services, due to a lack of early intervention. In part these impacts will depend on local circumstances, including existing levels of available local community services and supports. Therefore, identifying important economic costs incurred as a result of not taking action, is essential. These additional costs may be found in many different sectors such as for health, social care, education or housing services for people who have mental health conditions, compared to people who do not have mental health conditions.

This information can also be presented in advocacy arguments to governing and opposition political parties, other stakeholders and the media. Greater awareness of costs can raise the profile of the mental health of marginalised groups and influence policy and practice.

2.2. Co-identifying policy and practice interventions seldom-heard groups prefer to protect their mental health.

Civil society organisations can work in partnership with seldom-heard groups to discuss which types of intervention appeal to different audiences (e.g. by gender, culture or disability). If interventions are not appealing and do not lead to sustained engagement, they are unlikely to make a difference. Interventions that promote and protect mental health may have no direct connection with the health system, but address other risk factors including poverty, as well as lack of access to education, leisure, housing or employment.

Many of these issues will be common to all people at risk of poor mental health, but there may be specific issues faced by seldom-heard groups. Consultation is essential to identify specific issues, for example, the mental health of refugees is affected by the welcome received in their host community and the length of time needed to process their claims for asylum. Basic needs, such as having enough money for food, clothing and transport, as well as having access to independent accommodation and a sense of purpose, may prove very challenging. The need for cultural adaptation of services may also be important.



2.3. Co-assessing the costs of taking action to protect mental health

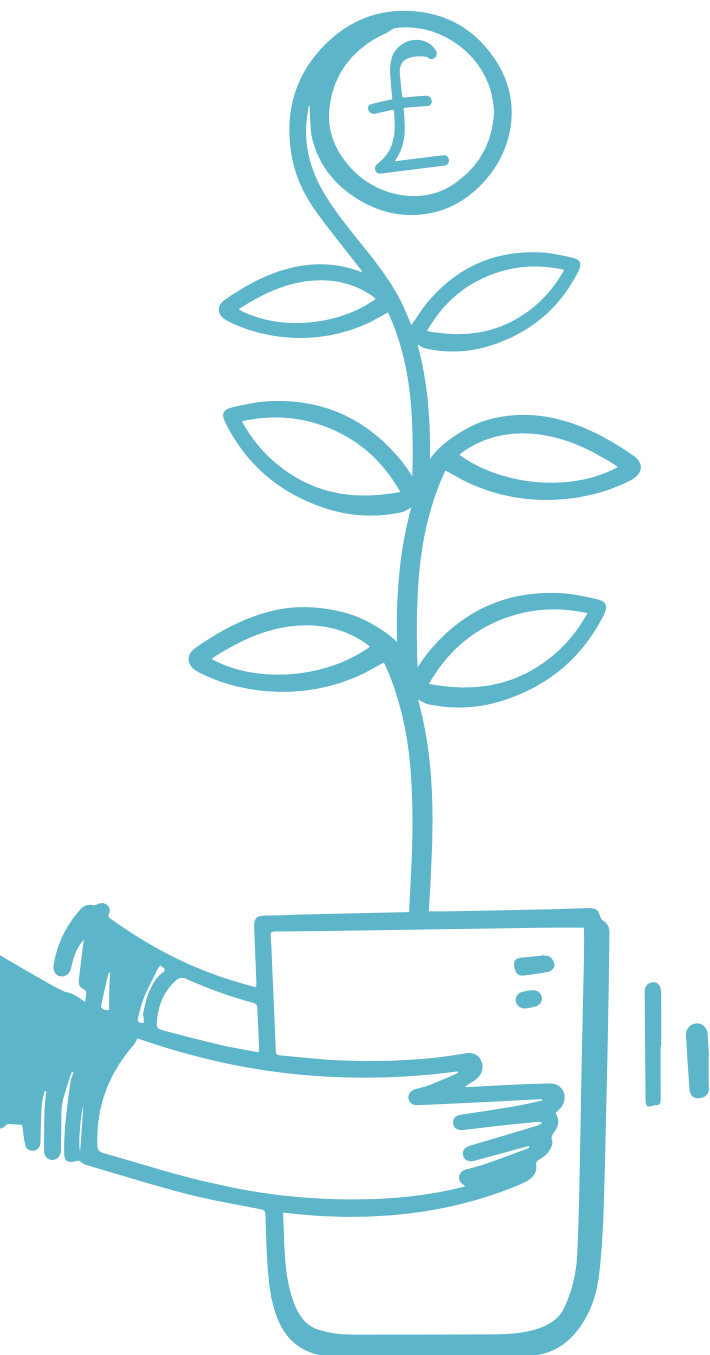
Policymakers need information on the resources required and the implementation costs of any proposed intervention. This is about much more than just estimating the full salary costs for any staff delivering an intervention. For instance, it is important to document administration costs, such as office maintenance, transport, advertising, as well as recruitment, training and other costs for volunteers. Volunteer time is also a cost and should be documented: there is no reason why a financial donation which supports salary costs should be captured, but a donation of time should be excluded.

