

QUALITATIVE RESEARCH METHODS

KCE PROCESS NOTE



MARIE DAUVRIN, LAURENCE KOHN, WENS CHRISTIAENS, NADIA BENAHMED, JUSTIEN CORNELIS,
ANJA DESOMER, JULIE PARADIS, IRINA CLEEMPUT



COLOPHON

Title:	KCE Process Note: Qualitative Research Methods
Authors:	Marie Dauvrin (KCE), Laurence Kohn (KCE), Wens Christiaens (KCE), Nadia Benahmed (KCE), Justien Cornelis (KCE), Anja Desomer (KCE), Julie Paradis (KCE), Irina Cleemput (KCE)
Senior supervisor:	Laurence Kohn
Programme manager:	Nathalie Swartenbroekx
Reviewers	Roos Leroy (KCE), Mélanie Lefèvre, (KCE), Wannes Van Hoof (Sciensano)
Acknowledgements	Céline Ricour (KCE), Elena Costa (KCE), Patrice Chalon (KCE), Jens Detollenaere (KCE), Stephan Devriese (KCE), Luc Hourlay (KCE), Nelle Stocquart (KCE), Nicolas Fairon (KCE), Elisabeth Petit (KCE), Emily Van Coolput (KCE), Ine Verhulst (KCE) and our “qualitative” colleagues from Sciensano.
Reported interests KCE members:	KCE is a federal institution funded by INAMI/RIZIV, by the Federal Public Service of Health, Food Chain Safety and Environment, and by the Federal Public Service of Social Security. The mission of KCE is to advise policymakers on decisions relating to health care and health insurance on the basis of scientific and objective research. It is expected to identify and shed light on the best possible solutions, in the context of an accessible, high-quality health care system with due regard for growing demand and budgetary constraints. KCE has no interest in companies (commercial or non-commercial, i.e. hospitals and universities), associations (e.g. professional associations, unions), individuals or organisations (e.g. lobby groups) that could be positively or negatively affected (financially or in any other way) by the implementation of the recommendations. All experts involved in the writing of the report, or the peer-review process completed a declaration of interest form. Information on potential conflicts of interest is published in the colophon of this report. All members of the KCE Expert Team make yearly declarations of interest and further details of these are available upon request.
Reported interests:	None declared
Layout:	Ine Verhulst
Disclaimer:	• This report describes a methodological guidance for qualitative research on health-related topics. Although it is in first instance intended for KCE projects, its applicability extends beyond these. Its broader use and referencing are encouraged. • This report does not contain policy recommendations that require approval by the Board of KCE. It has been reviewed by Belgian experts but has not followed the formal validation procedure by independent academic experts. The report will be updated regularly based on progressive insights. • Only the KCE is responsible for errors or omissions that could persist.
Publication date:	30 October 2025
Project number:	2025-071
Domain:	Method
MeSH:	Qualitative Research; Methods; Guideline as Topic
NLM Classification:	W 84.3 Health Services Research (General)
Language:	English



Format: Adobe® PDF™ (A4)
Legal depot: D/2025/10.273/43
ISSN: 2466-6459
Copyright: KCE reports are published under a “by/nc/nd” Creative Commons Licence
<http://kce.fgov.be/content/about-copyrights-for-kce-publications>.



How to refer to this document?

Dauvrin M, Kohn L, Christiaens W, Benahmed N, Cornelis J, Desomer A, Paradis J, Cleemput I. KCE Process Note: Qualitative Research Methods. Method Brussels: Belgian Health Care Knowledge Centre (KCE). 2025. KCE Reports 408. <https://doi.org/10.57598/R408C>.

This document is available on the website of the Belgian Health Care Knowledge Centre.



■ TABLE OF CONTENTS

◆	INTRODUCTION.....	12
1.	WHY THIS REPORT?	12
2.	AIMS	13
3.	METHODOLOGY.....	13
3.1	PREPARATORY WORK.....	13
3.2	GENERAL DESIGN AND PROCESS	13
3.3	HOW TO USE THIS REPORT	14
◆	PART 1–TRANSVERSAL DIMENSIONS OF QUALITATIVE RESEARCH.....	16
4.	WHAT ARE THE SPECIFICITIES OF QUALITATIVE RESEARCH?	16
4.1	KEY FEATURES OF QUALITATIVE RESEARCH	16
4.2	THEORETICAL APPROACHES IN QUALITATIVE RESEARCH.....	17
4.3	WHAT IS THE APPROACH TO QUALITATIVE RESEARCH AT KCE?	18
5.	FREQUENTLY ASKED QUESTIONS ABOUT QUALITATIVE RESEARCH STUDIES....	19
5.1	DOES THE STUDY REQUIRE A QUALITATIVE RESEARCH APPROACH?.....	19
5.2	CAN A RAPID QUALITATIVE RESEARCH APPROACH BE APPLIED?	21
5.3	DOES THE PROJECT REQUIRE PRIMARY QUALITATIVE DATA COLLECTION?.....	22
5.4	CAN RELEVANT AND ROBUST PREEXISTING QUALITATIVE DATA BE USED IN A RESEARCH PROJECT?	22
5.5	IS THE APPROVAL OF AN ETHICS COMMITTEE NECESSARY?.....	23
5.6	IS STAKEHOLDER CONSULTATION A QUALITATIVE RESEARCH APPROACH?	23
5.7	DOES PATIENT INVOLVEMENT REQUIRE QUALITATIVE RESEARCH METHODS?....	24
5.8	ARE EXPLORATORY INTERVIEWS AND SITE VISITS QUALITATIVE RESEARCH METHODS?	24
5.9	IS ARTIFICIAL INTELLIGENCE OF INTEREST FOR QUALITATIVE RESEARCH METHODS?	25
	5.9.1 Added value of artificial intelligence for qualitative research methods	27
	5.9.2 Bias and other concerns related to artificial intelligence	28
6.	PREPARING A QUALITATIVE RESEARCH STUDY.....	29
6.1	PLANNING A QUALITATIVE RESEARCH STUDY.....	29
6.2	QUALITATIVE RESEARCH PROTOCOL	30
6.3	CHOOSING AN A-PRIORI THEORETICAL FRAMEWORK	31
7.	ETHICAL ISSUES SPECIFIC TO QUALITATIVE HEALTH RESEARCH.....	32
7.1	ETHICAL ISSUES RAISED BY QUALITATIVE RESEARCH.....	32
7.2	HOW TO MANAGE ETHICAL ISSUES IN QUALITATIVE RESEARCH METHODS?	34
	7.2.1 Respecting ethical and deontological codes and guidelines	34



7.2.2	Data protection and archiving	34
7.2.3	Obtaining and proving informed consent.....	34
7.2.4	Ensuring a voluntary consent and avoiding pressure to participate	35
7.2.5	Avoiding adverse consequences for the participants	36
7.2.6	Anticipating the need for disclosure of personal information of study participants.....	37
7.2.7	Enabling participation	38
7.2.8	Protecting researchers from adverse consequences	38
7.3	IS THE APPROVAL OF AN ETHICS COMMITTEE NECESSARY?.....	39
8.	QUALITY AND VALIDITY OF QUALITATIVE RESEARCH METHODS.....	40
8.1	BIAS IN QUALITATIVE RESEARCH METHODS.....	40
8.2	GENERAL QUALITY CRITERIA.....	44
8.2.1	Credibility and dependability: triangulation	44
8.2.2	Transferability: thick description	45
8.2.3	Dependability: researcher triangulation and audit	45
8.2.4	Confirmability: audit and reflexivity	46
8.3	APPRAISAL TOOLS AND CHECKLISTS.....	47
8.3.1	Appraisal tools and checklists for qualitative syntheses and primary qualitative studies.....	47
8.3.2	Appraisal tools for Delphi processes	47
9.	REFLEXIVITY IN QUALITATIVE HEALTH RESEARCH	48
9.1	WHAT IS REFLEXIVITY?	48
9.2	WORKING ON ONE'S REFLEXIVE POSTURE AS A RESEARCHER: WHAT DOES THIS IMPLY?.....	49
9.3	HOW TO FEED THE REFLEXIVE POSTURE?	49
9.4	WHICH TOOLS CAN BE USED TO ENHANCE REFLEXIVITY?	50
9.5	WHEN TO THINK ABOUT REFLEXIVITY?	51
◆	PART 2 – QUALITATIVE RESEARCH METHODS BASED ON EXISTING DATA.....	52
10.	LITERATURE REVIEWS OF QUALITATIVE EVIDENCE	52
10.1	IS A SPECIFIC RESEARCH PROTOCOL NEEDED?	52
10.2	WHY AND WHEN TO CONDUCT A LITERATURE REVIEW OF QUALITATIVE EVIDENCE?	53
10.3	HOW TO CHOOSE BETWEEN A MAPPING, A SCOPING, OR A SYSTEMATIC LITERATURE REVIEW?.....	54
10.4	IS A SPECIFIC SEARCH STRATEGY NEEDED FOR EXPLORING QUALITATIVE EVIDENCE IN LITERATURE?.....	57
10.5	ARE THERE SPECIFIC DATABASES FOR QUALITATIVE RESEARCH?.....	58
10.6	ARE THERE DATABASES INCLUDING FRENCH OR DUTCH LITERATURE?	61
10.7	ARE THERE SPECIFIC FILTERS WHEN RETRIEVING QUALITATIVE EVIDENCE?	63



10.8	HOW TO MANAGE DATA EXTRACTION?	63
10.9	ARE THERE SPECIFIC METHODS FOR SYNTHESISING THE FINDINGS OF A QUALITATIVE LITERATURE REVIEW?	64
10.10	CAN QUALITATIVE FINDINGS BE INTEGRATED IN AN EFFECTIVENESS REVIEW? ..	65
11.	USE OF OPEN DATA IN QUALITATIVE RESEARCH	65
11.1	WHAT ARE OPEN QUALITATIVE DATA AND HOW TO FIND THEM?.....	65
11.2	WHAT ARE THE STRENGTHS OF USING OPEN QUALITATIVE DATA, AND FOR WHAT PURPOSES?	66
11.3	WHAT ARE THE WEAKNESSES OF USING OPEN QUALITATIVE DATA?.....	67
11.4	HOW TO ACCESS OPEN QUALITATIVE DATA?	68
11.5	HOW TO EVALUATE THE QUALITY OF OPEN QUALITATIVE DATA?	68
11.6	HOW TO ANALYSE OPEN QUALITATIVE DATA?	72
11.7	HOW TO REPORT OPEN QUALITATIVE DATA?	72
◆	PART 3 - QUALITATIVE RESEARCH METHODS BASED ON PRIMARY DATA.....	73
12.	GENERAL PRINCIPLES OF PRIMARY DATA COLLECTION.....	73
12.1	HOW TO PLAN THE PRIMARY DATA COLLECTION?	73
12.2	HOW TO CHOOSE THE DATA COLLECTION TECHNIQUE?	75
12.3	HOW TO DO THE SAMPLING?	81
12.3.1	How to select participants?	81
12.3.2	Can research be conducted with participants in vulnerable situations (including children under 18 years old)?	82
12.3.3	Can proxies be recruited as participants?	84
12.3.4	Can representatives be recruited as participants?	85
12.3.5	Which type of sample?	87
12.3.6	What is the expected sample size?	91
12.3.7	How to recruit participants?	92
12.3.8	Is it possible to accelerate the recruitment process?.....	94
12.3.9	Should the recruitment be done via gatekeepers?	94
12.3.10	Should participants be paid in a primary data collection process?.....	95
12.3.11	Where to find participants?	95
12.3.12	How to manage the follow-up of the recruitment process?	95
12.3.13	How to manage the first contact with a participant.....	96
12.4	HOW TO DEVELOP THE DATA COLLECTION MATERIAL?	97
12.4.1	How to construct a topic list or an interview guide?.....	97
12.4.2	What types of questions can be asked during an interview?	98
12.4.3	Should the same data collection material be used for interviews and focus groups?	



12.4.4	Should enabling techniques be used?	100
12.4.5	Should the data collection material be pilot tested?	101
12.5	HOW TO RUN THE DATA COLLECTION?	101
12.5.1	Should moderation and interviewing always be performed by qualitative researchers?	101
12.5.2	Can the data collection benefit from an online approach?	102
12.5.3	How to prepare for the interview?	108
12.5.4	How to conduct the interview?	109
12.5.5	How to take notes during an interview?	111
12.5.6	What are memos and summaries?	112
12.5.7	Should interpreters be used for the data collection?	112
13.	MORE THAN WHAT PEOPLE SAY: NATURALISTIC OBSERVATION	114
13.1	SHOULD THE STUDY INCLUDE OBSERVATIONS?	114
13.2	WHAT ARE THE STRENGTHS OF (NATURALISTIC) OBSERVATION, AND FOR WHAT PURPOSES?	115
13.3	WEAKNESSES OF OBSERVATIONS	116
13.4	HOW TO PLAN THE RESEARCH DESIGN?	117
13.5	MODALITIES OF DATA COLLECTION	117
13.5.1	Participant versus direct observation	117
13.5.2	Structured versus unstructured observation	118
13.5.3	Overt versus covert observation	118
13.5.4	Types of observation techniques	118
13.5.5	Data collection tools	119
13.5.6	Sampling	121
13.5.7	Required human resources	121
13.5.8	Practical aspects	122
13.6	HOW TO ANALYSE DATA FROM OBSERVATIONS?	122
13.7	HOW TO REPORT THE FINDINGS OF OBSERVATIONS?	122
13.8	SPECIFIC QUALITY CRITERIA	122
14.	WHAT PEOPLE SAYS WITHOUT INTERACTION: INTERVIEWS	123
14.1	SHOULD THE STUDY INCLUDE INDIVIDUAL INTERVIEWS?	123
14.2	WHAT ARE INDIVIDUAL INTERVIEWS?	123
14.3	WHEN TO USE INDIVIDUAL SEMI-STRUCTURED INTERVIEWS?	124
14.4	STRENGTHS AND WEAKNESSES OF INDIVIDUAL SEMI-STRUCTURED INTERVIEWS	125
14.5	MODALITIES OF DATA COLLECTION	125
14.5.1	Choosing the place of the interview	125



14.5.2	Choosing the interviewer	126
14.5.3	Is there a possibility to restrict the languages used when conducting interviews?	126
14.6	DATA COLLECTION TOOLS	127
14.7	REQUIRED HUMAN RESOURCES	127
14.8	HOW TO ACCELERATE THE DATA COLLECTION BY INTERVIEWS?	127
15.	SYNCHRONOUS INTERACTIONS BETWEEN PARTICIPANTS: FOCUS GROUPS	129
15.1	SHOULD THE STUDY INCLUDE FOCUS GROUPS?	129
15.2	WHAT ARE FOCUS GROUPS?	130
15.3	WHEN TO USE FOCUS GROUPS?	131
15.4	STRENGTHS AND WEAKNESSES OF USING FOCUS GROUPS	131
15.5	SPECIFIC ASPECTS OF SAMPLING FOR FOCUS GROUPS	132
15.5.1	Identification of units of analysis	132
15.5.2	Composition of the groups	132
15.5.3	Number of participants per group	132
15.5.4	Number of groups	133
15.5.5	Strategies to accelerate the recruitment process in RQR	133
15.6	DATA COLLECTION TOOLS	134
15.7	REQUIRED HUMAN RESOURCES	134
15.7.1	Focus groups in a single language	134
15.7.2	Focus-groups in two languages	135
15.8	HOW TO RUN THE DATA COLLECTION IN A FOCUS GROUP?	136
15.8.1	Should the focus group be held in hybrid format?	136
15.8.2	How to prepare for a focus group?	136
15.8.3	How to run the focus group?	137
15.9	SPECIFIC PRACTICAL ASPECTS RELATED TO FOCUS GROUPS	138
15.9.1	Location and timing	138
15.9.2	Duration	139
15.9.3	Material	139
15.10	HOW TO ANALYSE DATA FROM FOCUS GROUPS?	140
15.11	HOW TO REPORT FINDINGS FROM FOCUS GROUPS?	140
16.	ASYNCHRONOUS INTERACTIONS BETWEEN PARTICIPANTS: RESEARCH FORUM	140
16.1	SHOULD THE STUDY INCLUDE A RESEARCH FORUM?	140
16.2	WHAT IS A RESEARCH FORUM?	141
16.3	STRENGTHS AND WEAKNESSES OF RESEARCH FORUM	141
16.4	MODALITIES OF DATA COLLECTION	142



16.5	DATA COLLECTION TOOLS	143
16.6	SPECIFIC ASPECTS OF SAMPLING FOR RESEARCH FORUM	143
16.7	REQUIRED HUMAN RESOURCES	143
16.7.1	Forum administrator	143
16.7.2	Forum moderator	144
16.8	HOW TO RUN THE DATA COLLECTION IN A RESEARCH FORUM?	144
16.9	SPECIFIC PRACTICAL ASPECTS RELATED TO RESEARCH FORUM	144
16.9.1	Location	144
16.9.2	Duration	144
16.10	HOW TO ANALYSE DATA FROM A RESEARCH FORUM?	144
16.11	HOW TO REPORT FINDINGS FROM A RESEARCH FORUM?	144
17.	CONSENSUS WITHOUT INTERACTIONS: DELPHI PROCESS	145
17.1	SHOULD THE STUDY INCLUDE A DELPHI PROCESS?	145
17.2	WHAT IS A DELPHI PROCESS?	145
17.3	WHY AND WHEN TO USE A DELPHI PROCESS?	146
17.4	STRENGTHS AND WEAKNESSES OF THE DELPHI PROCESS	147
17.5	HOW TO PLAN THE RESEARCH DESIGN?	147
17.6	MODALITIES OF DATA COLLECTION	150
17.7	DATA COLLECTION TOOLS	150
17.8	SPECIFIC ASPECTS OF SAMPLING FOR THE DELPHI PROCESS	151
17.9	REQUIRED HUMAN RESOURCES	151
17.10	PRACTICAL ASPECTS	151
17.11	HOW TO ANALYSE?	151
17.12	HOW TO REPORT THE FINDINGS?	152
17.13	SPECIFIC QUALITY CRITERIA	153
18.	CONSENSUS WITH INTERACTIONS: NOMINAL GROUPS	153
18.1	SHOULD THE STUDY INCLUDE THE NOMINAL GROUPS?	153
18.2	WHAT ARE NOMINAL GROUPS?	153
18.3	WHY AND WHEN TO USE NOMINAL GROUPS?	153
18.4	STRENGTHS AND WEAKNESSES OF NOMINAL GROUPS	154
18.5	HOW TO ORGANISE NOMINAL GROUPS?	155
18.5.1	Group size and length	155
18.5.2	Nominal groups technique essentials	155
18.5.3	Process	157
18.5.4	Practical aspects	160
18.6	SPECIFIC QUALITY CRITERIA	160



◆	PART 4 – QUALITATIVE DATA ANALYSIS	161
19.	FREQUENTLY ASKED QUESTIONS IN QUALITATIVE DATA ANALYSIS	161
19.1	SHOULD ALL THE DATA BE COLLECTED BEFORE STARTING THE ANALYSIS?	161
19.2	SHOULD THE RESEARCHER IN CHARGE OF DATA COLLECTION CONDUCT THE DATA ANALYSIS?	161
19.3	SHOULD ONE RESEARCHER CONDUCT THE ENTIRE ANALYSIS OF THE CORPUS?	162
19.4	CAN THE ANALYSIS PROCESS BE EXPEDITED?	162
19.5	SHOULD THE DATA BE ANALYSED ACCORDING TO THEIR SOURCE?	162
19.6	SHOULD THE DATA BE ANALYSED WITH A QUALITATIVE DATA ANALYSIS SOFTWARE?	162
20.	THEORETICAL APPROACHES FOR QUALITATIVE DATA ANALYSIS	164
20.1	ANALYTIC APPROACHES	164
20.1.1	Thematic content analysis	164
20.1.2	Analysis using conceptualising categories	165
20.1.3	Phenomenological examination of the empirical data	166
20.2	HOW TO CHOOSE THE ANALYTICAL APPROACH	166
20.3	APPROACH TO QUALITATIVE DATA ANALYSIS AT KCE	166
21.	ANALYTIC JOURNEY	167
21.1	PREPARING THE DATA FOR ANALYSIS	167
21.2	FAMILIARISATION	168
21.3	CODING THE DATA	168
21.3.1	Initial coding	168
21.3.2	Thematization	169
21.3.3	Refine and regroup categories	170
21.3.4	Constant comparison	172
21.3.5	Accelerating the coding process	172
21.4	NEW DATA COLLECTION (OPTIONAL)	173
21.5	ABSTRACTION AND INTERPRETATION	173
21.6	DESCRIPTION OF THE FINDINGS AND REPORTING	174
◆	PART 5 - QUALITATIVE DATA REPORTING	175
22.	QUALITATIVE DATA REPORTING	175
22.1	HOW TO REPORT QUALITATIVE RESEARCH FINDINGS?	175
22.1.1	Is there a standardised structure for reporting qualitative findings?	175
22.1.2	How to present the qualitative research methods used?	176
22.1.3	How to present qualitative findings?	178
22.2	HOW TO USE QUOTES?	183



LIST OF FIGURES

Figure 1 – Overview of the steps when planning qualitative research methods	29
Figure 2 – Commonalities and differences between scoping reviews and mappings reviews	55
Figure 3 – Overview of the steps when planning a primary qualitative data collection	74
Figure 4 – Decision tree to choose between the methods proposed in the process note	76
Figure 5 – Interaction patterns in group interviews versus focus groups	130
Figure 6 – The Delphi process	148
Figure 7 – Simplified model of the process of nominal groups, including adaptations	156
Figure 8 – Conceptual representation of the analytic journey of qualitative data	167
Figure 9 – Example of a thematic tree illustrating the conditions facilitating the implementation of Infant- And Family-Centred Developmental Care (IFCDC)	171
Figure 10 – Example of a qualitative typology about the acceptance of mobile tools	174

LIST OF TABLES

Table 1 – Selection of different theoretical approaches in qualitative (health) research	17
Table 2 – Artificial intelligence assisted qualitative methods research activities	27
Table 3 – Main headings of a qualitative research protocol	30
Table 4 – Guiding questions for the development of the information and consent form	35
Table 5 – Sources of bias in qualitative research	41
Table 6 – Translation of criteria for assessing quality	44
Table 7 – Triangulation strategies	45
Table 8 – Comparison between mapping and scoping reviews	56
Table 9 – Frameworks for developing a research question for the review of qualitative evidence	57
Table 10 – Selection of databases according to the availability of qualitative literature	59
Table 11 – Selection of databases according to the availability of non-English literature	62
Table 12 – Repository of filters	63
Table 13 – Example of keywords for searching systematic qualitative reviews	63
Table 14 – Overview of methods for synthesizing qualitative evidence	64
Table 15 – Dimensions for assessing the quality of open qualitative data available online: essential criteria to be assessed	70
Table 16 – Dimensions for assessing the quality of open qualitative data available online: complementary criteria	71
Table 17 – Comparison of the various data collection methods presented in the process note	79
Table 18 – Comparison of the advantages and limitation of types of samples in qualitative research	90



Table 19 – Comparison of three recruitment strategies	93
Table 20 – How to prepare for an individual interview?	108
Table 21 – Strengths and weaknesses of individual semi-structured interviews	125
Table 22 – Strengths and weaknesses of focus groups	131
Table 23 – How to prepare for a focus group?	136
Table 24 – Strengths and weaknesses of research forum	141
Table 25 – Questions to be addressed when planning a research forum	142
Table 26 – Types of Delphi designs	145
Table 27 – Strengths and weaknesses of the Delphi process	147
Table 28 – Strengths and weaknesses of nominal groups	154
Table 29 – Checklist for preparing face-to-face or online nominal groups	160
Table 30 – Continuous thematization versus sequential thematization	169
Table 31 – Commonly used level of codes in QDA	172
Table 32 – Elements to include in qualitative research report*	176
Table 33 – Elements for the methods section*	177
Table 34 – Example of display of a recruitment strategy of participants in a qualitative study on personalised health care planning	178
Table 35 – Strategies to avoid quantification of qualitative findings	179

LIST OF TEXTBOXES

Textbox 1 – Key features of qualitative research	17
Textbox 2 – List of questions to help to prepare disclosure of participants' personal information	37
Textbox 3 – Information to be given during first contact	96
Textbox 4 – Asynchronous interviews using email ⁴⁷	104
Textbox 5 – Tips for conducting qualitative research interviews	110
Textbox 6 – How to effectively take notes during an interview or focus group	111
Textbox 7 – Recommendations for design of Delphi studies	149
Textbox 8 – Recommendations for data collection in Delphi studies	150
Textbox 9 – Recommendations for data analysis in Delphi studies	152
Textbox 10 – Recommendations for reporting in Delphi studies	152
Textbox 11 – Useful resources when using Nvivo	163
Textbox 12 – Theoretical example of quote editing	184



LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
AI	Artificial Intelligence
BAREC	Belgian Association of Research Ethics Committees
CRD	Centre for Reviews and Dissemination (UK)
DCAT	Delphi Critical Appraisal Tool
ESRO	Expedited Scientific Research and Reporting
GCP	Guidelines for Clinical Practice
HSR	Health Service Research
HTA	Health Technology Assessment
JBİ	Johanna Briggs Institute
NatCen	National Centre for Social Research (UK)
QDA	Qualitative Data Analysis
QRM	Qualitative Research Methods
QRT	Qualitative Research Team
RAP	Rapid Interviewing Process
RQR	Rapid Qualitative Research

■ SCIENTIFIC REPORT

DISCLAIMER

This report describes a methodological guidance for qualitative research on health-related topics. Although it is in first instance intended for KCE projects, its applicability extends beyond these. Its broader use and referencing are encouraged.

In the context of KCE research, this process note is aimed at:

- KCE experts with a training in qualitative research methods (QRM) – to support them in making appropriate methodological decisions and justifying these decisions to their team and / or validators.
- KCE experts without a training in QRM – to serve as an information source about QRM, to help them draft a preliminary version of a research protocol (and help them decide if an expert in QRM is needed in the team), to understand a research proposal or discussions related to QRM during a project.
- Subcontractors and validators collaborating with KCE – to help them understand how, why, and which QRM are used in the context of KCE (when submitting a proposal or validating a scientific report).

This process note is not:

- A training manual for those without any prior knowledge or experience with QRM.
- An exhaustive presentation of the whole diversity of the field of qualitative research.
- A binding document preventing researchers from exploring or applying other QRM.
- Frozen in time – it will evolve over time.

KCE experts should contact the Qualitative Research Team (QRT) of KCE as soon as possible when starting a research project involving QRM.



◆ INTRODUCTION

1. WHY THIS REPORT?

In 2012, the Belgian Health Care Knowledge Centre issued the first process note on qualitative research methods (QRM), as part of the collection of detailed process notes provided to KCE experts and subcontractors to help them deliver excellent quality scientific research based on the best evidence available.

The 2012 process note focused on clarifying what qualitative research is, stressing the utility of qualitative findings and addressing quality in qualitative studies as a means of assuring a place for qualitative research as “evidence”.¹ Indeed, as pointed by Kohn and Christiaens², referring to the work of Pope and May³ and Barbour⁴, “*Qualitative Research Methods (QRM) have a lot to offer to those studying health care and health services, furnishing in-depth information about patient’s and health care provider’s needs, wishes, experiences, and fears regarding health care. QRM could help researchers such as KCE researchers to strengthen the KCE capacity to formulate recommendations tailored to the needs of care seekers and providers, within a context of increasing demands and limited budgets*” (retrieved from Kohn and Christiaens, 2012, page 7).²

The scientific literature in public health has been expanded with new methodological references and recommendations for the continuous improvement of the quality and validity of studies incorporating qualitative approaches (for example, the thematic series of the European Journal of General Practice published in 2017). A quick search on PubMed reveals an increasing number of peer-reviewed journals dedicated to qualitative research in health (e.g. Qualitative Health Research, International Journal of Qualitative Studies on Health and Well-being, or Qualitative Research in Medicine and Healthcare). Between 2019 and 2024, there were 119 653 papers indexed under the keyword “qualitative research” on PubMed, showing the growing importance of this methodological approach in the field of health sciences research.

Since the publication of the KCE process note on QRM, QRM have been increasingly used, in complement to other data collection methods, to contribute to the excellence and quality of KCE studies. The creation of the Qualitative Research Team (QRT), an internal working group, launched by the KCE management in 2018, was a turning point in the development of QRM at KCE. The QRT aims at enhancing the internal expertise related to QRM by bringing together KCE experts with various levels of training and experience in QRM. Coordinated by two KCE experts in social sciences (Laurence Kohn and Wens Christiaens), the QRT serves as a platform to critically reflect on methodological choices related to qualitative research at KCE and to support KCE experts when opting for a qualitative research design in a study. Since 2023, researchers from Sciensano also attend the meetings of the QRT.

After more than 10 years of utilisation of the process note and based on the discussions among the experts of the Qualitative Research Team, it appears that the content needs to be developed and updated to better fit the needs of the KCE researchers. Moreover, several KCE research teams experimented with innovative qualitative approaches such as secondary analysis of qualitative data (e.g. KCE report 378 on the improvement of endometriosis care in Belgium)⁵, methodological approaches to capture patient needs (e.g. KCE report 348)⁶ or skills to interview people with specific needs (e.g. interviews using language easy to read and to understand with persons with intellectual disability⁷) or persons in vulnerable situations (e.g. KCE report 338 on access to somatic care for psychiatric patients⁸ and KCE report 361 on decisional capacity⁹). In addition, the COVID pandemic saw the emergence and the increasing use of online data collection techniques. To date, all these experiences are scattered between different reports, making it hard for KCE researchers to rely on them when needed.

More recently, the KCE report 396 on expedited scientific research and reporting has provided accelerated methodologies for situations in which a rapid response is required to address urgent requests or situations.¹⁰

All these elements supported the need to update and extend the KCE process note related to QRM to ensure that KCE researchers and subcontractors have access to up-to-date methodological guidelines. The Qualitative Research Team will regularly update this process note to consider the dynamic nature of both KCE and QRM.

2. AIMS

This document aims to update the existing process note on QRM by integrating the methodological evolutions and the experiences of KCE experts since its first publication. It integrates new methodological aspects for qualitative research strategies that are useful for KCE studies.

The process note aims to provide guidance for the use of QRM in the context of KCE studies and to broaden the knowledge base about QRM at KCE.

All KCE experts can use this document as a tool, regardless of their level of training and familiarity with QRM. However, as stated in the disclaimer, the level of training and expertise will determine how and for what purpose experts will use this process note.

Furthermore, not all aspects in this process note are specific to QRM: they are mentioned as a reminder of “good practices” when conducting research.

3. METHODOLOGY

3.1 Preparatory work

Based on internal discussion, the QRT, in agreement with the KCE management, decided to include the following topics in the update of the process note for qualitative research:

- Rapid qualitative methods (RQM)
- Online qualitative data collection
- Use of secondary online data in QRM
- Use of artificial intelligence (AI)
- Preparatory interviews and site visits, including reporting
- Additional qualitative data collection methods
- Posture of the qualitative researchers, including reflexivity and ethics

3.2 General design and process

The update was conducted during the first semester of 2025. This update was based on:

- An analysis of the KCE reports using qualitative methods, the activity reports and minutes of the Qualitative Research Team and other internal documents to identify best practices and attention points when it comes to QRM.
- A consultation of the current literature on QRM in health research. A “berry picking” model was used, consisting of an iterative process for exploring the literature where *“the query or information need itself (and the search terms used) is continually evolving.”*^{11, 12} *At each stage, the user identifies useful information and references. In other words, the query is satisfied not by a single final retrieved set, but by a series of selections of individual references and bits of information at each stage of the ever-modifying search*”(retrieved from Kohn and Christiaens, 2012, page 11)². The search was conducted in books available at the KCE library and in the online documentation gathered by the members of the QRT over the years (e.g. papers, training material, ad hoc search on a specific method, readings recommended by colleagues...). The lead author conducted



additional searches at the RESO documentation centre (UCLouvain), online in PubMed and CAIRN and on the websites of academic centres specialised in QRM (e.g. the International Institute for Qualitative Methods, the UK National Centre for Social Sciences (NatCen), the UK Social Research Association) or of academic teams known for using QRM.

- Work meetings with the QRT, the KCE knowledge management team, the data privacy officer, the coordinator of the Technology Watch group, the KCE jurist, a member of the KCE communication cell, an KCE expert in clinical research, a member of the KCE layout team and the KCE scientific direction.
- Internal validation process of specific tools.
 - Validation of the tools for assessing the quality and validity of QRM. The lead author (Marie Dauvrin) drafted a comparative table of the existing tools according to their proprieties and characteristics (scope, audience, main use, number of items and scoring system, limitations). The QRT discussed the tables and prioritised the different tools for applying them on 1) primary qualitative studies; 2) reviews of qualitative evidence. Members of the QRT blind-tested the tools on a paper reporting a single study and a literature review of qualitative evidence. The lead author collected the feedback, and the final decision was consensually made among the members of the QRT.
 - Validation of the criteria to assess the quality of online qualitative data (still ongoing in October 2025). An operational tool was developed alongside this process note to assess the validity of the online qualitative data. The content was first developed by Luc Hourlay, assisted by an AI companion. The selected dimensions were reviewed and adapted by the QRT during a work meeting. Five KCE experts blind tested a first version of the tool in September 2025 on 2 online data sources (a blog and an audiovisual source). Luc Hourlay and Marie Dauvrin further developed the operational tool, considering the feedback of the KCE experts. The final version of the operational tool is available on the KCE Extranet (see Table 15 for the dimensions included in the operational tool).

3.3 How to use this report

KCE experts or subcontractors can use this process note for the following purposes:

- Preparing a research protocol for a KCE project / looking for practical advice.
- Assessing a proposal from subcontractors or preparing a submission to an ethics committee or a validation.
- Developing basic knowledge about QRM.

This process note includes:

- Frequently asked questions about QRM – these sections aim to guide researchers when making decisions about QRM in a simplified way. These decisions should always be related to the research question, the aims, and the methods.
- Advice for putting QRM in practice – particularly in the context of KCE.
- (Limited) theoretical background about QRM.
- General advice on how to conduct a good (qualitative) research project

The following resources complement the process note.

- Bibliographical resources of the QRT Library (open access):
 - Zotero database available: https://www.zotero.org/groups/6199442/kce_qrt
- Templates of resources and examples of existing KCE projects (open access)
 - Available on the KCE Extranet:
<https://extranet.kce.be/index.php/s/TPQAWKGWMG3nHf7>
- Resources for **KCE researchers only**
 - KCE Project Guide for internal procedures and templates to be used in KCE context (at FileServer S:).
 - Intranet page of the QRT for support for QRM at KCE (under section “Experts”).



◆ PART 1–TRANSVERSAL DIMENSIONS OF QUALITATIVE RESEARCH

This first part explores transversal dimensions of qualitative research: the specificities of qualitative research (Chapter 4), including in the context of KCE, and frequently asked questions about qualitative research (Chapter 5) that could help to frame the research protocol (Chapter 6). The last three chapters of this first part address key dimensions of qualitative research: ethical issues (Chapter 7), the quality of qualitative research (Chapter 8) and reflexivity (Chapter 9).

4. WHAT ARE THE SPECIFICITIES OF QUALITATIVE RESEARCH?

4.1 Key features of qualitative research

“The goal of qualitative research is the development of concepts which help us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences, and views of all the participants” (retrieved from Mays, 1995, page 43).¹³

The aim of qualitative research is to develop a thick description^a and grounded or in-depth understanding of the focus of inquiry. The benefits of well-developed qualitative data collection are precisely richness of data and deeper insight into the problem studied. They do not only aim to describe but also help to obtain more meaningful explanations on a phenomenon. They can also be useful in generating hypotheses.¹⁵ Types of research questions typically answered by qualitative research are “What is going on? What are the dimensions of the concept? What variations exist? Why is this happening?”.¹⁶ Qualitative research techniques are primarily used to trace meanings that people give to social phenomena and interaction processes, including the interpretation of these interactions.¹⁷ *“They allow people to speak in their own voice, rather than conforming to categories and terms imposed on them by others”* (retrieved from Sofaer, 1999, page 1105).¹⁵ This kind of research is also appropriate to investigate social phenomena related to health.¹⁶

A qualitative research method is a research strategy covering a range of several qualitative data collection and analysis techniques, aiming to understand personal experiences and to explain social (aspects of) phenomena, such as health and illness.¹⁸

Qualitative research encompasses all forms of field research generating qualitative data. “Qualitative data” refers to **data in nonnumeric form**, such as words and narratives. There are diverse sources for qualitative data, such as observations, document analysis, interviews, pictures or videos and different approaches to collect data, such as interviews or observations in people’s natural settings, focus groups, or consensus-reaching techniques. Each of these data-gathering techniques has its strengths and weaknesses: the research team must reflect upon when choosing a qualitative research technique. Qualitative research in health care often employs **several different qualitative methods** to answer one and the same research question.³ This relates partly to what is called triangulation (see section 8.2.1).

^a A “thick description” of a human practice or behaviour include not only the focus of the study, but its context as well, so that it becomes meaningful to an outsider. The term was introduced in the social science literature by the anthropologist C. Geertz¹⁴.

Qualitative research is always **iterative**, starting with assumptions, hypotheses, mindsets, or general theories which change and develop throughout the successive steps of the research process. It is, therefore, desirable to make these initial assumptions explicit at the beginning of the process and document the acquired new insights or knowledge at each step.

Textbox 1 – Key features of qualitative research

- Qualitative research studies phenomena in the natural contexts of individuals or groups.
- Qualitative researchers try to gain a deeper understanding of people's experiences, perceptions, behaviours, and processes, and of the meanings they attach to them.
- During the research process, researchers use 'emerging design' to be flexible in adjusting to the context.
- Data collection and analysis are iterative processes that happen simultaneously as the research progresses.

Retrieved and adapted from Moser and Korsijens, 2017, page 272¹⁹

4.2 Theoretical approaches in qualitative research

In social sciences, the use of qualitative data is also closely related to different theoretical approaches trying to develop insight in social reality. Table 1 briefly presents an overview of a selection of different theoretical approaches relevant for qualitative health research in the context of KCE. These approaches will – in turn – influence the analysis of the data (see Chapter 20).

