National Institute for Health and Care Excellence

Final

Advocacy services for adults with health and social care needs

[K] Monitoring services and collecting data for quality improvement

NICE guideline NG227

Evidence review underpinning recommendations 1.8.8, 1.11.2 to 1.11.18 and 1.9.5, as well as research recommendation 1 in the NICE guideline

November 2022

Final

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Key theme

- Monitoring services and collecting data for quality improvement

Introduction

The aim of this review is to identify key aspects of monitoring and data collection which can be used to improve the quality of advocacy services.

Recommendations about advocacy have been made in a number of existing NICE guidelines. However, these have identified a lack of evidence relating to advocacy that would meet inclusion criteria for standard evidence reviews. Therefore, it was agreed that recommendations for this guideline would be developed by adopting and adapting advocacy-related recommendations from existing NICE guidelines, using a formal consensus process based on statements generated from a call for evidence, and documents identified by the guideline committee, and informal consensus methods to address any areas of the guideline scope that are not covered by the existing NICE guidelines or the formal consensus process.

Summary of the inclusion criteria

Please see Table 1 for a summary of the inclusion criteria applied to evidence received in response to the call for evidence and identified by the guideline committee.

Table 1: Summary of the inclusion criteria

Country	UK
Geographical level	National* *For policy or guidance documents, this means, the policies and recommendations apply nationally. For original research, this means the studies have been conducted in the national policy and practice context of our scope, i.e., the English health and social care system
Publication date	2011 onwards
Study design	Primary qualitative or quantitative studies (including unpublished research), excluding case-studies Systematic reviews of qualitative or quantitative studies, excluding case-studies Guidelines or policy documents that are based on qualitative or quantitative evidence, excluding case-studies
Topic areas	Monitoring services and collecting data for quality improvement

Methods and process

The process for identifying, adopting and adapting recommendations from existing NICE guidelines, the call for evidence and formal consensus methods are described in supplementary material 1.

Declarations of interest were recorded according to NICE's 2019 conflicts of interest policy (see Register of Interests).

Effectiveness evidence

Included studies

Existing NICE guidelines

Existing recommendations relevant to monitoring services and collecting data for quality improvement were identified from 2 NICE guidelines ([NG108] Decision-making and mental capacity, [NG189] Safeguarding adults in care homes). The audiences for these guidelines included: people with the condition or users of a services and their families and carers; health and social care professionals, practitioners and providers; service managers; commissioners, local authorities, and Safeguarding Adults Boards; and other staff who come into contact with people using services (for example, housing, education, employment, police and criminal justice staff). Both NG108 and NG189 specifically listed independent advocates (with statutory and non-statutory roles) among their target audiences.

Formal consensus

A single call for evidence was undertaken for all topics included in the scope of this guideline. Additional documents were identified by the guideline committee. See the study selection flow chart in appendix A.

Twelve documents were identified for this review (Lawson 2017, Lawson 2020, Macadam 2013, Mercer 2020, National Development Team for Inclusion [NDTi] 2014b, NDTi 2014c, NDTi 2016a, NDTi 2016b, Newbigging 2012, Ridley 2018, Roberts 2012, Turner 2012).

Four documents focused on providers and commissioners of independent advocacy (Lawson 2017, Lawson 2020, NDTi 2016a, NDTi 2016b). Two documents focused on people living with learning disabilities (Roberts 2012, Turner 2012). Two documents focused on people detained under the amended Mental Health Act 1983 (including people with and without capacity and children under the age of 16) (Newbigging 2012, Ridley 2018). Two documents focused on people living with disabilities (NDTi 2014b, NDTi 2014c). One document each focused on: people who use social care services (Macadam 2013) and independent advocacy services (Mercer 2020).

Excluded studies

Formal consensus

Documents not included in this review are listed, and reasons for their exclusions are provided in appendix D.

Summary of included studies

Summaries of the documents included in the formal consensus process for this review are presented in Table 2.

Table 2: Summary of documents included in the formal consensus process

Document	Population	Evidence base
Lawson 2017 Report England	Those who have duties to commission and arrange advocacy services for safeguarding adults	Report drawing on existing literature (including statutory guidance and core principles for safeguarding) to set out what needs to be done and what needs

Document	Population	Evidence base
		to be addressed to make safeguarding personal
Lawson 2020 Briefing report England	Those who have duties to commission and arrange advocacy services for safeguarding adults	Briefing generated by a series of conversations with 28 advocates from 18 advocacy providers across England, covering 33 local authority areas
Macadam 2013 Scoping review England	People who use social care services	Systematic scoping review and call for evidence with content analysis
Mercer 2020 Scoping review England	Independent advocacy services commissioned to provide advocacy to people accessing support/service through: i) s117 aftercare (under the Mental Health Act) ii) NHS CHC (adults) iii) Children and Young People's CC iv) Personal Health Budgets; v) Personal Wheelchair Budgets	Non-systematic scoping exercise including data from: Freedom of information requests to identify what services were commissioned, by whom and to which groups; advocacy survey for advocates to identify what advocacy providers are delivering; semi-structured telephone interviews with Independent Advocacy providers; review of legislation and guidance to identify current provision and identify gaps
NDTi 2014b Briefing note/Executive summary England	People living with disabilities	Survey (with 200+ responses) and fieldwork at 4 sites; also mentions 'mapping of the advocacy sector'
NDTi 2014c Briefing note/Executive summary England	People living with disabilities	Survey (with 200+ responses) and fieldwork at 4 sites; also mentions 'mapping of the advocacy sector'
NDTi 2016a Framework England	Providers and commissioners of independent advocacy	Literature review (no details reported) and consultation with two self-advocacy groups
NDTi 2016b Toolkit England	Providers and commissioners of independent advocacy	Literature review (no details reported) and consultation with two self-advocacy groups
Newbigging 2012 Research report England	People detained under the amended Mental Health Act 1983, who were eligible for support from IMHA services, including people with and	Multiple methods (including literature review, 11 focus groups, shadow visits with IMHAs, expert panel review) to obtain information on IMHA services to

Document	Population	Evidence base
	without capacity and children under the age of 16	develop draft quality indicators for IMHA services. Data from 8 case studies (NHS Trust areas) to understand experiences of qualifying service users and the commissioning and delivery of IMHA services and their relationship with mental health services
Ridley 2018 Review of 3 qualitative studies England	African and African Caribbean men using mental health services; adults and children detained under the Mental Health Act 1983; children and young people receiving advocacy services	Comparative analysis and synthesis of findings from 3 qualitative studies (including service user, advocate, professional and commissioner perspectives); data collected through focus groups and/or interviews
Roberts 2012 Survey England	People with learning disabilities	3 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies; provides information on, for example, funding and also discusses gaps in advocacy provision and barriers to accessing services
Turner 2012 Brief report England	People with learning disabilities	2 surveys (responses from 78 local authority commissioners and 88 advocacy providers) and 3 case studies (no detailed methods reported); provides advice and suggestions on actions for commissioners and advocacy groups to provide robust evidence on the effectiveness and reach of advocacy services

CC: continuing care; IMHA: Independent Mental Health Advocate; NDTi: National Development Team for Inclusion; NHS CHC: National Health Service Continuing Healthcare; ODI: Office for Disability Issues.

See the full evidence tables for documents included in the formal consensus process in appendix B and a summary of the qualitative assessment of these documents in appendix C.

Summary of the evidence

Existing NICE guidelines

A total of 3 existing recommendations related to monitoring services and collecting data for quality improvement were identified from the 2 NICE guidelines. The committee agreed all 3 recommendations should be adapted.

See Appendix F for a list of the existing recommendations, a summary of the supporting evidence behind these recommendations, and the decisions made based on the committee's discussion of these recommendations.

The quality of existing NICE guidelines was assessed using the Appraisal of Guidelines for Research & Evaluation Instrument (AGREE II). See the results of the quality assessment in appendix C.

Formal consensus round 1

Three included documents (Lawson, 2017; NDTi, 2016a; NDTi, 2016b) were assessed using AGREE II. Three documents (Macadam, 2013; Mercer, 2020; Ridley, 2018) were assessed using the Risk of Bias in Systematic reviews (ROBIS) checklist and 6 included documents (Lawson, 2020; NDTi, 2014b; NDTi, 2014c; Newbigging, 2012; Roberts, 2012; Turner, 2012) were assessed using the Critical Appraisal Skills Programme (CASP) tool for qualitative research. See the results of the quality assessment in the evidence tables in appendix B and quality assessment tables in appendix C.

The committee were presented with 139 statements in round 1 of the formal consensus exercise; responses were received from 11 of 13 committee members. Sixty-eight of these statements reached ≥80% agreement in round 1 and were included for the discussion with the committee. Forty statements had between 60% and 80% agreement. Thirty-seven of these were redrafted for round 2 and the remaining 3 statements were discarded; 2 statements were not used because the revisions required to address the comments were already covered by existing statements and 1 statement was not used because the committee agreed the issue raised by the statement would be addressed by recommendations made elsewhere in this guideline. Thirty one statements had <60% agreement; of these, 12 were redrafted for round 2, because the comments raised addressable issues and suggestions for revision, and the remaining 19 statements were discarded.

See appendix G for the statements that were rated by the committee and results of round 1, which are provided in Table 12.

Formal consensus round 2

The committee were presented with 51 statements in round 2 of the formal consensus exercise; responses were received from 12 of 13 committee members. Two sets of 3 statements were combined into 1 statement each, 1 set of 3 statements was combined in 2 statements and a pair of statements was combined; additionally, 1 statement was split into 3 statements and another was split into 7 statements. Forty-one statements reached ≥80% agreement and were included for the discussion with the committee. Nine statements had between 60% and 80% agreement. Five of these were included for the discussion with the committee, because the comments related to how the statements might inform recommendations rather than the content of the statements, and the remaining 4 statements were discarded. One statement had <60% agreement and was discarded.

See appendix G for the statement that was rated by the committee and results of round 2, which are provided in Table 13.

Economic evidence

Economic considerations will be taken into account together with resource impact.

The committee’s discussion and interpretation of the evidence

The outcomes that matter most

In the methods used for this guideline (adopting and adapting existing recommendations and formal consensus) no outcomes were considered formally by the committee; therefore, the committee were not required to determine which outcomes were critical or important.

The quality of the evidence

Existing NICE guidelines

The quality of the existing NICE guidelines was assessed using AGREE II. Overall, the guidelines are of a very high quality (2 or more domains scored ≥90%) and are recommended for use. One guideline scored lower in stakeholder involvement because there were fewer experts by experience included in the committee group compared to other guidelines. A few guidelines scored lower due to vague descriptions of facilitators and barriers to implementing recommendations in the applicability domain. In addition, the committee considered whether the recommendation could be generalised to a new context when making a decision about adopting or adapting the recommendations, which is documented in the benefits and harms section and appendix F.

Formal consensus

The quality of some of the documents identified by the committee and through the call for evidence was assessed using ROBIS and the AGREE II tool, which is explained in detail in the methods supplement for this guideline. ROBIS is intended for use in assessing the quality of systematic reviews but was also used for the purpose of this guideline to assess a number of reviews that were not intended by the authors to be systematic as it was the best available tool. The AGREE II instrument is intended for use assessing the quality of systematically developed clinical practice guidelines, including assessments of methodological rigour and transparency. Therefore, some domains of ROBIS and the AGREE II tool may be less relevant for these documents and they would not have followed reporting guidelines for systematic reviews. All supporting material published with documents was reviewed to inform quality assessment, however it was not feasible to contact the authors of each document. Therefore it is plausible that the documents may have scored lower on quality assessments than the underlying methodology would warrant had authors made their full methodology available or if more appropriate tools were available. The committee were aware of this in their discussions of the existing recommendations and statements extracted from documents identified from the call for evidence. Where shortcomings in the quality of documents impacted the committee's opinions about using the statements, this is described in the benefits and harms section below. On the whole however, where there was full committee support for a statement extracted from a lower quality document, the committee made the recommendation because their experiential knowledge corroborated the statement and strengthened the argument to use it as the basis for a recommendation.

The quality of 3 documents (Lawson, 2017; NDTi, 2016a; NDTi, 2016b) were assessed using the AGREE II instrument. High quality documents were defined as those where any two domains scored ≥ 70%. The 3 documents were not deemed to be high quality. The included documents scored between 22% and 28% for stakeholder involvement; between 4% and 46% for applicability; between 8% and 10% for rigour of development and between 0% and 17% for editorial independence. Overall, the documents did not provide sufficient information on the stakeholder involvement in the development of the document. It was unclear whether the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the document were considered. The methods used to formulate and update the recommendations, and details on whether a systematic process had been used to gather and synthesise the evidence, were not clearly described. Declaration of any bias or competing interests from the document development group members were not reported.

The included document scored between 22% and 61% for scope and purpose, and between 22% and 56% for clarity of presentation. Generally, the overall aim, specific health questions and target population for the documents were described, but details were sometimes limited. The document did not present recommendations in a clear and concise structure and format.

The quality of 3 documents (Macadam, 2013; Mercer, 2020; Ridley, 2018) were assessed using the ROBIS checklist for systematic reviews. One document (Macadam, 2013) was judged to have unclear risk of bias because insufficient details were provided to enable a judgement to be made. Two documents (Mercer, 2020; Ridley 2018) were judged to be at high risk of bias.

Methodological limitations included a lack of clear reporting or an absence of reporting about eligibility criteria. Other concerns related to insufficient information on study selection, lack of critical appraisal of included papers, and an absence of testing the robustness of the review findings.

The quality of 6 documents (Lawson, 2020; NDTi, 2014b; NDTi, 2014c; Newbigging, 2012; Roberts, 2012; Turner, 2012) were assessed using the CASP checklist for qualitative research. One document (Newbigging, 2012) was judged to have minor methodological limitations. The remaining 5 documents (Lawson, 2020; NDTi, 2014b; NDTi 2014c; Roberts, 2012; Turner, 2012) were judged to have serious methodological limitations because of insufficient detail relating to participant recruitment, data collection and data analysis. Other concerns related to the lack of adequate consideration for the relationship between researcher and participants, and lack of consideration regarding ethical issues.

Benefits and harms

The committee acknowledged that the majority of statements had been extracted from a documents judged to be of lower quality. However they were in full agreement with these statements and because their own knowledge and experience chimed with the point being made they concluded it would be important to make recommendations on that basis and that the benefits of doing so outweighed any risks of excluding these statements altogether.

Recording of anonymised information

Several statements (6, 10, 11, 14, 15, 31 and 34) covered recording information about people who use advocacy services. For clarity and to avoid repetition, the committee agreed to combine these statements into one recommendation covering information that should be recorded about people using advocacy services. From their knowledge and experience, the committee were aware that there is variation in what information about people using advocacy services is collected. They agreed that collecting information about this is important in order to capture how services are used, as this will help to identify gaps in service provision and assess if services are meeting local needs. The committee discussed the different types of information mentioned in the statements and agreed that the following information should be recorded: information on the nine protected characteristics from The Equality Act 2010, communication preferences, reasons for referral, and type of location, for example whether people are in an urban or rural area and whether they live in independence accommodation or a care home. Statements 15 and 34 specifically mentioned recording information on protected characteristics. The committee agreed that this was particularly important based on their knowledge and expert witness testimony (see evidence review F) that some populations are over-represented in mental health services and under-represented in advocacy services. Therefore, collecting information on protected characteristics would help to identify whether there are particular groups that are not receiving services that they would benefit from and help to reduce health and other inequalities. The committee agreed to include type of location in the data that could be collected as this is an example of something that would fall within the area of demographic characteristics (covered by statements 16, 15 and 34) that was not already covered by the inclusion of protected characteristics. Furthermore, including data on type of location could help to identify place based gaps in the availability and provision of advocacy. The committee also discussed that information on communication needs and preferences (covered by statement 10) and reasons for referral (covered by statement 11) are useful to record because it provides information about the profile of a person, which can then inform what the local need is, rather than simply collecting information about their characteristics. For the same reason, the committee agreed that it was important to record information about whether advocacy is instructed or non-instructed.

Collecting information on the impact of advocacy services

There were a large number of statements related to collecting data about the impact of advocacy services. The committee agreed that these statements could be broadly grouped into those related to the format or source of information (statements 19, 21, 33, 79-81, 97-98, 102, 109, 112, 125 and 135) and those that related to what outcomes should be measured in order to demonstrate the impact of advocacy services (statements 8, 13, 22, 23, 40, 55-72, 92, 94, 101, 103, 108, 110, 111, 114, 115 and 125).

The committee discussed that information about the impact of advocacy services is not routinely collected in a standardised format and agreed that doing so would facilitate evaluation of the data thereby helping to find out if services are effective and where improvements are needed. The committee discussed the different methods of collecting this information mentioned in the statements, including survey data (covered by statement 80), case studies (covered by statements 21, 81 and 102), numbers or proportion of people reporting or achieving an outcome (covered by statement 79), and people's experiences and views of advocacy services (covered by statements 19, 21, 79, 97-98, 102, 109, 112, 125 and 135). The committee agreed that all of these sources of information would be helpful to determine the effectiveness of advocacy services and for quality improvement so included them as examples in the recommendation. The committee discussed that although services may not routinely collect this information, most advocacy services should already have methods of collecting this information. In addition, statement 77 highlighted the need to analyse or evaluate data that is collected. The committee agreed that this is an important step in order to facilitate the sharing of key information with other organisations, which is discussed in more detail below.

The committee discussed that it is important to measure outcomes that show the impact of advocacy services across a broad range of areas to gain sufficiently detailed and meaningful information that can lead to real improvements in services. The committee agreed that currently advocacy services are largely focused on individual outcomes but that understanding population level needs provides a broader view of the services required in an area. The committee discussed that services, which are responsive to people's needs, are likely to be more efficient than those that only focus on the needs of some individuals. Although this would be a change in practice, the committee agreed it would help to commission more effective advocacy services and generate improvements across health and care systems. The committee also acknowledged that having a broader view of services is consistent with developments in Health and Social Care services, such as the move to Integrated Care Systems. The committee discussed the outcomes covered by the statements and agreed they could be categorised in terms of impact on individuals (statements 23, 40, 57-61, 70, 94, 101, 103 and 108), the health and care system (covered by statements 62-64 and 115), communities (covered by statements 13, 22, 64-68 and 110), and the how advocacy services are run (covered by statements 69, 70-72 and 111), according to the Advocacy Outcomes Framework (NDTi 2016a). The committee discussed that there are many outcomes from these different domains that could be investigated in order to understand the impact of advocacy and commission effective services, which gives services flexibility to collect information in different ways. The examples given in the recommendation were based on the content of the statements and the committee's knowledge and experience.

Measuring outcomes that show the impact of advocacy services

There were a number of statements that addressed the need to identify and define outcomes (statements 83-87) and agreeing outcomes and how these should be recorded, collaboratively (statements 37, 54, 78, 84 and 128). Further, statement 92 highlighted a lack of consistency in the information requested by commissioners. The committee discussed the merits of collaborative working in advocacy services and agreed that by gathering a range of perspectives and sharing insights for areas for improvement there is a broader and more holistic understanding of population needs. The committee discussed that collaborative work also offered the opportunity for different care providers to agree and work towards the same goal, which could lead to improved outcomes and more effective services, and so made a recommendation in line with this.

