Healthcare Improvement Scotland

A guide to conducting rapid qualitative evidence synthesis for health technology assessment

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NHS SCOTLAND

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About this guide

The current guidance document was designed to support those conducting rapid synthesis of qualitative studies for health technology assessment (HTA). The guide introduces a coding framework for qualitative synthesis and provides guidance through the process of using it. The coding framework was developed by the Scottish Health Technologies Group (SHTG) team within Health Improvement Scotland. SHTG is interested in collaborating with other researchers and organisations to test the coding framework and its application for HTA. The methodology for the development of the guide and the framework for qualitative synthesis is presented in the Methodology document.

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Introduction

A key component of a full health technology assessment[1] is consideration of the evidence about the experiences, attitudes, preferences, values and expectations of patients, their family members and caregivers about living with a health condition or using a specific health technology.[2, 3] Such information can be particularly useful in understanding the barriers and facilitators to the delivery or implementation of new technologies in practice.[1] One way of collecting patients' perspectives and experiences is conducting qualitative research. However, the collection of primary qualitative research data within HTA may not be possible due to constraints of time, money or other resources.[2]

Another possible route by which the views of stakeholders might be factored into a HTA to inform policy and practice, is by integrating individual qualitative studies within a qualitative evidence synthesis (QES).[2] Synthesis of findings across primary qualitative studies has become a useful and popular tool to inform policy and evidence-based health care because of its potential to provide an in-depth analysis of the findings and expand the understanding of the phenomena of interest. Conducting a QES, however, can also be a timely and resource intense activity considering the complexity of methods and the many stages involved in it. This in itself could prove to be a barrier to producing evidence in a rapid manner to inform policy and other decision makers.[4] Although there are published systematic guidelines to synthesising qualitative evidence[1, 5, 6], there is no guidance available on conducting rapid QES for HTA which can address these challenges. The current guidance document, therefore, is intended to support those conducting rapid QES for HTA by highlighting some of the challenges and difficulties related to the process and how these might be overcome. This guidance is not intended to provide a comprehensive guide on conducting qualitative evidence synthesis, it should be used in addition to existing guidance on synthesising qualitative research[i].

The guidance starts with a brief overview of what qualitative research is. It then introduces QES and its implication for HTA. It provides an overview of rapid reviews followed by recommendations for conducting a rapid QES; introduction and guidance through the process of using a framework for qualitative synthesis in HTA which was specifically developed for this guidance; and guidance on systematic reporting of QES. The methods used for the development of the current guidance are described in detail in the Methodology document.

[i] Soilemezi, D., & Linceviciute, S. (2018). Synthesizing Qualitative Research: Reflections and Lessons Learnt by Two New Reviewers. International Journal of Qualitative Methods. https://doi.org/10.1177/1609406918768014
Ring, N., Ritchie, K., Mandava, L., & Jepson, R. (2011). A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews. Available from: http://www.nhshealthquality.org/nhsqis/8837.html

Qualitative research

Qualitative research seeks to explore people's experiences, understandings, beliefs and attitudes of phenomena, as well as their behaviour and interactions through the systematic collection, organisation, and analysis of textual data from speech or observation.[7] By using data collection methods which involve close contact between the researcher and the research participants, which are interactive and developmental, qualitative research provides an in-depth and interpreted understanding of the social world of research participants.[8] The evidence that is produced by qualitative research is sometimes considered to be 'soft, based on perceptions, subjective assessments, opinions and biases'.[9] Qualitative research has also been criticised for a lack of generalisability due to its small sample sizes. According to Carroll (2017)[10] this criticism assumes that qualitative studies have the same purpose and measure the same outcomes as their quantitative equivalents, which is not the case Qualitative evidence in HTA, for example, seeks to identify patients' experiences of living with a health condition, and their experiences with and expectations of the health technology being studied and use this knowledge to inform the recommendations/advice developed.[3]

Qualitative research does not seek to measure efficacy or safety, it aims to identify and explain patients' experiences, behaviours and preferences, which the quantitative evidence sometimes fails to provide.[10] Qualitative research has also been used to prepare and guide quantitative studies.[11,12] Qualitative methods that have been used to inform quantitative studies include interviews[13,14], interviews combined with clinical field observations[13], and a nominal group technique[15] (a structured, multistep, facilitated group meeting technique used to elicit and prioritise responses to a specific question).

Qualitative evidence synthesis (QES)

QES is a process in which researchers systematically review and synthesise the evidence coming from individual qualitative studies on the same topic of interest to create new understanding by comparing and analysing concepts and findings.[5] QES enables researchers to 'go beyond' the findings of primary research studies and produce something that is more than their summary.[10] Like a secondary analysis of existing data, qualitative synthesis could involve reinterpretation, but unlike a secondary analysis it would be based on published findings rather than primary data.[16] The synthesis of several relevant qualitative studies on a particular topic can offer multiple perspectives, as well as provide evidence of contradictory viewpoints that might otherwise be missed when considering a single study alone.

It is important to recognise that qualitative synthesis is different from a summary of qualitative studies. Qualitative synthesis goes beyond the description and summarisation associated with a narrative literature review and is different to quantitative meta-analysis as it goes beyond the simple aggregation of findings.[16] Eaton (2010)[17] gives a quick overview of

the differences between summarising and synthesising information, some of which are presented in Table 1.

Table 1. Summary vs Synthesis

Summary	Synthesis
Pulls together information in order to highlight the important points.	Pulls together information not only to highlight the important points, but also to draw conclusions.
Addresses one set of information at a time, such as article, chapter, and document. Each source remains distinct.	Combines parts and elements from a variety of sources into one unified entity.
Demonstrates an understanding of the overall meaning.	Achieves new insight.

The basic rationale behind the synthesis of qualitative studies is to use the evidence for the purposes of informing policy and practice.[18] In HTA, a synthesis of qualitative evidence can take as a starting point questions such as how do people experience illness; why does an intervention work (or not), for whom and in what circumstances; and what are the barriers and facilitators to accessing health care. Furthermore, the use of synthesis of qualitative studies makes it possible to avoid disturbing very ill patients with unnecessary interviews, conversations, participant observations, etc.[19]

Rapid reviews

Over recent years, there has been a demand from commissioners of HTAs for reviews to be conducted in a more rapid and efficient way.[20] Although the literature does not elucidate any final definition of 'rapid reviews' (RRs), they can be described as a review type that can be completed more quickly than a standard systematic review.[4] There is no standardised methodology for conducting RRs.[21] Variations from systematic reviews methodology can take a variety of forms (for example, team roles, literature search strategies, inclusion and exclusion criteria, method of data extraction, and method of data synthesis).[20, 22] Rapid reports which perform evidence synthesis (qualitative, quantitative, or both) can be considered comparable to a standard systematic review because they provide the end user with an answer about the findings from the evidence and possibly the strength of the evidence.[23]

The time frame for rapid reviews also varies. The term 'rapid reviews' is framed in the literature as utilising various stipulated time frames between 1 and 6 months. Within the context of HTA, a rapid review response might take around 3 to 4 months. This guidance document only provides a framework for conducting rapid reviews. Researchers who are testing the framework are invited to make suggestions about the timespan required for its use in the synthesis of qualitative studies.