For example, participatory approaches are of particular interest when it comes to research projects with patient and public involvement while critical approaches could be of interest when evaluating the implementation of interventions.²⁰⁻²²

Table 1 – Selection of different theoretical approaches in qualitative (health) research^b

Theoretical approaches	Aims
Constructionism – <i>also called social constructionism</i>	Displaying 'constructed realities' of people in a particular setting, exploring their meanings and explanations
Grounded theory	Developing 'emergent' theories of social action through the identification of analytical categories from the data and the relationships between them
Phenomenology Ethnomethodology	– Understanding the 'constructs,' concepts or ideas people use in everyday life to make sense of their world. Uncovering meanings contained within conversation or text.
Interpretative approaches	Understanding the world from the point of view of participants in it, rather than an explanation of the world ²¹
Critical approaches – <i>including feminist theories and critical race theories</i>	Identifying ways in which material conditions (economic, political, gender, ethnic) influence beliefs, behaviours, and experiences (and in some cases using new understanding to facilitate change)

^b Not all these approaches are situated at the same level of abstraction (some can be considered as a paradigm while others are at the level of a middle-range theory). It is beyond the scope of this process note to further discuss the various levels of theorisation and conceptualisation of these different approaches. Interested readers can consult the QRT Library for theoretical references to further investigate theories related to QRM. https://www.zotero.org/groups/6199442/kce_qrt



Participatory approaches – including action research

Collaborating with participants to enact positive changes for them.

Retrieved and adapted from Ormston et al., 2014; Green and Thorogood, 2008²⁰⁻²²

The QRT Library includes a selection of reference books:

https://www.zotero.org/groups/6199442/kce_qrt

4.3 What is the approach to qualitative research at KCE?

The mission of KCE is to **advise policymakers** on decisions relating to healthcare and health insurance based on scientific and objective research. KCE is expected to propose the best possible solutions for an accessible, high-quality healthcare system with due regard for growing demand and budgetary constraints. This mission is operationalised through different activity domains: Health Services Research (HSR), Health Technology Assessment (HTA), Good Clinical Practice (GCP), and KCE Trials (a funding programme for non-commercial clinical trials financed by the public health authorities).

In this context, research at KCE, including qualitative research, has an **applied focus** rather than a theoretical focus, similar to that of other independent publicly funded research centres such as the National Institute for Health and Care Excellence (United Kingdom), the National Centre for Social Research (NatCen, United Kingdom), *ZonMW* (Netherlands), the *Haute Autorité de Santé* (France) or the *Institut de recherche et de documentation en économie de la santé* (France). Qualitative research methods are mostly used in HSR but can be used in all the activity domains of KCE such as GCP and HTA.

KCE's approach to qualitative research is mostly **pragmatic and realist**, with a view to **data sufficiency** when it comes to collecting data. Here, the KCE qualitative researchers tend to adopt the posture of NatCen, arguing that *"it is more important to choose the appropriate method or methods to address specific research questions than to align with a specific epistemological stance"* (retrieved from Ormston et al., 2014, page 22).²⁰ QRM are used as a **complement to other research methods**, hence promoting the **triangulation of methods and sources** to answer the research questions (see section 8.2.1). Analysis of qualitative findings is mainly descriptive, guided by a **deductive approach** and rooted in **framework analysis** (see section 20.1.1). However, this does not preclude inductive approaches or more interpretative analyses, as KCE researchers remain open to the different approaches to qualitative research. This posture is reflected in the content of this process note: the authors decided not to limit it to the more straightforward or commonly used approaches, as this restricts experts' creativity and opportunities to think out of the box. Thinking out of the box is key for KCE and research in general, as it motivates people in their work, is more exciting, avoids routine and stimulates innovation.

By providing up-to-date theoretical and practical knowledge in QRM and offering opportunities to **critically reflect** on QRM at KCE, the KCE Qualitative Research Team contributes to the **rigour** of QRM (see Chapter 9 Reflexivity in qualitative research). This supports KCE in the development of well-designed and well-conducted qualitative studies to generate well-founded evidence that can support decision-making.

5. FREQUENTLY ASKED QUESTIONS ABOUT QUALITATIVE RESEARCH STUDIES

5.1 Does the study require a qualitative research approach?

Yes, if

- The aim of the study is to answer why, how and/or in which context a phenomenon (in the broad sense) occurs.
- The research question starts with “why,” “how,” “to which extent” ...
- The aim is to capture diversity, variability, heterogeneity...

No, if

- The aim of the study is to measure the occurrence of a phenomenon.
- The research question starts with “how many,” “how much,” ...
- The aim is to obtain representative data from a statistical point of view.

Key considerations

- There is no black or white answer when it comes to qualitative research.
- Opting for a qualitative approach is always related to the research question. The research question determines the methodological approach, not the other way round.
- As for any research, a “good” qualitative research study starts with a well formulated research question.

RATIONALE

Although performing qualitative research is meaningful in itself, qualitative research is often defined by reference to quantitative research to highlight their differences. It is often assumed that, because qualitative research does not seek to quantify or enumerate, it does not ‘measure.’ Qualitative research generally **deals with words or discourse rather than numbers**, and measurement in qualitative research is usually concerned with taxonomies or classifications. “*Qualitative research answers questions such as, ‘what is X, and how does X vary in different circumstances, and why’, rather than ‘how big is X or how many X’s are there?’*” (retrieved from Pope, 2006, page 3).³

By emphasising the differences, qualitative and quantitative research approaches are presented as opposites. However, they should be regarded as **complementary and integrated** in the same research project. For example, in mixed methods research^c, the strengths of quantitative and qualitative research are combined for the purpose of obtaining a richer and deeper understanding.²⁴ Also, qualitative data could be analysed in a quantitative way by, for example, counting the occurrence of certain words.

Health services researchers often draw on multiple sources of data and multiple strategies of inquiry to explore the complex processes, structures, and outcomes of health care. It is common that quantitative and qualitative methods answer different questions to provide a well-integrated picture of the situation under study.²⁵ Especially in the field of health services research, qualitative and quantitative research

^c Mixed methods research (also called mixed research) is defined as “an approach to knowledge (theory and practice) that attempts to consider multiple viewpoints, perspectives, positions, and standpoints (always including the standpoints of qualitative and quantitative research)” (retrieved from Johnson et al. 2007, page 113).²³



methods are increasingly being used together in mixed method approaches. The ways QRMs could be used combined or not, are:

- Qualitative research only
 - To know the variation in experiences related to health(care) or illness.
Example: KCE report 383 Assessing and monitoring waiting times in healthcare - how to proceed in Belgium?²⁶
 - To build typologies regarding health services use, patient attitudes, health beliefs, etc.
Example: KCE report 374 Organisation of medical care in CBRNe incidents – a guidance²⁷
- Qualitative preliminary to quantitative
 - To explore new areas, new concepts or new behaviours before starting measurement.¹⁷
 - To build quantitative data collection tools (questionnaires): using appropriate wording, variables to submit, or developing reliable and valid survey instruments.^{15,17}
 - To pre-test survey instruments.¹⁵
- In supplement to quantitative work
 - As a part of a triangulation process that consist in confronting results coming from several data sources.¹⁷
 - To reach a different level of knowledge¹⁷: *“If we focus research only on what we already know how to quantify, indeed only on that which can ultimately be reliably quantified, we risk ignoring factors that are more significant in explaining important realities and relationships”* (retrieved from Sofaer, 1999, page 1102).¹⁵
 - To give a voice to understudied groups.²⁰
Example: KCE report 361 How to improve access to health care for people with intellectual disabilities?⁷
 - To explore complex phenomena or areas that are not reachable with quantitative approaches.¹⁷
Example: KCE report 339 For-K, Forensic-psychiatric intensive treatment units for adolescents in prison: Supply, use and need²⁸
- As part of the development of guidelines for clinical practice (GCP) and health technology assessment (HTA)
 - To elicit the preferences of individuals (citizens, patients, or professionals) to weight the final recommendations: qualitative evidence retrieved from literature could help to identify these preferences.
 - ▶ *To find out more about GCP at KCE, please refer to the KCE Process Note on GCP: <https://processbook.kce.be/about-good-clinical-practice-gcp>*
 - To better integrate patient experiences and potential patient issues in HTA: qualitative evidence from the literature could help to complete other data sources.
 - ▶ *To find out more about HTA at KCE, please refer to the KCE Process Note on HTA: <https://processbook.kce.be/about-health-technology-assessment-hta>*

Sofaer reminds that, in many cases, inquiry can move from being unstructured, largely qualitative in nature, to being structured and largely quantitative in nature. This is how she describes the continuum: *“(…) there is uncertainty not only about answers, but about what the right questions might be; about how they should be framed to get meaningful answers; and about where and to whom questions should be addressed. As understanding increases, some of the right questions emerge, but uncertainty remains*

about whether all of the right questions have been identified. Further along, confidence grows that almost all of the important questions have been identified and perhaps framed in more specific terms, but uncertainty still exists about the range of possible answers to those questions. Eventually, a high level of certainty is reached about the range of almost all of the possible answers”(retrieved from Sofaer, 1999, page 1103).¹⁵

In short, over time, investigations related to a certain area start with qualitative research to explore the field, find the appropriate research questions, prepare for more focused questions, and discover theories and hypotheses. Next, quantitative research is put in place to test hypotheses and finally, qualitative research can be used to deepen the findings or to search for explanations quantitative research techniques cannot provide.

5.2 Can a rapid qualitative research approach be applied?

Yes, if

- The decision-making concerns urgent, high priority health issues.¹⁰
- An expedited approach brings enough information to respond to decision-makers' needs.

No, when

- *“The time and resources available for the study are severely constrained*
- *There is a lack of existing evidence from the literature or previous research to help answering the research questions and objectives.*
- *There are obvious signs that the team will not be able to get access to the people or spaces [settings] required to carry out appropriate data collection for the study.*
- *The research questions cannot be answered with a rapid study design as they require long-term engagement with a specific topic or area.*
- *Researchers are being asked to ‘cut corners’ or carry out research in a way that might violate quality of ethical standards of research”* (retrieved from Vindrola-Padros, 2021, page 6).²⁹

RATIONALE

Rapid Qualitative Research (RQR) is a **qualitative study conducted over a short timeframe** (a few weeks to a few months). To be effective, it needs a **clear focus** (i.e., time is invested in a thorough scoping phase, to ensure the whole team agrees on the research questions, the study design, and the dissemination plan). It is **team-based**: researchers work collaboratively on all aspects of the research process. It relies on a **participatory design** (representatives of groups of interest such as patient associations or institutions engage in the research) with an early **involvement of stakeholders** in the process to create ownership. It combines multiple research methods and triangulates data during data analysis. **Data collection and analysis are held in parallel**.¹⁰

Including experts knowledgeable on the topics in the research team can help to expedite the data collection and analysis, but the experts should question themselves about their knowledge and remain open to alternative / new perspectives on the topic.

- *To find out more about expedited scientific research (ESRO) and Rapid Qualitative Research (RQR), please refer to the KCE Process Note on ESRO¹⁰: <https://kce.fgov.be/en/publications/all-reports/expedited-scientific-research-and-reporting-esro-at-kce>*



5.3 Does the project require primary qualitative data collection?

Yes, if

- After a (short) reviewing of the existing (grey) literature and of existing databases, qualitative evidence and data are not specific enough to be meaningful in the Belgian context and / or are of poor quality.
- The research question has been formulated in response to this gap and clearly demonstrates that existing data are insufficient to address the topic in the Belgian context.
- There is a need for qualitative data to triangulate with quantitative data to provide a comprehensive overview of the study topic.

► *Go to Chapter 12 for choosing the appropriate method(s)*

No if

- There is already extensive qualitative literature of decent quality relating to the research questions, and applicable to the Belgian setting. In this case, the research question should be re-evaluated to ensure it adds value beyond what existing data already provide. Existing data may also help reorient the research question toward a more relevant or feasible angle. Like with other literature reviews, one always needs to question the possible extrapolation to the Belgian context: this requires selecting qualitative studies of sufficient quality and with enough elements to understand the context and the target groups. One may think about selecting qualitative studies conducted in similar cultural, religious, or socioeconomic contexts (e.g. limiting to neighbouring countries of Belgium).

► *Go to Chapter 10 Literature review of qualitative data.*

- There are qualitative data publicly available that can be used to gain target groups' perspectives (e.g. via social networks, vlogs, or forums).
- There are data from previous studies that can be reused to answer the research question (providing that the participants were previously informed about the reuse of these data).

► *Go to Chapter 11 Use of qualitative open data in qualitative research.*

The recommendation to first search for existing data applies to all research, for pragmatic and ethical reasons (i.e. unnecessary solicitation of people), regardless of the urgency of the study. Depending on what exists and its applicability to the Belgian context, an original data collection could be conducted. Secondary data can help, if there is sufficient information about the data collection process, their quality, and the possible biases.

5.4 Can relevant and robust preexisting qualitative data be used in a research project?

Obviously, using existing datasets from previous research to perform analyses will result in saving precious time, particularly in the context of RQR. As mentioned above, it is always advisable to **first look for existing data and analyse it before undertaking any new data collection**. In this context, previous KCE studies can be a source of data (e.g. transcript of interviews conducted with patients). However, using existing qualitative data for a new research project (e.g. transcripts of previous interviews) also raises attention points.

These data may **not perfectly address the actual research question**. Moreover, careful appraisal of the quality, the validity, the trustworthiness, and the relevance of the data is required before use and may slow down the process.³⁰

Researchers also have limited control over the design and the data collection methods that were used. Participants must also have been informed that their data might be reused in other studies when signing

informed consent for the initial study. For example, in academic research, it is customary practice to mention that the information shared might be used for educational purposes, implying that, for example, quotes from interviews could be displayed during a lecture.

When considering the reuse of qualitative data from existing research projects, the UK Data Service recommends first addressing the following two questions:³¹

- Who is doing the reuse and, specifically, are any of the primary researchers involved in the reuse project?
- What are the purposes of the reuse, namely, are the new questions similar to, or hugely different from the questions of the original researchers?

The UK Data Service also distinguishes five ways data can be reused:³¹

- For descriptive purposes.
- For comparing data over time, between groups, between regions.

Theoretical example: comparing interviews conducted with patients before and after the introduction of a new legislation.

- For reanalysis when the researchers ask new questions to the data and aim to provide a different interpretation of the data.

Theoretical example: interviews with chronic patients were first analysed according to the model of access to health care of Andersen.³² Later, the same interviews were analysed using the self-care deficit theory of Orem.³³

- For research design and methodological advancement.
- For learning and teaching.

On a more practical note, particularly for comparison and reanalysis, reusing previous interviews or focus groups requires that the data be fully transcribed to facilitate the identification of the relevant material. It also implies that the researchers complete each transcript with their field notes to provide information about the context of the interview / focus group, non-verbal clues, or observations.

At KCE

- Reusing qualitative data from previous KCE projects has not been done so far (October 2025).
- Do not forget to mention in the informed consent that the data collected by KCE researchers can be used for other research projects (with respect to data privacy rules).

5.5 Is the approval of an ethics committee necessary?

► Go to section 7.3 for further instructions.

5.6 Is stakeholder consultation a qualitative research approach?

No, if the aim is to consult stakeholders for validating findings, to obtain feedback on recommendations or to triangulate perspectives. In that sense, stakeholder consultation is not framed by a specific methodology.

Yes, if the aim is to obtain data from the stakeholders to directly answer the research question(s). In that case, it is considered as a data collection embedded in qualitative research. In other words, if the participation of the stakeholders aims to produce new knowledge or added information, it is data collection and not a consultation. Stakeholder consultation is different from stakeholder involvement, where stakeholders are actively involved in the research process, and where the involvement is the objective of the project / the research. An example of stakeholder involvement would be a GCP project where stakeholders contribute to the elaboration of the research question(s).



- For more information about stakeholder involvement at KCE, please consult KCE report 174.³⁴

Key considerations

- The label “stakeholder” is often used in the context of KCE projects, but it encompasses different realities depending on the level of influence (=power) and the level of knowledge (=interest) about an issue.
- Conducting research with various stakeholders may involve different data collection techniques (not limited to QRM) such as an online quantitative survey, a Delphi process, or a nominal group technique.
- Identifying stakeholders is a crucial step to further elaborate the appropriate methodological approach.

5.7 Does patient involvement require qualitative research methods?

No: like stakeholder consultation, patient involvement is the final aim of the project and is not framed by a specific methodology.

“Patient Involvement in research differs from data collection in patients. Patients can be involved as PARTNERS in research at different times. The aim is to involve them in the implementation of the research (e.g. to choose or help develop tools for collecting data from patients) and not as ‘subject/object of data collection’ (i.e. not as participants in a survey or focus group, for example)” (retrieved from Kohn, Dauvrin and Cleemput, 2021 page 16).³⁵

Enabling techniques (or facilitation techniques) can be of interest to facilitate the interactions and expression of participants (see section 12.4.4). They are often used by moderators and facilitators, and are useful tools to support patient involvement, but these techniques are relational tools and not QRM.

- To know more about patient and public involvement at KCE, please refer to the KCE Position Paper and the KCE Process Note on Patient Involvement.^{35, 36}

5.8 Are exploratory interviews and site visits qualitative research methods?

Yes, as they use the methods and techniques of qualitative research.

Exploratory interviews should be understood as “preparatory” interviews, in the sense they usually take place early in a project. Almost all KCE researchers are likely to conduct such interviews, independently of their degree of training in QRM.

In the context of KCE, exploratory interviews should **not be confused with interviews conducted as part of the QRM**, i.e. interviews conducted to answer the research questions which can be, to some extent, exploratory. Different techniques of qualitative approaches are applied when conducting a preparatory interview. Qualitative data analysis (QDA) techniques are (usually) not used when these interviews are part of the scoping phase, but are definitively used when the exploratory interviews are part of the data collection phase (i.e. when the aim is to answer the research question(s)) (see Chapter 12 and Chapter 14 Interviews).

Similarly, **site visits** – during the scoping phase of a KCE project – should be understood as preparatory site visits to inform and orient the research questions and objectives. Again, QRM can be applied to better frame these visits. Site visits could also be used as part of the data collection phase but then pursue a different objective than exploratory site visits (see Chapter 13 Observations).

Exploratory interviews and site visits during the scoping phase pursue the following objectives:

- Discovering a topic and its key aspects
- Completing work orientations after first readings
- Highlighting hidden aspects of the topic

- Meeting the key actors
- Checking feasibility of the research plan and methods
- Paving the way for further collaboration
- Obtaining useful clues for the scoping
- Anticipating recommendations
- Preparing the scoping and the protocol meetings with KCE management

In short, exploratory interviews and site visits are more than “just a conversation” or “just a visit” and require careful preparation. Researchers involved in this exploratory phase should follow the same approach (e.g. having a clear agenda, using the same topic list). **The main challenge is to ensure the appropriate balance between having sufficient structure to be efficient and giving enough freedom to the participant to support emerging results.**

- ▶ *See Chapters 12, 13 and 14 for additional advice when conducting (exploratory) interviews and site visits*
- ▶ *See Chapter 21 for analysing data collected during exploratory phase.*
- ▶ *See Chapter 22 for reporting data collected during exploratory phase.*

5.9 Is artificial intelligence of interest for qualitative research methods?

Yes, for

- Drafting the research protocol and methodology: submitting the protocol to artificial intelligence (AI) to get additional ideas, critical appraisal of the QRM
- Scoping literature to identify gaps.
- Preparing data collection by drafting recruitment material (e.g. invitations or information documents for participants)
- Drafting a first set of questions to build the topic list for interviews or focus groups.
- Collecting data by scraping the web in a lawful way for online qualitative research via social media
- ▶ *See Chapter 11 on the use of qualitative open data in qualitative research.*
- Preparing data for analysis by transcribing audio material (only with local tools without connexion to the Internet such as Whisper AI)
- Analysing data, either for a specific part of the QDA (e.g. producing vignettes) or as a research companion for the whole analytical process (see e.g. Hitch, 2024³⁷ or Christou, 2023³⁸).
- ▶ *For AI tools that can be used for these purposes, please refer to the guidance of the KCE Technology Watch Group: <https://ikce.kce.be/technology-watch-group>.*

No, for

- Full analysis of the data, as the critical stance of the researchers cannot be replaced.
- Full draft of the research protocol
- Full data collection



Key considerations

- AI can support the qualitative researchers in their work but never replace the analytical work and the critical appraisal of the outputs generated by AI.
- Transparency about the use of AI in a (KCE) study – not only QRM – should be the norm.
- Be aware that some AI (e.g. OpenAI) cannot be used for data analysis, data transcription or translation as the privacy of participants cannot be guaranteed.

At the time of publication (30.10.2025), ChatGPT does not comply with the GDPR in force in the European Union.

At KCE

- Use of AI should be mentioned in a disclaimer according to the recommendations of KCE Technology Watch Group.
 - ▶ *Please contact the KCE Technology Watch Group to know more about the skills needed when using AI, the software that can be used in a safe way for QRM and the latest guidance: <https://ikce.kce.be/technology-watch-group>*

RATIONALE

Artificial intelligence is defined as the “development of computer systems capable of performing tasks that typically require the features of human intelligence, such as visual perception, speech recognition, decision-making, and problem solving” (Russel & Norvig, 2016 cited by Hitch, 2024).³⁷ Using AI as an assistance for improving written documents is well-established: AI can help with grammar, vocabulary and structure, also in the context of research publications.³⁸ Its use is increasing in qualitative research, hence the need to frame how AI can be of interest in the context of KCE qualitative research. Some authors plead for critical thinking about how to best adopt it, as this has become an almost “not-to-be-missed actor” for (qualitative) research.³⁷

As raised by Hitch, AI is particularly of added value in the context of RQR: AI can serve as a first approach to qualitative data when the priority is on providing solutions to patients and professionals when facing an emerging health issue. Hitch built this argument based on long COVID, where the experiences of patients and professionals were the first elements that pointed to the emergence of this health condition.³⁷ Transposed to KCE context, where research aims to support (rapid) decision-making, this could be seen as an argument to further understand how QRM can be helped by AI.

“As a pragmatist with a strong commitment to implementation, I would encourage anyone considering the use of AI in reflexive thematic analysis to also contemplate who we serve as qualitative researchers. From my perspective, it is not about us – it is about the impact our research can have for our participants. If AI supports the use of a systematic approach and the quicker completion of preliminary analyses, then this enables us to achieve this goal” (retrieved from Hitch, 2024, page 602).³⁷

5.9.1 Added value of artificial intelligence for qualitative research methods

Table 2 provides a summary of the QRM activities that could be assisted by AI in the context of KCE. The next sections detail the added value of AI according to the phases of a (KCE) research project.

Table 2 – Artificial intelligence assisted qualitative methods research activities

QRM activities	Support via AI	AI tools available at KCE
Drafting the research protocol and methodology	Obtaining additional ideas and a critical appraisal of the QRM	Copilot
Scoping the literature	Identifying gaps in literature	Copilot
Preparing the data collection	Drafting recruitment material Drafting a first set of questions to build the topic list	Copilot
Collecting data	Web scraping for online qualitative research via social media (see Chapter 11 on qualitative open data)	/
Preparing data	Transcription of audio material	Whisper AI
Analysing data	For a specific part of the QDA (e.g. producing vignettes, initial coding) As a research companion for the whole analytical process (e.g. Hitch, 2024 or Christou, 2024) ^{37,39}	AI assistant in Nvivo 15 (addon) - see section 19.6)

SCOPING PHASE

AI can play a role in the scoping phase of a project, by **identifying the knowledge gaps** in the current literature, helping researchers to “*identify unexplored areas, initiate new lines of inquiry, and contribute to expanding the knowledge base on the topic, or theory*” (retrieved from Christou, 2023, page 1971).³⁸ However, this is not specific to QRM but applies to all research projects.

DATA COLLECTION

In the data collection phase, AI can be used for “**web scraping**,” looking for data (e.g. blog posts, chats, pictures, or videos) shared on the Internet, including on social media. It also allows for **the integration of various formats of data** (e.g. texts, pictures, or videos). For Christou, AI can also serve as a support for **triangulation of sources**, enhancing the validity of the findings.³⁹

ANALYSIS

AI enhances the possibilities for **analysing large sample sizes**, e.g. analysis of 300 interviews⁴⁰, or the analysis of answers to open questions in a large online survey.⁴¹

Relying on AI-assisted Qualitative Data Analysis (QDA) is reported to save **time, money, and resources** (particularly as several AI products are free of charge, contrary to QDA software like Nvivo).³⁹

Within the analysis process, AI could inform the **development of new theoretical concepts by analysing existing research and frameworks**.^{38, 39} It helps to streamline the way qualitative data are processed, to automatise the coding and to summarise the data.^{37, 38, 40} Chubb used AI to produce vignettes on the basis of transcripts, obtaining a narrative of each interview she conducted that helped her to prepare her analysis.⁴⁰ Hitch conducted a reflexive thematic analysis with ChatGPT and reported how, at each step of the process, he interacted with the AI.³⁷ By doing so, Hitch found that AI contributed to the identification of themes, patterns, and other relationships between the data that he, as a researcher, did not find when doing the same analytical work.³⁷



By using AI as part of the analytic process, some argue that researchers (re)gain **more time for deepening their analyses and interpretation**, hereby improving the overall quality and relevance of the outcomes.³⁸ As pointed out by Chubb, *“it is a tool to make space to think more critically about the situatedness of research findings, freeing up more time to prepare results for impact”* (retrieved from Chubb, 2023, page 13).⁴⁰ It was also seen as helpful to stimulate reflexivity and critical thinking: *“AI may therefore reduce the risk of misinterpretation by providing an alternative analysis against which researchers can test, interrogate, and critique their own analysis. AI will not make reflexive thematic analysis more ‘correct,’ but it might support a deeper and more critical approach to reflexivity”* (retrieved from Hitch, 2024, page 601).³⁷

► Go to Chapter 9 for more about reflexivity in qualitative research.

5.9.2 Bias and other concerns related to artificial intelligence

Authors tended to agree that AI, particularly ChatGPT, reflects and perpetuates **biases, prejudices, and stereotypes**, as these are included in the texts that serve to build the knowledge base of AI.^{39, 42} Referring to other studies, Chubb pointed out that AI can replicate the use of offensive language, be discriminatory, racist, and sexist, vehiculate colonialist and imperialist opinions and contribute to misinformation.⁴⁰ In this sense, some criticise AI’s potential to perpetuate social inequalities and injustice. It seems developers attempt to prevent these biases, but this could have an adverse effect for those working on issues such as gender, race and sexuality.⁴²

Consequently, the outputs produced by AI can include **hallucinations, inaccurate, false, or non-reliable information, leading to biased interpretation of the research findings**.^{38, 40} This was experienced by Chubb when using ChatPDF to produce vignettes: she had to give additional prompts to ensure that the vignette reflected the content of the transcript.⁴⁰

Initial prompt: “Can you produce a narrative vignette from [Name’s] journey map?”

Adapted prompt: “Can you provide an example of how [Name’s] journey map could be presented in a vignette that brings in her discussion of menses and different ways she experienced sexual learning while growing up?” (retrieved from Chubb, 2023, pages 3-4)⁴⁰

This implies that the researchers play a **pivotal role in interacting with the AI tool**. Researchers need to be trained to interact efficiently with the machine (prompting techniques), but they also need to familiarise themselves with the raw data, be sufficiently aware of the theoretical models and concepts underlying their topic of interest and keep a critical mind when receiving the outputs. Chubb also emphasised the need for a strong methodological approach, aligned with the research questions, where there has been a rigorous questioning about the added value of relying on AI.⁴⁰ AI is not capable of complex thinking: AI fails to understand nuances and emotions, which leads to outputs that are not able to grasp the complexity of an issue and provide and (over)simplified analysis. To some extent, AI performs “content analysis” rather than “thematic analysis,” as the underlying algorithms are overly relying on the frequency of words, sentences, and other linguistic patterns.³⁹ Authors highlighted the need for critical thinking and appraisal throughout the whole research process (see Chapter 9).^{37-40, 42}

Another major concern related to AI is the **data privacy**. Information and data inserted in AI platforms contribute to the learning process of the computers. When included in AI tools, such as ChatGPT, this information and these data also fall into the public domain. As explained by Gal, the more data are fed to the AI, the more the AI is trained and becomes able to detect patterns that will further generate the outputs.⁴³ For example, if a researcher asks ChatGPT to analyse the transcript of an interview with a patient, the content of the transcript will be added to the ChatGPT database. This increases the risk of the patient being inadvertently identified (even if the transcript was anonymised).

Gal listed the following issues of the data collection and analysis by AI:

- AI platforms do not formally request approval from users to use their data.

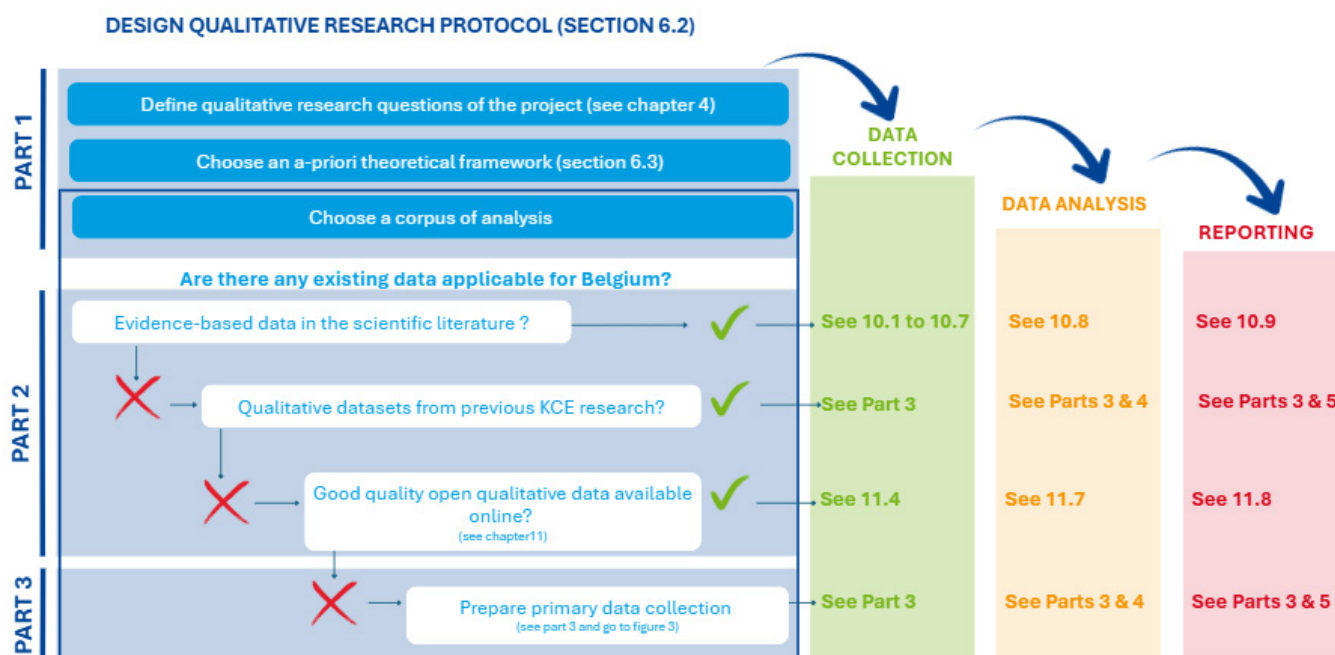
- For public data, there is no respect of the textual integrity, implying that the AI may modify a document without indicating that modifications have been made.
- There is no procedure to allow individuals to check how AI companies store their data or whether they can be deleted.
- There is no “right to be forgotten,” even if the data are false or inaccurate.
- AI does not respect intellectual property and copyright.
- AI may share users’ personal information with unspecified third parties, without informing them.
- AI companies do not pay for the data they use.^{37, 43}

6. PREPARING A QUALITATIVE RESEARCH STUDY

6.1 Planning a qualitative research study

Figure 1 presents the steps to follow when planning a qualitative research study. This schematic approach to qualitative research should not occult the **possibility of combining different qualitative methods to answer the research question(s)**. For example, a literature review of qualitative evidence can be combined with interviews with Belgian patients to obtain more contextualised data or using interview data from a previous KCE project can be combined with focus groups with professionals to triangulate perspectives.

Figure 1 – Overview of the steps when planning qualitative research methods



In Part 3, Qualitative research methods based on primary data, further details the steps to follow when the research team decides to opt for a primary data collection.



6.2 Qualitative research protocol

Like any research protocol, a qualitative research protocol describes **what, why and how qualitative research methods fit in the study**. The research protocol should give enough details to ensure agreement about the research process among the members of the research team, but also with the commissioners of the study. It also helps to keep track of the rationale behind methodological choices and orientations. It supports a common language, and the elicitation of the expectations related to the different research activities. This can prevent further questioning in a later stage of the process, particularly when new team members are incorporated.

The research protocol should **not be seen as a binding contract** preventing the research team from making alterations depending on the evolution of the different research activities. If the protocol can evolve during the research process, it is necessary to document every change in the methodological orientations. The protocol will provide the framework upon which to build the methods section in the final report. The research protocol also serves as a guide to better plan the resources needed (human, technical and financial).

When applied to a qualitative literature review, having a protocol allows for **consistency between the researchers** reviewing the papers, helps to reduce the divergences regarding what constitutes “data” and ensure a non-arbitrary process of data extraction and synthesis.⁴⁴ Examples of protocols for literature reviews of qualitative evidence can be found on PROSPERO.^d

► See Chapter 10 Literature reviews of qualitative evidence

Table 3 gives an overview of the sections and content that need to be included in a qualitative research protocol.

Table 3 – Main headings of a qualitative research protocol

Sections	Content	Specific for KCE
Aims and objectives	The ‘what’ of the study, including the broad aim (what you are going to do), broken down in measurable objectives	Refer to the PF
Background	The ‘why’: why this is an interesting question, an important question, or a policy-relevant question	Can be common with the overall study
Methods	The ‘how’: rationale for conducting a qualitative approach (including the theoretical framework, if any), a detailed description of what data you will collect and how, including sample size, if appropriate, and issues of access to the participants / target groups for data collection, data collection tools, procedures for data collection, analysis strategy (including data management)	Do not forget to justify why a qualitative approach was needed and how it fits in the overall research design
Ethical issues	Whether you need ethical approval, and how you will address ethical issues (e.g. vulnerable groups, need for disclosure)	Do not forget to refer to privacy issues

^d More about PROSPERO: <https://www.crd.york.ac.uk/PROSPERO/>

	See Chapter 7	
Team management & support	Reflexivity, protection of the researchers, roles of the team members...	Also think about the support that you may need from colleagues external to the research team (e.g. for reviewing the data collection material), from KCE staff for practical aspects or from external experts (e.g. patient representatives to validate the data collection strategy)
Resources	Costing for staff, travel, and materials	Ask project manager for assistance
Time scale	This should include important milestones, such as start and completion of fieldwork, draft report completion.	Refer to the forward planning
Dissemination and outputs	How will you inform others, including participants, of the findings? What other outputs are you expecting? Would you like to publish your protocol?	If specific outputs are envisioned, plan a meeting with KCE Communication Team and KCE Layout

Retrieved and adapted from Green & Thorogood, 2004 page 45²¹

At KCE

- For literature reviews, the necessity of recording the protocol on PROSPERO should be discussed during the “Protocol” milestone meeting.
- For primary data collection, it is possible to register the research protocol on the platform of the Centre for Open Sciences <https://osf.io/> This is recommended but not compulsory.

Resources

- Templates of protocols for primary data collection and literature review in qualitative research are available on the KCE Extranet: <https://extranet.kce.be/index.php/s/TPQAWKGWMG3nHf7>
- For examples of existing protocols at KCE (for KCE experts only), please contact the Qualitative Research Team

6.3 Choosing an a-priori theoretical framework

The choice of an a-priori theoretical framework will depend on the research question and of the theoretical approach to QRM. A theoretical framework provides a **structure for conceptualising and conducting the study**, guiding every step from the formulation of research questions to the interpretation of findings. The framework helps ensure that the research is grounded in relevant theory and contributes to the advancement of knowledge in the field, in constructing the interview guide and in analysing and interpreting the results (see section 20.1).

Example: KCE study 364 on the prevention of Post-Intensive Care Syndrome relied on the Theoretical Domains Framework that synthesises constructs from 33 behaviour change theories into 14 “construct domains” or clusters of related constructs that may explain practice change or absence of change.⁴⁵



To identify the model(s), the research team can conduct a rapid exploratory review of the literature and critically analyse the findings to find the most adequate model. It is also possible to consult with experts in the field, i.e. as part of the scoping phase. A good knowledge and understanding of the topics are also an asset at this stage. Even during a RQR, it is important to devote sufficient time to the theoretical grounding: *“lack of theoretical grounding of rapid qualitative research due to time pressures and the provision of more actionable findings, leads to the production of research that is instrumental, atheoretical and without a critical angle”* (retrieved from Vindrola-Padros, 2021, page 7).²⁹

However, **not all qualitative research starts from a theoretical framework**. Yet, it should be realised that relying on a theoretical framework linked to the topic can be useful because it saves time, particularly for the data collection and analysis phases, even more in the context of RQR.

7. ETHICAL ISSUES SPECIFIC TO QUALITATIVE HEALTH RESEARCH

Ethical dilemmas in qualitative research will never be solved by applying standardised methods and guidelines. What is produced is not produced by someone but with someone, as qualitative research is rooted in interactions, which creates specific challenges. Faced with the diversity of situations and persons encountered by qualitative researchers, ethics in qualitative (health) research needs to be negotiated and situated, that is paying attention and be adapted to the specific context (in a broad sense) in which the research takes place.^{46, 47}

7.1 Ethical issues raised by qualitative research

Qualitative research depends on the researcher building up **effective relationships** to gather high quality data. But this could lead to a form of pseudo-intimacy or fake friendship where relations do not occur “naturally.” The researchers can “self-disclose” personal information to establish a “better” relationship between the researcher and the participant. But this strategy could have adverse effects as *‘often through a sharing of experiences, the interviewer paradoxically exemplifies differences between themselves [the participants] and the interviewee’* (retrieved from O’Conner, 2017, page 428).⁴⁷ Additionally, an effective relationship may require that the researchers adapt themselves to the participants’ language and approach: this is even more important when the researchers have to interact with participants experiencing communication difficulties in understanding and/or expression (see section 12.3.2 on involvement of participants in vulnerable situations).

Yeo et al. go further by questioning the nature and the meaning of the relationship between interviewer and interviewee.⁴⁸ Do we consider the interview a reciprocal relationship or a relationship with distinct roles? It will depend on the posture of the researchers. In some approaches, the interview is perceived as a reciprocal interaction where the researchers share personal details about themselves (e.g. critical and feminist researcher, user-led research, emancipatory research, participatory research). This is research where the power dynamics are addressed, aiming to advance interests or empowering a group. In that approach, interviews are seen as a **collaboration**. This is a different approach than a conventional interview where the focus is on a **form of distance**, implying that the researchers adopt a “neutral” position while placing boundaries around their role. This posture is believed by some authors to contribute to the imbalance of power.⁴⁸ These two approaches to interviewing are elements that can be discussed as part of the reflexivity and, to some extent, agreed in the research team.

The **boundaries of the role of researchers** are particularly important in qualitative health research as the researchers should not slip into a role of counsellor / therapist. This could be particularly challenging for qualitative researchers whose background is that of a health care professional or a social worker when facing patients or persons in vulnerable situations (e.g. frail elder, single parent, or a person with a disability). Again, there is a need to anticipate how to set these boundaries appropriately (see section 7.2.6 Disclosure).