Evaluating the effectiveness and quality of advocacy services

There were a number of statements (119b, 125, 130, 131 and 132) that highlighted the need for commissioners to monitor advocacy services. Additionally, statement 3 covered the sharing of information between advocacy groups and commissioners in order to determine if needs are being met. The committee agreed that commissioning is the continual process of planning, agreeing and monitoring services, and encompasses many actions including continuous quality assessment. However, in the committee's experience, commissioners do not always use information gathered from advocacy services to inform improvements in practice. The committee agreed that commissioners should evaluate the data to identify themes and insights they can use to generate continuous improvement in services. The committee agreed that this is necessary because, in their experience, feedback from people using advocacy services is not always positive.

Sharing of information from data collected through delivery of advocacy services

Several statements (22, 96, 99, 100, 105, 106, 107, 116) covered sharing information with other organisations, particularly in relation to highlighting areas where improvement is needed. In the committee's experience, sharing of information is necessary to enable services to respond to the issues raised and make changes as required to improve the quality of services and ensure they meet the needs of the population. However, this is not happening consistently. The committee agreed that the sharing of information would also facilitate collaboration between services. They were also aware that addressing common themes and issues affecting people using the service with commissioners and providers of other services is stated in the Advocacy Quality Performance Mark (2018). Statements 1, 24, 25 in partnership working (see evidence review G) were also used to inform this recommendation as they covered advocacy services increasing awareness of issues and highlighting gaps in service provision.

Evaluating information reported by advocacy services

Statements 100 and 109 covered taking appropriate action in response to feedback. Similarly, statements 8 and 9 in partnership working (see evidence review G) covered acting on trends and themes for service change and improvement. The committee agreed that it is important that this is done in order to enable improvements to services as outlined above. However, in the committee's experience, this is not happening consistently. They agreed that the action required, namely evaluating the information reported by advocacy services and making any changes to services that are needed, should be stated more clearly and the statements combined to avoid unnecessary repetition.

Fulfilment of statutory duties

Statement 95 covered advocacy providers reporting on the extent to which partners fulfil statutory duties in relation to advocacy and safeguarding. The committee discussed the seriousness of safeguarding and were aware that sometimes advocates are not informed about safeguarding concerns in a timely manner. The committee agreed that it is not the responsibility of advocates to decide whether statutory duties are being fulfilled or not, but that they are in a good position to play a part in recognising when this is not being done. This was supported by statement 93, which covered the need for reporting and assurance on safeguarding from all partners. Further, the committee agreed that this activity could be incorporated into processes for collecting and sharing information, discussed above.

Monitoring of safeguarding processes

An existing recommendation from the NICE guideline on safeguarding in adult care homes [NG189] covered Safeguarding Adults Boards being assured that local authorities monitor how residents and their advocates are included in safeguarding enquiries. Further details about the committee's decisions to adopt or adapt existing NICE recommendations in the area of monitoring services and collecting data are given in appendix F. The committee agreed that this was important and were aware that the 'Making Safeguarding Personal' documents from the Local Government Association (Lawson 2017, 2020) highlighted concerns about the quality of safeguarding and that the role of advocacy in safeguarding can be strengthened. The committee were aware that there is a statutory requirement to involve an independent advocate to support people subject to a safeguarding enquiry or safeguarding adult review, as outlined in the statutory guidance for the 2014 Care Act (Department of Health & Social Care 2022). They agreed that monitoring the involvement of advocates is an important way of ensuring that this legal duty is being upheld. The committee agreed that the recommendation should cover all safeguarding activity, not just safeguarding enquiries, as advocacy involvement earlier in the process could help prevent situations escalating to formal enquiries; this is consistent with the 'Making Safeguarding Personal' approach mentioned above. Finally, the committee agreed to broaden the scope of the recommendation as limiting the population in the existing recommendation was due to the population of interest for NG189, rather than a limit on the responsibilities of Safeguarding Adults Boards.

Monitoring provision of information

Another existing recommendation from NG189 covered local authorities and commissioners monitoring whether care homes tell residents about advocacy and the criteria for accessing it and how advocates are involved in the management of safeguarding concerns. The committee agreed it was important that both of these are monitored but agreed the actions required by the recommendations would be clearer if they were separated, so split the recommendation into two. As with the above recommendation, the committee agreed that monitoring the involvement of advocates in safeguarding would help to ensure that the legal right described above is upheld. However, the wording was amended as the committee agreed that the role of advocates in safeguarding is to support those experiencing safeguarding concerns, not to manage these. The committee agreed that local authorities and commissioners should monitor whether health and social care providers give information about advocacy services to help drive improvements in access to advocacy for those who need it, as in the committee's experience, information about advocacy services is not provided consistently (see evidence review C).

Agreed methods of collecting data

There were a number of statements (7, 26, 31, 34, 89, 90, 91, 117, 125, 127, 131 and 132) that highlighted the need to agree methods of collecting data (and that such methods need to consistent and robust). The committee discussed that recording and collecting data is a core part of contracts set by commissioners. The information and data used by commissioners is diverse, as it varies according to area and local need. The committee agreed that standardised data recording and collection methods, where the same type of information is collected by different commissioners and in different areas, would produce comparative data that is more consistent and transparent. This transparency and the ability to compare data across services may in turn help improve the quality of services by holding people to account. The committee agreed that a coordinated approach across the sector could facilitate robust data collection and recording, and so they made a recommendation in light of this. However, it is not within the remit of NICE guidelines to recommend that this be standardised nationally, as recommended in statements 131 and 132.

Methods of quality assurance

Statement 2 covered commissioners monitoring contracts to ensure that advocates are working to published quality standards. The committee agreed that quality standards are important for providing a benchmark against which performance can be measured in order to promote a consistent, high quality service and identify where improvements are needed. However, as advocacy is an emerging field, relative to other areas of health and social care, there are no evidence-based standards currently in place. Statement 5 covered two examples of monitoring tools, the Advocacy Quality Performance Mark (QPM) and Lost in Translation. The committee were aware that the QPM is a widely used quality assurance assessment, which is given to organisations demonstrating excellent service provision in line with QPM standards (NDTi 2018a), the Advocacy Charter (NDTi 2018b), and the Advocacy Code of Practice (NDTi, Empowerment Matters 2014). The QPM is available to providers of statutory and non-statutory independent advocacy and is recognised by the Mental Capacity Act 2005 Code of Practice (Department for Constitutional Affairs 2007), although it is not a legal requirement specified in the Mental Capacity Act itself. Given that the effectiveness of the Quality Performance Mark was not reviewed as part of this guideline and is not legally required, the committee were unable to make a strong recommendation supporting its use. However, they agreed that it is an example of an external quality accreditation that commissioners may want to consider. Further, in the absence of being able to make a stronger recommendation about published quality standards, the committee agreed it was important that commissioners check that advocacy providers have robust methods of quality assurance in place to ensure that providers are taking steps to ensure that they are delivering a high quality service, irrespective of the methods used to assess this.

Gathering feedback from advocacy service users

Statement 134 covered advocacy providers having consistent, practical and robust methods of seeking feedback that: avoids conflicts of interest; standardises who feedback should be sought from and what information should be collected; and tailors the format and method based on the communication needs and preferences of the individuals. The committee were aware that often collecting feedback could be difficult, as some people prefer to move on after using a service. However, the committee agreed that it was important to get feedback from those using advocacy services so that services are responsive to population needs and can make changes needed in order to improve the service provided. The committee agreed that the concept of having consistent and robust methods of seeking feedback would be covered by the recommendation above on developing data collection methods. The committee discussed that avoiding a conflict of interest is important in order to assure that feedback is honest and meaningful. The committee discussed that this can be difficult as the person providing the service would typically be the point of contact regarding feedback, but were aware of ways that this could be done that would minimise the involvement of the provider, such as anonymous electronic surveys. The committee were concerned that standardising what information is collected and from whom, could risk excluding key people, as this may vary depending on the context. For example, getting feedback from people's families or carers may be particularly important in the case of non-instructed advocacy. Similarly, the committee agreed that there should be flexibility in what information is collected and the space for open-ended feedback to avoid being too prescriptive and allow individuals to raise what is important to them. Therefore, the committee agreed that maximising the opportunity for feedback was more important than standardisation. The committee agreed on the importance of supporting individual preferences and communication needs to facilitate getting information from the full spectrum of people accessing services. Without this, there may be a risk of excluding certain groups from feedback and, therefore, having an incomplete view of whether services are meeting the needs of the local population and any improvements needed. The committee acknowledged that, this might also include seeking feedback from families and carers, where people would be unable to provide feedback themselves. The committee agreed that tailoring the format and methods of seeking feedback is crucial for enabling feedback that can drive meaningful change as required, so made a separate recommendation about this to give it more prominence.

Adhering to statutory duties

The existing recommendation from the NICE guideline on decision-making and mental capacity [NG108] covered ensuring that statutory duties to involve advocacy are adhered to and monitored and that failure in statutory duties are addressed. From their knowledge and experience, the committee were aware that there is a longstanding issue of referrals not being made when they are necessary. The committee agreed it is important to ensure that referrals are made when they should be and that in cases where this is not happening, this needs to be addressed. The committee discussed that complying with statutory duties is essential so that rights are upheld. The committee agreed that commissioners have the power to help enforce this compliance, as they are the ones responsible for the funding and the contracts, so adapted the recommendation to focus on commissioners.

Keeping independence and integrity of advocacy organisations

Statement 4 covered that outcomes or activity monitoring should not compromise the independence or integrity of advocacy providers. From their knowledge and experience, the committee were aware that in some cases advocates might face pressure from other services or commissioners to prioritise certain outcomes or not to raise their concerns. The committee agreed that it is not possible for advocates to remain independent when put under such pressures so made a recommendation to ensure that this core tenant of advocacy is protected. Further, the committee discussed that sometimes advocates are asked for unnecessary information that could be used to identify individuals. Not only would sharing such information potentially be a breach of the 2018 Data Protection Act, it could be damaging to relationships between advocates and the people they support. Therefore, the committee agreed it is important that individual privacy is also protected during monitoring and incorporated this into the recommendation.

Regular support and supervision

Statement 121d covered advocacy organisations ensuring arrangements are in place for the regular support and supervision of Independent Mental Health Advocates (IMHAs). The committee agreed that supervision is crucial for ensuring consistency across services and that advocates are meeting the required standards. Further, it provides an important opportunity for developing skills and learning from others. For these reasons, the committee agreed that this recommendation should apply to all advocates, not just IMHAs. The committee agreed that this recommendation should be moved to the area of training for advocates (see evidence review I).

Research recommendation

Statements 49/51a and 50/51b recommended that research should focus on identifying the components of advocacy services which are effective for the wide range of people using the service and that there should be a focus on identifying the most effective components of advocacy services for specific groups, for example people living with dementia and people from black and minority ethnic groups. Similarly, statement 133 covered evaluating the impact of specialist health advocacy in order to further understand its benefits. In addition, statement 27 recommended that future research should distinguish between short and long term outcomes and statement 29, that research should include an assessment of cost-effectiveness. On the basis of these statements and their knowledge about gaps in evidence, about the factors that make an advocacy service effective, the committee recommended that future research should examine the effectiveness of advocacy delivered in different ways, for example, delivered by a peer advocate, in the same age group as the person being supported, with the same ethnicity as the person being supported, by an advocate who has completed culturally competent advocate training or by an advocate with lived experience.

They agreed the success of these different approaches should be assessed using individual level outcomes including independence and control, social care related quality of life and physical and mental health related quality of life as well as service or organisation outcomes such as service use, referral rates and the competency and wellbeing of advocates. They also agreed about the importance of wider, community level outcomes such as social inclusion and access to community services. As well as a quantitative assessment of the effectiveness of different approaches the committee also agreed about the importance of understanding people’s views and experiences about these different approaches, which is why they recommended mixed, quantitative and qualitative research to gain a complete understanding. For the full details of the research recommendation including the rationale and PICO table, see appendix E.

Statements not used in this review

There were a number of statements carried forward to committee discussions that were not ultimately used to inform recommendations. Statements 24, 75, 76, 82 and 113 were not used because they did not provide enough detail about what action should be taken. Similarly, statement 104 did not provide detail about what the multiagency approach should be used to review and reflect on concerns, issues and adverse events, and the committee agreed that organisations should already have processes in place for reviewing serious incidents and near misses, so they did not think a recommendation about this was needed. Statements 20, 121a, 137 and 138, which covered commissioners ensuring that requirements for recording, reporting, and monitoring are added to contracts, were also not used to inform recommendations as the committee agreed the concepts covered in these statements (for example, specifying requirements for recording, reporting, and monitoring in contracts, clear leadership, and sufficient staffing levels) are not specific to advocacy services and are standard processes that should be happening anyway.

Statement 41 covered commissioners developing benchmarks that can be used to measure the performance and quality of advocacy services. This statement was not used to inform a recommendation as the committee agreed it would partly be covered by the recommendation discussed above on agreeing objectives and outcomes and that other benchmarks (such as waiting times for meetings) would be a standard part of contracts that is happening anyway. There were several other statements that were not used to inform recommendations as the committee agreed they would be, at least in part, covered by other recommendations made in this area. Statement 1 covered quarterly reporting between advocacy providers and commissioners. The committee were not sure that reporting information on a quarterly basis was feasible, or necessary, but the need for reporting information more broadly is covered above. The combined statements 46, 47 & 48 suggested future research focussing on comprehensive mapping of advocacy organisations. The committee agreed that mapping of advocacy services, including identifying trends, was an ongoing monitoring activity and covered by the recommendations above, rather than a research activity. Statement 124 covered two key concepts: having a plan for how services will meet a diverse range of needs and undertaking equalities monitoring. The committee agreed that the concept of equalities monitoring would be addressed by the recommendation above that included collecting information about protected characteristics and that ensuring services can meet diverse needs would be covered by:

- the recommendation above that included making changes needed to services in order to meet the needs of all communities they work with,
- recommendations 1.6.1, 1.6.2 and 1.6.12 under the area of effective advocacy (see evidence review F),
- recommendation 1.7.10 under partnership working (see evidence review G), and
- recommendation 1.9.1 under training for advocates (see evidence review I).

Other statements were not used to inform recommendations because the committee agreed that the concepts covered were already addressed by recommendations made in other areas of this guideline. Statement 12, which covered requesting and recording information about any known risks to ensure safety of advocates is covered by recommendation 1.7.7 under the area of partnership working (see evidence review G). Statement 35 covered developing agreement about the definitions and role of advocacy to improve data collection and service evaluation. The committee agreed that the issues of uncertainty in the role of advocates would be dealt with by recommendations 1.8.6, 1.8.7 and 1.8.9 under planning and commissioning (see evidence review H) about specifying the role of advocates in contracts. Statement 119a was about the quality of IMHA services depending on the effectiveness of commissioning, with a number of examples of how effective commissioning could be achieved. The committee agreed that how to achieve effective commissioning was already covered by recommendations made under the area of planning and commissioning (see evidence review H). Statement 119c highlighted the need for interfaces between IMHA services and other forms of advocacy being easy to navigate. The committee agreed that this issue was addressed by recommendation 1.4.5 under improving access (see evidence review D). Statement 120 about the quality of IMHA services being influenced by the availability and accessibility of IMHA services, was not used to inform a recommendation as the committee agreed that the areas of the statement were already covered by other recommendations in this guideline, such as:

- availability and access (including increasing uptake) is covered by recommendations in the improving access section (see evidence review D),
- eligibility for IMHA services is covered by recommendations in the legal right section (see evidence review A), and
- understanding the role of IMHA services is covered by recommendations in the training for practitioners section (see evidence review J).

Statement 121b covered services being able to respond to changing needs and retaining high quality staff and expertise. The committee agreed that the recommendation about basing commissioning on assessment of local needs (recommendation 1.8.1 in planning and commissioning, see evidence review H) would enable services to respond to changing needs and that recommendations made in the training advocates section (see evidence review I) would help rating high quality staff and expertise. The committee agreed the issue in statement 121g, namely the quality of IMHA services being improved by IMHAs being able to devote the time needed to each individual case, would be addressed by recommendation 1.8.6 in planning and commissioning (see evidence review H). Statement 122 covered IMAH services having a clear recovery focus and link with opportunities for peer support. The committee agreed that having a recovery focus was covered by recommendation 1.6.2 under the area of effective advocacy (see evidence review F) and that peer support was just one example of a source of support that advocates should be routinely providing people with information about.

Finally, statement 126 about the quality of IMHA services being influenced by the understanding of other health professionals, was not used to inform a recommendation because the committee agreed that it was a broad statement and particular areas were covered by other recommendations in this guideline, such as:

- understanding and respecting the role is covered by recommendations in the training practitioners section (see evidence review J),
- promoting access is covered by recommendations in the improving access section (see evidence review D),
- developing staff and training is covered by recommendations in the training advocates section (see evidence review I),
- common concerns are covered by recommendations in the partnership working section (see evidence review G), and

- organisational context is covered by recommendations in the planning and commissioning section (see evidence review H).

Cost effectiveness and resource use

It is not expected that collecting data or the type of data that is collected will lead to any long term increase in resource use as the vast majority of centres will already have data collection and monitoring processes in place, however there will be some upfront costs for some recommendations discussed below. There is likely be benefits in terms of providing advocacy services through more complete and standardised collected data and the way it is used and monitored. Data collection including resource use, especially at the population level, should allow for the design and commissioning of more effective and cost effective services in future.

There will be some short term costs from these recommendations where monitoring, data collection or quality assurance systems are not in-line with the recommendations. There will also be some upfront costs from initial meetings between advocacy services and commissioners to decide on which data to collect, develop consistent reporting methods and to ensure dissemination around insight from data collection are consistent and effective. This will most likely be achieved through the development of protocols or operating procedures. These will require some update after development to allow them to change with practice or problems identified in their use but this is expected to be minimal. As above better and standardised monitoring, data collection and quality assurance should lead to more effective and efficient advocacy services with potentially saving large costs.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.8.8, 1.11.2 to 1.11.18 and 1.9.5, and the research recommendation on the effectiveness and acceptability of providing advocacy through different approaches. Other evidence supporting these recommendations can be found in the evidence reviews on partnership and working (see evidence review G).

References – included studies

Existing NICE guidelines

National Institute for Health and Care Excellence 2018

National Institute for Health and Care Excellence (2018). Decision-making and mental capacity (NICE Guideline 108). Available at: https://www.nice.org.uk/guidance/ng108/evidence/full-guideline-pdf-6542486605

National Institute for Health and Care Excellence 2021

National Institute for Health and Care Excellence (2021). Safeguarding adults in care homes (NICE Guideline 189). Available at: https://www.nice.org.uk/guidance/ng189/resources/safeguarding-adults-in-care-homes-pdf-66142030079941

Formal consensus

Lawson 2017

Lawson, J. (2017). Making Safeguarding Personal. What might ‘good’ look like for advocacy? Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.30%20-%20Chip_MSP%20Advocacy_WEB_2.pdf [Accessed 07/04/2021]

Lawson 2020

Lawson, J., Petty, G. (2020). Strengthening the role of advocacy in Making Safeguarding Personal, Local Government Association. Available at: https://www.local.gov.uk/sites/default/files/documents/25.167%20Strengthening%20the%20role%20of%20advocacy%20in%20MSP_04.pdf [Accessed 07/04/2021]

Macadam 2013

Macadam, A., Watts, R., Greig, R. (2013). SSCR Scoping Review: The Impact of Advocacy for People Who Use Social Care Services. Available at: https://www.ndti.org.uk/assets/files/SSCR-scoping-review_SR007.pdf [Accessed 06/04/2021]

Mercer 2020

Mercer, K., Petty, G. (2020). Scoping Exercise Report – An overview of advocacy delivery in relation to Personal Health Budgets and other Health Funded support. Available at: https://www.ndti.org.uk/assets/files/Advocacy-Health-Funded-Support-Report-pdf.pdf [Accessed 07/05/2021]

National Development Team for Inclusion 2014b

National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to Advocacy Project: Summary Findings Minister's Briefing Note. Unpublished

National Development Team for Inclusion 2014c

National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished

National Development Team for Inclusion 2016a

National Development Team for Inclusion (2016a). Advocacy Outcomes Framework. Measuring the impact of independent advocacy. Available at: https://www.ndti.org.uk/assets/files/Advocacy_framework.pdf [Accessed 06/04/2021]

National Development Team for Inclusion 2016b

National Development Team for Inclusion (2016b). Advocacy Outcomes Toolkit. An accompanying guide to the advocacy outcomes framework. Available at: https://www.ndti.org.uk/assets/files/Advocacy_Outcomes_Toolkit.pdf [Accessed 06/04/2021]

Newbigging 2012

Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, L., et al. (2012). The Right to Be Heard: Review of the Quality of Independent mental Health Advocate (IMHA) Services in England, University of Central Lancashire. Available at: https://www.firah.org/upload/notices3/2012/uclan.pdf [Accessed 13/05/2021]

Ridley 2018

Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, Vol. 23(4), 280-292.