Recommendations for rapid HTA process

A review of the literature did not identify any recommendations for conducting rapid qualitative evidence synthesis. Based on recommendations developed for systemic reviews, several steps were identified as relevant for the process of conducting a rapid qualitative synthesis. While the following steps are presented in a linear fashion, in practice and as is typical in qualitative research, there is often iteration and movement back and forth between steps to ensure a useful analysis. Iteration within the context of qualitative research is understood as a deeply reflexive process which is key to developing insight and meaning from the analysed data, progressively leading to refined focus and understanding.[24] Even in the rapid context, there might be one or two points in the process where iteration may occur (for example, once there is a set of included literature, it should be determined if it is adequate to meet the end-user needs). Whatever the chosen methodological process and concessions are, it is recommended that a rapid review should contain clear and transparent description and discussion of the utilised methodology and acknowledge any limitations.[20]

Deciding on the research question

Designing a well–constructed and clearly articulated research question before the beginning of the qualitative synthesis is crucial.[21, 25] A reviewer may need to consider the exact nature of the planned synthesis; the context of the research such as the relevant policy and practice; how the findings from the synthesis are aimed to be used; and who the synthesis is aimed at (for example, policy makers, health care professionals, and/or patients).[1] Direct involvement of the commissioner/end-user will also be helpful and this might require them to clarify the type of evidence that is most useful to them.

The Cochrane guidance on question formulation suggests that a question formulation structure can be used to refine the research question for the synthesis. One such framework is the SPICE question formulations framework which refers to setting, perspectives, interest/phenomenon of, comparison (if any), and evaluation. For example, a systematic review of qualitative research related to patients' experiences of a health technology could ask the following research question:

Among patients with severe symptomatic aortic stenosis at intermediate surgical risk, what are their knowledge, beliefs and practices in relation to transcatheter aortic valve implantation (TAVI)?

This translates into the SPICE framework as follows:

Table 2. SPICE Framework - example

Setting	Perspective(s)	Phenomenon of interest	Comparison	Evaluation
In the community	Patients with severe symptomatic aortic stenosis at intermediate surgical risk	Transcatheter aortic valve implantation (TAVI)	By implication only, compared with those at low or high risk	Knowledge, beliefs, and practices

At this stage, depending on the timeline of the project, it might also be helpful to conduct a short scoping exercise, to understand the breadth of data available, and therefore an approximate number of studies that might be eligible for the synthesis. Qualitative research relating to a new technology may be limited.

In qualitative research, very few primary studies are likely to have exactly the same research question or focus as the planned synthesis. Nonetheless, there may be a large number of primary research studies containing some relevant data to inform the decision (whether it be on an analogous technology or patients' experiences of living with a health condition). By broadening the scope of the qualitative synthesis to include exploration of the phenomenon of the condition and the lived experience of patients with the target condition, the researcher can refine a question to be sure they get enough useful and relevant literature.[2] Such research question, for example, could be 'What are the lived experiences of patients with chronic wounds?'

Number of researchers carrying out the rapid synthesis

The majority of rapid reviews are carried out by one researcher or sometimes with different researchers working on the discrete parts of the review.[20] Consideration of the context and timelines in which the work is done can help in identifying and allocating the number of researchers that will carry out each stage of the synthesis- refining the research question; developing a synthesis protocol; conducting a literature search; screening titles, abstracts and full-text articles; critical appraisal of studies; conducting and writing up the synthesis. Where the time allows it, a second researcher should be involved in the data synthesis stage which might help add depth to analysis even with a short time frame. They could do so by carrying out an independent analysis of a small sub-set of papers or by asking probing and clarifying questions about the first researchers' analysis/write up.

Literature search strategy

To accommodate the abbreviated timeline, searches for rapid reviews are generally less extensive than those executed for full systematic reviews and HTAs.[4] For the consideration of patient and social aspects of the rapid review, the first step in the literature search strategy

process is to identify any existing qualitative syntheses on the research topic. If no syntheses are identified from the initial search, a further search should be conducted to identify primary qualitative studies.

There are different concessions which could be applied during this stage of the research, such as restricting the search to a limited number of databases, exclusion of unpublished literature and hand searching of reference lists, applying date and language limitations and/or limiting the type and scope of studies.[21] Combining both electronic and manual searches has been found to provide more comprehensive results.[26] For rapid reviews, however, a manual search of reference lists may not be possible.

Excluding grey literature is another commonly used approach in rapid reviews[22] and, therefore, it is recommended that this approach is applied for rapid qualitative synthesis. The search can also be limited to English language only and to studies conducted most recently (for example, 3-5 years or whatever specific time line is appropriate for the topic in question). This will, however, depend on the amount of literature that has been published and the search would need to be adapted accordingly. The details of what searching is undertaken should be clearly reported in the methodology section of the qualitative synthesis.

Another source of data about patients' views and preferences are social media platforms. There has been a growing use of the information from patient conversations that are taking place online (on online forums, blogs, microblogs (i.e. Twitter), Wikipedia, video blogs, social networks and content communities) in research through open-access social media listening (SML) analysis.[27-29] Social media data has been used by social research due to its distinctive feature of producing naturally occurring or 'user-generated' data at the level of populations in real or near-real-time.[30] Consequently, it offers the possibility of studying social processes as they unfold at the level of populations. Studying such online interactions through SML provides an opportunity to track behaviours and interactions of patients, and to understand values and expectations about their disease condition and its management. SML within a QES could be performed if no primary qualitative studies are identified through the literature screening. However, this approach might be time consuming and, therefore, might not be suitable if the review needs to be performed within a limited timeframe.

Healthcare Improvement Scotland qualitative search filter

There are some existing search filters designed to retrieve qualitative studies[31] and studies on patients' views and preferences.[32, 33] Three search filters (one for qualitative studies and two for patients' views and preferences) were tested against references from the patient and social aspect section of SHTG Evidence Notes by an information scientist. Based on the filter analysis two Health Services Researchers adapted the qualitative filter[31] and combined the two patient aspects filters.[32, 33] The new filters are presented in Appendix 1 and can be used to identify qualitative literature on patient and social aspects for HTA.

Screening the literature

In systematic reviews, it is recommended that two or more reviewers are involved in the literature screening and the data abstraction stage in order to increase the reliability of article selection.[34] Rapid reviews, on the other hand, might involve only one reviewer in the screening process (screening titles, abstracts and full-texts) to save time.[22] Although this approach has been considered to introduce a risk of bias by missing potentially relevant studies, it has been used in rapid reviews to save time.[22] There are, however, some strategies which could be employed to mitigate the risk of bias, such as the involvement of peer reviewers to identify any missing studies that they are aware of.

