

Increasing seldom-heard groups' visibility and involvement in research to make the economic case for better mental health

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Brief summary

This report examines how to strengthen the economic evidence base for investing in actions that protect and promote the mental health of 'seldom-heard' population groups. They can be at very high risk of experiencing mental health conditions yet typically have very little opportunity to contribute to policy making processes affecting their mental health because of power imbalances in society.

One step in redressing these imbalances is to promote their involvement in health economic (and wider) research. Involvement is about a lot more than being participants in research studies. It is about giving people from these groups the agency to be full partners in all aspects of the research process, from the initial prioritisation of research ideas, through all stages of design, implementation, analysis and communication of results.

In this report, we set out some of the impacts on the mental health of seldom-heard groups and highlight the important role of economic research in policy making. We look at challenges to the involvement of seldom-heard groups in economic research and offer potential solutions. At the heart of these solutions is the overarching principle that no research should be undertaken without the direct involvement of the people being researched. Moreover, there should be equitable partnerships between seldom heard groups and researchers in all aspects of the research process.

We describe approaches to co-production of research and emphasise the critical facilitating role that can be played by civil society organisations that work with seldom-heard groups. They are well placed to act as a bridge between researchers and the seldom-heard groups that they are trying to reach. 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.

Throughout, we provide examples on how health economics research with seldom-heard groups has been conducted, and the extent of any co-production. The evidence base remains all too limited; there are still far too few examples of health economics co-production with seldom-heard groups. Drawing on the available evidence, as well as focus groups conducted for this report, we provide case studies for two seldom-heard groups: refugees and other sanctuary seekers, and young people.

We have chosen these groups as they are examples of high-risk groups for mental distress, as well as having been more negatively affected by the pandemic than the general population. They are also priority groups for the Mental Health Foundation's current strategy. Case studies look at the economic case for various brief therapies for refugees, while for young people we focus on the links between housing and mental health.

The report ends by recognising that more inclusive, equitable involvement of seldom-heard groups has many implications for civil society organisations, researcher and research funders. This includes the need to adequately compensate civil society organisations for their role in research studies. Researchers and civil society organisations also need to take steps to integrate researchers from seldom-heard groups and ensure that they have employment contracts, with appropriate levels of pay. They also should ensure all these researchers have access to mentoring and opportunities for training to increase their research skills.

1. Background and aims

This report examines how to strengthen the economic evidence base for investing in actions that protect and promote the mental health of 'seldom-heard' population groups. At the outset it is important to recognise that the language used to refer to population groups that do not receive sufficient support relative to their needs is contested and many different expressions could be used. Here we focus on individuals having lived experience or higher risk of mental health problems, as well as also being in 'seldom-heard' groups due to discrimination, prejudice and disadvantage. We have used the term 'seldom-heard' 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.

There are many seldom-heard groups. We acknowledge that we cannot provide an exhaustive list. They will include people with lived experience of being in the LGBTQ+ community, as well as those 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 being otherwise displaced, or being homeless.

We also acknowledge that lived experience, both of poor mental health and exclusion from society, can also take different forms: there will be the direct experience of having experienced these challenges, but it can also refer to having a close personal or working relationship with someone who has experienced challenges (Killackey 2023). That said, these different types of lived experience can themselves entail different states of power or powerlessness, e.g. carers of people with severe mental disorders may have more power under the law than those with the disorder.

People from seldom-heard groups may be reluctant to engage in research, having suspicions or distrust of researchers, reflecting their wider interaction with society. Other barriers to engagement can include language, different cultural or religious norms, as well as a lack of money and/or access to transport. Professional researchers may also have their own lived experience of poor mental, but may be reluctant to disclose this, fearing that this may adversely affect their standing in academia.

This report pays particular attention to the question of how to strengthen health economics research. It places an emphasis on looking at ways in which we can build trust and strengthen the involvement of people with lived experience in seldom-heard groups at all stages in the process of co-creation and co-production of economics research knowledge. This includes working with seldom-heard groups to identify and make use of outcome/impact measures that are of specific relevance to them. It also looks at practical ways to help civil society organisations facilitate the involvement of the groups they support in economic research. These organisations may find it difficult to engage in research because of capacity and funding constraints.

Throughout the report, we focus, in particular, on the mental health of seldom-heard young people and refugees/displaced people as exemplar population groups. We have chosen these groups as they are examples of high-risk groups for mental distress, as well as being more negatively affected by the COVID-19 pandemic than the general population. They are also priority groups for the Mental Health Foundation's current strategy.

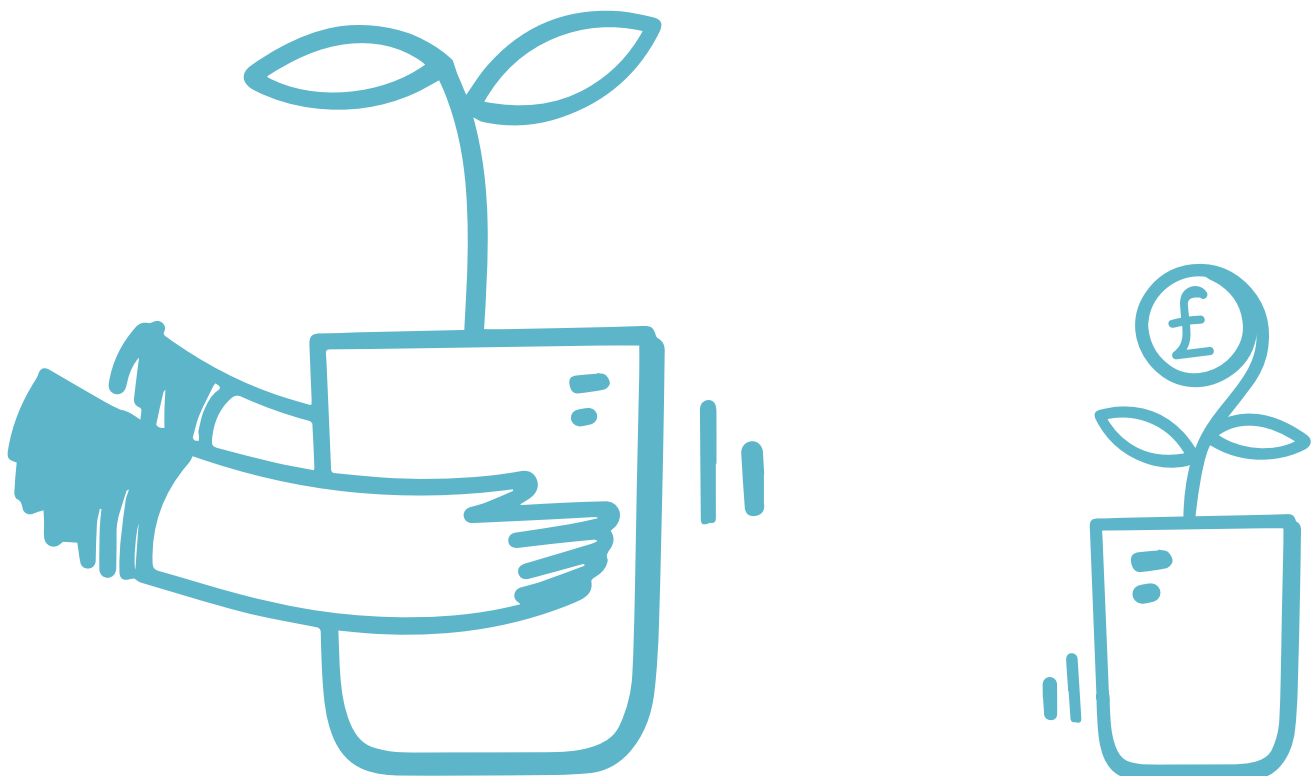
1.1 Approach

We are conscious that this report is itself only partially co-produced. It was written by a professional research team working in an academic setting, with advice from professional researchers at three other academic institutions and the Mental Health Foundation.

While the lead authors of the report have worked for many years with people with lived experience of poor mental health, and the lead author also has disclosed lived experience of being the primary carer for someone with mental health difficulties, as professional researchers we are in a privileged position.

We recognise that our own experiences could never be a substitute for the perspectives of different people from seldom-heard groups.

That said, we have tried to provide opportunities for seldom-heard groups to shape the way this report has been drafted. Two focus groups were held, one with a group of young people (Young Leaders) and one with organisations working with seldom-heard groups and these informed both the scope and content of the research and the related guidance. We also drew on existing literature, some of it written by people with lived experience, looking at approaches to co-design and co-production of research. However, much of the technical material on methods of economic analysis is based on the authors' own health economics (rather than lived experience) expertise, while examples of the ways in which economic analyses have involved seldom-heard groups in research were mainly identified through rapid literature reviews of the PubMed and PsycInfo academic literature databases. An appendix also provides summary information on all the economic analyses that have been included in this report.



2. Why do we need to specifically address the economic case for preventing poor mental health in seldom-heard groups?

Poor mental health can have profound personal, societal and economic impacts. In a previous report for the Mental Health Foundation we conservatively estimated that in the UK alone these costs to society are at least £118 billion per annum (McDaid, Park et al. 2022). In that report we also identified a growing literature on the economic case for investing in measures to prevent mental health conditions.

However, much of the economic evidence on the case for prevention has focused on mainstream population groups at risk of mental health conditions, with much less specific focus on often seldom-heard groups, such as the LGBTQ+ community, looked after children and care-leavers, refugees and asylum seekers, ethnic and cultural minorities or homeless people.

This is a significant gap in our knowledge, as numerous studies point to the increased risk of mental and physical health adversities for seldom-heard groups. For example, various immigrant groups to Great Britain, such as people from the Caribbean, South Asia and Ireland, as well as their descendants, have experienced higher levels of poor mental and/or physical health than the general population (Das-Munshi, Clark et al. 2014, Das-Munshi, Chang et al. 2019, Halvorsrud, Nazroo et al. 2019). Experience of discrimination by seldom-heard groups can be associated with lower rates of access to mental and other health services, and more dissatisfaction with services when used, as seen for Irish Travellers in the All-Ireland Traveller Health Study (Quirke, Heinen et al. 2022).

A 2022 scoping review also looked specifically at the experiences of children and young people from ethnic minorities in accessing mental health care and support

in the UK (Coelho, Price et al. 2022). It identified 22 qualitative studies for a range of minority child groups, which indicated a range of reasons for lack of use of services. Reasons included distrust of services, a lack of awareness of mental health issues and/or different cultural perspectives on mental health. It also highlighted poor access to information on available services.

The lack of specific analysis for seldom-heard populations in studies on preventive interventions means that it can be misleading to assume that the existing evidence on the effectiveness and cost-effectiveness of preventive interventions will apply to all population sub-groups. For interventions to be effective and cost-effective they have to be accessible and acceptable to their target populations. More research is needed to look at whether interventions that are cost-effective for the mental health of general or non-seldom-heard population groups produce the same benefits for some seldom-heard groups within the population. Moreover, we need to know if there are differences, what are the reasons? Is it because of poorer rates of uptake, lack of cultural adaptation, socio-economic circumstances, etc.?

A review in the wider public health and health promotion arena found that effective public health interventions, including those to promote mental health, can end up widening health inequalities if some community groups do not engage with them (O'Mara-Eves, Brunton et al. 2013). That review also found some weak evidence indicating the cost-effectiveness of specific measures (such as health literacy efforts and additional financial support) to improve engagement with these minority population groups.

Research also needs to look further at the case for targeted interventions. It may be the case that actions that are not considered cost-effective from a whole-population perspective may be cost-effective if targeted at some seldom-heard populations at higher risk of poor mental health.

We know that some mental health conditions are particularly disabling, such as psychosis or long lasting, such as persistent conduct disorder or treatment-resistant depression. For example, poor mental health that emerges in disadvantaged young people, including the onset of psychosis, can have personal and socio-economic consequences that can last for decades (McGorry, Mei et al. 2024). These can include reduced lifetime opportunities for education, employment and family life. Economic studies that look at the longer term impacts of intervention in these groups might provide a further compelling reason for policy makers to take action.

One example of how the involvement of seldom-heard groups in research can have economic benefits can be seen in work involving homeless people. A systematic review looked at the involvement of homeless adults in the co-design of mental health evaluation studies (Schiffler, Kapan et al. 2023).

Four studies were identified: two in Canada and two in the USA. Interventions included peer-delivered navigation services and use of the Housing First model that places people in accommodation first and then responds to their mental health and other needs. None of these were preventive interventions, as all study participants already had mental health needs; nonetheless, the involvement of homeless people in co-designing interventions seemed potentially economically beneficial.

The review authors noted that co-designed interventions “positively impacted people experiencing homelessness’ mental health and housing situation or reduced hospital and emergency department admissions and increased primary care utilisation.”

This is just one isolated example of the potential benefits that can be gained. However, unless more research is focused on both the effectiveness of, and the economic case, for intervention in seldom-heard population groups, relative to the wider population, gaps will remain in what we know. We need to know about what works, at what cost, for which populations, and in what circumstances. Indeed, without better understanding there is a risk that the health and social inequalities already faced by these groups will be widened further.

3. What are the challenges in building an economic evidence base for seldom-heard groups?

Many barriers and challenges have to be overcome in order to strengthen the economic case for better mental health for many seldom-heard populations. We would stress that most of these challenges are relevant to the generation of evidence in general and are not just related to economic evidence.

3.1 Reluctance of seldom-heard groups to engage in research

One key barrier is the challenge of engaging with seldom-heard groups in order to undertake research related to them. Some seldom-heard groups may have a much greater level of distrust of any 'outsider' groups, including professional researchers, because of historical injustices they have experienced at the hands of governments, authorities, 'officialdom', researchers and society. In some cases, they may have been denied fundamental human rights and/or subjected to different forms of discrimination and prejudice.

For some groups, for instance the Afro-Caribbean, African and South Asian communities in the UK, there may be legacies arising from slavery, racism and colonialism, as well as current injustices, that continue to have an impact on their experiences of poor mental health and contacts with mental health services (Tew, Gould et al. 2006, Coelho, Price et al. 2022). There may also be distrust of research on interventions and services, if they are perceived not to take account of these oppressive experiences, as well as what can be more coercive pathways for mental health issues.

Seldom-heard groups may also be worried about how any information or input they provide to research may be used (or misused), while researchers in the past may have taken a 'paternalistic approach' as to whether

people from 'seldom-heard' backgrounds were even capable of participating in research (Bonevski, Randell et al. 2014, Condon, Bedford et al. 2019).

Seldom-heard groups within society may also feel that they do not have a voice; in the case of young people, especially below age 16 from seldom-heard groups, the situation can also be complicated by the requirement to obtain parental/guardian consent for any participation in research (Mitchell, Slowther et al. 2019). Parents/guardians may not want their children to give their views, which can also make participation in research difficult, even if young people wish to participate. Young people may also be worried that any information that they provide, for instance about their sexual or religious identities, will not be treated in confidence and will get back to their parents.

Another example of a population whose voice is seldom-heard in research is that of people experiencing homelessness. Higher risks of poor mental health and poorer rates of service use are seen in people who are homeless, including those living in temporary accommodation (McNeill, O'Donovan et al. 2022). Involving people experiencing homelessness in research is challenging in part because they may have no fixed abode, or be evicted from temporary accommodation; moreover they are less likely to be digitally connected at a time when more and more research is conducted online (Padwa, Henwood et al. 2023).

There are exceptions. In the US a national homeless research project involves a group of academic researchers none of whom had experienced homelessness, working with a group of fully-paid lived experience researchers. The partnership is intended to be equal. The partnership has led to changes in recruitment strategies and in qualitative research methods. In a co-written article the lived experience researchers state:

“For some of us, this research is one of the first opportunities we have had to contribute to something positive by making our voices heard. We also recognise that through this collaboration, we speak not only for ourselves, but for all of the people who are still suffering on the streets. We are empowered by the fact that when we contribute to this group and to research, and we are speaking for all of those who are suffering, but who have not yet found their voices or had a chance to be heard” Padwa, Henwood et al. 2023.

3.2 Reaching new groups of seldom-heard people

What we consider to be seldom-heard population groups do not remain static, they continually evolve. For example, there will always be people seeking refuge in the UK, but the countries that they come from change over time. There are new patterns of recent migration into the UK, including from conflict-affected countries such as Afghanistan, Iraq, Syria and Ukraine. An additional practical challenge may therefore also be reaching people within some of these newer seldom-heard population groups. While the Ukrainian community is well established in the UK and is perhaps relatively easy to reach through established community organisations, this is much less the case for people from Afghanistan, Iraq and Syria.

One recent example of the challenges in reaching seldom-heard groups concerns assessment of the effectiveness and cost-effectiveness of brief psychological therapies for refugees and asylum seekers in the north-west of England (Dowrick, Rosala-Hallas et al. 2022). This randomised control pilot trial could not be completed, in part due to the difficulties caused by COVID, but also because of the practical challenges in reaching refugees, who had been dispersed throughout the community, coming from multiple countries (mainly in the Middle East and Africa), speaking multiple languages and with different cultural and religious perceptions of mental health.

3.3 Changing the ‘research done to us’ rather than ‘research done with us’ or ‘research led by us’ mentality

Even if populations can be engaged with, it is important to involve seldom-heard populations in the research process. These seldom-heard population groups may, however, be reluctant to engage in research if they feel it is ‘research done to us’ rather than ‘research done with us’ or ‘research led by us’. It is also important that user involvement in research is not tokenistic (Romsland, Milosavljevic et al. 2019).