Participants may envision their participation to the research as a form of “transaction” where the participants have “*their own agenda and goals for taking part in research*”.⁴⁶ In these situations, the researchers are seen by the participants as “gatekeepers” to e.g. the access to certain benefits, privileges, and knowledge (see section 12.3.9). This could put the researchers in an uncomfortable situation as the participants may come to the interview or the focus group with personal requests that the researchers will not address (see section 7.2.6).

In contrast to quantitative methods, qualitative data collection has a “*flexible and responsive nature*.” This implies that the outcomes of the data collection activities are unpredictable, i.e. there is no guarantee that the data collected will serve the purpose of the research. The researchers do not control how the participants will contribute to the encounter regarding “*topic direction, coverage and depth*”.⁴⁶ When a data collection activity does not match the expectations of the research team, this is a key topic for a team discussion (but positive outcomes could also be discussed), also considering the methodological openness (see Chapter 9).^{46, 49, 50}

When conducting dyadic interviews (e.g. a parent/child or informal caregiver/patient), the researchers may face issues such as who should be given the opportunity to speak, how to manage potential conflicts, and how to respect privacy (e.g., not asking a question about caregiver burden in front of the patient).⁵¹

When collaborating with **gatekeepers** (see section 12.3.9), Webster et al. point to some specific ethical issues.⁴⁶ The gatekeepers play a role in selecting the participants: there is a risk of excluding potential participants for unfair reasons (e.g. the gatekeepers might assume that a person is not interested in the topic, or be afraid that the participants might share negative opinions about the gatekeepers). Another risk is that the gatekeepers do not provide all the intended information, preventing the participants from making an informed choice to participate. Depending on the role of the gatekeepers, they may exert (in)direct pressure on the target group to participate, particularly if they anticipate that the research could lead to benefits for their organisation (e.g. the gatekeepers pressure the “good” patients to participate so they can give a positive feedback on the service, helping the service to remain open). However, relying on gatekeepers also prevents the research team from intruding where they are not welcome or other missteps (e.g. using written data collection material with illiterate participants, or soliciting a team of nurses half of whom are on sick leave due to burnout, or a patient organisation that has already responded to 3 surveys in the last 3 months). In that sense, gatekeepers undeniably have added value for research projects involving vulnerable groups or when choosing appropriate methods (see section 12.3.9).

In QRM, there are more risks of **breaking confidentiality and anonymity** of participants than in quantitative research, particularly when the sample size is small, when the topic is not frequent or when the participants are likely to know each other. The proximity between the researchers and the participants could negatively impact confidentiality but the researchers themselves could also inadvertently jeopardise confidentiality “*where there are connections between participants and where the line of questioning taken in one interview is influenced by what has been heard in another*”.⁴⁶ Focus groups (and nominal groups) are most prone to confidentiality breaches: the research cannot guarantee that participants will respect the confidentiality rules. A form of signed agreement could be of interest but needs to be adequately presented to the participants. However, the research team could also wrongly assume that participants want to “*be treated anonymously when they do not*”.⁴⁶ It is then advised to directly ask the participants, particularly when these participants are representatives or stakeholders.

Finally, the researchers themselves could breach confidentiality when no support mechanism is put in place to help them voice confronting experiences during the research. Without support, the researchers may seek help from family or friends, sharing confidential information exchanged during an interview or a focus group (see Chapter 9 Reflexivity).⁴⁶



Resources

More resources on ethical issues in qualitative health research are available in the KCE QRT Library: https://www.zotero.org/groups/6199442/kce_qrt

7.2 How to manage ethical issues in Qualitative Research Methods?

7.2.1 Respecting ethical and deontological codes and guidelines

In Belgium, researchers applying for ethical approval should have a certificate of good clinical practice. However, to date, these certifications mostly focus on clinical and biomedical research and poorly consider specific ethical issues related to QRM.

At KCE

- Certification of good clinical practices is organised on a regular basis.
- ▶ *Information for submitting a protocol to an Ethics Committee is in the KCE Project Guide.*

7.2.2 Data protection and archiving

Data protection and archiving should be clearly established and should follow the legal framework related to health research and privacy.

At KCE

- ▶ *Procedure for the data protection and archiving of (qualitative) data is in the KCE Project Guide.*

7.2.3 Obtaining and proving informed consent

Obtaining informed consent should be seen as a **process**, where the research team needs to check at distinct stages of the research that the consent is still granted (= “staged approach” to consent).⁴⁶

In biomedical and clinical research, the gold standard is to obtain a **signed informed consent**. Belgian ethics committees require providing the form that will be used to gain such consent, prior to approval of a research project. By signing an informed consent document, some participants, could feel a form of pressure to participate and could find it more difficult to withdraw: this could even more problematic for vulnerable persons (the elderly, persons with mental health issues...).⁴⁶ Moreover, as the form is accompanied by an information document containing references to insurance, risks, and other potential problems, it could – for some participants – lead to anxiety rather than to reassurance. In some cases, it may even be absurd to require a signed consent from persons who cannot read or are excluded from citizenship rights, as happened in KCE project 257 on access to health care for undocumented migrants.⁵²

In fact, the key question is “is the written and signed consent form a protection for the researchers, or for the participants?” If the researchers need reassurance or feel that they need to be protected (e.g. by setting a clear framework around the research), a written consent may not be the appropriate solution. However, to date, Belgian ethics committees require written and signed consent forms. If the consent is more an “administrative” requirement than a “real” protection for the patients, Webster et al. advise to acknowledge that the consent is used to this end.⁴⁶

Table 4 presents questions to help guide the development of the information and consent form, which complements the administrative compulsory information (e.g. GDPR, data privacy, and information about KCE). The researchers are invited to put themselves in the shoes of a potential study participant.

Table 4 – Guiding questions for the development of the information and consent form

- What would you want to know about the nature and extent of the study?
- Steps to protect confidentiality and how you would feel if they were compromised.
- The types of methods you would consider acceptable to gather information from you.
- How would you feel seeing your experience / testimony shared in a written report, months after initial consent to participate was provided?

Adapted and retrieved from Webster et al., 2014, page 84⁴⁶

At KCE

- When appropriate, have an adapted document with content that is easy to read and understand by any participant in addition to the legal text, to avoid de facto exclusion of some participants. As an example, in KCE project 361 on access to health care for persons with intellectual disability, the informed consent form was adapted to persons living with intellectual disabilities.⁷
 - ▶ *Templates for informed consents are available via the KCE Project Guide.*
 - ▶ *Examples of informed consents used in previous studies are available via the KCE Project Guide.*
 - ▶ *Videos presenting informed consents are available via the KCE Project Guide.*

7.2.4 Ensuring a voluntary consent and avoiding pressure to participate

Participation to research is commonly motivated by the expectation that it will lead to better health care services or policies.⁴⁶ However, one should always be prudent when describing the project and its objectives as it may raise elevated expectations that cannot be reached, e.g. because the researchers are not responsible for the implementation of the recommendations following from the research, as is the case with KCE. Researchers must make this fact clear to participants and, if necessary, repeat this information regularly.

In the literature, the use of incentives for participation (e.g. vouchers) requires **careful consideration**, in order to find a proper balance between giving a mark of appreciation and (indirectly) pressuring individuals to participate in the study.⁴⁶ Moreover, the nature of the incentive itself needs to be discussed. Additionally, **no consensus emerges about the appropriateness of financial incentives.**⁴⁶ Offering financial incentives when recruiting could orient the selection of the participants and bias the overall process. Moreover, a financial incentive could have negative consequences for the participants (e.g. the participant cannot accept money because of his or her employer, the participant receives an invalidity allowance from a sickness fund...). On the other hand, a financial compensation could be granted after the activity as a form of acknowledgement.

In 2023, the Belgian Association of Research Ethics Committee (BAREC) published a guidance document on fair compensation of subjects for their participation in clinical research in Belgium.⁵³ Some of these principles are applicable to qualitative research in public health.^e

The BAREC distinguishes:

- **Compensation for study-related expenses and costs:** travel, food and drinks, accommodation, babysitting, and other costs related to the research design. In a qualitative study, study related costs are usually related to travel and subsistence.

^e For more about BAREC and their latest guidance: <http://www.barec.be>



- **Compensation for time investment** – the rule suggested by BAREC being that over 2 hours at the investigational centre is compensated to all participants.
- **Token of appreciation** (a form of compensation for willingness to participate): under the form of items / goods / services of low value (e.g. gift card) or items / goods / services with higher (non-material) value. In qualitative research, when a token of appreciation is planned, it is usually an item / good / service of low value.
- **Incentives, rewards or bonuses** – these practices are not recommended as they are likely to induce undue influence.⁵³

At KCE

- No incentives, rewards or bonuses are paid to participants.
- Compensation for study-related costs, compensation for time investment and tokens of appreciation for the participants should be discussed by the research team when planning the study and approved by KCE management.
- No distinction should be made between patients and professionals involved in the same KCE study (i.e. a token of appreciation should be granted to all).

7.2.5 Avoiding adverse consequences for the participants

One ethical principle to respect is the **non-maleficence**, implying that the research team needs to avoid adverse consequences as much as possible when interacting with participants (whether these are professionals or patients).

Adverse consequences can be anticipated for some research topics. Whenever this is the case, risk **mitigation strategies** must be developed in the planning phase of the study.

When interacting with participants, Webster et al. suggest:

- *Being clear with the participants that it is their choice how much they say, that they are free not to answer questions or to say they do not want to discuss a topic further.*
- *Being alert to signs of discomfort or potential withdrawal of consent.*
- *Giving examples of wording to use if participants do want to withdraw from a question / interview.*
- *Providing some information to all participants about support services* (retrieved from Webster et al. 2014, page 94).⁴⁶

With regard to the last item, this could be realised by providing, at the end of the interview or of the focus group, information about patients' associations, websites where the participants can find further information (e.g. about ONE or Kind & Gezin), or contact addresses of specialised services (e.g. addresses of free clinics for homeless persons). It is recommended to use existing material but, if there is none, the research team needs to prepare a minimum set of information to share with the participants.

Despite it not being a "therapeutic" conversation, it appears that some participants experience discussing their personal (sensitive) experience with researchers as a form of "**cathartic encounter**." By allowing participants to voice their (traumatic) experience, the researchers contribute – to some extent – to a form of legitimisation of this experience.⁴⁶ For example, the KCE project 344 on Long Covid, interviews were conducted at a time when Long Covid was not yet formally acknowledged as a public health problem.⁵⁴ The opportunity to share their experiences with researchers may, in a way, have contributed to a certain legitimisation of these experiences. This has potential implications for the researchers: if they delve into participants' experiences, they must be prepared and able to respond adequately and appropriately to potential distress of the respondents.⁴⁶ Moreover, researchers should be aware that this may also happen with apparently "benign" topics (see section 7.2.6 Disclosure).

[...] This highlights the importance of thinking in advance about ways which what seems like benign topics might connect with difficult experiences for participants in every qualitative study – but also of expecting the unexpected and being adept at managing this in the fieldwork situation [...] (retrieved from Webster, Lewis and Brown, 2014, page 96).⁴⁶

The data collection process through interviews might also lead to researchers receiving information from participants that triggers the **moral obligation** of the researchers to help the respondent. This could imply providing specific information to the participants so that they can receive proper support. For example, during the KCE project 257 on access to health care for undocumented migrants, a participant explained to the researcher that a social assistant of the municipal social welfare centre threatened to have her baby taken away by the police if she did not reveal her home address.⁵² As the researcher knew that this is against the law, after the interview, she gave the participant information about a legal service that could help her.

7.2.6 Anticipating the need for disclosure of personal information of study participants

When addressing some research topics or working with some groups in vulnerable situations, researchers may find themselves in a situation where they have to **disclose the information that has been shared with them to a third party** (e.g. social service, health professional, police...), hereby breaking the confidentiality. The risks identified by the researchers can directly concern the participants or another person. This can concern physical, psychological, emotional, financial, or sexual violences; serious health problems for which the participants do not receive proper support; suicidal thoughts; past or planned criminal activities; violations of institutional rules and regulations. This can be particularly complex to manage for researchers with certain professional roles such as health care professionals, social workers, or safety officers.⁴⁶

In practice, participants should be informed about the **disclosure policy** before the start of the data collection (whether in the real world or online). It implies that the research team anticipates the situations in which they will have to disclose the participants' information, how and to whom. It also requires that the research team checks that the contact data of the participants are correctly completed. Decisions on disclosure need to be made by the research team and not by a researcher alone. Textbox 2 presents a list of questions to help preparing disclosure of participants' personal information. The answers to these questions will depend on the research questions and the target groups.

Textbox 2 – List of questions to help to prepare disclosure of participants' personal information

- Which type of harm or risk may trigger a disclosure of personal information?
- Who will be involved in deciding whether the conditions for disclosure of personal information are met?
- Will the research team seek consent to disclose patient information or inform participants that they are going to or have disclosed their personal information? Will this happen during the research encounter or later and only after consultation with colleagues or others?
- Will participants be encouraged and supported to seek help themselves instead of disclosing personal information? What would this involve, who needs to be involved, how would this approach be supported and what follow-up might be needed?
- To which individual or organisation will the research team disclose participants' information? Are the responsibilities of this individual or organisation clear and will they be willing to accept disclosed information?
- Will the research team follow up in any way?
- What implications will disclosure of participants' information have for continuing the research relationship with the participant?



- What risk will disclosure of personal information of participants imply for the researchers or their organisation / institution, and how does this need to be managed?

Retrieved and adapted from Webster et al. 2014, page 101⁴⁶

At KCE

- *Internal procedure for disclosure is available in the KCE Project Guide.*

7.2.7 Enabling participation

Enabling participation requires that the research team pays sufficient attention to all “*people’s right to participate and to have their views and experiences heard and taken into account in public policy formulation*” (retrieved from Webster et al. 2014, page 103).⁴⁶

It means including a **diversity of perspectives around the research topic**, not only the perspectives of those who are easy to reach / easy to include (see section 12.3.2). It also implies that the researchers **think out of the box when drafting the research protocol** and carefully prepare the communication of the information around the research project (e.g. using visual supports, providing interpreters, adapting the practical aspects of the data collection).

Enabling participation should be reflected in the reporting by “*ensuring that data are reported with integrity and that research findings are not distorted*” (retrieved from Webster et al. 2014, page 103).⁴⁶

Enabling participation requires **resources**: when asking the research team to comply with unrealistic schedules and budgets, commissioners may jeopardise the inclusiveness and the quality of the research project.^{10, 21, 46} Therefore, it might sometimes be better to refuse performing a study rather than performing a study that does not allow for inclusiveness and thereby critically biases the results.

7.2.8 Protecting researchers from adverse consequences

When thinking about ethical issues, one tends to neglect the need to protect the researchers from adverse consequences of the research.

Risks could arise from diverse sources (and reinforce each other): the research environment, fieldwork and interactions with the participants, or the research topic itself. When not properly addressed, these could cause researchers to experience guilt, anger, frustration and even “vicarious trauma,” which is considered like post-traumatic stress disorder.

At KCE

- **Qualitative Research Team:** *helps to discuss experiences during qualitative research, provides support for research-related issues and shares good practices. For example, a researcher may find it difficult to ask questions about sexuality during interviews and wants to learn how other researchers handle these issues. <https://ikce.kce.be/qualitative-cell>*
- **Persons of trust** (*personnes de confiance / vertrouwenspersonen*): *offer non-professional support and reorientation for well-being issues linked to the work environment (see KCE Intranet). Knowing this, if an emotional discomfort arises during research, they can offer a first listening. For example, a researcher interviewed a patient who has a terminal illness. The person of trust can listen and if needed reorient the research to the appropriate support.*
- **Management** (including project managers): *offers support for issues related to the research team or issues for which the research team needs a legal / formal support (e.g. disclosure).*
- **EMPREVA:** *external prevention service.*

7.3 Is the approval of an ethics committee necessary?^f

Yes, if

- Data collection involves asking participants to provide personal information about their (physical, mental, social, emotional) health, their experiences with the health care system, their needs, or their preferences (do not hesitate to consult the GDPR to correctly identify sensitive data).
- Data collection involves asking proxies to answer on behalf of a relative that is unable to participate himself / herself (e.g. due to severe cognitive problems, patients in coma or any other circumstance preventing the participant from giving proper consent).
- Data collection involves asking professionals to provide personal information (e.g. their stress level, the health problems they face).

No, if

- Data collection is conducted among patient representatives who share information on behalf of their association and not their personal (private) experiences.
- Data collection is conducted among professionals about their experiences as professionals.

Key considerations

- Ethical approval is not related to QRM only, but rather to the **nature of the collected data**.
- Ethical approval may be needed to interview health professionals, depending on the nature of the collected data: do not assume that there is no ethical approval needed when targeting health care professionals.
- The **interventional nature of interviews or focus-groups** should not be underestimated. For some participants, sharing their personal experience can trigger strong emotions such as sadness, guilt, anger, aggressivity... It can lead to violent verbal or physical reactions (e.g. insults or threats).
- This phase can be particularly **time-consuming** due to the extensive preparation required for submission files and the subsequent delays in the review process by the ethics committee. It frequently poses challenges for (KCE) researchers, especially regarding the appropriateness of submitting qualitative research protocols to current ethics committees. This uncertainty arises because the procedures in place often do not align with the specific needs of qualitative research, as they are typically modelled after criteria more suited to clinical research assessments. If a research team is aiming for rapid research, the procedure for evaluating the study protocol by an ethics committee seems to be the main bottleneck.⁵⁵
- Ethical approvals remain under the **control of the ethics committees**. One can only expedite this process by selecting an ethics committee reputed for its rapidity / with two or more meetings per month according to an agenda accessible to the researchers.

At KCE

- Anticipate the need for an ethical approval during the scoping phase of the project, independently of the study design.
 - ▶ *Consult with the data protection officer, the project manager, and the Qualitative Research Team in case of doubt.*
 - ▶ *Consult the KCE Project Guide for more information and resources.*

^f This section presents the current recommendations and practices at KCE (October 2025).



8. QUALITY AND VALIDITY OF QUALITATIVE RESEARCH METHODS

“Whatever the method, it needs to be well-defined, well-argued, and well-executed.”(Snijders, 2007)⁵⁶

The increasing demand for qualitative research within health and health services research has emerged alongside an increasing demand for the demonstration of methodological rigor and justification of research findings.⁵⁷ This chapter addresses quality criteria for qualitative research. It aims to 1) guide KCE researchers applying QRM in their research project(s); 2) assess existing qualitative studies or publications resulting from qualitative studies.

Before going further, we want to issue a warning against the rigid use of checklists and quality criteria in qualitative research. Barbour criticises the widespread use and description of assumed quality indicators like theoretical sampling, grounded theory, multiple coding, and triangulation in scientific articles, as an unequivocal guarantee of robustness. These dimensions of qualitative research should be embedded within a broader understanding of the qualitative research design and not *“stuck on as a badge of merit”* (retrieved from Barbour, 2001, page 1115).¹² As pointed by Walsh and Downe, a **checklist is indicative of good quality research, but not a guarantee.**⁵⁸

8.1 Bias in Qualitative Research Methods

Bias can be defined as *“any influence that distorts the results of a research study. Bias may derive either from a conscious or unconscious tendency on the behalf of the researcher to collect data or interpret them in such a way to produce erroneous conclusions that favour their own beliefs or commitments”* (retrieved from Bloor and Wood, 2006, page 21).⁵⁹

In QRM, **bias may arise from various sources**, at different steps of the project. Table 5 lists the most frequent sources of bias that could occur in a QRM, alongside strategies to reduce the impact of these biases on the findings.

**Table 5 – Sources of bias in qualitative research**

Type of bias	What? ⁹	Examples	Mitigation strategies
Availability bias	A bias that arises from the use of the information or information sources which are most readily available, rather than the information (sources) which is (are) most representative.	Researchers who want to interview homeless persons about access to healthcare always go to the same homeless centre.	Combine different recruitment strategies. Discuss the impact of choosing this strategy on the findings (use of natural groups is a pragmatic strategy acceptable in QRM – see Chapter 15).
Hawthorne effect	Occurs when individuals modify (an aspect of) their behaviour in response to their awareness of being observed.	During hand hygiene inspection, if the observer is clearly identified, nurses tend to wash their hands more frequently than usual.	If observation is a key component of the study, one may consider “hidden” observations (with appropriate ethical precautions) or repeating the observation.
Information bias	Bias that arises from systematic differences in the collection, recall, recording or handling of information used in a study. In QRM, data as shared by participants during data collection are considered “true” from the participants’ perspectives.	In QRM, this could be forgetting to record sociodemographic data or to ask key questions during the data collection. For example, it is unlikely that there will be a comparison of the information shared by participants with the information from their medical files.	At the end of the data collection activity (interview or focus-group), quickly check that all key information has been collected / provide a summary of the key points that were shared.
Non-response bias	A bias that occurs due to systematic differences between responders and non-responders. In QRM, this is more likely to occur once the participants register and do not show up. It could also occur when the target group is well defined.	Focus groups are organised to discuss patient safety in nursing homes. None of the participants were nurses, only care assistants participated.	When possible, provide information about the non-responders and how this might influence your findings

⁹ All definitions are retrieved and adapted from the Catalogue of Bias which focuses on quantitative and clinical studies <https://www.riskofbias.info/welcome>



Novelty bias	The tendency for an intervention to appear better when it is new.	Interviews are held with services that do not have a community health worker. Despite already offering the same services as a community health worker would, they express their need to have one.	When interpreting your findings, examine to which extent the novelty bias could play a role
Observer bias	The process of observing and recording information which includes systematic discrepancies from the truth. In QRM, it could imply that the researchers have preconceived ideas about a topic.	The researcher has previous clinical experience and expects doctors to adopt the same attitude he had when practicing.	See Chapter 9 Reflexivity in qualitative health research
Perception bias	The tendency to be subjective about people and events, causing biased information to be collected in a study or biased interpretation of a study's results. In QRM, this bias is mostly likely to be implicit, the researchers usually being not aware of these perceptions.	The interview takes place at the patient's home. The patient has a dog who comes to greet the researcher, who likes dog. The interview does not provide particularly interesting findings when compared to the other interviews, but the researcher describes it as being rich and interesting.	See Chapter 9 Reflexivity in qualitative health research
Racial bias	A distortion arising from systemic, institutional, interpersonal, or individual forms of explicit (conscious) or implicit (unconscious) prejudice against individuals or groups based on social constructs of race or ethnicity that influences the planning, methods, results, interpretation, dissemination, and application of health research.	In an interview about mental health, a patient explains that his depression is a curse from an evil entity. When interpreting the findings, the researcher interprets this belief as "childish and erroneous."	See Chapter 9 Reflexivity in qualitative health research
Recall bias	Systematic error due to differences in accuracy or completeness of recall to memory of past events or experiences.	Focus-group discussions are held with patients who underwent a bariatric surgery 10 years ago. None of the participants recalled how the surgery was explained to them and which support they received.	When investigating events in the past, specify a period when recruiting (e.g. did you have a surgery in the last 2 years)
Selection bias	Occurs when individuals or groups in a study differ systematically from the population of interest, leading to a systematic error in an association or outcome. In QRM, it could imply that the researchers systematically rely on the same recruitment channels to reach their participants.	In a study on the knowledge of patient rights, patients were recruited via patient associations who provided such information. Patients were perceived as knowledgeable, but this is not the case of the general population.	Diversify the recruitment channels and strategies. When relevant, compare the findings between the groups based on the recruitment channel. Clearly report on recruitment strategies.



			Discuss the impact of these strategies on the findings.
Unacceptability bias / social desirability bias	A systematic difference in response rates or uptake of tests due to their “unacceptability.” In QRM, it could imply that participants hesitate to disclose information because they perceive it as embarrassing, hurtful or too intimate, or because they feel it is “unacceptable” from a societal point of view.	Patients may hesitate to report non-compliance to prescribed treatment when receiving costly ones. Patients may not report the impact of their disease on their sexual life and sexual habits. Medical doctors may not report that they do not follow guidelines.	Develop an appropriate data collection tool and evaluate it. Adopt an attitude that helps participants feel comfortable to share intimate / sensitive information. Provide guarantees for anonymity.
Volunteer bias	Participants volunteering to take part in a study intrinsically have distinctive characteristics from the general population of interest. It was found that volunteers usually are more educated and have higher socioeconomic status. It is also reported that women tend to volunteer more. Volunteers may have an agenda to follow / a specific message to convey: only accepting applications from these persons leads to a selection bias.⁶⁰	The same patients register to participate to different research projects.	Develop different recruitment strategies / rely on different recruitment channels to obtain a diverse and heterogeneous sample.



8.2 General quality criteria

“Being qualitative research instead of quantitative research should not be used as an assessment criterion if it is used irrespectively of the research problem at hand. Similarly, qualitative research should not be required to be combined with quantitative research per se – unless mixed methods research is judged as inherently better than single-method research” (retrieved from Busetto, Wick and Gumbinger, 2020, page 8).⁶¹

Most quality criteria are applicable to all research, both quantitative and qualitative. Cohen and Crabtree reviewed and synthesised published criteria for good qualitative research.⁶² They identified the following general evaluative criteria: 1) ethical research, 2) importance of the research, 3) clarity and coherence of the research report, 4) use of appropriate and rigorous methods, 5) importance of reflexivity or attending to researcher bias, 6) importance of establishing validity or credibility, 7) importance of verification or reliability. Only the last three criteria are specific to QRM, the others being applicable to all research designs.

Additionally, some quantitative criteria such as internal or external validity, strict adherence to protocol (reliability), or objectivity checks are not suited to qualitative research; these evaluation criteria have been adapted to better match the specificities of qualitative research. Table 6 presents the way the criteria for assessing the quality of quantitative research are translated into criteria for qualitative research. The following sections present a selection of methods to ensure quality according to these overarching criteria.

Table 6 – Translation of criteria for assessing quality

Quantitative research	Qualitative research	Methods to ensure quality
Internal validity	Credibility <i>Are the findings credible?</i>	Member checks; prolonged engagement in the field; data triangulation (see section 8.2.1 Triangulation)
External validity	Transferability <i>Are the findings applicable in other contexts?</i>	Thick description of setting and/or participants, i.e. rich qualitative data allowing not only the description of social behaviour, but also its connection to the broader context in which it occurred. ⁶³ (see definition in section 4.1)
Reliability	Dependability <i>Are the findings consistent and could they be repeated?</i>	Audit – researcher’s documentation of data, methods, and decisions; researcher triangulation (section 8.2.1 Triangulation)
Objectivity	Confirmability <i>To which extent are the findings shaped by the respondents and not by researcher bias, motivation, or interests?</i>	Audit and reflexivity – e.g. awareness of position as a researcher and its influence on the data and findings (see Chapter 9)

Retrieved and adapted from Finley, 2006⁶⁴, based on the work of Lincoln and Guba’s

8.2.1 Credibility and dependability: triangulation

Triangulation helps to reinforce the credibility and the dependability of the qualitative findings. Triangulation is the use of **several scientific methods, both qualitative and quantitative, to answer the same research question**.⁵⁹ Often triangulation is understood as producing the same results by means of several methods, sources, or analysts. Different methods or types of inquiry are sensitive to different nuances, so that they may lead to different results. In fact, triangulation is more about finding inconsistencies to gain deeper insight into the relationship between the inquiry approach and the subject

under study. Thus, finding inconsistencies does not weaken the credibility of the results, but rather strengthens it.²⁵

Table 7 presents five strategies of triangulation that can contribute to the quality and consistency of qualitative data analysis. These kinds of triangulation protect the researcher against the accusation that findings are an artifact of a single method, or of source or investigator's biases.²⁵ Each project, even a RQR, should **at least include one triangulation strategy**, the most appropriate strategy will therefore depend on the research question and the design of the research.

Table 7 – Triangulation strategies

Strategies	Definition
Methods triangulation	Information obtained through different methods is compared. These methods can be qualitative, quantitative or both. Often qualitative and quantitative data can be fruitfully combined as they mostly elucidate complementary aspects of the same phenomenon. ²⁵ This is the most commonly used strategy at KCE.
Triangulation of sources	Information derived from different sources is compared, e.g. comparing observational data with interview data, but also comparing what people say in public with what they say in private. ²⁵
Analyst triangulation	Different observers, interviewers, researchers, or analysts are used. In this way, the potential bias that comes from a single person doing all the data collection and/or data analysis is reduced. In addition to several researchers or data analysts, analytical triangulation may also consist in having the final findings reviewed by the persons who were studied. ²⁵
Theory perspective or triangulation	This involves the use of different theoretical perspectives or different stakeholder perspectives to look at the same data. ²⁵
Member validation	A popular kind of triangulation that consists in “ <i>checking the accuracy of early findings</i> ” with study participants. ⁵⁹ Participants may be asked to read transcripts of dialogues in which they have participated to check whether their words match what they actually intended ⁶⁵ , or they may be asked to check the accuracy of early findings. ⁵⁹ This last strategy is not recommended in the context of KCE. This differs from analyst triangulation, where the revision is done on the final findings and not the early ones.

8.2.2 Transferability: thick description

Qualitative research is **context sensitive and not meant for generalising to the wider population**. This may seem to contradict the notion of transferability, which is precisely about the extent to which the findings of one study can be applied to other situations (external validity).⁶⁶

Transferability refers to the responsibility of the researchers to provide sufficient contextual information about the fieldwork to enable the readers to determine how far they can be confident in transferring the findings to other situations (**=thick description**).⁶⁷ For example, in a project involving interviews about advanced practice nursing, the contextual information could concern the different settings in which these nurses work (e.g. hospitals, primary care and revalidation centres). However, in this project, interviews were only conducted with nurses working in hospitals and revalidation centres.

It might occur that factors considered unimportant by the researcher are critical in the eyes of a reader. Therefore, it is important to be very conscious of what is or is not reported and make sure that even aspects that are considered less relevant are reported, to be as transparent and complete as possible.⁶⁷

8.2.3 Dependability: researcher triangulation and audit

Dependability “*establishes whether the research findings would be consistently repeated if the research were to be replicated, either with the same investigator or with another, either in the same context or in a different one*” (retrieved from Megheirkouni and Moir, 2023, page 849).⁶⁸



This implies that the research team carefully and accurately **documents the research process**, including the decisions made during the project. To this purpose, it is possible to use **an audit trail**, i.e. a “*systematic and comprehensive record of the research process that enables an external reviewer to trace the study’s path and assess the dependability and confirmability of the findings*” (retrieved from McLeod, 2024, page 1).⁶⁹

The following information can be found in an audit trail:⁶⁹

- Raw data: Field notes, interview transcripts, audio/video recordings, and documents collected.
- Data reduction and analysis products: Codes, memos, summaries, and working hypotheses.
- Data reconstruction and synthesis products: Thematic categories, interpretations, and inferences.
- Process notes: Methodological decisions, challenges encountered, and reflections on the research process.
- Materials related to intentions and dispositions: Research proposal, field journal, and reflexivity notes.
- Instrument development information: Pilot forms, surveys, and interview guides.

It is advised to maintain a **chronological order** to highlight the evolution of the research process, to have a clear organisation system (with some ground rules to maintain a consistent filling system), and to include sufficient information to understand the rationale of the decisions.⁶⁸

At KCE

- The project fiche, the research protocol and the living document are tools helping the research team to document the research process and decisions. The principal investigator should ensure that these various documents are completed throughout the research process with sufficient information to ensure dependability.
 - These documents should also include the repartition of the tasks among the members of the research team and information on who has access to which data (e.g. not all team members should have access to the audio recording of the interviews) – as this is a requirement of the ethics committees.
- *Additional resources (including template of a living document and of the project fiche) are available in the KCE Project Guide.*

8.2.4 Confirmability: audit and reflexivity

“Reflexivity is an awareness of the self in the situation of action and of the role of the self in constructing that situation” (retrieved from Bloor and Wood, 2006, page 145).⁵⁹

In addition to the audit trail, reflexivity is one of the strategies that can be used to enhance confirmability of the qualitative findings. Because in qualitative research, the researchers cannot be ‘blinded,’ they must consider subjectivity in an explicit way. As reflexivity is more than a quality criterion, strategies to put reflexivity into practice are described in Chapter 9.

8.3 Appraisal tools and checklists

8.3.1 Appraisal tools and checklists for qualitative syntheses and primary qualitative studies

Different quality appraisal tools and checklists for qualitative research exist. Fourteen tools were found in the literature (see section 3.2 for the method). Three are recommended by the EQUATOR network^h: COREQ, ENTREQ and SRQR. The generic checklists of the 2012 process note were also included in the test of the tools by the QRT (Coté & Turgeon^{70, 71} and Walsh and Downe⁷²), as well as the critical appraisal tool for focus groups of Vermeire et al.⁷³ Additional checklists and appraisal tools were found in the compendium of quality appraisal tools of Majid and Vanstone, including the guidelines of the Johanna Briggs Institute (JBI).⁷⁴ AMSTAR-2 was also included, as it is used at KCE for the assessment of quality in systematic reviews. Based on their critical appraisal, Majid and Vanstone proposed an Appraisal Tool Guide to help qualitative researchers select the most appropriate tool.⁷⁴ Considering their recommendations and KCE's needs, two JBI tools were tested by experts of the KCE QRT.

At KCE

- The **JBI checklist for systematic reviews and research syntheses** should be used for the critical appraisal of literature reviews of qualitative evidence. <https://jbi-global-wiki.refined.site/space/MANUAL/355860482/3.+Systematic+reviews+of+qualitative+evidence>
- The GRADE Evidence Series provides additional advice on how to assess the different dimensions of quality for qualitative evidence synthesis findings.⁷⁵
- The **JBI checklist for qualitative research** should be used for the critical appraisal of primary qualitative studies (studies involving interviews, focus groups, online research forums and other techniques of primary data collection). <https://jbi-global-wiki.refined.site/space/MANUAL/355860482/3.+Systematic+reviews+of+qualitative+evidence>
- For researchers less familiar with key terms and concepts in qualitative research, apart from this report, the following resources can be of interest:
 - The QRT Library https://www.zotero.org/groups/6199442/kce_qrt
 - The Sage Encyclopaedia of Qualitative Research Methods (online): <https://methods.sagepub.com/ency/edvol/sage-encyc-qualitative-research-methods/toc>

8.3.2 Appraisal tools for Delphi processes

The above-mentioned checklists can be applied to a wide range of qualitative methods. Delphi studies, however, do not fall under the “traditional” appraisal tools because of their design. Two checklists for appraising the quality of Delphi studies were found: the DELPHISTAR⁷⁶ and the Delphi Critical Appraisal Tool (DCAT).⁷⁷ DELPHISTAR does not use a scoring system: it consists of a checklist where the reviewers need to assess whether the item is included in the report. It was not further considered for use at KCE.

► *Go to Chapter 17 Delphi process to know more about this technique.*

Developed by RAND, DCAT can be used to assess existing Delphi studies and as a validation to ensure the quality of the process and the reporting of a Delphi study.⁷⁷ DCAT consists of 16 items, organised in 4 core items and 12 additional items. The 4 core items concern the key characteristics of a Delphi process: 1) the anonymity of the data collection and of the reporting; 2) the iteration of the process; 3)

^h The EQUATOR (Enhancing the QUALity and Transparency Of health Research) Network is an international initiative that seeks to improve the reliability and value of published health research literature by promoting transparent and accurate reporting and wider use of robust reporting guideline. <https://www.equator-network.org/>



the controlled feedback to the participants; and 4) the statistical summary of the results. According to RAND, these 4 characteristics are critical to a Delphi process, although their implementation may vary according to the type of Delphi used. RAND then advised the researchers to adapt their assessment of the item according to the Delphi.

For each item, there are 3 possibilities for responding:

- Yes – the Delphi process complies with the standards.
- No – the Delphi process does not comply with the standards.
- Unsure – there is not enough information to accurately assess the standards.

To date, no appraisal tools for nominal groups have been identified.

At KCE

- The Delphi Critical Appraisal Tool (DCAT) should be used to assess the quality of Delphi studies.

Resources

The full version of the Delphi Critical Appraisal Tool (DCAT) developed by Khodyakov et. is available on the website of RAND via the following URL: <https://www.rand.org/pubs/tools/TLA3082-1.html>

9. REFLEXIVITY IN QUALITATIVE HEALTH RESEARCH

This chapter further develops the concept of **reflexivity** in qualitative research, a key dimension of the validity of qualitative research, but also of the **posture of the qualitative researcher** (see Chapter 8).

9.1 What is reflexivity?

Bloor and Wood define reflexivity as "*an awareness of the self in the situation of action and of the role of the self in constructing that situation*" (retrieved from Bloor and Wood, 2009, page 145).⁵⁹ Reflexivity is one of the **validity criteria** of qualitative research and can be found in various quality assessment grids for qualitative research, including the appraisal tool for qualitative research of the JBI recommended for the analysis of literature reviews at KCE (see Chapter 8).

Reflexivity cannot be taken for granted; it must be worked on and nurtured throughout a research career. It involves **taking a step back from oneself and one's research subject and being aware of the role that the researcher's identity can play in the research process, from conception to completion**. Reflexivity requires taking a critical approach to one's own work. In doing so, researchers contribute to the validity and trustworthiness of their research. Explaining one's 'commitment' as a researcher in relation to the subject of the research enables readers to better appreciate the choices made and the interpretation of the data. However, researchers can experience it as frightening, abstract, and even intrusive.²¹ It is therefore important to find the right balance between somewhat 'empty' statements which do not make the role of the researcher explicit (e.g. "as a healthy man in my forties, I am aware of the influence of my posture when interviewing women about endometriosis") and very personal details of researcher's own story (e.g. "I was walking in the hall of the hospital pre-occupied by the questions I wanted to ask to the participant, when I saw a girl in a wheelchair that made me think of my grandmother who had polyarthritis and was also in a wheelchair").^{21, 59}

9.2 Working on one's reflexive posture as a researcher: what does this imply?

Firstly, researchers must **be aware of their biases**, whether these are favourable or unfavourable to the object of their research.

Theoretical example: the researcher is a medical doctor and has, prior to his KCE work, had personal clinical experience which involved collaborating with specialist doctors. These specialist doctors did not take the patients' opinion into consideration. The researcher has internalised a bias, even a stereotype, that medical specialists are unwilling to take patients' opinions into consideration when deciding on treatments.

Secondly, researchers must **be aware of their values** and the impact these may have on the study.

Theoretical example: the researcher has a strong commitment to society outside KCE, advocating solidarity with disadvantaged groups. When working on a project on access to health for disadvantaged groups, unconsciously, the researcher tends to attribute more "value" to the discourses of the disadvantaged people than to the discourses of professionals.

Thirdly, researchers must be aware that **life and professional experiences** can influence their relationship with the object of study.

Theoretical example: a researcher has lost a family member due to disease X and is working on the needs of patients with disease X. The researcher recognises the experiences and problems reported to him during the interviews by the participants in the study.