Critical appraisal

Critical appraisal seeks to assess the validity and reliability of a research study and its findings. Critical appraisal of qualitative studies, however, is not a straight forward process. Due to the philosophical and epistemological diversity of qualitative research, there is a lack of consensus among qualitative researchers on how meaningful the appraisal of qualitative research is and how it should be used in qualitative syntheses.[35-37] More specifically, there is disagreement about the characteristics that define good quality qualitative research and whether criteria for quality should even exist at all.[36] It has also been noted that studies considered 'low quality' due to methodological flaws may still provide valuable insights arising from the data and, conversely, methodologically strong studies may suffer from poor or limited interpretation of their data, leading to limited insights into the phenomena under investigation.[38] Poor reporting of methods does not always equate with poorly conducted research, and use of critical appraisal in a synthesis can attempt to acknowledge this, by including studies that score poorly if they have apparently valid insights to offer.[39]

There is also a debate among researchers about the use of structured approaches when appraising qualitative research. Structured approaches have mainly been criticised for being biased towards procedural aspects.[40] The Critical Appraisal Skills Programme (CASP) Qualitative Checklist[41], for example, due to its structured nature and checklist format, may focus its evaluation of quality on how qualitative research studies are reported in their journal articles rather than on evidence of analytic rigor, originality, or scholarly contribution to the field. Dixon-Woods et al. (2007)[40] found that a structured approach does not appear to produce higher levels of agreement between researchers when compared with unstructured judgments. Garside (2014)[42] states further that whether or not a study satisfies any given criteria can depend on the requirements placed upon the study's author (for example, by the journal or by the discipline of the research). Other researchers, however, suggest that the process of exploring a study report in a structured way is, in itself, valuable and fulfills criteria for being a systematic approach.[37] Some researchers also believe that using a structured appraisal tool for quality assessment provides an objective evaluation of the rigour of research.[43] A guiding principle for using a structured critical appraisal tool is that it should be

used as a way of engaging with and better understanding the methodological strengths and limitations of primary studies and how these limitations play out at the level of review findings.[5] It should, furthermore, be used to provide a context to the reader about the methodological quality of studies included in the QES.

Despite the debate in the research community about the usefulness and role of quality assessment of qualitative studies, reviewers and commissioners expect that some form of critical appraisal of primary studies is undertaken when conducting QES. Assessment of methodological strength and limitations of included studies are considered essential to the Cochrane review process. Many QES authors still choose to appraise the quality of studies included in their syntheses, with the intention of ensuring a representation of the literature, assisting readers to evaluate the credibility of conclusions, and allowing decision-makers to understand the transferability of findings.[43]

The next sections present two critical appraisal tools which can be used in the case that a critical appraisal is required or is possible within the limited time frame during which the rapid synthesis is being conducted.

Critical Appraisal Skills Programme (CASP)

CASP is currently the most commonly used tool for QES in Cochrane and World Health Organisation (WHO) guideline processes.[44] CASP is a tool that captures ten criteria which guide quality appraisal.[16] The ten checklist questions can be answered with 'yes', 'no' or 'cannot tell'. The criteria are presented in Table 3.

Table 3. CASP qualitative research checklist

1. Was there a clear statement of the aims of the research? Yes/ Cannot tell/ No
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

The first two questions are screening questions which refer to the aims of study and appropriateness of qualitative methodology to aims. If the first two questions are answered with 'yes', the researcher should proceed to answering the appraisal questions (3-10). If the aims of the study are not clear and the qualitative methodology is not appropriate to the aims, the study should be excluded from the synthesis. More detailed information on how to use the CASP appraisal tool can be found here.

While checklists, such as CASP, have many disadvantages, they also may equip novice qualitative researchers with the resources to evaluate qualitative research efficiently. However, CASP has been considered by some researchers to be time consuming and sometimes difficult to interpret.

Another critical appraisal tool (Quality of Reporting tool (QuaRT) which includes less criteria and has been most typically utilised alongside examples of 'best fit' framework synthesis - the synthesis approach presented in this guide – might be a more appropriate evaluation tool when conducting rapid QES.[45] QuaRT might be a preferred appraisal tool by researchers who have more experience of engaging with qualitative research.

Quality of Reporting Tool (QuaRT)

Quality of Reporting Tool (QuaRT) provides a structured way of exploring a study report and identifying which aspects of study reporting are addressed by which portions of a published article.[46] Although the QuaRT tool can be used independently of any particular method of qualitative synthesis, it has been most typically utilised alongside examples of 'best fit' framework synthesis. QuaRT includes a relatively small number of easily defined criteria which have been seen to apply to qualitative studies universally and to be more practical than long checklists.[47] In this regard, QuaRT may be better suited for a rapid synthesis approach

QuaRT focuses on how an article reports its methodological details related to four components of a study that are commonly described in qualitative research:

a) description of the study objective
b) description of the study design
b) its sampling strategies, and
c) the reporting of its methods of data, collection and analysis.[48]

Despite the fact that QuaRT focuses on quality of reporting, this tool allows researchers to identify which aspects of study reporting are addressed by which portions of a published article which makes it a fairly accessible technical process, particularly when compared with judgments of appropriateness or epistemological "fit" required by other quality assessment tools. While it is acknowledged that there is always uncertainty concerning how well or poorly a study has been conducted, if authors clearly describe their approach and sampling, data collection and analysis methods, then this potentially lends greater robustness to the study's findings.[47] This does not preclude the possibility that an 'inadequately reported' study has actually been well-conducted, or that a well reported study is flawed in design, but it does form a reasonable basis for making a quality assessment. When using the QuaRT tool a summary score for the included studies is not calculated; rather, a review of the strengths and limitations of each included study are described narratively (see Table 4).

Satisfactory, good or very good studies provide details on all or most of the four criteria, and inferior studies might only report on as few as one. The aim of this assessment is to explore quality (in terms of what is reported) as an explanation for any differences in the results of otherwise similar studies, and to consider its impact on the internal validity of the review.[48] An overview of the four criteria of the QuaRT tool is presented in Table 4[47]:

Table 4. Overview of the four dimensions in the QuaRT tool

Criteria categorisation and definition	Tick a box	Enter the relevant text from the article
Question and study design: **Yes** If e.g., "a case study approach was used because . . .", "interviews were used because . . ." **No** If paper does not specify question and study design **Unclear** If unsure	□ ***Yes*** □ ***No*** □ ***Unclear***	
Selection of participants: **Yes** If the selection of participants is described in full or explicitly, e.g., purposive, convenience, theoretical and so forth. **No** If only details of participants are given, e.g. age, gender, number **Unclear** If unsure	□ ***Yes*** □ ***No*** □ ***Unclear***	
Method of data collection: **Yes** If details of the data collection method are given e.g., piloting; topic guides for interviews; number of items in a survey; use of open or closed items; validation, and so forth. **No** If only states "focus group", "interviews were used" or "questionnaire was used" **Unclear** If unsure	□ ***Yes*** □ ***No*** □ ***Unclear***	
Methods of data analysis: **Yes** If full details of analysis method are given, e.g., transcription and form of analysis (with reference or full description of method), validation tests, and so forth. **No** If only states "content analysis" or that "data were analysed" **Unclear** If unsure	□ ***Yes*** □ ***No*** □ ***Unclear***	

The next section provides information about what researchers might need to consider when including or excluding studies in a qualitative synthesis.

Inclusion and exclusion of studies in the synthesis

Decisions on whether to include or exclude a study in QES can depend on different criteria. Guidance developed by the Cochrane Qualitative and Implementation Methods Group[5] lists several examples of criteria to be considered when deciding whether to include or exclude qualitative studies from a synthesis. These are presented below.

- Consider the adequacy of the review sample. Is it likely that studies are sufficiently plentiful to develop a coherent finding with adequate and relevant data of sufficient methodological quality? Will any particular subgroups be poorly represented through application of an arbitrary methodological quality threshold?
- Need for inclusion of specific elements of context as specified in the qualitative evidence synthesis question. Consider whether all contextual elements are adequately represented in the included qualitative studies. For example, different regions of a

country, different socio-economic groups/settings, or different health conditions using the technology of interest. Consider if it is desirable to include all relevant perspectives on the phenomena of interest and whether to do so would entail including studies with some methodological limitations.