A survey in the UK in 2022 conducted by the disabled people’s and service-user network Shaping Our Lives (SOL) noted that some survey participants felt that their involvement was “sometimes unwelcome and prevented by organisations”, which left some people “feeling used and believing that the involvement process was tokenistic” (Gillian Batty, Gemma Humphrey et al. 2022).

Academic researchers can also themselves be a barrier to genuine user involvement in research. It has been noted that some academic researchers may hold the view that “the participation of users as co-researchers is regarded as degrading the researchers’ competence and lacking respect for what creates quality in research” (Askheim 2022). These attitudes need to change.

Research funders should require researchers to involve representatives from seldom-heard groups as equal-partners in such studies, and researchers need to be supported to engage these service users respectfully and productively.

3.4 Measuring the right outcomes

Another issue is that the outcomes captured in economic and other evaluations typically reflect outcomes that researchers and/or policymakers consider as important to measure. These may not be the outcomes that are considered of primary importance to seldom-heard population groups. It might be the case, for example, that studies focus narrowly on clinical measures related to symptoms of poor mental health without also looking at measures associated with social functioning and recovery, such as living in decent housing or having stable employment, that may be of greater importance to the populations that are being evaluated. If so, the full economic benefits associated with any preventive intervention may not be captured accurately; this may apply even when measuring generic outcomes such as quality of life.

For instance, living with a high level of quality of life is not necessarily the same as having a high level of subjective wellbeing; there also are wider aspects of life to consider, such as how included seldom-heard populations feel within society, or whether they feel they have opportunities to fulfil their aspirations. These may not be captured by the selected measures. Determining which outcomes are of most importance can only be achieved by fully involving the target population group into the economic evaluation process.

3.5 Sceptical attitudes towards economics

Researchers should also carefully think about how best to engage with different groups to describe the merits of economic analysis. Looking specifically at economic evaluations, there may be scepticism within seldom-heard (and other) populations about the value of this type of research. For this report we looked for studies that examined the general public's and seldom-heard groups attitudes towards economic evaluation. We found almost no studies (through a rapid search of PubMed and Google Scholar) that focused on this issue, although guidelines on the reporting of broad patient and public involvement in economic studies have recently been published (Staniszewska, Jakab et al. 2023).

We were, however, able to identify a survey of more than 1,700 individuals from the UK looking at public understanding of economics in general (rather than health economics). It reported that 65% of respondents have little or no trust in information provided by economists on national or international issues. Scepticism of economics was high, but the public would like to learn more (ING 2017).

Another example of scepticism with health economics can be seen in the BBC Panorama documentary on the 'Price of Life' which looked at the way in which the National Institute for Health and Care Excellence (NICE) made decisions on NHS funding for new medicines in England. It revealed that among the public (Wishart 2009) too often, economic evaluation can be perceived as an exercise that is purely about working out how to save money. This also suggests that communication about the purpose and nature of evaluation may need to be improved in order to increase participation.

3.6 Low priority given to research on the needs of some seldom-heard groups

Among research funders there may also be scepticism about the value of interventions targeted at seldom-heard (and therefore often small) population groups. Lack of political power among seldom-heard populations may also mean that their needs are not likely to be considered a priority. The very limited evidence on the cost-effectiveness of interventions to support the mental health of refugees and other displaced people, compared with information on the cost-effectiveness of interventions to screen for communicable disease among these groups is illustrative of this point.

Policymakers are more willing to invest in communicable disease screening measures because they perceive that this can reduce risks to their own populations' health; they are less likely to identify benefits of better refugee mental health for their existing populations (McDaid and Park 2023). Better communication of the short, medium and long-term economic benefits of intervention for target populations and wider society, as well as the consequences of not taking action, is needed.

3.7 Small size of some seldom-heard population groups and civil-society organisations

Another challenge related to the size of seldom-heard population groups will be that any preventive interventions themselves may be very localised, small-scale in nature and delivered by civil-society organisations or community groups.

The small scale of these groups and limited funding means that they are unlikely to have the financial, human and time resource to engage in research.

Moreover, many activities may be dependent on time-limited precarious grant funding, which can limit the scope for long-term evaluation. Some of these smaller seldom-heard groups may also be quite mobile, such as young people and refugees, so they may not be available for the duration of a research project. This is in addition to other factors that may deter them from taking the time to be involved in research, such as ongoing trauma and simply trying to survive on a day-to-day basis.



4. How can challenges be overcome in working together with seldom-heard groups?

Having set out some of the challenges to be faced when looking specifically at economic evaluation and other research with seldom-heard population groups we now set out some ways in which challenges can be overcome. Some of these issues are concerned with evaluation in general and some specifically with economic analysis. 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, in particular, can play a vital role in 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.

4.1 Building trust with seldom-heard communities

A first critical step is to think about how to build trust with seldom-heard population groups. Building trust with seldom-heard communities may take time, but it is essential for improved direct involvement of seldom-heard communities in economic and other evaluative research. There are many different ways in which this can be done. Working with community peers to reach out to the community can be one way of helping to build trust (Condon, Bedford et al. 2019), as can initiatives to raise awareness of how evaluation can help improve people's lives.

Civil society organisations that work with seldom-heard groups are well placed to act as a bridge between researchers and the seldom-heard groups that they are trying to reach. 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, notably 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.

4.1.1 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.

4.2 Involving seldom-heard communities more fully in design and evaluation of research

One way of building trust is to formally ensure that the population in question, in this case seldom-heard communities, is involved in the conduct of research. In general there has been some shift away from 'research on people to research with them' (Nind 2017). This is the case in countries such as the UK, Norway, Sweden and Canada, that have reasonably good social welfare systems and liberal political traditions. It also reflects some change in the power dynamic among relevant key stakeholders, with service users moving from being passive subjects in research to active study participants alongside others, developing more horizontal relationships between researchers and co-investigators. This, in theory, means performing research together, with mutual respect.

The Research Governance Framework regulating research in the UK, including within the health system, also states that "relevant service users and caregivers or their representative groups should be involved wherever possible in designing, conducting, analysing, and reporting of research." (Department of Health 2005) Thus, the concept of Patient and Public Involvement (PPI) in the UK became an essential requirement in applied health research almost 20 years ago (Ives, Damery et al. 2013). Another example is that of Norwegian Research Council-funded research, which also mandates service user and public involvement (Romsland, Milosavljevic et al. 2019).

In both the UK and Norway, the extent of involvement by the target population in a research proposal is a key criterion on which proposals are ranked. The involvement of the target population in producing research has made a real difference to outcomes and mental health policy, as can be seen in some research in the UK (Gillard, Borschmann et al. 2010).

This approach needs to be reinforced when looking at seldom-heard groups within the population living with or vulnerable to poor mental health. Focus groups we have undertaken for this project indicate that they are much less likely to have the time or resource to participate in research, so issues of additional resourcing to facilitate participation need to be considered. It will also be important to have wide-ranging capacity building measures, for example to help seldom-heard groups understand the research process, as well as to develop skills to conduct research within these populations. This will allow more co-creation of research.

4.2.1 Co-production, co-creation, co-design

There are many different ways to describe user involvement: co-production, co-creation, co-design and other terms can all be used. For instance, Sherry Arnstein set out her ladder of co-production, with eight rungs of a ladder, from coercion/manipulation through to what she referred to as citizen control (Arnstein 1969). This ladder, however, was never designed to look specifically at participation in research, but rather on shaping public services.

The NIHR INVOLVE group, (now NIHR Centre for Engagement and Dissemination) made a distinction between co-produced research and co-produced public services. They stated that "co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge" (Farr, Davies et al. 2020).

These are just two of a huge number of different definitions. These terms are all contested and there is no perfect definition. With this in mind a very useful overview of co-production through the lens of facilitating participatory research indicates three broad conceptualisations of co-production (Smith, Williams et al. 2022) (See Box 4.1).

Box 4.1 A typology of co-production (reproduced from (Smith, Williams et al. 2022))

<p>Citizens' Contributions to Public Services</p>	<p>A process in which voluntary contributions from members of the public significantly influence the effectiveness, efficiency, and sometimes even existence, of public services and their delivery.</p>
<p>Integrated Knowledge Translation</p>	<p>A collaborative process in which academic researchers work with "knowledge users" e.g. clinicians, policy-makers, health system leaders, industry partners, throughout the research process, with the aim of increasing the utility and impact of research. This sometimes involves people or communities with relevant lived experience/ experiential knowledge, but this is not inevitable nor considered essential.</p>
<p>Equitable and Experientially-Informed Research</p>	<p>A collaborative research process in which the lived experience and experiential knowledge of particular communities, citizens and/or service users is considered essential. Equitable partnerships with community and citizen partners are formed by explicitly addressing inequalities in power so that they can actively contribute to, influence, and even direct, the research process. Such research endeavours can also be initiated and led by communities, citizens, and/or service users."</p>

From this typology a key point is that just because someone says that they have made use of co-production, this does not necessarily equate to meaningful genuine research collaboration between the end users of research and professional researchers. The first approach in the typology is not satisfactory; the voices and actions of service users may influence the final shape of research and interpretation, but this is only in a very passive way. It still means that 'traditional' (i.e. academic) researchers are likely to drive any research process, with people in the seldom-heard target group being only reactive to the proposed research.

The second approach could mean that lived-experience researchers from within seldom-heard population group(s) play a more proactive role in the entire research project, but this is still far from certain. The third, collaborative, approach, is the only one that sees co-creation/co-production as being essential. This is the approach that should be adopted for conducting research with seldom-heard populations, as it should mean that by jointly developing ideas and conducting research, the controlling power will be more equally spread (Bigby, Frawley et al. 2014). This is also in line with the NIHR Involve approach. They emphasised a number of key principles for meaningful and genuine co-production (See Box 4.2) (NIHR 2021). For this to be effective, resources also have to be invested in research training programmes for lived-experience researchers.

Box 4.2 Key principles when co-producing a research project (NIHR 2021)

- **sharing of power** – the research is jointly owned and people work together to achieve a joint understanding
- **including all perspectives and skills** – make sure the research team includes all those who can make a contribution
- **respecting and valuing the knowledge of all those working together on the research** – everyone is of equal importance
- **reciprocity** – everybody benefits from working together
- **building and maintaining relationships** – an emphasis on relationships is key to sharing power

4.3 Making more use of qualitative research approaches to inform economic analyses

We have emphasised the importance of involving people with lived experience of marginalisation fully within the research process and indicated different levels of involvement. One key area where people with lived experience need to provide critical input is in shaping the types of services and interventions they prefer to receive, as well as determining what they consider to be the key aspects of the preventive action or service delivery, and their preferred outcomes of these interventions.

Many different qualitative approaches can be used to provide such information. These can be co-produced with people with lived experience, and commonly used approaches are **focus groups** and **interviews**. These techniques can be used to elicit rich descriptions of intervention pathways, for instance obtaining multiple descriptions of paths to initial – and, where necessary, sustained – engagement with preventive interventions. These multiple descriptions of service pathways can then subsequently be used to inform pathways that are used in economic modelling analyses (see section 7.2 for more on modelling).

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.

4.3.1 Example: Using the Theory of Change approach

Stakeholders, such as seldom-heard populations, could also be brought together with other stakeholder groups to look at the way in which interventions could be shaped and implemented through what is known as a **Theory of Change** approach. This is an increasingly widely used approach to help co-produce research (Breuer, Lee et al. 2016). This process could also consider the costs and potential benefits that are anticipated to be associated with different interventions.

The Theory of Change methodology can be defined as a process that can identify different theories on why, how and when interventions/policies/programmes work, identifying all assumptions and any evidence supporting these interventions. The idea then is to design a method of evaluation to determine whether not these program theories hold (Weiss 1995).

For example, the Theory of Change approach has been used in Wales to look at how universal whole school approaches can be used to promote the mental health and wellbeing of children (Brown, Van Godwin et al. 2021, Brown, Van Godwin et al. 2023). This Theory of Change approach included interviews with some school pupils, as well as two group consultations with members of an existing young people's research advisory group (ALPHA) in South Wales. This group of young people aged 14-21 was recruited through youth centres and projects.

Theory of Change can be used to inform the design of economic evaluations involving seldom-heard populations. This may have been the case for an

economic evaluation of interventions to protect the mental and physical health of young caregivers looking after their parents with substance abuse or mental health problems in England (Crossroads Caring for Carers and Princess Royal Trust for Carers 2008). A theory of change workshop was held to bring together diverse views from multiple stakeholders at the local and national levels on actions to support young carers. In this study it is not clear, however, if the young carers were directly involved in the workshop as stakeholders.

Mechanisms on how different interventions were expected to work, what inputs were required, as well as what outcomes were expected and in what ways they might be achieved were documented. This included identification of outcomes related to mental health, such as reduced risk of self-harm, and lower need for mental health support, as well as broader outcomes such as reduced risk of a young carer being taken into local authority care and improving school outcomes. This work subsequently informed a return on investment modelling analysis, along with a review of literature, that estimated that for every £1 invested there would be a £6.72 return to society from a package of young carer support.

4.4 Making use of conjoint analysis and discrete choice experiments

There are also specific approaches that can be used in health economic research to elicit preferences from any population group that are consistent with a more fully inclusive research process. They can be used to facilitate genuine co-creation and co-development in both research and service design.

Here we highlight two specific and somewhat similar types of research methodology that have been used by health economists and other social science researchers. These two methods, '**conjoint analysis**' (CA) and '**discrete choice experiments**' (DCE) ask people, often those who might benefit from, or currently make use of a service, or fall into a client group, to compare the strengths and weakness of different scenarios, such as the way in which preventive services and supports are provided. The methods could also be used to help choose between alternative mechanisms for prevention,

each of which might have different strengths and weakness, as well as differing levels of effect and cost.

Both methodologies can therefore help determine the relative importance of different aspects of a service from the perspective of the target population and specifically take on board their views. For example, young people who are at increased risk of mental health problems, such as 'looked-after' young people about to leave the care system, could identify those aspects of any transitional support service that they feel are most important to them.

While both methods are well established, they appear not to have been used widely in mental health related research in general, let alone for research on prevention. One recent scoping review looking at the use of these two methods over a twenty-year period to 2019, only identified 30 studies that have used either of these methods, including just two papers describing the use of the conjoint analysis approach in the UK (Larsen, Tele et al. 2021). Moreover, only two of the 30 studies looked at the prevention of mental health conditions. This seems like a missed opportunity as these methods can present an excellent opportunity to directly involve seldom-heard population groups in mental health related or public health research in a meaningful way.

We provide four examples of how CA and DCE have been used. For either of these approaches a starting point can be to organise online or face to face focus groups involving seldom-heard people to identify aspects of a service, strategy or indeed a mental health condition that they feel are most important to them. For instance, perhaps it could be flexibility in how the services work, or the confidentiality of the support given.

Not all of the examples we have provided involved seldom-heard groups helping to determine what the potential priority attributes may be; however this can be done. One way to bring these viewpoints together initially to help design the CA or DCE would be to use an approach called the nominal group technique approach as this can help to come to a consensus on agreed priorities, in this case the most important attributes of a specific intervention or strategy to improve mental health. The nominal group approach has been used for mental health specific research, including with young people with lived experience of mental health conditions (Kabacińska, McLeod et al. 2022, Li, Honey et al. 2022)

4.4.1 Examples of use of conjoint analysis

We can see how these approaches could work by reference to previous research. Firstly, we can look at the two previous UK papers identified in the recent systematic review. Both concerned the same study where a conjoint analysis was used to identify preferences and the relative importance of different aspects of day treatment and care in England for existing adult service users (Townend 2000, Townend and Shackley 2002).

A focus group with eight people with lived experience was first held to identify the key elements (known as attributes) of services, and to then inform different levels of these attributes related to all of these services, for instance such as levels of satisfaction or for example the amount of time needed to receive the service. The focus group were also asked to rank the importance of these attributes. The five attributes and associated levels identified in the study are shown in Table 4.1. These were used to generate 48 scenarios with unique combinations of levels of attributes.

48 of 60 invited service users then completed a conjoint analysis survey, ranking eight different randomly selected scenarios. It was then possible to use appropriate statistical methods to identify the relative importance of the different attributes around a service.

The studies concluded that the most important aspects of the service were not actually the treatments offered but rather the degree of supportiveness in relationships with service staff, the level of involvement that service users had in service planning and the nature of information received about diagnosis and treatment.

A more recent example comes from Japan, where conjoint analysis has been used to identify preferred suicide prevention strategies among university students (Sueki 2018). This study asked students to indicate preferences between six different suicide prevention strategies. They were provided with information on the effectiveness of each strategy. One of the attributes for each intervention was potential cost to the taxpayer, for which there were six levels ranging from 100 Yen (£0.62) to 4000 Yen (£24.75). This meant that it was possible to also calculate the willingness to pay to invest in different combinations of suicide prevention measure.

249 students, including 87 (34.9%) who had previously experienced suicidal ideation, were presented with 12 virtual suicide prevention policy profiles from 384 possible scenarios. The highest level of willingness to pay (and therefore most preferred elements for a policy) was associated with restrictions on access to means, followed by enhancement of psychiatric services.

Table 4.1 Attributes considered important by users of adult mental health services

Attribute	Level
Support	Lots Little
Type of service provided	Talking therapies Vocational rehabilitation
Staff availability	15 minutes 30 minutes 45 minutes
Planning care	No opportunity for involvement Have the opportunity for involvement
Information	Little Lots

The authors concluded that these strategies were most important from a taxpayer perspective, with awareness raising measures and follow up support for people following a suicidal event seen as the lowest priority as they had the lowest levels of willingness to pay. The study also indicated that students took into account more than evidence on suicide strategies, noting that there is multiple study evidence on the effectiveness of follow-up support, yet this was not seen as a priority. These preferences may also reflect cultural differences in attitudes to suicide. They suggested that students may have chosen strategies that had more spillover benefits beyond suicide prevention, such as preventing accidents through introduction of safety doors at railway stations, as well improved mental health through better access to psychiatric services.