Roberts 2012

Roberts, H., Turner, S., Baines, S., Hatton, C. (2012). Advocacy by and for adults with learning disabilities in England. Available at: https://www.ndti.org.uk/assets/files/IHAL_2012-03_Advocacy.pdf [Accessed 06/04/2021]

Turner 2012

Turner, S. (2012). Advocacy by and for adults with learning disabilities in England: Evidence into practice report no.5, Improving Health and Lives: Learning Disabilities Observatory. Available at: https://www.ndti.org.uk/assets/files/IHAL-ev-_2012-01.pdf [Accessed 06/04/2021]

Other

Care Act 2014

Care Act 2014, c. 23. Available at: https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted [Accessed 31/01/2022]

Department for Constitutional Affairs 2007

Department for Constitutional Affairs (2007). Mental Capacity Act 2005: Code of Practice. Available at: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice [Accessed 15/02/2022]

Department of Health & Social Care 2022

Department of Health & Social Care. Care and support statutory guidance. Available at: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#using-the-care-act-guidance [Accessed 31/01/2022]

Mental Capacity Act 2005

Mental Capacity Act, 2005 (c.9). Available at: http://www.legislation.gov.uk/ukpga/2005/9/contents [Accessed 23/02/2021]

National Development Team for Inclusion and Empowerment Matters CIC (2014)

National Development Team for Inclusion and Empowerment Matters CIC. (2014) Advocacy Quality Performance Mark (QPM). Recognising Quality in independent advocacy. Code of Practice 2014

National Development Team for Inclusion 2018a

National Development Team for Inclusion. (2018a). Advocacy QPM: Assessment Workbook. Available at: https://qualityadvocacy.org.uk/wp-content/uploads/2021/12/QPM-Assessment-Workbook_V4_V1.3_Dec-2021.pdf [Accessed 16/02/2022]

National Development Team for Inclusion 2018b

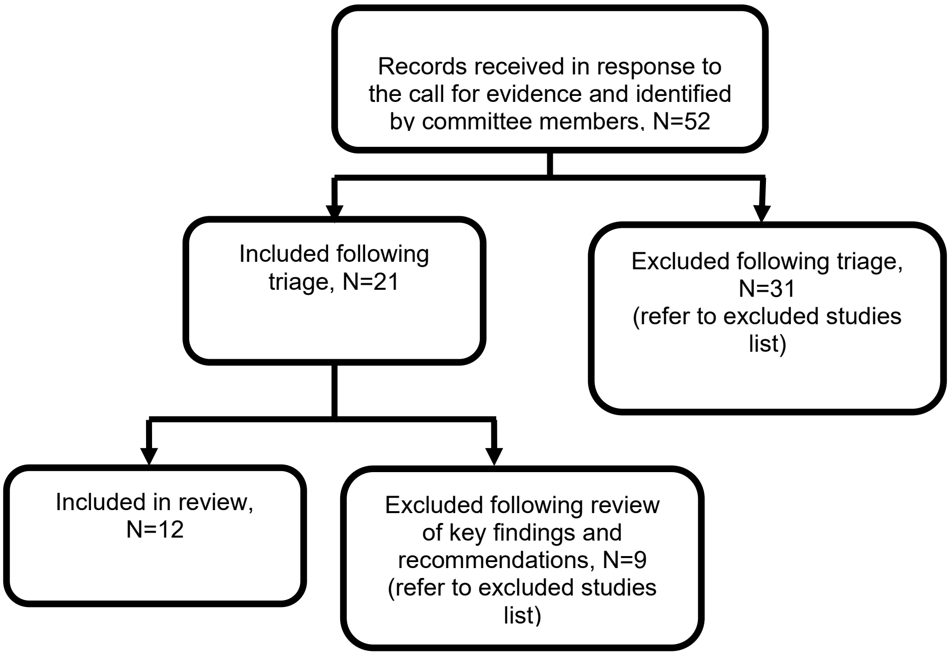
National Development Team for Inclusion. (2018b). The Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/Advocacy-Charter-A3.pdf [Accessed 16/02/2022]

Appendices

Appendix A Study selection for formal consensus process

Study selection for scope area: Monitoring services and collecting data for quality improvement

Figure 1: Study selection flow chart



Appendix B Evidence tables

Evidence tables for scope area: Monitoring services and collecting data for quality improvement

Table 3: Evidence tables

Study details	Population	Recommendations/key findings	Quality assessment
Full citation Lawson, J. (2017). Making Safeguarding Personal. What might 'good' look like for advocacy? Local Government Association **Country/ies where the study was carried out** England **Study type** Report/review **Study dates** 2017 **Source of funding** No sources of funding reported	Those who have duties to commission and arrange advocacy services	**Key findings** • Basic considerations between advocacy outcomes framework and key steps for Making Safeguarding Personal, including: • Outcomes for individuals, reflecting core principles for safeguarding and the wellbeing principle. • Outcomes for health and social care, including reflecting the need to engage people in offering feedback and the need for services to respond to this. • Impact on communities (and prevention) embracing the wider impact of advocacy support on issues such as: isolation and social exclusion; increased contributions of individuals to communities facilitated through advocacy. • Impact on how advocacy services are run and commissioned: responding to feedback from people who are supported by advocacy and shaping services accordingly.	**Quality assessment using AGREE II** **1) Scope and Purpose** 61% Overall objective and population are described. Health question is not specifically described but alluded to. **2) Stakeholder involvement** 22% Target users are defined but not information on guideline development group and views and preferences from population has been included. **3) Rigour of development** 8% Health benefits when describing recommendations have been considered. No information on systematic methods, criteria selection, strengths and limitations, and methods for formulating recommendations have been provided. Link between recommendations and supporting evidence not clear. No information on external reviewing, and procedure for updating have been provided. **4) Clarity of presentation** 22% Recommendations are not always specific and easily identifiable. No mentioning of different options for management. **5) Applicability** 4%

Study details	Population	Recommendations/key findings	Quality assessment
		• Commissioners must seek qualitative information on outcomes as well as quantitative analysis, such as case studies and feedback from people who have used advocacy services. • Work on understanding progress and outcomes in Making Safeguarding Personal should influence the development of data collection about advocacy. This will help achieve a more accurate understanding about offers of and provision of statutory independent advocacy compared to informal advocacy. • Step 6: Ensure there is a clear focus on prevention and early intervention The Making Safeguarding Personal approach applies in prevention as well as to responses to abuse and neglect. Prevention and early intervention requires empowering people living in communities to recognise the potential for abuse or neglect and to raise concerns. • There is a clear role for advocacy in prevention and early intervention, this includes encouraging “people to be supported in ways that increase contact with friends,	Some mentioning of potential tools provided. No further information on facilitators/barriers, potential resource implications, and auditing criteria provided. **6) Editorial independence** 0.0% No funding body and competing interest have been identified. **Overall rating** 29%

Study details	Population	Recommendations/key findings	Quality assessment
		family and community. This reduces people's vulnerability as well as reducing isolation, enhancing quality of life and supporting citizenship and inclusion". **Recommendations** • Commissioners should specify services and monitor contracts to ensure that advocacy are working to published quality standards, core principles and the advocacy charter. This in turn connects with core principles for safeguarding and Making Safeguarding Personal.	
Full citation Lawson, J., Petty, G. (2020). Strengthening the role of advocacy in Making Safeguarding Personal, Local Government Association. **Country/ies where the study was carried out** England **Study type** Qualitative (focus group discussions) **Study dates** 2020 **Source of funding** No sources of funding reported	Those who have duties to commission and arrange advocacy services	**Key findings** • Suggesting quarterly reporting between advocacy provider and commissioners, consistent across all local authority areas. • There was variation in practice and methods among advocacy providers in respect of recording and reporting of individual advocacy outcomes. Some providers had robust and sophisticated governance reporting systems, but there is a lack of consistency in the way information about issues, trends, numbers of referrals, and outcomes are collected and shared. Such information may be fed into monitoring	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes – to support strengthening the role of all types of advocacy in safeguarding adults, specifically in Making Safeguarding Personal by generating multi-agency conversations based on the briefing and stimulating local action to address some of the core messages that emerge from this. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes.

Study details	Population	Recommendations/key findings	Quality assessment
		reports (usually quarterly, but not always) for commissioners. • Advocates reported that there is little consistency in the information requested by commissioners and contract managers, with an emphasis on outputs rather than outcomes and impact. • There is a need for reporting and assurance on safeguarding from all partners. The contribution from advocacy requires a focus and a response from organisational leaders and SABs. Advocacy providers can: ○ Evaluate and report on the extent to which the provision of advocacy supports effective safeguarding outcomes for individuals. ○ Report on the extent to which partners fulfil statutory duties in relation to advocacy and safeguarding. ○ Alert SABs to issues that are connected to SABs wider safeguarding responsibilities in relation to prevention and support. ○ Advocacy providers, in partnership with commissioners, can develop consistent and robust	**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Yes. Semi-structured focus group discussions on teleconference calls were held with 28 advocates from 18 advocacy providers across England, covering 33 Local Authority areas. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. Findings are discussed but researchers did not discuss credibility of their findings. **10. How valuable is the research?**

Study details	Population	Recommendations/key findings	Quality assessment
		methods to record and report outcomes across the sector to support the impact of advocacy on individuals, health and social care and the wider community. • The views of people who use services and their carers will maximise effectiveness of independent advocacy and inform improvements in safeguarding (co-production is a fundamental principle of independent advocacy). • Facilitated national forums to support advocacy providers to share and develop best practice were reported to be helpful but were not routinely available. • There is a need for local multi-agency governance arrangements that support the sharing of themes and trends of concerns in provider services and facilitate taking robust action where needed. These arrangements should include advocacy partners, CQC and/or Healthwatch who have intelligence to share. • Information reported to be helpful: ○ Data and information demonstrating the impact on individuals and local need.	Valuable - the authors discuss issues arising in relation to providing advocacy services in relation to safeguarding adults and provide suggestions on how to address the key issues. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.

Study details	Population	Recommendations/key findings	Quality assessment
		○ Qualitative information and case studies to demonstrate real impact and outcomes for people. ○ Moving away from tick boxes. ○ Local, multiagency audits and digging deeper on specific issues that come to light. ○ Robust and consistent systems for recording and collating information and clear routes for sharing this to make a difference. • What can help includes: ○ Quarterly reporting between advocacy provider and commissioners, consistent across all local authority areas. ○ Further development and roll out of the NDTi outcomes framework with involvement from providers and commissioners and people who may need advocacy support. ○ Systems that support commissioners and provider to take joint responsibility for brining key information from quarterly reports to the attention of those who can do something to address issues and themes.	

Study details	Population	Recommendations/key findings	Quality assessment
		○ Commissioners should engage with and share the 'bigger picture' issues that emerge from advocacy services.	
Full citation Macadam, A., Watts, R., Greig, R. (2013). The Impact of Advocacy for People who Use Social Care Services, NIHR School for Social Care Research Scoping Review. **Country/ies where the study was carried out** England **Study type** Scoping review **Study dates** 2013 **Source of funding** No sources of funding reported	People who use social care services	**Key findings** • Key features and characteristics of all forms of advocacy have been captured in various quality marks and advocacy qualifications, such as independence, promoting empowerment, providing people with a voice, and challenging inequality. For example, the Advocacy Quality Performance Mark which builds on the Advocacy Charter and Quality Standards for Advocacy Schemes (2002) and Code of Practice (2006). There are also national or local advocacy standards developed for specific groups (including children, black and minority ethnic communities and people who use mental health services) [Lawton 2009, Equalities National Council 2012]. • A survey of Welsh advocacy schemes reported that 56% used the advocacy standards developed by Action for Advocacy, while the remaining 44% used a variety of frameworks, such as those	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** Probably yes – No full protocol available but pre-defined criteria are supplied. **1.2 Were the eligibility criteria appropriate for the review question?** Yes. **1.3 Were eligibility criteria unambiguous?** Probably no. The scope of documents considered relevant for the review is outlined but the authors note that there were some deviations from the parameters but provide minimal information about this. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** Yes – Restrictions were minimal. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** Yes. ***Concerns regarding specification of study eligibility criteria*** Low concern – Considerable effort to clearly define review question and specify eligibility criteria, has been made.

Study details	Population	Recommendations/key findings	Quality assessment
		developed by the Welsh Assembly Government [Dunning 2010]. • Models that had been developed to evaluate advocacy outcomes did not seem to be widely used, which resulted in a lack of consistency in information recorded in different areas. • There is a lack of longitudinal evidence contributing to the difficulties in identifying whether outcomes are short- or long-terms (Manthorpe and Marineau 2010). • There appears to be an overall lack of research and evaluation of advocacy, particularly when considering the amount of investment made and the political profile and priority given to advocacy. For example, “There are many examples of individual advocacy schemes but their range is wide and evaluations are rare.” (p.13) [Manthorpe and Martineau 2009, p.6] • The lack of robust research and evidence prevents conclusions to be drawn as to whether advocacy has a positive impact or whether it is a cost-effective use of public resources.	**2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** Yes. **2.2 Were methods additional to database searching used to identify relevant reports?** Yes. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?** Yes. **2.4 Were restrictions based on date, publication format, or language appropriate?** No (restricted to English). **2.5 Were efforts made to minimise errors in selection of studies?** Yes. ***Concerns regarding methods used to identify and/or select studies*** Low concern. **3.1 Were efforts made to minimise error in data collection?** No (Data collection likely conducted by one researcher). **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** Yes.

Study details	Population	Recommendations/key findings	Quality assessment
		• GAIN (2012) reported that advocacy projects mainly report outputs (for example, time spent with clients, number of meetings) rather than outcomes (such as increased choice and control, improved health and wellbeing). • Advocacy organisations collect data on the characteristics of people who are supported, but not consistently or robustly. For example: ○ Roberts (2012) reported that 93% of advocacy organisations from their survey collected data on certain types of characteristics (for example, age, gender, disability), but only 28% collected data on all characteristics. ○ The EHRC (2012) suggested that data on which users received advocacy support were often based on estimates rather than actual data. • *Practical, uniform methods for capturing information do not exist.* Information about advocacy organisations is collected in various ways, including quarterly and annual reports, meetings, contract	**3.3 Were all relevant study results collected for use in the synthesis?** No information. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** No information. **3.5 Were efforts made to minimise error in risk of bias assessment?** No information. ***Concerns regarding methods used to collect data and appraise studies*** Unclear concern (Insufficient details provided). **4.1 Did the synthesis include all studies that it should?** No information. **4.2 Were all predefined analyses followed or departures explained?** No information. **4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies?** No information. **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** No information.

Study details	Population	Recommendations/key findings	Quality assessment
		monitoring meetings (Hakim and Pollard 2011) and other general means of communication (for example, websites, newsletters, Partnerships Boards) (Roberts 2012, Hussein 2006) – there is no consistent method for capturing information relating to the provision of advocacy support. • In addition, some providers reported inconsistent referral mechanisms for advocacy support which means that recording relevant data is not always possible (Mencap 2006). • *Commissioners in a similar position to advocacy providers.* Roberts (2012) reported that some commissioners had done little to monitor advocacy outcomes while others monitored advocacy by looking at reports from advocacy groups, outcomes of people with learning disabilities, and feedback from professionals and people with learning disabilities. 44% of commissioners responding to the survey reported that advocacy organisations were monitored through numbers or reports; often monitoring was	**4.5 Were the findings robust, e.g. as demonstrated through funnel plot or sensitivity analyses?** No information. **4.6 Were biases in primary studies minimal or addressed in the synthesis?** No information. ***Concerns regarding the synthesis and findings*** Unclear concern (Insufficient detail provided). ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** Yes **B. Was the relevance of identified studies to the review's research question appropriately considered?** Yes **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Yes **Risk of bias** – Unclear risk of bias

Study details	Population	Recommendations/key findings	Quality assessment

		only associated with the renewal of contracts.
		- Challenges to evidencing advocacy outcomes included:
		  - *Definition and boundaries:* Obtaining evidence is hampered by a lack of agreement about definitions of advocacy and understanding of the role of advocacy (Stewart 2013). In addition, the diverse range of services working towards different aims and objectives results in a lack of coherence, making it difficult to form a coherent picture and compare the impact of advocacy (Williams 2007).
		  - *Defining outcomes:* The lack of agreement on identifying and defining outcomes hampers the gathering of evidence. Other challenges include people who use advocacy services having difficulty in clearly identifying or expressing goals and/or outcomes; difficulties in quantifying and measuring specific types of advocacy (for example, people living with dementia); difficulties in measuring a final state or change because advocacy is often about moving towards a goal and	

Study details	Population	Recommendations/key findings	Quality assessment
		developing the potential of people rather than achieving a concrete result (Action for Advocacy 2009); absence of widely agreed benchmarks against which performance can be measured. ○ *Methodological challenges:* Lack of a comparison group results in major limitations in establishing causalities between advocacy and outcomes. • GAIN (2012) has developed the Advocacy Outcomes Scale Tool to help evidence the difference that advocacy support makes on individuals across 5 areas (that is, choice; health and wellbeing; control; independence; dignity and respect). **Recommendations** Main areas for potential future research: • Comprehensive mapping of advocacy organisations, including: ○ Trends in income levels. ○ Client groups receiving advocacy. ○ Gaps in the provision of advocacy. ○ Trends in demand.	

Study details	Population	Recommendations/key findings	Quality assessment
		○ Types of advocacy provided and trends associated with this. ○ Trends in the number of staff and volunteers. • Research on the impact of advocacy for particular groups of people who are likely to use social care services and where evidence appears particularly limited at present (for example, people with dementia, people from BME backgrounds). • Research on typical characteristics of advocacy provision and the extent to which these affect its impact (for example, types of advocacy).	
Full citation Mercer, K., Petty, G. (2020). Scoping Exercise Report – An overview of advocacy delivery in relation to Personal Health Budgets and other health funded support. **Country/ies where the study was carried out** England **Study type** Report of a scoping exercise (including freedom of information requests, advocate survey, semi-structured telephone interviews and desktop review of legislation and guidance)	Independent advocacy services commissioned to provide advocacy to people accessing support/service through: i) s117 aftercare (under the MHA). ii) NHS Continuing	**Key findings** • Minimal, if any, data were reportedly kept in relation to people accessing or using advocacy. Increased, systematic data collection in relation to advocacy commissioning and delivery would enable a greater understanding of the national picture of delivery and the 'postcode' lottery of provision that potentially exists. **Recommendations** • Design and implement standardised national and/or	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** Probably no - There was no evidence of eligibility criteria but pre-specification of objectives the scoping exercise are provided. **1.2 Were the eligibility criteria appropriate for the review question?** No information - Eligibility criteria were not provided. The scoping exercise included a freedom of information request, advocate survey, semi-structured telephone interviews and desktop review of legislation and guidance which appear to be conducted by the authors themselves.