- Maturity of the topic (new or well established area). Consider where on the spectrum the specific topic lies and whether it is important to include all evidence if the topic is critically under researched or new. Could identifying gaps be an important function of the synthesis?
- Individual study methodological strengths and limitations. Consider any methodological concerns of individual studies and their contribution to the development and interpretation of findings. What is the likelihood of excluding valuable insights on the basis of quality? Consider if excluding a study will affect assessments of adequacy or coherence of the findings? Do multiple qualitative studies with methodological concerns report similar consistent findings?
- Consider if excluding qualitative studies will reduce ability to report alternative explanations and hypotheses.
- Ability of the selected method of synthesis to accommodate all or a sample of qualitative studies.
- The tipping point at which adding another qualitative study is not likely to alter the review finding. The aim of qualitative synthesis is to analyse as many sources as are necessary to achieve *thematic saturation*, where thematic saturation refers to the point at which no new themes are emerging from the data.[49]

There is no rule on what is considered an adequate number of studies to be included in order to produce a meaningful synthesis.[1, 50] Because the analysis of qualitative data requires a detailed engagement with text, the inclusion of too many studies in the synthesis might make it difficult to move from descriptive or aggregative analysis to more interpretative analysis.[51, 52] In this regard, fewer but more conceptually rich studies might contribute more than a large number of thin studies. The aim of qualitative synthesis is to understand the phenomenon of interest and how it plays out in a context which requires gathering data from various different contexts and respondent groups relevant to understanding the phenomenon.[51] Furthermore, QES seeks to achieve conceptual and not statistical generalisability. In this regard, balance is needed between including too many and too few studies.[52] In practice, the number of included studies is usually relatively small. Sometimes it varies between 8 and 13 and for some topics it could even be between 3 and 5. What is expected from the researcher conducting the synthesis is that they explicitly and transparently state the criteria for including studies in the synthesis.

Data abstraction and data synthesis

A review of the literature (for more details see Methodology document) did not identify any agreed and tested approaches to the rapid synthesis of qualitative findings.[53] However, there are some methodologies for synthesising qualitative evidence which are considered as more rapid than others and, therefore, are more likely to be suitable for using within rapid review timescales. Review methods which require shorter timeframes for execution are: textual narrative synthesis, thematic synthesis, framework synthesis, 'best fit' framework synthesis. These methods are explained below.

Textual narrative synthesis

A textual narrative synthesis[54] involves three steps of analysis:

- Study grouping: studies are grouped into sub-groups depending on study characteristics, context, quality, and findings.
- Study commentaries: commentaries which summarise key aspects of the studies in relation to the sub-group within which they were included are produced.
- Sub-group synthesis: the commentaries of each sub-group are synthesised to produce the findings of the synthesis.

Thematic synthesis

Thematic synthesis is based on the thematic analysis approach used to analyse primary qualitative data and consists of three stages[55]:

- line-by-line coding of the findings of primary studies included in the synthesis
- organisation of the codes from the first stage into related areas to construct descriptive themes, and
- generating analytical themes.

Framework synthesis

The framework synthesis approach is based on the framework approach for the analysis of primary qualitative data and consists of five stages of data analysis.[47] In the context of a rapid synthesis, some of the final stages might need to be limited or excluded. An advantage of this approach is that it can be used with or without an *a priori* framework:

- Familiarisation: familiarisation with the studies included in the synthesis in order to list key ideas and recurrent themes.
- Identifying a thematic framework: identification of all key themes and concepts to form the coding framework.

- Indexing: applying the thematic framework to the findings section of all studies included in the synthesis.
- Charting: creation of a matrix of findings for each theme by study (each cell of the chart contains a summary of the study's contribution to the theme and a reference that can be directly linked to the text).

Mapping and interpretation: using the charts to define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to providing explanation for the findings.

Best fit framework approach

'Best fit' framework synthesis is based on the framework synthesis approach and offers a structured approach to analysing qualitative data by developing *a priori* themes against which data can be coded.[1, 47, 56] The approach, therefore, is augmentative and deductive (building on an existing model or framework), rather than grounded or inductive (starting with a completely blank sheet).[47] This makes the 'best fit' framework approach more rapid when compared to other more exclusively interpretative forms of synthesis (such as textual narrative synthesis or thematic synthesis).

The 'best fit' framework methodology is different from other approaches to qualitative evidence synthesis in part because it employs a systematic method for identifying published frameworks, models or theories in order to create the framework for the synthesis.[56] The 'best fit' approach uses a predefined framework but is not limited to it and allows for the thematic framework to be expanded by additional codes.[56] According to Dixon-Woods (2011) 'a practical benefit of doing this is that it enables questions or issues identified in advance by various stakeholders (such as policymakers, practitioners, or user groups) to be explicitly and systematically considered in the analysis, while also facilitating enough flexibility to detect and characterise issues that emerge from the data' (p. 1).[57]

The 'best fit' framework approach can be utilised for rapid qualitative evidence synthesis for HTA. The 'best fit' framework enables much of the extraction and synthesis to be completed rapidly and consistently because the existence of the framework minimises the interpretive and iterative processes involved in qualitative synthesis.[58]

A literature search (for more details see Methodology document) identified published frameworks that were considered relevant for generating an *a priori* framework for conducting QES in HTA. The next section provides guidance on how to use the designed framework for qualitative synthesis in HTA.

Framework for qualitative synthesis in HTA

The framework presented in this section is designed for use in the analysis of qualitative studies which look at patient and social aspects related to the use of a health technology. The framework provides pre-existing themes against which data extracted from the primary qualitative studies can be coded.

The framework should not be considered as prescriptive but rather seen as a guide to code and analyse the included qualitative studies. For example, if there is no data from the included qualitative studies to support all themes in the framework, then not all themes should be included in the final synthesis. Respectively, if some of the data cannot be reliably assigned to any of the pre-existing themes, further thematic analysis of data would be required from which new themes will emerge.

At this stage a direct involvement of the commissioner/end-user might be necessary in order to clarify the type of evidence that is most useful to them and respectively the selection of the relevant *a priori* themes and subthemes for analysis.

Relationships between individual themes should also be explored with reference to the evidence, which, in turn, can lead to clustering of new concepts and the creation of a new conceptual model describing and reflecting the behaviour of interest. Relationships between the themes of the framework are then either recreated or generated based on the evidence from the primary research studies included in the synthesis.

If there is no published evidence related to the use of the health technology that is being reviewed by SHTG, the framework could be adapted to analyse and synthesise qualitative studies looking at patient experiences of living with the health condition being studied. An adapted version of each theme and subtheme was developed and is presented alongside the respective themes. The framework is presented in the next section followed by an outline to guide you through the steps of its application.