4.4.2 Examples of use of discrete choice experiments

A discrete choice experiment was conducted in Canada to understand how the design of early intervention services for people with mental health conditions aged 16+ could help identify what factors were of appeal to different groups of potential service users (Becker, Christensen et al. 2016). The study also looked at the preferences of family members and mental health professionals, as the views of both these groups might also influence the level of engagement with services. Using DCE meant that different groups of individuals who preferred different aspects of services could be identified.

This was done using a statistical procedure called 'latent class analysis' which determines qualitatively different subgroups on the basis of shared characteristics, in this case preferences around early intervention services. Participants had to complete an online survey lasting around 15 minutes; they had 18 choices to make on the service that people with mental health conditions would be most likely to contact. The research team determined what these attributes would be; this team included a 'peer support representative'. Each choice was between 3 possible combinations of 16 four-level attributes on services, such as the referral process, waiting time, service atmosphere, cultural background of service providers and evidence on service effective.

After analysing responses from 562 people, including 249 mental health service users, two distinct groups were identified: those that preferred 'conventional' type services and the other who preferred services that were more 'convenient', such as being delivered at home rather than in a health care facility. Differences in service preferences suggested that a range of service models were needed in order to maximise service engagement.

Another DCE example from the UK, looked at the cost-effectiveness of Group Family Nurse Partnerships (GFNP) alongside a multi-centre randomised controlled (Barnes, Stuart et al. 2017). This nurse visiting programme was targeted at groups of vulnerable pregnant women aged under 20 who had given birth previously, or had low educational attainment, were aged 20-24 and expectant for the first time. The intervention consisted of 14 GFNP sessions during pregnancy and 30 sessions during the first year after giving birth. The economic analysis had indicated that the cost per quality adjusted life year (QALY) gained, would not be considered cost-effective in reducing the risk of child abuse or child neglect.

A DCE of more than 600 respondents, 200 pregnant women, as well as 400 members of the general public (both women and men), revealed that the primary outcome measure, QALYs gained was seen as less important than other impacts of the intervention, including more parental empathy, not feeling stressed in the role as parent, having a high level of understanding of their child's needs and better access to social support from family and friends. The attributes were chosen from various instruments already used in the economic analysis, including two questions from the EQ-5D-5L quality of life instrument, relating to depression/anxiety and impact on usual activities.

The authors suggested that this meant that the economic case for supporting this seldom-heard population should not be judged on cost per QALY alone (which we noted was not favourable); and that it would be important to identify other outcomes that may be important to the target population.

4.5 Improving recording and making more use of available routine datasets

Where it is not possible to reach seldom-heard populations, for instance because they are reluctant to be identified or participate in research, or simply because the number of people reached in any one location may be very small, it may be possible in some circumstances to learn more about mental health outcomes and use of services from existing datasets. By learning more about outcomes and service utilisation, it may be possible to identify areas of unmet need and also estimate the costs of not taking action to prevent the onset of mental health conditions.

Many datasets may not provide sufficiently accurate information on the socio-economic characteristics of seldom-heard populations; this may sometimes be because of self-stigma, reticence to disclose, or poor understanding or prejudice on the part of the data collector. Steps might be taken to consider what might be done to collect more information on individual socio-economic and ethnicity characteristics within datasets.

Looking at how datasets can be used, one study in Wales examined the feasibility of using routine electronic health records, as well as place-based data, to identify the use of health care services for mental health conditions, as well as self-harm, in children and young people from the Traveller and Gypsy communities (Rees, Fry et al. 2023). The need to combine routine health record data with place-based data was due to Gypsy and Traveller ethnicity not normally being recorded in datasets, even though they are legal ethnic groups.

It was however possible to make use of Welsh government data on the postcodes where Gypsies and Travellers caravan sites were situated to come up with higher and lower estimates of young people (aged 11 – 25) from these communities between 2010 and 2019 drawn from the Welsh Adolescent Mental Health Platform.

The authors indicated that it was feasible to combine geographical and health data to generate useful information on contacts with health services for mental health needs, which otherwise would have remained unknown. However, the approach would still have missed potentially large numbers of the Gypsy and Traveller community not living within authorised caravan sites, such as in normal 'brick and mortar' houses or in unauthorised sites. Individuals not registered with a GP would also have been missing from the analysis. They concluded that it remains essential to improve ethnicity coding (for all ethnic groups) on routine health records to further strengthen understanding of needs, health status and service utilisation.

Another example of how existing data can be used can be illustrated by reference to a study looking at differences in suicide rates across ethnic minority groups in England and Wales (Hunt, Richards et al. 2021). The lack of information on ethnicity on death certificates available at the time of the study meant that there was very limited data from large-scale studies on ethnicity and suicide rates. To overcome this limitation, the study was able to obtain data from the Office of National Statistics on more than 14,000 individuals who had been in contact with mental health services in the previous 12 months prior to death by suicide. Ethnicity information was then obtained through a questionnaire sent to mental health clinicians who had been delivering care to these individuals.

Doing this the authors were able to report, in contrast to many small-scale studies, that overall suicide rates were lower in ethnic minority patients compared to White patients. The study also revealed that factors that may have led to suicide varied among population groups, with minority populations more likely to be affected by social adversity. They recommended that more holistic approaches to mental health support, including the use of social prescribing, might be important strategies for some ethnic minority populations. Moreover, as there were differences in suicide rates between minority population groups, the authors noted that "approaches to prevention should not treat minority ethnic patients as homogenous groups" (Hunt, Richards et al. 2021).

5. How can co-produced economic arguments be used to support investment in the mental health of seldom-heard groups?

In this section we set out some ways in which economics can be used to advocate for action to promote the mental health of seldom-heard groups. These economic arguments are NOT only about trying to save money. Box 5.1 highlights five key areas where economic evidence can help influence policy.

Box 5.1: Key messages

There are five key economic questions to answer to strengthen the case for action to promote and protect the mental health of seldom-heard population groups. All of 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.

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

Policy makers are not always aware of the consequences of not taking action to support mental health. Inaction 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 because of a lack of preventive or 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 that will be incurred in different sectors for people who have mental health conditions compared to people who do not have mental health conditions is essential. This can include the impacts on poor mental health for health, social care, education or housing services. 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 seldom-heard groups and influence policy and practice.

5.2. Co-identifying policy and practice interventions seldom-heard groups would like to engage with 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. 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 (Juárez, Honkaniemi et al. 2019). 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 information, assessment tools and services may also be important.

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

Policy makers also need information on resources required and implementation costs of any proposed intervention. This is about much more than just estimating the full salary costs for any staff delivering an intervention. Moreover, the very process of identifying categories of information to collect, as well as the subsequent collection process, requires co-production. For instance, it is important to document resources and costs associated with administration, such as office maintenance, transport, advertising, as well as

recruitment, training and other support for volunteers. Volunteer time is also a resource and should be documented; if this is not done then the value of volunteer time will not be reflected in economic analyses and potentially substantially underestimate the costs of delivering interventions. Resources used, costs and budgetary impact will also 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 require additional capacity and infrastructure. This is very important when making arguments to scale up access to services.

5.4 Co-identifying what outcomes 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 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.

If people with lived experience were to consider 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 some of the value that these interventions deliver. 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 simply by the number of people reached; there may be significant changes in wellbeing for individuals, even if the number of individuals reached is modest.

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

Probably the most useful piece of economic information for policy makers is the value for money of any intervention for mental health compared to other possible ways in which money could be spent. This is technically known as an economic evaluation, and often referred to in everyday language as a cost-effective analysis or a cost-benefit analysis. Economists may use several methods for economic evaluation (see section 6 for a brief overview of these methods); all 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.

One common misconception is to think that this economic evaluation process is all about finding the cheapest ways to deliver services and avoid spending money. 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 sometime can, especially when mental health problems are prevented); it is potentially about spending a lot more money in order to achieve better mental health and potential other health and broader outcomes, such as better inclusion in education in employment or education.

5.5.1 Sources of effectiveness evidence in economic evaluations

There are different ways in which health economic studies identify evidence on effectiveness to be used in economic evaluation; these can be broadly divided into two types: data obtained from a specific evaluation of different options, and modelling studies where data on effectiveness may be obtained from multiple sources, typically previously published effectiveness studies.

5.5.2 Approaches to collecting effectiveness data in individual studies

Where economic evaluations are conducted using data from a single evaluation of effectiveness, arguably the most robust approach is obtaining data from a randomised controlled trial. In this case, study participants are randomly allocated to receive one of at least two different intervention options. This process of randomisation should reduce the chances that the results of an evaluation are biased in some way, e.g. people are allocated to one of the study groups purposively because of certain characteristics, e.g. related to age, health status or being a member of a seldom-heard group.

This process is even more robust if both the study investigators and study participants are 'blind' to group allocation, i.e. they do not know about group allocation. This is only revealed when all the evaluation analyses have been conducted. This reduces the possibility that analysis of results is influenced by knowing which arm of the study refers to the intervention group; in the case of study participants their behaviour can also be influenced if they know what group they are in. This latter impact is known as the 'Hawthorne Effect' – readers who may wish to learn about this might by looking at a recently published review of the impact of this phenomenon (Berkhout, Berbra et al. 2022).

Comparator groups in a randomised controlled trial can often be offered usual care or support, or no intervention. It is important that whatever comparator is chosen is clearly described and a justification for its use provided, as this can make a difference to how effective a strategy appears to be. Randomised trials can be complex and often expensive; many evaluations use other approaches, e.g. 'before and after' observational studies where the effects of outcomes of interest after an intervention has been introduced are compared to outcomes before the intervention was available.

A weakness of the 'before and after' type of design is that the lack of a comparison group means that it is not possible to be certain if any changes in outcomes are due to receipt of the intervention or some other factor. For example, if we used this design to look at the impacts of providing brief talking therapies to a seldom heard group, while it is useful to know if their mental

health has improved since receiving therapy, we do not know if this is because of the therapy or some other factor, such as a change in the level of financial support provided to everyone. We would only be able to eliminate this possibility if there was a comparison group of people who did not benefit from any change in financial support. In order to mitigate this limitation, evaluators using 'before and after' design may try and match their study participants with a non-randomly selected comparison group.

There are sophisticated approaches that go beyond this report that can be used to do this in a way which makes the results more robust. The interested reader might, for example, want to look at literature on approaches such as 'difference in differences' analysis or 'interrupted time series analysis'. These approaches have been used alongside economic evaluation to evaluate the impact of new alternatives to inpatient care, such as short stay crisis units without beds, for people experiencing a mental health crisis (Gillard, Anderson et al. 2023, Smith, Anderson et al. 2024).

5.5.3 Taking effectiveness data from multiple sources for use in modelling studies

In section 7.2 we look at how economic evaluation modelling studies can be co-produced with seldom-heard groups. Here we briefly highlight that there are different ways in which effectiveness data from multiple studies can be used in models. The most robust approach involves a systematic search process across multiple databases to identify evidence on pre-defined outcomes of interest. This process is commonly referred to as a systematic review. This systematic approach is again intended to help reduce the chances that the evidence used in a modelling study is not representative of the wider literature. If more than one source of evidence on effectiveness is identified (which is usually

the case), then ideally special statistical methods can be used to combine these data and come up with an overall level of effectiveness.

The most common approach used is called meta-analysis. It allows effectiveness evidence from multiple trials, often from different countries and with very different numbers of study participants to be combined. For example, the evidence on effectiveness could be taken from some studies with thousands of participants, while another may have less than 50 participants. Statistical adjustments are made so that more weight is given to the larger studies when combining estimates of effect.

One of the limitations of conventional meta-analysis is that it is often difficult to come up with a single estimate of effect when studies may have very different comparator options for the same intervention. An even more complex approach called network-meta-analysis is increasingly used to address this issue.

Usually it is possible in health economic modelling studies to draw on an estimate of effect from one of these published meta-analyses or network meta-analyses without having to do all of this work, which can be very time consuming. For instance, an organisation called the Cochrane Review publishes a huge number of free-to-access studies on the evaluation of health-related interventions. A sister organisation called the Campbell Collaboration publishes reviews on interventions outside of the health sector, for education, criminal justice and social care/social welfare. Many prevention strategies lie outside of the health sector, so meta-analysis of these studies can also be highly relevant. For the interested reader more information on both methods and published evidence is available from both these organisations ([cochrane.org](https://www.cochrane.org) and [campbellcollaboration.org](https://www.campbellcollaboration.org)).

6. What economic evaluation methods can be used to support policy-making?

Box 6: Key messages

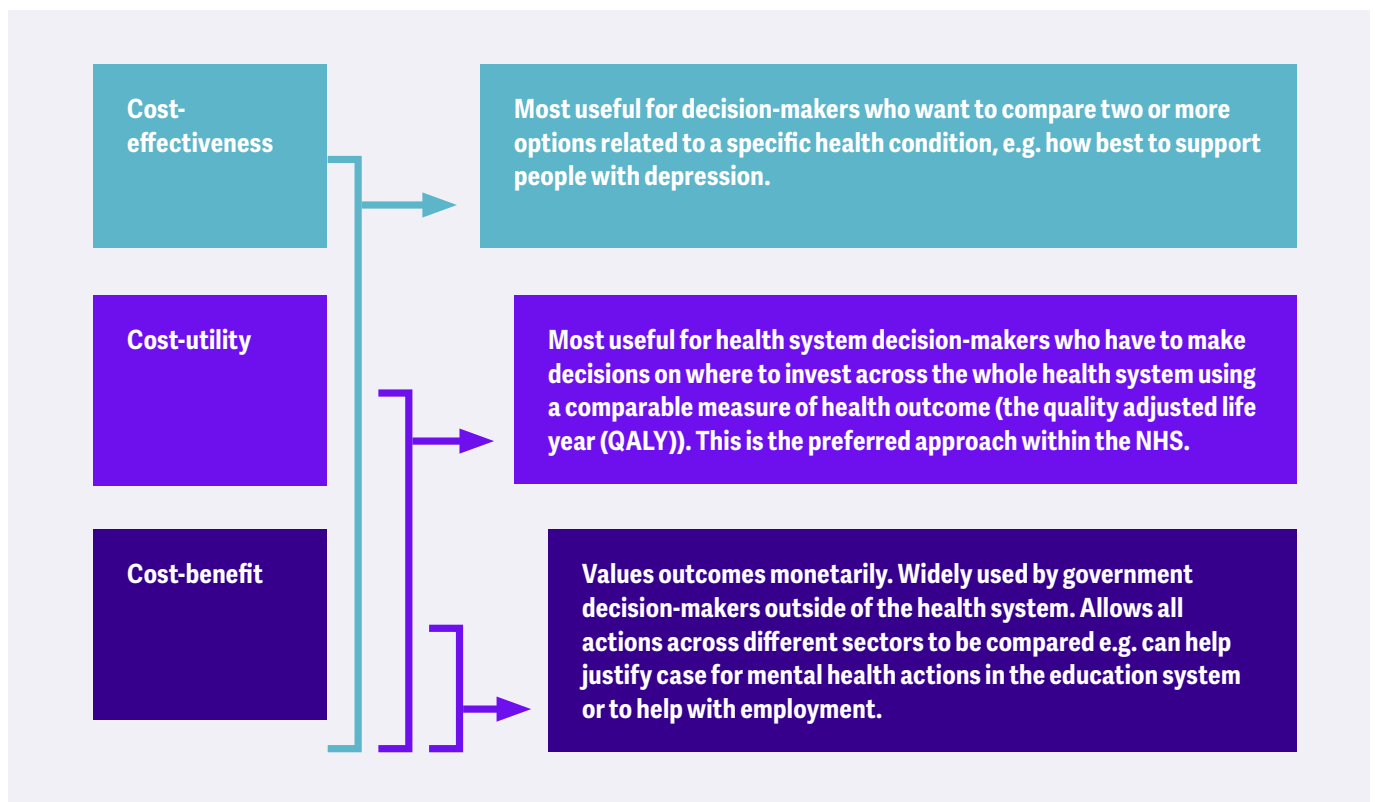
There are several different economic evaluation methods that can be used in supporting policymaking:

- 1 Cost-effectiveness analysis looks at condition-specific outcomes, e.g. changes in severity of depression compared to costs for two or more interventions. It is most useful for very narrow decision-making such as in this example, on actions to prevent depression.
- 2 Cost-utility analysis typically measures changes in quality of life; this means that all health-related interventions and their costs can be compared. This 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. This is most useful for reaching policy makers who need to make decisions about actions that affect multiple sectors, as both health and non-health related outcomes (e.g. improved participation in employment) can be compared. This is the main method used outside of the health care system in the UK. It is also frequently used when looking at preventive measures in health systems, because of their impacts across multiple sectors.
- 4 Return on investment analysis compares the costs of different interventions with the costs incurred or avoided as a result of intervention. This is not strictly a method for economic evaluation but is increasingly used as an alternative to cost-benefit analysis for multi-sectoral interventions.

The terminology around economic evaluation can be confusing; common approaches used 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 (See Figure 6.1).

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 these evaluations. This could make an important difference in showing the value of actions focused on seldom-heard groups.



Figure 6.1 : How are different types of economic evaluation used to inform decision making?