Resources used, costs and budgetary impact will depend on the scale of the service, such as the number of people reached, and how long they are supported. Policymakers will also want to know whether interventions can be delivered using the existing workforce, or if they require additional capacity and infrastructure.

2.4 Co-identifying what outcomes and impacts are considered most important to people in seldom-heard groups

It is important that civil society organisations work with people in seldom-heard groups to identify outcomes/impacts that they feel are most important to them. Too often, outcomes used in assessing the effectiveness and cost-effectiveness of any mental health-related intervention are determined by mental health care professionals and/or professional researchers without involving people with lived experience in these decisions. For example, if people with lived experience considered that improved participation in work or higher rates of living independently in stable accommodation to be of great importance, but an evaluation only looks at clinical symptoms of poor mental health, then it will miss these impacts.

This could mean some interventions may have little impact on clinical symptom measures, but still make a profound difference to social functioning. It is also important that success is not judged only by the number of people reached; there may be significant changes in wellbeing for individuals, even if the number of individuals reached is modest.



2.5 Co-assessing the value for money of interventions to protect mental health

Probably the most useful piece of economic information for policymakers is the value for money of any intervention for mental health compared to other possible ways in which money could be spent. This is often referred to as a cost-effective analysis or a cost-benefit analysis, and economists may use several methods to conduct the analysis (see section 4). All the methods involve comparison of costs and outcomes of two or more policy options, which may include a comparison with usual practice or no intervention.

In publicly funded health systems information on cost effectiveness can be crucial in determining whether interventions are funded. In England, for example, the National Institute for Health and Care Excellence (NICE) always looks at the value for money of an intervention, as well as its effectiveness, when making recommendations on what should be funded by the NHS.

A common misconception is to think that this process is focused on finding the cheapest ways to deliver services and avoid spending money. However, it is actually about finding the best ways to make use of available resources; if something is cost effective this does not mean it has to save money (although it sometimes can), it is potentially about spending a lot more money in order to achieve better mental health and other outcomes.



3. What can civil society organisations do to help generate co-produced health economic research?

Box 2: Key messages

- 1 Seldom-heard groups should have the opportunity to co-design and co-produce health economic (and other) research.
- 2 Civil society organisations can create conditions to establish trust between professional researchers and seldom-heard groups, for example through the creation of trusted and respectful places.
- 3 Civil society organisations can put in place routine data collection systems to support the future evaluation of services for seldom-heard groups and create further opportunities for seldom-heard groups to express views on the services received.
- 4 Civil society organisations can help facilitate the co-design of questionnaires/interview guides to elicit information on impacts on mental health as well as their economic consequences.
- 5 Civil society organisations can facilitate opportunities to collect narrative experiences on the mental health of seldom-heard groups, as well as what matters most to them in potential research.
- 6 Civil society organisations can help magnify the impact of co-produced research by communicating the results to policymakers and the wider public.

An overarching principle is that seldom-heard groups should have the opportunity to co-design and co-produce health economic (and other) research. Civil society organisations can play a vital role facilitating this objective. A further principle is the importance of early engagement with seldom-heard groups regarding all aspects of research. The more that the groups who would benefit from research are genuinely involved as early as possible, the more likely they are to feel a sense of ownership of the research findings. This section sets out multiple ways in which this can be achieved, in order to provide input for the different types of evidence highlighted in section 2.

Facilitating lived experience involvement in research

Many major research funding programmes, such as the National Institute for Health Research in the UK, stipulate that people with lived experience should be actively involved in the design and conduct of research proposals. Civil society organisations can be a bridge between professional researchers and seldom-heard groups. They can help empower seldom-heard people to feel more confident not only in engaging with professional researchers, but also in being fully-paid members of research teams, helping to co-design and co-produce research.

One way of doing this is for civil society organisations to be partners in research bids, thus ensuring funding is allocated for people from seldom-heard groups to fully participate in research. Civil society organisations may also be well-placed to facilitate research training for these people in partnership with professional

researchers, including an understanding of the role of health economics and how it can be used to inform policy and practice. Such training courses may lead to future opportunities for lived experience researchers to undertake formal academic training to supplement lived experience research knowledge and be employed within research groups as professional researchers.

Some civil society organisations in the UK already focus on involving people with lived experience fully in research, such as the McPin Foundation (www.mcpin.org). However, there appears to be no civil society organisation that focuses on developing health economics capacity and involvement for people with lived experience of poor mental health, discrimination or disadvantage. This represents a missed opportunity to help facilitate positive change.