Study details	Population	Recommendations/key findings	Quality assessment
Study dates January to March 2020 **Source of funding** Commissioned by NHS England and NHS Improvement	Healthcare (adults). iii) Children and Young People's Continuing Care. iv) Personal Health Budgets. v) Personal Wheelchair Budgets.	local data collection in relation to the commissioning and delivery of independent advocacy, ensuring that data supports an understanding of how existing inequalities impact on take up of or access to independent advocacy, in addition to mitigating factors. • Evaluate the impact of specialist 'health' advocacy to further understand its benefits to individuals, potential improvement to personalised care, and the impact on the broader health and social care 'system'.	**1.3 Were eligibility criteria unambiguous?** No - Specific queries remain about the eligibility criteria including ambiguities about the types of study, population, interventions, comparators and outcomes. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** No information - Restrictions around the studies characteristics are not provided. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** No information - Restrictions applied on the basis of sources of information were not clearly described. ***Concerns regarding specification of study eligibility criteria*** High concern - There were insufficient details regarding study eligibility criteria to judge whether the appropriate studies were included in the scoping exercise. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** No information – No systematic searches appear to have been conducted. **2.2 Were methods additional to database searching used to identify relevant reports?** No information – Additional database searching appears not to have been conducted.

Study details	Population	Recommendations/key findings	Quality assessment
			2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible? No information. **2.4 Were restrictions based on date, publication format, or language appropriate?** No information. **2.5 Were efforts made to minimise errors in selection of studies?** No information. ***Concerns regarding methods used to identify and/or select studies*** High concern - There is insufficient information reported however it appears as though some eligible studies are likely to be missing from the scoping exercise. **3.1 Were efforts made to minimise error in data collection?** No information. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** No – study characteristics were not reported. **3.3 Were all relevant study results collected for use in the synthesis?** Probably no – Unclear whether all relevant study results were included. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?**

Study details	Population	Recommendations/key findings	Quality assessment
			No - Study quality was not formally assessed. **3.5 Were efforts made to minimise error in risk of bias assessment?** No. ***Concerns regarding methods used to collect data and appraise studies*** High concern - Some bias may have been introduced through the data collection and no risk of bias assessment completed. **4.1 Did the synthesis include all studies that it should?** No information. **4.2 Were all predefined analyses followed or departures explained?** No information. **4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies?** No information. **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** No information. **4.5 Was robustness of the finding(s) assessed e.g. through funnel plot or sensitivity analyses?** No information. **4.6 Were biases in primary studies minimal or addressed in the synthesis?**

Study details	Population	Recommendations/key findings	Quality assessment
			No - The studies were not explicitly evaluated for quality or risk of bias ***Concerns regarding the synthesis and findings*** Unclear concern - There is insufficient information reported to make a judgement on risk of bias. ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** No. **B. Was the relevance of identified studies to the review's research question appropriately considered?** No. **C. Did the reviewers avoid emphasizing results on the basis of their statistical significance?** Yes. **Risk of bias** – High concern.
Full citation National Development Team for Inclusion (2014b). Office for Disabilities Issues Access to Advocacy Project: Summary Findings Minister's Briefing Note. Unpublished **Country/ies where the study was carried out** England **Study type** Briefing Note/Survey	Disabled people	**Key findings** • Further work is needed to improve the recording, interpretation and use of outcome measures for advocacy services, in order to support local and national innovation in service delivery.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes – to summarise the findings of the survey to highlight what good advocacy for disabled people should look like. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Can't tell – Survey included over 200 advocacy providers but no more information was included.

Study details	Population	Recommendations/key findings	Quality assessment
Study dates 2014 **Source of funding** No sources of funding reported			**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Can't tell – Insufficient information regarding the survey. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Can't tell - insufficient detail provided on recruitment strategy. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – insufficient detail on data collection **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. Findings are clearly discussed but researchers do not discuss credibility of their findings.

Study details	Population	Recommendations/key findings	Quality assessment
			10. How valuable is the research? Valuable - the authors discuss issues in delivering advocacy for disabled people and highlight key areas to improve on as well as providing a summary as to what 'good' advocacy should look like. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.
Full citation National Development Team for Inclusion (2014c). Office for Disabilities Issues Access to Advocacy Project: Executive Summary. Unpublished **Country/ies where the study was carried out** England **Study type** See 'Office for Disability Issues Access to Advocacy Project: Summary Findings Minister's Briefing Note' **Study dates** 2014 **Source of funding** No sources of funding reported	Disabled people	**Key findings** • A focus on outcomes not outputs, and the use of outcome measures to ensure effective personalised support and wider service improvements. **Recommendations** Develop a national network of influential stakeholders from across the advocacy sector to provide a forum to share and learn from best practice.	See 'Office for Disability Issues Access to Advocacy Project: Summary Findings Minister's Briefing Note'

Study details	Population	Recommendations/key findings	Quality assessment
Full citation National Development Team for Inclusion (2016a). Advocacy Outcomes Framework. Measuring the impact of independent advocacy **Country/ies where the study was carried out** England **Study type** Framework **Study dates** 2016 **Source of funding** Esmee Fairbairn Foundation	Providers, commissioners and users of independent Advocacy	**Key findings** Gap in evidence identified in relation to the effectiveness of independent advocacy. • Outcomes framework developed in 4 impact areas: ○ In the lives of individuals who use advocacy services. ○ In the way that the health and social care sector delivers services and responds to people. ○ In the way communities can support people to be included and enriched by peoples' full participation and involvement. ○ In the way that advocacy services learn, develop, listen and grow. • Four-stage process to using the framework: ○ Advocacy organisations (potentially with its funders/commissioners) consider the 4 areas and discuss the different outcomes it sees its services as particularly aiming to achieve within each domain. ○ If the advocacy organisation has methods to collect and report on outcomes, then such data are used to 'populate' each outcome domain. If not, the toolkit	**Quality assessment using AGREE II** **1) Scope and Purpose** 22% Overall objective is described. Health question is alluded to but not specifically stated. No information about population is provided. **2) Stakeholder involvement** 28% Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear. **3) Rigour of development** 10% Health benefits have seemingly been considered when describing recommendations. No information regarding systematic methods, criteria for selection, strengths and limitations, and methods for formulating recommendations have been provided. Links between recommendations and evidence are not clear. No information on external reviews and no information on updating has been provided. **4) Clarity of presentation** 56% Key recommendations are easily identifiable and mostly specific enough. Different options are not clearly presented but alluded to. **5) Applicability** 21% Advice on how to put recommendations into practice is alluded to but not clearly defined. No information facilitators and barriers, potential resource implications, auditing criteria are provided.

Study details	Population	Recommendations/key findings	Quality assessment
		could be used (see NDTi 2016b). ○ Organisations collect information to identify what has been achieved in relation to each of the framework domains. ○ Organisations reflect on what has and has not been achieved to identify what should be done differently and/or develop in the future to improve outcomes for people. • Outcomes that result in changes for individuals: ○ Increased voice and personal control; indicators include the person and relevant others having influenced decision making processes. ○ Improved opportunities; indicators include people moving to more appropriate accommodation or health services. ○ Challenging injustice; indicators include people being supported to report a safeguarding concern. ○ Increased independence; indicators include people reporting they are more confident.	**6) Editorial independence** 17% Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided. **Overall rating** 34%

Study details	Population	Recommendations/key findings	Quality assessment
		○ Had rights upheld; indicators include decision making processes having been successfully challenged. • Outcomes that demonstrate change in the health and care system as a result of advocacy: ○ Improving the quality of service response and service experience by people who use it; indicators include advocacy services experiencing an increase in appropriate referrals. ○ Service change and improvement; indicators include changes in the way services are delivered. ○ Person-led decision making has improved; indicators include support for self-advocates to be involved in co-producing a new service design. • Outcomes that demonstrate changes to communities: ○ Increased social inclusion of people using the service; indicators include changes to the delivery of community services. ○ Increased social contribution by people accessing the advocacy service; indicators include more people	

Study details	Population	Recommendations/key findings	Quality assessment
		contributing to community events. ○ People have improved access to community services; indicators include advocacy services receiving referrals from a broader range of community organisations. ○ Increased democratic participation; indicators include more self-advocates feeling confident to vote. • Outcomes that demonstrate change in the way the advocacy service is run: ○ Improvements in accessibility to advocacy; indicators include an increase in Serious Medical Treatment referrals from the local general hospital. ○ Increased social contribution by advocacy service users; indicators include changes to advocacy delivery. ○ Governance and best practice; indicators include all advocates receiving 1-to-1 supervision at least 10 times per year. ○ Ensuring strong co-production; indicators include people who access the service receiving support to set up an involvement board that links to the board	

Study details	Population	Recommendations/key findings	Quality assessment

		of trustees and to influence decisions.
		Recommendations
		- When implementing an outcomes reporting system, some areas to bear in mind:
		  - Take time.
		  - Work as an organisation – bring everyone together (managers, advocates, contact centre staff, business support, board members, and people who access the services. It can also be helpful to involve commissioners/funders.
		  - Where possible, embed processes in to current practice.
		  - Keep it as simple as possible but still ensure there is a good, robust system in place.
		  - Practice analysing and presenting data so that it is in a useful format for the organisation and commissioners and funders, and general public.
		- Where possible, providers and funders/commissioners should work together to ensure agreement on outcomes to be achieved and how they will be reported. For each outcome, the organisation needs to	

Study details	Population	Recommendations/key findings	Quality assessment
		decide what the indicators of success are and how it is going to evidence what has been achieved: ○ Collection of hard facts and figures, including numbers of people who reported a particular outcome. ○ Survey data on, for example, satisfaction of the service provided. ○ Examples or short case studies describing what had changed or how it had changed. ○ Make it as easy as possible for advocates to complete (some organisations design their database, casefiles or other systems to support the collection of outcome data).	
Full citation National Development Team for Inclusion. (2016b). Advocacy Outcomes Toolkit. An accompanying guide to the advocacy outcomes framework **Country/ies where the study was carried out** England **Study type** Toolkit	See NDTi 2016a	**Key findings** • 4 steps to create a robust approach to measuring the impact of advocacy: ○ Define the objectives the advocacy service sets out to achieve. Adopt a co-productive model (people who use the services and others such as commissioners, carers) to decide on the objective(s). This can improve service delivery; improve experiences of people using	**Quality assessment using AGREE II** **1) Scope and Purpose** 39% Overall objectives are described and a description of questions is provided. The target population is mentioned but no further details provided. **2) Stakeholder involvement** 28% Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear. **3) Rigour of development** 8%

Study details	Population	Recommendations/key findings	Quality assessment
Study dates 2016 **Source of funding** See NDTi 2016a		services and carers; increase community capacity; create outcome-focused and preventative services; support integration. ○ Identify the elements that contribute to the objective because these are the outcomes to be measured. ○ Identify indicators of success and how this will be measured. Measuring what works (or otherwise) is important to improve the impact of advocacy. ○ Define the data to be measured, the frequency of measurement, and the tools required. For example, subjective (attitudinal) data on people's experience and attitudes towards the quality and impact of advocacy; quantitative objective measures. ○ Analyse and report the data to identify whether outcomes have been achieved. • Use of a logic model approach: ○ Objective: What are the key issues the project is addressing? ○ Rationale: Why are you addressing these?	Health benefits from measuring outcomes have been considered. Recommendations on how to measure advocacy outcomes are presented. No information on external reviews and no information on updating has been provided. **4) Clarity of presentation** 50% Key recommendations on how to measure advocacy outcomes are easily identifiable and mostly specific enough. **5) Applicability** 46% Advice on how to put recommendations on the toolkit into practice is clearly defined. Information provided on facilitators and barriers. Limited information provided on potential resource implications, auditing criteria. **6) Editorial independence** 17% Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided. **Overall rating** 38%

Study details	Population	Recommendations/key findings	Quality assessment
		○ Inputs: What resources are available to the project? ○ Actions: What activities are you going to develop? ○ Outputs: What will be the immediate results of the project? ○ Outcomes: What change will result from your activities? ○ Long term impact: What are the longer term aims? • Toolkit co-produced with people who use advocacy, people who commission advocacy and people who deliver advocacy support.	
Full citation Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., et al. (2012). The Right to Be Heard: Review of the Quality of Independent Mental Health Advocate (IMHA) Services in England **Country/ies where the study was carried out** England **Study type** Mixed methods: literature review, qualitative research (focus groups and interviews), case studies **Study dates** 2010 to 2012	Patients detained under the amended MHA 1983, who are eligible for support from IMHA services (including people with and without capacity and children under the age of 16 years)	**Key findings** • Review of IMHA Services. • Developing systematic methods for recording and sharing information between IMHA and mental health services to assess access and uptake. • The quality of information gathered to inform the commissioning and availability of IMHA services was reported to be generally poor. This was made worse by the lack of systematic recording of who is accessing services, which forms the basis for evaluating uptake and access of services to determine whether current investment is appropriate.	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to review the extent to which IMHA services in England are providing accessible, effective and appropriate advocacy support to people who qualify for these services under the MHA 1983. To identify the factors that affect the quality of IMHA services. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes.

Study details	Population	Recommendations/key findings	Quality assessment
Source of funding Department of Health		• A key finding suggested that the quality of IMHA services is dependent on the quality of commissioning, the host mental health provider context within which the service is delivered, and the organisation and management of the IMHA services. **Quality indicators included:** **Effective commissioning for IMHA services:** • Quality indicator 1 – Working in partnership with mental health commissioners. ○ Commissioners of IMHA services work in partnership with commissioners of mental health services, so the impact of IMHA provision on mental health service development can be understood and maximised. • Quality indicator 2 – Assessment of need for IMHA services . ○ Commissioning IMHA services should be based upon a local needs assessment (including for example, demographic profile; nature of the geography); an understanding of the factors influencing historical	**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Yes - how IMHA services and service users were identified is explained, in addition to identification of carers and family members, mental health staff and commissioners. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Yes - the methods used were explicitly described and justifications for their use were provided, although saturation of data was not discussed. **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** Yes - the authors acknowledged the potential for the quality of the data collection and analysis to be influenced by the researchers. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** Yes - ethical approval was received from the Cambridgeshire 3 Research Ethics Committee and the International School for Communities, Rights and Inclusion Ethics Committee at the University of Central Lancashire. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Yes - the authors describe the analysis process and sufficient data are presented to support the findings. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes.

Study details	Population	Recommendations/key findings	Quality assessment
		patterns of demand for and use of IMHA services; the views and experience of qualifying patients of IMHA services and community organisations with specific experience of potential needs of underserved communities; an equality analysis to ensure that provision is non-discriminatory and meets the diverse range of needs. • Quality indicator 3 – Co-design with mental health service users and carers . ○ Commissioners work with a range of services users, including IMHA partners, and carers and community organisations to ensure a thorough understanding of IMHA services and co-design appropriate services. ○ Service users, particularly IMHA partners and carers, are involved in the tendering process and contract monitoring. ○ Support and appropriate reimbursement is provided to support service user and carer involvement in commissioning. • Quality indicator 4 – Designing IMHA services.	**10. How valuable is the research?** Valuable - the authors highlight gaps in the evidence, how the evidence relates to previous research, and implications for practice and policy and future research. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Minor limitations.

Study details	Population	Recommendations/key findings	Quality assessment
		○ IMHA services design includes instructed and non-instructed advocacy. ○ IMHA services designed to meet diverse needs of qualifying patients and attention paid to IMHA provision for: children and young people; older people; people from BME communities; gender sensitive provision; LGBT people; people with learning difficulties, physical disabilities or sensory impairments. ○ Design reflects a whole system approach to ensure interfaces with other forms of advocacy are easy to navigate, particularly generic mental health advocacy, IMCA services, peer advocacy and advocacy for specific groups. • Quality indicator 5 – Investment matched to need. ○ Level of investment in IMHA services reflects the local demands and needs, as established through the needs assessment process. ○ Reassess this on an annual basis and adjust to reflect changing rates of qualifying patients and specific issues	

Study details	Population	Recommendations/key findings	Quality assessment
		encountered by the IMHA service. • Quality indicator 6 – Service specification and contracts. ○ Local commissioning of IMHA services adheres to national minimum standards and agreed service specification and reflect minimum levels of investment, agreed nationally. ○ Service specification and contracts include time for activities other than direct contact, particularly relating to building awareness of the role, stimulating demand for the service and infrastructure costs including staff development and training and administrative time to support service monitoring and time to train mental health professionals. Also measures to ensure that the diversity of qualifying patients are able to access appropriate IMHA services (including, for example, specifying partnership arrangements with community organisations and/or investment to develop their capacity to provide IMHA services and ensure IMHA	

Study details	Population	Recommendations/key findings	Quality assessment
		services are available across the age range and as people move across different services. ○ Contracts with IMHA services are established for a minimum of 3 years. ○ Commissioners fund IMHA services for people using mental health services in their area, including people who are not usually resident in the area. • Quality indicator 7 – Monitoring: ○ Commissioners monitor IMHA services on specified outcomes of IMHA provision, agreed with IMHA providers. ○ Commissioners monitor statutory mental health services on providing information and facilitating access to IMHAs for qualifying patients. ○ There are clear methods for people who have used IMHA services in providing feedback on their experience. **Availability and accessibility of IMHA services:** • Quality indicator 8 – Availability of IMHA services.	

Study details	Population	Recommendations/key findings	Quality assessment
		○ Minimum provision and other standards for IMHA services agreed nationally. ○ Sufficient number of local IMHAs to meet assessed need and a suitable number and variety of IMHA services are funded to meet the diversity of local need. ○ Availability and access to all eligible people including people from diverse communities, people with physical disabilities, people of all eligible ages and people on CTOs should be monitored regularly and involve service users and carers. • Quality indicator 9 – Access. ○ Routinely offer opt-out system for IMHA services. ○ Share information between mental health NHS Trusts and IMAH services about who qualifies for IMHA services. ○ IMHA services easy to contact and respond promptly. ○ Easy access to interpreters or signers for deaf people, where services aren’t provided directly by people from those communities.	