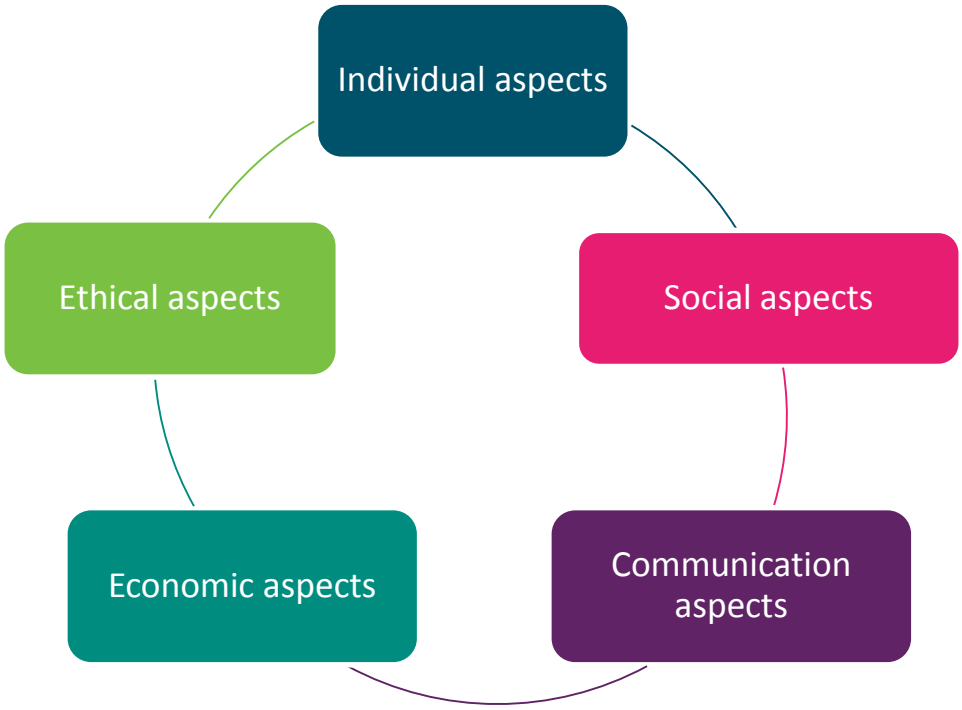
The coding framework

The coding framework was designed based on the thematic analysis of four frameworks - the NHS Patient Experience Framework[59], the EUnetha coreModel[60], the Warwick Patient Experience Framework[61], and an analytical patient experiences model published in the Danish Centre for Health Technology Assessment HTA (DACHENTA) Handbook[62] – and two qualitative evidence syntheses exploring patients' experiences of a health technology.[63, 64] The methodology for the development of the framework is described in the Methodology document.

The five overarching themes used in the coding framework were adopted from the DACHENTA handbook which presents an analytical model setting out relevant patient aspects within HTA. These overarching themes cover from a patients' perspective what influence a particular health technology might have on various different aspects of patients' lives (for example, in relation to them as individuals, the influence it has on their independence or on their family relations).

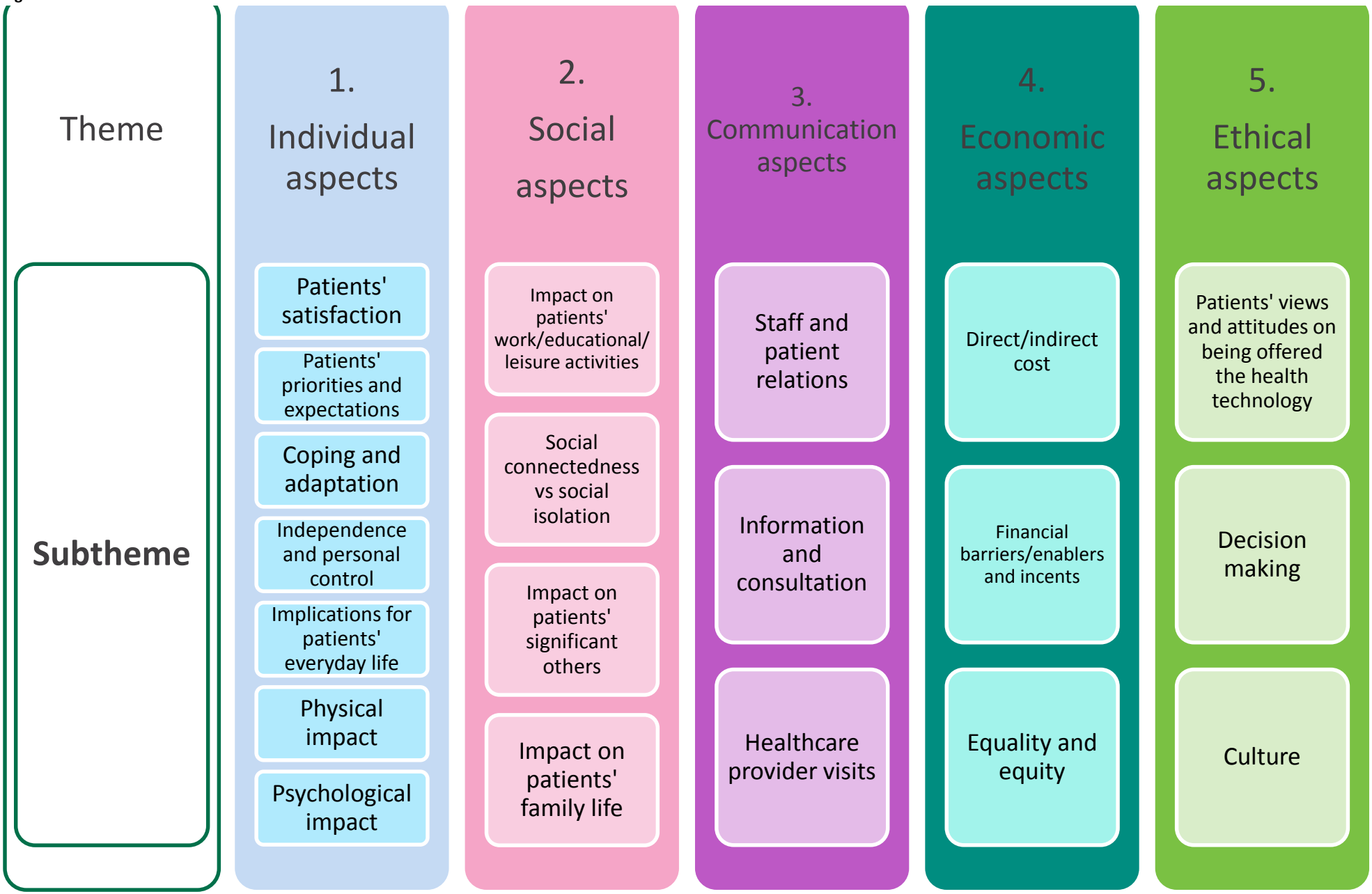
It must be noted that these aspects cannot be considered in isolation from one another and they might sometimes overlap when they are analysed because they would be informed by patients' actual experience. When performing the framework synthesis, it is the researcher's responsibility to find patterns and relationships between the themes and subthemes of the framework based on the evidence that has been identified from the studies included in the synthesis. Furthermore, the researcher might identify information which could be coded under two different themes and it is again the researcher's responsibility to decide how to manage that.

Figure 1 Overarching themes



A thematic analysis of the four frameworks[59,60,61,62] and the two syntheses[63, 64] was then carried out (for more details see Methodology document) to identify potential subthemes for each overarching theme (see Figure 2).

Figure 2 Themes and subthemes



Individual themes and subthemes are presented and explained in the tables below.