Creation of trusted and respectful spaces for lived experience involvement

Civil society organisations led by people from the groups they are supporting, are more likely to be well-placed to ensure issues such as culture, gender, colonialism and all forms of discrimination are fully considered in any research, in a way that may be more difficult for professional researchers who do not have this background. Civil society organisations can provide a trusted and respectful space where people from seldom-heard groups can share experiences about mental health and factors that have influenced their mental (and physical) health and wider life chances. The spaces themselves can be flexible – either virtual or physical depending on preferences. Civil society organisations can also help bring professional researchers and people with seldom-heard voices together in a trusted space where everyone's voice has equal weight to discuss issues.

Types of data for Health Economics Research



Activity data

- Frequency
- Rate
- Duration
- Dropout



User feedback

- Satisfaction
- Strengths
- Weaknesses



Outcomes data

- Quality of life
- Mental wellbeing

Routine data collection on service use to aid future evaluation

Civil society organisations that deliver services to support people from various lived experience groups are well placed to set up routine data collection systems that can help in cost effectiveness studies. These could include monitoring the frequency of services provided to the target population, including staff travel expenses and time spent with clients, rates of initial engagement, sustained participation and dropouts. People who make use of their services may also be invited to voluntarily complete surveys upon entry and exit; including questions on the services' strengths/weaknesses and user satisfaction. Changes in important outcome indicators, such as quality of life and mental wellbeing, could also be collected.

Civil society organisations should be able to provide a potential funder with information on the initial development and ongoing running costs of any service they provide, including expected average cost per person for intervention use. This could be done in two ways. The first, a 'top-down' approach looks at total relevant expenditure over a specified time period for an intervention, typically one year, and then divides total expenditure by the total number of people using that intervention, to estimate average cost.

This approach is relatively simple to use, but the disadvantage is that it may be difficult to identify which costs are associated with which interventions. It also is likely to miss other inputs such as volunteer time and any in-kind provision of resources that don't directly lead to expenditure. These are not 'free' resources, they have an economic value. For example, volunteer time could be valued using the wage rate that would be paid to someone for doing the same work, or the rent that would be charged for office space donated to a service.

The second, a bottom-up approach, is a more accurate but more time-consuming alternative that would overcome these limitations. This involves identifying each individual resource input for any intervention, and attaching an appropriate cost to each element. This unit cost is then multiplied by the number of individuals served over a fixed time period, for example a year, to estimate the total expected average cost of providing the service.

Co-designing questionnaires/ interview guides to elicit information on impacts on mental health, as well as their economic consequences

Civil society organisations can work with people in seldom-heard groups to co-design brief questionnaires/ interview guides to collect information on impacts on their mental health, as well as their use of health and other services. Questionnaires could also ask about broader aspects of life, for example time away volunteering or caring, contact with the justice system, employment and education opportunities, as well as geographical mobility. They could also ask about access to and engagement with services such as welfare benefits or secure housing. This could help amplify and signpost to services and supports that are working well. Co-designed questionnaires can also be used to estimate changes in impacts on their mental health, as well as changes in service use/cost following implementation of an intervention.

Questionnaires could also look at impacts on families, as family members may have to invest additional time in providing love and support for relatives with mental health needs. Their own mental health may also be adversely impacted. All of these broader impacts are very important as we know that most of the costs of living with poor mental health are felt outside of health care systems. The time periods covered by these questionnaires tend to be quite short, as it can be difficult to accurately remember service use for a period of more than three months.

Recording/communicating lived experience narratives

Civil society organisations can also work with seldom-heard groups to record narratives about their life experiences and impacts on mental health. This could be through individual or group conversations where people talk about what they feel to be the most important impacts on their lives. The structure of conversations could be co-designed and outputs used to produce advocacy documents highlighting consequences of a lack of support and/or benefits of additional intervention for mental health. Often the most influential advocacy strategy is to use lived experience narratives and economic analysis as complements: the former provides depth and qualitative insight, and the latter a sense of the scale of the problem and the opportunity for improvement.

Great care is needed on how conversations are conducted, including provision for mental health support where there is a risk of triggering memories of traumatic events. If consent is given, direct quotes from interviewees can be a very powerful way of highlighting the challenges experienced. Narratives could also be co-analysed with professional and peer researchers to identify some of the economic consequences of poor mental health.

Examples of factors that could be identified through conversations include unequal rights to participate in employment, as well as restrictions on access to public services and welfare benefits. People from specific ethnic, cultural, disability and sexual orientation groups may have specific challenges, such as racial and religious discrimination, homophobia or stigma around specific chronic health conditions, such as diabetes or obesity. People in some disadvantaged groups may also be more likely to experience greater levels of loneliness, social isolation and a lack of community integration.

Facilitating opportunities to identify what matters most to people from seldom-heard groups

Civil society organisations can help to facilitate opportunities for seldom-heard groups to express their views on what matters most to them on different aspects of research. This includes consideration of interventions to be evaluated as well as key outcomes to measure. Our technical report describes different ways in which this could be done, including workshops, focus groups, interviews and special types of surveys. Examples include consultative exercises where participants come up with a list of outcomes that they consider to be potentially important, and then go through a process to rank and prioritise outcomes for use in the evaluation of an intervention.