Study details	Population	Recommendations/key findings	Quality assessment
		○ Proactive approach to address inequalities of access. ○ Mental health professional understand the contribution of IMHA services and their role in facilitating access. ○ Responsible health authority/NHS Trust to ensure all qualifying patients and their carers receive information about entitlement to IMHA services in their area. • Quality indicator 10 – Service promotion. ○ Promotional materials in a range of formats available in full range of mental health services. ○ IMHA services provide and promote clear, accessible information for qualifying patients about the IMHA role and access to IHA (for example, posters). ○ IMHAs operate regular drop-in sessions on hospital wards and in community-based services, and provide information to nearest relatives and carers about IMHA services. ○ Information about IMHA services widely disseminated through	

Study details	Population	Recommendations/key findings	Quality assessment
		service user and carer networks. • Quality indicator 11 – strategies to increase uptake. ○ Advocacy services able to evidence what proactive strategies they have used to increase uptake from marginalised groups (for example access to specialist services for people from diverse communities). ○ Mental health services and IMHA services able to provide evidence of measures to provide information about entitlement and access to IMHA services to people on CTOs. ○ Reasonable uptake by people on CTOs, determined by local needs assessment and monitoring information. ○ Where necessary, there is ready access to interpreters and training for IMHAs to work with interpreters, with agreement about how the costs of interpreters are to be met. • Quality indicator 12 – Understanding of IMHA role. ○ Advocacy services have clear, accessible information for service users and carers	

Study details	Population	Recommendations/key findings	Quality assessment
		about the IMHA role and how to access advocacy services. ○ Advocacy services take steps to raise mental health professionals' awareness and understanding of the IMHA role and responsibilities. ○ Mental health staff have received specific training on advocacy and the specific role of IMHAs and how this differs from their role. **IMHA Service Characteristics:** • Quality indicator 13 – Independence. • Quality indicator 14 – Person-centred focus. • Quality indicator 15 – Recovery focus. **Organisation and management of IMHA services:** • Quality indicator 16 – Strategic planning ○ IMHA services have the capacity to plan for future provision and can ensure that the service could respond to changing needs and retain high quality staff and expertise. ○ Services can describe how they involve people who use their services in service	

Study details	Population	Recommendations/key findings	Quality assessment
		design and development and people who use IMHA services are aware of opportunities to be involved in and influence service developments. ○ Services have assessed and considered how to best meet the diverse needs of qualifying patients. • Quality indicator 17 – Leadership and management ○ The IMHA service has clear leadership, coordination and a clear direction. ○ The IMHA service can show clear plans for how IMHA provision will be delivered, including a system for managing IMHAs. ○ The IMHA service has clear policies and procedures, as well as clear lines of accountability. ○ There is a system in place for managing caseloads that takes account of the complexity of cases as opposed to number of cases. ○ There is a culture of continuous learning and improvement and investment in monitoring and regular reviews of the service, which includes	

Study details	Population	Recommendations/key findings	Quality assessment
		people who have used the service and their carers. • Quality indicator 18 – Organisation and staffing ○ IMHA services are provided as part of a suite of advocacy services and sit alongside generic mental health advocacy, IMCA and peer advocacy. ○ IMHA services are staffed by suitably qualified and experienced staff as defined by nationally agreed standards. ○ The size and experience of the IMHA service reflects the local needs assessment or formal partnership arrangements are in place with other organisations, that have specific skills and knowledge to draw on to enable to enable all qualifying patients to have their advocacy needs met appropriately. ○ There are arrangements in place for the regular support and supervision of IMHAs. ○ Services have sufficient administrative support to enable them to carry out regular monitoring and review.	

Study details	Population	Recommendations/key findings	Quality assessment
		○ IMHA services are equal opportunities employers. ○ The organisation has standard policies (including equal opportunities, lone worker, health & safety etc.) for IMHA provision. ○ IMHA providers publish clear statements about the service response times service users can expect. ○ Arrangements are in place for the regular support and supervision of IMHAs. • Quality indicator 19 – Caseload management ○ IMHA services are able to provide a degree of choice of advocate and/or work with other relevant organisations to facilitate this. ○ IMHA services have caseload management and review mechanism in place and review caseloads frequently. ○ IMHAs are able to devote the time needed to each individual case by having a balanced caseload. ○ IMHA services are able to demonstrate a strategy for meeting individuals' broader needs. **The IMHA role:**	

Study details	Population	Recommendations/key findings	Quality assessment
		• Quality indicator 20 – Role clarity for IMHAs. • Quality indicator 21 – Promoting self-determination. **Meeting diverse needs:** • Quality indicator 22 – Meeting diverse needs. **Monitoring and outcomes of IMHA services:** • Quality indicator 23 – Systematic information capture. • Quality indicator 24 – An outcomes-based approach. • Quality indicator 25 – Experience of IMHA partners. • The mental health services context: • Quality indicator 26 – Promoting access to IMHA services. • Quality indicator 27 – Respecting the IMHA role. • Quality indicator 28 - Staff development and training. • Quality indicator 29 – Addressing common concerns. • Quality indicator 30 – Providing an organisational context for IMHA provision. Recommendations • Establish an agreed information system to be able	

Study details	Population	Recommendations/key findings	Quality assessment
		to evaluate access and uptake. - Develop meaningful outcome measures, in partnership with qualifying patients, mental health service users and carers.	
Full citation Ridley, J., Newbigging, K., Street, C. (2018). Mental health advocacy outcomes from service user perspectives, Mental Health Review Journal, 23(4), 280-292 **Country/ies where the study was carried out** England **Study type** Qualitative meta-synthesis **Study dates** Not reported **Source of funding** No sources of funding reported	*Study 1*: African and African Caribbean men with experience of mental health services. *Study 2*: Adults and children who were subject to compulsion under the MHA 1983, and therefore eligible for (but not necessarily accessing) an IMHA under the 2007 MHA. *Study 3*: Children and young people receiving advocacy services.	**Key findings** - IMHA providers in study 2 indicated that the extent and quality of data collection and analysis were very varied; IMHA partners had been asked to provide written or verbal feedback about advocacy support they had received, but this was not consistent across IMHA services. - IMHA services reported using outcome measurement tools that gathered information from IMHA partners at the start and end of advocacy input, but services didn't necessarily combine these data to provide an overall assessment of service effectiveness. - In study 3, young women were unaware of the advocacy provider collecting data about the impact of advocacy; young people felt it was helpful for their advocate to keep a log of issues and actions taken to inform reviews of issue resolution.	**Quality assessment using ROBIS** ***Phase two*** **1.1 Did the review adhere to pre-defined objectives and eligibility criteria?** No information - There was no evidence of pre-specification of objectives and eligibility criteria. **1.2 Were the eligibility criteria appropriate for the review question?** No - Eligibility criteria were not provided. However, the included studies appear to have been selected due to being research studies previously undertaken by the authors on independent mental health advocacy. **1.3 Were eligibility criteria unambiguous?** No - Specific queries remain about the eligibility criteria including ambiguities about the population. **1.4 Were all restrictions in eligibility criteria based on study characteristics appropriate?** No information - Restrictions around the studies characteristics are not provided. **1.5 Were any restrictions in eligibility criteria based on sources of information appropriate?** No information - Restrictions applied on the basis of sources of information were not clearly described.

Study details	Population	Recommendations/key findings	Quality assessment
		• There was little evidence from the studies that service users were routinely involved in making decisions on advocacy outcomes, or about how the impact of advocacy should be captured and measured.	***Concerns regarding specification of study eligibility criteria*** High concern - There were insufficient details regarding study eligibility criteria to judge whether the appropriate studies were included in the review. **2.1 Did the search include an appropriate range of databases/ electronic sources for published and unpublished reports?** No information – Searches appear not to have been conducted. **2.2 Were methods additional to database searching used to identify relevant reports?** No information – Additional database searching appears not to have been conducted. **2.3 Were the terms and structure of the search strategy likely to retrieve as many eligible studies as possible?** No information – No search strategy provided. **2.4 Were restrictions based on date, publication format, or language appropriate?** No information. **2.5 Were efforts made to minimise errors in selection of studies?** No information. ***Concerns regarding methods used to identify and/or select studies*** Unclear concern - There is insufficient information reported.

Study details	Population	Recommendations/key findings	Quality assessment
			3.1 Were efforts made to minimise error in data collection? No information. **3.2 Were sufficient study characteristics available for both review authors and readers to be able to interpret the results?** Probably yes – Summary of key service user characteristics in each study in Table I. **3.3 Were all relevant study results collected for use in the synthesis?** Probably yes – Lines of enquiry from study participants in Box 1. **3.4 Was risk of bias (or methodological quality) formally assessed using appropriate criteria?** No - Study quality was not formally assessed. **3.5 Were efforts made to minimise error in risk of bias assessment?** No. ***Concerns regarding methods used to collect data and appraise studies*** High concern - Some bias may have been introduced through the data collection and no risk of bias assessment completed. **4.1 Did the synthesis include all studies that it should?** No information. **4.2 Were all predefined analyses followed or departures explained?** No information.

Study details	Population	Recommendations/key findings	Quality assessment
			4.3 Was the synthesis appropriate given the nature and similarity in the research questions, study designs and outcomes across included studies? Yes – Qualitative synthesis appears appropriate. **4.4 Was between-studies variation (heterogeneity) minimal or addressed in the synthesis?** Not applicable – Qualitative synthesis. **4.5 Was robustness of the finding(s) assessed e.g. through funnel plot or sensitivity analyses?** Not applicable – Qualitative synthesis. **4.6 Were biases in primary studies minimal or addressed in the synthesis?** No - The studies were not explicitly evaluated for quality or risk of bias. ***Concerns regarding the synthesis and findings*** Unclear concern - There is insufficient information reported to make a judgement on risk of bias. ***Phase three*** **A. Did the interpretation of findings address all of the concerns identified the Phase 2 assessment?** No. **B. Was the relevance of identified studies to the review's research question appropriately considered?** No. **C. Did the reviewers avoid emphasising results on the basis of their statistical significance?**

Study details	Population	Recommendations/key findings	Quality assessment
			Not applicable. **Risk of bias –** High concern.
Full citation Roberts, H., Turner, S., Baines, S., Hatton, C. (2012). Advocacy by and for adults with learning disabilities in England, Improving Health and Lives: Learning Disabilities Observatory **Country/ies where the study was carried out** England **Study type** Survey (open and closed ended questions) and case studies **Study dates** December 2011 and January 2012 **Source of funding** Supported by the Department of Health	A range of people including people living with learning disabilities	**Key findings** • 93% of 54 advocacy organisations stated they recorded information about the people they provided advocacy services to (including age, gender, ethnicity and disability): • 15 organisations (28%) recorded information for all 4 characteristics. 7 (13%) recorded this information on monitoring forms or as part of their monitoring processes. Other information recorded included: eligibility for council services; communication preferences/needs; postcode or address; reasons for referral; risks or behaviour issues; successes. • Commissioners reported receiving information on the demographic characteristics of people using advocacy services, although most advocacy organisations said they recorded this information: 89% of commissioners stated these aspects were monitored. 4 commissioners stated that these data were reported to	**Quality assessment using CASP qualitative studies checklist** **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** Yes - to explore the nature and extent of advocacy services for people with learning disabilities in England, how funding changes affect these services, and the impact of advocacy on health and health services for people with learning disabilities. **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)** Yes. **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)** Yes. **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** Yes - how advocacy organisations and commissioners of advocacy services were identified is explained to some extent. **5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)** Can't tell – limited information on methods of data collection and no other details provided.

Study details	Population	Recommendations/key findings	Quality assessment
		them during quarterly or annual reports or reviews. • Some commissioners reported having done little to monitor advocacy outcomes, whilst others monitored advocacy by looking at reports from advocacy groups, outcomes for people with learning disabilities, and feedback from professionals and people with learning disabilities. 44% of commissioners reported that groups were monitored through numbers or reports from the advocacy organisations. This varied from statistics covering user groups and frequency of use, to biannual reports incorporating case studies. For some this was part of a broader range of measures which also looked at, for example, outcomes, feedback. For example, "Contract monitoring process - they tell us what they have done and provide some numbers etc." [50] (p.39) • Other monitoring methods included looking at outcomes, but some commissioners were not specific about what outcomes they measured. Specific outcomes listed included health monitoring,	**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)** No - the authors did not discuss their own role in the formulation of the research questions, or consider the researchers influence on the respondents. **7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** No - ethical issues and approval for the study were not discussed. **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** Can't tell – no details provided. **9. Is there a clear statement of findings? (Yes/Can't tell/No)** Yes – to some extent. The findings are clearly stated, but the researchers did not discuss the credibility of their findings. **10. How valuable is the research?** Valuable - the authors provide evidence on gaps in the provision of advocacy services and areas for further research. **Overall methodological limitations (No or minor/Minor/Moderate/Serious)** Serious limitations.

Study details	Population	Recommendations/key findings	Quality assessment
		increasing numbers coming forward to be advocates, and success and participation in schemes. - Advocacy was also monitored through feedback from professionals or people with learning disabilities. - Some areas did not currently monitor advocacy whereas others were seeking to do so with the renewal of contracts. For example, "Previously there has been very little monitoring in place and the new contract deals with this issue." [2] (p.39) - Advocacy was also monitored through looking at case studies and the level of engagement of people with learning disabilities with Partnership Boards.	
Full citation Turner, S. (2012). Advocacy by and for adults with learning disabilities in England: Evidence into practice report no.5, Improving Health and Lives: Learning Disabilities Observatory. **Country/ies where the study was carried out** England **Study type**	A range of people including people living with learning disabilities	**Key findings** - Only 53% of commissioners reported receiving information on the demographic characteristics of people using advocacy services, although most advocacy organisations stated that they did record this information. - There was a difference in the number of advocacy groups reporting that they worked to include groups known to be at	**Quality assessment using CASP qualitative studies checklist** See Roberts 2012.

Study details	Population	Recommendations/key findings	Quality assessment
Survey (open and closed ended questions) and case studies **Study dates** See Roberts 2012 **Source of funding** Supported by the Department of Health		risk of exclusion from advocacy and the number of commissioners who reported that they received this information. • Survey responses indicated that parents with learning disabilities and young people in transition may struggle to access advocacy; better sharing of information between advocacy groups and commissioners should ensure both parties are in a better position to judge whether the needs of some of those most at risk of exclusion are being met. • Data from advocacy organisations indicated that there had been an overall reduction in funding levels since 2009/10, although the picture was less clear when distinctions were made between those providing advocacy for a generic client base and those providing only for people with learning disabilities. • Any outcomes or activity monitoring should not compromise the independence or integrity of the advocacy organisation. • Monitoring tools include, for example, Action for Advocacy	

Study details	Population	Recommendations/key findings	Quality assessment
		QPM which is a nationally recognised robust test for the quality of advocacy provision; Lost in Translation, a toolkit for understanding, defining, measuring and communicating advocacy outcomes. **Recommendations** • Collect information about the number and demographic characteristics of people accessing advocacy services, including information on groups who struggle to access advocacy. • Include the information collected in the Joint Strategic Needs Assessment. • Agree a way of monitoring activity and outcomes with advocacy groups. • Gather information on the role advocacy groups play in improving health and social care services and consider these roles when reviewing advocacy funding.	

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; BME: Black and minority ethnic; CASP: Critical Appraisal Skills Programme; CTO: community treatment order; CQC: Care Quality Commission; EHRC: Equality and Human Rights Commission; GAIN: Gateshead Advocacy Information Network; IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; MHA: Mental Health Act; NDTi: National Development Team for Inclusion; NHS: National Health Service; QPM: quality performance mark; ROBIS: Risk of Bias Assessment Tool for Systematic Reviews; SAB: safeguarding adults board.

Appendix C Quality Assessment

Quality assessment tables for scope area: Monitoring services and collecting data for quality improvement

Existing NICE guidelines

Table 4: AGREE II quality assessment of NICE guidelines

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Decision-making and mental capacity (NICE Guideline 108)	2018	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	100 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. The views of the target audiences were included in guideline development. The target users of the guideline are clearly defined.	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate information of	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of recommendati	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the guideline.	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicitly.	99

Domains								
				the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation phase prior to	ons are summarised as flow charts.	There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		

Domains								
				its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.				
Safeguarding adults in care homes (NICE Guideline 189)	2021	100 The overall objective of the guideline, the health question covered by the guideline, and the population to whom the guideline applies are specifically described.	89 The guideline development group included a range of individuals from relevant professional groups, and information about their profession and discipline is reported in detail. A few views from the target audiences were included in guideline development. The target users of the	96 Systematic methods were used to search for evidence and have been reported transparently. The criteria for selecting the evidence are clearly described in the review protocol. The risk of bias for the body of evidence has been conducted and reported clearly. There is clear and adequate	100 The recommendations are specific and unambiguous, and the different options for management of the condition or health issue are clearly presented. Key recommendations are easily identifiable and specific recommendations are grouped together in one section. The description of	96 There is description of the facilitators and barriers and how these influenced the formation of the recommendations. Feedback from key stakeholders were obtained. There is a clear description of how the recommendations can be put into practice and there is an implementation section in the	100 The funding body has been stated and there is an explicit statement reporting the funding body has not influenced the content of the guideline. Competing interests of guideline development group members have been recorded and addressed explicity.	97

Domains								
			guideline are clearly defined.	information of the recommendation development process. There are supporting data and discussions of the benefits and harms of the evidence and it is clear that this has been considered when making recommendations. The guideline describes how the guideline development group linked and used the evidence to inform recommendations, and each recommendation is linked to a key evidence description. The guideline has been externally review by experts in a consultation	recommendations are summarised as flow charts.	guideline. There are references to tools and resources to facilitate application and there are directions on how users can access these. There are details given on the potential resource implications of applying the recommendations. There are identification criteria to assess guideline implementation and monitoring or auditing criteria.		

Domains								
				phase prior to its publication, and details of this process are available. A statement that the guideline will be updated is provided though the methodology for this procedure is unavailable.				

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; NICE: National Institute for Health and Care Excellence

Formal consensus

Table 5: AGREE II quality assessment of included guidelines

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
Lawson 2017	2017	61 Overall objective and population are described. Health question is not specifically described but alluded to.	22 Target users are defined but not information on guideline development group and views and preferences from population has been included.	8 Health benefits when describing recommendations have been considered. No information on systematic methods, criteria selection, strengths and	22 Recommendations are not always specific and easily identifiable. No mentioning of different options for management.	4 Some mentioning of potential tools provided. No further information on facilitators/barriers, potential resource	0 No funding body and competing interest have been identified.	29

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				limitations, and methods for formulating recommendations have been provided. Link between recommendations and supporting evidence not clear. No information on external reviewing, and procedure for updating have been provided.		implications, and auditing criteria provided.		
NDTi 2016a	2016	22 Overall objective is described. Health question is alluded to but not specifically stated. No information about population is provided.	28 Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear.	10 Health benefits have seemingly been considered when describing recommendations. No information regarding systematic methods, criteria for selection, strengths and	56 Key recommendations are easily identifiable and mostly specific enough. Different options are not clearly presented but alluded to.	21 Advice on how to put recommendations into practice is alluded to but not clearly defined. No information facilitators and barriers, potential resource implications, auditing	17 Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided.	34

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				limitations, and methods for formulating recommendations have been provided. Links between recommendations and evidence are not clear. No information on external reviews and no information on updating has been provided.		criteria are provided.		
NDTi 2016b	2016	39 Overall objectives are described and a description of questions is provided. The target population is mentioned but no further details provided.	28 Target users have been mentioned but not clearly defined. Guideline development group and views and preferences from population are unclear.	8 Health benefits from measuring outcomes have been considered. Recommendations on how to measure advocacy outcomes are presented. No information on external reviews and no information on	50 Key recommendations on how to measure advocacy outcomes are easily identifiable and mostly specific enough	46 Advice on how to put recommendations on the toolkit into practice is clearly defined. Information provided on facilitators and barriers. Limited information provided on potential resource	17 Funding body has been identified but not how/if it influenced the content of the guideline. No information about competing interests were provided.	38

Domains								
Guideline reference	**Year**	**Scope and purpose %**	**Stakeholder involvement %**	**Rigour of development %**	**Clarity of presentation %**	**Applicability %**	**Editorial Independence %**	**Overall rating %**
				updating has been provided.		implications, auditing criteria.		