1. Individual aspects This theme refers to any psychological or physical issues related to the use of the technology, patients' perceptions of possible effects of the technology	
Subtheme	**Explanation**
Patients' satisfaction	Patient satisfaction with being offered the technology and willingness to recommend the technology. Satisfaction with the course of management: structural aspects (equipment, location, access, time, coordination) and interpersonal aspects (information, skills and attitudes of professional health care professionals, relationship with professional staff, internal communication amongst staff).
Patients' expectations	Patients' priorities and expectations from using the technology.
Coping and adaptation	Patients' experiences of adjusting and adapting to using the technology.
Autonomy and personal control	The influence of the technology on patients' autonomy in managing their condition, for example, self-care. The impact of the technology on patients' independence in conducting daily activities.
Implications for patients' everyday life	The impact of the technology on patients' everyday life.
Physical impact	The impact of the technology on patients' physical health. For example, does the technology reduce or increase the experience of pain?
Psychological impact	Does the technology reduce or increase experiences of worry, anxiety, stress, guilt, etc.? Does it induce any positive experiences of joy, relief, peace of mind? The impact of the technology on patients' self-esteem.

If no studies about patients' experiences of the health technology are identified, the framework can be used to synthesise studies about patients' experiences of the studied health condition. Respectively, the sub-themes can be adapted and an example is presented in a separate box (see below). Only three of the main themes (individual, social and communication aspects) were deemed relevant to patient experiences of a health condition.

Individual aspects related to a health condition
Patients' experiences of adjusting and adapting to the health condition
The impact of the health condition on patients' independence in conducting daily activities
The impact of the health condition on patients' everyday life
The physical impact of the condition
The psychological impact of the health condition. The impact of the health condition on patients' self-esteem

2. Social aspects This theme refers to the consequences that a technology may have for the daily and work life of patients and their significant others	
Subtheme	**Explanation**
Impact on patients' work/educational/leisure activities	The impact of the technology on patients' ability to work/return to work. For example, does the use of the technology lead to patients' absence from work? Does the use of the technology influence patients' ability to perform educational or leisure activities?
Social connectedness vs social isolation	The impact of the technology on patients' social connectedness
Impact on patients' significant others (children, family members, friends)	The impact of the technology on patients' significant others. For example, impact on their health, quality of life, social relations, etc. Do significant others face any challenges when supporting patients to use the technology?
Impact on patients' family relations and relations with significant others	The impact of the technology on the patients' experience of their family relations and relations with significant others
Social aspects related to a health condition	
The impact of the health condition on patients' ability to work/educational activities	
The impact of the health condition on patients' social connectedness	
The impact of the health condition on patients' significant others (for example, do they have to provide care, do they face any challenges related to providing care for the patient)	
The impact of the health condition on patients' family relations	

3. Communication aspects This theme refers to any communication aspect which can influence patients' use of the technology	
Subtheme	**Explanation**
Healthcare professionals and patient relations	The impact of the technology on the healthcare professional and patient relationship. For example, patients may have different preferences for support from professionals - emotional support vs. purely practical support in relation to using the technology.
Information and consultation	The usefulness and accessibility of information about the technology. For example, to enable self-care, shared decision-making, active participation in health care, to develop knowledge and understanding of the technology, the eventual side effects and outcomes.
Healthcare provider visits	Patients' experience of healthcare provider visits. For example, do patients need to visit healthcare providers more regularly or not as a result of using the technology? How is this perceived by patients? Are patients being treated with respect?

Communication aspects related to a health condition
The usefulness and accessibility of information about the health condition. For example, to enables self-care, shared decision-making, active participation in health care, to develop knowledge and understanding of the health condition.

4. Economic and financial aspects This theme refers to any direct or indirect costs related to the use and accessibility of the technology	
Subtheme	**Explanation**
Direct/indirect cost	The direct/indirect cost that the technology entails in relation to work, family life, leisure time, lifestyle, and quality of life
Financial barriers/enablers and incents	Patients' experiences of accessing the technology. Barriers/enablers in accessing/using the technology. For example, cost, travel
Equality and equity	Patients' experiences of discrimination in relation to access to the technology. For example, due to geographical distance, waiting time, contact with the health care system.

5. Ethical aspects This theme refers to the ethical concerns and considerations that arise in relation to the actual use of the technology	
Subtheme	**Explanation**
Patients' concerns about being offered the technology	Patients' concerns about using the technology, for example stem cell based technologies
Decision making	The extent to which the patient is involved in decision-making in relation to the use of the technology
Culture	The extent to which cultural practices and beliefs are reflected and taken into consideration when a health technology is being implemented

How to use the framework?

This section is an adaptation of the framework synthesis approach on which the best fit framework approach is based. It consists of four stages and presents a rapid approach to framework data synthesis.

Familiarisation

This stage involves reading the studies in detail to become familiar with them and to identify if any of the themes from the coding framework resonate with the data of the studies. You may have already familiarised yourself with the studies included in the synthesis as part of the critical appraisal stage, if such has been conducted. However, this stage is distinct from the critical appraisal stage, and you would need to read the studies again to become more familiar with their findings before the indexing stage.

At this stage it may also be useful to engage with the commissioner/end user in the selection of the *a priori* themes and subthemes for analysis. This means that the commissioner/end user of the synthesis report would be given the opportunity to choose from the standard set themes and subthemes proposed in the framework depending on what they are most interested in.

Data analysis

At this stage you will systematically apply the qualitative evidence synthesis framework to the results, discussion, and conclusion sections of all included studies in the synthesis. You will use the coding framework as a guide to theme relevant data from the studies. Relevant data for each category could be extracted through multiple, iterative cycles towards theoretical saturation. Through this process, the coder remains open to new codes and different way to represent emergent categories, themes, and concepts. During the data analysis process, you will develop a narrative summary that will synthesise the concepts contained in the themes of each category. Once a narrative summary is generated for each category, you will collate the summaries to produce a more integrative and holistic interpretation of findings that provide tailored evidence for the health technology assessment.

A coding template (see Excel table) was designed to assist you in managing the narrative summary of findings. The extraction table also provides you with an opportunity to write a summary of findings for each theme in the framework which would further help with approaching the write up of the synthesis. It is often a challenge to decide the selection and length of the text or quotation to extract and analyse. What is crucial at this stage is to create a rigorous opportunity to extract insights that might not be possible on the basis of single studies alone.[65]

Adding new themes

The published literature on the use of 'best fit' framework approach recommends that a secondary thematic analysis is conducted to capture any new themes which can be added to the analysis.[47, 58] This method applies the principles of a standard thematic analysis[66] in the context of secondary research. Thematic analysis involves the searching across a data set to find repeated

patterns of meaning[66] and in this respect is an interpretive and inductive approach.[47] Inductive thematic analysis, however, can be very time consuming and generating themes could some time go on ad infinitum.[66] You can instead code any new themes which emerge from the findings of the qualitative studies during the familiarisation or indexing stage to save time. It must be noted, however, that new themes should only be coded if they have been identified as relevant to the question of interest.

Synthesising the findings

The process of qualitative data synthesis is not a linear process, it involves continual reflection about the findings and as such, there is no single set of rules. Analysing and interpreting are highly intuitive processes. Analysis is essentially about searching for patterns and themes, that is the trends you see emerging from among your findings.[67] Interpretation involves attaching significance to what was found, making sense of findings, considering different meanings, and offering potential explanations and conclusions.[67] Therefore, this section is not intended to provide instructions on how a synthesis of findings should be conducted but rather serve as a generic guideline for researchers who are performing the qualitative synthesis.