Ultimately, this approach should help lead to the inclusion of more outcomes/economic indicators that are feasible to measure and are important to people with seldom-heard voices, as well as researchers and when making a case to policymakers and service funders. It will probably mean multiple impacts and outcomes will need to be measured.

Communicating the results of co-produced research

Civil society organisations are well placed to communicate the results of co-produced research to policymakers and the wider public. They tend to have considerable experience, unlike some professional researchers, in directly engaging with policymakers using accessible language. Additionally, they have a critical role in raising awareness of the value of supporting seldom-heard groups to the general public, and of their positive contribution to society.

4. What economic evaluation methods are used to support policymaking?

Box 3: Key messages

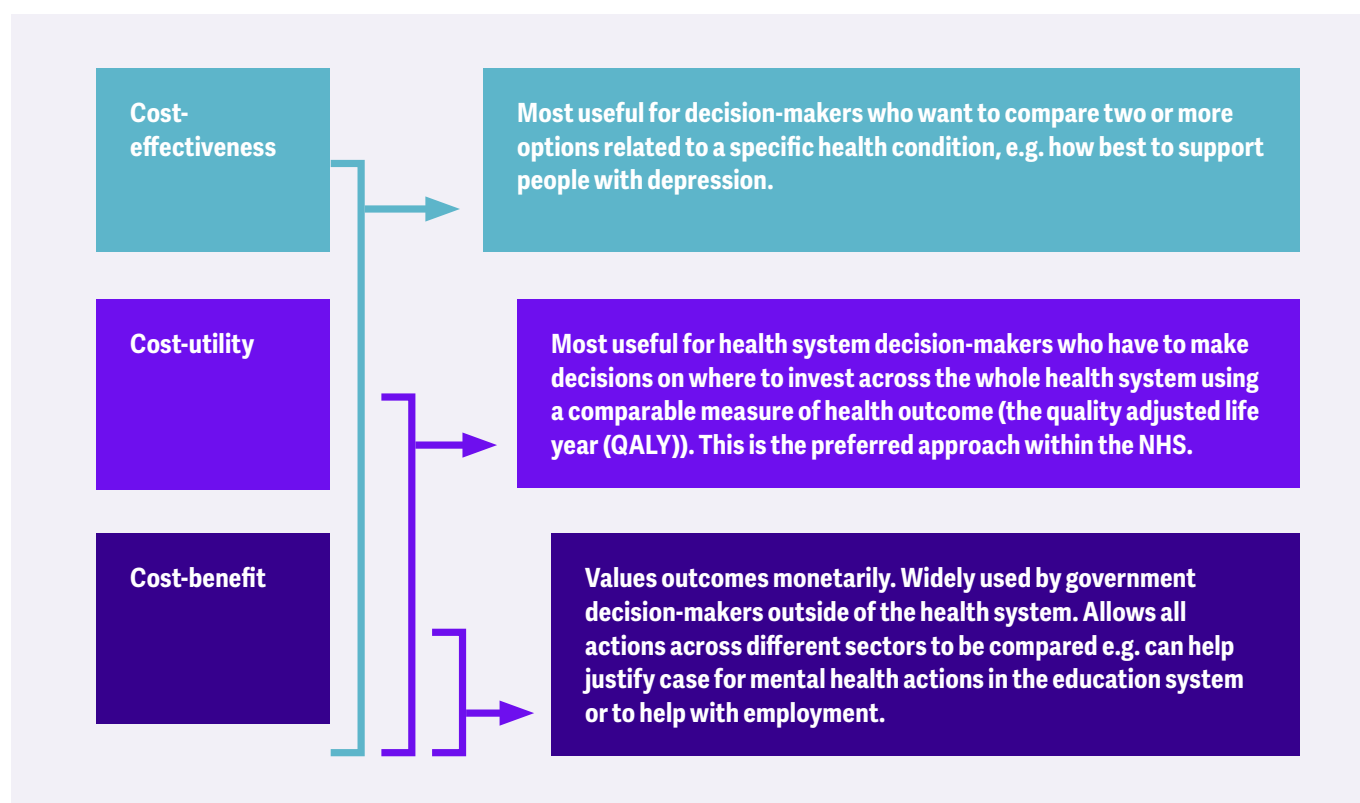
There are several different economic evaluation methods that can be used in supporting policymaking:

- 1** Cost-effectiveness analysis looks at condition-specific outcomes, such as changes in the severity of depression, compared to costs, of two or more approaches. This analysis is most useful for very narrow decision-making, in this example, on actions to prevent depression.
- 2** Cost-utility analysis typically measures quality of life; this means that all health-related interventions and their costs can be compared. It is the main method used in the UK to make decisions within the health system.
- 3** Cost-benefit analysis values all outcomes in monetary terms. It is typically most useful for reaching policymakers who need to make decisions about actions that affect multiple sectors, as both health and non-health related outcomes, for example improved participation in employment, can be compared. This is the main method used outside of the health care system in the UK.
- 4** Return on investment analysis compares the costs of different interventions with the costs incurred or avoided as a result of intervention. This method is increasingly used as an alternative to cost-benefit analysis for multi-sectoral interventions.