AGREE: Appraisal of Guidelines for Research & Evaluation Instrument; NDTi: National Development Team for Inclusion

Table 6: ROBIS quality assessment of included systematic reviews

Domains (Low concern/High concern/Unclear concern)						
Systematic review reference	**Year**	**Study eligibility criteria**	**Identification and selection of studies**	**Data collection and study appraisal**	**Synthesis and findings**	**Overall risk of bias**
Macadam 2013	2013	Low concern	Low concern	Unclear concern	Unclear concern	Unclear concern
Mercer 2020	2020	High concern	High concern	High concern	Unclear concern	High concern
Ridley 2018	2018	High concern	Unclear concern	High concern	Unclear concern	High concern

ROBIS: Risk of Bias Assessment Tool for Systematic Reviews

Table 7: CASP quality assessment of included qualitative studies

Screening questions (Yes/No/Can't tell)											
Qualitative study reference	**Year**	**Clear statement of aims of research**	**Appropriate methodology**	**Research design appropriate to address aims**	**Appropriate recruitment strategy**	**Appropriate data collection methods**	**Relationship between researcher and participants adequately considered**	**Ethical issues taken into consideration**	**Data analysis sufficiently rigorous**	**Clear statement of findings**	**How valuable is the research**
Lawson 2020	2020	Yes	Yes	Yes	Can't tell	Yes	No	No	Can't tell	Yes	Valuable
NDTi 2014b	2014b	Yes	Can't tell	Can't tell	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
NDTi 2014c	2014c	Yes	Can't tell	Can't tell	Can't tell	Can't tell	No	No	Can't tell	Yes	Valuable
Newbigging 2012	2012	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Roberts 2012	2012	Yes	Yes	Yes	Yes	Can't tell	No	No	Can't tell	Yes	Valuable

Screening questions (Yes/No/Can't tell)											
Qualitative study reference	**Year**	**Clear statement of aims of research**	**Appropriate methodology**	**Research design appropriate to address aims**	**Appropriate recruitment strategy**	**Appropriate data collection methods**	**Relationship between researcher and participants adequately considered**	**Ethical issues taken into consideration**	**Data analysis sufficiently rigorous**	**Clear statement of findings**	**How valuable is the research**
Turner 2012	2012	Yes	Yes	Yes	Yes	Can't tell	No	No	Can't tell	Yes	Valuable

CASP: Critical Appraisal Skills Programme; NDTi: National Development Team for Inclusion

Appendix D Excluded studies

Excluded studies for scope area: Monitoring services and collecting data for quality improvement

Formal consensus (documents identified by the call for evidence and the guideline committee)

Table 8: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Bauer, B., Wistow, G., Dixon, J., Knapp, M. (2013). Investing in Advocacy Interventions for Parents with Learning Disabilities: What is the Economic Argument? Personal Social Services Research Unit. Available at: http://eprints.lse.ac.uk/51114/1/Investing%20in%20advocay.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Chatfield, D., Lee, S., Cowley, J., Kitzinger, C., Kitzinger, J., Menon, D. (2018). Is there a broader role for independent mental capacity advocates in critical care? An exploratory study. Nursing in Critical Care, 23(2), 82-87.	No key findings or recommendations relevant to Monitoring services and collecting data for quality improvement
Davies, L., Townsley, R., Ward, L., Marriott A. (2009). A framework for research on costs and benefits of independent advocacy, Office for Disability Issues. Available at https://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/odiframework.pdf [Accessed 16/02/2022]	Publication has no evidence base
EY (2017). Society's return on investment (SROI) in older people's cancer advocacy services. Available at: https://opaal.org.uk/?s=Society%27s+return+on+investment+%28SROI%29+in+older+people%E2%80%99s+cancer+advocacy+services [Accessed 16/02/2022]	Publication is based on case-studies.
Feeney, M., Evers, C., Agpalo, D., Cone, L., Fleisher, J., Schroeder, K. (2020). Utilizing patient advocates in Parkinson's disease: A proposed framework for patient engagement and the modern metrics that can determine its success. Health Expectations, 23, 722-730.	Non-UK based (International)
Harflett, N., Turner, S., Bown, H., National Development Team for Inclusion (2015). The impact of personalisation on the lives of the most isolated people with learning disabilities. A review of the evidence. Available at: https://www.ndti.org.uk/assets/files/Isolation_and_personalisation_evidence_review_final_02_06_15.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Monitoring services and collecting data for quality improvement
Healthwatch (2015). Independent Complaints Advocacy: Standards to support the commissioning, delivery and monitoring of the service. Available at: https://www.healthwatch.co.uk/sites/healthwatch	Publication is based on case-studies.

Study	Reason for Exclusion
.co.uk/files/healthwatch_advocacy_standards_10022015.pdf [Accessed 16/02/2022]	
Kilinç, S. Erdem, H., Healer, R., Cole, J. (2020). Finding meaning and purpose: a framework for the self-management of neurological conditions. Disability and Rehabilitation, 44(2), 219-230.	Publication is based on case-studies.
National Development Team for Inclusion (2012). Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities. Available at: https://www.ndti.org.uk/assets/files/Reasonably-adjusted_2020-12-30-150637.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Monitoring services and collecting data for quality improvement
National Development Team for Inclusion (2014). The impact of advocacy for people who use social care services: a review of the evidence, NDTi Insights. Available at: https://www.ndti.org.uk/assets/files/Insights_19_Impact_of_Advocacy_FINAL.pdf [Accessed 11/02/2022]	No key findings or recommendations relevant to any scope area
National Development Team for Inclusion (2020). Valuing voices: Protecting rights through the pandemic and beyond. Available at: https://www.ndti.org.uk/assets/files/Valuing_voices_-_Protection_rights_through_the_pandemic_and_beyond_Oct_2020.pdf [Accessed 07/04/2021]	No key findings or recommendations relevant to Monitoring services and collecting data for quality improvement
National Development Team for Inclusion (2020). Valuing voices in Wales: Protecting rights through the pandemic and beyond. Available at: https://www.dewiscil.org.uk/news/valuing-voices-in-wales-report [Accessed 07/04/2021]	No key findings or recommendations relevant to Monitoring services and collecting data for quality improvement
National Development Team for Inclusion. (2018). The Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/Advocacy-Charter-A3.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion. (2018). The Easy Read Advocacy Charter (Poster). Available at: https://www.ndti.org.uk/assets/files/The-Advocacy-Charter-Easy-Read.pdf [Accessed 16/02/2022]	Publication has no evidence base
National Development Team for Inclusion. (2018/2019). The Quality Performance Mark Advocacy standards. Assessment Workbook Quality Performance Mark. A National Development Team for Inclusion programme	Publication has no evidence base
National Development Team for Inclusion and Empowerment Matters CIC. (2014) Advocacy Quality Performance Mark (QPM). Recognising Quality in independent advocacy. Code of Practice 2014	Publication has no evidence base

Study	**Reason for Exclusion**
Newbigging, K., Ridley, J., McKeown, M., Machin, K., Poursanidou, D., Able, L., et al. (2012). The Right to Be Heard: Review of the Quality of Independent mental Health Advocate (IMHA) Services in England, University of Central Lancashire. Available at: https://www.firah.org/upload/notices3/2012/uclan.pdf [Accessed 13/05/2021]	No key findings or recommendations relevant to Monitoring services and collecting data for quality improvement
Newbigging, K., Ridley, J., McKeown, M., Machin, K., Sadd, J., Machin, K., et al. (2015). Independent Mental Health Advocacy – The Right to Be Heard: Context, Values and Good Practice. Jessica Kingsley Publishers: London, UK.	Publication is a book/book-chapter.
Newbigging, K., McKeown, M., French B. (2011). Mental health advocacy and African and Caribbean men: Good practice principles and organizational models for delivery. Health Expectations, 16(1), 80-104.	No key findings or recommendations relevant to Monitoring services and collecting data for quality improvement
Older People's Advocacy Alliance (2014). Every Step of the Way. 13 stories illustrating the difference independent advocacy support makes to older people affected by cancer. available at: https://opaal.org.uk/app/uploads/2015/09/Advocacy-Stories.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Older People's Advocacy Alliance (2016). Facing Cancer Together. Demonstrating the power of independent advocacy. Available at: https://opaal.org.uk/app/uploads/2016/12/Facing-Cancer-Together.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
Older People's Advocacy Alliance (2017). Time: Our Gift to You – why cancer advocacy volunteers support their peers. Available at: https://opaal.org.uk/app/uploads/2017/02/Time-our-gift-to-you.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
SERIO (2021). The Veterans' Advocacy People: Final Evaluation Report and Social Return on Investment Analysis, The Advocacy People. Available at: https://www.vfrhub.com/wp-content/uploads/2021/01/898ed6_d72d832632234777aa1b5b68e8c314e6.pdf [Accessed 06/04/2021]	No key findings or recommendations relevant to Monitoring services and collecting data for quality improvement
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-users/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence, University of Central Lancashire (2015). At a glance 68: Understanding Independent Mental Health Advocacy (IMHA) for people who use services, easy read version. Available at: https://www.scie.org.uk/independent-mental-	Publication has no evidence base

Study	Reason for Exclusion
health-advocacy/resources-for-users/understanding/easy-read/ [Accessed 16/02/2022]	
Social Care Institute for Excellence, University of Central Lancashire (2014). At a glance 67: Understanding Independent Mental Health Advocacy (IMHA) for mental health staff. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/ [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence and University of Central Lancashire (2015). Flowchart for Open Access IMHA. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/improving-access/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving access to Independent Mental Health Advocacy for providers of mental health services. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/improving-access/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a briefing for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/briefing/ [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence and University of Central Lancashire (2015). Improving equality of access to Independent Mental Health Advocacy (IMHA): a report for providers. Available at: https://www.scie.org.uk/independent-mental-health-advocacy/improving-equality-of-access/report/ [Accessed 16/02/2022]	Publication is based on case-studies.
Social Care Institute for Excellence, University of Central Lancashire (2015). Commissioning Independent Mental Health Advocacy (IMHA) services in England: 10 top tips for commissioners. https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/10-top-tips.asp [Accessed 16/02/2022]	Publication has no evidence base
Social Care Institute for Excellence, University of Central Lancashire (2015). What does a good IMHA service look like? (Self-assessment tool) Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/what-good-imha-service-looks-like/ [Accessed 16/02/2022]	Publication has no evidence base

Study	Reason for Exclusion
Social Care Institute for Excellence, University of Central Lancashire (2015). Making a difference: measuring the impact of Independent Mental Health Advocacy (IMHA). Available at: https://www.scie.org.uk/independent-mental-health-advocacy/measuring-effectiveness-and-commissioning/impact/ [Accessed 16/02/2022]	Publication is based on case-studies.
Strong, S. (2012). User-led organisation leadership of support planning and brokerage. The International Journal of Leadership in Public Services, 8(2), 83-89.	Publication is based on case-studies.
Taylor & Francis Production Disability and Rehabilitation (IDRE). My Life Tool (self-management tool): www.mylifetool.co.uk	Publication has no evidence base
Teeside University (2015/2016). UTREG Online Module Specification. Advocacy - Evolution, Equality and Equity. Unpublished	Publication has no evidence base
Townsley, R., Marriott, A., Ward, L. (2009). Access to independent advocacy: an evidence review, Office for Disability Issues. Available at: http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/iar-exec-summary-standard.pdf [Accessed 16/02/2022]	Not published in the last 10 years
Turner, S., Giraud-Saunders, A. (2014). Personal health budgets: Including people with learning disabilities, Think Local act Personal. Available at: https://www.thinklocalactpersonal.org.uk/_assets/Reports/TLAPIncludingLD.pdf [Accessed 16/02/2022]	Publication is based on case-studies.
VoiceAbility (2021). STOMP and STAMP: Stopping the over medication of children, young people and adults with a learning disability, autism or both.	Publication has no evidence base
VoiceAbility (2021). Preventing over-medication: STOMP top tips for advocates: How you can help to stop the over-medication of people with a learning disability, autism or both. Available at: https://www.voiceability.org/assets/download/STOMP-2021B.pdf [Accessed 16/02/2022]	Publication has no evidence base

Excluded economic studies

No economic evidence was considered for this scope area.

Appendix E Research recommendations – full details

Research recommendations for scope area: Monitoring services and collecting data for quality improvement

E.1.1 Research recommendation

What is the effectiveness and acceptability of providing advocacy through different approaches?

E.1.2 Why this is important

Research on this question is needed because there is currently no national evidence to inform decisions based on a shared understanding of what good advocacy looks like and what makes it effective. Research would take a broad view of factors which have a possible impact on the availability, effectiveness and acceptability of advocacy. Factors to consider include commissioning arrangements (particularly how statutory and non-statutory advocacy are commissioned), what makes good advocacy, how advocacy can and should be measured, what people want from an advocate, different models of delivery, what factors make a good advocate, long term funding of advocacy and how it is costed, training and support for advocates, use and efficacy of the Quality Performance Mark in assessing the quality of advocacy services.

Research into these factors will help commissioners, users and providers of advocacy to understand what quality advocacy looks like, which will help improve consistency, efficacy and the use of public resources. This will lead to increased confidence in advocacy by people who draw on advocacy and their family members.

It is important that research clearly identifies the individual and various factors which may influence the effectiveness of advocacy including take up of advocacy services by specific groups within the population. Examples of these factors include the availability of choice of advocate based on gender specific, shared culture or ethnic background as the person drawing on advocacy. It will also be important to explore other factors that may influence the effectiveness or acceptability of advocacy such as whether the advocate has lived experience of drawing on health, care or advocacy services.

Research will also need to consider the different types of advocacy, including peer, self, 1:1, group and non-instructed advocacy and establish how effective they are in achieving their stated goal of promoting voice, choice and increasing citizenship.

E.1.3 Rationale for research recommendation

Table 9: Research recommendation rationale

Importance to 'patients' or the population	Any adult may want or need to access advocacy at different points in their life. The advocacy they access must be effective and impactful. Currently there is no UK evidence base demonstrating what good effective advocacy looks like. This means that people cannot access any national evidence based information on what to expect from effective services. It is further important that people receive effective advocacy wherever they draw on advocacy – research would reduce inconsistencies in how advocacy is delivered. In turn this would build

	trust in services and ensure the aims of advocacy are implemented.
Relevance to NICE guidance	Evidence generated by this research would provide the basis for additional and stronger recommendations to be made in future updates of this guideline.
Relevance to the NHS	The recommended research has the following practice relevance: • Findings would inform training, professional development and accreditation standards (such as the Quality Performance Mark). • Advocates will have increased confidence in the support they provide, leading to better quality service provision. • Evidence informed commissioning would lead to a better, more efficient use of public funds. • More people will access good quality advocacy which will support health and social care services, and other community and voluntary sectors, to provide a better and more responsive service. Research into effective advocacy will lead to increased confidence in advocacy by people who commission or fund advocacy and professionals who work alongside advocates.
National priorities	Current and forthcoming legislation places a high priority on advocacy (for example Reforming the Mental Health Act 2021 (white paper), Liberty Protection Safeguards introduced within the Mental Capacity (Amendment) Act 2019). However, there has been limited research that looks at what effective advocacy looks like. Research would contribute to the aims of legislation in making sure people can access good quality advocacy. The NHS long term plan seeks to reduce health inequalities, increase personalisation and address unwarranted variation and effective advocacy can significantly contribute to these targets. The Community Mental Health Transformation Programme to increase the number of services based in communities. The intention is to make it easier for people to engage with other services and effective advocacy will be vital in achieving this. With the increasing professionalisation of advocacy, requirements to regulate and accredit advocates are being considered (for example within the Mental Health Act white paper). Research into effective advocacy will ensure that those advocates who are accredited are practising in accordance with agreed evidence based standards of effective advocacy. Any

	regulatory body that is set up for advocates will set standards for evidence based training and quality standards and any person wishing to practice as an advocate would need to have the required evidence based training and conform to evidence based quality standards. This will help to ensure consistency across the advocacy sector in standards for both individual advocates an advocacy organisations. Research would also inform any potential creation of regulatory bodies.
Current evidence base	No recommendations about effective advocacy were identified from existing NICE guidelines. There were 74 statements generated for the formal consensus process for this scope area, based on documents received in response to the call for evidence and identified by the guideline committee. However, a number of the statements lacked detail on how to provide effective advocacy and there were gaps in relation to effective advocacy services for specific populations, such as people from racialised communities. Further, the committee were aware of the Quality Performance Mark, which is a commonly used quality standard for advocacy services, based on the Advocacy Code of Practice & Advocacy Charter. However, this is not evidence based and, therefore, could not be recommended in the current guideline.
Equality considerations	The proposed research will focus on all adults using advocacy services but it is recommended that data are disaggregated to understand the impact of different factors in the delivery of advocacy on people with protected characteristics. This is important as research (Right to be heard) has identified certain groups are at risk of not accessing effective advocacy. This has led to focused development of culturally appropriate advocacy, LGBTQ sensitive advocacy, deaf advocacy and advocacy with people who have a learning disability and people with autism. However there is no specific evidence on what actually works and leads to impactful advocacy.

IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate; LGBTQ: lesbian, gay, bi-sexual, transgender and queer or questioning; QPM: Quality Performance Mark

E.1.4 Modified PICO table

Table 10: Research recommendation modified PICO table

Population	People with health and social care needs in all adult settings, including those who have a legal right to an advocate and those who fund their own social care. Special consideration should be given to people with characteristics protected under the Equality Act 2010, in particular:

	• People from Black, Asian or minority ethnic backgrounds • Deaf people • People with a learning disability • Autistic people • People who cannot instruct an advocate (or having fluctuating capacity) • People who might need a 'specialist' advocate (IMHA, IMCA, Care Act) • People who use non-verbal communication • People who identify as LGBTQ Also, people subject to restrictive practices.
Intervention	Intervention arms designed to assess the effectiveness of advocacy services which are characterised by certain key factors such as: • Delivery by an advocate in the same age group as the person being supported • Delivery by an advocate with the same ethnicity as the person being supported • Delivery by an advocate who has completed culturally competent advocacy training • Delivery by an advocate with lived experience of health and social care services Results should be stratified according to whether the characteristics of the advocate are in line with the person's expressed preferences.
Comparator	Comparisons with each intervention group characterised by an 'absence' of relevant key factors such as: • Delivery by an advocate in a different age group as the person being supported • Delivery by an advocate with a different ethnic background to the person being supported • Delivery by an advocate who has not completed culturally competent advocacy training • Delivery by an advocate with no lived experience of health and social care services Results should be stratified according to whether the characteristics of the advocate are in line with the person's expressed preferences.
Outcome	Individual outcomes: • Care contacts (for example mental health services, acute care, primary care, social work, adult safeguarding) • Independence and control • Social care quality of life including wellbeing • Physical and mental health related quality of life

	• Satisfaction with advocacy service • Employment • Protection of human rights (for example an increased understanding or use of human rights) • Personal advocacy skills (measured through changes in ability to self-advocate, and changes in confidence) • Challenging decisions • Raising concerns (including complaints) • Participation within decision making processes Service or organisational outcomes: • Service use, for example client contacts • Referral rates • Resource use • Competency and wellbeing of advocates • Use of QPM and qualification training • Outputs and key performance indicators Wider, community outcomes: • Social inclusion • Access to community services • Active engagement with community groups/ organisations • Increased citizenship (such as voting behaviour) The qualitative element will explore the following key themes related to the different approaches to delivering advocacy: • Lived experiences of using advocacy services • Satisfaction with the advocacy services • Preferences about using advocacy, for example the role of culture, identity and diversity. • Subject perceptions of the success of the different advocacy services, for example in terms of feeling better connected with the community or social life, feeling better protected from abuse and neglect. • Advocate’s experiences of delivering services.
Study design	Mixed methods: Randomised Controlled Trial or prospective cohort study with controls for confounding plus qualitative design.
Timeframe	The research should take place over 2 to 3 years with follow up points at 12 and 18 months.
Additional information	N/A

IMHA: Independent Mental Health Advocate; NICE: National Institute for Health and Care Excellence; QPM: Quality Performance Mark

Appendix F Existing NICE recommendations

Table 11: Existing NICE recommendations for scope area: Monitoring services and collecting data for quality improvement

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
Local authorities and commissioners should monitor: whether care homes are telling residents about advocacy and the criteria for accessing this and how advocates are involved in the management of safeguarding concerns.	**Safeguarding adults in care homes [NG189] – 1.8.14** The committee used qualitative themes from research evidence on responding to and managing safeguarding concerns in care homes, and support and information needs for everyone involved in safeguarding concerns in care homes. The evidence showed that residents benefit when they are involved and kept informed throughout the safeguarding process. The evidence also emphasised the value that residents place on support from family, friends or advocates in helping them achieve their desired outcomes. However, the committee had some concerns about the quality of the data, which had some methodological limitations as well as questionable relevance (it was not always clear whether findings related specifically to care home settings). The committee therefore also used the Making Safeguarding Personal framework and the Care Act 2014. These sources highlight the importance of involving people fully as possible in decisions and giving them the information and support they need to participate. The committee recognised that there should be a clear difference and understanding of the roles of the practitioners and independent advocate involved in safeguarding. Although the practitioner might be acting in the best interest of	**Adapted** This recommendation was split into two bullet points to make the actions clearer and the wording was amended to clarify the role of advocates in safeguarding. See the Benefits and Harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Local authorities and commissioners should monitor: • whether health and social care providers are telling people about advocacy and the criteria for accessing it • access to advocacy and take up of it by different populations in the local community

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	the person, they may be operating within the constraints of their role. It is only the independent advocate who acts according to instruction from the person. Residents will often need emotional and practical support while an enquiry is taking place. In addition, they may need this support to continue afterwards, and their needs should be reassessed after the enquiry.		
Commissioners, public bodies and providers of statutory advocacy services should work closely to ensure that: • statutory duties on public bodies to refer to and involve advocacy are consistently adhered to and monitored and • failures in the duty to refer to statutory advocacy are addressed.	**Decision-making and mental capacity [NG108] – 1.1.10** Other considerations: Recommendations 1.1.10 and 1.1.11 were drafted on the basis of lengthy committee discussions, drawing on members' expertise and knowledge of similar findings in a number of reports by the Department of Health, the Care Quality Commission and the House of Lords. The consistent message from this body of work, as it was interpreted by the committee, was that practitioners and people using services lack understanding of the critical role that Independent Advocacy can play in upholding rights.	**Adapted** The target audience for this recommendation was adapted to focus on commissioners only. See the Benefits and Harms section of The committee's discussion and interpretation of the evidence in this review for more information.	Commissioners should ensure that: • statutory duties on public bodies to refer to and involve advocacy are consistently adhered to and monitored • failures in the duty to refer to statutory advocacy are addressed.
Safeguarding Adults Boards should be assured that local authorities have auditing processes in place to monitor how residents and their advocates are included in safeguarding enquiries.	**Safeguarding adults in care homes [NG189] – 1.8.6** The committee used qualitative themes from research evidence on responding to and managing safeguarding concerns in care homes, and support and information needs for everyone involved in safeguarding concerns in care homes. The evidence showed that residents benefit when they are involved and kept informed throughout the safeguarding process. The evidence also emphasised the value that residents place on	**Adapted** This recommendation was broadened to include the full population of this guideline and cover the whole spectrum of safeguarding activity. See the Benefits and Harms section of The committee's discussion and interpretation	Safeguarding Adults Boards should be assured that local authorities have auditing processes in place to monitor how people and their advocates are included in safeguarding processes.

Original recommendation	Underpinning evidence (from original NICE guideline)	Action taken	Final recommendation
	support from family, friends or advocates in helping them achieve their desired outcomes. However, the committee had some concerns about the quality of the data, which had some methodological limitations as well as questionable relevance (it was not always clear whether findings related specifically to care home settings). The committee therefore also used the Making Safeguarding Personal framework and the Care Act 2014. These sources highlight the importance of involving people fully as possible in decisions and giving them the information and support they need to participate. The committee recognised that there should be a clear difference and understanding of the roles of the practitioners and independent advocate involved in safeguarding. Although the practitioner might be acting in the best interest of the person, they may be operating within the constraints of their role. It is only the independent advocate who acts according to instruction from the person. Residents will often need emotional and practical support while an enquiry is taking place. In addition, they may need this support to continue afterwards, and their needs should be reassessed after the enquiry.	of the evidence in this review for more information.	

Appendix G Formal consensus

Additional information related to scope area: Monitoring services and collecting data for quality improvement

Table 12: Formal consensus round 1 statements and results for scope area: Monitoring services and collecting data for quality improvement

Statement no.	Statement	Percentage agreement	Reference	Action taken
1	There should be quarterly reporting between advocacy provider and commissioners, consistent across all local authority areas.	80.00%	Lawson, 2020	Carried forward to committee discussion
2	Commissioners should monitor contracts to ensure that advocates are working to published quality standards.	100.00%	Lawson, 2017	Carried forward to committee discussion
3	There should be better sharing between advocacy groups and commissioners to ensure that they are in a better position to judge whether the needs of some of those most at risk of exclusion are being met.	80.00%	Turner, 2012	Carried forward to committee discussion
4	Any outcomes or activity monitoring should not compromise the independence or integrity of the advocacy organisation.	81.82%	Turner, 2012	Carried forward to committee discussion
5	Monitoring tools include, for example, Action for Advocacy Quality Performance Mark (QPM) which is a nationally recognised robust test for the quality of advocacy provision; Lost in Translation, a toolkit for understanding, defining, measuring and communicating advocacy outcomes.	100.00%	Turner, 2012	Carried forward to committee discussion
6	Information about the number and demographic characteristics of people accessing advocacy services, including information on groups who struggle to access advocacy, should be included in the Joint Strategy Needs Assessment.	100.00%	Turner, 2012	Carried forward to committee discussion
7	It is recommended that commissioners and advocacy organisations agree a way of monitoring activity and outcomes with advocacy groups.	90.91%	Turner, 2012	Carried forward to committee discussion
8	Information on the role advocacy groups play in improving health and social care services should be collected.	72.73%	Turner, 2012	Redrafted for round 2
9	Advocacy organisations should record information including eligibility for council services.	40.00%	Roberts, 2012	Discarded

Statement no.	Statement	Percentage agreement	Reference	Action taken
10	Advocacy organisations should record information including communication preferences/needs.	90.91%	Roberts, 2012	Carried forward to committee discussion
11	Advocacy organisations should record information including reasons for referral.	81.82%	Roberts, 2012	Carried forward to committee discussion
12	Advocacy organisations should record information including risks or behaviour issues.	63.64%	Roberts, 2012	Redrafted for round 2
13	Advocacy organisations should record information including successes.	63.64%	Roberts, 2012	Redrafted for round 2
14	Data on demographic characteristics of people using advocacy services should be reported during quarterly or annual reports or reviews, and data should be shared with commissioners.	81.82%	Roberts, 2012	Carried forward to committee discussion
15	Advocacy organisations should record information about the people they provided advocacy services to (including age, gender, ethnicity, disability, and demographic characteristics).	81.82%	Turner, 2012; Roberts, 2012	Carried forward to committee discussion
16	Some commissioners and local areas do little to monitor advocacy outcomes.	37.50%	Roberts, 2012	Discarded
17	Commissioners monitor advocacy by looking at reports from advocacy groups.	25.00%	Roberts, 2012	Discarded
18	Commissioners monitor advocacy by looking at outcomes for people with learning disabilities.	28.57%	Roberts, 2012	Discarded
19	Commissioners monitor advocacy by looking at feedback from professionals and people with learning disabilities.	37.50%	Roberts, 2012	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
20	Some areas are seekings to monitor advocacy with the renewal of contracts.	42.86%	Roberts, 2012	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
21	Advocacy can be monitored through looking at case studies.	70.00%	Roberts, 2012	Redrafted for round 2

Statement no.	Statement	Percentage agreement	Reference	Action taken
22	Advocacy can be monitored through the level of engagement of people with learning disabilities with Partnership Boards.	44.44%	Roberts, 2012	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
23	Key features and characteristics of all forms of advocacy are captured in various quality marks and advocacy qualifications, such as independence, promoting empowerment, providing people with a voice and challenging inequality.	75.00%	NDTi 2014a	Redrafted for round 2
24	There are national or local advocacy standards developed for specific groups (including children, black and minority ethnic communities and people who use mental health services).	88.89%	NDTi 2014a	Carried forward to committee discussion
25	Models that had been developed to evaluate advocacy outcomes are not widely used.	33.33%	NDTi 2014a	Discarded
26	Advocacy providers, in partnership with commissioners, should develop consistent, practical and robust methods to record and report information and outcomes across the sector.	100.00%	NDTi 2014a	Carried forward to committee discussion
27	There is a lack of longitudinal evidence contributing to the difficulties in identifying whether outcomes are short- or long-terms.	66.67%	NDTi 2014a	Redrafted for round 2
28	The lack of robust research and evidence prevents conclusions to be drawn as to whether advocacy has a positive impact.	33.33%	NDTi 2014a	Discarded
29	The lack of robust research and evidence prevents conclusions to be drawn as to whether advocacy is a cost-effective use of public resources.	37.50%	NDTi 2014a	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
30	Advocacy projects mainly report outputs (for example, time spent with clients, number of meetings) rather than outcomes (such as increased choice and control, improved health and wellbeing).	62.50%	NDTi 2014a	Discarded (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
31	Advocacy organisations collect data on the characteristics of people who are supported, but not consistently or robustly.	42.86%	NDTi 2014a, Roberts, 2012	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)

Statement no.	Statement	Percentage agreement	Reference	Action taken
32	Practical, uniform methods for capturing information do not exist.	42.86%	Lawson, 2020; NDTi 2014a	Discarded
33	Information about advocacy organisations is collected in various ways, including quarterly and annual reports, meetings, contract monitoring meetings, and other general means of communication.	85.71%	NDTi 2014a	Carried forward to committee discussion
34	There is an inconsistent referral mechanisms for advocacy support which means that recording relevant data is not always possible.	62.50%	NDTi 2014a	Redrafted for round 2
35	Obtaining evidence is hampered by a lack of agreement about definitions of advocacy and understanding of the role of advocacy.	62.50%	NDTi 2014a	Redrafted for round 2
36	The diverse range of services working towards different aims and objectives results in a lack of coherence, making it difficult to form a coherent picture and compare the impact of advocacy.	57.14%	NDTi 2014a	Discarded
37	A lack of agreement on identifying and defining outcomes hampers the gathering of evidence.	77.78%	NDTi 2014a	Redrafted for round 2
38	Gathering of evidence is also hampered by people who use advocacy services having difficulties in clearly identifying or expressing goals and/or outcomes.	33.33%	NDTi 2014a	Discarded
39	There are difficulties in quantifying and measuring specific types of advocacy.	55.56%	NDTi 2014a	Discarded
40	There are difficulties in measuring a final state or change because advocacy is often about moving towards a goal and developing the potential of people rather than achieving a concrete result.	70.00%	NDTi 2014a	Redrafted for round 2
41	Challenges in defining outcomes include the absence of widely agreed benchmarks against which performance can be measured.	60.00%	NDTi 2014a	Redrafted for round 2
42	A lack of a comparison group results in major limitations in establishing causalities between advocacy and outcomes.	37.50%	NDTi 2014a	Discarded
43	Future research should focus on comprehensive mapping of advocacy organisations, including trends in income levels.	40.00%	NDTi 2014a	Discarded
44	Future research should focus on comprehensive mapping of advocacy organisations, including client groups receiving advocacy.	50.00%	NDTi 2014a	Discarded

Statement no.	Statement	Percentage agreement	Reference	Action taken
45	Future research should focus on comprehensive mapping of advocacy organisations, including gaps in the provision of advocacy.	70.00%	NDTi 2014a	Discarded (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
46	Future research should focus on comprehensive mapping of advocacy organisations, including trends in demand.	60.00%	NDTi 2014a	Redrafted for round 2
47	Future research should focus on comprehensive mapping of advocacy organisations, including types of advocacy provided and trends associated with this.	70.00%	NDTi 2014a	Redrafted for round 2
48	Future research should focus on comprehensive mapping of advocacy organisations, including trends in the number of staff and volunteers.	40.00%	NDTi 2014a	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
49	Future research should focus on the impact of advocacy for particular groups of people who are likely to use social care services.	70.00%	NDTi 2014a	Redrafted for round 2
50	Future research should focus on the impact of advocacy for particular groups of people where evidence appears particularly limited at present (for example, people with dementia, people from BME backgrounds).	72.73%	NDTi 2014a	Redrafted for round 2
51	Future research should focus on typical characteristics of advocacy provision and the extent to which these affect its impact (for example, types of advocacy).	66.67%	NDTi 2014a	Redrafted for round 2
52	There is gap in evidence in relation to the effectiveness of independent advocacy.	20.00%	NDTi 2014a; NDTi 2016a	Discarded
53	The lives of individuals who use advocacy services should be included in outcome frameworks to measure the impact of independent advocacy.	25.00%	NDTi 2016a; Ridley, 2018	Discarded
54	Advocacy organisations should have methods to collect and report on agreed outcomes.	80.00%	NDTi 2016a	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
55	Advocacy organisation should collect information to identify what has been achieved.	80.00%	NDTi 2016a	Carried forward to committee discussion
56	Advocacy organisations should reflect on what has and has not been achieved to identify what should be done differently and/or develop in the future to improve outcomes for people.	90.00%	NDTi 2016a	Carried forward to committee discussion
57	Outcomes that result in changes for individuals include an increased voice and personal control.	100.00%	NDTi 2016a	Carried forward to committee discussion
58	Outcomes that result in changes for individuals include improved opportunities.	100.00%	NDTi 2016a	Carried forward to committee discussion
59	Outcomes that result in changes for individuals include challenging injustice.	100.00%	NDTi 2016a	Carried forward to committee discussion
60	Outcomes that result in changes for individuals include increased independence.	80.00%	NDTi 2016a	Carried forward to committee discussion
61	Outcomes that result in changes for individuals include having rights upheld.	100.00%	NDTi 2016a	Carried forward to committee discussion
62	Outcomes that demonstrate a change in the health and care system as a result of advocacy include improving the quality of service response and service experience by people who use it.	100.00%	NDTi 2016a	Carried forward to committee discussion
63	Outcomes that demonstrate a change in the health and care system as a result of advocacy include service change and improvement.	100.00%	NDTi 2016a	Carried forward to committee discussion
64	Outcomes that demonstrate a change in the health and care system as a result of advocacy include that person-led decision making has improved.	90.00%	NDTi 2016a	Carried forward to committee discussion
65	Outcomes that demonstrate changes to communities include increased social inclusion of people using the service.	90.00%	NDTi 2016a	Carried forward to committee discussion
66	Outcomes that demonstrate changes to communities include increased social contribution by people accessing the advocacy service.	70.00%	NDTi 2016a	Redrafted for round 2
67	Outcomes that demonstrate changes to communities include that people have improved access to community services.	100.00%	NDTi 2016a	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
68	Outcomes that demonstrate changes to communities include increased democratic participation.	80.00%	NDTi 2016a	Carried forward to committee discussion
69	Outcomes that demonstrate a change in the way the advocacy service is run include improvements in accessibility to advocacy.	100.00%	NDTi 2016a	Carried forward to committee discussion
70	Outcomes that demonstrate a change in the way the advocacy service is run include increased social contribution by advocacy service users.	70.00%	NDTi 2016a	Redrafted for round 2
71	Outcomes that demonstrate a change in the way the advocacy service is run include governance and best practice.	80.00%	NDTi 2016a	Carried forward to committee discussion
72	Outcomes that demonstrate a change in the way the advocacy service is run include ensuring strong co-production.	88.89%	NDTi 2016a	Carried forward to committee discussion
73	Time should be taken when implementing an outcomes reporting system.	75.00%	NDTi 2016a	Redrafted for round 2
74	When implementing an outcome reporting system, people should work as an organisation and bring everyone together.	77.78%	NDTi 2016a	Redrafted for round 2
75	When implementing an outcome reporting system, processes should be embeded in to current practice, where possible.	60.00%	NDTi 2016a	Redrafted for round 2
76	When implementing an outcome reporting system, it should be kept as simple as possible.	80.00%	NDTi 2016a	Carried forward to committee discussion
77	When implementing an outcome reporting system, analysing and presenting data should be practiced.	90.00%	NDTi 2016a	Carried forward to committee discussion
78	When implementing an outcome reporting system, providers and funders/commissioners should work together to ensure agreement on outcomes to be achieved and how they will be reported.	90.00%	NDTi 2016a	Carried forward to committee discussion
79	When implementing an outcome reporting system, hard facts and figures should be collected.	60.00%	NDTi 2016a	Redrafted for round 2
80	When implementing an outcome reporting system, survey data (eg satisfaction of the service provided) should be collected.	90.00%	NDTi 2016a	Carried forward to committee discussion
81	When implementing an outcome reporting system, examples or short case studies describing what had changed or how it changed should be collected .	90.00%	NDTi 2016a	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
82	When implementing an outcome reporting system, it should be made as easy as possible to complete for advocates.	90.00%	NDTi 2016a	Carried forward to committee discussion
83	Measuring the impact of advocacy includes defining the objectives the advocacy service sets out to achieve.	90.00%	NDTi 2016a; NDTi 2016b	Carried forward to committee discussion
84	Measuring the impact of advocacy includes adopting a co-productive model to decide on the objectives.	90.00%	NDTi 2016b	Carried forward to committee discussion
85	Measuring the impact of advocacy includes identifying the elements that contribute to the objective because these are the outcomes to be measured.	80.00%	NDTi 2016b	Carried forward to committee discussion
86	Measuring the impact of advocacy includes identifying indicators of success and how this will be measured.	90.91%	NDTi 2016b	Carried forward to committee discussion
87	Measuring the impact of advocacy includes defining the data to be measured, the frequency of measurement, and the tools required.	81.82%	NDTi 2016b	Carried forward to committee discussion
88	A logical model approach including objectives, a rationale, inputs, actions, outputs, outcomes, and long term impact, should be used.	60.00%	NDTi 2016b	Discarded (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
89	A toolkit should be co-produced with people who use advocacy.	54.55%	NDTi 2016b	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
90	A toolkit should be co-produced with people who commission advocacy.	45.45%	NDTi 2016b	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
91	A toolkit should be co-produced with people who deliver advocacy support.	54.55%	NDTi 2016b	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)