Theoretical example: when interpreting data, a researcher with experience as a carer may not be surprised by what patients say because it resonates with her own experience, unlike someone who is not familiar with the care environment. Similarly, a young researcher may be surprised by certain results that an experienced researcher has already encountered more than once before.

Finally, researchers must be aware that **their personal characteristics** (age, gender, ethnic origin, profession) can influence the course of the research (see section 12.5.4).

Theoretical examples: a male researcher may not get the same answers as a female researcher when interviewing women about endometriosis. Novice researchers do not have the same relationship with their interviewees as experienced researchers. A researcher trained as a health professional will not interact in the same way as a researcher with a background in social sciences. A physician moderating a discussion group with nurses will not have the same relationship with the group as a nurse moderating a group of nurses.

It should be noted that not all biases and assumptions are conscious.²¹ Good practices can therefore help researchers to find a proper approach to reflexivity.

9.3 How to feed the reflexive posture?

Green and Thorogood suggested four strategies for developing a reflexive awareness in qualitative health research:²¹

- **Methodological openness**, where the researchers are explicit about the data collection, the analytic process, the how and why of methodological decisions and the alternatives that were not considered as part of the project. For example, it may be explaining why were interviews conducted with representatives of patients rather than patients themselves.²¹ This is also a plea to avoid replicating the same methodological approach in every project because the research team feels comfortable with these methods. Researchers are invited to "take risks" and "think outside the box" when developing their methodology.
- **Theoretical openness**, implying that the researchers address the "*theoretical starting points and assumptions*," including how these shaped the research project. For example, in a study on access



to healthcare, the research team decided to use the Andersen healthcare utilisation model as theoretical background, which shaped the interview guide and the framework for analysis.³²

- **Awareness of the social setting of the research itself**, where the researchers show their awareness of the fact that their data result from the interactions between them and their participants, and of the way these interactions shape the data. For example, having a medical doctor conducting interviews with chronic patients may induce questions or reactions of the participants like the interactions happening in a consultation. On the contrary, having a sociologist doing the same interviews will lead to a different dynamic.
- **Awareness of the wider social context**, where researchers may consider how the sociopolitical context supports (or constrains) the research and then shapes the data, also considering the wider historical and political context. For example, KCE project 327 on nursing consultations took place in the context of an overall shortage of nursing staff. The project did not aim to solve this problem, but it was nonetheless necessary to consider this factor when discussing the findings of the interviews with stakeholders.⁷⁸

As part of the reflexive posture, researchers are also invited to develop an ethical conscience (see Chapter 7). An ethical conscience is strongly related to reflexivity, as it requires the researchers to take distance from their research. Opportunities to discuss ethical issues with colleagues need to be preserved.

[...] Strong ethical practice in qualitative research means both anticipating and responding to ethical dilemmas, making decisions that are responsive to the needs of participants on a study-by-study basis. Doing so means having time to think through decisions, to reflect on ethical practice, to discuss with others including participants, to think about how lessons learnt from one study can be used effectively in the future, and above all to try to put yourself into a participant's shoes and consider possible options from all perspectives. This is how an ethical conscience is developed.

Reflecting on our ethical practice also means having the confidence to discuss dilemmas and uncertainties with colleagues, peers, and supervisors, and to seek out challenges and alternative perspectives. [...] (retrieved from Webster et al., 2014, page 109).⁴⁶

9.4 Which tools can be used to enhance reflexivity?

- **Research diary** – A (research) diary aims to “[examine] one’s own conceptual lens, explicit and implicit assumptions, preconceptions and values, and how these affect research decisions in all phases of qualitative studies” (retrieved from Korstjens and Moser, 2017, page 121).⁷⁹ It may include personal reflections, which will never be shared with colleagues (like the personal diaries where authors voice their experiences, feelings, and other personal thoughts). It goes beyond the “field diary,” which tends to focus on the data collection phase. Some researchers have a single research diary covering all projects, allowing them to make connections between different projects, while others prefer having a research diary per project. For some research methods (e.g. observation), the research diary is an essential component.⁸⁰ The format and the organisation of the research diary is left at the appreciation of the researchers, as it needs to match their needs.⁸¹
- **Systematic debriefing** of each data collection activity with a colleague / with the research team. “Debriefings are a discrete moment in the qualitative data collection process where a research manager sits with a data collector (or data collection team) to discuss the tenor, flow and resulting findings from a recently undertaken data collection activity” (retrieved from McMahon and Winch,

2018).⁸² Systematic debriefing also plays a role in ensuring the emotional and psychological safety of the researchers collecting the data. It can be helped by a template.ⁱ

- **KCE Living document** (template available in the KCE Project Guide), where the team can keep track of their decision-making regarding methodology and theoretical background, hereby contributing to document the methodological and theoretical openness (this applies to all decisions made during the project, related or not to QRM). Some authors advise to have an “audit trail”, defined as “*a thorough collection of documentation regarding all aspects of the research*” (retrieved from Given, 2008, page 44).⁸³
- **Sharing experiences during the meetings of the Qualitative Research Team:** this also gives opportunities to discuss ethical concerns emerging during the research project. It differs from the systematic debriefing, as it is done with researchers external to the project, providing a distinct perspective on the project. It also provides a “qualitative-oriented” perspective.
- **Lifelong learning** in qualitative research methods (e.g. attending training, conferences, or workshop).
- **Dedicated reading moments** to discover / deepen relevant conceptual models and theories in key areas of KCE.

Resource

Template for a debriefing is available on the KCE Extranet:
<https://extranet.kce.be/index.php/s/TPQAWKGWMG3nHf>

9.5 When to think about reflexivity?

Ideally, reflexivity is a **continuous process**, but the following key moments in the research project are particularly suitable for prompting this questioning.

- **When choosing a method:** avoid using a method just because that it is the way it always has been done, think carefully about matching the method to the research questions. What worked with one target group may not work with another.
- **When choosing the researchers** who will conduct the fieldwork/moderate a focus group/contact the potential participants.
- **After a data collection activity.**
- **When analysing and interpreting the data.**
- **At the end of the project.**

Discussions and decisions need to be **carefully documented** (e.g. in the living document), as these will be further reported in the final report (e.g. when presenting the methods or when discussing the findings and limitations of the research). There are no universal rules for accounting for reflexivity, but the absence of rules should not prevent researchers from doing it (see Chapter 22 Qualitative Data Reporting).

ⁱ See, for example, the template of K. Scott: <https://gh.bmj.com/content/bmjgh/3/5/e000837/DC2/embed/inline-supplementary-material-2.pdf>



◆ PART 2 – QUALITATIVE RESEARCH METHODS BASED ON EXISTING DATA

This second part explores two different methodological approaches based on existing qualitative data: **literature reviews of qualitative studies** (Chapter 10) and **use of data available online** (Chapter 11).

This part does not concern the secondary analysis of qualitative data. Secondary analysis is defined as “*involving the use of data collected in prior research to pursue some new direction or answer new research questions and is thus differentiated from meta-analysis or systematic review*” (Carmichael, 2017, page 510).⁸⁴ This aspect is briefly discussed in section 5.4.

10. LITERATURE REVIEWS OF QUALITATIVE EVIDENCE

This section focuses on the specific aspects related to the management of qualitative research evidence in the context of a literature review.

- ▶ *For KCE guidance on literature reviews, please refer to the KCE Process Note on Literature Review.⁸⁵*
- ▶ *For the assessment of the quality of qualitative research papers, see Chapter 8.*

10.1 Is a specific research protocol needed?

Yes, despite commonalities with a protocol for reviewing quantitative evidence, there are also specificities to exploring qualitative literature such as the research question, the search strategy, the data extraction, and the analysis. These aspects are detailed in the sections below.

Examples of research protocols for literature reviews of qualitative evidence can be found on the PROSPERO database (using keywords such as qualitative synthesis, qualitative, meta-synthesis...).

At KCE

- Ask support to the KCE information specialist or the knowledge manager for the validation of your literature review protocol.
- Check PROSPERO for any ongoing literature review that can be of interest and do not hesitate to contact the authors for collaboration.
- Register the protocol for the qualitative literature review on PROSPERO: this is not an obligation, but it is recommended

Resources

A template for drafting a protocol for a literature review of qualitative evidence is available on the KCE Extranet: <https://extranet.kce.be/index.php/s/TPQAWKGMG3nHf7>

For detailed guidance on research protocols for literature reviews of qualitative evidence, please refer to:

Johanna Briggs Institute manual:

<https://jbi-global-wiki.refined.site/space/MANUAL/355860482/3.+Systematic+reviews+of+qualitative+evidence>

Cochrane Training guidance: <https://training.cochrane.org/handbook/current/chapter-21>

10.2 Why and when to conduct a literature review of qualitative evidence?

Referring to the work of Stern, Jordan, and McArthur, Butler et al. state that qualitative literature reviews “aim to present a comprehensive understanding of participant experiences and perceptions rather than assess the effectiveness of an intervention” (retrieved from Butler et al., 2016, page 241).⁴⁴ Based on this general objective, several reasons emerge for consulting the qualitative research literature (non-exhaustive list):

- To assess whether qualitative evidence about the topic under investigation is already available (in this case, a rapid search with a higher or lesser degree of rigor might be sufficient to obtain the required information).

Example: responding to a project call (this is less likely to occur in the context of KCE)

- To prepare for primary data collection (e.g. getting inspiration for questions, methodologies, outcomes, or target sample)

Example: Walcott et al. developed a protocol for a systematic review and narrative synthesis of studies using community-centred qualitative methods, participatory action research and creative methods in research with marginalised and underrepresented communities.⁸⁶ This review is organised around 8 objectives, all aiming to develop a framework for inclusive, community-led research, ensuring practical applicability of data.

- To prepare for the analysis of qualitative data

Example: Ambrosio et al. conducted a meta-synthesis of qualitative studies to investigate patients' experiences of living with a chronic illness.⁸⁷ This meta-synthesis reviewed qualitative studies on chronic illness experiences and identified key themes such as identity transformation, emotional adaptation, and self-management. These themes were used to inform coding frameworks in subsequent qualitative research.

- To get different perspectives on a defined topic

Theoretical example: research on patient and public perspectives on genetics.

- To gather data for answering a qualitative research question

Theoretical example: to understand barriers and facilitators related to the use of a specific service / product, to gather experiential data from patients or professionals regarding a health(care) topic, to understand attitudes, behaviours, motivations... of patients, professionals, or caregivers.

When integrated in a systematic review alongside quantitative evidence, Dixon-Woods et al. suggested the following roles for qualitative evidence:

- “Identify and refine the question of the review,
- Identify the relevant outcomes of interest,
- Identify the relevant types of participants and interventions,
- Augment the data to be included in a quantitative synthesis,
- Provide data for a non-numerical synthesis of research,
- Highlight inadequacies in the methods used in the quantitative studies,
- Explain the findings of a quantitative synthesis,
- Assist in the interpretation of the significance and applicability of the review.
- Assist in making recommendations to practitioners and planners about implementing the conclusions of the review” (retrieved from Dixon-Woods et al., 2001, page 126).⁸⁸



At KCE

- A rapid literature review – in the scoping phase – could help to identify the need for primary data collection, implying that the analysis needs to assess the degree of adaptability of the data to the Belgian context.
- In the context of rapid qualitative research, a literature review could be preferred over a primary data collection when the delays for obtaining ethical approval or collecting data in the field are perceived as too long.
- Literature reviews of qualitative data, particularly of patient perspectives, could be of interest as part of GCP and HTA projects to better integrate patient experiences and potential patient issues.

10.3 How to choose between a mapping, a scoping, or a systematic literature review?

This section specifically highlights **scoping and mapping reviews** as these two approaches to literature allow for the integration of various sources of evidence, including grey literature, various QRM (e.g. individual interviews and focus-groups), different theoretical approaches to QRM (e.g. grounded theory and phenomenology) and even qualitative, mixed and quantitative research methods. Systematic reviews are better adapted when a single type of studies is selected (e.g. qualitative studies based on interviews with a thematic analysis). Systematic literature reviews are detailed in the KCE Process Note on literature reviews and international comparisons.

As for literature reviews of quantitative evidence, the reasons for opting for a scoping review, a mapping review or a systematic literature review of qualitative evidence depends on the research questions.

Scoping reviews are defined as “a type of evidence synthesis that aims to systematically identify and map the breadth of evidence available on a particular topic, field, concept, or issue, often irrespective of source (i.e., primary research, reviews, non-empirical evidence) within or across particular contexts” (retrieved from Campbell et al., 2023, page 47).⁸⁹ It aims to **clarify concepts or definitions** as well as the characteristics and aspects related to these concepts and definitions, including attention to methodologies.⁹⁰ Scoping reviews allow for a great diversity of data to be included in the review: qualitative and quantitative, scientific, and grey. It can address, for example, research questions such as “what is decontamination.”

Example: *Cognitive behavioural therapies for individuals with cerebral palsy: A scoping review.* This scoping review describes the current evidence about cognitive behavioural therapies in children with cerebral palsy. It describes key themes such as study population, intervention (including cognitive and behavioural characteristics of the intervention), barriers and facilitators.⁹¹

Example: *Supported-standing interventions for children and young adults with non-ambulant cerebral palsy: A scoping review.* This scoping review describes all evidence in the literature including qualitative and quantitative studies, reviews, guidelines, and cross-sectional studies to address the complexity of the recommendations for the supported standing interventions in children with cerebral palsy. They highlight evidence from systematic reviews appraising quality of evidence, which they cross-reference with participants’ lived experiences and clinical guidelines to provide a more comprehensive view of clinical implementation and the gaps remaining to be addressed.⁹²

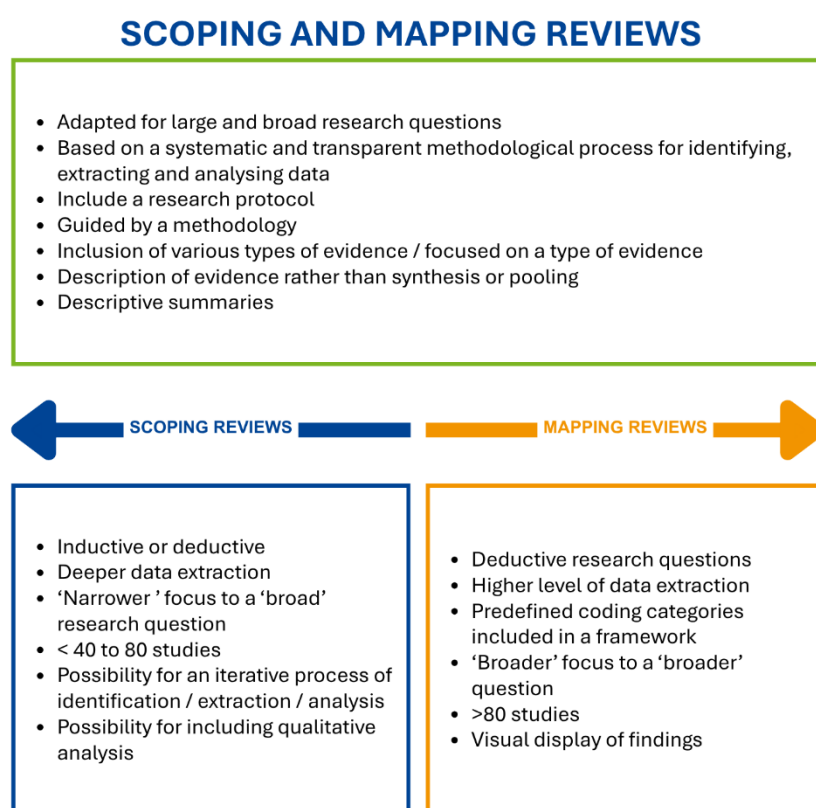
Mapping reviews aim to “**collate, describe, and catalogue the available evidence relating to the question of interest**” (retrieved from James et al., 2016, page 6).⁹³ It consists in a “**systematic presentation of all relevant evidence of a specified kind for a particular sector, sub-sector, or geography**” (retrieved from Campbell et al., 2023, page 5).⁸⁹ A mapping review will answer questions like “what do we know about this topic,” or “what research exists on a particular area, and where”.⁸⁹ It can also be used to identify **evidence gaps**. Mapping reviews are mostly descriptive. They are a form of systematic evidence synthesis product in which the evidence related to a research question is presented via a

visual and interactive output.⁸⁹ It can address, for example, research questions such as “What are the alternatives to hospitalisation?”

Example: A mapping review on the needs of children was performed to adapt the adult NEED framework to the paediatric population.^{6, 94} The review was based on qualitative studies, quantitative studies, and reviews. Using the NEED Adult framework, the retrieved data were mapped onto existing indicators and criteria. When data did not correspond to any predefined elements, new criteria or indicators were developed to accommodate them. A categorical rule was established to guide the analysis, resulting in a preliminary proposal for a paediatric NEED framework. This framework follows the adult NEED hierarchical structure: dimension → criterion → indicator → measure. The structure and content of the framework were evaluated through multiple internal discussions, supported by visual tools such as figures and mapping to facilitate dialogue. A pre-final version of the paediatric framework was then submitted to a panel of experts for content validation (*work in progress – contact KCE to know more*).

Figure 2 presents the commonalities and differences between scoping reviews and mappings reviews.

Figure 2 – Commonalities and differences between scoping reviews and mappings reviews



Retrieved and adapted from Campbell et al., 2023⁸⁹

Table 8 compares mapping and scoping reviews regarding five of their key characteristics, including their usefulness in the context of KCE.



Table 8 – Comparison between mapping and scoping reviews

	Mapping reviews	Scoping reviews
<i>Main objective</i>	Aims to describe	Aims to describe and analyse
<i>Added value</i>	Help to prioritise the research questions / the area of research / the scope. Help to give a broad view of the context	Help to further scope an already focused research question
<i>Type of topics</i>	Adapted when the issue is developed by different disciplines (e.g. forensic youth psychiatric at the intersection of justice, psychiatry, and child welfare), for issues with an environmental exposure (e.g. chemical pollution) or a “one health” dimension (e.g. climate change where humans, animals and environment are impacted)	Adapted for exploring and clarifying concepts (e.g. self-care) / interventions (e.g. case management) / services (e.g. hospital at home)
<i>Place in the research process</i>	Can prelude another data collection (scoping reviews, interviews, quantitative online survey) / help to justify the need for a systematic review / help to explain the heterogeneity of results of a systematic literature review	Can be a stand-alone research activity
<i>Usefulness at KCE</i>	When collaborating with stakeholders from different disciplines or with diverse backgrounds and interests (e.g. patient associations), first step in describing the context and guiding subsequent data collection (e.g. as a first stage of a Delphi process)	When evaluating an intervention / a service / a program When there is a need to clarify a concept

When opting for a **systematic review**, the choice between a review of reviews (also called umbrella reviews) and a review of original studies is influenced by various factors: the time available for performing the review and the number of reviews available, the applicability of the reviews, their recency, their methodological quality, the number of papers included, the availability of the meta-reviews.⁸⁵

At KCE

- Most of the literature reviews of qualitative and quantitative evidence are umbrella reviews (review of reviews), particularly in HSR projects, due to time constraints.
- Review of primary qualitative studies will be conducted when there is no review of qualitative evidence available.

10.4 Is a specific search strategy needed for exploring qualitative evidence in literature?

Yes, literature reviews of qualitative evidence require a specific research question and, consequently, a different search strategy.

Table 9 presents different frameworks to develop a suitable research question for searching for qualitative evidence. A key dimension of each framework is **the context / perspective** that needs to be investigated. The research question, the topic of the review and its aims will influence the choice of the framework, which should be decided by the research team.

Table 9 – Frameworks for developing a research question for the review of qualitative evidence

	Dimensions	Strengths	Weaknesses	Examples of research questions and dimensions
PEO⁴⁴	Population Exposure Outcomes	Similar to PICO More adapted to clinical / epidemiological questions	Risk of having too many quantitative studies	<i>How do pregnant women perceive their risk of exposure to PFAS?</i> Pregnant women Exposure to PFAS Perceptions
Perspective⁹⁵	Perspective Setting Phenomenon of interest/problem Environment (optional) Comparison) Time/timing Findings	Useful to investigate complexity	May be difficult to operationalise	<i>Why do informal carers refuse respite care when caring for a dying relative at home?</i> Informal carers Home Respite care Caring for a dying person End-of-life Refusal of care
PICo^{44j}	Population Interest Context	More adapted to clinical questions	Risk of having too many quantitative studies	<i>Why do chronic pain patients refuse multimodal treatments in a hospital setting?</i> Chronic pain patients Multimodal treatment Hospitals
SPICE⁹⁰	Setting Perspective Interest, Phenomenon of	Promoted by JBI Useful for outcomes of a	May be less adapted to non-	<i>How do pregnant youths perceive the</i>

^j PICo is a variation of the PICO which stands for Population / Intervention / Comparison / Outcomes.



	Comparison Evaluation	service / project / intervention	interventional studies	<i>home visits of childcare services?</i> Home Pregnant youths Childcare services No comparison Perceptions
SPIDER⁹⁶	Sample, Phenomenon of Interest, Design, Evaluation, Research type	Applicable to qualitative and mixed methods search	May be difficult to operationalise. Requires good knowledge about different methods	<i>How do social workers experience barriers to urgent medical care for undocumented migrants?</i> Social workers Barriers to care Focus groups / interviews / observations / case studies Experiences Qualitative research

At KCE

- Once the research team agrees on the specific qualitative research question, the researcher can prepare the search strategy and ask the information specialist for validation.

10.5 Are there specific databases for qualitative research?

No, there are no dedicated databases for qualitative research.

Existing databases contain qualitative studies, with some databases containing more literature or having more sensitivity to identify such studies.

Table 10 presents an overview of databases and search engines that can be used for qualitative literature searches. Databases are distinguished according to their level of priority. **Essential databases are databases which offer the large coverage of literature and include a structured indexing system with an uniformised lexicon.** They are usually recommended by expertise centres promoting evidence-based decisions such as JBI or the Cochrane Collaboration. Essential databases are MedLine, Embase, CINAHL and ProQuest, which constitute the basis for identifying systematic literature reviews of qualitative evidence in biomedical and health sciences.

If the essential databases generate insufficient results or if there is a need for grey literature, Scopus, Web of Science, Sociological Abstracts, PsycINFO or BASE are examples of **complementary databases** that could help to complete the search. These databases usually have a more limited coverage of the literature, and not all these databases include a structured indexation system or a thesaurus. They are therefore useful as they provide various sources of data.

If the literature search encompasses **grey literature**, it is recommended to favour ProQuest, BASE, and Trip Database. OpenGrey is no longer supported (no references have been added since 2021) but the interface still exists. The content up to 2020 is still available and remains a useful source of grey literature.



Table 10 – Selection of databases according to the availability of qualitative literature

Database / search engine	Type	Level of priority	Main discipline	Relevance for qualitative research	Language of the interface / Filters available	Type of access to the database	Recommended by	Comments / recommendations	Access link
PubMed / MEDLINE*	Academic	Essential	Medicine, biomedical sciences	High	English / Yes	Open access	PRISMA, Cochrane	Methodological filters, MESH useful for qualitative studies	https://pubmed.ncbi.nlm.nih.gov/
Ovid/ MEDLINE* ¹	Academic	Essential	Medicine, biomedical sciences	High	English / Yes	Institutional access / paying	PRISMA, Cochrane	Methodological filters, MESH useful for qualitative studies	https://www.wolterskluwer.com/en/solutions/ovid/ovid-medline-901
Embase (Elsevier)*	Academic	Essential	Biomedicine, pharmacology	Very high	Multilingual / Yes	Institutional access / paying	PRISMA, JBI	Good coverage of EU literature, Rich EmTree terms	https://www.embase.com/
CINAHL (EBSCO)*	Academic	Essential	Nursing, public health	Very high	Multilingual / Yes	Institutional access / paying	EBI, PRISMA	Abundant corpus of qualitative studies, nursing care	https://www.ebsco.com/products/research-databases/cinahl-database
PsycINFO (APA)*	Academic	Complementary	Psychology, mental health	High	English / Yes	Institutional access	PRISMA	Relevant for mental health and behavioural studies	https://www.apa.org/pubs/databases/psycinfo
Scopus*	Academic	Complementary	Multidisciplinary	Medium to high	Multilingual / Yes	Institutional access / paying ³	PRISMA	Good coverage, useful for citation tracking	https://www.scopus.com/
Web of Science*	Academic	Complementary	Multidisciplinary	Medium	Multilingual / Yes	Institutional access	PRISMA	Bibliometric analysis, large coverage	https://www.webofscience.com/
ProQuest D&T Global	Academic	Essential	PhD theses, master theses	High	English / Yes	Institutional access	PRISMA	Search key for theses and grey literature	ProQuest Dissertations & Theses Global
BASE*	Non-academic	Complementary	Multidisciplinary	Medium	Multilingual / Yes	Open access	PRISMA (non-standardised)	Reports, institutional publications	https://www.base-search.net/



OpenGrey ^{*4}	Non-academic	Complementary	Grey literature	Medium	Multilingual / Yes	Open access	-	European database, no longer sustained	http://www.opengrey.eu/
Trip Database ^{*2}	Non-academic	Essential	Evidence-based medicine	Medium to high	English / Yes	Partial open access	PRISMA	Recommendations, systematic reviews	https://www.tripdatabase.com/
Epistemonikos [*]	Academic	Complementary	Evidence-based medicine	Medium to high	Multilingual / Yes	Open access	PRISMA	Visual relationships between studies	https://www.epistemonikos.org/
ERIC [*]	Academic	Complementary	Health education, public health	Medium	English / Yes	Open access	JBI		https://eric.ed.gov/
Health Systems Evidence [*]	Academic	Complementary	Health policies	Medium	English / Yes	Open access	PRISMA		https://www.healthsystemsevidence.org/
Sociological abstracts [*]	Academic	Complementary	Sociology, social sciences	High	Multilingual / Yes	Institutional access / paying	PRISMA	Useful for sociological perspectives and social determinants of health	https://www.proquest.com/sociologicalabstracts/

^{*} Available at KCE (institutional account either via VDIC or via CEBAM CDHL)

¹The content is the same as PubMed / MEDLINE, but with a different user interface for consulting the database.

²An open access version is available: a professional access is possible based on an individual annual subscription. Contact the KCE library manager for more information.

³A free but limited interface is available (limited search engine with a consultation of basic information)

⁴OpenGrey is no longer supported since 2021: sources indexed up to 2021 remain therefore available.

10.6 Are there databases including French or Dutch literature?

An important concern in qualitative research is having access to scientific and / or grey literature in the language of the data collection.

Even if the translation is of an extremely high quality, the mere fact of translating can affect the nuances and variations of the primary data. Some expressions and words have no equivalent in another language. Depending on the research question and objectives, it is therefore important to be able to access the source data in its original language.

To our knowledge, **there is no specific database for Dutch grey or scientific literature.**

Regarding the literature published in French, Table 11 presents an overview of various databases where French literature can be found.

In the other databases, using **language filters** remains the most appropriate strategy to access literature in French or Dutch.

In practice

- **Belgian universities and other institutions for higher education** are expected to follow an Open Science Policy: scientific reports, datasets and other relevant sources of information can be found via the institutional repositories.
- **Specialised documentation centres** exist across Belgium that give access to professional and grey literature on various topics. For example, ResoDoc (UCLouvain) and SIPES (ULiège) are specialised in health promotion, patient (health) education and other public health topics.
- **Federations or non-profit organisations** have their own documentation repositories, like e.g. the *Vlaams Expertisepunt Mantelzorg*, the *Fédération Wallonne des Soins Palliatifs*, or the PAQS.
- In the Brussels region, *Bruxelles-Social / Sociaal Brussel* has a documentation centre, including a repository and an interactive mapping of health and social services that could serve as additional information source. The *Kenniscentrum Welzijn, Wonen, Zorg* in combination with the *Vlaamse Sociale Kaart* offers the same service for the Flemish region.



Table 11 – Selection of databases according to the availability of non-English literature

Database or search engine	Type	Level of priority	Main discipline	Relevance for qualitative research	Language of the interface / Filters available	Access type	Recommended by	Comments / recommendations	Access link
Érudit	Academic	Essential	Human and social sciences	High	French interface, language filters	Open access	Not specified	Good coverage of French publications	Érudit
Cairn.info	Academic	Essential	Human and social sciences	High	French interface, language filters	Open access	Not specified	Good coverage of French publications Index of some nursing / public health journals	Cairn.info
Google Scholar	Search engine	Essential	Multidisciplinary	Medium	Multilingual interface language filters	Open access	Not specified	OK for a preliminary large search	Google Scholar
MEDLINE (via PubMed)	Academic	Complementary	Medicine, biomedical	Medium	English interface, language filters	Open access	PRISMA, Cochrane	Particularly useful for systematic reviews	PubMed
Santécom	Academic	Complementary	Public health	Medium	French interface, language filters	Open access	Not specified	Catalogue of publications of more than 50 Quebec organisations	Santécom
Medicus Quebecensis	Academic	Complementary	Medicine	Medium	French interface, language filters	Open access	Not specified	References of papers published by Quebec authors	Medicus Quebecensis

10.7 Are there specific filters when retrieving qualitative evidence?

While there are MeSH terms covering for qualitative methods, qualitative research is **poorly indexed** in existing databases. It is advised to search in title and abstract to capture qualitative research, with specific attention to the methods section to identify the proper design. Consequently, a **hand search** of the literature is often required. Nevertheless, there are filters on the methods that could be applied.

CINAHL and Embase are considered as the two most performant databases to specifically identify qualitative studies: <https://guides.bium.ch/recherche-structuree/filtres#6.%20rs%20quali>.

Table 12 lists three websites where search filters for qualitative literature reviews can be found.

Table 12 – Repository of filters

- [ISSG Search Filter Resource](#)
Repository developed by the InterTASC Information Specialists' Sub-Group.
Contains published and non-published research filters.
- [Search Filters for Various Databases \(University of Texas School of Public Health\)](#)
Filters developed by the Library & Graduate Communication Centre at UTHealth Houston School of Public Health.
Includes advice on how to choose filters and their validation.
- [CADTH Search Filters Database / ACMTS Base de données de filtres de recherche](#)
Repository of filters developed by the Canadian Drug and Health Technology Agency (CADTH)

Table 13 presents examples of **keywords** that the researchers could use in combination with the search equation for locating systematic reviews of qualitative evidence in PubMed and CINAHL.

Table 13 – Example of keywords for searching systematic qualitative reviews

PubMed	CINAHL
(your search equation) AND ((systematic[<i>sb</i>] AND (qualitative[<i>ti</i>] OR mixed-method*[<i>ti</i>])) OR meta-synthesis[<i>ti</i>])	(your search equation) AND ((PT Systematic review AND TI (qualitative OR mixed-method*)) OR PT Meta Synthesis)

10.8 How to manage data extraction?

Before starting data extraction, there must be an agreement on whether data are “*first order constructs i.e. participants’ quotes or second order constructs (researcher interpretations, statements, assumptions, and ideas)*” (retrieved from Butler et al. 2016, page 245).⁴⁴ Butler et al. therefore advise to extract both forms of data, as this will help the researchers to work with both **raw data** (i.e. the quotes) and the **interpretations made by the authors** of the original research and ensuring that the results of the review are “*thoroughly grounded in the original experience of the participants*” (retrieved from Butler et al. 2016, page 246).⁴⁴

At KCE

- It is recommended to follow the **JB1 guidance** for the data extraction, as this guidance is regularly updated and is congruent with the choice of the JBI checklists as critical appraisal tools:
- **Covidence** can be used for study selection and data extraction.
- **Literature analysis can rely on various approaches:** at KCE, literature is usually analysed via a thematic approach or a framework analysis (see Chapter 20). Depending on the research question, the same analytical strategy could be applied to the whole corpus (e.g. using the same framework to analyse interviews and literature).



- The software **Nvivo** can be used to extract and analyse data in a literature review (whatever the analytical approach chosen):
https://www.youtube.com/watch?v=U0YxxjdDC0I&ab_channel=NVivo
- Literature reviews mostly remain at a descriptive level, implying that a **synthesis** of the qualitative literature can be an appropriate format for the output (see section 10.9).
- **Evidence tables** should accompany this synthesis to ensure the transparency of the process. Evidence tables should reflect the analytical approach. For example, the section on findings in an evidence table could be drafted according to the thematic tree (emerging in thematic content analysis)⁹⁷ or according to the framework (in framework analysis).⁹⁸

Resources for qualitative literature reviews

JBI Guidance

<https://jbi-global-wiki.refined.site/space/MANUAL/355860482/3.+Systematic+reviews+of+qualitative+evidence>

10.9 Are there specific methods for synthesising the findings of a qualitative literature review?

Yes, different methods exist for presenting a synthesis of qualitative evidence. These methods are related to the underlying theoretical approach to qualitative data and the ways this data is analysed (see Chapters 20 and 21). There is no clear-cut answer to “what is the best way to do this synthesis.”

It is interesting to note that **findings from different qualitative approaches can be combined**, some considering “*the combining of data from multiple theoretical and methodological traditions a strength of the review*” (retrieved from Centre for Reviews and Dissemination, 2009, page 228).⁹⁹ For example, a literature review of qualitative evidence can combine findings of ethnographic studies with participatory approaches and grounded theory interviews.

Table 14 succinctly presents the different methods for the synthesis of qualitative evidence. Three methods aim to “quantify” qualitative findings: qualitative meta-summary, case survey and qualitative comparative analysis.

Table 14 – Overview of methods for synthesizing qualitative evidence

Synthesis method	Description
Thematic analysis / synthesis	See Chapters 19 and 21
Content analysis	See Chapters 19 and 21
Grounded theory	Also referred to as constant comparative method - see Chapter 20
Narrative synthesis	General framework and specific tools and techniques helping to increase transparency and trustworthiness, for both qualitative and quantitative data
Qualitative meta-synthesis	Set of techniques of interpretive integration of qualitative research findings
Meta-ethnography	Set of techniques for synthesising qualitative studies with the aim of creating new interpretations or concepts
Qualitative meta-summary	Set of techniques for the quantitative aggregation of qualitative research findings

Case survey	Formal process for coding data from qualitative cases into a quantitative form
Qualitative comparative analysis	Method for summarising and comparing data from case studies using Boolean logic

Retrieved and adapted from CRD, 2009, pages 228-229⁹⁹

10.10 Can qualitative findings be integrated in an effectiveness review?

Yes, if the research question of the qualitative literature search was planned to allow for it.

There are three possibilities:⁹⁹

- Findings of one (or more) qualitative study(ies) are used as part of the discussion of **quantitative studies to contribute to the interpretation and the contextualisation of the findings**. There is no separate synthesis of the qualitative findings. For an example, please refer to Thomas et al.¹⁰⁰
- Review of qualitative studies is done in parallel to the review of the quantitative studies: **the findings from the qualitative synthesis are used in the interpretation of the results of the quantitative review**. For an example, please refer to Noyes and Popay.¹⁰¹
- **Combination of both qualitative and quantitative evidence**: these approaches are called *multi-level, sequenced, cross-design or meta-syntheses*. For an example, please refer to Harden et al.¹⁰²

11. USE OF OPEN DATA IN QUALITATIVE RESEARCH

This chapter focuses on the use and analysis of open data, i.e. written and audiovisual data made available online by their owners. Open data refer to data made available to all and include data shared online, in a public way.

11.1 What are open qualitative data and how to find them?

The use of open data comes down to what Janetzko refers to as a “**non-reactive data collection**,” that is a data collection where “*people under investigation are usually not aware that they are being studied so that their behaviour is not affected by the data collection procedure*.” (retrieved from Janetzko, 2017, page 77).¹⁰³ Among other things, it entails the scraping of social media to look for information shared by participants.¹⁰³ Other forms could involve simple observations in a public space, archival records or the use of large datasets compiled by administrations for research purposes (note that the introduction of GDPR has modified the degree of awareness of people regarding the use of their data). However, this data is quantitative and therefore falls outside our scope.

In the context of this process note, open qualitative data encompasses 1) **written data** such as posts on blogs, forums, social platforms, groups of instant messaging technology and other online written documents such press articles, and 2) **audiovisual data** such as vlogs, podcasts, online videos shared on social platforms, documentaries, reportages and other audiovisual material.

This data can be **self-produced**, meaning individuals generate the content themselves, based on their perspectives, preferences, and motivations. This is typically the case for blogs and vlogs.

Data can also be **hetero produced**, for instance when a third party gathers data from individuals about a specific topic and arranges it in a chosen format. This can be the case for an audiovisual documentary where participants are selected by a director based on a set of criteria.

Blogs constitute one form of open data that can be of interest. Blogs offer “*spontaneous narratives produced in the course of everyday life unprovoked by a researcher*” (retrieved from Hookway and Snee, 2017, page 381).¹⁰⁴ Numerous scholars, cited by Hookway and Snee, consider blogs as “*contemporary document of life*”, reflecting the confessional society where people “*curate and reflect on upon their personal lives in the public realm*”, leading to a blurred frontier between private and public



spheres (retrieved from Hookway and Snee, 2017, pages 380-381).¹⁰⁴ When it comes to health-related issues, some authors of blogs will also provide health information, education, and prevention messages, based on scientific evidence or personal experience with a disease. Authors could be patients, relatives, informal and formal caregivers, or professionals. **Vlogs** (synonym: video blog or video log) are a form of blog where the messages are disseminated by means of videos, potentially combined with texts, images, pictures, and other data. Vlogs can be disseminated via online platforms such as YouTube, allowing the authors to share and interact with a large audience.

Examples: Gibson et al. used vlogs to analyse end-of-life narratives of patients diagnosed with a terminal illness.¹⁰⁵ Cook and O'Halloran consulted YouTube vlogs to study sexual violence based on the experiences of women rallying the #MeToo social movement.¹⁰⁶

Online forums differ from blogs in the sense that they offer a space for discussion and exchanges. They can be a component of a blog or a website, or independent platforms. Discussions in an online forum are stored to allow asynchronous discussions. Forums are classified according to the archiving system of the messages: discussion forums where messages are organised by chronological order and questions / answers forums where messages are grouped according to the number of votes allocated to the answers.¹⁰⁷ Discussions in a forum can start from different contributors, with overlapping interactions and no clear end of the exchange (as discussions are archived, an old discussion can be reactivated by simply adding a new comment).

Examples: Alzahrani et al. analysed the use of complementary and alternative medicine use in self-management of diabetes, based on the content of patient and user conversations in online forums while Mitchell et al. studied the use of cannabis among persons suffering from attention deficit / hyperactivity disorder.^{108, 109}

Instant messaging technology is a semi-public computer-mediated means of communication mimicking a “real-life” conversation, characterised by the synchronicity of the transmission of the messages between at least 2 individuals. It usually occurs between individuals who have a form of acquaintance (a username, a phone number or a screen name is required to initiate a session). Instant messaging can lead to the creation of discussion groups among individuals sharing a common interest.