The terminology around economic evaluation can be confusing; common approaches in the UK are cost-effectiveness analysis (CEA), cost-utility analysis (CUA) and cost-benefit analysis (CBA). These approaches can be used to inform different types of decision-making (See Figure 1). The more that co-production work involving seldom-heard groups is part of this economic evaluation process, the more likely it will be that both costs and outcomes important to these groups are included in the evaluations. This could make an important difference in showing the value of actions focused on seldom-heard groups.

Within health systems, the most important of these is CUA. It is important because official bodies, such as the National Institute for Health and Care Excellence (NICE) in England and Wales, place a lot of emphasis on this type of analysis before making recommendations about whether a service should be funded by the health system.

CUA looks at the different impacts of interventions on the quality of life relative to its impact on health system (and sometimes non-health system) costs. The primary outcome measure is additional cost per quality adjusted life year (QALY) gained when using an intervention rather than an alternative such as usual care, or no intervention at all. This measure takes account not only of length of life but also of the quality of life. NICE uses QALYs because the quality of life for all health conditions, mental or physical, can be estimated in the same way, meaning that health policymakers can compare an investment in better mental health with a very different health-related intervention, such as cataract eye surgery or drugs to better manage heart health.

Figure 1: How are different types of economic evaluation used to inform decision making?

There are several standardised and validated questionnaires that must be used to estimate quality of life in economic evaluations. For CUA the choice of questionnaire to use might vary by condition and age of respondents, but the most frequently used measure in the UK is the EQ-5D² measure, which is recommended by NICE. The EQ-5D covers five domains of quality of life: mobility, self-care, impact on usual activities, level of pain/discomfort and anxiety/depression. For each of these five domains there are either three or five levels of quality of life. For example, in the three-level version of the instrument the levels for pain and discomfort are: *I have no pain or discomfort, I have moderate pain or discomfort, and I have extreme pain or discomfort.*

Recently a mental health specific quality of life instrument REQOL (Recovering Quality of Life)³ has been designed in the UK for use in economic evaluation. There are two versions: one with 10 and one with 20 questions on different aspects of quality of life. In the 10-item version questions include: *I felt able to trust others, I felt unable to cope, I thought my life was not worth living, and I felt confident in myself.*

The choice of quality-of-life measure to be used always needs to be discussed carefully and guided by both people with lived experience and professional researchers. In some circumstances there may also be a cost to pay to use questionnaires, although the EQ-5D can usually be used free of charge for charity and public purse funded studies.

How do these measures work?

Regardless of which quality of life instrument used, in all, perfect quality health has a value of one while death has a value of zero.⁴ Therefore, if someone spends five years living a reduced quality of life of 80% rather than being in perfect health because of the adverse impacts of chronic depression this would be equivalent to just to four years in perfect quality health.

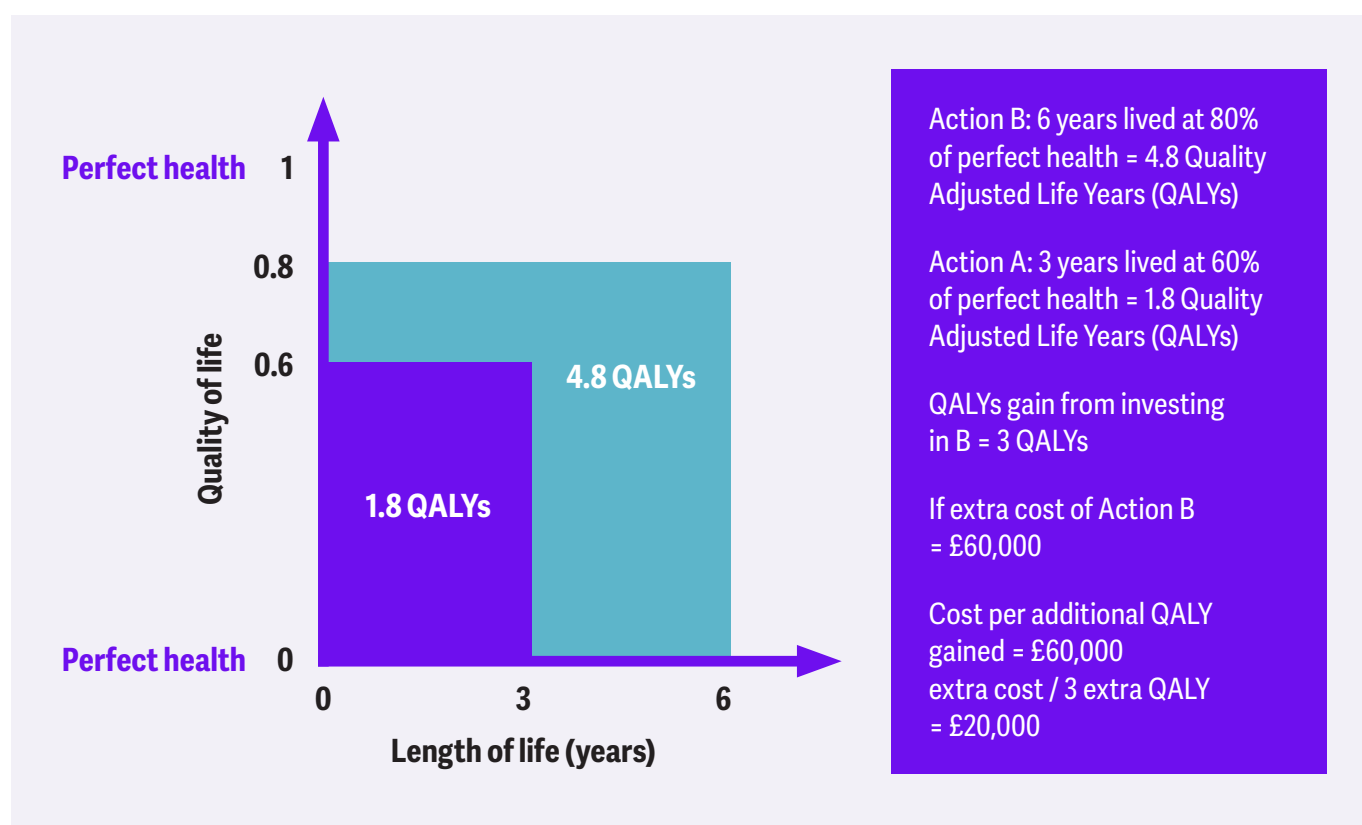
Using this approach how is value for money assessed?