6.1 Cost-utility analysis

Within health systems, the most important of these approaches to economic evaluation is called cost-utility analysis. It is important because official bodies such as 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 quality of life relative to their 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 use QALYs because the quality of life for all health conditions, mental or physical, can be estimated in the same way, meaning that health policy makers 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.

There are several standardised and validated questionnaires that must be used to estimate quality of life in economic evaluations. For a cost-utility analysis the choice of questionnaire to use might vary by condition and age of respondents, but the most frequently used measure in the UK is called the EQ-5D (Devlin and Brooks 2017). Originally known as the EuroQOL instrument, it is the measure that NICE recommends.

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 (EQ-5D-3L and EQ-5D-5L). 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*. There is also a version called the EQ-5D-Y, which has slightly different wording considered more appropriate for children and young people.

The EQ-5D has sometimes been criticised as not being sensitive enough to changes in mental health-related quality of life. Recently a mental health specific quality of life instrument REQOL (Recovering Quality of Life)¹ 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, for instance 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 civil society and public purse-funded studies.

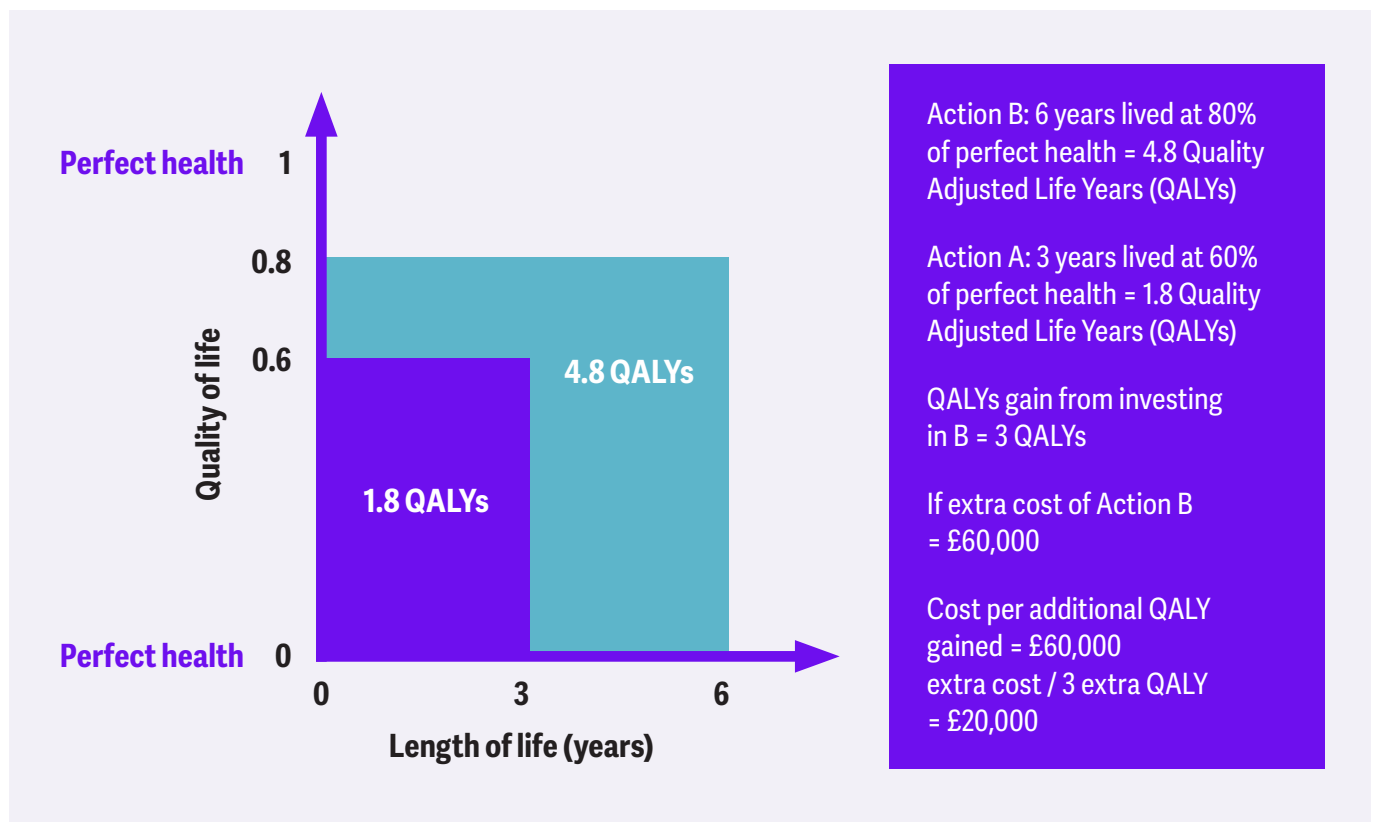
Regardless of which quality of life instrument is used, in all, perfect quality health has a value of 1 while death has a value of zero². Therefore, if someone spends 5 years living a reduced quality of life of 80% rather than being in perfect health because of the adverse impacts of chronic depression, this would be equivalent to just 4 years in perfect quality health.

6.1.1 Using this approach how is value for money assessed?

If an intervention has better QALY outcomes and is also less costly, then it is definitely good value for money, while any intervention that has both poorer outcomes and higher costs is definitely not value for money. However, many interventions will cost more than what is currently available, but also have better outcomes. In this case society has to make a value judgement on how much it is willing to spend for these quality of life gains. This cost per QALY gained 'threshold' will vary across countries. In England, NICE recommends that interventions should routinely be funded within the NHS if they cost no more than £20,000 to £30,000 per additional quality-adjusted life year gained.

Consider the illustrated example In Figure 6.2. 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 is improved and also 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; if this is to be funded then other factors will need to be taken into account. Most typically these include the importance of protecting life, or to extend 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.

1. See <https://innovation.ox.ac.uk/outcome-measures/recovering-quality-life-reqol-questionnaire/>
 2. Some health states can also be considered worse than death and have a value below zero.

Figure 6.2 : Calculating and valuing gains in quality of life

6.2 Cost-effectiveness analysis

Cost-effectiveness analysis (CEA) is similar to CUA but is more limited for policy making as it looks at 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 interventions to prevent falls. This may weaken the argument for investment within the NHS.

6.3 Cost-benefit analysis

While CUA may be more useful to health system policymakers compared to CEA, many health promotion and prevention interventions are funded outside of health care systems, so quality of life gains may not be seen as critical to non-sector health funders. 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. One of the most common approaches is

through surveys asking people how much they would be willing to pay to avoid a bad outcome, such as poor mental health. 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 published, e.g. (Heeks, Reed et al. 2018, Steinhauser, Lancsar et al. 2022).

CBA is increasingly used in looking at 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 within and external to the health care sector.

6.4 Return on investment studies

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 (McDaid, Park et al. 2017).

In that particular analysis, the monetary costs to different sectors were modelled so that it was possible to identify which sectors financially benefited more and which benefited less, as well as to estimate the overall return on investment.

This type of analysis can demonstrate why a government may want to provide financial incentives to any sector which has to bear the cost but does not gain the benefits of an intervention, if the overall return to the public purse is positive. Changes in return on investment over time can also be calculated as part of a modelling analysis; this can also be helpful to policy makers as they will be able to see the minimum amount of time needed before interventions generate a positive return on investment.

A specific type of ROI is the social return on investment analysis (SROI). Unlike ROI which tend to be restricted to measuring the costs of changes in service use, SROI also seeks to put a monetary value on a wide range of benefits that are less easy to measure. An SROI should start with a discussion with relevant stakeholders, such as people with lived experience, to identify why and how they believe an action will work; researchers then proceed to estimate the size of the effects and place 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 (Social Value Lab 2011). In the SROI, researchers then 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, where there is a focus mainly on resource impacts and costs to the NHS, local government, and sometimes other public sector organisations.

7. How can the economic evidence base for seldom-heard groups be strengthened?

7.1 Calculating long term costs that can be attributed to the adverse experiences of seldom-heard populations

Well established techniques in public health research can be used to calculate the population attributable fraction, that is the fraction of all cases of a particular disease or other adverse condition in a population that is attributable to a specific exposure (Mansournia and Altman 2018). Most famously the technique was used to estimate the number of lung-cancer related deaths that could be attributable to smoking back in the 1950s.

It has much more recently been used to estimate the association between adverse childhood experiences, such as neglect and different forms of abuse, with health risks across the life course (Hughes, Ford et al. 2021). In this study, a systematic review and meta-analysis was used to estimate lifetime population attributable fractions for a wide range of health conditions, both mental and physical, across 28 countries. The number of disability-adjusted life years lost due to these health conditions was then estimated and a monetary value attached.

This approach could potentially be further used to look at long term risks of adverse health outcomes in different seldom-heard population groups. It can also be used along with other types of research to look for potential interventions or circumstances that may mitigate some of these future outcomes. For instance, again looking at adverse childhood experiences, recent thesis work in Wales has suggested that one area for further evaluation in the UK as a protective measure against risks of mental and physical health conditions in adulthood may be the presence and capacity of 'trusted adults' (Lloyd-Williams 2023).

7.2 Making use of modelling

In section 5.5.2 we outlined the value of generating evidence from randomised controlled trials because this type of study design is very robust and therefore very credible to policy makers. We also noted that such trials can be very expensive and take considerable time which can limit their use. One alternative way of generating evidence more quickly is to make use of modelling studies.

In section 5.5. we briefly described how information from multiple sources can be used to inform modelling studies. Various forms of decision-analytical modelling techniques are frequently used in health economic evaluation to provide evidence on the likelihood that different interventions and/or strategies are cost-effective under different circumstances. Models can bring together data from multiple sources on the effectiveness and resource consequences for different interventions.

There are many different reasons why evidence from models is used as an alternative to relying on evidence collected as part of a trial or observational study. Many of these reasons are highly relevant when looking at the economic case for any action to support seldom-heard populations. At the core of any modelling exercise will be the need to assess assumptions about the effectiveness of any action, for instance by looking at already existing evidence from one or more controlled trials, observational studies evaluations or existing datasets. In the absence of evidence, assumptions may even be based on expert opinion. Models can also be used to look at the potential effects of structural interventions on specific populations, such as social welfare programmes.

A model, for example, might look at the evidence of effectiveness reported in multiple small-scale studies on seldom-heard populations and either formally pool these data using meta-analytical or other techniques (or use a previously published meta-analysis), or make an assumption about the likely level of effect based on the range of effect sizes seen in these different studies.

A model could also be used to look at the potential economic case for any intervention if the effects seen for the general population or another population subgroup could also apply to a specific seldom-heard population. Adjustments could also be explored: for example, one possibility would be looking at what the economic case would be if the intervention had a lower or greater level of effectiveness when targeted to a seldom-heard population. Modelling could also look at how the economic case would change if it was necessary to invest additional resources to tailor existing interventions for seldom-heard population groups or to invest additional resources in order to reach and engage with these population groups.

Another reason why modelling is used is to assess the economic case over a longer time period than covered in most empirical evaluations. This is particularly useful when seeking to determine the economic case for investing in prevention actions related to mental health, as the potential economic benefits of prevention, such as higher rates of employment and better levels of educational attainment may accumulate over many years (McDaid, Park et al. 2019).

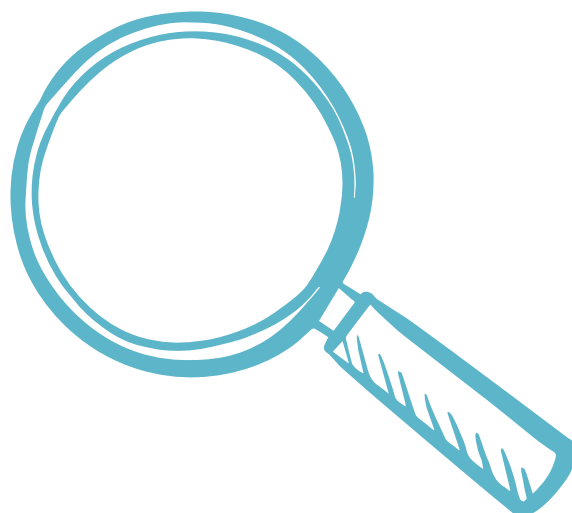
The need to assess the long-term benefits of early intervention to prevent mental health conditions in seldom-heard child and adolescent populations is one area where a long-term focus is needed, given the many studies pointing to adverse long-term consequences of mental health in children in general, as well as in seldom-heard child and adolescent groups. For example, a systematic review looking at people who had experienced a range of adverse childhood experiences (ACE) in Europe and North America estimated that ACE's were linked with between 30% and 40% of cases of anxiety and depression respectively (Bellis, Hughes et al. 2019).

The sensitivity of any model to changes in assumptions about parameters such as resource costs, effectiveness, level of uptake and duration of effect can also be explored. This means that it can be possible to use models to present policy makers with both an estimate on potential cost-effectiveness, as well as the likelihood that such a level of cost-effectiveness could be achieved. This might negate the need for additional empirical data collection in order to justify a policy action.

Indeed, a complementary technique known as value of information analysis can quantify the expected value of research in reducing any decision uncertainty shown in modelling. This can help guide policy makers on whether it is worth investing additional resource in a trial or other form of empirical data collection to reduce uncertainty or whether it is more optimal to make a case based on existing evidence (Claxton 1999).

Modelling approaches might also be used to consider how feasible it may be to expand access to a service to additional seldom-heard population groups. For example, mental health interventions targeted at Syrian refugees in Switzerland are being expanded to other Arabic speaking refugee population groups from North Africa who have also experienced conflict-related trauma (see <https://arq.org/en/projects/problem-management-plus-pm>).

One example of how modelling is used with a seldom-heard population group, LGBTIA+ young people, is shown in Box 7.1.



Box 7.1: Example: Modelling the harmful consequences of inappropriate intervention for LGBTIA+ young people

Few studies have looked at some of the consequences of adverse mental health in young people who identify as lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual and more (LGBTQIA+). But one modelling study highlighted the economic costs of providing a harmful intervention. This study from the USA modelled the economic costs and consequences for young LGBTQ people aged 13-17 receiving conversion therapy with those receiving affirmative therapy or no intervention (Forsythe, Pick et al. 2022).

Conversion therapy was defined by the authors as *'dangerous, discredited practices rooted in false beliefs that being lesbian, gay, bisexual, transgender, queer, or questioning (LGBTQ) is pathologic'*, while affirmative therapy was defined by the authors as *'psychotherapy validating the positive expression of sexual and gender identities and recognising the association of macrolevel forces, such as heterosexism and homophobia, with well-being.'* In the USA conversion therapy has been delivered by licenced psychotherapists and/or religion-based practitioners.

The economic model drew together data from multiple sources, for instance intervention costs were based on unit costs per session reported by the American Psychological Association, as well as expert opinion. A systematic literature review identified 28

studies focusing on the costs and consequences of conversion therapy programmes for adolescents and young adults, as they are considered to be especially vulnerable and have been common targets of these programmes. Insufficient information on some harms, such as suicide, was available, in which case the authors assumed these risks to conservatively be the same as the general population for all groups. Similarly, there was a lack of quality of life data specifically for LGBTQ young people, so quality of life values associated with different mental health outcomes regardless of sexual identity were used. The costs of adverse outcomes such as diagnosed mental health conditions, self-harm and suicide, substance and alcohol abuse were drawn from large scale US electronic medical record data.

Overall, the model estimated that affirmative therapy was cost-saving compared to conversion therapy or no intervention at all, with lower costs and higher levels of quality of life. The model indicated that the conversion therapy group compared to those who did not receive therapy had more non-fatal suicidal events (58% vs 39%). The authors estimated that the costs of adverse harms over a three-year period for more than 0.5 million LGBTQ young people at risk annually of receiving conversion therapy that could be avoided, if affirmative therapy were received instead would be \$6.19 billion or \$1.81 billion compared to no intervention.

Modelling may also be helpful in generating arguments relatively quickly for policy change. A good example of this concerns the potential cost-effectiveness and impacts on mental health of the pilot trial of an unconditional basic income payment of £1,600 per month for 24 months for 635 care leavers in Wales. The scheme will not be continued beyond the pilot, primarily because of budget concerns (Gwilym and Beck 2023). The evaluation results for the scheme (including an economic evaluation) will not be available until two years after the pilot scheme ends. Modelling could have been used to bring together early data from Wales, potentially with longer term data from other sources, to determine the longer-term costs and benefits of the scheme.

Yet elsewhere, data from a large scale UK wide longitudinal study, Understanding Society (see more in section 9.3.3), has been used to model the potential mental health and economic impacts of different levels of a Universal Basic Income scheme for everyone in the UK (Chen, Reed et al. 2023). The modelling analysis found that, overall, all variants of the scheme would have a positive cost benefit ratio and that the scheme would be particularly beneficial for young people, improving their mental health, while at the same time substantially reducing their use of health and social care services. A similar rapid modelling analysis of the Welsh scheme for care leavers, drawing on these data, would be welcome.

7.3 Identifying and quantifying additional benefits of preventive interventions beyond seldom-heard population groups

In building up evidence on the cost-effectiveness of preventive actions for seldom-heard groups, it can also be helpful to identify whether there may be spillover benefits to other population groups. Demonstrating that there are wider benefits might help strengthen the case to potential service funders of the value of preventive actions. Stigmatising attitudes and prejudice towards seldom-heard populations might also have a negative impact on policymaker perceptions of the need for support; one example of this could be the level of support for refugees and asylum seekers.

Policy makers in some countries may feel that any support for externally displaced persons means that they are having to divert their own very limited mental health resources away from their own population's health. Domestic politics might also play a role, with a reluctance of some politicians in Germany, for example, to be seen to be funding services for refugees (Biddle, Wahedi et al. 2022).