Statement no.	Statement	Percentage agreement	Reference	Action taken
92	There is little consistency in the information requested by commissioners and contract managers, with an emphasis on outputs rather than outcomes and impact.	85.71%	Lawson, 2020	Carried forward to committee discussion
93	There is a need for reporting and assurance on safeguarding from all partners.	80.00%	Lawson, 2020	Carried forward to committee discussion
94	Advocacy providers should evaluate and report on the extent to which the provision of advocacy supports effective safeguarding outcomes for individuals.	90.00%	Lawson, 2020	Carried forward to committee discussion
95	Advocacy providers should report on the extent to which partners fulfil statutory duties in relation to advocacy and safeguarding	90.00%	Lawson, 2020	Carried forward to committee discussion
96	Advocacy providers should alert SABs to issues that are connected to SABs wider safeguarding responsibilities in relation to prevention and support.	100.00%	Lawson, 2020	Carried forward to committee discussion
97	The views of people who use services and their carers will maximise effectiveness of independent advocacy.	80.00%	Lawson, 2020	Carried forward to committee discussion
98	The views of people who use services and their carers will inform improvements in safeguarding.	80.00%	Lawson, 2020	Carried forward to committee discussion
99	Facilitated national forums to support advocacy providers to share and develop best practice are helpful but not routinely available.	66.67%	Lawson, 2020	Redrafted for round 2
100	There is a need for local multi-agency governance arrangements that support the sharing of themes and trends of concerns in provider services and facilitate taking robust action where needed.	66.67%	Lawson, 2020	Redrafted for round 2
101	Data and information demonstrating the impact on individuals and local need, should be reported.	80.00%	Lawson, 2020	Carried forward to committee discussion
102	Qualitative information and case studies to demonstrate real impact and outcomes for people should be reported.	80.00%	Lawson, 2020	Carried forward to committee discussion
103	Moving away from ticking the box to say a person was referred for advocacy and so their voice was heard to recording information about what difference advocacy support made for the individual would be helpful.	90.00%	Lawson, 2020	Carried forward to committee discussion
104	Local, multiagency audits and digging deeper on specific issues that come to light, is reported to be helpful.	75.00%	Lawson, 2020	Redrafted for round 2

Statement no.	Statement	Percentage agreement	Reference	Action taken
105	Robust and consistent systems for recording and collating information and clear routes for sharing this to make a difference, are reported to be helpful.	77.78%	Lawson, 2020	Redrafted for round 2
106	Systems should support commissioners and provider to take joint responsibility for bringing key information from quarterly reports to the attention of those who can do something to address issues and themes.	80.00%	Lawson, 2020	Carried forward to committee discussion
107	Commissioners should engage with and share the ‘bigger picture’ issues that emerge from advocacy services.	90.00%	Lawson, 2020	Carried forward to committee discussion
108	Considerations between advocacy outcomes framework and key steps for Making Safeguarding Personal should include, outcomes for individuals, reflecting core principles for safeguarding and the wellbeing principle.	81.82%	Lawson, 2017	Carried forward to committee discussion
109	Considerations between advocacy outcomes framework and key steps for Making Safeguarding Personal should include, outcomes for health and social care, including reflecting the need to engage people in offering feedback and the need for services to respond to this.	72.73%	Lawson, 2017	Redrafted for round 2
110	Considerations between advocacy outcomes framework and key steps for Making Safeguarding Personal should include, the impact on communities, which includes embracing the wider impact of advocacy support on issues such as: isolation and social exclusion and increased contributions of individuals to communities facilitated through advocacy.	72.73%	Lawson, 2017	Redrafted for round 2
111	Considerations between advocacy outcomes framework and key steps for Making Safeguarding Personal should include, the impact on how advocacy services are run and commissioned.	80.00%	Lawson, 2017	Carried forward to committee discussion
112	Considerations between advocacy outcomes framework and key steps for Making Safeguarding Personal should include, commissioners seeking qualitative information on outcomes as well as quantitative analysis.	81.82%	Lawson, 2017	Carried forward to committee discussion
113	Making Safeguarding Personal should influence the development of data collection about advocacy.	80.00%	Lawson, 2017	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Reference	Action taken
114	There should be a focus on outcomes not outputs.	72.73%	NDTi, 2014c	Redrafted for round 2
115	There should be a focus on the use of outcome measures to ensure effective personalised support and wider service improvements.	90.91%	NDTi, 2014c	Carried forward to committee discussion
116	A national network of influential stakeholders from across the advocacy sector should be developed, in order to provide a forum to share and learn from best practice.	81.82%	NDTi, 2014c	Carried forward to committee discussion
117	Systematic methods should be developed for recording and sharing information between IMHA and mental health services to assess access and uptake.	90.00%	Newbigging, 2012	Carried forward to committee discussion
118	The quality of information gathered to inform the commissioning and availability of IMHA services is generally poor	42.86%	Newbigging, 2012	Discarded
119	Indicators of the quality of IMHA services include effective commissioning for IMHA services.	75.00%	Newbigging, 2012	Redrafted for round 2
120	Indicators of the quality of IMHA services includes the availability and accessibility of IMHA services.	75.00%	Newbigging, 2012	Redrafted for round 2
121	Indicators of the quality of IMHA services include the organisation and management of IMHA services.	75.00%	Newbigging, 2012	Redrafted for round 2
122	Indicators of the quality of IMHA services includes IMHA service characteristics	50.00%	Newbigging, 2012	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
123	Indicators of the quality of IMHA services include the IMHA role.	50.00%	Newbigging, 2012	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
124	Indicators of the quality of IMHA services include meeting diverse needs.	77.78%	Newbigging, 2012	Redrafted for round 2
125	Indicators of the quality of IMHA services include monitoring and outcomes of IMHA services.	66.67%	Newbigging, 2012	Redrafted for round 2
126	Indicators of the quality of IMHA services include the role of and relationship with mental health services.	66.67%	Newbigging, 2012	Redrafted for round 2

Statement no.	Statement	Percentage agreement	Reference	Action taken
127	IMHA services need to establish an agreed information system to be able to evaluate access and uptake.	90.00%	Newbigging, 2012	Carried forward to committee discussion
128	IMHA services should develop meaningful outcome measures, in partnership with qualifying patients, mental health service users and carers.	90.91%	Newbigging, 2012	Carried forward to committee discussion
129	Minimal data is kept in relation to people accessing or using advocacy.	28.57%	Mercer, 2020	Discarded
130	Increased, systematic data collection in relation to advocacy commissioning and delivery would enable a greater understanding of the national picture of delivery and the 'postcode' lottery of provision that potentially exists.	81.82%	Mercer, 2020	Carried forward to committee discussion
131	It is recommended to design and implement standardised national and/or local data collection in relation to the commissioning and delivery of independent advocacy.	100.00%	Mercer, 2020	Carried forward to committee discussion
132	It is recommended to design and implement standardised national and/or local data collection to ensure that data supports an understanding of how existing inequalities impact on take up of or access to independent advocacy, in addition to mitigating factors.	81.82%	Mercer, 2020	Carried forward to committee discussion
133	It is recommended to evaluate the impact of specialist 'health' advocacy to further understand its benefits to individuals, potential improvement to personalised care, and the impact on the broader health and social care 'system'.	90.00%	Mercer, 2020	Carried forward to committee discussion
134	In some occasions IMHA partners are asked to provide written or verbal feedback about advocacy support they had received, but this is not consistent across IMHA services.	50.00%	Ridley, 2018	Redrafted for round 2 (see section Formal Consensus Round 1 under Summary of Evidence for further explanation)
135	IMHA services should use outcome measurement tools that gather information from IMHA partners at the start and end of advocacy input.	100.00%	Ridley, 2018	Carried forward to committee discussion
136	Services do not necessarily combine data to provide an overall assessment of service effectiveness.	50.00%	Ridley, 2018	Discarded

Statement no.	Statement	Percentage agreement	Reference	Action taken
137	People using advocacy services can be unaware of the advocacy provider collecting data about the impact of advocacy.	66.67%	Ridley, 2018	Redrafted for round 2
138	People using advocacy services feel it is helpful for their advocate to keep a log of issues and actions taken to inform reviews of issue resolution.	75.00%	Ridley, 2018	Redrafted for round 2
139	There is little evidence about how the impact of advocacy should be captured and measured.	57.14%	Ridley, 2018	Discarded

IMHA: Independent Mental Health Advocate.

Table 13: Formal consensus round 2 statements and results for scope area: Monitoring services and collecting data for quality improvement

Statement no.	Statement	Percentage agreement	Action taken
8	The role of advocacy in improving health and social care may be better understood through the collection and reporting of data to demonstrate the quality and impact of advocacy services and outcomes achieved.	100.00%	Carried forward to committee discussion
12	Advocacy providers should request and record information about any known risks to ensure the safety of advocates.	91.67%	Carried forward to committee discussion
13	Advocacy providers should record and report information on advocacy activities and outcomes and their local impact, including where these are deemed to have been successful.	100.00%	Carried forward to committee discussion
19	Advocacy providers should seek feedback about individuals satisfaction about the quality of the advocacy services, including from individuals receiving advocacy support and professionals, and this information should be shared with commissioners.	100.00%	Carried forward to committee discussion
20	Commissioners should ensure that requirements for recording, reporting and monitoring of the advocacy service are included in contracts.	91.67%	Carried forward to committee discussion
21	Advocacy organisations should produce quarterly advocacy reports that include qualitative and quantitative data on advocacy outcomes, including examples from case studies that demonstrate the impact of advocacy.	91.67%	Carried forward to committee discussion
22	Advocacy Providers should monitor and report on the ways advocacy services and people who use advocacy services engage with local forums, such as partnership boards and safeguarding adult boards.	100.00%	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Action taken
23	Advocacy providers should be aware of key advocacy principles as set out in quality marks and advocacy qualifications, such as independence, promoting empowerment, providing people with a voice and challenging inequality, to ensure they work in line with these principles and are able to demonstrate this within their monitoring reports and case studies.	91.67%	Carried forward to committee discussion
27	Further research is needed to understand the long-term impact of advocacy and help distinguish between short- and long-term outcomes.	83.33%	Carried forward to committee discussion
29	Future research should focus on the cost-effectiveness and return on investment of advocacy services.	72.73%	Carried forward to committee discussion
31	Advocacy providers, in partnership with commissioners, should develop consistent, practical and robust methods across the sector to record and report information on the characteristics of people who use advocacy services.	100.00%	Carried forward to committee discussion
34	Advocacy providers should use consistent and robust methods to collect relevant information about people who access the service at the point of referral, e.g. demographic and protected characteristics.	91.67%	Carried forward to committee discussion
35	Advocacy providers and commissioners should develop agreement about the definitions and role of advocacy to improve data collection and service evaluation.	91.67%	Carried forward to committee discussion
37	Advocacy providers and commissioners should develop agreement about how to identify and define outcomes to improve data collection and service evaluation.	91.67%	Carried forward to committee discussion
40	In addition to measuring final outcomes and results achieved for people accessing advocacy services, advocacy organisations should support people to reflect on how they have developed, for example, in terms of independence and empowerment.	75.00%	Carried forward to committee discussion
41	Advocacy providers and commissioners should develop agreed benchmarks that can be used to measure the performance and quality of advocacy services.	91.67%	Carried forward to committee discussion
46,47 & 48	Future research should focus on comprehensive mapping of advocacy organisations, including identifying trends in: demands, different types of advocacy provided, levels of staff and volunteers, and groups of people who require advocacy support.	83.33%	Carried forward to committee discussion
49 & 51a	Future research should focus on identifying the components of advocacy services that are effective for the wide range of people accessing advocacy support.	90.91%	Carried forward to committee discussion
50 & 51b	Future research should focus on identifying the most effective components of advocacy services for specific groups accessing advocacy support (for example, people with dementia, people from BME backgrounds).	91.67%	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Action taken
66	Outcomes that demonstrate wider community benefits include increasing the opportunity for people accessing advocacy services to contribute positively to society and get involved in their local community.	81.82%	Carried forward to committee discussion
70	Outcomes that demonstrate positive changes in the way the advocacy service is run include improvements in the way the organisation delivers advocacy, increased effectiveness in meeting people's advocacy needs, and increased confidence that the person receiving support felt the advocate understood their issues.	90.91%	Carried forward to committee discussion
73 & 74	When implementing an outcome reporting system, time should be taken and people should work together as an organisation to ensure there is good communication about what changes are being made and why, and that there is the opportunity for testing, feedback and refinement of the system.	66.67%	Discarded
75	When implementing an outcome reporting system, processes should be embedded into current practice, where existing systems are good and effective. However, current practice may need to change to facilitate outcome focused reporting.	90.91%	Carried forward to committee discussion
79	When implementing an outcome reporting system, hard facts and figures should be collected (e.g. number of people reporting a particular outcome or the proportion of people who achieved a particular outcome) in addition to other data such as experiences and views of people using advocacy services.	81.82%	Carried forward to committee discussion
89, 90 & 91	A toolkit to assist advocacy services in capturing and measuring outcomes should be co-produced with people who use advocacy services, commissioners of advocacy services, people who deliver advocacy support and other stakeholders.	83.33%	Carried forward to committee discussion
99	Advocacy providers should engage with facilitated national forums that support advocacy providers to share and develop best practice.	90.91%	Carried forward to committee discussion
100	There is a need for local multi-agency governance arrangements that support the sharing of themes and trends of concerns in provider services and this information should be fed back to health and social care providers, voluntary and community sector organisations and commissioners to ensure appropriate action can be taken where this is needed.	90.00%	Carried forward to committee discussion
104	It is important that a multiagency approach is used to review and reflect on concerns, issues and adverse events to identify what happened and prevent similar occurrences in the future.	81.82%	Carried forward to committee discussion
105	Robust and consistent systems for recording, collating and sharing information should be used to identify trends and patterns that might identify what has and has not worked well in relation to safeguarding issues.	90.91%	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Action taken
109	Key steps in developing Making Safeguarding Personal for advocacy should include engaging with and including people that use services to provide feedback on their experiences so that advocacy and safeguarding services and strategies are influenced by the people who use them. This should ensure that advocacy services and other organisations are able to respond appropriately to the issues that people have themselves identified in their feedback.	91.67%	Carried forward to committee discussion
110	Key steps in developing Making Safeguarding Personal involves a clear role for advocacy in prevention and early intervention. This can be improved by measuring the impact of advocacy services on communities and embracing the wider impact of advocacy support on issues such as isolation and social exclusion and increased contributions of individuals to communities facilitated through advocacy. Advocacy services can respond appropriately to improve outcomes by, for example, encouraging people to be supported in ways that increase contact with friends, family and community to reduce people's vulnerability and isolation; and empowering people living in communities to recognise the potential for abuse or neglect and to raise concerns.	75.00%	Carried forward to committee discussion
114	Data collected and reported by advocacy services should focus on outcomes in addition to outputs.	100.00%	Carried forward to committee discussion
119a	The quality of IMHA services depends on the effectiveness of commissioning for IMHA services. Effective commissioning can be achieved through, for example, working in partnership with mental health commissioners, assessment of need for IMHA services, designing IMHA services and co-designing appropriate IMHA services with mental health service users and carers, matching the level of investment in IMHA services to reflect local demands and needs, agreeing and developing service specifications and contracts, and monitoring IMHA services.	100.00%	Carried forward to committee discussion
119b	Commissioners of IMHA services should consider undertaking an equality analysis to ensure that provision of services is non-discriminatory and meets the diverse range of needs.	90.91%	Carried forward to committee discussion
119c	IMHA services should be designed to reflect a whole system approach so that the interfaces with other forms of advocacy are easy to navigate, particularly generic mental health advocacy, IMCA services, peer advocacy and advocacy for specific groups.	100.00%	Carried forward to committee discussion
120	The quality of IMHA services is influenced by the availability and accessibility of IMHA services and will be impacted by factors such as availability of and access to IMHA services for all eligible people, service promotion, strategies to increase uptake, and understanding the role of IMHA services.	75.00%	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Action taken
121a	The quality of IMHA services depends on the organisation and management of IMHA services and will be influenced by, for example, IMHA services strategically planning for future provision, having clear leadership and lines of accountability, sufficient staffing levels, and caseload management.	83.33%	Carried forward to committee discussion
121b	The quality of IMHA services depends on the organisation and management of IMHA services and will be influenced by IMHA services having the capacity to plan for future provision and ensuring that the service is able to respond appropriately to changing needs and to retain high quality staff and expertise.	83.33%	Carried forward to committee discussion
121c	The quality of IMHA services depends on the organisation and management of IMHA services and may be improved through services showing clear plans for how IMHA provision will be delivered. This could include developing a system for managing IMHAs and ensuring IMHA providers publish clear statements about the service response times service users can expect.	75.00%	Discarded
121d	Advocacy organisations should ensure arrangements are in place for the regular support and supervision of IMHAs.	91.67%	Carried forward to committee discussion
121e	Advocacy services should have sufficient administrative support to enable them to carry out regular monitoring and review.	75.00%	Discarded
121f	The quality of IMHA services may be improved through providing a degree of choice of advocacy services and/or working in partnership with other relevant organisations to facilitate this.	58.33%	Discarded
121g	The quality of IMHA services may be improved by IMHAs being able to devote the time needed to each individual case and this may be achieved by them having a balanced caseload that takes into account the complexity of cases as opposed to number of cases.	83.33%	Carried forward to committee discussion
122	The quality of IMHA services will be determined by IMHA service characteristics, including, for example, the extent to which services have a clear recovery focus and identify and link with opportunities for peer support.	83.33%	Carried forward to committee discussion
123	The quality of IMHA services could be improved by clarifying the role of IMHAs (for example, by providing clear strategies and job descriptions outlining roles and responsibilities of IMHAS), and promoting self-determination (for example, by providing information on using Advance Directives, and accessing peer support and service user initiatives).	75.00%	Discarded
124	The quality of IMHA services will depend on how well services meet the diverse needs of people and they should: 1) have a plan in place detailing how the service will be delivered to	75.00%	Carried forward to committee discussion

Statement no.	Statement	Percentage agreement	Action taken
	people with a diverse range of needs and how they will ensure that they have appropriately skilled advocates to do so (e.g., by employing workers that represent the local population and working with other specialist agencies and community organisations); and 2) routinely undertake equalities monitoring.		
125	The quality of IMHA services can be assessed through monitoring the outcomes of IMHA services. For example, by implementing systematic monitoring of information, adopting an outcomes based approach to monitor the effectiveness of IMHA support, and measuring and monitoring the experience of IMHA partners in their use of IMHA services.	100.00%	Carried forward to committee discussion
126	The quality of IMHA services will be influenced by the level of understanding of the IMHA role by other health professionals and the relationship with mental health services. Quality may be improved through, for example, promoting access to IMHA services, respecting the IMHA role, developing staff and providing training, IMHA services and mental health providers addressing common concerns, and providing an organisational context for IMHA provision.	83.33%	Carried forward to committee discussion
134	Advocacy providers in partnership with commissioners, should develop consistent, practical and robust methods of seeking feedback about advocacy support provided, that: 1) avoids conflicts of interests, 2) standardises who feedback should be sought from and what information should be collected, and 3) tailors the format and method based on the communication needs and preferences of the individual.	100.00%	Carried forward to committee discussion
137	Advocacy providers should ensure that people who use advocacy services are aware of the data they collect about the impact of advocacy and that people understand their rights under relevant legislation, including their rights to access this data.	91.67%	Carried forward to committee discussion
138	It is important that advocacy services clearly record all information (including emails and telephone calls) relating to issues and actions taken with and on behalf of the person receiving advocacy support, and keep a record of the extent to which issues have been resolved.	100.00%	Carried forward to committee discussion

IMCA: Independent Mental Capacity Advocate; IMHA: Independent Mental Health Advocate