If an intervention has better QALY outcomes and it is also less costly, then it is definitively good value for money. While an intervention that has both poorer outcomes and higher costs is not value for money.

Many interventions will cost more than what is currently available, but will also have better outcomes. In this case society must make a value judgement on how much it is willing to spend for better quality of life. The cost per QALY gained 'threshold' will vary across countries. In England, NICE recommends that interventions should normally be funded within the NHS if they cost no more than £20,000 to £30,000 per additional quality adjusted life year gained.

Figure 2 below, shows that investing in Action B (improved depression prevention programme) leads to a gain of 3 QALYs for an individual compared with Action A (usual practice), because quality of life and length of life is improved. If the extra costs of Action B are £60,000 then the cost per QALY gained is £20,000. If intervention costs were to rise above £90,000 then the cost per QALY gained would be above £30,000. For this to be funded other factors will need to be taken into account, and these typically include the importance of protecting life, or extending life for terminally ill people. They could also potentially include a willingness in society to spend more to reduce health inequalities for specific population groups, such as minority population groups, or those already experiencing high levels of deprivation.

Figure 2: Calculating and valuing gains in quality of life



CEA is similar to CUA but is more limited for policymaking as it considers the differences in costs and a condition-specific outcome, between two or more interventions. This means that the value for money can only be easily compared if interventions can be assessed using the same outcome. Civil society organisations might still want to work with researchers to undertake this type of economic evaluation if, for example, it is difficult to measure quality of life and potential intervention funders are very interested in how mental health can be improved. The lack of a common outcome means that while different interventions for a similar mental health condition such as depression might be compared easily, it is more difficult to compare an intervention to prevent depression with other non-mental health uses of health care resources, such as an intervention to prevent falls. This may weaken the argument for investment within the NHS.

While CUA may be more useful to health system policymakers than CEA, many mental health interventions may need to be funded outside of health systems. They are also likely to have substantial impacts in many other sectors of society, such as on participation in employment and education, as well as in contact with welfare, criminal justice and housing services.

Outside of health care systems the most common method of economic evaluation used in the UK is CBA, which values all costs and outcomes (benefits) in the same (monetary) units. CBAs are attractive, as they can help decision-makers to allocate resources not only within the health sector, but across different sectors, for example comparing investments in health with those in housing, social care, education or transport. There are different ways of estimating the monetary value of benefits, with the use of surveys asking people how much they would be willing to pay to avoid a bad outcome, such as poor mental health, being a common approach. Governments may also publish data from surveys on the monetary value of some outcomes, for example in the UK and many other countries, estimates of the monetary value of avoiding unexpected death or serious injury from road traffic accidents or violence are routinely published.

CBA is increasingly used when considering the case for investing in interventions that help promote health and prevent disease, because of the multi-sectoral impacts

of preventive measures. CBA is also intuitively easy to understand; if the monetary value of benefits of any intervention are greater than the costs it is considered value for money. With two or more alternatives, the intervention with the greatest net benefit would be considered the best value for money. It is also possible to put a monetary value on QALYs gained and therefore also generate a cost-benefit ratio, which may be helpful if trying to make a case to potential funders both within and external to the health care sector.