All of these factors may mean that in designing economic evaluations, it is important to assess not only the potential costs and benefits of the intervention to the target population, but to also look at potential wider impacts in the short, as well as long-term, for the local population. Modelling analyses could be used to estimate the economic benefits of extending coverage of an effective intervention to wider population groups.

In the case of conflict-affected refugees who are at increased risk of trauma, depression and anxiety, effective interventions could often also benefit military veterans who have also been exposed to conflict-related trauma. This may also help to sustain the capacity and maintain skills for delivering interventions, as there will be fluctuations over time in the need to support refugees and internally displaced people (McDaid, Park et al. 2022). In fact psychological and other interventions targeted at refugees are now being adapted to support the mental health of high-risk population groups during the COVID-19 and future pandemics, for example health and social care workers (Ottisova, Gillard et al. 2022).

7.4 Identifying and quantifying additional benefits of preventive interventions beyond mental health

Even if our focus is on looking at the case for prevention of poor mental health, it can still be prudent to identify and value additional benefits from preventive interventions, for instance for physical health, education, employment and social functioning. Potential funders of services may prioritise some of these other impacts over mental health, particularly given that many preventive interventions are not delivered within the mental health system. This may be particularly important when assessing the cost-effectiveness of non-health system interventions such as welfare, education, labour market and housing support.

7.5 Establishing routine data collection systems in small-scale community organisations to aid future economic evaluation with service programmes

Civil society organisations that deliver services to support people from various lived experience groups are also 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 dropout. People who make use of their services might also be invited to voluntarily complete surveys upon entry and exit; these surveys could ask about strengths/weaknesses and satisfaction with these services. Changes in important outcome indicators, such as quality of life and mental wellbeing, could also be collected at this time.

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 instance, volunteer time could be valued using the wage rate that could be paid to someone for doing the same work, or the rent that would be charged for any office space donated to a service.

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

7.6 Evaluate the cost-effectiveness of approaches to reach seldom-heard population groups

It is also important to evaluate the cost-effectiveness of different approaches to reach and sustain engagement with seldom-heard populations. This is an area where only limited economic research has taken place (O'Mara-Eves, Brunton et al. 2013), but it is essential to improve understanding of what works in these areas. For example, a systematic review looking specifically for studies on the cost-effectiveness of methods to identify children at risk of, or experiencing mental health problems, was only able to identify a single study (Anderson, Ford et al. 2019). This was a conference paper that concluded that a universal screening approach for suicide risk was more cost-effective than curriculum-based or in-service training programmes (Burke, Wasserman et al. 2013).

This is also an area where techniques such as conjoint analysis or discrete choice experiments could be used to inform the design of interventions and their evaluation. For instance, economists could work with seldom-heard groups to identify their preferences on methods of reach and engagement. This could, for example, help identify whether time and money to engage are barriers; this could apply both to everyday connection with an intervention, as well as the more immediate issue of reducing barriers to participation in research studies. This is something typically overlooked in economic analyses.

Evaluations can also look at the cost and benefits of cultural adaptation and how this may impact on outreach; this is something that was considered as part of evaluations to strengthen the mental health of Syrian refugees in Europe and the Middle East (Sijbrandij, Acarturk et al. 2017).

Another area where this issue of reach and engagement could be explored concerns delivery of online interventions versus face-to-face interventions for seldom-heard population groups. In general, online delivery can be of similar effectiveness to face-to-face delivery for many talking therapies for conditions such as depression and anxiety for both children and adults (Moshe, Terhorst et al. 2021, Cuijpers, Karyotaki et al. 2023). Individuals, however, may have different preferences for mode of intervention, some may prefer online (or phone-based) delivery because they may feel that this is more discreet and may reduce any fear they have of being stigmatised for seeking help with their mental health. Thus, increasing choice may increase the uptake rate and scope for interventions to be cost-effective.

Evaluation of hybrid online and face-to-face interventions as a way of increasing reach and sustained uptake of services can also be examined. For example, a recent trial compared parent-led CBT augmented by online therapist support for child anxiety, with treatment as usual (Creswell, Taylor et al. 2024). The intervention had similar effectiveness to usual care but at lower costs.

8. Thematic area 1: Promoting and protecting the mental health of refugees, asylum seekers and other displaced people

One seldom-heard population group is refugees, asylum seekers and other displaced people. Arguments supporting the economic, as well as moral and public health, imperatives to invest more in protecting the mental health of refugees may help strengthen support for these populations. Evidence from systematic reviews indicates that higher rates of depression and PTSD seen in refugees can last for many years, suggesting the need for long-term support systems (Blackmore, Boyle et al. 2020, Hoell, Kourmpeli et al. 2021). For children especially there may be profound impacts on future life chances, if schooling becomes further disrupted because of unaddressed depression, anxiety and PTSD (Blackmore, Gray et al. 2020).

Here we briefly summarise economic evidence on both prevention and early intervention for mental health conditions for refugees who are being hosted in high-income country settings. This includes studies that have looked at the longer-term costs of poor mental health in refugees as well as intervention studies. To do this we searched for any economic evaluations looking to better manage the mental health of refugees and displaced populations hosted in high-income countries. This extended a previous review that had been undertaken (McDaid, Park et al. 2022).

The search covered the PubMed, PsycINFO and Embase databases until February 2023, as well as a limited search of Google Scholar. The search revealed very few economic evaluations in high-income countries, although in addition we did also identify a handful of economic studies in low and middle income countries, as well as some studies looking at the long term consequences of poor mental health in refugees.

8.1 Resource utilisation and costing analyses

We turn first to studies that have looked at utilisation and costs of health and other service use associated with poor mental health. Despite the significance of the issue, and the prominence of health economic research in the UK, we were only able to identify one UK study which sought to quantify these costs. This was a study where patterns of mental health need and mental health service use in London were examined in 143 Somali refugees who had been living for less than 5 years in the UK (McCrone, Bhui et al. 2005) (See Box 8.1).

In Ireland a questionnaire was also used to identify differences in health status and health service utilisation, including mental health services, between people still going through the asylum seeking process and those who had been granted official refugee status (legal residency) (Toar, O'Brien et al. 2009). The questionnaire was targeted to both asylum seekers living in two 'direct provision centres' (group accommodation for asylum seekers) and refugees living in the local community in the same areas of rural Ireland. It included questions on contacts with GPs and other primary care services in previous 2 months, hospital admissions and mental health service contacts in previous 12 months and use of medication.

The study found no differences in use of hospital-based services between the two groups, but GP contacts were greater in the asylum seeker group. Asylum seekers were also found to have significantly higher levels of post-migration stressors compared to refugees. Mental health service utilisation in both groups was very low with the authors recommending more availability of

interpreters and cultural adaptation of mental health and GP services to increase uptake rates.

Additionally, some qualitative research from the UK has also been undertaken. In Wales focus groups with 50 refugees, as well as support workers and volunteers, were organised to identify barriers to service utilisation, including use of mental health services (Khanom, Alanazy et al. 2021). Peer researchers were fully integrated into this study and led on recruitment of study participants. In this research only 22 (44%) of the refugee participants in these focus groups spoke English and multiple translators were needed, given that the participants came from 13 countries around the globe.

The study suggested that refugees understood how GP services operate and were in favour of specialist NHS and non-governmental organisation operated services that helped facilitate access to health services. Barriers to service use focused on language barriers, health literacy, costs of transport and different perspectives on mental health needs, for instance not seeing this as something to contact a GP about. Future economic studies could potentially build on this and other qualitative research to help design evaluative studies, for instance potentially evaluating the cost-effectiveness of increased access to language interpretation services, as well as cultural adaptations of services to take account of different perceptions of mental health.

Box 8.1: Quantifying service use and unmet need among Somali refugees in London (McCrone, Bhui et al. 2005)

The study aimed to measure service use and costs, and how these costs may differ depending on the method used to identify refugees and further to identify factors that are predictive of variations in cost. Given the lack of data on Somali ethnicity in the 2001 UK Census (which remained the case in the 2021 Census) the authors adopted two different approaches to identifying refugees. The first involved looking for Somali surnames on GP records and then Somali members of the research team would contact these individuals to confirm that they were of Somali origin and seek consent for study participation.

The second approach was to visit places that Somalis attended, including Somali cafés, community centres, mosques, community colleges and refugee hostels. Once recruited, Somali interviewers asked participants to indicate their use of services over the previous six months using a Somali version of the Client Service Receipt Inventory (CSRI), an instrument widely used to obtain information on health, social care and other service use (Knapp and Beecham 1990).

This version of the CSRI included use of health care, other community health care professionals, hospital services, social care, day care, criminal justice system, medication and specialist refugee services. The Camberwell Assessment of Need instrument

was also used to determine health, social functioning and other service needs (Phelan, Slade et al. 1995).

76% of participants had applied for asylum immediately on entry to the UK and 83% had had their legal status resolved. 51% had lived for more than two years in the UK while 27%, 19% and 14% had depression, panic/agoraphobia, or PTSD, respectively. High levels of unmet need were identified, including for accommodation, food, physical health, psychological treatment and literacy skills. The study also noted that *'Although a large proportion of the sample had mental health problems service use appears to be relatively low. This may be indicative of the fact that in inner cities much of the focus is on serious mental illness.'*

There was little difference in service costs between refugees recruited via GPs or community venues, with higher use of non-hospital services being associated with shorter stay in the UK. The panic disorder/agoraphobia group had significantly lower non-inpatient costs which the authors suggested may be due to 'phobic avoidance' of services. The authors concluded by stating that the study "suggests that Somalis with mental health and social care needs do not receive organised care, and their receipt of interventions is haphazard, perhaps reflecting their high geographical mobility in the early part of the asylum seeking process".

Elsewhere in Europe multiple studies on health service utilisation in countries that host high levels of refugees, including Germany, Sweden and Switzerland, can be found. All of these countries are able to take advantage of the availability of large-scale electronic health registry data.

In Germany initial annual mental health service use and general health service use for Syrian refugees with untreated PTSD were much lower than for the local population with similar mental health needs, potentially because of barriers such as mental health stigma, language, coverage restrictions and a lack of awareness of services among refugees (Grochtdreis, Röhr et al. 2021). At the same time another German study indicated rates of emergency hospitalisation due to mental health conditions in asylum seekers were twice as high as those in the general insured population (Bauhoff and Göppfarth 2018); this may have been due to the lack of entitlement at the time of the study to access mental health services under the German social health insurance system during the first 15 months of their stay in Germany. Earlier use of these services potentially would have reduced the risk of need for emergency mental health care. The study also suggested increased access to primary care-led mental health services, including preventive services, would reduce costs.

There is a long tradition in the Nordic countries of epidemiological and economic research as part of data linkage studies where longitudinal information on health, welfare and other characteristics can be linked together. Even though ethnicity is often not recorded in these databases, data on refugee and/or migrant status is available. This has allowed large-scale research on refugee mental health, including psychiatric and other service utilisation as well as mental health outcomes.

In Sweden registry data has been used to explore differences in service utilisation and outcomes between different groups of refugees and the non-refugee population. For example, differences in the use of psychiatric health care services in Sweden between unaccompanied refugee, accompanied refugee and Swedish born children over up to nine years have been examined at a national level using linked longitudinal datasets (Axelsson, Bäärnhielm et al. 2020).

The study was able to include all eligible children in the country in the study, more than 1.3 million children, including more than 6,300 unaccompanied children and 54,000 accompanied children. It found that unaccompanied child refugees had a higher rate of psychiatric service utilisation than Swedish born children; in contrast refugee children who were accompanied had a significantly lower use of psychiatric services than Swedish born children.

The authors speculated that this higher rate of service use in unaccompanied children was not only due to a higher risk of mental health problems as a result of having no family support, but also because the new guardians of these children in Sweden were much more familiar with how to access the mental health system than the guardians of accompanied refugee children, who themselves were refugees.

Another analysis looked at ten-year use of mental health services (including mental health services within primary care) for different groups of children in Stockholm: migrants, unaccompanied refugees, accompanied refugees and Swedish born (Gubi, Sjöqvist et al. 2022). This study again reported that unaccompanied refugee children made more use of mental health services than Swedish born children but after six years being in country unaccompanied children had a similar lower rate of mental health service use to accompanied refugee children. Sub-group analysis indicated that refugee children below the age of ten had a similar level of mental health service utilisation to Swedish born children, but older refugee children and adolescents had significantly lower rates of mental health service utilisation.

The analysis did not find any evidence of differences in service utilisation by country of origin, which the authors suggested meant that more than cultural adaptation is required to promote better access. The authors suggested that additionally structural measures in settings such as schools, general health care, social welfare and legal services to improve signposting and referral to mental health services are required.

Another Swedish example can be seen in work looking at mental health service utilisation before and after non-fatal suicidal events. To do this, one study linked databases with data on hospital-presenting non-fatal suicidal events, with detailed longitudinal socio-economic data on labour market participation, including sickness absence and disability benefits claims, along with national data on health status and inpatient and outpatient health service use. This allowed researchers over a nine year period to examine at national level whether there were differences in health service utilisation and welfare characteristics in the three years prior to and post a hospital presenting non-fatal suicidal event between refugees and Swedish-born individuals (Amin, Rahman et al. 2021). This study found that refugees used less specialist health care in the year before and after a suicide attempt and that future qualitative research was needed to understand the reasons behind this lower rate of service utilisation.

These are just some of multiple examples from Scandinavia that make use of various electronic registry data. For example, analysis in Denmark has compared the mental health service utilisation of refugees between childhood and adulthood with that of the descendants of labour migrants from Morocco, Pakistan and Turkey, as well as with individuals who had two Danish-born parents (de Montgomery, Petersen et al. 2020). This analysis was able to make use of data on the entire population of Denmark and concluded that the likelihood of diagnosis-specific contacts at psychiatric services was lower for most conditions (the exception being schizophrenia) for both refugees and other minority group children. This was unlikely to be due to language barriers, as all refugees arrived in early childhood and spoke Danish. Possible explanations for low access and use of services put forward concerned class and culture-based barriers to engagement with services, as well as the potential for health care professionals to misinterpret signs of poor mental health as simply being ethnic or cultural issues.

Earlier analyses in Norway using national registry data looked at the use of specialist mental health services by migrants, including sub-group analysis for those who migrated as refugees, again indicating an under-utilisation of services compared to ethnic Norwegians (Abebe, Lien et al. 2017).

Similarly, Norwegian registry data have also been used to demonstrate that refugees were more likely to use primary health care services and make use of drugs to address mental health issues such as depression compared to non-refugees from the same countries (Straiton, Reneflot et al. 2017). The authors suggested this may have been due to greater levels of trauma before migration for refugees, as well as more stressors due to the asylum process after their arrival in Norway.

Other examples are also available from Switzerland. Interviews with 78 asylum seekers in Switzerland, as well as use of electronic health records, suggest that annual health care costs for refugees are almost double those for the Swiss general population, with a key potential driver being undiagnosed mental disorders; moreover the costs for refugees with a mental health condition may be even greater than for refugees without these conditions (Maier, Schmidt et al. 2010).

Longer-term analysis in Switzerland using health insurance system data also indicates asylum seekers with mental health conditions have increasing health care costs over time compared to asylum seekers without these conditions. A lack of early intervention to identify and refer asylum seekers to appropriate services may contribute to this increasing cost trajectory (Tzogiou, Spycher et al. 2022).

These are just some of the examples of the power of access to linked longitudinal databases where it is possible to identify seldom-heard population groups such as refugees. More interrogation of these databases in different settings could provide valuable information on risks to mental health associated with a lack of mental health support, as well as the benefits of early intervention to protect mental health and prevent mental health problems, along with the benefits of better continued access to appropriate mental health and other services.

8.2 Economic evaluations

Very few economic evaluations focused on the mental health of refugees appear to have been conducted. Only one was concerned with a strategy to screen for mental health conditions among refugees. This was an exploratory decision-analytical modelling study in Germany which estimated that the incremental costs per QALY gained for universal screening followed by cognitive behavioural therapy for mild and moderate depression in newly arrived refugees in Germany would be €19,779, compared to case-finding via self-referral followed by psychosocial care (Biddle, Miners et al. 2019). Although no formal QALY decision-making threshold exists in Germany, the authors concluded screening may be a cost-effective strategy.

A randomised controlled trial (RCT) looked at a smartphone delivered cognitive behavioural therapy-based self-help intervention for Syrian refugees with PTSD in Germany (Rohr, Jung et al. 2021). This study found that there was only a 20% chance of the intervention being cost-effective at four month follow up at a notional cost per QALY threshold of €50,000. The authors concluded that on its own the intervention was not more effective and highly unlikely to be cost-effective, although as the app was well used and not associated with any harms, potentially its role as one step in a stepped care or collaborative care approach to mental health support for refugees might be evaluated.

There is some more encouraging economic evidence for face-to-face brief psychological therapies for refugees. In the Netherlands a pilot trial looked at the cost-effectiveness of a brief face to face delivered psychological therapy (PM+) plus usual care for 60 Syrian refugees with elevated psychological distress and reduced psychosocial functioning compared to usual care only (de Graaff, Cuijpers et al. 2020). Significant improvements in levels of depression, anxiety and social functioning were found in the PM+ group. The economic analysis considered a broad range of factors; while health and social service utilisation and costs were higher, productivity losses due to time out of employment or education, and need for family informal care were lower.

Overall, better outcomes were reported with no significant difference seen in costs, with an incremental cost per recovery from anxiety and depression of €5,047 and €2,266 from health system and societal perspectives. Further work to look at cost-effectiveness over a one-year period is being conducted.