Examples: WhatsApp groups have been recently pointed out as important diffusion channels of (mis)information (see, for example, Sharma et al. or Kemei et al. regarding the role of WhatsApp during the COVID pandemic).^{110, 111}

11.2 What are the strengths of using open qualitative data, and for what purposes?

Open data can be of interest during **the scoping phase** of a project, e.g. when the issue is not yet addressed by the scientific literature or when the public concerned is difficult to identify or to engage in a research project.

Example: In a blog-based study, Petty et al. searched for data from blogs to describe what a meaningful social connection, including the conditions contributing to well-being, means for adults with autism, and analysed via a thematic analysis.¹¹²

It can be used when **the research question specifically targets this kind of data**, using it to examine “*representations of wider social practices and everyday life*”.¹⁰⁴ An example would be a review of the information available to the public about a given health issue.

Examples: In a scoping review on mental health issues, Murphy et al. aimed to explore the experiences and perceptions of persons with mental health difficulties based on the content of blogs.¹¹³ In a mixed-methods study, Tamminga et al. evaluated qualitatively and quantitatively the digital social context of parenting blogs that shape parents' decisions about children's photoprotection to better understand sunscreen and photoprotection misinformation.¹¹⁴

The use of open data can also be a strategy to collect data on **hard-to-reach groups** or to avoid “bothering” participants who already shared their experience.

It can be used when data are needed within a **short timeframe** and asking for ethical approval for primary data collection would take too long. It helps to bypass the recruitment process as the data are already available. Also, as the data are not collected regarding a defined research question, this prevents a bias related to the research question and the data obtained are more comprehensive.

Examples: in KCE project on the prevention of the post-intensive care syndrome for general practitioners published during the COVID pandemic, testimonies of patients published online on blogs or in the online press were analysed.¹¹⁵ In KCE project 378 on the improvement on the endometriosis care in Belgium, conducting interviews with patients was impossible due to time constraints, while numerous testimonies (from Dutch speaking and French speaking) patients were already available. These were analysed after written approval of the patients' association that collected them.⁵

At KCE

- Use of open qualitative data could inform the scoping phase of a project.
- Use of open qualitative data could be used as part of a RQR when obtaining ethical approval risks to take too long.
- Use of open qualitative data can be considered as a data collection strategy, with clear reporting of the quality assessment and the limitations surrounding these data.

11.3 What are the weaknesses of using open qualitative data?

Open data are secondary data, which implies that the data themselves, the way they are collected and the way they are presented are **not determined by the researchers**. As these data are not collected in a scientific manner (unlike secondary data obtained through a search of the scientific literature), one should be cautious about the value attributed to them.

There is **no control on the sample**, as the researchers do not know how and why the participants joined the online platform where they share information. It will be unclear whether the sample reflects the diversity of the population, and whether the data reflect the different perspectives surrounding the topic. Online discussions tend to be polarised between extreme opinions. There is no information about the context, which could complicate the interpretation of the findings (and it will be difficult to contact participants to get more information). Regarding testimonies, unless this is disclosed on the online media, there is no indication about the questions that have been asked. On online platforms where a moderator is present, it is not always possible to know their role and posture. There is no guarantee that the moderator holds a neutral posture, nor any way of knowing whether he or she has a "hidden" agenda.

Searching for data online is particularly **time-consuming**, as there is no consensual format for the medium used and the quality of the data needs to be checked (including assessing the "reality" of the source – e.g. fake blogs or fake forums exist to bait people). A substantial number of sources may be needed to reach a relevant and diverse sample (Snee reviewed over 700 blogs to finally reach a sample size of 39 blogs included in her study).¹⁰⁴

The **nature of the data itself can be complex** to apprehend, as sources can combine written texts with pictures, videos, emojis, emoticons, or links to other sources. Besides, some codes for written texts do not apply in the same way online and offline (typically regarding the use of punctuation, which emerges as a source of misunderstandings between generations). These sources are also **dynamic**: new posts can be added to forums every day, resulting in additional information and constantly changing data.

Snee and Hookway also raised concerns about the homogeneity of the "blog population" regarding age, socioeconomic status, ethnocultural background and gender, and about the authenticity and trustworthiness of the blog data.¹⁰⁴ Homogeneity should not be seen as a barrier for using blogs as a data source, but rather as an attention point when analysing and discussing the results. Assessing authenticity and trustworthiness requires obtaining some background data about the authors of the posts but, even when this information is disclosed, there is no guarantee that these data are real (note,



however, that this is a potential issue with any form of data collection, as participants can lie). The need for truthfulness and authenticity must be weighed against the research objectives and the overall quest for quality in qualitative research. This calls for careful decision-making about the adequacy of these data sources for the research, and about whether additional sources are needed (e.g. interviews).¹⁰⁴

Finally, it will be important to provide a **detailed description** of the process used for selecting and obtaining the data. A copy of the data should be stored on a permanent server for the length of the legal period of conservation of the data. In case the data are no longer available online, this should allow for a clear identification of the original data.

At KCE

- *Contact the data privacy officer for the rules for the conservation of the data at KCE.*

11.4 How to access open qualitative data?

Open qualitative data are public, no further authorisation for use is required. As mentioned by Hookway and Snee, “*informed consent is required when researching human subjects, but this does not apply to public, published material*” (retrieved from Hookway and Snee, 2017, page 392).¹⁰⁴

However, attention should be paid to **copyright and licences** related to the content.

For some groups, forums, and instant messaging groups (e.g. a group of parents from a same school), a registration is needed to access the content. In this case, using data may be subjected to the prior authorisation of the moderators and / or the contributors. Similarly, ethical approval may be required when the data fulfils to the criteria for requiring such approval. This could be the case even more for forums or online groups where participants need to register and conform to a code of conduct.

Depending on the platform hosting these data, a search engine may help to locate the most appropriate sources. The use of # can help to locate posts based on keywords on social media.

When searching for blogs, Hookway and Snee recommend relying on “**searching and trawling**.”¹⁰⁴ Searching is based on the use of search engines to identify posts containing relevant keywords, while trawling consists of searching for bloggers sharing particular characteristics to find interesting posts. This strategy could be extended to other forms of open data.

11.5 How to evaluate the quality of open qualitative data?

Several checklists exist for evaluating the quality of open data such as the Fair Principles^k, the Open Data Maturity Report^l, the CRAAP Test (Currency, Relevance, Authority, Accuracy, and Purpose Test)^m and the Recommendations for reusing data published on the Internet of the French *Commission Nationale de l'Informatique et des Libertés* (CNIL).ⁿ Reda and Zellou (2023) also systematically reviewed the literature to develop an approach to assess the quality of social media content.¹¹⁶ RESTORE provides a guidance for the Assessment and Development of New Methods for the Analysis of Media Content^o

Based on these various checklists, we selected, with the assistance of AI, **dimensions for assessing the quality of the data available online in the context of KCE** (see section 3.2). Table 15 presents

^k FAIR Principles <https://www.go-fair.org/fair-principles/>

^l Open Data Maturity Report: https://data.europa.eu/sites/default/files/odm2024_full_report.pdf

^m CRAAP Test: <https://researchguides.ben.edu/source-evaluation>

ⁿ CNIL: https://www.cnil.fr/sites/cnil/files/2024-06/recommandations_reutilisateurs_donnees_publiees_sur_internet.pdf

^o RESTORE <https://www.restore.ac.uk/lboro/>



the essential criteria to be checked while Table 16 presents the complementary criteria. The notation legend is presented below each table.

Similar to the assessment of the quality of literature, the assessment of the quality of the online qualitative data is also guided by the research question and the research objectives. Researchers can also use the operational tool to inform their data extraction process.

Resources

The KCE operational tool for assessing the quality of online qualitative data is available on the KCE Extranet:

<https://extranet.kce.be/index.php/s/TPQAWKGWMG3nHf7>



Table 15 – Dimensions for assessing the quality of open qualitative data available online: essential criteria to be assessed

Criteria for assessment	Description of the criteria	Aim of criteria	Existing strategies for assessment	Applicable to	Score (0-5)
Reliability of the source	The source is identified, institutional or acknowledged.	Check authenticity and authority.	CRAAP Test, Trust Indicators ^p	Audiovisual and text	0-5
Traceability of the source	The source of the content is identifiable and indexed.	Ensure accountability for content.	Manual search, WHOIS	Audiovisual and text	0-5
Publication date	The publication date is clearly stated.	Assess the recentness of information.	Visual check	Audiovisual and text	0-5
Accessibility of the content	The content is openly accessible without technical or juridical barrier	Facilitate access for evaluation.	Critical analysis by researcher	Audiovisual and text	0-5
Stability of the URL	The link is sustainable and remains active over time.	Avoid the disappearance of sources.	Wayback Machine ^q , DOI, ISBN, ISSN	Audiovisual and text	0-5
Clarity of the content	The message is understandable, clearly articulated and without ambiguities.	Support correct interpretation.	Critical analysis by researcher	Audiovisual and text	0-5
Neutrality of the content	The content is factual, without excessive ideological orientation.	Preserve scientific objectivity.	CRAAP Test, documentary evaluation	Audiovisual and text	0-5
Provenance of data	The primary source of data is clear.	Ensure data validity.	FAIR principles, traceability	Audiovisual and text	0-5

Scoring: 0= criterion not met at all, 1= criterion only slightly met; 2= criterion only partially met; 3= criterion only moderately met; 4= criterion almost fully met; 5 = criterion fully met

^p Trust Indicators: <https://thetrustproject.org/trust-indicators/>

^q Wayback Machine: <https://web.archive.org/>

**Table 16 – Dimensions for assessing the quality of open qualitative data available online: complementary criteria**

Criteria for assessment	Description of the criteria	Aim of criteria	Existing strategies for assessment	Applicable to	Score (0-5)
<i>Readability of content</i>	Content is structured and easy to read.	Facilitate human analysis.	Readability tools	Audiovisual and text	0-5
<i>Availability of cited sources</i>	References are mentioned and can be checked.	Check the reliability of the information.	Bibliographical verification	Written	0-5
<i>Update of content</i>	Content is regularly updated.	Ensure temporal relevance.	Manual inspection	Audiovisual and text	0-5
<i>Technical quality (audio/video)</i>	Format, resolution and sound are adequate.	Guarantee unhindered use.	Visual and audio analysis	Audiovisual	0-5
<i>Clarity of metadata</i>	Metadata are available and correctly referred.	Enable cataloguing and archiving.	Open Data Maturity	Audiovisual and text	0-5
<i>Clearly identified user licence</i>	The content explicitly mentions a licence.	Guarantee legal re-use.	Creative Commons, site source	Audiovisual and text	0-5
<i>Congruence of formats</i>	Formats are open, permanent, and compatible.	Support technical re-use.	FAIR, Open Data Maturity	Audiovisual and text	0-5

Scoring: 0= criterion not met at all, 1= criterion only slightly met; 2= criterion only partially met; 3= criterion only moderately met; 4= criterion almost fully met; 5 = criterion fully met



11.6 How to analyse open qualitative data?

Analysis of online data, in the context of a KCE study, will preferably remain **descriptive**. In the absence of contextual information and information about how the data were collected (e.g. which questions were asked), it seems inappropriate to envision a more complex level of analysis than a purely descriptive one. Chapters 20 and 21 provide further guidance for the choice of the appropriate analytical approach, based on the overall design of the study (see Chapters 20 and 21).

11.7 How to report open qualitative data?

Reporting of the findings should consider the **anonymity** of the authors of the open qualitative data but – as pointed by previous researchers – it is easy to retrace the identity of a blogger (unless this person uses a pseudonym). There is no golden rule and various practices for reporting exist, depending on the qualitative approach.

“Some researchers consequently advocate paraphrasing rather than direct quotations in qualitative personal research (Wilkinson and Thelwall, 2011). On the other hand, we may view bloggers as authors and recognise this authorship through appropriate citation (Bassett and O’Riordan, 2002: 244)” (retrieved from Hookway and Snee, 2017, pages 392-393).¹⁰⁴

However, one could also argue that, from the moment a person shares personal and confidential information on the Internet, they implicitly acknowledge that this data could be used to other ends.

Some suggest that data posted in an open online space without password or membership restrictions could be considered as belonging to the public domain and available without informed consent of the individual contributors, while data obtained by joining a closed online community need consent.¹¹⁷

This does not mean that the source should not be adequately **cited and referenced** in the report as these data are subjected to intellectual property and may be covered by a copyright.^r

At KCE

- Check if the source is protected by a copyright or if the owner of the data provides guidance on how to use the source.
- Contact the owner / author to ask permission for reusing and citing the source.
- Please contact the information specialist or the librarian if you need assistance to properly refer a source.

^r Rules regarding intellectual property and copyright on the Internet can be consulted on the website of the Federal Public Service Economy: <https://economie.fgov.be/en/themes/intellectual-property/intellectual-property-rights/copyright-and-related-rights/copyright/copyright-internet>

◆ PART 3 - QUALITATIVE RESEARCH METHODS BASED ON PRIMARY DATA

This third part focuses on **primary data collection in qualitative research**. Chapter 12 explains the general principles of primary data collection, including how to do the sampling, develop the data collection material and run the data collection. The general principles explained in Chapter 12 relate to interviews but are applicable – with tailoring – to all primary data collection methods. The following chapters further detail a selection of data collection methods which are relevant in the context of KCE: observations (Chapter 13), interviews (Chapter 14), focus groups (Chapter 15), forums (Chapter 16), the Delphi process (Chapter 17) and nominal groups (Chapter 18).

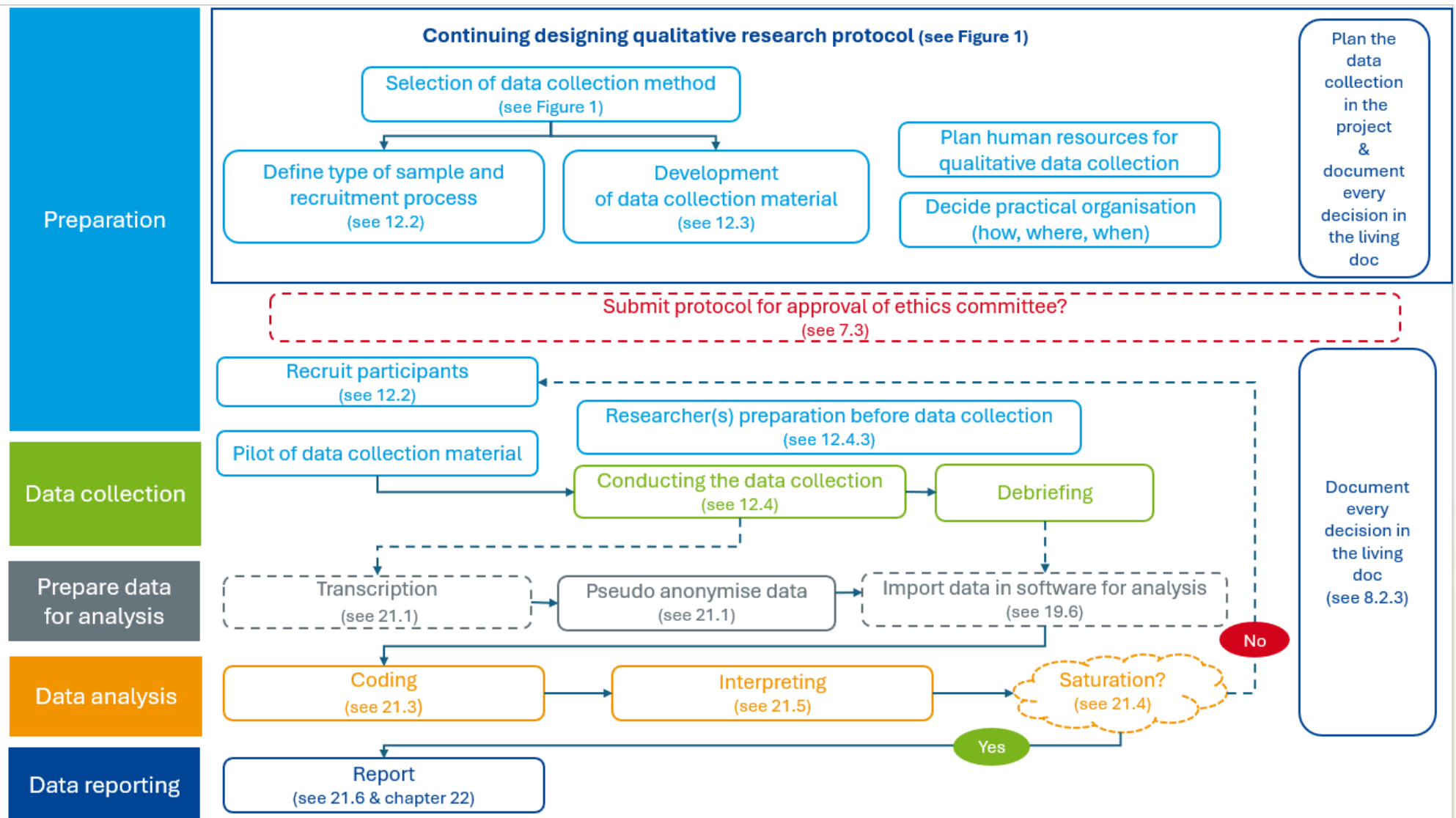
12. GENERAL PRINCIPLES OF PRIMARY DATA COLLECTION

12.1 How to plan the primary data collection?

Once the research team has agreed on the need for a primary data collection (see Figure 1), there are different steps to follow when planning the data collection. Figure 3 presents these different steps: each of these steps are presented in this Chapter (follow the section number indicated in the figure).



Figure 3 – Overview of the steps when planning a primary qualitative data collection



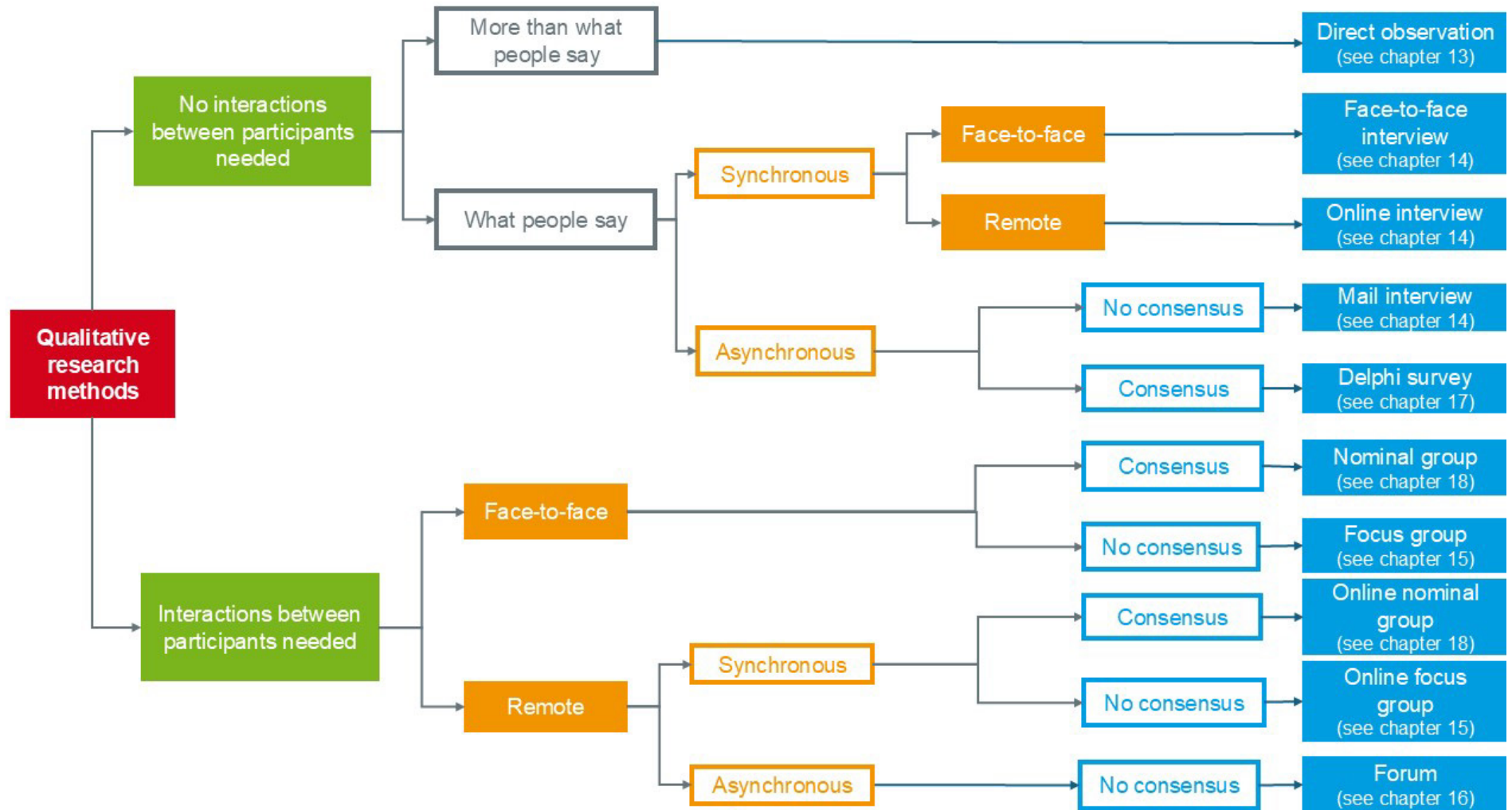
12.2 How to choose the data collection technique?

This update includes six types of QRM suitable for KCE research projects when looking for primary data: interviews (individually or in focus groups), forum, naturalistic observations, Delphi process and nominal groups. Figure 4 presents an overview of relevant techniques for primary data collection in the context of KCE. **Each technique has a different objective and methodology, but these techniques are not mutually exclusive.** They can be combined as they will bring different sources of data to answer the research question(s) (see section 8.2)

The next chapters of Part 3 detail these techniques.



Figure 4 – Decision tree to choose between the methods proposed in the process note



Observation is useful to understand more than what people say about (complex) situations.¹¹⁸ This can include attitudes, behaviours, interactions between individuals or the way people interact with the environment. In the context of KCE research, it will be useful, for example, for site visits, when preparing a report on a hospital, health service or procedure. See Chapter 13

Semi-structured individual interviews aim to obtain data by questioning the respondent using conversational techniques, “... *being shaped partly by the interviewer’s pre-existing topic guide and partly by concerns that are emergent in the interview*” (retrieved from Bloor and Wood, 2006, page 104).⁵⁹ “*It gives the opportunity to the respondents to tell their own stories in they own words*” (retrieved from Bowling, 1997, page 336).¹¹⁸ In the context of KCE research, the use of this method is appropriate when the aim is to identify different points of view, beliefs, attitudes or experiences among people such as patients, practitioners, stakeholders, etc. when no interaction between the respondents is required or appropriate (based on the topic, for example). It might also be chosen for practical reasons, e.g. when participants are not easily ‘displaceable’ or lack time. It can be organised online or in person. A particular form of individual interview is the **mail interview** (see Textbox 4). **Structured and unstructured (comprehensive) interviews** are briefly presented in Chapter 14 but are not part of this process note. See Chapter 14

Focus groups are a form of semi-structured interviews involving not individual respondents, but groups of people. They consist of group discussions moderated by a researcher and should **not be confounded with group interviews** (see section 14.2). Each group involves different participants, selected based on predefined criteria. The focus groups aims to “*provide data (via the capture of intra-group interaction) on groups beliefs and group norms in respect of a particular topic or set of issues*” (retrieved from Bloor and Wood, 2006, page 88).⁵⁹ This is useful “*where we need interactivity to enhance brainstorming among the participants, gain insights and generate ideas in order to pursue a topic in greater depth*” (retrieved from Bowling, 1997, page 352).¹¹⁸ Focus groups can be organised online or in person. In the context of KCE research, focus groups can be used when different groups of participants have a specific experience regarding a common issue. For example, one can discuss the facilitators and barriers regarding the multimodal treatment of chronic pain with a group of patients, a group of nurses and a group of physicians specialised in chronic pain. See Chapter 15

A forum is a form of group discussion hosted on an online platform, where interactions between participants mostly occur asynchronously.^{119, 120} In this section, we refer specifically to situations where a forum dedicated to the research project is launched for the purpose of data collection, not to the use of existing forums (see Chapter 11). A forum is useful for group discussions about sensitive topics, notably because it provides the participants with a degree of anonymity and distance. A forum requires inputs from a moderator to keep the flow alive. In the context of KCE research, this can be useful when the topic of the study concerns the whole population (e.g. KCE project 296 on appropriate care at the end-of-life addressed the entire Belgian population)¹²¹ or when it is difficult to identify appropriate recruitment channels (e.g. as there was not yet an official diagnosis for Long Covid when KCE researchers started the KCE project 344, it was difficult to reach participants).⁵⁴ See Chapter 16

Delphi process and **nominal groups** both aim at structuring discussions (usually amongst experts) and achieving consensus on a specific topic. They are frequently used in qualitative health care research. Both techniques are, for instance, useful to organise “*qualitative judgments and [...] understand the meanings that people use when making decisions about health care*” (retrieved from Black, 2006, page 132).¹²² They are characterised by the provision of information prior to the discussion, opportunity for participants to change their view and explicit and transparent derivation of the group decision, based on (statistical) analysis.¹²² These techniques may use quantitative data collection tools (questionnaires, scales), and include quantitative elements in the analysis (statistics), and are therefore not considered as ‘purely’ qualitative methods.

Delphi process aims to achieve this consensus or define positions among experts (i.e. the Delphi participants) through iterations of anonymous opinions and of proposed compromise statements from the group moderator.⁵⁹ In the context of KCE research, this method might be useful, for instance, for



setting priorities, clarifying the acceptability of an innovative technology, system or intervention, or gaining a consensus on recommendations. See Chapter 17

Nominal groups (NG) also aim to achieve consensus based on a structured group discussion, divided in four steps: generating ideas, recording ideas, discussing ideas, and voting on ideas.¹²³ This is a variant of the Delphi approach involving interactions between the participants, and therefore without the anonymous character of the Delphi process. It can be organised online or in person. See Chapter 18

Table 17 compares the practical aspects of these various techniques. Although the research questions and the expected outputs are deciding factors for the choice of a method, practical factors also need to be considered to optimise the research process. This table is based on the experiences of KCE experts over the years and only provides a general indication. Practical aspects are influenced, among other factors, by the research question, the context of the research and the duration of the projects. The following chapters detail each data collection technique.



Table 17 – Comparison of the various data collection methods presented in the process note

	Observation	Semi-structured interview	Focus group	Forum	Nominal group	Delphi
Suitable for virtual	No	yes	Yes	Yes – exclusively virtual	Yes – but more adapted to face-to-face	Yes
Suitable for RQR	Yes	Yes	Yes	No	Yes	No
Suitable for reaching a consensus	No	No	No	No	Yes	Yes
Suitable for using enabling techniques	No	Yes	Yes	No	Yes	No
Direct costs related to the method (incl. transportation costs, software, transcripts, human resources, audiovisual material, IT-support)	€	€ €	€€	€ € €	€	€ €
Implementation	Easy	Easy	Easy	Moderately difficult	Moderately difficult	Difficult
Specific material needed	Observation grid	Topic guide	Topic guide	Online platform + topic guide	Topic guide	Online platform + topic guide
Number of participants	No limit	Min. 15	8 to 12 per group (6 to 8 online)	No limit	6 to 12 per group in face-to-face	Average 10 (min. 4), but no limit
Participants' profile	No restriction	Able to communicate orally	Able to communicate orally	Able to communicate in a written form	Experts* able to engage in a constructive discussion – suitable for participants with low digital literacy when onsite	Experts – with digital literacy – suitable when strong divergent opinions are expected
Number of researchers needed	1 to 2	1 to 2	2 to 3	Depends on the number of	2 to 3	1 to 2



				participants (min. 2)		
Is a moderator needed?	No	No	Yes	Yes	Yes	No
Is a transcription needed?**	No	Yes	Yes	No	No	No
Duration	Depending on the topic	±1h per interview	Min 2h	Min. 1 month (excluding preparation)	±2h to 2h30 per topic	Min. 1 month (excluding preparation)

* “Expert” is used here in the broadest sense: the expertise of the participant is acquired via knowledge, or experience, following the principles of the epistemic justice acknowledging the co-existence of professional knowledge, academic knowledge, experiential knowledge and political knowledge – without any hierarchical view of these different sources of knowledge.^{124, 125}

** If interviews or focus groups are part of a rapid qualitative research (RQR), follow the guidance of KCE report on expedited scientific research and reporting (ESRO): <https://kce.fgov.be/en/publications/all-reports/expedited-scientific-research-and-reporting-esro-at-kce>

12.3 How to do the sampling?

In qualitative research, participants are selected because they are **likely to provide the most relevant information**.¹⁶ To design the sample so as to cover all variability around the research question, the researchers must have an idea of the different perspectives that should be represented in the sample. This is called “field mapping” of the key players who have a certain interest in the problem under study. The role of this explicit “field mapping” is often underestimated but essential to build a purposive sample, i.e. “*identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest*”(retrieved from Palinkas, 2015, page 534).¹²⁶ This “field map” might evolve during data collection. In this context, “representativeness” should not be understood in a statistical sense. **The idea of representation is seen as a “representation of perspectives, meanings, opinions and ideas” of different stakeholders in relation to the problem researched and to their interest.** To select the participants for interviews or focus groups, the question that should be asked is: “*do we expect that this person can talk about (represent) the perspectives (meanings given to the situation) of this stakeholder group?*” The aim is to maximize the opportunity of producing enough data to answer the research question.²¹

12.3.1 How to select participants?

Ideally, there should be a **mix of different population characteristics** to ensure that the arguments and ideas of the participants represent the opinions and attitudes of the relevant population. Also, the unit of analysis should be considered. This could be, for example, individuals for their personal opinions/experience/expertise (e.g. persons living with chronic pain, specialist nurses in chronic wound management or parents of premature babies) or individuals representing organisational perspectives (e.g. hospital managers, representatives of a medical union or policymakers).

Two key points for choosing the selection criteria are:

- **Symbolic representation** – i.e., a “*unit is chosen to both represent and symbolise features of relevance to the investigation*” (retrieved from Ritchie et al. 2014, page 116).¹²⁷

Theoretical example: in a study about prenatal care, the unit of investigation is a mother of a newborn.

- **Diversity within the parameters of study population** to maximise the probability of identifying all relevant aspects related to the topic and to support – to some extent – the interdependency between some of these aspects.¹²⁷

Theoretical example: in a study about prenatal care, among the population of mothers of newborn infants, the parameters of interest can include the socioeconomic status, the number of children, single mothers, the ethnocultural background or the presence of a comorbidity.

The following aspects help inform the selection:¹²⁷

- **Review of relevant literature / previous studies**, helping to identify characteristics that could influence perspectives on the topic.
- **“Compulsory” variables**, to ensure a form of balance in the sample: typically, the language spoken is one of the indispensable characteristics in a KCE study. Other frequently used variables are gender, age group and socioeconomic status.
- **Hypotheses** that require the selection of subgroups.

Theoretical example: in the context of a project on medical part-time work, the researchers hypothesise that it is easier for people who have the possibility of teleworking to return to work via medical part-time working. Consequently, recruitment should make sure to include participants who are able to perform all their professional activity remotely, rather than participants who cannot work remotely due to the nature of their job.



- **Subgroups** for whom there is little data available, but that need to be considered.¹²⁷

Theoretical example: in palliative care, there is a lack of data on the experiences of palliative psychiatric patients. If the research team plans to conduct a study on the needs of palliative care patients, it will be necessary to ensure that patients with psychiatric conditions are included in the selection.

- **Subgroups that should be excluded** – because of characteristics that put them outside the scope of the study, or because it is perceived inappropriate or even harmful to include them.

Theoretical example: asking grieving parents to participate in a study about perinatal mourning just after the death of their newborn would be inappropriate, but it might be fine to ask them, i.e., three to six months later.

- **Comparisons necessary within and between types of participants:** the sample design should consider the characteristics that will be compared (e.g. age group, socioeconomic status, gender...).

Example: in KCE report 349, the research team wanted to understand how patients experience decisional incapacity. Participants included persons who would be faced with a permanent decisional incapacity at some point because of Alzheimer's disease, and persons faced with a temporary decisional incapacity because of a psychiatric condition.⁹

- **Selection of participants via a multi-stage design**, meaning that a "unit" is first selected based on organisational / meso criteria, before the person / the group that will participate to the data collection activity is identified.

Theoretical example: in a study investigating the management of chronic pain, a first selection can be performed based on the type of health facility (e.g. academic hospital versus general hospital), followed by a selection of the health care professionals to be interviewed (e.g. medical doctors, nurses, or physiotherapists).

- **Nesting of criteria**, which is the case when the level of a criterion is hierarchically subsumed under (or nested within) the level of another criterion.¹²⁸

Theoretical example: among cancer patients, there will be nested criteria such as the stage of the disease, the type of cancer, the type of treatment or the place of treatment.

- ▶ *For specificities related to sampling for observations, go to section 13.5.6*
- ▶ *For the specificities of the sampling and selection for focus-groups, go to section 15.5*
- ▶ *For specificities of the selection of the participants for a Delphi process, go to section 17.8*
- ▶ *For specificities of the selection of the participants for nominal groups technique, go to section 18.5.1*

12.3.2 Can research be conducted with participants in vulnerable situations (including children under 18 years old)?

Yes

- Vulnerability is not an argument for not involving people in the study. It is possible to conduct research with vulnerable groups, providing certain precautions are taken, including:
 - The documents to obtain consent to participate are adapted.
 - The data collection process – including the competences of the researchers – is adapted.
 - The methodology for obtaining data is adapted.

No, if

- The available resources do not allow the research team to adapt the data collection and the methodology to include the participants in vulnerable situations. For example, there is no researcher trained to conduct interviews with persons with intellectual disabilities in the team or there is not enough time to obtain consent of parents of minor children.

Rationale

Participants in vulnerable situations are defined as those whose personal situation can prevent them from giving their informed consent to participate in research, e.g. children, adults with cognitive conditions or psychiatric problems, persons with cognitive issues linked to language or disability, persons faced with complex social situations such as prisoners or undocumented migrants, patients with a stigmatised disease or health condition...

Specific attention points for conducting qualitative research with children⁵⁰

- **Parents** (or a person *in loco parentis*) are usually the gatekeeper to get access to the children (see section 12.3.9).
- Researchers need to **clarify if the consent of both parents is necessary**: although the consent of both parents is usually the norm, an ethics committee can decide, on a case-by-case basis, that the consent of one of the parents is sufficient (e.g. in case of transgender children when the parents are legally divorced and one of the parent does not accept the choice of the child; the parent left the family home and has no longer contact with the child).
- A distinction needs to be made between **consent to approach children** (e.g. informing them about the research) and **consent to participate** in the research.
- It is recommended to leave the decision to participate in the research to the appreciation of the children themselves.
- **For some topics, using parents as gatekeepers is not recommended**, as the children may not want to disclose certain things to their parents (e.g. tobacco consumption, use of illegal substances, sexual behaviours, or preferences...).⁵⁰

Examples of KCE projects involving vulnerable groups

These three examples list the precautions that were taken by the research team when working with vulnerable groups.

- KCE report 257 on **access to health care for undocumented migrants⁵²**
Two external research teams conducted the interviews with undocumented migrants. Two researchers were also trained as health care professionals and knew the support network. Interpreters supported interviews. Recruitment was organised via non-profit organisations who shared information material to the participants and organised the contact between the undocumented migrants and the researchers. Interviews took place at the non-profit organisations' premises to provide participants with a safe place. At the end of the interview, participants received a food voucher as an expression of gratitude for participation (this was not announced before the interview). Researchers also provided the participants with supporting information (e.g. how to get access to health care).
- KCE report 349 on **decisional capacity⁹**
KCE researchers conducted online interviews with persons living with severe mental illness and people with dementia (Alzheimer). Participants were encouraged to attend the interview with a relative or person of trust.



- KCE report 361 on **access to health care for persons living with intellectual disability**⁷

KCE researchers were trained in “easy to read and understand” language to allow them to interact more effectively with persons living with intellectual disabilities. The participants were recruited via organisations who shared the recruitment flyer. Participants (or their relatives) then directly contacted the research team. Adapted communication material for recruitment and adapted informed consent documents in easy-to-read language were used. Participants were encouraged to attend the interview with a relative or a person of trust (*personne de confiance / vertrouwenspersoon*). During the interview, the researchers used the patient journey as an enabling technique (see section 12.4.4) in the interview guide. At the end of the project, the results were disseminated in easy-to-read language.

- KCE Project 2023-80-6 (ongoing) **Identifying the unmet needs of patients with psychotic disorders**

An external research team conducted interviews with adult patients living with a psychotic disorder. Participants can be assisted by a person of trust or be represented by their legal representative. Interviews were held though videoconferencing: this helped to offer a safe environment for the researchers as some participants were emotionally unstable although able to give their informed consent. Because of the nature of their disease, some participants made statements that could be considered delusional. It implies that the researchers need to take sufficient distance and strive to contextualise the statements of the participants as much as possible.^s

- To date (October 2025), no research project has been conducted with children at KCE.

12.3.3 Can proxies be recruited as participants?

Yes, if

- The target population is not able to give informed consent / if obtaining informed consent is too complicated (e.g. gatekeepers).
- The proxy can share the individual perspective of a person affected by the issue under investigation.
- The aim is to collect the individual and unique experience of a single person.

No, if

- There is a risk of lack of authenticity.
- The proxies have different expectations than the persons they speak for about the outcome of the project (e.g. parents are against the euthanasia of children, while children who can benefit from it are in favour).
- It is not possible to formally assess that the proxy is effectively acting on behalf of a third person.
- The proxy has no close relationship with the patient.
- The proxy is a professional caring for the patient / individual / person.

Rationale

A proxy is defined as **someone who provides information on behalf of the patient**. This person must have a **close relationship** with the patient (e.g., a family member, neighbour, volunteer) AND spend **significant time** with him/her AND **be familiar** with his/her situation, experiences, and preferences. Close people with a recognised legal status as a 'carer' are considered proxies, provided they meet the above criteria (retrieved from Paradis, work in progress, KCE NEEDS program).^{129, 130} Proxies intervene

^s The end of this project is scheduled for March 2026.

in research **on behalf of participants that are not able to give their informed consent** (e.g. adults with severe cognitive issues, patients in coma, toddlers) **or are hard to reach** (e.g. marginalised groups, people faced with a language barrier or a stigmatised health problem). Proxies can have a personal relationship with the participant, and can also be affected by the issue at stake: spouse, relative, friend... These proxies are expected to give the **answers that the persons unable to participate would give** if they were able to. The proxies can also be the legal representatives of the person, provided they meet the above criteria (e.g. parents of a minor child, person of trust or administrator).