Return on investment analysis

An increasingly common alternative method for assessing value for money is return on investment (ROI) analysis. ROI looks at the difference between the costs of intervention and costs that can be avoided as a result of intervention, for instance changes in the use of health and other services or participation in employment. As with CBAs, this approach means impacts across multiple sectors can be included, and if benefits are greater than costs then the intervention would be considered value for money. This approach has been used to inform the case for investing in mental health promoting interventions in England.⁵

A specific type of ROI is the social return on investment (SROI) analysis. Unlike ROI, which tends to be restricted to measuring the costs of changes in service use, SROI also places a monetary value on a wide range of benefits that are less easy to measure. An SROI analysis starts with a discussion with the relevant stakeholders, such as people with lived experience, to identify why and how they believe an action will work; before proceeding to estimate the size of the effects and placing a monetary value on them. For instance, in the evaluation of a community café to reduce isolation and loneliness in Glasgow one of the outcomes that participants felt was important was the development of new friendships.⁶ In the SROI, researchers placed a monetary value on each additional friendship and provided a justification for this value. SROI is a very different way of assessing costs and benefits to that typically used to make a case for health and social care service funders in the UK, which is focused mainly on resource impacts and costs to the NHS, local government, and sometimes other public sector organisations.

5. How does the evaluation perspective influence value for money?

Regardless of the type of economic evaluation used it is important to recognise that what economists call the 'perspective' of the analysis will influence whether an intervention is considered to be good value for money. It is always important to be transparent about the perspective adopted.

A narrow perspective usually focuses only on costs to a specific part of the economy, such as the health system; a wider perspective considers, for example, all costs to the public sector. A societal perspective tries to estimate all impacts to the economy.

When looking at mental health interventions, it makes sense to not only look at impacts to the health system, but also to look at impacts more broadly as good mental health benefits us all. This may mean that when conducting an economic evaluation it is done from multiple perspectives.

While results from a narrow health system perspective can be used to inform health system decision-making, incorporating a wider perspective may help in making the case for investment to other sectors. A good example of where this can be very helpful is the evaluation of any intervention intended to help people enter into and/or stay in employment. Participation in good quality employment can be associated with better mental and physical health, while also reducing the need to claim unemployment or sickness-related welfare payments.



6. Potential professional research partners and how to work with them

Box 4: Key messages

- 1 Build trustful and transparent relationships
- 2 Have clear information on the value and purpose of research
- 3 Create opportunities for seldom-heard groups to be authors of research
- 4 As a default, peer researchers should be fully paid, and seldom-heard research participants fully compensated

A good place for civil society organisations to start looking for partners is the websites of local universities to see if they conduct health economic research. This could then provide the opportunity to potentially partner with universities to co-create research with people from seldom-heard groups. Other potential partners include research consultancy companies and government organisations that conduct health economic research.

Civil society organisations may also act as brokers, by setting up schemes to help organisations representing seldom-heard groups to engage in research with professional research groups that are looking to work collaboratively with seldom-heard groups. Establishing a database of civil society organisations that are willing to participate in research would help facilitate this collaboration.

There are mutual benefits of collaboration. Professional research organisations will benefit from collaborating with organisations already delivering services, as many research funding schemes, especially those related to public health, only cover costs of evaluation and not service delivery. **Civil society organisations can benefit from linking with professional researchers willing to provide their expertise to help determine the economic benefits of the services they provide.**



The factors that help facilitate successful collaboration include:

Building trustful and transparent relationships

Civil society organisations and professional research groups need to build trustful relationships with each other, the kind that recognise the central importance of research co-production with people from seldom-heard groups. Co-production should be transparent about the values or ways of working, recognising and developing shared values between groups. This would help to overcome any distrust from past negative experiences around co-production with professional research groups.

Providing clear information on the purpose and potential impact of research

Professional researchers need to provide a clear explanation, in accessible language, of the purpose of research and how it will be conducted. This should include co-production, what will happen to the research findings, how these will be communicated to everyone who takes part in the research, and the potential difference it can make. Subsequently, sharing information on the actual impact of the co-produced research can also help both with future implementation and to further build trust.

Recognition as authors

Civil society organisation should ensure that professional research partners have opportunities to be authors of academic publications arising from co-produced research, subject to meeting the standard criteria required for authorship by journals. There should also be opportunities for people with lived experience to be lead authors on research outputs and recognition that they may need training and mentorship support. Additionally, research outputs should acknowledge the contribution of all other research participants, includes naming individuals, when permission is given.



Compensation for research participants from seldom-heard groups

Peer researchers, just like professional researchers, should be fully paid and have employment contracts. Funding for the participation of lived experience researchers should become the norm. This is in addition to ensuring that there is full funding in any grant for the involvement of civil society organisation staff in research. All research participants from seldom-heard groups should have any additional expenses covered and be compensated for their time providing input to research. If monetary payments are not possible due to legal restrictions, other forms of permitted compensation, such as vouchers, should be provided.