The aim of qualitative synthesis is to identify patterns in the findings of different primary qualitative studies, to combine the individual units of analysis into a more integrated whole and to tell the story of the findings while providing sufficient evidence of the themes within the primary data (for example, provide enough data extracts to demonstrate the breadth of concepts or findings relevant to the theme). Synthesis is a process of bringing the following points together:

- How the research questions are answered by the findings.
- To what extent the findings emanating from your data-collection methods can be interpreted in the same way.
- How the findings relate to the existing literature.
- How the findings relate to the researcher's prior assumptions about the study.[67]

It is important at this stage that the researcher creates a rigorous opportunity to extract insights that might not be possible on the basis of single studies alone. What is crucial at this stage is to document the steps that have been followed in the analysis.

Perhaps the biggest challenge at this stage is to draw the conclusions and recommendations for practice and research based on the synthesised findings and to remain specific about the claims that can be made. It is important to identify and report the negative cases, such as limitations and barriers in one of the synthesis processes: identification, screening, eligibility and analysis. In order to enhance rigor in the analysis of the rapid synthesis, a second researcher should also be involved to probe the analysis written by a single reviewer. This might help add depth to the analysis even within a short time frame. Furthermore, the author of the synthesis should make

transparent their conflicts of interests, prior beliefs, and potential/actual prejudices with potential to impact on data interpretation.[44]

The issue of context may need particularly careful interpretation with regard to the applicability of the findings.[1] When considering the relevance of data from different studies, the researcher may need to think of how findings from different geographical locations may be relevant and applicable to what population and how this may inform their conclusions and recommendations.[65]

Reporting systematic QES

This is not a comprehensive guidance on reporting qualitative evidence synthesis but should be used in addition to existing guidance on reporting systematic QES.[ii]

Search strategy

To be transparent and systematic in the information-retrieval process, it is important to record all search activities (for example, search terms and databases searched) in such a detail that others can replicate them. The search strategy could be published as an Appendix to the synthesis report, or be made available online.

Selection of studies

The inclusion and exclusion criteria, as well as the selection procedure and number of reviewers involved should be included in the report.

Critical appraisal

The synthesis should include a paragraph explaining the critical appraisal method (if such has been performed), including the number of reviewers involved, and a rationale for the excluded studies (if any) based on quality criteria. A table with the critical appraisal of included and excluded studies should be prepared and saved in the project folder.

[ii] Saini, M., & Shlonsky, A. (2012). Systematic Synthesis of Qualitative Research. Oxford Scholarship Online.

Data extraction

A summary of included studies (after appraisal) should be described in a table, so that the reader has a quick description of the studies. A sample table is presented below (Table 5). The headings may change depending on the focus and purpose of the synthesis.

Table 5. Data extraction

Author and year	Study sample	Participant characteristics	Children: number and age	Method of data collection	Method of data analysis	Recruitment/Setting	Quality rating	Included/excluded
Coons et al. (2016)	Mothers (n=58): biological (n=12), step-parent (n=2), adoptive (n=39), foster (n=5). Fathers (n=26): biological (n=4), step-parent (n=3), adoptive (n=16), foster (n=3).	Mothers' average age – 50.74, married – 67.2% Father's average age – 54.35, married – 80.8%	Age range: 1 to 36	Semi-structured interviews	Interpretative phenomenological analysis	Ontario, Canada	High	Included
Granitsas (2004)	Adoptive parents (n=5)	n/a	n/a	Unstructured interviews	Interpretative phenomenological analysis	Developmental clinic, Commonwealth of Massachusetts, US	High	Included

Data synthesis

For clarity of reporting the analysis process, authors should define which sections of the included articles were actually analysed (for example, results and/or discussion) and describe the process of coding, comparing and interpreting the data. Details about use of software and number of authors involved in coding and analysis can allow readers to assess the dependability of the findings and to assess whether data are managed in a systemic way.

You can use the sample text below to explain your approach to analysing the data from the included studies.

"The data for analysis were extracted from the results sections of included papers and consisted either of verbatim quotations from study participants or findings reported by authors that were clearly supported by study data. The researcher coded the results data for all papers against the *a priori* framework. New themes that could not be accommodated by the *a priori* framework were generated during the familiarisation and data extraction stages and were included in the coding framework."

Reporting results

The results section should include information about the quantity and quality of included studies, as well as the synthesised themes - the results from the coding against the *a priori* themes. Results can be presented in different ways including topical tables and concept maps. Concept maps provide a graphic representation of concepts or categories of interest to the review question.[68,69] Concept maps highlight the key concepts relevant to the review question and display a relationship among the identified concepts.[69] Key insights from the primary studies can also be displayed in table format so that broad conceptual comparisons can be made across studies.[69] Depending on the complexity of these comparisons, these matrices can increase in complexity to demonstrate the various connections among primary studies and to highlight the differences between them.[70] When reporting the results, quotations from the primary studies should be included to illustrate the themes or constructs identified. The target audience should also be considered when reporting and presenting the synthesis output. Ultimately, the synthesis should generate rich, compelling and new insights that go beyond a summary of the primary studies.

Discussion

The discussion can be structured around major themes, issues, or topics, and the ways these are woven together. What is important in this section of the QES is the logic and coherence of the argument, how effectively the reviewer has tied their argument to the literature and prior research, and their ability to contextualise their discussion into some broad and relevant discourse.[67]

The discussion should include information about:

- key messages in direct relation to the health technology assessment based on major findings of the synthesis
- strengths and weaknesses of the findings (for example, population included in the primary studies, location of studies, methods of studies, etc.), and
- limitations of the synthesis (for example, language bias, publication bias).

It is important to remember that all studies have limitations but the key is to articulate how these limitations might be influencing the findings.

Appendix 1.

Qualitative Filter - Medline

1. Qualitative Research/

2. Interview/

3. (theme$ or thematic).mp.

4. qualitative.af.

5. Nursing Methodology Research/

6. questionnaire$.mp.

7. ethnological research.mp.

8. ethnograph$.mp.

9. ethnonursing.af.

10. phenomenol$.af.

11. (grounded adj (theor$ or study or studies or research or analys?s)).af.

12. (life stor$ or women* stor$).mp.

13. (emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or participant observ$.tw.

14. (social construct$ or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or post modern$ or post-modern$ or feminis$ or interpret$).mp.

15. (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp.

16. (humanistic or existential or experiential or paradigm$).mp.

17. (field adj (study or studies or research)).tw.

18. human science.tw.

19. biographical method.tw.

20. theoretical sampl$.af.

21. ((purpos$ adj4 sampl$) or (focus adj group$)).af.

22. (account or accounts or unstructured or openended or open ended or text$ or narrative$).mp.

23. (life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.