Professionals, i.e. people who are paid to provide care services (e.g. healthcare professionals, social workers, or educators) cannot participate as proxies. They rarely meet the criteria for being a proxy. Besides, it appears **unethical and contrary to professional deontology to ask a professional** to speak on behalf of a specific person/patient/individual, as this may endanger the therapeutic relationship. This is why, in general, it is not recommended relying on a professional as an information source on a person in particular.

However, there may be exceptions, for example when the person has no entourage, and the professional has a close but still professional relationship with the person. For example, an educator caring for a person with an intellectual disability living in an institution may participate as a proxy under the condition that the educator is the referent person, the person is present during the data collection and, to some extent, fulfils the criteria mentioned above. The reasons for using professionals as proxies should be clearly reported in the research protocol.

Proxies are not gatekeepers: gatekeepers hold an intermediary position between the researchers and the participants. They help the researchers to recruit participants (or not). A person can be both a proxy and a gatekeeper, but this is not always the case.

In practice

- Recruitment material and data collection tools should be clear about the role of proxies to ensure the quality of the retrieved data.
- Involvement of proxies acting on behalf of individual participants is likely to be subject to the prior approval of the ethics committee, depending on the nature of the information that is collected.
- The researchers should provide clear instructions about the perspectives that the participants need to endorse.
- The researchers should clearly report how the proxies were identified and recruited in the methods section and explain in the discussion section the biases that may have occurred and the way with which they were dealt.

12.3.4 Can representatives be recruited as participants?

Yes, if

- The research question addresses organisational, systemic, or institutional topics, “non-personal topics” or “non-sensitive data” (e.g. experiences in different services or perceptions about problems encountered in the health care system in general).
- In the context of rapid qualitative research (RQR).¹⁰
- The aim is to collect the perspectives of a group of individuals and not personal and unique experiences.

¹⁰ Sensitive data according to European Commission: https://commission.europa.eu/law/law-topic/data-protection/reform/rules-business-and-organisations/legal-grounds-processing-data/sensitive-data/what-personal-data-considered-sensitive_en



- Providing the representatives are clearly identified (e.g. they belong to a professional or other organisation) and used to act on behalf of a larger group.

No, if

- The research questions address personal and individual experiences related to a specific topic.
- The representatives have no clear mandate to voice the concerns and experiences of a larger group ("self-identified" representatives).
- The representatives of professionals do not reflect the diversity of the professional profiles and have no connection with those active on the field.

Key considerations

- The expected outcomes differ from directly collecting data with individuals: patient representatives will provide experiential expertise and collective knowledge through their own experiences and exchanges with multiple other patients with similar experiences.
- Concerning patient representatives, KCE distinguishes 4 distinct groups (adapted from Kohn et al., 2019, page 226)³⁵
 - **Individual patients with collective experiential knowledge:** patients with collective knowledge based on contacts with other patients, either through a patient association or through an informal gathering of patients (e.g. as moderator of a Facebook group or spokesperson of a group of people). These patients do not formally represent a patient organisation.
 - **Patient associations/organisations:** formal gathering of patients (and professionals) aim to advocate, support, and promote patient issues and rights. The size, the degree of formalisation, the presence of health care professionals and the objectives, among others, vary from one organisation to another. Patient organisations usually focus on a specific disease, health condition or symptom.
 - **Sickness funds:** sickness funds represent patients as health care consumers under the terms of the national health insurance. They represent all the patients registered to their funds and are – in a certain sense – influenced by a specific "ideological" perspective (socialist, liberal, Christian, independent), although those differences are more historic than of real influence on current practices.
 - **Umbrella patient organisations:** umbrella organisations bring together patient organisations and aim to advocate for patient rights from a general perspective – without referring to a specific disease, health condition or symptom. Patient umbrella organisations can also represent patients for whom no organisation exist. Not all patient organisations are members of patient umbrella organisations.
- It is important to keep in mind that patient organisations cannot provide information about all issues experienced by users of the health care system (e.g. there is no patient organisation for prisoners).
- For representatives of professionals, the following categories can be envisioned: scientific societies, professional associations, federations of services and institutions, consultative committees or councils, expert groups...
- **Depending on the circumstances and the project, professionals could participate as representatives of some patient groups.** These can be, for example, groups or individuals whose direct participation is hindered by legal, deontological or safety barriers (for the individuals or for the researchers). To be effective, this strategy requires that the professionals have a minimum level of professional experience with the target group, regular direct contacts (e.g. a manager is not the best representative) at various points in time (e.g. the physiotherapist who sees the target group only once a day will not provide the same perspective as the health care assistant who sees the target group day and night and during the weekend). For example, in KCE project 339 on forensic

pedo-psychiatry, the target group were minor children with a psychiatric diagnosis and a court order / a social service decision of placement into a forensic facility.²⁸ Asking their parents to give their consent to participate was not an option as some of them were in a conflictual situation (e.g. some youths may have been victims of abuse from their parents or have assaulted their parents). Asking their lawyer or the social worker of the administration was not an option either, and neither was asking their psychiatrist or educator. One option could have been to ask the educators to share the perspectives of the youths, as they stay with them on a permanent basis.

- Researchers should pay attention to the **bias** that can occur (see Chapter 8). As recalled by Vindrola-Padros, “*due to time pressures, researchers will recruit participants or observe situations that are easily accessible. This might mean that views of some participants will feature more prominently or that a multiplicity of voices will be lost. Rapid qualitative researchers have tried to address this potential challenge, by designing sampling guides where researchers map the different groups of participants they would like to include in the study and set out sampling targets for each*” (retrieved from Vindrola-Padros, 2021, page 7).²⁹
- **Ethical concerns may be less apparent** in these cases, since patient representatives may be less inclined to disclose information about their own health, and time could also be gained because asking for ethical clearance would not be necessary.

At KCE

- ▶ *Contact the KCE Patient Involvement Cell for collaboration with patient associations.*
- ▶ *Additional resources for contacting representatives and stakeholders are available via the KCE Project Guide.*

12.3.5 Which type of sample?

There is a wide range of sampling approaches (e.g. Miles and Huberman, Patton, Strauss and Corbin).^{131,132,133} In qualitative research, it is not uncommon for the research team to continue making sampling decisions during the process of collecting and analysing data. However, a clear documentation of the sampling criteria is needed when performing qualitative research. These criteria should cover **all relevant aspects of the research topic**. The researcher should identify the central criteria (the most important concepts / dimensions) and translate them in observable sample criteria. In addition, the chosen criteria should leave enough variation to explore the research topic.⁶³

A randomized sample is not useful in qualitative research, since generalisability to the general population is not the aim. Moreover, with a random sample, the researcher would run the risk of selecting people who have no link to the research subject, and thus have nothing to say about it.⁶³ **All the sampling strategies in QRM are non-probabilistic and purposive** (there is always a minimum set of inclusion criteria such as the language spoken), the sampling criteria being the starting point.

Eight types of samples co-exist, depending on the research aim, and can be combined. The section below defines the different types of samples. Table 18 compares the advantages and limitations of these different types of samples.

- **Stratified sampling:** stratification by selecting specific persons that differ by a key dimension/characteristic (e.g. a sample of professionals from large hospitals, and a different sample of professionals from small hospitals).^{126, 134} The selection ideally represents the various positions within the ‘system’ or phenomenon under investigation. This can be considered as equivalent to the stratification criteria with independent variables in quantitative research. It requires thinking ahead about independent variables which could provide new information regarding the research topic (e.g. during the scoping phase of the project).

Example: stratified purposive sampling was used to recruit participants in KCE report 344 on Long Covid⁵⁴ and in KCE report 377 on the needs of patients with Crohn’s disease.¹³⁵ In KCE report 344, patients with a Long Covid were stratified according to the duration of the symptoms post infection,



the differences in perceived health status pre/post infection and if the patient was hospitalised because of Covid. In KCE report 377, patients with Crohn's disease were stratified according to their age, the time elapsed since diagnosis and the type of treatment that they receive.

- **Homogenous sampling:** selection of participants because they are alike, to focus on one process or situation they have in common, to minimise the variation between participants.⁶³ It is also used when the goal of the research is to develop an in-depth understanding and description of a particular group with similar characteristics, or of people on equal footing. This does not exclude comparisons between types of participants, because, for example, unanticipated dimensions might emerge from the data. It is useful to consider hierarchy, as this might create a bias in the responses.

Example: KCE study 154 on the use of alternative medicines¹³⁶⁻¹³⁸: homogeneous sampling of regular users.

- **Heterogeneous sampling variation:** selection of respondents to maximise of the variation between respondents, relevant to the research question.¹²⁷

Theoretical example: in a study about the barriers and facilitators to vaccination against COVID in the general population, the sampling strategy will aim to obtain a highly heterogeneous group of participants.

- **Extreme or deviant cases sampling:** search for outliers or highly unusual persons or representatives of opinions.¹²⁷ This is done after of the data collection and partial analysis, and is always used as a complement to other sampling strategies.

Theoretical example: in a study comparing preferences regarding delivery, the researchers may decide to recruit women who prefer a "full" natural childbirth (e.g. no health care professional, in the great outdoors...) versus women who prefer hyper medicalised childbirth (e.g. in a highly specialised maternity ward, with epidural anaesthesia...).

- **Typical cases:** selection of cases from which it is expected that they will provide information about a typical situation. These cases can provide the basic knowledge necessary to construct theoretical explanations, preparatory to the search for more variation in cases. The typical case is defined as one that occurs frequently.⁶³

Theoretical example: in a study on the overuse of emergency services, patients without a GP may constitute a typical case.

- **Theoretical sampling:** process of selecting "*incidents, slices of life, time periods, or people on the basis of their potential manifestation or representation of important theoretical constructs*" (retrieved from Patton, 1999, page 238).²⁵ This kind of sampling is done after a first data collection and partial analysis.

Example: it emerged from interviews with chronic patients that they relied on alternative medicine to develop personalised health care strategies to cope with their chronic disease. The research team decided to include interviews with these practitioners (e.g. reiki expert, hypnotherapist, meditation guide...) in complement to those conducted with conventional health care professionals (e.g. medical doctors, nurses, physiotherapists...).¹³⁹

- **Confirming and disconfirming cases:** selection of cases to lend further support to an initial analysis or theory (confirming cases), or to disconfirm the theory and provide alternative explanations (disconfirming cases).¹²⁷ It is used to develop a richer, more in-depth understanding of a phenomenon and to lend credibility to one's research account.

Theoretical example: after an online survey on the use of alternative medicine, the research team may decide to conduct interviews with participants who declared themselves highly in favour of such health care practices to better understand their choices and perspectives.



- **Convenience sampling**, often mentioned as a strategy by some researchers, is neither purposive nor strategic.¹²⁶ It consists in selecting the participants for inclusion because they are easy to reach. This should not be used as a sampling strategy.

Theoretical example: Convenience sampling is often used in marketing where the interviewers ask their questions to all the persons passing by in a street.



Table 18 – Comparison of the advantages and limitation of types of samples in qualitative research

Sample types	Advantages	Limitations	RQR compatible?
Stratified purposive sampling	Easy to put in practice. Clear criteria for selection	Needs a careful anticipation of the sampling criteria. Risk of missing key variables if the selection of criteria is not sufficiently prepared	Yes
Homogenous sampling	Useful for focus group recruitment Allows for recruiting by snowballing	May limit the generation of innovative ideas. Saturation could occur quickly	Yes
Heterogeneous sampling variation	Helps cover the diversity of perspectives regarding a specific topic. Useful for emerging / understudied issues	Can complexify the analysis because of variations in the sample	Yes
Extreme or deviant cases sampling	Selecting persons that emerge from an analysis as 'the exception to the rule', which can be considered to get a better understanding of these outliers or 'negative cases'	Risk of discreditation of extreme successes or failures that may appear as being too extreme or unusual to yield useful information, leading one to select cases that manifest sufficient intensity to illuminate the nature of success or failure, but not in the extreme. ¹²⁶	No
Typical cases	Useful in case of a new research area. Useful for the scoping phase / to prepare a larger data collection. Helps limit the scope of the data collection	Not to make generalized statements about the experiences of all participants ^{126, 132}	Yes
Theoretical sampling	Helps refine the data collection by focusing on emerging findings	Time-consuming Iterative process	No
Confirming and disconfirming cases	Useful in theory-generating research	Time-consuming Iterative process	No

12.3.6 What is the expected sample size?

“Determining adequate sample size in qualitative research is ultimately a matter of judgement and experience in evaluating the quality of the information collected against the uses to which it will be put, the particular research method and purposeful sampling strategy employed, and the research product intended” (retrieved from Sandelowski, 1995, page 199).¹⁴⁰

Typically, in qualitative research, one should continue sampling until **saturation (also referred as data sufficiency)**^u is reached: this is the point at which no new information or themes are emerging from the data.⁵⁹ In other words, the general rule on sample size for interviews is that when the same stories, themes, issues, and topics keep emerging from the participants, a sufficient sample size has been reached.¹⁴¹

The same consideration applies for RQR. The number of interviews, observations and focus groups in RQR is highly variable across the different studies, from 11 interviews¹⁴² to more than 300.¹⁴³ This variability can have different explanations: the complexity of the study topic, the available material and human resources, and the time dedicated to the data collection. In theory, therefore, it is **difficult to predict the number of interviews** required.¹⁰

Several factors will influence the sample size (adapted from Ritchie et al. 2014, page 118)¹²⁷:

- **Heterogeneity of the population:** the more diverse the population, the larger the sample size.
Theoretical example: a study on the experiences of cancer patients with hospital care.
- **Number of selection criteria:** the more criteria, the larger the sample size
Theoretical example: a study on unplanned acute care will require a selection of emergency departments, GP wards and out-of-hours GP practices, in urban centres and in remote areas, in the three regions of Belgium, with French-speaking and Dutch-speaking participants.
- **Need for nesting of criteria**, i.e. when two criteria are related, if there is a nesting of criteria, a larger sample size is required.
Theoretical example: the target group concerns patients with cancer, but not all cancer patients are at the same stage of their disease (6 months after diagnosis, one year after diagnosis, remission) or receive the same treatment (chemo only, chemo and radiotherapy, chemotherapy, and surgery).
- **Presence of groups requiring extra attention**, which will increase the final size.
Theoretical example: the study concerns the digital literacy of the Belgian population; it will require a group of participants with a home computer or smartphone.
- **Need for multiple samples in the study**, when there is a need for comparing experiences or because the target population includes participants with a different relation to the topic of interest.
Theoretical example: the study concerns the financial accessibility of health care and the perceptions of the fee-for-service payment system. Generalist practitioners in community health centres are expected to have a different perception than solo generalist practitioners.
- **Method of data collection:** to achieve saturation, one will have to conduct more individual interviews than focus groups (see Chapters 14 and 15).

Therefore, sampling goes hand in hand with data analysis and cannot entirely be planned beforehand: it implies keeping a **degree of flexibility** regarding the sample size. In every research institution, the sample size is also determined by the available budget, time, and human resources. This means

^u Qualitative approaches based on grounded theory mostly use the concept of “saturation” while thematic analysis / framework analysis mostly refer to the concept of “data sufficiency.”



practical aspects of the research project often constrain the size of the sample before theoretical saturation is reached. This is also true for KCE projects since budgets and time schedules are limited. However, administrative constraints, availability of the resources and reachability of the target group(s) should not “*undermine the need for a robust, well thought-out and justifiable sample*” (retrieved from Ritchie et al. 2014, page 118).¹²⁷

Beware that saturation (see above) can be reached prematurely if one's sampling frame is too narrow, if one's analytical perspective is biased or limited; if the data collection method is not resulting in rich, in-depth information or when the researcher is unable to get beyond the surface. There is no consensus in the scientific community to determine when saturation is reached. As an illustration, based on a systematic review, Hennink and Kaiser found that saturation was reached after 9 to 17 interviews and 4 to 8 focus group discussions.¹⁴⁴

It is possible to limit the number of study participants, particularly in RQR. However, this requires careful planning of the data collection instruments, a thorough selection of the characteristics of interest of the participants and a progressive analysis of the data during the collection process. This will ensure that diversity and saturation are gradually reached, even with a limited sample size.¹⁰

In practice

- It is **difficult to anticipate the exact number of interviews or focus groups** that will be necessary at the beginning of the project, as this depends on the scope, the nature of the topic, the sampling criteria, the resources, and the design.^{145, 146}
- It is usually advised to consider **12 to 60 individual interviews** (in both languages) and **6 to 12 focus groups**. More than 50 interviews or more than 15 focus groups might compromise the quality and depth of the analyses.
- In KCE studies, because of the limited time resources, the number of the interviews is usually fixed a priori, and the building of the sample is usually based on **maximum 2 or 3 priority criteria** (on top of the language of the participants) to reach maximum diversity within the chosen sample size. Moreover, KCE qualitative studies never try to reach perfect saturation.¹⁰
- Attention needs to be paid to the **quality of the sampling strategy**, particularly if the sample size is expected to be small: this ensures the richness of the sample regarding characteristics, diversity, and other aspects.^{21, 127}
- Additional or supplementary samples can be planned if the rationale for doing so is clearly explained. Remember to adapt the research protocol accordingly.
- The conclusion is that there is **no golden rule about the number of interviews or focus groups**.

12.3.7 How to recruit participants?

There are three strategies for the recruitment of participants, which can be used as well for interviews as for focus-groups, for online or face-to-face data collection. The Delphi process and nominal groups require a different approach (see sections 17.8 and 18.5.4).

- **Convenience sampling** is a pragmatic solution, meaning that the selection of respondents is based on ease, speed, and low cost, without any in-depth considerations on the selection of the participants. This strategy should ideally be avoided, but in some cases, it is the only feasible option due to practical reasons (such as time, costs, etc.).⁶² A good description of the sample and the recruitment strategy is especially important with convenience sampling, so that the reader can know how the results came about.

Theoretical example: in a project exploring the experiences of diabetic patients, participants are recruited through patient organisations.

- **Snowball sampling** aims to identify cases of interest from sampling people who know people with similar characteristics who, in turn, know people who also have similar characteristics. It starts by asking key informants or well-situated people “who know a lot about...”^{126, 132} The researchers search for one or a few respondents and ask them who else they know who could provide information. These individuals are contacted and, in turn, asked whether they know other potential respondents. Once the same individuals keep getting mentioned, the sample has reached maximum size.⁶³

Example: during KCE project 374 on the organisation of medical care in case of CBRNe incidents, researchers had to meet participants outside the field of public health such as the Belgian Army and firefighters: interviews started with participants from the field of public health, who were asked to provide contacts of additional participants.²⁷

- **At random, but still purposive:** it can be used when one of the abovementioned sampling strategies yields more cases than the researchers can interview or observe with the available time and resources. In that situation, randomness can be an additional selection criterion (although this is not “pure random”).⁶³

Theoretical example: 50 participants register for an interview about their difficulties in accessing health care because of financial barriers. As the timeframe of the project only allows for 30 interviews, the researchers randomly pick respondents.

Table 19 presents the advantages and bias of each recruitment strategy. When the recruitment is organised through existing online platforms, forum or social networks, a best practice is to first ask the moderator permission to publish the call for participation, even when there is no restriction for accessing the support.^{47, 147}

Table 19 – Comparison of three recruitment strategies

Recruitment strategy	Advantages	Bias
Convenience sampling	Easy to do. Time-efficient.	Risk of missing the key characteristics of the population. Selection bias.
Snowball sampling	Useful when the researchers have no clear idea where to find participants or who could provide them with the information they need. Useful when stakeholders are not clearly identified. Easy to put into practice. Allows to reach some marginalised / less visible groups. ¹⁴⁸	Risk of selection bias (maximal when the researchers use their own network). Confidentiality concerns as the participants may know who was interviewed. Participants require an initial awareness of others who potentially fit the research criteria. Participants may make their choices of additional contacts based upon their perception that these new contacts will be willing and cooperative contributors (and exclude those they think will not want to participate). Low participation because of fear of confidentiality breach / lack of anonymity. ¹⁴⁸
Random but purposive sampling	Allows to complete an existing sample when too many individuals volunteer to participate.	Risk of missing the key characteristics of the population. Selection bias.



12.3.8 Is it possible to accelerate the recruitment process?

The following facilitators of a recruitment process were identified and might apply to any data collection:

- Having **pre-existing collaboration** with potential participants (e.g. research team belonging to an academic hospital or having former colleagues working at a site of interest).
- Offering **incentives for participation** (see section 12.3.10): incentives need to be sufficiently attractive and reflect the nature of the participation. However, ensuring participants understand they might not receive tangible benefits is crucial. This is why the issue of offering incentives can be contentious, though options such as reimbursing travel expenses or providing a modest compensation or a small gift are a possibility.
- **Being known as a research centre**: when recruiting in a large audience (e.g. via social networks), being clearly identified as an official research centre with a strong expertise can contribute to an increased awareness among the population which, in turn, might be more willing to participate in studies.
- **Collaborating closely with stakeholders** who can help with recruitment by disseminating information or directly contacting participants: in this case, stakeholders endorse a role of gatekeepers. Here, collaboration with patient (umbrella) organisations is particularly valuable.
- Having an **inventory of key representative structures** in and outside of the healthcare sector (e.g. the Belgian Disability Forum, the Observatory of Chronic Diseases or the Council of Elder): relying on these structures can be useful when the topic is well defined and when an 'expert' perspective is needed (assuming that people in those structures are more informed and aware than the general population).

At KCE

- ▶ *Contact the KCE Patient Involvement Cell for collaboration with patient associations.*
- ▶ *Additional resources for contacting representatives and stakeholders are available via the KCE Project Guide.*

12.3.9 Should the recruitment be done via gatekeepers?

The recruitment process could rely on **gatekeepers, who are individuals** (e.g. health care professionals) or organisations (e.g. patient associations) **through whom participants will be contacted and recruited**.

Yes, if

- The target group is hard to reach or marginalised (e.g. persons living with intellectual disabilities).
- The target group is difficult to identify (e.g. for a study on the quality of the home environment, the GP can indicate families whose home is ill-adapted).
- The target group has experienced exclusion, discrimination, or mutual mistrust with the authorities – in a broad sense – (e.g. drug users, undocumented migrants, Roma communities...) and the gatekeepers have their trust.
- There is a form of 'social protocol' that needs to be respected (e.g. first asking a community leader).
- There are specific aspects related to communication, data collection and recruitment for which an external perspective is of added value.

No, if

- There is a risk of unfairly excluding relevant stakeholders (e.g. patients not affiliated with a patient organisation) because they are not offered the opportunity to participate.

- There is a risk of gatekeepers not disseminating the information (e.g. the secretary of the community health centre does not distribute the invitation to participate).
- There is a risk that the gatekeepers might exert indirect or direct pressure to obtain participation (e.g. a hospital manager plans the research interviews for the administrative employees).
- Participants feel obligated to participate (e.g. a family may feel obligated to participate to 'please' their GP).
- Gatekeepers may have a form of power over the participants (e.g. a head nurse over her staff).¹²⁷

Key considerations

- The cost-benefit balance of relying on gatekeepers needs to be carefully appraised.
- When gatekeepers are used, it is important to ensure that the research team can have some time with the participants to discuss their motivation to participate without the gatekeepers.¹²⁷
- The research team needs to be clear about the expected contribution of the gatekeepers: informing, planning appointments, sharing personal contact data...
- The role of the gatekeepers should be clearly explained in the report, as well as the way the gatekeepers influence the research process.

12.3.10 *Should participants be paid in a primary data collection process?*

No, at KCE, participants to a primary data collection process should not be offered (financial) incentives, rewards or bonuses to participate (e.g. winning cinema tickets, receiving coupons...)(see Chapter 7).

It is imperative that participants be aware that they will receive no tangible benefit for participation. That is why the question of offering incentives is often rather contentious.¹⁴⁹ However, their traveling costs could be reimbursed, they could be offered a (small) compensation for their time investment or a token of appreciation (see section 7.2.7). For example, in KCE project 257 on access to health care for undocumented migrants, participants received a food voucher after the interview: they were not informed before the interview about it.⁵²

Not paying participants does not mean that their participation should not be acknowledged. This could also be achieved by mentioning the name of a patient organisation in the Colophon (not in the text!), offering a nice lunch or presenting the final report during a dedicated event.

12.3.11 *Where to find participants?*

- *For projects involving patients or patient representatives, please contact the KCE Patient and Public Involvement Cell.*
- *Resources for identifying professionals, policymakers and stakeholders are available via the KCE Project Guide.*

12.3.12 *How to manage the follow-up of the recruitment process?*

Once the recruitment process has started, it is useful to **track the outcomes** of this process, to identify and prevent potential gaps in the final sample.

Ritchie et al. advised collecting information about the following outcomes:¹²⁷

- **Ineligible participants or out-of-scope:** participants were contacted but turned out not to match the selection criteria once the first contact had been established.

Theoretical example: the study targets pregnant women but the contacted participant is no longer pregnant at the time of the interview.



- **Non-contacts:** problem with the contact information or any other reason preventing the contact.
Theoretical example: in accordance with the GDPR, the hospitals provided the email addresses of patients, but some of them are no longer in use.
- **Not meeting quota requirements:** participants correspond to the inclusion criteria, but the sample already includes enough participants with these characteristics.
Theoretical example: in a study about prenatal care for premature children, there are already ten interviews with parents of a single child and none with parents of twins.
- **Refusal to participate:** the research team documents, whenever possible, the reasons why the person declined participation.
- **Agreement to participate:** the participant consented to join the study but has not yet effectively participated.
- **Participation:** the research team records it when the person effectively participates in the data collection activity. Some participants may have given their consent but finally did not participate in the data collection for various reasons.

These data should be part of the reporting (see Table 34).

12.3.13 *How to manage the first contact with a participant*

The first contact with a participant is often **made by email**, allowing to provide written information but, more importantly, setting the tone for the rest of the interviewing. The invitation email should be accompanied by an information letter. Textbox 3 presents information that can be provided during the invitation to participate.

However, as most people – particularly professionals – face an overflow of emails, a direct telephone contact can be of added value as a first contact: this phone contact can also serve to arrange the practical details about how the data collection will occur. A **direct phone call** is also more personal and can facilitate the connection between the researcher and the participants: it can be an opportunity to explain why participating could be valuable for the participants themselves (rather than laying out arguments relating to the importance of the research). Information provided during this first contact should not be excessive, and the researcher should refrain from pressuring the participants to join.

Textbox 3 – Information to be given during first contact

- **Background information**
 - Goal of the study and of the activity to which the participant is invited
 - Person(s) responsible for the research (+ contact details)
 - Reason(s) the participant is invited to participate
 - How the participant was recruited
 - Reason(s) the participant is contacted at that specific point in time (why now)
 - Information about the research centre, data privacy policy and ethics approval (when applicable)
- **Arguments pro participation**
 - How the results of the research will be reported, including (non)anonymity issues (e.g. in quotations)
 - Influence of the results on policymaking

- Potential impact of the results for the participants (with caution, as there is no direct effect on the participants themselves)
- **Practical aspects of participation**
 - The kind of information the respondent is expected to provide
 - The estimated duration of the data collection activity
 - The mode of data collection (face-to-face or online – including technical requirements)
 - The recording of the discussion
 - (Non) anonymity of the provided information
 - How the recording of the data will be treated after the data collection
 - Registration modalities (including deadline and administrative documents to be filled in)

Adapted from Emans, 1986¹⁵⁰ cited by Mortelmans, 2009⁶³

At KCE

- ▶ *Examples and templates of informed consents are available in the KCE Project Guide.*
- ▶ *Questions related to data privacy should be addressed to the KCE data privacy officer.*

12.4 How to develop the data collection material?

This section addresses the development of the data collection material for interviewing methods, i.e. individual or in group interviews, focus groups. These principles apply to any data collection material with adaptations; specificities are highlighted in the chapters detailing each data collection method.

12.4.1 How to construct a topic list or an interview guide?

A **topic list** covers all the topics the researcher should discuss with the participant. It enables the researcher to guide the interaction while allowing the discussion to flow naturally. The sequence of topics moves **from general to specific**. The sequencing of topics can be introduced in a flexible way, and within a general framework of topics, the focus of the discussion can be reset. A topic list is also used in preparation of the semi-structured interview guide.

In an **interview guide**, semi-structured questions are formulated in speaking language and are asked as such during the interview. The same questions with the same formulation, sometimes in the same sequence, are asked in each interview. The disadvantage, however, is that it can disrupt the natural flow of the conversation.

The interview guide should be adapted to the language and vocabulary of the participant(s) and generally consists of three components:

1. A reminder of the goal of the research.
2. The main topics or questions the researcher wants to address during the interaction.
3. Relaunching / probing questions.

Both for the topic list and the semi-structured interview guide, it is obvious that questions/topics should be selected in function of the research objectives. **Open-ended questions** are important to enable the interviewee to talk freely without being influenced by the assumptions of the interviewer. For example, a question like “Did you worry about the surgery?” could be replaced by “How did you feel about the surgery?”



A topic list or a semi-structured interview guide may be adapted or improved during the research, in line with the iterative nature of QRM. The more interviews the researchers have done, the more they know and the more specific or detailed their questions can be.⁶³ However, continuity should be ensured, and the topics of the first interviews should also be discussed in subsequent ones, although those can also contain much more detailed questions.

12.4.2 What types of questions can be asked during an interview?

The interview starts with an **easy opening question**, which is meant mostly to put the participant at their ease, break the ice and get to know each other. The researcher does not expect this question to yield a lot of useful information; its main function is to start up the conversation.^{21, 63, 151}

Example: “How are you today?” or “Why did you agree to participate in this interview?”

After that, the conversation is started with a **first general and easy-to-answer question addressing the content of the research**. It can be an attitude question, to enable the participants to roll into the conversation.^{21, 63, 151}

Example: “If you hear the words ‘breast cancer screening,’ what are your first thoughts?”

Next, **transition questions** involve the participants in the research subject, for example through asking questions about individual experiences or specific behaviour regarding the topic. Attitudinal questions are more difficult to answer and should therefore be addressed later in the interview.^{21, 63, 151}

Example: “How did you experience your eye surgery?”

Subsequently, the **key questions** are addressed. These questions are the reason(s) for the interview, and the interviewer can make it clear that the participant can take time to answer them. These questions need to be limited (not too many questions) and specific (digging into the topic). They are formulated in an open way.^{21, 63, 151}

Example: “Which difficulties did you experience after your eye surgery?”

The key questions can be accompanied by **relaunching / probing questions**. Relaunching questions are an essential part of the interaction. It may happen that the interviewee does not give an answer to the question or gives an unexpected answer. In that case, the interviewer can probe to delve deeper. If a respondent mentions an aspect the researcher thought of in advance or is particularly interested in, it is possible to bring up the question again, focusing on that specific issue.^{21, 63, 151}

Example: after the initial question (“which difficulties did you experience after your surgery”), the participant might mention all kinds of worries and inconveniences but did not refer to aftercare. To understand if it is because the participant did not receive aftercare at all or if it is because the aftercare was not sufficient, the researcher can then explicitly ask “How did you experience the organisation of aftercare?”

Finally, the interview is terminated by means of a **concluding question** and by **thanking** the interviewees for their participation. Two (complementary) concluding strategies can be distinguished:

- The researcher can provide the participant with a summary of what he / she has told.

Example: “during our interview, you talked about the lack of information after the eye surgery and this was, for you, a stressful experience. You looked for support by yourself to have aftercare corresponding to your needs.”

- Final questions can address elements that have not been mentioned during the interview.

Example: “Is there anything else you would like to add to this interview?”

The researcher needs to make sure to allow enough time for the concluding questions.

After conducting, for example, three or five interviews and starting the analysis, the interview guide can be completed with additional questions or topics emerging from the fieldwork. This should be discussed with the other researchers conducting interviews and documented as part of the research methodology.

The same questioning strategy is applied during focus groups (from ice-breaker questions to concluding questions and thanking participants).

In practice

- Topic lists can be informed by literature, scoping interviews or a theoretical model.
- The support can be structured according to a theoretical framework (e.g. the access to care model of Andersen)³² or a grid (e.g. a SWOT framework or a patient journey) to facilitate the discussion.
- The degree to which a topic list is formalised is left at the discretion of the researcher (e.g. some researchers prefer not to have written questions beforehand to be able to adapt what they say to the participants).¹⁵¹
- When several researchers conduct the data collection, the topic list and the questions need to be written and agreed upon to ensure consistency during the data collection.¹⁵¹

Resources

Templates for interview guides / focus group guides in Dutch and French are available on the KCE Extranet <https://extranet.kce.be/index.php/s/TPQAWKGWMG3nHf7>

The toolbox of the NEED project (including interview guides) is available on the KCE website:

<https://kce.fgov.be/en/publications/all-reports/need-research-toolbox-instruments-and-tools-for-examining-unmet-health-related-patient-and-societal>

Examples of published interview guides / focus group guides are available via the KCE QRT Library https://www.zotero.org/groups/6199442/kce_qrt

12.4.3 Should the same data collection material be used for interviews and focus groups?

Yes, if

- There is no specific expectation related to the data that will be obtained via the interviews and focus groups, meaning that the research team expects that both data collections will lead to the same findings.
- There is no difference in the theoretical background of the methods, meaning that the same theoretical approach is used for both methods.
- It is also a pragmatic way of approaching the data collection, which can particularly be of interest in RQR.

No, if

- The focus groups and interviews are conceived as part of a triangulation strategy (see section 8.2.1). In this case, it is recommended to have a separate guide for focus groups and interviews as each data collection corresponds to a different research question or a different theoretical approach.¹⁵²
- Using the same data collection material (e.g. the same questions) could fail to identify the respective contributions of focus groups and interviews.



12.4.4 Should enabling techniques be used?

Yes, if

- The participants are not used to express themselves or have poor health literacy, cognitive problems, or concentration problems.
- The group of participants is heterogeneous, with various levels of expertise related to the topic, or there is a power imbalance between participants.
- The enabling techniques can help accelerate the data collection process in RQR.
 - *For a selection of enabling / facilitating techniques and their compatibility with (online) data collection methods, please refer to KCE report 340 bis on enabling techniques.¹⁵³*

No, if

- The research team does not feel comfortable using an enabling / facilitation technique.
- The participants are used to participating in group activities or already know each other.
- The enabling technique is meant to be used for data collection, but the resulting data cannot be used for analysis / the analysis strategy cannot be planned.

Key considerations

- Carefully choose and practice the enabling technique before using it with participants.

Rationale

Enabling techniques, including facilitation techniques and support material (e.g. pictures, photographs), are useful to **make the interactions and collaboration more effective and comfortable, but also for collecting data**. Enabling techniques can pursue different objectives:

- **“Breaking the ice,”** supporting each participant to feel at ease or helping people to get to know each other, which is particularly critical when the same group of participants is likely to collaborate during several months or years.

Example: Rich Picture¹⁵³

- Overcoming the **loss of concentration**.

Example: when using the Problem Tree, participants circulate in the room to add sticky notes on a “tree”.¹⁵³

- **Collecting and analysing data**, e.g. facilitating the elaboration of a common language, identifying gaps and solutions, or building a consensus.

Example: in KCE study 361 on access to health care for people with intellectual disability, interviews were conducted with persons living with intellectual disability.⁷ To help them structure and focus their thoughts during an online interview, a patient journey was used as a way to structure the interview.¹⁵³

Audiovisual methods, included in the enabling techniques, can be used as both alternative or complementary methods to collect and generate data (not to be confounded with the use of visualisation techniques for presenting findings). In RQR, the use of video or photography can facilitate the intensive periods of data collection.^{29, 153}

Example: Singh et al. relied on visual summary maps of the individual interviews but also maps representing similar settings and sites, which were combined to form “meta-maps” representing the group’s experience.¹⁵⁴

At KCE

- A selection of enabling techniques is presented in KCE report 340 bis.¹⁵³

12.4.5 Should the data collection material be pilot tested?

Yes

- It is useful to conduct a pilot of the material that will be used for the data collection to test, assess and validate the format and the appropriateness of the topic guide or the interview guide. The pilot consists in a formal team meeting after three interviews, where the research team discusses the interview guide and adapts it if necessary. The same applies to focus groups: material should always be tested but could be done after the first group.
- It is part of the quality of the methodology.

Key considerations

- Revision of the documents by the research team is not piloting the tools for data collection, as it will focus on grammar and spelling, not on the structure, the completeness of the support and the relevance of the questions.
- The pilots should preferably be organised with participants sharing the same characteristics than the intended target group.
- Pilot interviews can be included in the dataset, as the interview guide can evolve during the project (do not forget to report adaptations in the report).
- The pilot is also a training opportunity for (novice) researchers.
- The pilot should mimic the data collection procedure: if the topic guide is planned for a group, the research team should apply it on a group. If the topic guide is planned for an individual interview, the research team should practice it on an individual participant.
- After the pilot, adaptations can be made to the data collection material.

At KCE

- Before conducting the pilot, it is a good practice to ask the **KCE communication cell** to read all the documents (interview guide and / or invitation letter) to ensure that they are adapted to the target group, whether patients or professionals. The research team needs to plan sufficient time for this revision.

12.5 How to run the data collection?

This section addresses the running of the data collection in the context of an interview. Principles described here apply to any data collection with adaptations (interviews, focus-groups, forum, nominal groups, Delphi process): specificities are highlighted in the chapters detailing each data collection method.

12.5.1 Should moderation and interviewing always be performed by qualitative researchers?

No, being able to conduct an interview or moderating a focus group relies on **posture** rather than on the mastering of a research method. However, having some hands-on knowledge on the specificity of data collection in QRM and/or previous experience, or even a form of mentorship from a more experienced expert, will help researchers to collect proper qualitative data. **Conversational techniques** are useful during a qualitative data collection activity. Additionally, previous knowledge of the field will help researchers interact properly with the participants (although a naïve stance could also be of interest).

► To know more about running an interview, go to section 12.5.4



Key considerations

- A research interview requires another posture than a “simple” discussion or a therapeutic interview, as the aims are different.
 - ▶ *Go to Chapter 7 Ethical issues specific to qualitative health research*
- For researchers with no or little experience in conducting interviews, it is good practice to conduct the first interview(s) together with an experienced researcher and to have a debriefing afterwards. For example, it is interesting to read the transcript to examine how the questions were asked.
 - ▶ *To know more about the competences of an interviewer when running an interview, go to section 12.5.4*
- Similarly, moderating a focus group discussion is different from chairing a meeting. The same advice as for interviews applies.
 - ▶ *To know more about the role of a moderator, go to section 15.7.1.1*

12.5.2 Can the data collection benefit from an online approach?

Caution: this section only discusses primary data collection using an online method (interviews, focus groups, mail interviews and forums). Online data collection should not be confused online sampling (participants are selected to participate because they exhibit some characteristics that can be identified online) or with online recruitment (participants are invited to participate via social networks).⁴⁷

- ▶ *For the use of qualitative open data as a QRM, go to Chapter 11*
- ▶ *For details about data collection methods with an online approach, see section 12.5.2*

Yes, if

- The QRM occurs in the context of a RQR where data needs to be acquired quickly.
- There is a large geographical dispersion of the participants, the participants have mobility problems (e.g. because of their health issue), the issue is dispersed among the population, or the participants are busy.
- The research team can build trust with the participants.
- There is no other method that can give the participants the opportunity to contribute to the data collection.
- The technological infrastructure allows for smooth data collection.
- IT support is available for the participants, including for pretest.
- The issue to be discussed requires a form of anonymity that can be offered by the online data collection (e.g. an online interview with the camera turned off).
- The absence of synchronicity in the data collection is of added value, as it allows participants to contribute during their own time (only applicable to forums and mail interviews).