Models of stepped care where the most intensive intervention support is only provided to those with the greatest levels of enduring mental health need may prove potentially attractive, as they have less resource impact than strategies where all participants receive all levels of care. A four-level strategy in Germany involving watchful waiting, peer or phone support, group and then finally individual psychological therapies has been evaluated in a trial of almost 600 Arabic or Farsi speaking refugees and asylum seekers with at least mild depressive symptoms (Böge, Karnouk et al. 2022). Subsequent health service costs over a one-year period were significantly lower in the intervention group, with improvements in depression also seen. The strategy appeared to be highly likely to be cost-effective in sensitivity analyses, with lower overall costs and slightly better QALY outcomes than care as usual.

The importance of looking at the long-term impacts, as well as the wider benefits of intervention for families and communities, can be seen in an economic evaluation as part of an observational study of traumatised refugees living in Denmark who have been victims of torture (Bager, Hansen et al. 2018). Using registry data, the study compared the long-term employment and health service utilisation costs over 14 years for 44 refugees who received multi-disciplinary rehabilitation with a matched group of refugees on a wait list for treatment. While benefits did not outweigh costs when looking at impacts to individuals alone, once impacts on immediate families were also considered, the intervention generated a positive net benefit after three years.

8.3 A need to strengthen the evidence base on refugee mental health

Our analysis indicates that there is a dearth of information on the economic case for investing in measures to prevent and/or intervene early to promote the mental health of refugees in the UK. This is despite a recognition in recent qualitative research of multiple barriers to mental health service access across the UK, as well as some discussion of the limited funding allocated in England to the former Clinical Commissioning Groups to support all the health needs of Syrian refugees (Pollard and Howard 2021).

We could only identify one study that looked at the economic consequences for refugees from Somalia that took place 18 years ago (McCrone, Bhui et al. 2005). We also noted some recent qualitative work in Wales engaging with refugees in order to explore access to and utilisation of services (Khanom, Alanazy et al. 2021). More generally, some qualitative work around the experience of being a refugee can be identified but economic concerns do not appear to be visible (Pollard and Howard 2021).

No economic evaluations on interventions focused on refugee mental health in the UK were identified; we are aware however of an economic evaluation planned alongside randomised controlled trial of a brief psychological therapy for refugees, but this was not completed due to the difficulty of recruiting refugees to a trial during a period badly affected by COVID (Dowrick, Rosala-Hallas et al. 2022).

More generally, the lack of economic evaluations in high income countries looking at refugee mental health may reflect a lack of funding for research of this type, and historically perhaps the low priority given to refugee mental health issues. Overall, we only identified five economic evaluations in high income countries, including three studies linked to trials, one modelling analysis and an observational/modelling study making use of registry data. More data may become available as a result of major refugee movements into Europe from Syria, Afghanistan and more recently from Ukraine. It is perhaps no coincidence that the economic evaluations

we identified have all been in countries that have received relatively high numbers of refugees, such as Germany, Denmark and Sweden.

The European Union has also funded research that is looking at the effectiveness and cost-effectiveness of brief psychological interventions for Syrian refugees at high risk of major depression, anxiety and/or PTSD in both Europe and in the Middle East; as well as an initial study in the Netherlands (de Graaff, Cuijpers et al. 2020) and the service utilisation analysis in Switzerland (Spaaij, Kiselev et al. 2022), further studies looking at the impact of these face to face interventions in these countries over a 12 month period are being completed, alongside studies looking at the economic case for online interventions in Germany and Sweden (Sijbrandij, Acarturk et al. 2017). An economic evaluation is also being undertaken as part of an evaluation of brief psychological support for various recent migrant populations in Italy (Purgato, Turrini et al. 2023).

Although we have not here focused on evidence in low and middle income countries, a broader scoping review on the economic case for investing in refugee mental health only identified a handful of additional studies. This included an economic analysis indicating a favourable cost per QALY gained for a self-help intervention for Syrian refugees in Turkey (Park, Waldmann et al. 2022); a similar evaluation for Syrian refugees in Europe has also been conducted by the same research group. There may be scope for modelling other interventions in a European context, especially if they are being delivered to similar population groups and have already been culturally and linguistically adapted for these groups.

In addition to simply undertaking more economic evaluations of preventive actions to support refugee mental health, what else can be done to strengthen the evidence base? One critical area which we have emphasised throughout this report is the importance of directly involving refugees and other migrant groups more fully in the research process. We believe that it is feasible, with language and other supports as needed, to conduct qualitative research to inform economic evaluations, for instance using discrete choice experiments to identify those aspects of mental health services that need to be tailored and culturally adapted

to these needs of refugees. These services could then be evaluated in trials, as well as in modelling studies with some of the parameters for models taken not only from existing literature but also from qualitative expert inputs. This can include the refugee perspective on pathways of care to be used in models. It can also look more at the cost-effectiveness of peer delivered mental health related interventions, which arguably may help to overcome some of the cultural and linguistic barriers to service use.

There is also more scope for work to understand the long-term economic consequences associated with poor mental health in refugees. To do this it would be helpful if longitudinal datasets include an indicator of current or past refugee status. As we have seen, this has been the case in some datasets, including in the Nordic countries. In a UK context, in addition to exploring what may be feasible by use of existing datasets and cohort studies, there may also be lessons to learn about some of the consequences for minority migrant populations by looking at the experience of previous immigrants such as people from Ireland, the Caribbean, west and east Africa, as well as South Asia.

Where it is not possible to make use of existing longitudinal datasets, it may be possible to work with refugees (probably via civil society organisations) to collect data on contact with health and other services, as well as changes in employment, education and housing status over time to help build up more data on long term impacts. Examples of such surveys can be seen, for example, they have been used to observe that the mental health of 353 Syrian refugees was documented to have improved after leaving Lebanon and moving to Norway (Strømme, Haj-Younes et al. 2020). Changes in some health service use were also documented.

For such surveys, while it may be relatively easy to identify refugees if they are living in dedicated refugee accommodation, one challenge will be reaching refugees in the wider community and multiple approaches may be required, for example involving refugee peers to reach people. Potentially there may be scope, where it is not easy to identify refugee populations, to use approaches, as we have previously noted have been used in Wales, where geographical information on areas where

members of the Traveller and Gypsy communities were known to live, and link this with electronic health service utilisation. Perhaps also some approaches linked to surnames on GP registers, as previously used to identify Somali refugees, might be feasible to use for some refugee groups.

Time may also be needed to build trust, particularly among people whose legal status may not be clear. In some refugee host countries, it might also be feasible to conduct (or add questions to) general population surveys on longer-term health and social outcomes, such as participation in employment and level of earnings.

There are now new opportunities to potentially look at the differences in mental health outcomes and economic costs between different refugee groups, given the difference in the way in which refugee groups have been supported. Ukrainian refugees have immediately been granted rights to welfare benefits as well as the right to work in the UK and elsewhere in Europe; this is in contrast to other groups where the process of obtaining legal status can take a long time and be subject to considerable uncertainty.

This wider context on the 'welcome' given to refugees, asylum seekers and displaced people within economic analyses is likely to be very important; there is some evidence from a recent systematic review of the increased risks to mental (and physical) health linked to more restrictive entry policies and tighter rules on access to general welfare, labour market and housing support (Juárez, Honkaniemi et al. 2019). For example, a 30 month follow up study of unaccompanied male child and adolescent refugees seeking asylum in Norway found that their mental health was not only adversely affected by their claims for asylum being rejected, but also when they were located in low-support facilities and/or reception centres for adults rather than children (Jakobsen, Meyer DeMott et al. 2017). There will be economic costs associated with these outcomes, and this may strengthen the case for better welfare and legal processes to support refugees.

8.4 What is the state of the evidence base?

In summary, there are well documented increased risks of mental health conditions such as depression, anxiety and traumatic stress disorders, yet there appears to be a substantial gap in what we know about the economic case for better asylum seeker and refugee mental health. Where long-term studies have been conducted it is possible to point to growing evidence on the profound long-term adverse consequences of poor mental health to refugees, asylum seekers and other displaced people, including increased costs to health services for both mental and physical health needs and reduced participation in work and education.

There remains, however, very limited economic evidence on the case for action; evaluations are needed, particularly for early intervention within and outside of the care system to support asylum seeker and refugee mental health. These evaluations should involve the asylum seeker and refugee community in the design and analysis of evaluation; this can include helping to determine which outcomes are of most importance to asylum seekers and refugees, as well as ensuring that interventions are culturally appropriate; asylum seekers and refugees may be involved directly in the delivery of services.

The value of facilitators, such as better access to interpreters, on the uptake and effective of preventive interventions for better mental health could also be separately assessed.

In contrast to the economic case for asylum seeker and refugee mental health, there are many more economic studies that have looked at the case for screening and treating communicable disease in asylum seekers and refugees. That may be because local policymakers also want to be able to consider potential impacts on the resident population in host countries. Asylum seekers and refugees may be seen as a low political priority in countries, especially when resources are tight (Biddle, Wahedi et al. 2022, McDaid and Park 2023). This is why it is also important for any economic evaluation of the benefits of improving asylum seeker and refugee mental health to consider whether this may have spillover impacts for the local population; one example might be increased capacity to support all people who have been exposed to trauma not just from conflict and man-made violence, but also from natural disaster. This could include the pressures experienced by health and other frontline workers when responding to emergencies.



9. Thematic area 2: Promoting and protecting the mental health of seldom-heard young people

A second case study area we explored is strengthening the evidence base related to actions to prevent mental health conditions in seldom-heard young people. While our previous report did identify economic evaluations focused on the prevention of mental health conditions in young people, it did not reveal many studies that explicitly focused on seldom-heard populations.

For this case study we first wanted to know what young people consider important both to the mental health of seldom-heard young people, as well as for youth mental health more generally. We held an online focus group with MHF Young Leaders³ to inform this and then looked to see whether these outcomes have been included in any economic analysis for seldom-heard groups of young people.

We also wanted to know to what extent seldom-heard young people have been involved in shaping economic research. We also highlight some examples of current evaluations and the methods that they are adopting.

9.1 What outcomes do young people consider to be important?

The online focus group involving members of the MHF Young Leaders Group lasted for 2 hours and began with a brief overview setting out how economic evidence can be used to promote the case for better mental health in seldom-heard young people and consisted of discussions among all participants as well as break-out sessions. Participants could also draft down any thoughts on virtual 'Post It' notes which were then used to also help identify some of the broad themes.

3. The Mental Health Foundation Young Leaders is an innovative model, run in partnership with Leaders Unlocked, that enables young people to work alongside the Foundation to address mental health and emotional wellbeing on a national level. For more information, see <https://www.mentalhealth.org.uk/our-work/programmes/programmes-families-children-and-young-people/mhf-young-leaders>

Economic evaluations looking at youth mental health in general tend to focus on mental health outcomes, and perhaps also outcomes such as quality of life, education, labour market participation, and contact with the criminal justice system. The focus group, in contrast, hardly touched on these outcomes. All of the issues raised were relevant to all young people, but they did recognise the special need for support for minority and displaced populations including refugees.

They emphasised the importance of developing and maintaining friendships and social networks. They emphasised the need for these friendships to be deep rather than shallow in nature. They spoke about the importance of love. Another important issue for these young people was better understanding and awareness of mental health issues, i.e. mental health literacy, including awareness of the meaning of wellbeing and how to promote and protect it. There were also some concerns expressed about the current and future impacts of climate change on their mental health, as well as threats to their aspirations to get onto the housing ladder. Indeed, the issue of housing, not just home ownership but decent accommodation figured heavily in some break-out discussions.

Other issues raised included the importance of financial literacy, with a recognition that poor financial literacy can have negative impacts on mental health; concerns around 'negative news'; and the need for young people to be genuinely involved in any consultation/decision making process on issues that are about their future, including housing, climate change and urban planning. All of this indicates the value of researchers working with young people to identify what is important to them.

9.2 Are outcomes of interest to young people included in economic studies on the prevention of mental health problems in seldom-heard young people?

9.2.1 Looked after children

We have noted the limited focus in economic studies on the prevention of mental health problems in seldom-heard population groups. One area where we did identify economic evaluations concerns the mental health and wellbeing of looked after children. This includes a published study protocol incorporating an economic evaluation as part of a multi-centre randomised controlled trial in England of a group-based, psychoeducational intervention for foster carers, known as the Reflective Fostering Programme (Midgley, Irvine et al. 2021).

The primary outcome of the trial is the behavioural and emotional wellbeing of the children who are aged between 4 and 13, measured using the Strengths and Difficulties Questionnaire (SDQ), while the economic evaluation focuses on quality of life measured by the foster carers rather than the young people.

The study is also making use of a tailored service utilisation questionnaire specifically designed for use in studies with looked after children. This will include education and social care service use in addition to health service use. A process evaluation will also interview foster carers on their experience of using the psychoeducational intervention and also include focus groups with various stakeholders. Foster carers will co-deliver some of these process activities.

An earlier economic evaluation alongside a controlled trial in the US reported the net monetary benefits of Multidimensional Treatment Foster Care, a multi-component programme involving long term psychological support for pre-school children with mental health difficulties, plus additional training and support for foster carers (Lynch, Dickerson et al. 2014). Changes in mental health were not the prime outcome measure, instead this was the number of permanent placements, such as adoption, as the authors noted that these have been associated with better mental

health and other outcomes, such as school attainment. Health and social service costs were included and the intervention had positive net benefits, with better rates of permanent placement and lower costs than usual support.

Another example is the Best Services Trial which aims to determine the effectiveness and cost-effectiveness of approaches for assessment of and intervention for children entering formal foster care or kinship care in Glasgow due to abuse and neglect (Crawford, Fitzpatrick et al. 2022). The primary outcome of this ongoing trial is child mental health, also measured using the SDQ. The specific approach being evaluated is called the New Orleans Intervention Model (NIM). This offers families who have a child who enters care due to abuse or neglect a structured assessment of family relationships followed by an intensive treatment that aims to improve family functioning and child mental health. If adequate change is achieved a recommendation is made for the child to return home but, if not, the recommendation is for adoption.

Previous US research suggests that the intervention might reduce future maltreatment and improve child mental health. NIM is being compared to standard care as usual. The economic evaluation looks at short term outcomes from the trial and will also use modelling techniques to look at longer term costs and benefits. PedsQL, a quality of life measure, is the primary outcome in the economic analysis, but the study protocol did not provide detail on service utilisation and costs reported.

Our previous MHF review identified a US study looking at the long term (15 year) cost and benefits of a group preventive intervention for divorced women living with at least one child, with the aim of addressing risk factors that impact on their children's post-divorce mental health (Herman, Mahrer et al. 2015). A previous effectiveness evaluation of the intervention unusually included 15-year follow up data, collected through interviews. The economic analysis compared the costs of the programme with benefits from reduced use of mental health services and psychiatric medications by the now adult children and their mothers, as well as any change in costs to the criminal justice system for these children. The authors concluded that the monetary value of costs avoided in the 15th year alone more than offset the costs of intervention.

9.2.2 Children living with a parent with a mental health condition

Another area where economic evidence is growing concerns the prevention of mental health conditions in the children of people who themselves have poor mental health. In the US the cost-effectiveness of a cognitive behavioural prevention programme to prevent depression in all young people aged 13-17 with sub-clinical levels of depression has been shown to be cost-effective (Lynch, Dickerson et al. 2019). While this study did not focus specifically on seldom-heard young people, sub-group analysis for study participants whose parents were depressed (and arguably more seldom-heard) revealed that the intervention was not cost-effective compared to usual care.

A trial-based evaluation in Ireland has evaluated a manualised, strengths-based, seven-session, weekly programme, known as Family Talk, for families where one or both parents have a mental health condition (Furlong, McGilloway et al. 2021, Furlong, McGuinness et al. 2024). It was compared with a wait-list control group who received care as usual. As a part of the study, a detailed estimate was made of the budgetary impact of the intervention. An adapted version of the Client Service Receipt Inventory collected information in face-to-face interviews with parents on health care, social care, and educational service use. Diaries were kept by programme facilitators to more accurately estimate the costs of training, and then delivering the intervention.

The primary outcome measures in the analysis were the SDQ, as well as a measure of family functioning. Importantly, focus groups were held with parents and interviews held with some children aged between 12 and 18 years to gain their insights on participation in Family Talk. The views of some younger children were also taken into account indirectly through an 'interview story' approach involving an imaginary family where a parent has problems with their mental health. Children, with the aid of story cards, were able to express their views on this situation. There were significant improvements in family functioning and child-behaviour at six-month follow up, although benefits were most pronounced in families with lower levels of mental health difficulties and/or more economic resources (Furlong, McGuinness et al. 2024).

Two studies from Germany also add further to what is known in this area. One study looked at the costs of mental health treatment and use of social services by children and adolescents with parents with mental illness (Waldmann, Stiawa et al. 2021). Using self-reported data from a similar questionnaire to the CSRI, the study found that health and social care service costs were typically €4,000 greater over a one-year period for children with parents with a mental health condition compared to children in families without any parental mental health conditions. Most of these costs were for psychiatric inpatient care, use of child and youth outpatient services and additional support in school. Using statistical methods the authors estimated that each one unit improvement on a German child mental health functioning scale was associated with a €214 decrease in annual costs.