24. ((lived or life) adj experience$).mp.
25. cluster sampl$.mp.
26. observational method$.af.
27. content analysis.af.
28. (constant adj (comparative or comparison)).af.
29. ((discourse$ or discurs$) adj3 analys?s).tw.
30. narrative analys?s.af.
31. heidegger$.tw.
32. colaizzi$.tw.
33. spiegelberg$.tw.
34. (van adj manen$).tw.
35. (van adj kaam$).tw.
36. (merleau adj ponty$).tw.
37. husserl$.tw.
38. foucault$.tw.
39. (corbin$ adj2 strauss$).tw.
40. glaser$.tw.
41. or/1-40

Qualitative Filter - PsycINFO

1. Qualitative Methods/
2. Interviews/
3. (theme$ or thematic).mp.
4. qualitative.af.
5. questionnaire$.mp.
6. ethnological research.mp.
7. ethnograph$.mp.
8. ethnonursing.af.
9. phenomenol$.af.
10. (grounded adj (theor$ or study or studies or research or analys?s)).af.
11. (life stor$ or women* stor$).mp.
12. (emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or participant observ$.tw.
13. (social construct$ or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or post modern$ or post-modern$ or feminis$ or interpret$).mp.
14. (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp.
15. (humanistic or existential or experiential or paradigm$).mp.
16. (field adj (study or studies or research)).tw.
17. human science.tw.
18. biographical method.tw.
19. theoretical sampl$.af.
20. ((purpos$ adj4 sampl$) or (focus adj group$)).af.
21. (account or accounts or unstructured or openended or open ended or text$ or narrative$).mp.
22. (life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.
23. ((lived or life) adj experience$).mp.
24. cluster sampl$.mp.
25. observational method$.af.
26. content analysis.af.

27. (constant adj (comparative or comparison)).af.
28. ((discourse$ or discurs$) adj3 analys?s).tw.
29. narrative analys?s.af.
30. heidegger$.tw.
31. colaizzi$.tw.
32. spiegelberg$.tw.
33. (van adj manen$).tw.
34. (van adj kaam$).tw.
35. (merleau adj ponty$).tw.
36. husserl$.tw.
37. foucault$.tw.
38. (corbin$ adj2 strauss$).tw.
39. glaser$.tw.
40. or/1-39

Patient views and preferences Filter - Medline

1. Attitude to Health/
2. Patient Preference/
3. preference*.ti,ab.
4. choice.ti.
5. choices.ti.
6. value*.ti.
7. expectation*.ti,ab.
8. attitude*.ti,ab.
9. acceptab*.ti,ab.
10. point of view.ti,ab.
11. patient perspective.ti,ab.
12. patients perspective.ti,ab.
13. patients' perspective.ti,ab.
14. patient's perspective.ti,ab.
15. user perspective*.ti,ab.
16. users perspective*.ti,ab.
17. users' perspective*.ti,ab.
18. user's perspective*.ti,ab.
19. patient perce*.ti,ab.
20. patients perce*.ti,ab.
21. patients' perce*.ti,ab.
22. patient's perce*.ti,ab.
23. health perception*.ti,ab.
24. user perce*.ti,ab.
25. users perce*.ti,ab.
26. users' perce*.ti,ab.
27. user's perce*.ti,ab.
28. user view*.ti,ab.
29. users view*.ti,ab.
30. users' view*.ti,ab.
31. user's view*.ti,ab.

32. patient view*.ti,ab.

33. patients view*.ti,ab.

34. patients' view*.ti,ab.

35. patient's view*.ti,ab.

36. ((decision* and mak*).ti. or (decision mak* or decisions mak*).ti,ab.) and (patient* or user* or men or women).ti,ab.

37. decision-support.ti,ab.

38. decision tool*.ti,ab.

39. decision aid*.ti,ab.

40. or/1-39

41. "Patient Acceptance of Health Care"/

42. *Consumer Behavior/

43. health knowledge, attitudes, practice/

44. *"Quality of Life"/

45. "Quality of Life"/px

46. Life Change Events/

47. Attitude to Death/

48. focus groups/

49. narration/

50. ((patient or consumer*) adj3 (participat* or decisi* or decid*)).ti,ab.

51. (patient adj3 (attitude? or preference)).ti,ab.

52. "patient satisfaction".ti.

53. coping.ti,ab.

54. ("self perception" or "self concept").ti,ab.

55. ("informed choice" or "shared decision making").ti,ab.

56. empowerment.ti,ab.

57. ("focus group*" adj3 (patient* or parent* or famil* or spouse*)).ti,ab.

58. (QoL or "Quality of life").ti.

59. ((patient* or consumer* or parent* or famil* or spouse*) adj (attitude* or involvement or desir* or perspective* or activation or view* or preference*)).ti,ab.

60. "expert patient*".ti,ab.

61. "focus group*".ti,ab.

62. qualitative.ti.

63. (Stress, Psychological/ or Emotions/ or vignette*.ti,ab.) and (exp Patients/px or patient*.ti. or consumer*.ti.)

64. or/41-63

65. 40 or 64

Patient views and preferences - PsycINFO

1. health attitudes/
2. Client Attitudes/
3. preference*.ti,ab.
4. choice.ti.
5. choices.ti.
6. value*.ti.
7. expectation*.ti,ab.
8. attitude*.ti,ab.
9. acceptab*.ti,ab.
10. point of view.ti,ab.
11. patient perspective.ti,ab.
12. patients perspective.ti,ab.
13. patients' perspective.ti,ab.
14. patient's perspective.ti,ab.
15. user perspective*.ti,ab.
16. users perspective*.ti,ab.
17. users' perspective*.ti,ab.
18. user's perspective*.ti,ab.
19. patient perce*.ti,ab.
20. patients perce*.ti,ab.
21. patients' perce*.ti,ab.
22. patient's perce*.ti,ab.
23. health perception*.ti,ab.
24. user perce*.ti,ab.
25. users perce*.ti,ab.
26. users' perce*.ti,ab.
27. user's perce*.ti,ab.
28. user view*.ti,ab.
29. users view*.ti,ab.
30. users' view*.ti,ab.
31. user's view*.ti,ab.
32. patient view*.ti,ab.
33. patients view*.ti,ab.

34. patients' view*.ti,ab.

35. patient's view*.ti,ab.

36. (client* adj1 (view or perce* or perspective)).ti,ab.

37. ((decision* and mak*).ti. or (decision mak* or decisions mak*).ti,ab.) and (patient* or user* or men or women).ti,ab.

38. decision-support.ti,ab.

39. decision tool*.ti,ab.

40. decision aid*.ti,ab.

41. or/1-40

42. *Consumer Behavior/

43. *"Quality of Life"/

44. ((patient or consumer*) adj3 (participat* or decisi* or decid*)).ti,ab.

45. (patient adj3 (attitude? or preference)).ti,ab.

46. "patient satisfaction".ti.

47. coping.ti,ab.

48. ("self perception" or "self concept").ti,ab.

49. ("informed choice" or "shared decision making").ti,ab.

50. empowerment.ti,ab.

51. ("focus group*" adj3 (patient* or parent* or famil* or spouse*)).ti,ab.

52. (QoL or "Quality of life").ti.

53. ((patient* or consumer* or parent* or famil* or spouse*) adj (attitude* or involvement or desir* or perspective* or activation or view* or preference*)).ti,ab.

54. "expert patient*".ti,ab.

55. "focus group*".ti,ab.

56. qualitative.ti.

57. (Stress, Psychological/ or Emotions/ or vignette*.ti,ab.) and (exp Patients/px or patient*.ti. or consumer*.ti.)

58. health knowledge/

59. life changes/

60. death attitudes/

61. exp focus group/

62. narratives/

63. or/42-62

64. 41 or 63

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