No, if

- The target group is expected to have low digital literacy or no material resources (e.g. elders, marginalised groups, no equipment for connecting online). Attention needs to be paid to literacy in general, as the participants may be required to write in the chatroom.
- The research team has no experience with moderating an online focus group or conducting interviews online.

- The practical arrangements for participation cannot ensure sufficient privacy for the target group (e.g. asking a nurse to join an interview on their work environment from their workplace).
- The target group has health conditions preventing them from effectively using technology (e.g. persons with behavioural or cognitive problems).
- Meeting the participants online poses a risk for the safety of the researchers, who cannot properly address the emotional issues that may arise during the interaction.
- There is a research need to access the physical reality of the participants or their living / working environment.

12.5.2.1 Added value of online data collection

“One of the lasting methodological legacies of the COVID-19 pandemic has been the normalisation of video interviews as a standard component of the qualitative research toolkit” (retrieved from Rzeszewski et al., 2024, 103295).¹⁵⁵

Over the last years, the use of online tools for qualitative data collection has been rising and different studies have compared the benefits and risks associated with online data collection methods. If, in the early years of using online tools for data collection, face-to-face was still referred to as ‘the gold standard’ in social sciences, experiences at KCE have resulted in a **shift from face-to-face to online methods** over the years.

The first advantage of online data collection is its **efficiency and convenience** when compared to in-person data collection methods.¹⁵⁵⁻¹⁵⁹ It allows for a faster acquisition of data (qualitative as well as quantitative). When the online data collection is asynchronous, implying that participants provide written answers, transcripts are no longer needed.¹⁶⁰ The argument of efficiency is even used for enlarging the sample size in online data collection.^{158, 159}

Savings in cost and time would allow for qualitative research to be conducted within quantitative trials without undue pressure upon the overall budget, providing greater understanding and context of the quantitative findings (retrieved from Krouwel et al. 2019, page 7).¹⁵⁹

The second advantage is that online data collection allows for a **large geographical spread**.^{155, 156} As no travel is necessary, it makes it possible to recruit participants from remote areas but also makes it much easier to set up international studies (written material provided by the participants was found particularly suitable for studies using multiple languages).^{160, 161} Moreover, there is **no cost or waste of time in case of no-shows**.⁴⁷ Online data collection also has added value for research on topics that are **highly dispersed among the population**, like rare diseases or the use of a specific health service, or when the participants have mobility problems.¹⁵⁹ Yeo et al. also praise online data collection as a suitable approach for ‘busy’ target groups, e.g. health care professionals, parents, or policymakers.⁴⁸ From the perspective of participants, online data collection is also perceived as more convenient, cheaper, and more flexible than face-to-face data collection.^{155, 156} Online data collection also allows the **involvement of hard-to-reach groups**; for example, online forums or blogs can be used to identify persons sharing the same interests before inviting them to participate in an online data collection activity.¹⁵⁷ Online methods – particularly when deployed in the context of participatory action research – can enhance the inclusion of some marginalised^v populations in research, providing they are offered the necessary resources for effective participation.¹⁶²

Additionally, when the topic under investigation is particularly sensitive or involves entering potentially dangerous situations, some found that online data collection is perceived as **safer for both researchers and participants**.^{48, 155, 159} For example, Yeo et al. reported the use of online interviews for investigating eating disorders where *“the physical presence of a problematic body can prove problematic”* (retrieved from Yeo et al. 2014, page 182).⁴⁸ This is even more the case when the camera is not activated or when the data collection is done through a chatroom, a forum, or by email.⁴⁷ Some

^v However, keep in mind that marginalised populations represent a highly diverse and heterogeneous group, where some may benefit from online data collection while others may be excluded.



also found that the absence of nonverbal cues could prevent erroneous interpretations by the researchers when reading the material. Moreover, it was found that the **guarantee of anonymity** appears to increase the candour of answers and, in case of written interviews, the length of the answers in comparison with face-to-face interactions.⁴⁷ The **asynchronous character** is viewed by some as presenting added value as it allows for more reflectivity and introspection.¹⁶⁰ The researchers can then review the answers and probe the participants with more focus and depth.¹⁶⁰

► For asynchronous online data collection techniques, go to Textbox 4 or Chapter 16

As the **online space is “neutral”**, it can also be safer, as the researchers do not have to enter an unfamiliar place (e.g. by conducting interviews at the participant’s home) and the participants are not “forced” to go to a place chosen by the researcher (e.g. an interview in the hospital where the participant receives medical follow-up).^{155, 159} Additionally, when the data collection has to be planned in the evening or at night (e.g. because the respondents are busy during the day), it may also be safer to organise it online.⁴⁷

Finally, it should be mentioned that the possibility of conducting interviews in the **metaverse** by using virtual reality meets with increasing interest but also raises questions. Metaverse platforms differ from videoconference platforms as they aim to create a ‘*place illusion of embodied co-presence with other people inside an immersive digital environment*.’ Rzeszewski et al. root their questioning in the notion of social virtual reality where users have opportunities for interaction and socialisation in a “*shared, interoperable and immersive virtual environment*”.¹⁵⁵ Interactions occur through an avatar. As the participants are immersed in an “environment,” they are more likely to experience the interview as being like a face-to-face interview than to an online interview. Participants reported being immersed and feeling presence, although the use of avatars complexified the relationship. The experience was perceived as positive overall, but the technological and physiological limitations need to be considered. At the time of drafting this report, this approach remains quite innovative; in future, attention should also be paid to biases and limitations.

Textbox 4 – Asynchronous interviews using email⁴⁷

Asynchronous interviews using email consist in **sending open questions to participants** and to engage in a **back-and-forth email exchange**, with the researchers asking additional questions based on the answers.

This approach is useful for persons faced with verbal, hearing or cognitive impairment who cannot take part in a face-to-face interview. Questions can be answered at the participant’s convenience. This approach also allows for more reflexivity both in the participants and in the researchers. It generates more personalised answers and helps the researchers to dig deeper into issues raised by the participants. There are **practically no costs associated** and there is no need for transcription, making it a cheap data collection method.

There is no need for the exchange to be fast paced, which can be both a benefit and an inconvenience. Time lag is often mentioned as the first limitation.

However, there is a higher risk of answers that are **socially desirable** and of overall **lower quality**. Non-verbal data is lost, and no knowledge questions are possible as the participants can look for answers before replying. It is easier to ignore questions than in a direct face-to-face interaction. As this is an online method, there are also concerns about the (grey) digital divide^w it could induce.

Examples of projects using email interviews are those led by the European Observatory of Health Systems, the WHO or other international research centres to collect qualitative data on health

^w Grey digital divide refers to the elderly populations falling far behind in using (healthcare) technologies such as smartphones, computers and other IT interfaces in a digital world.¹⁶³

services (e.g. palliative care and end-of-life care, mapping the well-being economy policies, health system performance assessment and governance...).

12.5.2.2 Key considerations and biases

It can be tempting to switch to data collection via online tools, given the significant advantages on a practical level and the inexistent costs. **However, opting for an online approach solely based on its practicality and costs is certainly not recommended. This choice must be based on the same methodological reflection that precludes the choice of any other data collection method.**¹⁶⁴ As stated by Pocock et al., ‘traditional’ and virtual data collection methods share numerous similarities, implying that *“both require congruence across all aspects of study design (Braun et al., 2017b); benefit from thorough planning and piloting to ensure trustworthiness, reliability, and validity (Hewson, 2017); and are underpinned by the need to consider study design and conduct when analysing, interpreting, and concluding findings (Salmons, 2012)”* (retrieved from Pocock et al. 2021, page 2404).¹⁵⁶

Online data collection **hampers interactions** between participants and nonverbal cues can be lost.^{47, 159, 165} Qualitative research is particularly concerned with the unconscious, nonverbal, and emotional cues that are shared during an interaction.⁴⁷ Online data collection can also negatively impact the preferences, understanding and engagement of participants.¹⁶⁶

Participants (including researchers) are also **more likely to be distracted or less concentrated**, both during individual and during group interactions (the latter being influenced by the group size).^{47, 160} During video calls, users have to look off centre to ‘make eye contact’ and frequently see themselves on the screen, which encourages them to talk to themselves.¹⁵⁹ The situation can be even more complex in group calls: *“on video, gaze must be directed at the camera to appear like making eye contact with an observer, and during conferences with 3 or more people, it can be impossible to distinguish mutual gaze between any 2 people”* (retrieved from Lee, 2020, online).¹⁶⁷ This can induce what has been described as “Zoom fatigue”, *“a tiredness, worry or burnout associated with overusing virtual platforms of communication”* (retrieved from Lee, 2020, online).¹⁶⁷ It seems to be a vicious circle: as there are less interactions in online activities, participants feel less stimulated, which causes them to be more easily distracted. Rzeszewski et al. point out the **‘disembodied’ character** of online interviews, which makes it difficult to engage with participants.¹⁵⁵ Cited by Krouwel et al., Weller uses the term ‘talking heads perspective’ to reflect the limited access to body language. This impacts the ability of the interviewer (or moderator) to reassure or comfort participants when they experience distress during the interactions (e.g. when the participant starts crying).¹⁵⁹ When moderating groups online, this can be even more complex, leaving out participants who might then feel out-talked by others.¹⁶⁰ When the online data collection takes place on a platform with a chatroom, some participants might also start a separate discussion through instant messaging, thereby impacting the group dynamic (because the chat discussion can end up taking precedence over the live discussion).¹⁶⁰ When it comes to hybrid focus groups, the researchers have a **different connection with participants present onsite than with those offline**: they have more opportunities for informal exchanges and establish a different relation in person.

While **hybrid focus groups** may offer the benefits of online data collection, they are **also more challenging for moderators and participants**.¹⁶⁸ For the moderators, it implies connecting two groups of participants and ensuring that they all have the same opportunities to express themselves. It is easier to exclude those attending online, notably because of the loss of non-verbal communication. Participants may find it hard to engage with each other for the same reasons, but also because those online have trouble identifying who speaks from the meeting room and vice-versa. There is also a risk of people talking over each other, and of online participants not having the same opportunities of expressing themselves (online participants have icons, while those onsite can directly intervene in the discussion). Additionally, in case of a hybrid focus group, researchers could obtain more social and emotional data from participants attending in person than from those attending online, leading to an



imbalance of information. The risk of distraction is also higher than in a full online discussion, and the meeting may take longer.¹⁶⁸

Some also felt that not being able to see the living environment of the participants entailed a **loss of contextual data**.^{155, 160} However, Krouwel et al. also experienced that participants often preferred to have face-to-face interviews away from home, which means the environment where the interview took place was, per definition, not the living environment of the participants.¹⁵⁹ The importance of the environment when conducting qualitative data collection with professionals raises different questions. Having the possibility of seeing their working environment could be interesting for research purposes (see e.g. KCE report 394 on palliative care)¹⁶⁹ and, in that sense, online data collection may not be appropriate.

Another problem with online data collection is the **increased risk of being interrupted** (by family members, pets, colleagues), with some participants more likely to answer their phone during group discussions.¹⁵⁹ This might be more frequent when the group is too large, when participants have difficulties engaging with each other, and in hybrid discussions.^{160, 168}

When the data collection is asynchronous or when the participants are allowed to remain anonymous (e.g. by turning off their camera), some authors raise concerns about **establishing the respondents' identity** (i.e. how can we be sure that the person joining the discussion is the person who agreed to participate?).⁴⁷ The lack of visual connection precludes the use of 'traditional' interviewing techniques, requiring adaptations from the researchers to manage silences and non-responses.⁴⁷ For written forms of online data collection, not having to transcribe also has negative sides, as editing may still be needed. More importantly, the research team needs to understand the use of punctuation signs, emojis, emoticons or intentional misspellings, as these elements are part of the message that the participants want to share and should not be misinterpreted.

A **selection bias** occurs, as the participants need to have sufficient digital literacy, the required IT equipment, and a stable Internet connection. This could be even more true for a hybrid format, where those with the necessary equipment could choose to attend online while those who do not have to travel to the meeting location. Even when the researchers provide the necessary resources, those without prior access to technologies may still be excluded, as the use of those technologies may require **digital skills** that some participants do not master.¹⁶⁶ Additionally, Internet use and familiarity with technologies is also influenced by age, gender, language, culture, and ethnicity.⁴⁷ Consequently, the **digital divide**^x is a major limitation that needs to be considered when opting for an 'all-online' data collection.

The **risk of drop-out / no-show is higher online**, requiring oversampling to ensure that the minimal expected sample size is reached. With some groups, this can be difficult to achieve.⁴⁷

A final concern is the **quality of the data** obtained via online collection compared to face-to-face methods. Abrams et al. found that face-to-face focus groups and online focus group generated the same data richness (however, this does not imply that there is no bias associated with online data collection methods).¹⁶¹ Online and face-to-face focus groups were seen as equally suitable for word associations and lists of ideas.⁴⁷ Daniels et al. reported that studies directly comparing the quality of data obtained during face-to-face interactions and online interactions showed very **few differences in the richness of the collected data**.¹⁶⁵ Both these studies compared synchronous data collection. When comparing different modes of conducting interviews, Krouwel et al. found that face-to-face interviews were longer, used more words and entailed deeper discussions.¹⁵⁹ However, when further analysing their data, they found that both approaches generated the same data volume (words) and the same codes. Of particular interest, they therefore concluded that the face-to-face interviews generated more individual and personal statements about the topics investigated.¹⁵⁹

^x Digital divide refers to the gap between people who have adequate access to information communication technology (ICT) and people who have poor or no access to ICT (Soomro et al., 2020).



12.5.2.3 Modalities of data collection

In practice (list adapted and completed from Pocock et al. 2021, page 2406)¹⁵⁶

- Consider the 'best fit' method and technology for the population and topic.¹⁵⁶
- Technology considerations should involve cost, user-friendliness, accessibility, available features, and security settings.¹⁵⁶
- Limit the number of online data collection activities per day to prevent fatigue.
- Adapt the length and the group size of the data collection activity when online (shorter and smaller than in real-life).
- Over-recruit to compensate for high attrition rates.
- Consider mixed approaches (face-to-face AND online data collection) to avoid selection bias.¹⁵⁹ This could be of particular interest for interviews.
- **Never use a hybrid mode for group-based data collection, i.e. having participants to the same group online and offline** (see 15.8.1).
- Draft a short text to introduce the research team in case of asynchronous data collection or when there is no direct interaction.⁴⁷
- Develop protocols for the research team, detailing standards for upholding privacy and confidentiality (e.g. use of headphones, being alone in the room), professionalism (e.g. wearing appropriate attire, being aware of what is visible in camera view), and how to respond to challenges (e.g. develop a technical support guide).¹⁵⁶
- Have a contingency plan to address technological problems and scheduling conflicts.¹⁵⁶
- Before the online data collection
 - Inform the participants about technical requirements needed to ensure smooth data collection.
 - Assess technological abilities of participants and provide technology training.¹⁵⁶
 - Inform participants if they will need to turn on their camera.
 - Inform participants if they will need to have a profile picture / use their own name.
 - Inform participants if the meeting is to be recorded.
 - Offer a demo session to the participants before the activity (this can particularly be of interest for online group activities).
 - Conduct practice sessions to ensure all researchers are comfortable with the audio-visual platform being used.¹⁵⁶
 - Connect 30 minutes in advance for a last IT check.
- When starting the online data collection
 - Provide clear instructions about the technology and communication.
 - Provide clear instructions about the use of the chatroom to prevent parallel discussions occurring.
 - Dedicate a researcher to the management of the chatroom.
 - Plan time to explain the features of the software at the beginning of the activity.
 - Never assume that participants are sufficiently skilled to master the technological aspects.
 - Keep a back-up audio file of the online interview or focus group discussion.¹⁵⁶



12.5.3 How to prepare for the interview?

Preparations for the interview (or the focus group) encompass the recruitment of participants and the making of appointments, becoming knowledgeable about the research topic, including learning the interview guide by heart, anticipating questions of participants regarding the research project, access to a physical space where the interviews can take place and preparation of the recording equipment.¹⁷⁰ Well-functioning recorders are crucial, so batteries, tapes and microphones should be carefully checked. It might be advisable to have a back-up recorder (even when the data collection is organised online). The researchers should have a field notebook, a pen, and the topic list / guide for the data collection.

If the interview follows a previous data collection activity (e.g. the participant completed a questionnaire online), it might be interesting to read their answers before the interview (if relevant regarding the research question and the objective of the interview).

Table 20 presents the preparation for an individual interview, with a distinction between face-to-face (offline) data collection and online data collection. The same applies to group interviews.

Table 20 – How to prepare for an individual interview?

	Face-to-face	Online
	(outside KCE offices) Submit a KCE mission request (at KCE) Do not forget to inform KCE support for access badges	Before the interview, inform the participants about the software that will be used, with explanations on how to install and use it if necessary. Plan a demo session (if needed). Book a meeting room with sufficient time before and after the appointment to avoid being interrupted by colleagues. For privacy reasons, avoid conducting interviews in your KCE office unless you are certain to be alone for the duration of the interview. If you do, • Always close the door to your office • Put a "Do not disturb"-sign on the door
Equipment	• Digital tape recorder + spare batteries • OR fully charged smartphone (provided that this smartphone has a sufficient level of protection to guarantee privacy) • Field notebook & pens	• Computer with charger (not on battery) • Webcam (use the computer webcam to facilitate the visual contact) • Microphone • Headphones (if needed) • Field notebook and pens
Infrastructure	• Chairs need to be placed to allow participants to see each other in a comfortable way. • Quiet place where the interviewee feels at ease • Have a surface where to position the recorder • Avoid the presence of third parties* • Have a box of tissues at hand	• When working with multiple screens, always face the screen that has the camera • Use split screens to visualise your topic guide to avoid moving from one page to another, • Choose a neutral background (attention that blurred background could be disturbing) but with warm elements (e.g. a plant always gives a feeling of warmth).

Interview package	• Interview guide (in the appropriate language) • Informed consent forms (one for the interviewer, one for the participant, in the appropriate language) • Participant reimbursement (if applicable)	• Interview guide (in the appropriate language) • Digital informed consent form to be completed and signed via Adobe Sign)** • Participant reimbursement (if applicable)
--------------------------	--	--

*A third party can be present (e.g. person of trust, tutor, parent).

**For practical reasons, the informed consent can be sent before the interview: the participant can already sign it and send it back to the researcher, unless there are questions remaining. At the beginning of the interview, the researcher should check that all the information, even when the consent was signed, are clear. At the end of the interview, the researcher completes and sends the document back to the participant.

Retrieved and adapted from Mack, 2005¹⁷⁰

12.5.4 How to conduct the interview?

Informed consent should be obtained from each participant before starting the interview. Also, **permission should be asked to record the interview**, with explanations about how the recording will be used and stored. Mobile phones should be switched off^y during the interview: this avoids unexpected interruptions and give importance to the participant's testimony.

The research aims should be briefly repeated (even if they were already explained during the first contact with the participants as an argument for participation). During the interview, all the themes of the topic list or questions in the interview guide need to be addressed. Participants are probed for elaboration of their answers in order to learn everything they want to share about the research topic.¹⁷⁰

To dig deeper or redirect the discussion, probing techniques can be used:

- Repeat the question, but with a different wording

Example: "What are the barriers to..." can become "What prevents you from..."

- Summarise the relevant aspects of the answer of the participant, in an interrogative way

Example: "To sum it up, what you're saying is..."

- Probe explicitly

Example: "What do you mean?" or "Could you give me a second example?"

- Purposive probing

Example: "Why was it that you...?" or "What happened then?"

- Repeat the few couple of words in an interrogative way.

Example: "Participant: (...) I think it is dangerous, and I don't trust doctors." Interviewer: "You don't trust doctors?"

- Introduce a short silence.
- Verbalise emotions.

Example: "I can see that thinking of that discussion makes you very angry."

The interview is closed by **thanking the participant(s)**. It is also interesting to **explain the next steps** of the project, when the results will be available and how the participant(s) can obtain them.

^y Unless they are used for recording purposes. It is therefore not advised to use personal mobile phone for recording interviews during personal and sensitive data are shared (e.g. with patients) for privacy reasons.



An experienced interviewer would be able to decide whether to follow the flow of the interview or to return to the sequence of the interview guide.

Theoretical example: after the first questions, the participant already discusses the third topic. The researcher may decide to continue probing the participant about this topic and come back later to the first topic.

During the interview, **the researchers should not share their individual opinions, advice, and thoughts about the topic**. They need to avoid influencing the orientation of the discussion by sharing too much information retrieved from other interviews. Depending on the research topic and the approach to data collection and analysis, the researcher may present elements of previous interviews, in an anonymised way and share it with precautions if the researchers want to confirm / disconfirm these findings.

Theoretical example: in the interview with participant A, the participant explains how the team of the community health centre helped organise childcare for her toddlers when she had a heart surgery. The researcher then conducts an interview with participant B, who attends the same community health centre. The researcher wishes to know if the team provided the same kind of help to participant B. Instead of saying “participant A told me that XXX,” the researcher will ask e.g. “to which extent did the community health centre help you to organise care for your children when you were sick”?

After the interview, the researchers should **store the recording in a secured location** (preferably with a back-up copy stored in a different place). Each recording should have its own identifier. Researchers need to refer to their institutional policy for the rules of storage and archiving of the original data.

Textbox 5 gives twelve tips for conducting qualitative research interviews.

Textbox 5 – Tips for conducting qualitative research interviews

- Tip 1: Identify when qualitative research interviews are appropriate.
- Tip 2: Prepare yourself as an interviewer.
- Tip 3: Construct an interview guide and test your questions.
- Tip 4: Consider cultural and power dimensions of the interview situation.
- Tip 5: Build a relationship with your respondents.
- Tip 6: Remember you are a co-creator of the data.
- Tip 7: Talk less and listen more.
- Tip 8: Allow yourself to adjust the interview guide.
- Tip 9: Be prepared to handle unanticipated emotions.
- Tip 10: Transcribe the interviews / review the automated transcription to complete it as soon as possible.
- Tip 11: Check the data.
- Tip 12: Initiate analysis early.

Retrieved and adapted from McGrath et al. 2019¹⁷¹

At KCE

- ▶ *Procedures for the storage of qualitative data is available in the KCE Project Guide.*
- ▶ *Procedure for a transcription via an external service is available in the KCE Project Guide.*

12.5.5 How to take notes during an interview?

It is highly recommended to **take back-up notes** during the interview. The interviewee's behaviours and contextual aspects of the interview are observed and documented as part of the field notes; these will be expanded as soon as possible after each interview, preferably within 24 hours, while the memory is still fresh (see section 9.4).¹⁷⁰ Textbox 6 provides advice for an effective note-taking.

Textbox 6 – How to effectively take notes during an interview or focus group

Before

- Read the interview guide to familiarise yourself with the questions that will to be asked.
- Print the interview guide for yourself – leaving blank spaces in the interview guide to make room for adding personal notes, comments on the questions to help you...
- *(when the participants already filled a questionnaire)* add notes from the questionnaire to help focus the interview (e.g. they said in the questionnaire that they lacked support, in the interview it can be further investigated).

During

- If possible, write the answers directly next to the questions if the interview guide allows it.
- Write down the questions that participants ask you so that you can answer them directly and keep track of your answers.
- Make a note of what the participants said and how (e.g. track the main points of what they were saying and try to catch phrasing or expressions that are of particular interest...). This can also help to formulate probing questions.
- If personal thoughts emerge, write them down separately and identify them as such.

After

- Immediately: write down your personal feelings and the key points you have retained
- Within 24 hours: digitalise your notes or handwrite more clearly, clearly distinguishing between what was said by the participants and personal reflection.
- When copying the notes:
 - No summarising – even if redundant,
 - No interpretation (at this stage),
 - Respect the structure of the discussion,
 - Write down questions of the interview guide,
 - Do not group responses under thematic headings,
 - Point out what is not understood.



12.5.6 What are memos and summaries?

Memos are a written form of abstract thinking about the data, hereby contributing to the iterative process of data collection and analysis.²¹ They are operational notes about the data, emerging hypotheses about relationships between labels and themes and the properties of these labels and themes. McMahon and Winch recommend systematically writing a memo after each data collection activity to record how the researcher shapes the activity.⁸² Memos also allow the researchers to stop and think about their data, allowing them to go beyond descriptive labels and themes to think about how these can be further developed in the analysis. They contribute to the comparison of the data. To put it simply, memos help to extract meaning from the data.¹⁷² Additionally, memos help the researchers to keep writing during the whole research process.⁸¹ On the practical side, they could also help to map research activities (including documenting the decision-making trail).¹⁷²

Memos are not limited to the data collection or analytical part of research. They can start from the very beginning of the project, making up a kind of 'research diary' where researchers can document their personal journey (see section 9.4).¹⁷² It helps maintain 'momentum', i.e. it *"provides a mechanism by which the perspective of the researcher can be recorded for later critical review or confirmation. Memos are contemporaneous, a snapshot of thought processes at a given stage of the research that facilitate an understanding of what perspectives were held and why decisions were made. Such a record obviates the need to go over old ground, reconsidered previous thought processes or locate threads of analytical cloth that would otherwise be lost"* (retrieved from Birks et al., 2008, page 71).¹⁷²

Summaries are syntheses of the material, without any interpretation or analysis. Summaries could take the form of a vignette (see section 22.1.3.3), to present the key elements in a narrative form.⁴⁰ Summaries are also useful to brief other researchers about the sample and the profile of the participants. To write useful summaries, *"the general principle should be to include enough details and context so that the analyst is not required to go back to the transcribed data to understand the point being made, but not include so much that the matrices become full of undigested material (...)"* (retrieved from Spencer et al., 2014, page 309).¹⁷³

12.5.7 Should interpreters be used for the data collection?

Yes, if

- The participants are **not fluent in any of the languages** used by researchers (including sign language).
 - The research team may decide to collaborate with interpreters. We refer here to professional interpreters and intercultural mediators, and not to family members / relatives that could play this role.
 - In this situation, the researcher asks the question, the interpreter translates, the participant replies, and the interpreter translates the answer. The process is asynchronous.
 - In addition to the normal process for data collection, the researcher needs to brief the interpreter about the objectives and the content before the research interview. During the interview, the researcher needs to address the questions to the participant and not to the interpreter. After the interview, the researcher debriefs with the interpreter.

Example: During KCE project 257 on access to health care for undocumented migrants, interpreters were necessary to get access to some undocumented migrants.⁵² Without interpreters, the final sample would have been limited to undocumented migrants able to speak French (undocumented migrants rarely spoke Dutch before coming to Belgium), a common language in some sub-Saharan and North-African countries. The experiences of those with language barriers would have been absent from the data collection, leading to biased findings.

- The participants are **only fluent in either Dutch or French** and the topic requires a meeting involving participants from both linguistic communities.^{z aa}
 - As not all health care professionals or patients are fluent in both languages, it may be necessary to ensure a simultaneous translation. The interpreter voices over the researcher almost synchronously.
 - Before the meeting, the research team should brief the interpreters and provide them with support documents to help them understand the topics. All material communicated to the participants should be shared with the interpreters. Any specific vocabulary should be explained before the meeting. After the meeting, a debriefing is planned with the interpreters.

Example: During the KCE project 374 on the medical organisation in case of CBRNe incidents, as the topic was complex, with actors from different fields, it was decided to organise the final focus group discussion with the support of interpreters. The presence of interpreters allows participants to build on each other's discourse, leading to richer exchanges than without the support of interpreters.²⁷

No, if

- There is a limited period for collecting the data (e.g. RQR).
- There are unsurmountable practical difficulties.

In practice

- Plan at the beginning of the project if you intend to involve interpreters.
- Interviews assisted by interpreters take longer to plan and to conduct.
- Brief interpreters about the topic and share supporting documents with them before the meeting.
- Interpreting could be organised online via Zoom (separate channels for interpreters).

At KCE

- ▶ *The procedure for involving interpreters is available in the KCE Project Guide.*
- ▶ *Contact the project manager for the practical aspects.*

For more about qualitative data analysis, go to Part 4.

- ▶ *For the frequently asked questions in Qualitative Data Analysis, go to Chapter 19*
- ▶ *For the theoretical approaches for Qualitative Data Analysis, go to Chapter 20*
- ▶ *For the Analytical Journey, go to Chapter 21*

For more about reporting qualitative data, go to Part 5.

^z For bilingual meetings with participants who need interpreting in sign languages, it can be necessary to have interpreters in Dutch sign language and French sign language.

^{aa} German is the official third language in Belgium. To date, there is no KCE project where interpreters assisted for data collection with participants speaking German. During site visits in the German community, some professionals interpret on behalf of their colleagues. Stakeholders and policymakers usually speak French, but this is less frequent among patients and professionals.



13. MORE THAN WHAT PEOPLE SAY: NATURALISTIC OBSERVATION

Observations are mostly used in ethnography, a discipline rooted in social and cultural anthropology. Ethnography implies that the researchers are being **directly immersed in the living environment** of the participants (e.g. a nursing home or a hospital ward).¹⁷⁴ When applied to health sciences and public health, ethnography allows for better understanding and interpreting behaviours and attitudes of a group of participants sharing the same “culture”, that is a group of individuals (e.g. a team of nurses or a patient association) who share common values, meanings, habits and experiences.¹⁷⁵ During the immersion period, observations and other data collection techniques help the researchers “to produce a comprehensive account of the social phenomena that occurred during the research period”.¹⁷⁴ Because they are immersed in the environment of the participants, the researchers are able to produce account of actions, behaviours, interactions, events...with the perspective of those belonging to the group.¹⁷⁴ This allows to obtain **data that are not accessible via other data collection techniques** such as semi-directive interviews or focus groups.^{174, 175} Ethnography was, for example, used to understand the ethical, legal and professional accountability of nurses in emergency departments¹⁷⁶, the communication culture of nurses in cancer care¹⁷⁷, or the teamwork in antimicrobial stewardship.¹⁷⁸ At KCE, only observations are used, as a data collection technique.

13.1 Should the study include observations?

Yes

- To collect data on naturally occurring behaviours in their usual contexts.¹⁷⁰ Observation also captures the whole social setting in which people function by recording the context in which they live¹⁷⁹, their use of a specific equipment or device, etc.¹⁸⁰

Theoretical example: observing how patients interact with the information screens in the hall of a hospital.

- To check whether what people say they do is the same as what they actually do (when there is an interest for more than what people say).¹⁷⁹ What people perceive they do and what they actually do are, however, both valid in their own right. They just represent different perspectives on the data.¹⁷⁹ Observations capture “real behaviours” rather than “self-reported behaviours”, that is behaviours / discourses adopted by individuals under the influence of social norms or pressures.¹⁸⁰

Theoretical example: observing how medical doctors provide health prevention advice to patients with intellectual disabilities.

- To study the working of organisations and peoples’ roles and functioning within organisations.¹³

Theoretical example: observing how work is organised between nurses, medical doctors, and care assistants in a hospital setting.

- To uncover behaviours or routines of which the people observed are not aware themselves.¹³ What the researcher considers an important finding may be a self-evident aspect of daily life from the participants’ point of view. Observations help to collect data on “*subconscious or instinctive actions, behaviours, that are not obvious or of which participants may not be aware, things that are so every day or “normal” that people find them it hard to convey in words*” (retrieved from McNaughton-Nicolls et al., 2014, page 245).¹⁸⁰

Theoretical example: observing how patients with mobility problems manage their journey from their home to the GP practice.

- To understand data collected through other methods (e.g. interviews), and to design the right questions for those methods.¹⁷⁰

Example: observing the process to access the medical unit in a prison helped understand the barriers faced by professionals and by prisoners.¹⁸¹

- To elicit complex interactions or processes which would be difficult to describe accurately or fully.¹⁸⁰

Theoretical example: observing how different professionals from diverse backgrounds interact when taking care of a polytrauma victim in a car accident.

No, if

- Accessing the setting is too complicated.
- The context in which the observation would need to take place can compromise the safety of the researchers.
- The presence of the researchers will jeopardise the usual way of acting of individuals.
- There are issues related to ethics and privacy that cannot be solved (e.g. obtaining consent).
- Organising the observations would take too much time and / or mobilises too many resources to reach sufficient data.

So far, no observational studies have been conducted at KCE, although observations can be useful in health services research and are – to some extent – used in the scoping phase of projects.

Example: De Brauwier spent 450 hours observing how older people are taken care of in three Belgian emergency departments as part of her thesis project.¹⁸² She documented 70 health care trajectories of older patients: her analysis helped identify positive and negative factors influencing the management of these patients by the staff of the emergency department.

At KCE

- Observations can be of added value as part of the scoping phase of a project, to help the research team become more familiar with the topic and the setting (see section 5.8).

13.2 What are the strengths of (naturalistic) observation, and for what purposes?

Observing is more than looking around, it is **actively registering information along a number of dimensions**, namely places (physical place or setting), persons (the actors involved) and activities (a series of acts).¹⁸³ Observing means having attention for (1) the detail of the observation, (2) visual as well as auditory information, (3) the time dimension, (4) the interaction between people, and (5) making links with mental categories.⁶³

Unstructured observation illustrates the whole picture, captures context/process and informs about the influence of the physical environment.¹⁷⁹ Observation is also an **ongoing dynamic activity** that is more likely than interviews to provide evidence for processes, things that are continually moving and evolving.¹⁷⁹

Additionally, observation has the advantage of **capturing data in more natural circumstances**.¹⁷⁹ The Hawthorne effect is an obvious drawback but past the initial stages of the researchers entering the field, most professionals are too busy to maintain behaviour that is radically different from normal (see section 8.1).¹⁷⁹

As observations do not require specific training, it can be possible to design a data collection where participants themselves collect data about their environment based on their observations. This is – for example – the case with enabling techniques such as photovoice or walking diagnosis.

Observing includes three steps:

1. **A descriptive step:** the researchers enter the research setting and get a general overview of the social setting.



Theoretical example: in a project aiming to study the organisation of emergency care in Belgium, the researchers first perform descriptive observations in the emergency department of hospitals to get an idea of the general structures and processes characteristic of emergency care.

2. **A focused step:** more focused observations are a step closer to the research question. The aim is to search for relationships or connections between different elements in the research question, for example X is a characteristic of Y, or X is the result of Y.

Theoretical example: in a next step of the project on emergency care, the researchers turn to their research question, which concerns the way cost-effectiveness of emergency care could be attained. The focus of the observation will relate to all costs, and to those which could be avoided.

3. **A selective step:** in this last phase, observations are conducted about a specific aspect of the research question, for which data is lacking.¹⁸³

Theoretical example: in the last step of the project on emergency care, the researchers may have analysed their data (field notes) and have identified a lack of information on one specific category of costs (e.g. cleaning and housekeeping costs) and may therefore decide to perform extra observations in function of this specific aspect.

Observations can have different degrees of structure, ranging from '**completely unstructured**' to '**based on structured observation guides**.' Unstructured observations rely on the collection of data in the form of field notes in a field diary, without maintaining any pre-established categories to organise these notes. The researchers freely record their observations and afterwards transcribe and code it. In (semi-)structured observations, the research establishes **specific areas of observations** before the start of data collection and gathers data in a table or pro forma per observation episode to make sure all the required data is collected.

13.3 Weaknesses of observations

It can be difficult to get **access to the setting**. Observers are often experienced as a threat, especially if the setting is not asking for the research to take place. Observation (and especially participant observation) might lead to knowledge of informal procedures or rules which people do not want uncovered. Also, the researchers can be perceived as a barrier for the normal daily routine in the setting.⁶³ In direct observation, the researchers do not participate in the setting, hence are known as strangers and get only access to the public or formal layers of the social reality. They do not become insiders and will miss inside information because they are too distant from the actors they are observing.⁶³

"Access, then, is not a straightforward process of speaking to the person in charge and obtaining the approval of the ethics committee. It usually involves considerable time and effort and a constant endeavour to strive for 'cultural acceptability' with the gatekeepers and participants in research sites" (retrieved from Mulhall, 2003, page 310).¹⁷⁹

Once inside the setting, there is the **problem of avoiding 'going native'**, i.e. "*becoming so immersed in the group culture that the research agenda is lost or that it becomes extremely difficult or emotionally draining to exit the field and conclude the data collection*" (Mays, 1995, page 183).¹³ Observers can get **emotionally involved** in what they observe and thus lose their neutrality. This bias implies that researchers conducting observations need to enhance their reflexive posture and have opportunities to debrief their work (see Chapter 9 Reflexivity).

Observational data are, more than interview data, **subject to interpretation** by the researchers. As recalled by McNaughton Nicolls et al., "*what we observe is always subject to interpretation*" (McNaughton Nicolls et al. 2014, page 245).¹⁸⁰ Observers have a great degree of freedom and autonomy regarding what they choose to observe and how they filter the information.¹⁷⁹ This is why it is recommended to have several observers but also to ensure that observers can have discussions with fellow researchers and triangulate the data sources.

Observations are **time-consuming** and challenging work at every hour of the day.

It is impossible to write down everything that is important while observing (and participating). The researchers must rely on their memory and have the discipline to write down and expand the field notes as soon and as completely as possible.¹⁷⁰

13.4 How to plan the research design?

Observations are often carried out at the **beginning of the data collection phase**, but the method can also be used at a later stage of the research process, to address questions suggested by data collected through other methods.¹⁷⁰ For example, observations can be conducted alongside interviews to focus on various aspects of the topics or to delve deeper into some results. When conducted at the end of the project, observations may be of interest to explore interactions / elements that were found to be important during the data collection phase. They can also be a form of validation of the findings.¹⁸⁰

Before starting the observations, the researchers should try to find out as much as possible about the site where they will take place.

At KCE

- **Site visits** include (unstructured) observations almost automatically because site visits imply looking around, paying attention to the setting and the interactions taking place as part of the familiarisation with the context of the research topic. Site visits often also include interviews or less formalized talks with key persons on the site. After a number of site visits, the scope of the research project is determined, and precise research questions are formulated (see section 5.8).