An economic evaluation was conducted alongside a randomised controlled trial of a manualised programme consisting on average of eight semi structured sessions (50–90 min) provided by a psychiatrist or psychotherapist over 6 months to children of parents with a mental health condition (Waldmann, Schaible et al. 2023). The study reported lower health and social care costs, as well as better quality of life outcomes in the intervention group, although these differences were not statistically significant. If a monetary value was placed on quality of life gains then there would be net monetary benefits of between €25,000 and €125,000. While there was too much uncertainty over study findings to draw any firm conclusions, the authors suggested that the intervention was promising as wider impacts on families were not included. They also said that, potentially, benefits may have been greater if the study had looked at outcomes and costs over a longer time frame than a one year follow up period.

The results of some other studies in this area are difficult to interpret because they do not report cost per QALY or a cost benefit ratio, making it difficult for policy makers to make a judgement on whether improved outcomes gained represent a good use of resources. This, for example, is the case for a Dutch study that looked at the impact of an intervention to promote better parenting among parents who have a mental health condition; the focus here also was on parenting quality and no direct mental health outcomes measures for children were included. Such measures might further help make the case for investment (Wansink, Drost et al. 2016).

9.2.3 Increasing the involvement of young people in evaluations

Few of the economic studies we have identified that are focused on seldom-heard young people appear to have provided many opportunities for their direct involvement in shaping the evaluation or even in understanding some of the factors that may influence their uptake of an intervention. Reviews also indicate that there are few very high quality effectiveness evaluations, and the views of children and young people in their design are not prominent (Tarren-Sweeney 2021).

That said, the age of children will have a bearing on their input in any evaluation; in this case other proxies from seldom-heard groups could provide input. In Australia an evaluation of a treatment programme for looked after children looked at differences in outcomes in children with an Aboriginal and Torres Strait Islanders background compared with other children. The team included a researcher from an Aboriginal background, with other ongoing input and feedback from four medical staff with an Aboriginal and Torres Strait Islanders background in order to ensure cultural appropriateness (Eadie, Douch et al. 2022). The evaluation led to positive outcomes for the children in the study and was a culturally supportive mental health service.

For older children and young people, one example of how their views can be taken directly into account can be seen in a process evaluation undertaken alongside a controlled trial, including economic evaluation, in the Netherlands of an online course to support young people aged 16-25 who have a parent with a mental health condition (Woolderink, Bindels et al. 2015). Interviews with some participants highlighted both positive and negative aspects of the online intervention, helping the researchers interpret the reasons for drop out in the trial. This, they indicated, could then be used in the design of subsequent evaluations.

A further issue that cannot be overlooked is the importance of continuing to work with adults and older people from seldom-heard groups who had experience of adverse childhood circumstances in research, particularly where very long term outcomes are being looked at. They also will have a 'memory' of the adversities which newer generations will not have;

moreover these experiences may be helpful to consider when designing interventions to address today's issues, such as the impact of lockdowns during the pandemic and the latest refugee crises. For example, potential economic evaluations on interventions for child refugees and asylum seekers could be informed by the experience of earlier generations, for instance on the long term mental health of children who were evacuated from their homes due to conflict in the second world war (Santavirta, Santavirta et al. 2015, Santavirta, Santavirta et al. 2018), or from children who were malnourished because of conflict (van den Broek and Fleischmann 2019).

9.3 Case study: The impact of housing

We noted that one of the key outcomes that young people felt was important to them in the focus group related to good housing. This appears to be an area with very little economic research on seldom-heard groups, other than homeless people.

We also explored what has been written about the economic impacts of housing conditions, as well as the affordability of housing, on mental health in the general population and young people in particular, as well as in those with poor mental health problems. These challenges may be further increased due to the persistence of much higher levels of energy cost and increased risk of fuel poverty as a consequence of the war in Ukraine. We explore how some approaches in current research looking at the economic value of support to access housing generally could be tailored to seldom-heard populations. One way of doing this can be to make use of already available population data sets.

9.3.1 Housing affordability and mental health

In the Netherlands data for more than 14,000 people has been used to look at the relationship between housing affordability and mental health between 2008 and 2019 (Arundel, Li et al. 2021). The population included in the data set were selected in a way to increase representativeness for what they called 'hard to reach' population groups and survey questions covered housing tenure, housing cost and mental wellbeing.

The analysis indicated that, overall, higher levels of poor mental health were associated with people having higher levels of worry about whether they could afford to pay rent or the mortgage on their homes. The impacts on mental health associated with worries over housing affordability stress were much more pronounced in renters and in the youngest age group (in this case 25-34 year olds).

Future studies could go further and explore whether minority status, such as not being born in the Netherlands, is associated with poorer mental health outcomes. It should also be feasible to attach an economic value to poor mental health seen in this and in other studies. From a policy making perspective, this could help in making the case for additional financial support and/or rent controls.

In the UK, Understanding Society – the UK Household Longitudinal Study, contains a wealth of data for people of all ages. It contains indicators for potentially seldom-heard population groups, as well as having sampling boosters to increase the number of ethnic minority and migrant populations included in the dataset. It also has geographical linkage data which may allow for identification of seldom-heard populations in areas where they are more heavily located (e.g. recent news coverage has indicated that Chagos Islanders who have resettled in England are highly concentrated in the Crawley area of Sussex).

Data from more than 30,000 participants in Understanding Society was also used to explore the relationship between housing affordability problems and mental health status (Dotsikas, Osborn et al. 2022). The authors found that sustained exposure to housing affordability problems (defined as spending more than 30% of income on housing) was associated with poorer mental health. This analysis did not find any differences by ethnicity but argued that further research was required given that some groups, such as Gypsy or Irish Travellers, Black Africans and Bangladeshis were more likely to face housing deprivation.

9.3.2 Housing quality and mental health

The Understanding Society dataset has also been used to look at how living in poor quality housing may be associated with future poor mental health (Pevalin,

Reeves et al. 2017). The survey asks participants six questions about housing quality: not enough light; lack of adequate heating; condensation; leaky roof; damp walls or roof; and rot in the walls or floor. The study found that persistent housing quality problems were associated with long-term poorer mental health regardless of differences in tenancy. It did not assess the impacts on specific seldom-heard groups, but this is an issue that could be considered in future research.

Another example in England, uses data from the Avon Longitudinal Study of Parents and Children (ALSPAC) to examine the association between housing and neighbourhood quality and differences in childhood mental and physical health (Nasim 2022). Again, poor housing quality was associated with worse mental health in these children.

We have highlighted the links between housing affordability problems or poor housing in a UK or Dutch context, but this represents just a snapshot of such studies. Other studies around the world use population datasets to examine this issue, such as in Australia (Bentley, Baker et al. 2011, Baker, Lester et al. 2020) and New Zealand (Pierse, Carter et al. 2016).

These studies, if replicated in seldom-heard populations, could identify several areas where the cost-effectiveness of various interventions to prevent the onset of mental health problems needs evaluation. These can include financial support to reduce the risk of housing affordability issues, as well as measures to improve the quality of housing or to safeguard tenancy. Measures to reduce the risk of fuel poverty can also be assessed.

9.3.3 Economic evaluations to improve housing quality and affordability

We have looked at how to generate evidence on the association between housing and mental health. Here we briefly point to some illustrative examples of economic analyses of housing interventions to prevent and/or protect mental health in individuals at higher risk because of their housing situation. These interventions are not necessarily focused on young people or other seldom-heard population groups, but in principle the same approach could be used to evaluate impacts on various seldom-heard population groups.

One example is an economic analysis undertaken alongside a 'before and after' cohort study looking at the impact of the installation of new double-glazed windows to replace single-glazed windows, and installation of a new energy-efficient combi-boiler in social housing in north-east England (Bray, Burns et al. 2017). Costs of the intervention were documented and a modified version of the CSRI was used to collect data on the use of health care services by all household members over a six-month period. The primary outcome measure was self-reported health status for the household and also the main tenant; in addition, quality of life was measured for the main tenant using the EQ-5D-3L while wellbeing was measured using the Short Warwick-Edinburgh Mental Wellbeing Scale. Fuel poverty was assessed by recording how many rooms were left unheated due to energy costs, and what percentage of their household income was spent on energy bills.

After receipt of the intervention there was a significant reduction in the use of secondary health care services, with fewer rooms being left unheated and overall health status improved, although no difference in mental health was observed. Although a major limitation of this study is the lack of a control group, the study still gives an indication of what potentially can be done to build up an evidence base retrospectively for small-scale community interventions. Future studies might also be able to draw on literature to look at impacts without intervention, if it is not possible to include a control group in the evaluation.

The lack of randomised controlled trials or large-scale longitudinal studies that evaluate the impact of housing improvements were cited as key reasons for an evaluation in Wales looking at the benefits of a housing improvement scheme to bring social housing up to the Welsh Housing Quality Standard (Rodgers, Bailey et al. 2018). Impacts on health service utilisation, including changes in use of hospital accident and emergency, as well as GP services, for mental health were assessed. The impact on health service costs was then estimated. It was possible to link data records kept by Carmarthenshire County Council on residents of social housing with their demographic information, and a range of electronic health records including hospital admissions, accident and emergency attendance, and use of primary care services. While this study did

not find any specific impacts related to mental health service utilisation, it did report a reduction in hospital admissions. In the absence of controlled trials, in principle, this type of approach using data linkage might be used to further explore retrospectively whether there are specific impacts on seldom-heard population groups.

Although not an economic evaluation, we highlight a third and final example here, which is an evaluation again making use of data from Understanding Society to look at the introduction of an austerity measure to reduce governmental expenditure on social housing in England (Kim, Teo et al. 2022). We do this to illustrate how it can be possible to make use of longitudinal datasets to assess the impact of policy change. We have also previously noted that this dataset includes detailed markers of ethnicity and measures of mental health, potentially allowing for future work targeted more at different seldom-heard population groups.

In this example the study looked at the impact of the introduction of an "under-occupancy penalty" (popularly known as the 'bedroom tax') as part of the UK Welfare Reform Act 2012. This measure (still in place) reduces the Housing Benefit received by those on low incomes by 14% if one bedroom is unoccupied and by 25% if two or more bedrooms are unoccupied. The study, looked specifically at the impacts of this austerity measure on psychological distress using a 'difference in differences' methodology, comparing levels of psychological distress measured using the GHQ pre and post the introduction of the measure in intervention and comparator populations. A statistical technique known as 'propensity score matching' was used to create a comparator group from within the Understanding Society cohort that was matched on age, sex, marital status, education, ethnicity, employment status, presence of chronic illness, and place of residence.

Using this approach, the authors were able to judge that the 'bedroom tax' was associated with subsequent and persistent increases in psychological distress among Housing Benefit recipients. We can also point to evidence, again using longitudinal data, from the United States indicating that the opposite action, to provide additional financial support for renters, was associated with lower levels of psychological distress compared to renters not receiving this support (Denary, Fenelon et al. 2021).

In addition, it may be possible to retrospectively add an economic dimension to different studies that have already shown that interventions do have benefits for mental health. For example, one Glasgow study of a housing improvement and neighbourhood renewal project suggested an association between “external improvements including insulation, cladding, roof renewal and balcony repairs” and improvement in mental health (Curl and Kearns 2015). The costs of these improvements could be calculated and compared with the economic value of improvements in mental health.

9.4 What is the state of the evidence base?

In summary, despite many studies that focus on protecting the mental health of young people, there appear to be very few economic studies where there are opportunities for young-people in general, let alone seldom-heard young people, to have direct involvement in co-designing and co-producing the research. Outcomes that were considered to be important by young people in our focus group, such as the importance of friendships and more certainty over their future housing situation, are very different to the outcome measures, such as measures of clinical symptoms or behavioural problems, that are often favoured in economic evaluations. Our literature review suggests that some ongoing studies are putting some emphasis on working with young people, but the impact of this engagement on economic evaluation research design and outcomes remains to be seen. There remains a pressing need for more emphasis on age-appropriate forms of engagement with children and young people in the design of economic research if it is to better reflect their concerns.



10. Making it happen

Creating the conditions for more genuine collaboration with seldom-heard groups in research has implications for civil society organisations, researchers and research funders. In the final section of this report, we briefly set out some of the issues and how they may be addressed. It draws on feedback from focus group participants, literature discussed in earlier chapters on lived experience in research, as well as the authors' own experience.

10.1 Facilitating collaboration between civil society organisations and researchers

A good place for civil society organisations to start looking for partners would be to check the websites of local universities to see if they conduct health economic research. They might then reach out to universities to potentially co-create research with people from seldom-heard groups. As well as universities, other potential partners include research consultancy companies and government organisations that undertake health economic research.

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

10.2 Factors that help facilitate successful collaboration

10.2.1 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 co-production of research with people from seldom heard groups. Co-production should be transparent about values or ways of working, recognising and building shared values between groups. This can help overcome any distrust from past negative experiences around co-production with professional research groups.

10.2.2 Clear information on purpose and potential impact of research

Professional researchers need to provide a clear explanation, in accessible language, of the purpose of research, how it will be conducted, including co-production, what will happen to 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 this co-produced research can also help both with future implementation and further building trust.

10.2.3 Recognition as authors

Civil society organisations should also ensure that peer 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. Moreover, there should 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, where permission is given.

10.2.4 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. More generally, all research participants from seldom-heard groups should have any additional expenses covered and be compensated for their time providing input to research. Where monetary payments are not possible (because of legal restrictions), other forms of permitted compensation, such as vouchers should be provided.

10.2.5 Compensation for civil society organisations

It is also important that civil society organisations should be 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 means including financial (and potentially technical) support for data collection, as well as engagement with, and/or training, of seldom-heard groups.

10.3 Further implications for researchers/research funders

Finally, while this report is focused on facilitating the engagement of seldom-heard groups, often through 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 understanding health economic research will be limited within many civil society organisations.

Funders of research also have a critical role to play. 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 fairly funded for their participation. Similar support might also be provided to civil society organisation representatives.



Conclusions

We have seen how people in seldom-heard population groups can be at very high risk of experiencing mental health conditions, yet there is relatively little economic evidence on interventions to support their mental health. These groups typically have very little opportunity to contribute to policy making processes affecting their mental health because of power imbalances in society. They also appear to have relatively limited participation in the co-production of research, although this may be beginning to change. They need to be full partners in all aspects of the research process, from the initial prioritisation of research ideas, through all stages of design, implementation, analysis and communication of results. Research partnerships need to be equal and built on mutual trust, recognising that everyone has different valuable skills and insights to bring to the research process.

Where health economics research has focused on seldom-heard groups, it has been able to demonstrate the economic case for investing in various interventions, but this evidence base needs to be strengthened considerably. This includes co-producing health economic research on the costs and benefits of different strategies to reach seldom-groups and promote the uptake of cost-effective interventions.



Not all of this economic research relies on the need to conduct new empirical studies; economic modelling studies can bring together data from different sources to look at the likelihood of an intervention being cost-effective. This could be crucial; we refer in the report to the decision not to renew, let alone expand, the pilot programme providing young people who have left the care system in Wales with a monthly income. The evaluation of the programme, including economic evaluation, will not be completed until after the programme has ended. Yet, we also note that a modelling study looking at access to universal basic income in the UK suggests that not only does this improve mental health, but it actually is cost-saving. The evidence from that study might have been modified to make a similar case for the Welsh programme.

Finally, we want to emphasise the very important role that can be played by civil society organisations. We have separately produced a guidance document on co-producing health economics research for these organisations (see mentalhealth.org.uk/our-work/research/increasing-visibility-seldom-heard-groups-co-producing-health-economics-research-guidance-civil). Civil society organisations are likely to be critical in building trust between researchers and seldom-heard groups. Civil society organisations in turn need to be adequately compensated by research funders for their role in research studies. We heard from one of our focus groups that they may not otherwise have any time and resource for research participation. Researchers from seldom-heard groups should also be paid in the same way as other researchers and be given opportunities to strengthen their research skills and build research careers.

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Appendix 1: Table of economic analyses

Author, year, country of study	Study population	Source of data	Evidence of role of seldom-heard groups in design and outputs of research	Objective	Key findings
Abebe et al, 2017, Norway	All population aged 0-59 using specialist mental health services between 2008–2011.	Norwegian Patient Registry for health service use linked to socio-demographic info from Statistics Norway.	None	Examine use of specialist mental health services among ethnic Norwegians and specific immigrant groups.	Compared with ethnic Norwegians, use of mental health services was higher in migrants from Iran and Iraq (higher), similar in migrants from Bosnia-Herzegovina, Pakistan, Russia, Sweden and Turkey and significantly lower in migrants from Poland, Somalia, Sri Lanka, and Vietnam. Refugees also generally have a slightly higher use of services, whereas economic migrants have a lower use of services.
Amin et al, 2021, Sweden	All refugees and Swedish-born individuals aged 20–64 receiving specialist care following suicide attempt between 2004–2013.	Swedish Patient Registry for health service use linked to socio-demographic info from Statistics Sweden.	None	Examine use of specialist mental and physical health services 3 years before and after a suicide attempt, between refugees and the Swedish-born individuals in Sweden. Also determine if differences among refugees by sex, age, education or receipt of disability pension.	Refugees used less specialised health care services, before and after a suicide attempt, relative to Swedish-born. Refugees receiving disability pensions had significantly higher use of specialist health care services than other refugees.
Arundel et al, 2021, Netherlands	All population aged 25-65, excluding those still living with parents.	Representative panel dataset of taken from Netherlands Population Registry.	None	Examines trends in housing affordability and link to mental health by age and type of housing tenure.	Unaffordable housing is concentrated within the rental sector and much more likely to impact young people. Clear association between housing unaffordability and poorer mental health, especially among renters and younger people.
Axelsson et al, 2020, Sweden	All children born 1988-1988 followed from 2002 to 2011 who were either born in Sweden to two Swedish parents or permanent residents who had arrived as accompanied or unaccompanied child refugees.	Swedish Patient Registry for health service use linked to socio-demographic info from Statistics Sweden.	None	Examine use of mental health services by unaccompanied and accompanied child refugees, as well as Swedish-born children.	Swedish-born children were less likely to use mental health services compared with unaccompanied refugee children but more likely to use mental health services compared to accompanied migrant child refugees. Unaccompanied child refugees may be better embedded in Swedish society than other child refugees and have fewer barriers to service access.