Compensation for civil society organisations

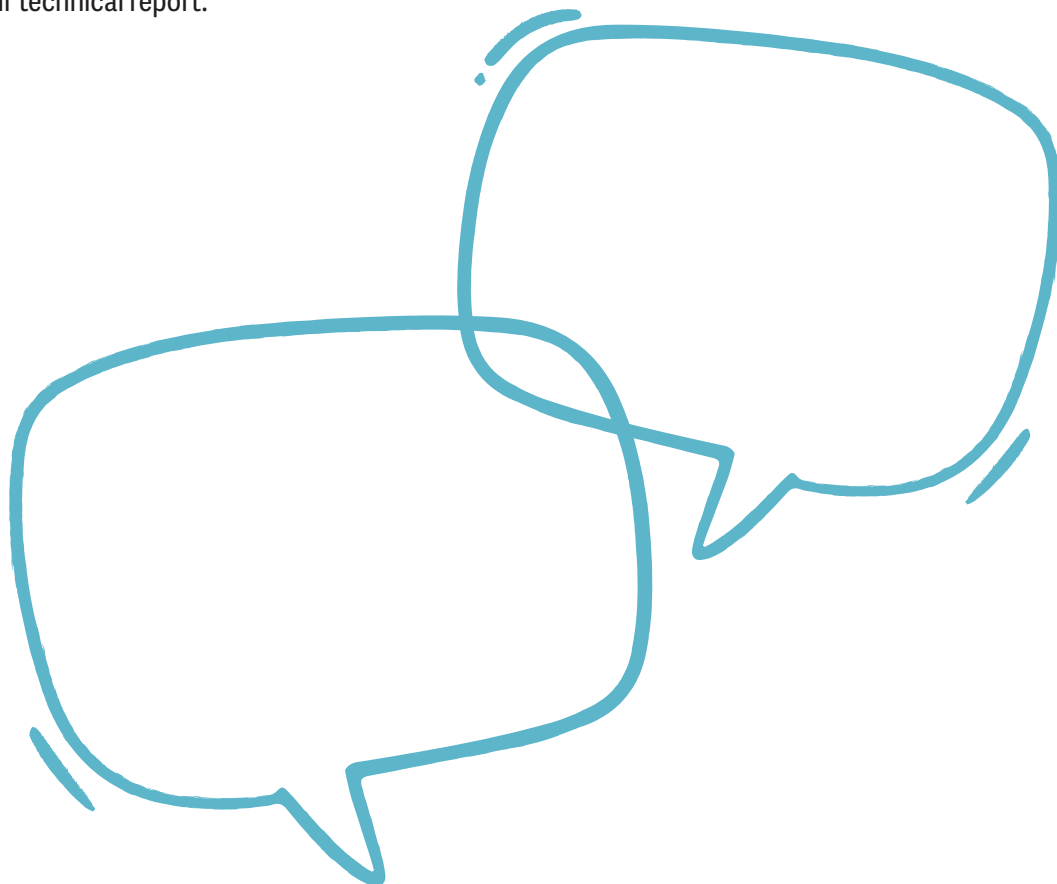
It is important that civil society organisations are fully compensated for their participation and/or facilitation of co-produced research. They can incur substantial costs, just to help make things happen, even before research is fully underway. In addition to covering their own researcher time, this should include financial (and potentially technical support) for data collection, as well as engagement with, and/or training, of seldom-heard groups.

7. Recognise that professional research partners and research funders also need to take action

In conclusion, although this guidance document is focused on civil society organisations, collaboration will only work well if professional researchers recognise their responsibility in involving those with lived experience and work with civil society organisations to build a shared understanding of what an equitable approach to research should look like.

Professional research organisations could also offer more research capacity building workshops targeted at civil society organisations, providing information and some basic training on the purpose and use of health economic research, as capacity in health economic research understanding within many civil society organisations will be limited. This aspect is discussed in more detail in our technical report.

Funders of research also have a critical role. Already, many funders make grant-funding conditional on the involvement of people with relevant lived experience. They could go further and make grant funding conditional on professional research groups offering people with lived experience the opportunity to be members of the research team and to be fairly funded for their participation. Similar support might also be provided to civil society organisation representatives.



Notes

1. McDaid D, Park AL, Davidson G, John A, Knifton L, McDaid S, Morton A, Thorpe L, Wilson N (2022) *The economic case for investing in the prevention of mental health conditions in the UK*, available at: www.mentalhealth.org.uk.
2. See <https://euroqol.org/>.
3. See <https://innovation.ox.ac.uk/outcome-measures/recovering-quality-life-reqol-questionnaire/>.
4. Some health states can also be considered worse than death and have a value below zero.
5. See <https://www.gov.uk/government/publications/mental-health-services-cost-effective-commissioning>.
6. See <http://www.socialvaluelab.org.uk/our-work/case-studies/gauging-the-social-return-from-the-craft-cafe-programme/>.



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