Bauhoff et al, 2018, Germany	3,639 Children and adult asylum seekers registered with health insurer and matched with resident population group.	Health record data from a social health insurance company in Germany.	None	Examine the morbidity, use and costs of care for asylum-seekers compared to resident population.	Average total expenditures were 10% higher for asylum-seekers than for regularly insured. Asylum seekers had double the rate of admissions for mental health, but lower rates of outpatient mental health service use. Prior insurance authorisation and cultural issues may act as barriers to mental health service use.
De Montgomery et al, 2020, Denmark	Permanent residents between 1995 to 2016, and born between 1980 and 1994. Including child refugees and children of economic migrants from Morocco, Pakistan or Turkey.	Data from multiple national registries linked using unique personal identifiers.	None	Examine mental health service use during transition from childhood to adulthood for refugees, children of labour migrants and the rest of population.	Refugees and children of economic migrants were less likely than rest of population to make use of services for most mental health conditions other than schizophrenia in boys which was similar to general population. Children from the minority groups that did have contact with mental health services could have the same or higher rates of inpatient and emergency care contacts, but significantly lower rates of outpatient contacts with mental health services. Suggested that refugees and other ethnic minority groups face barriers to initial and continuing use of services.
Denary et al, 2021, USA	Longitudinal data from a cohort of 400 low-income adults living in New Haven, CT.	Justice, Housing, and Health Study (JustHouHS) survey of low income residents in New Haven.	None	Examine how access to rental assistance affects mental health.	Rental assistance associated with significantly less psychological distress than those waiting for assistance. Obtaining rental assistance may also be associated with decreases in psychological distress, but this was not significant. Expanding rental assistance may help promote mental health of low-income individuals.
Dotsikas et al, 2022, UK	30,025 households from around the UK, with varied income and housing situations.	Data from Understanding Society, a longitudinal household survey in UK.	None	Examine the association between trajectories of housing affordability problems and mental health.	Trajectories of housing affordability problems over nine years were associated with worse mental health. Continued years of housing affordability problems are associated with worse mental health than regular exposure to few or no affordability problems.
Grochtdreis et al, 2021, Germany	133 Syrian refugees in Germany aged between 18 and 65	Baseline data from participants of a trial of a self-help app for Syrian refugees with PTSS.	None	Examine use of health care services, their costs and quality of life of Syrian refugees with mild to moderate post-traumatic stress symptoms in Germany.	Health care use and costs of Syrian refugees who are not currently receiving mental health treatment are low. Higher severity of symptoms was associated with lower quality of life. The low use of services and costs could imply an under use of services.

Gubi et al, 2022, Sweden	Children and young adults (n = 591,816), born between 1991 and 2011 and living in Stockholm county between 2006 and 2015. All individuals were permanent residence.	Swedish Patient Registry for health service use linked to socio-demographic info from Statistics Sweden on people in Stockholm.	None	Examine the use of mental health services by migrant children and young people and determine whether any low use of services might be linked to lower rates of mental health assessment.	Migrant children and young people youth used significantly less mental health services than the rest of the population. The one exception was young unaccompanied refugees (0–10 years) who had similar rates of service use to general population. Lower rates of service use may, in part, be linked to lower likelihood of being diagnosed with a mental health condition.
Hughes et al, 2021, EU	All relevant studies that had data that could be used to estimate costs of adverse childhood events (ACE).	Systematic review of literature and meta-analysis.	None	To estimate the annual health and financial burden of ACE in 28 European countries.	ACEs are associated with major health and financial costs across European countries. Anxiety and depression were among the most substantial costs that were linked to ACEs, along with violence, harmful alcohol use, illicit drug use.
Kim et al, 2022, UK	UK Households receiving housing benefit.	Data from UK Household Longitudinal Study (2010-2014.)	None	Examine impact of the underoccupancy penalty (bedroom tax) on levels of mental health distress.	The implementation of the reform was associated with a moderate increase in psychological distress among housing benefit recipients.
Maier et al, 2010, Switzerland	78 asylum seekers from the Zurich area.	Survey of non-random sample of asylum seekers via list provided by Federal Office of Migration. Health care use taken from insurance records.	None	Examine the current mental health status and health care service use for adult asylum seekers.	41% of asylum seekers had at least one psychiatric disorder, primarily major depression and posttraumatic stress disorder. Healthcare costs were 1.8 times greater than those of the average resident population. Although asylum seekers had higher contact rates with medical services when they had significant mental health problems they received little treatment.
McCrone et al, 2005, England	143 Somali refugees in east and south London. Half living in UK for more than 2 years.	Survey of Somalis recruited in areas of London where known to live by identifying surnames and also by reaching out at venues used by Somali community café's, mosques, colleges etc.	Research team included Somali researchers.	Examine mental health needs and service use of Somali refugees living in London.	Needs of refugees high, but needs not being well met. Most frequently used services were GP and specialist refugee services. Very low contact with psychiatrists. No use of including community mental health nurses and social workers.

Straiton et al, 2017, Norway	53,747 immigrants in Norway.	Norwegian Patient Registry for health service use linked to socio-demographic info from Statistics Norway.	None	Examine whether the use of mental health services in Norway differs between refugees and non-refugees originating from the same countries.	Refugees were more likely to use primary health care services than non-refugees.
Stromme et al, 2020, Norway	353 Syrian refugees aged 16+ relocated from Lebanon to Norway.	Client service receipt inventory (CSRI) Survey of adult Syrian refugees in Lebanon subsequently followed up one year later in Norway.	Survey piloted with refugees and then adapted.	Examine changes over time in physical and mental health status and medication use among Syrian refugees relocating from Lebanon to Norway.	Mental health outcomes improve from a conflict-near transit setting in Lebanon to early resettlement setting in Norway. There was no change in physical health, pain or medication use.
Sueki, 2018, Japan	249 university students.	Students recruited through a university lecture completed 'conjoint analysis' questionnaire.	None	To undertake survey to elicit people's preferences regarding suicide prevention strategies adopted in Japan.	The highest level of willingness to pay for suicide prevention strategies was for restriction of access to means and improved psychiatric services. Public awareness campaigns were the least preferred strategy.
Toar et al, 2009, Ireland	Asylum seekers and refugees aged 18+. Asylum seekers were living in two direct provision centres in Sligo and Leitrim, Ireland with refugees living in the same local communities.	Survey on health status and health service utilisation for asylum seekers.	None	Examine utilisation of health services by asylum seekers and refugees in Ireland.	Asylum seekers use GP services more often than refugees, while no significant difference was found between these groups for use of dentists, medication, hospitalisation or mental health services.
Waldmann et al, 2021, Germany	332 children and adolescents with parents with mental illness taking part in trial in Germany.	Completion of Child and Adolescent Mental Health Service Receipt Inventory (CAMHSRI) as part of a trial.	None	Examine use and costs of mental health and social services for children and adolescents with parents with mental illness in six regions of Germany.	Children with a psychiatric diagnosis had mean costs €5,692 compared to €1,245 for children without a psychiatric diagnosis. Although costs higher for children with diagnosis condition, those without diagnosis also made substantial use of mental health services.

Table of economic evaluations

Author, Year, country of study	Setting and study population (age, sex, size)	Intervention details (study design, description of intervention, and comparator)	Evidence of role of seldom-heard groups in research	Type of economic analysis / Study duration	Key economic findings
Bager, 2018, Denmark	45 adult refugees (66% Iraqi) who has been severely traumatised as a result of torture. 44 matched controls for long term CBA.	Observational study. Intervention: Multi-disciplinary rehabilitation programme for severely traumatised torture survivors. Mean 14.3 months of treatment Control: refugees currently on waiting list for treatment only for CBA.	None	CUA and CBA 23 months (CUA) 14 years (CBA)	Cost per QALY gained DKK 262,530 (Authors note within UK cost effectiveness threshold). In CBA from individual perspective after 14 years costs outweigh benefits. From family perspective positive net benefits after 3 years.
Barnes et al, 2017, UK	166 expectant mothers.	RCT: Group Family Nurse Partnership (gFNP), a home-based nurse home-visiting programme to support vulnerable parents, compared with usual care.	Not involved in design, but interviews and discrete choice experiment informed results	CUA 12 Months	gFNP only had a 3% chance of have a cost per QALY value that would be considered cost effective. However, a discrete choice experiment highlighted the value placed by both pregnant women and members of the general population on other non-health outcomes including having enough support from family and friends or having a high level of understanding of the needs of the child.
Biddle, 2019, Germany	Hypothetical population of 1,000 newly arrived adult refugees and asylum seekers.	Modelling study. Intervention: Nurse screening using PHQ-9 for depression with 12 sessions of CBT over 3 months for moderate/severe depression. Comparator: Case-finding via self-referrals and follow-up care by non-profit psychosocial centres.	None	CUA 15 months	Cost per QALY gained €19,779. 83% chance of cost per QALY gained below €50,000.
Boge et al, 2022, Germany	584 Arabic or Farsi speaking refugees and asylum seekers aged 14-65 with at least mild depressive symptoms (PHQ-9 or PHQ-Adolescents score of 5 or more) and psychological distress (Refugee Health Screener RHS-15).	RCT. Intervention: 4 Level Stepped Care and Collaborative Care Model. Comparator: Treatment as usual. Maximum treatment duration for each level 12 weeks.	None	CEA and CUA 1 year	The intervention was dominant with significantly lower health system costs and (non-significantly) improved QALYs gained. High probably of being cost effective in uncertainty analysis.

Key: CBA: Cost-Benefit Analysis, CEA: Cost-Effectiveness Analysis, CUA: Cost-Utility Analysis, CCA: Cost Consequences Analysis, ROI: Return on Investment Analysis, QALY: Quality Adjusted Life Year

Bray et al, 2017, England	228 social housing tenants in the north east of England.	Observational study: warmth-related social housing improvements compared to existing, unmodified social housing.	None	CCA 12 months	Average intervention cost £3725 with 16% reduction in health service use and significant improvements in health status. Authors concluded warmth-related housing improvements may be cost-effective in improving the health and reducing health service costs of social housing tenants.
Chen et al, 2023, UK	Hypothetical individuals, with characteristics informed by Understanding Society cohort study.	Modelling study: to examine case for introduction of regular Universal Basic Income payment (UBI) to all adults to support basic needs.	None	CBA 21 years	UBI could substantially protect young people's mental health, and would be associated with substantial long term health costs averted. Potential long-term savings of up to £4.6 billion.
Cresswell et al, 2024, England and Northern Ireland	444 children aged 5-13 with child anxiety problems.	RCT: Therapist-supported, parent-led cognitive behavioural therapy using a Online Support and Intervention (OSI) for child anxiety platform compared with treatment as usual for child aged 5–12 with anxiety problems.	None	CUA 26 weeks	OSI plus therapist support is likely to be cost effective, but there is a high level of uncertainty because of the marginal positive impact on quality of life.
Crossroads, 2008, England	Hypothetical population of young carers.	ROI: Young carers projects for young carers of parents with mental illness or substance abuse.	Carers told their own stories of experience – this was used to inform ROI estimates.	ROI 12 months	ROI of £6.72 for every £1 invested. Young carers projects have an 11% impact on reducing truancy among the young carers they work with. Such projects are estimated to have a 1% impact on reducing the risk of the young carers with whom they work being taken into local authority care; and a 2.5% impact on reducing the risk of the young carers they work with from becoming teenage parents.
De Graaf et al, 2021, Netherlands	60 adult Syrian refugees with psychological distress.	RCT. Intervention: 5 weekly sessions of Problem Management Plus (PM+) plus care as usual. Control: care as usual.	Syrian peers members of research team	CEA 3 months	Incremental cost per recovery achieved €5,047 and €2,266 from health system and societal perspectives.
Forsythe et al, 2022, USA	LGBTQ young people aged 13 to 24 years in US States where conversion therapy was legal.	Modelling study: Sexual orientation and gender identity change efforts (conversion therapy) versus no intervention.	None	CUA Lifetime	Conversion therapy would cost in \$97 985 lifetime costs per individual with a mean loss of 1.61 QALYs lost versus no intervention. Extrapolated to all US States where such therapy is legal would cost an \$650 million to implement and associated with additional lifetime harms of \$9.23 billion.

Furlong et al, 2021 and 2024, Ireland	83 families with children aged 5-18 with a parent with mental illness.	RCT: Family therapy versus usual care for children aged 5-18 with a parent with mental illness.	None	CCA 6 months	Significant improvements in family functioning and child behaviour at six-month follow up when compared to usual services with an implementation cost of €761.50 per family.
Gillard et al, 2023, England	Detailed data on use of services by adults at Mental Health Trusts and general hospitals in England.	Observational: Mental health decision units (short stay crisis care units without beds) were compared to usual care for a mental health crisis.	People with lived experience were full members of research team	CCA, ROI 12 months	Marginal reduction in cost to specialist mental health service providers at site level observed in interrupted time series analysis. Large differential in annual mental health decision unit costs linked to staffing levels; and costs of units not offset by potential cost savings. Potential to be cost if modest quality of life gains achieved.
Herman et al, 2015, USA	202 (84.2 % of those randomly assigned to group) mothers and 194 (80.8 %) of young people (originally aged 9-12) participated in the 15-year follow-up.	RCT: two versions of New Beginnings Programme, a single-component parenting-after-divorce programme (Mother Programme, MP) and a two-component parenting-after-divorce and child-coping programme (Mother-Plus-Child Programme, MPCP), plus hypothetical control group.	None	CBA 15 years	Discounted incremental benefits were \$1077 per family, outweighing cost of \$633 per family for the MP version of the programme.
Lynch et al, 2014, USA	117 pre-school children entering a new foster placement.	RCT: Multidimensional Treatment Foster Care for Pre school children in foster care versus regular foster care.	None	CBA 9-12 months per child	Mean total cost for the intervention group significantly lower than regular foster care group. Positive net benefits when economic value of additional successful placements with families included in analysis.
Lynch et al, 2019, USA	316 adolescents, aged 13–17, at high risk for depression because they previously experienced depressive disorder, subthreshold depressive symptoms, or both, and had parents with a prior or current depressive disorder.	RCT: Cognitive-behavioural prevention (CBP) program versus usual care (UC for prevention of depression in high risk adolescents.	None	CUA 9 months and 33 months	For children whose parents were not depressed at baseline, at 33 months the incremental cost per QALY gained of \$10,498, would be considered highly cost effective in the US. For children whose parents were depressed at baseline, the intervention has no significant effect and was more costly, so it would not be considered cost effective.

Park et al, 2022, Türkiye	627 adult Syrian refugees with mild psychological distress.	RCT. Intervention: Self-Help Plus, a five-session, group-based, stress management course in which participants learned self-help skills. Includes illustrative book plus enhanced usual care. Comparator: enhanced usual care.	None	CUA 1 year	Incremental cost per QALY gained T€6,068, well within reported cost effectiveness thresholds in Türkiye.
Rodgers et al, 2018, Wales	32,009 residents registered for a minimum of 60 days at 8558 social homes that received housing improvements between January 2005 and March 2015 in Carmarthenshire.	Multiple internal and external housing improvements, e.g. wall and loft insulation, windows and doors, heating and kitchen upgrades.	None	CCA Up to 123 months	Significant reduction in use of health care services and costs averted which help offset some of the cost of implementing the intervention.
Rohr et al, 2021, Germany	133 Syrian refugees aged 18-65 with mild to moderate posttraumatic stress symptom severity.	RCT. Intervention: smartphone app providing cognitive behavioural therapy-based self-help. Comparator: Psychoeducational reading material.	None	CUA 4 months	The intervention was very unlikely to be cost-effective. Only a 20% chance at a plausible cost per QALY threshold of €50,000.
Social Value Lab, 2011, Scotland	Hypothetical participants of craft café.	ROI: Craft café pilots to help reduce isolation and loneliness in older people.	Interviews with 19 older participants informed analysis.	ROI	Craft Café pilots estimated to have a social return on investment of £8.27 : £1.
Spaaij et al, 2022, Switzerland	59 adult Syrian refugees. 75% had the right to work in Switzerland.	Pilot RCT: Individual brief psychological therapy (Problem Management Plus) versus usual care for conflict affected Syrian refugees.	None	CUA 3 months	All clinical outcomes improved in both treatment arms. There was no significant difference in service use at baseline, nor at post-intervention or 3 month follow up between trial arms. Definitive trial needed to determine cost effectiveness.
Waldmann et al, 2023, Germany	337 families with a child aged 3-19 and at least one parent who had received treatment for mental illness within the previous five years.	RCT: CHIMPs, a manualised eight session psychologist psychological intervention for families where parent has a mental illness. The control group received usual care.	None	CUA 24 months	There was no significant different in quality of life or in costs between the intervention and control group.
Wansik et al, 2016, Netherlands	99 parents with longstanding mental health problems, being currently treated and having a child aged between 3 and 10 years of age.	RCT: Family-focused strength-oriented rehabilitation model versus control group receiving information sheet on impact of parental problems on children.	None	CEA 18 months	Cost per one point improvement on HOME scale (a measure of parenting quality) were €461 Euros (healthcare perspective), €215 Euros (social care perspective) and €175 Euros (societal perspective).

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