13.5 Modalities of data collection

13.5.1 Participant versus direct observation

The role to adopt during observation and the extent to which participants are fully informed are somewhat intertwined.¹⁷⁹ Typically, researchers refer to Gold's typology of research roles:¹⁸⁴

- **The complete observer**, who maintains distance, does not interact and whose role is concealed.
- **The observer as participant**, who undertakes intermittent observation alongside interviewing, but whose role is known.
- **The participant as observer**, who undertakes prolonged observation, engages in all the central activities of the organization and whose role is known.
- **The complete participant**, who interacts within the social situation, but whose role is again concealed. This occurs when the researcher wants to better understand the local perspective, or to avoid calling attention to oneself.¹⁷⁰

Mack et al. describe observing as remaining an 'outsider' and simply observing and documenting events or behaviours being studied, while participating is taking part in the activity while also documenting it.¹⁷⁰ Pure observing without any participation is a situation that seldom occurs because, once a person is present, they are also visible, influence the activities around them and participate to some degree.

"The purpose of participant observation is partly to confirm what you already know (or think you know) but is mostly to discover unanticipated truths. It is an exercise of discovery."(retrieved from Mack, 2005, page 23)¹⁷⁰

In fact, there is nearly always participation involved in observing, unless the researchers are covered behind - for example - a one-way mirror (e.g. this is used for studies in behavioural psychology). In all other cases, the researchers are present in a setting and, hence, inevitably become part of the setting.



13.5.2 Structured versus unstructured observation

Structured observations are associated with the positivist paradigm and aim to record physical and verbal behaviour by means of a list of predetermined behaviours.¹⁷⁹

Unstructured observations are not 'unstructured' in the sense of unsystematic or messy, *"instead, observers using unstructured methods usually enter 'the field' with no predetermined notions as to the discrete behaviours that they might observe. They may have some ideas as to what to observe, but these may change over time as they gather data and gain experience in the particular setting. Moreover, in unstructured observation the researcher may adopt a number of roles from complete participant to complete observer, whereas in structured observation the intention is always to 'stand apart' from that which is being observed"* (retrieved from Mulhall, 2003, page 307).¹⁷⁹

13.5.3 Overt versus covert observation

Covert observation corresponds to two roles in Gold's typology, i.e. complete observer and complete participant.¹⁸⁴ Most authors agree that covert observation is only legitimate in extremely specific circumstances and should be avoided. Mack et al. formulate the following ethical guideline regarding observations: *"when conducting participant observation, you should be discreet enough about who you are and what you are doing that you do not disrupt normal activity, yet open enough that the people you observe and interact with do not feel that your presence compromises their privacy"* (retrieved from Mack et al. 2005, page 16).¹⁷⁰

As with all QRM, researchers must also protect the identities of the people they observe or with whom they interact, even informally: *"maintaining confidentiality means ensuring that particular individuals can never be linked to the data they provide"* (retrieved from Mack et al. 2005, page 16).¹⁷⁰

13.5.4 Types of observation techniques

Among the distinct types of observations identified as useful for enhancing the data collection process, the following types could be suitable for KCE research²⁹:

- **Shadowing:** can be considered as a sort of movement or tracking in the form of a tour but is often used to understand the steps involved in a process or the stages of an individual's normal routine. Shadowing is used often in health services research to understand patient or staff experiences with a clinical pathway or their interactions with different areas of a hospital. This kind of observation can give information on complex clinical activities such as information transfer and communication patterns that might have an impact on patient experience and care. It also allows the researcher to capture and experience movement through areas and over time, which could be considered as a more accurate representation of patient experiences. It also allows the documentation of high volumes of data in short periods of time. To prevent researcher and participant exhaustion, Vindrola-Padros recommends limiting the shadowing sessions to two hours.²⁹

Example: the study of De Brauer mentioned above could be seen as an example of shadowing. De Brauer is also geriatrician: to some extent, this gave her a form of legitimacy to carry her observations in the emergency departments.¹⁸²

- **Hanging out observations:** This kind of observation is like shadowing but does not entail movement in the form of a tour or shadowing. It involves being present in an area without a pre-established agenda and just allowing yourself to document what goes on around you (e.g. movement, informal conversations, body language, sounds and smells). In RQR, this kind of observation is often limited in time. However, 'hanging out' sessions can be purposively scheduled to document informal interactions in each setting.

Theoretical example: the researchers spend time together in coffee break rooms, clinic waiting rooms or gardens.

- **Tour observations:** a tour of the area where the research will be carried out (whether it is a community, hospital, or office) is a 'symbolic introduction' of the researcher to the location and to those who will participate in the study. It might be the first exposure to the context and can be an important data collections exercise. Notes from a tour are often unstructured observations and first impressions. A tour can also be used to create an initial map of the areas, situations or events that need to be observed for the study.

Example: as part of the preparatory phase of KCE project 405 on the development of a pilot study for a new payment system for home nursing, each member of the KCE research team accompanied a nurse during one or two rounds. Observations were guided by a checklist: experiences and observations were shared with the research team to further orient the project.¹⁸⁵

13.5.5 Data collection tools

CHECKLISTS

Before entering the setting and starting the observation, it might be a clever idea to have questions in mind. It may be helpful for the researchers to carry a checklist to help them remember what they are meant to observe.¹⁷⁰

There are predefined checklists to support observational studies but some of these checklists have been designed with quantitative objectives in mind (e.g. counting the number of patients coming into a facility).^{bb}

In the field of human geography and in community health, walking diagnosis, territorial diagnosis and exploratory walks rely on observations as a data collection technique. Canvases exist to guide the observation: they can be generic, applicable to any setting, or focused on a theme (e.g. risk of aggression against women, accessibility of resources).¹⁸⁶

FIELD GUIDES AND MANUALS

More structured data collection through observations uses field guides or manuals. According to Vindrola-Padros, structured observation guides have been particularly useful in studies where the researcher is already familiar with the context (due to previous research) or in focused studies in which detailed information is searched for, e.g. documenting how patients are referred to during hospital card rounds, documenting the use of a new medical technology.²⁹ These structured guides can vary in terms of level of detail and can also ensure that all team members collect data in the same way.

FIELD NOTES

Note-taking can vary depending on how structured or unstructured the observations are, and on the level of detail, completeness, and type of data the researcher is documenting. Depending on the research questions, the researcher will be interested in different aspects of social reality. Mulhalls' schema includes the following types of field notes, each covering an aspect of social reality:¹⁷⁹

- **Structural and organisational features** – what the actual buildings and environment look like and how they are used.
- **People** – how they behave, interact, dress, move.
- **Daily process of activities.**
- **'Extraordinary' events** – in a hospital ward, this might be the consultant's round or the multidisciplinary team meeting.

^{bb} Examples of observation grids: <https://www.diagnostic-territoire.org/uploads/documents/ea649678b398a6b6f3530eb6da05e97ee5604374.pdf>



- **Dialogue.**
- An **everyday diary of events** as they occur chronologically – both in the field and before entering the field.
- A **personal/reflective** diary – this includes both thoughts about going into the field and being there, and reflections on the researchers' own life experiences that might influence the way in which they filter what they observe (see section 9.4).
- It is particularly important to detail any contradictory or negative cases. Unusual things often reveal most about the setting or situation.¹³

Documenting observations consists of the following steps:^{170, 187}

- Quick notes during the observation.
- Once the researchers have left the setting, they expand their notes into field notes. This means they read them through and add other things they can remember but have not yet written down. Note-taking in the setting is not self-evident, and it is impossible to write down everything. Therefore, good notetaking should trigger the memory by means of keywords, symbols, or drawings, to name a few.
- After expansion, the researchers 'translate' their shorthand into sentences.
- Together with the translation phase, a descriptive narrative can be composed. The researchers write down a description of what happened and what they have learned about the setting.

The researchers should be aware of the **difference between describing what they observe and interpreting what they observed**. Reporting interpretations rather than an objective account of the observations should be avoided.¹⁷⁰

Theoretical example: An interpretive description of a patient could be "*he was in terrible pain.*" An objective description would be "*he was screaming and his face turned pale while grimacing.*"

"To interpret is to impose your own judgment on what you see"(retrieved from Mack, 2005, page 23).¹⁷⁰

The danger is that interpretations can turn out to be wrong. Therefore, the researchers should ask themselves "*what is my evidence for this claim?*"¹⁷⁰ One way of separating descriptions and interpretations is by separating them visually on paper or screen (e.g. using colours or symbols).

Field notes may vary in length and level of detail, but also as to their purpose:²⁹

- **Substantive notes:** describe situations and conversations, as detailed as possible.
- **Reflective notes:** document the researcher's activities in the research setting, the way they feel others see them and the way their presence might change the dynamics at their field site.
- **Analytic notes:** begin developing the interpretive work that will later be refined as all notes and other data sources are analysed.

Scrimshaw and Hurtado report three types of information records that each researcher needs to maintain during a study:¹⁸⁸

- **Brief diary:** notes on what was done each day, to act as chronological record.
- **Brief field notes:** words on what was seen or heard.
- **Expanded field notes:** on the same day, the researcher should expand on the brief field notes and add comments and impressions in parentheses. The development of these expanded notes can already identify gaps in data collection, so that the researcher can collect this lacking data during the next observation.

It is worth recalling that qualitative researchers are expected to use memos as part of the data collection and analytic process but also as part of (self-)reflexivity (see section 12.5.6).⁴⁹

MAP OF THE SETTING(S)

Maps might support the memory and are a tool to reconstruct interactions and movements of people in a room. Pictures of the setting(s) can also be of interest if they respect the privacy rules.

Additionally, mapping can be carried out by a researcher who is external to a community or area to obtain a sense of spatial surroundings, or can also be carried out in a more participatory approach, for example used by community members to represent specific areas of their communities, identify problems and potential strategies to address these (the so-called community-led mapping or perception mapping). Vindrola-Padros used rapid mapping of clinical pathways to identify barriers to care.^{29, 189} The mapping approach combined guided discussions with members of the clinical teams to develop an initial sketch of the pathway and data collection with patients and health care workers delivering care across the pathway to understand how these operate in practice. An observational shadowing (with a structured observation guide) was combined with semi-structured interviews. The sketch (or mapping) of the clinical pathway was used to generate discussions during the interviews.

AUDIO OR VIDEO RECORDING(S)

Audio or video recordings of observations are generally not permissible unless all ethical requirements are fulfilled and informed consent has been obtained.

13.5.6 Sampling

BEFORE GOING FURTHER – READ SECTION 12.3

Sampling of settings or groups for observations is **purposive**. Specifically for observation, the **sampling units are places, locations, and blocks of time**, but usually not individuals. The aim is to select 'information-rich' cases, but in practice site selection is often a pragmatic decision based on existing networks and accessibility. Ideally, however, sites are chosen because they typify larger population of sites (such as clinics) or perhaps because they are 'exceptional' (e.g. there is an innovative practice, the patients differ from the general population, or the staff has a specific training). Observation methods may be used across multiple sites, and one could select the ones representing a range of typical settings.¹⁴⁹

13.5.7 Required human resources

Observations can be the work of **one researcher, a pair of researchers, or a whole team**. Which arrangement is most appropriate depends on the research questions and the features of the setting. Also, members of a team can disperse to various locations individually, or in pairs or groups, to construct a more complete picture of the issues being studied.

One of the advantages of teamwork is that researchers can compare field notes and that team members can question each other about assertions being made.

“Taking another perspective on validity Graneheim et al. (2001) used multiple data collectors with different perspectives (insider or outsider) to observe the same situation. This may not accord with the idea that every researcher may produce a unique account of a situation that is valid in its own right. But with extensive mutual reflection, as undertaken by Graneheim and colleagues, these combined observations may have consensual validity. However, from a practical standpoint few projects are afforded the luxury of multiple data collectors” (retrieved from Mulhall, 2003, page 309).¹⁷⁹

Observations can also **be conducted by the target groups themselves**, based on a framework provided by the research team. This can be used as a strategy for patient and public involvement in



the scoping phase or in the data collection phase of a research project.¹⁸⁰ As with a research team, the observations can be conducted by a single participant, a dyad or a group (with or without the researchers). It can be envisioned as a photovoice / video voice experience (see section 12.4.4).

13.5.8 Practical aspects

As observers, researchers should **try to be 'invisible.'** It is recommended that they adapt to the setting in which the observations will be conducted, in terms of dress code, behaviour, and of what the other actors in the setting expect from them.

It is also recommended to **start with short observations** to explore the field and to get used to the role of observer. This implies getting an idea of the 'normal' way of things in a setting, before being able to identify unusual or abnormal situations. Circumstances may make it difficult or unacceptable to make **field notes**. In this case, the researchers may have to write down their observations afterwards, which can lead to a memory bias. Depending on the setting, researchers can make voice notes on a smartphone. For example, if the observations occur in a hospital hall where lots of persons are busy on the phone, it may appear normal to record a voice message or to write a text message (lead author's personal experience based on the principles of first person action research).¹⁹⁰ Field notes should not contain interpretations, but merely descriptions (see Textbox 6).

There is also the practical problem of **how to inform and obtain consent** from everyone who might 'enter' the field of observation, especially in large and busy social settings, like an emergency department.¹⁷⁹

Note that once inside the setting it might be difficult to get out again, particularly when the observation occurs over an extended period. Ending the fieldwork should not happen abruptly. The researchers must **take time to 'ease out.'** During this 'easing out phase,' the researchers are more frequently absent from the setting. This means that researchers come back to their office and have more time to analyse the data. When returning to the setting during the "easing out phase", the researchers can confront their preliminary analysis with new observations in the setting.⁶³ Even when the observations take place at a single point in time, it is recommended to keep in contact with the setting until the final report is written.¹⁹¹

13.6 How to analyse data from observations?

Field notes are extremely detailed and are highly descriptive. To find explanations or answers to the research questions, the researcher should develop categories and test them against hypotheses and refine them. This is an **iterative process that starts during the data collection phase**.

► *For more about qualitative data analysis, go to Part 4*

13.7 How to report the findings of observations?

As with other qualitative research methods, it is important that evidence from the data is presented to support the conclusions of the researcher, by means of examples or quotations.

► *For more about reporting qualitative findings, go to Part 5*

13.8 Specific quality criteria

The quality of observational studies strongly depends on the **quality of the descriptions of data collection and analyses provided by the researcher**. Details about how the research was conducted are crucial and should be well documented (e.g. how much time was spent in the field, how typical were the events recorded, description of the attempts to verify the observations made, etc.).

► *For more about quality and validity of Qualitative Research, go to Chapter 8*

14. WHAT PEOPLE SAYS WITHOUT INTERACTION: INTERVIEWS

14.1 Should the study include individual interviews?

Yes, if

- The research aims to collect in-depth understanding of the issue under investigation.
- The research aims to collect individual experiences of the participants about the research topic.
- The topic is sensitive, intimate and requires anonymity that a group cannot guarantee.

► *For general principles of data collection, go to Chapter 12.*

No, if

- The research is interested in the interactions between a group of participants.
 - *Go to Chapter 15 Focus groups.*
- The research aims to reach a consensus.
 - *Go to Chapter 17 Delphi process if no interaction between participants is needed.*
 - *Go to Chapter 18 Nominal groups if interactions are needed.*
- The research aims to collect data on what people say or do, or on how they interact with their environment.
 - *Go to Chapter 13 Naturalistic observation.*

14.2 What are individual interviews?

Essentially, an interview consists of **someone who asks questions (interviewer), someone who answers these questions (interviewee) and the registration of those answers in some way.**⁶³ Interviews are used in many contexts (journalism, human resource managers, etc.) and for many purposes (entertainment, recruitment of personnel, etc.), hence scientific data collection is only one specific application, which should not be confused with other applications. Interviews are easily trivialised, as they are a frequent practice in the media landscape surrounding us. Fontana and Frey even speak about ‘the interview society’ according to Atkinson and Silverman.^{192, 193} Practicing health professionals routinely interview patients during their clinical work, and they may wonder whether simply talking to people constitutes a legitimate form of research.¹⁹⁴

In social sciences, however, interviewing is a well-established research technique. The interview as a QRM differs from other forms of interviewing used in various domains. Mortelmans highlights four characteristics:⁶³

- **Internal and external flexibility:** Internal flexibility points to the fact that the sequence of the prepared interview questions and themes should stand in function of the interviewee to guard the natural flow of the conversation. External flexibility refers to the iterative use of interviewing and data analysis, i.e. the structure and content of subsequent interviews may be changed in function of the analysis of previous ones.
- **The interviewee ‘leads’ the conversation.** The interviewer only guards the scope of the conversation and makes sure that all the topics are covered.
- **Non-directiveness:** the interviewee steers the interview, and the interviewer only makes sure that the conversation does not go too far astray by means of non-directive interview techniques.



- **Direct face-to-face contact** is important to build trust and obtain in-depth information, but this depends on the topic and should be considered on a case-by-case basis.

Three types of interviews can be distinguished: structured, semi-structured and unstructured.

Structured interviews are defined as interviews during which the researcher follows “a specific set of questions in a predetermined order with a limited number of response categories” (retrieved from Denzin, 2008, page 124).¹⁹⁵ These forms of interviews may consist of administering structured questionnaires producing quantitative data (e.g. Sciensano Health Interview Survey) and are not part of QRM.

Semi-structured interviews are often the sole data source in a qualitative research project. A set of predetermined open-ended questions is used to guide the interview, but other questions emerging from the dialogue can be added.¹⁹⁶ The researchers can navigate across the questions to follow the rhythm of the interview as influenced by the participants.²¹ Also, the iterative nature of the research process in which preliminary data analysis coincides with data collection results in altering questions as the research process proceeds. Even so, questions that are not effective in eliciting the necessary information can be dropped or replaced by new ones.¹⁹⁶

Unstructured interviews (also called comprehensive interviews) are more or less equivalent to guided conversations.¹⁹⁴ Originally, they were part of ethnographers’ field work, consisting of participant observation and interviewing participants on an ongoing basis to elicit information about the meaning of observed behaviours, interactions, or artifacts.¹⁹⁴ There is no list of questions or interview guide; the questions asked are based on the responses of the interviewee, as in the natural flow of a conversation.¹⁹⁶ The researcher therefore uses a topic list to ensure that the interview covers the relevant themes but follows the flow of the conversation to inject it rather than tackling the topics in a predefined order.¹³⁹ This last type of interview is less used at KCE because of the research questions addressed by KCE.

Group interviews (not to be confounded with focus groups – see section 15.2) are semi-structured interviews conducted with several participants at the same time (e.g. a family, a group of friends or a group of stakeholders).¹⁹⁷ Participants do not require being “*tethered unto a common experience, nor for participants to share homogeneous professional and social statuses*” (retrieved from Halpern, 2023, online).¹⁹⁷ All participants can answer the questions on an equal foot at the difference of an individual interview where the participant can be accompanied by a relative but the questions are all directed to the participant and not the accompanying person. In a group interview, there is no moderation of the discussion (contrary to a focus group): the exchange takes place as in an individual interview but with multiple participants.

14.3 When to use individual semi-structured interviews?

Individual semi-structured interviews are useful to:

- Collect data on individuals’ personal histories, perspectives, and experiences, particularly when sensitive topics are being explored.¹⁷⁰
- Elicit a vivid picture of the participant’s perspective.¹⁷⁰
- Provide context to other data, offering a more complete picture.¹⁴¹
- Learn about the perspectives of individuals, as opposed to, for example, group norms of a community, for which focus groups are more appropriate.¹⁷⁰
- Get people to talk about their personal feelings, opinions, and experiences.¹⁷⁰
- Gain insight into how people interpret and order the world on the research topic.¹⁷⁰
- Address sensitive topics that people might be reluctant to discuss in a group setting.¹⁷⁰
- Elicit information from key informants.¹⁵

- Examine people's experiences, attitudes and beliefs.¹⁶

Group interviews are useful, among others, to:

- *“Provide the opportunity to artificially generate social interactions among a diversity of participants”*
- *“Identify and make sense of a plurality of perspectives, interests, and values, as well as shedding light on contradictions and ambiguities”* (e.g. an interview with a parent and a child about the added value of HPV vaccination)
- (in the scoping phase of a project) gather a first insight about an understudied topic / emerging issue when there are few data sources or when these sources are insufficiently diversified (e.g. the study wish to understand how occupational therapists can contribute to the self-management of chronic fatigue but there are only studies conducted in hospitals)
- *“Foster insightful perspectives on a given topic that would have remained hidden in observations or one-to-one interviews”*
- *“Artificially generate a set of social interactions to express shared views or disagreements on a given topic”* (retrieved and adapted from Halpern, 2023, online).¹⁹⁷

14.4 Strengths and weaknesses of individual semi-structured interviews

Table 21 presents the strengths and weaknesses of individual semi-structured interviews.

Table 21 – Strengths and weaknesses of individual semi-structured interviews

Strengths	Weaknesses
• They provide much more detailed information than what is available through other data collection methods, such as quantitative survey and email interviews.¹⁴¹ • Questions can be prepared ahead of time: this allows the interviewer to be prepared and appear competent during the interview.⁶² • They give informants the freedom to express their views in their own words.⁶² • They provide reliable, comparable qualitative data.⁶² • They provide valuable information, particularly when supplementing other methods of data collection.	• They are time-consuming because of the time it takes to recruit participants, conduct interviews, (transcribe them), and analyse the results.¹⁴¹ • They require appropriate training of the researchers in interviewing techniques: to obtain the most detailed and richest data from an interviewee, the interviewer must make that person comfortable and appear interested in what they are saying. They must also be sure to use effective interviewing techniques, such as avoiding yes/no and leading questions, using appropriate body language, and keeping their personal opinions in check.¹⁴¹ • Data from individual semi-structured interviews cannot be generalised in a statistical way but is theoretically transferrable, because small samples are chosen, and no random sampling methods are used.

14.5 Modalities of data collection

14.5.1 Choosing the place of the interview

It is recommended to leave the choice of the place of the interview (including online) up to the respondents, to facilitate their participation. The context in which the interview takes place partly determines the interactions during the interview. For example, patients will disclose various kinds of information at home than in the waiting room of a hospital, not only because they may feel more comfortable, but also because this setting triggers other associations and thoughts. If the interview takes place online, the interaction will again be different, and the experience may vary depending on



whether the participant joins from home, from work or from a different place (e.g. a student who has no Internet connexion and uses a public library) (see section 12.5.2.3).

The interviewer/researcher should be aware of and anticipate the impact the interview location is likely to have on the data generated.

In practice

- Data collection can take place in **the participant's personal environment** (e.g. workplace or home). In case of interviews at a patient's home, it is advisable to have two researchers to ensure the safety of the researchers.
- In case of interviews at the participant's workplace, it is advisable to remind the participants about the need of having a **calm environment** before the interview takes place. Ensure sufficient time before the data collection to familiarise with the environment.

At KCE

- Individual interviews can take place in a KCE meeting room. This can impact the dynamic of the interview by preventing the participants from feeling at ease (in contrast to, for instance, an interview where participants are sitting in armchairs in a neutral place). Additionally, coming to KCE implies that the researchers have 'control' of the place, which could make some participants feel uncomfortable.
- Plan more time than the planned length of the interview to avoid interruptions by colleagues.
- Do not forget to fill a mission request for interviews outside KCE (also for insurance purposes)

14.5.2 Choosing the interviewer

The same is true of the characteristics of the interviewer. In a qualitative interview, the researcher **empathises with the participants** and views their situation from their own points of view.^{48, 198} In general, this empathic stance and gaining trust from the participant are facilitated if the interviewer and the participant **share similar characteristics** relevant to the research topic (e.g. a Muslim researcher for questioning Muslim women about their role of their faith when it comes to the loss of a child). Gender, however, is an exception to this rule. There is a debate in literature about whether same sex or opposite sex is preferable to achieve a better connexion during interviews. It has been argued that men are more comfortable talking with women (especially about intimate topics) than they are talking with other men.¹⁹⁸

In practice

- Researchers leading the data collection should feel comfortable with the topic.

At KCE

- Data collection can be done by a KCE expert outside the Qualitative Research Team if this expert has the skills to ensure the quality of the data collection (see section 12.5.1).

14.5.3 Is there a possibility to restrict the languages used when conducting interviews?

No, selecting a single language for the data collection is not recommended and can lead to biased outcomes, as the spoken language is also a proxy for relevant contextual variables.¹⁰

Because Belgium has three official languages (Dutch, French and German), a multilingual sample can be expected in KCE studies, theoretically leading to a need to triple all recruitment material such as information documents, invitations, mailing lists... For practical reasons, data is only collected in French and Dutch, the country's two main languages. However, this is still very time- and resource-consuming.

Multilingual sampling makes sense if there are theoretical expectations related to the linguistic and cultural affiliation – in other words, if speaking French or Dutch is considered as having an impact on the thematic under study. For example, based on statistics, we can hypothesise that euthanasia or transgender identity are topics where cultural differences between Flemish and French patients are likely to occur. However, the language a person speaks can also be linked to other aspects such as the place of living or the influence of regional policies on the participant's responses. Another example is the investigation on access to cervix cancer screening: it needs to be considered by region because of the different regional policies and thus requires bilingual recruitment. For other topics, the region or province plays a key role, making it necessary to recruit participants not in both language communities, but across the country: investigating access to emergency departments only in the Brussels region, for instance, can lead to biased recommendations.

The literature does not provide advice on how to accelerate the recruitment in multilingual settings. Only two studies reported RQR conducted in multilingual settings: a cross-national study in South America¹⁹⁹ and an international study relying on eight different languages.²⁰⁰ In fact, conducting RQR in multilingual settings appears to be the exception rather than the rule.

In practice

- Language matching is the key variable for selecting the researcher leading the data collection.

14.6 Data collection tools

BEFORE GOING FURTHER – READ SECTION 12.4

The data collection tools to conduct interviews are **topic lists, interview guides and field notes**.

Researchers use field notes to record observations and fragments of speech. Field notes should be written as soon as possible after the events to which they refer. If possible, short memory aids or audio recorders may be used in fieldwork settings, to facilitate later expansion of the notes into proper field notes (see section 12.5.5).⁵⁹

14.7 Required human resources

In an ideal scenario, **researchers plan, organise, conduct, and transcribe the interviews themselves, to be completely immersed in the data**. Nowadays, transcriptions are helped by AI and IT software, but researchers will always have to review the transcripts as it is part of the preparatory phase of the analytical process (see Chapter 21).

The **revision of the transcripts** is also important when a different researcher conducts the analysis. The transcript should include the date and place of the interview, and the name of the researcher who conducted the interview (and of the observer, if any).

14.8 How to accelerate the data collection by interviews?

Researchers can use what Vindrola-Padros calls a '**rapid interviewing process**.' She suggests adapting the interviewing methodology as follows to turn it into a more expedited process:²⁹

- **During the interview:** each interviewer audio records the interview but also takes notes documenting the conversation. The notes are helpful for guiding the discussion, can serve as safety net in case the audio recording fails and allows to have a summary of the main findings at the end of the interview.
- **After the interview:** the summary of the findings should be entered in a Rapid interviewing Process (RAP) sheet (which should be developed and agreed on by the team. At the end of each data collection day, the team has a summary of the main findings from all the interviews conducted



to date. If data is being collected from different data sources, it can also be added to the same RAP sheet. The RAP sheet can then also be a triangulation tool.

- **As interviews are ongoing:** RAP sheets can be used to cross-check data collection and ensure all researchers are collecting data in the same way. RAP sheets are modifiable throughout the data collection stage, removing or adding topics. New questions can be added to the interview topic guide or changes can be made to the sampling strategy. RAP sheets can be used for different aims of the study, such as the comparison of data across different team members (with one RAP sheet per researcher), or to compare data across different research sites or cases (one RAP sheet per study site). Even if data is collected from multiple sources, it would be added to the same RAP sheet of the specific case or site. At the end of the data collection phase, the RAP sheets can facilitate cross-case comparisons. For comparisons across populations (e.g. patient groups), a RAP sheet per sample group is more appropriate. RAP sheets can also be used to capture changes over time, with distinct RAP sheets at various stages in the studies. For instance, if the study aims to capture changes before and after implementation of an intervention, the team can compare findings across the different RAP sheets, filled in at various stages of the study.
- **After data collection is complete:** the team can make the choice of conducting full or selective transcriptions during or after data collection. RAP sheets can also be used to identify salient topics and then go back to the transcripts for more details.

Focus groups can follow the same process, i.e. use of detailed notes to identify the main findings. Focus groups are longer and require more participants than interviews. Opting for the latter could accelerate the data collection process, but to the detriment of the richness provided by the interactions between participants.

Rapid interviewing process was used in KCE project 374 on the organisation of medical care in case of CBRNe incident.²⁷ A RAP sheet was drafted according to the key themes of the topic guide. Data were gradually added after each interview.

Resources

Template of a RAP sheet is available on the KCE Extranet

<https://extranet.kce.be/index.php/s/TPQAWKGWMG3nHf7>

Kaiser Permanente developed a methodological set to apply a rapid group analysis process (Rap-GAP)

https://www.act-center.org/application/files/1516/8298/5348/Rap-GAP_Instructions_and_templates.pdf

15. SYNCHRONOUS INTERACTIONS BETWEEN PARTICIPANTS: FOCUS GROUPS

15.1 Should the study include focus groups?

Yes, if

- There is a strong interest in the interactions between participants.²⁰¹
- There is a need to highlight the respondents' attitudes, priorities, language, and framework of understanding.
- The research team wishes to "*encourage participants to generate and explore their own questions, and to develop their own analysis of common experiences*" (retrieved from Kitzinger, 2006, page 22).²⁰¹
- The research team wants to "*encourage a variety of communication from participants – tapping into a wide range and different forms of discourse*" (Kitzinger, op. cit.).²⁰¹
- The interactions are seen as helpful for identifying group norms/cultural values related to the topic under discussion.²⁰¹
- There is a need to gather "*insight into the operation of group social processes in the articulation of knowledge (e.g. through the examination of what information is sensitive within the group)*" (Kitzinger, op. cit.).²⁰¹
- The research team wants to "*encourage open conversation about embarrassing subjects and to permit the expression of criticism*" (Kitzinger, op. cit.).²⁰¹
- The interactions could "*facilitate the expression of ideas and experiences that might be left underdeveloped in an interview, and to illuminate the research patient's perspectives through the debate with the group*" (Kitzinger, op. cit.).²⁰¹
- This allows topics which participants have given little thought in advance to emerge from the discussion.²⁰²
- It aims to answer questions like "what does a group think" and "how and why does a group think this way".¹⁵²

No, if

- There is no need for / no interest in the interactions between participants.
- The topic is too personal, intimate or may generate emotional reactions or conflicts that may be difficult to manage.
- It is difficult to bring the different target groups together at the same time.
- There are not enough researchers available to carefully plan and organise all the activities and tasks related to the focus groups.

► Go to Chapter 14 - Individual Interviews

- There is a need to find a consensus.

► Go to Chapter 17 - Delphi Process

► Go to Chapter 18 - Nominal Groups



15.2 What are focus groups?

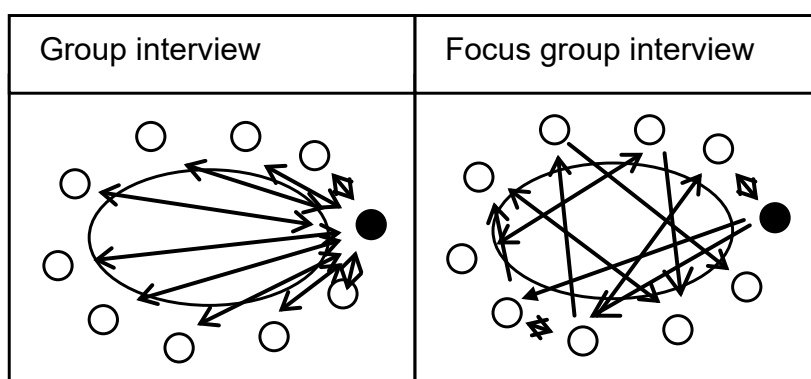
“In essence, a focus group is a small (usually 6-12 people) group brought together to discuss a particular issue (...) under the direction of a facilitator who has a list of topics to discuss” (Green and Thorogood, 2009, page 111).¹⁴⁹

Focus groups are **group** semi-structured interviews used for the purpose of collecting information **focused** on a specific subject or area of concern, for exploration and discovery, in-depth understanding of a problem as it is experienced in context, to assess needs, preferences, attitudes and interests related (in the context of KCE research) to health and health care issues. The participants are **gathered in function of their specific profiles or characteristics** to explore a limited number of ‘focused questions’.¹⁵ Groups are generally **homogenous on one or several criteria** relevant to the focus of the discussion.

Focus groups differ from individual semi-structured interviews, as the interaction component is used to bring out insights and understandings in ways which may not be achievable through questionnaire items or individual questions. The interaction between the moderator and the group, as well as the interaction between group members, may result in more in-depth information and elicit differing perspectives related to carefully designed questions. **Focus groups are thus not to be considered as a pragmatic time-saving substitute for individual semi-structured interviews (e.g. if for any reason the planning does not allow for individual interviews), as the methodological groundings of both techniques differ.**

A focus group is not synonymous with ‘group interview’ (although the techniques described in Chapter 12 apply). For a focus group, people are recruited specifically to participate in a research protocol, using a certain method. It is a group interview in the sense that it gathers data simultaneously from different participants.¹⁴⁹ However, it differs from a group interview in the importance that is attached to the interactions between participants. Participants might change their perspective during the focus group interview because of this interaction. Figure 5 presents the interaction patterns in a group interview versus interaction patterns in a focus group: in a group interview, interaction occurs mainly between researcher and participants, and interaction between participants is limited.

Figure 5 – Interaction patterns in group interviews versus focus groups



15.3 When to use focus groups?

Focus groups can be used as a **single research strategy**, or in combination with other methods in a **multi-method research strategy**.

When considered in combination with other methods, Caillaud and Flick suggest considering the objectives of the focus groups in relation to the sequence of the research project:¹⁵²

- **Before** using another method, it supports the emergence of (theoretical) hypotheses, the identification of aspects that need to be further explored or the development of a data collection tool.
- **After** using another method, it helps to understand unexpected or deviant data or to interpret results.

Focus groups can be used in a **sequential research design** (e.g. first interviews then focus groups – the findings of the interviews can be then used to support the discussion in the focus groups) or in a parallel research design (e.g. focus-groups are organised simultaneously with interviews or a quantitative online survey).¹⁵²

15.4 Strengths and weaknesses of using focus groups

Table 22 presents the strengths and weaknesses of focus groups.

Table 22 – Strengths and weaknesses of focus groups

Strengths	Weaknesses
• Interaction between participants.¹⁴⁹ • Ability to produce a large amount of data on a topic in a short time.²⁰³ • Access to topics that might otherwise be unobservable.²⁰³ • Access to explore sensitive topics, such as dissatisfaction with a service: it can be easier for an interviewee if negative ideas are reported as coming from a group than from one single person.¹⁴⁹ • Ability to ensure that data directly targets the researcher's topic.²⁰³ • Access to comparisons that focus group participants make between their experiences. This can be very valuable and provide access to consensus/diversity of experiences on a topic.⁶²	• Inappropriate to uncover marginal or deviant opinions.^{149cc} • Importance of social norms: participants are influencing each other, creating a certain kind of implicit norm or consensus.²⁰⁴ • Sometimes group dynamics may contribute to crystallisation of opinions. • Not easy to organise: several selected people must be gathered in the same place for a couple of hours.

^{cc} It does not imply that clashing perspectives / deviant opinions will never appear in a focus-group. When appearing, the moderator should explore it.



15.5 Specific aspects of sampling for focus groups

BEFORE GOING FURTHER – READ SECTION 12.3

15.5.1 Identification of units of analysis

The starting point for selecting participants for focus groups is to **identify the unit of analysis**. Is the unit of analysis 'individuals for their personal opinions/experience/expertise,' or is it 'individuals because they represent organisational perspectives'? This has a major impact on the people invited to the focus group interview and should therefore be clearly described.

The sample of focus groups will consist of **groups of people** instead of individuals. People who are invited to take part need to have an interest in the subject and be willing to share and discuss it. Interest in a topic should not be confused with conflict of interest.

15.5.2 Composition of the groups

Ideally, the participants to the same group are **internally homogenous on criteria relevant to the topic**, but the participants are **externally heterogeneous between the different groups** (e.g. there are 3 focus groups with professionals to discuss on palliative care: one group includes only physicians, one group only includes nurses and the last group only includes psychologists). Homogeneity in the group capitalizes on people's shared experiences.²⁰¹

It is best to select people **who do not know one another but have similar relationships to the topic** being investigated (although in practice, this could be difficult for certain topics). Selecting participants who are similar may help them to share ideas more freely and develop an in-depth analysis of a topic (homogeneous groups).

Sometimes, heterogeneous groups can be used after the primary analysis of homogeneous focus groups has started. Heterogeneous groups are used to 'confront' diverging opinions. In general terms, heterogeneous groups are composed of representatives of all relevant stakeholders.

In this case, the researcher must pay attention to potential power differences or inequalities between participants. This may prevent some people from talking freely during the discussion and, as a result, prevent the collection of rich data.²⁰¹ Enabling techniques could help facilitate the data collection in this situation (see section 12.4.4).

In the Belgian context, focus group can be conducted with French-speaking, Dutch-speaking, and even German-speaking participants. It is **advisable to conduct unilingual groups**: it is easier and richer for moderators and participants. For heterogeneous groups, like stakeholders, it might be difficult to divide people in groups according to native language. In this case, it is important that participants express themselves in their native language and to be sure that every participant understands the other language. Hence, the moderator must be bilingual. An alternative is to have a duo of moderators (one from one each linguistic role), under the condition that they coordinate. A second alternative consists in providing simultaneous interpreting (see section 12.5.7).

15.5.3 Number of participants per group

For a face-to-face focus group, **a group of 6 to 12 people is sufficient**. The ideal size for a focus group is 8 to 10 respondents. In general, the smaller the group, the more manageable it is. From experience, a group of 6 to 8 participants allows enough time for discussion and is easier to manage. Where the purpose is to generate in-depth expression from participants, a smaller group size may be preferable in combination with conducting more focus groups to attain saturation.

For an online focus group, it is advised to have a **smaller group of 5 to 6 participants**, as interactions and moderation are more complex online.¹⁰

To make sure that a group includes enough participants, it is advisable to **recruit 25% more people than required**.¹⁴⁹ If too few participants turn up, one should foresee an additional focus group to substitute for the low attendance.

15.5.4 Number of groups

The number of focus groups needed depends on the aims and available resources. It is almost impossible to give clear standardised guidelines on the number of focus groups needed.

A total number of 6 to 12 groups is often recommended, each group corresponding to one unit of analysis. More than 15 groups risk compromising the quality of the analysis. The same guidance applies for online focus groups, although more groups can be organised online as these are perceived as easier to organise than face-to-face groups.

It is methodologically important to conduct **at least two focus groups per 'type of participants,'** i.e. based on selection criteria. Relying on one focus group only to draw conclusions is risky, since the opinions expressed may have reflected the group dynamics (i.e. of the persuasive skills of one or two members) rather than a true sampling of the opinions of the population that the group represents. Even the preset number of two focus groups is generally too limited to make in-depth analyses, especially if the topics discussed are rather 'broad' or general. Having two homogeneous groups that yield different results suggests that more information is necessary (data saturation is not reached). One rule of thumb is to conduct focus groups until they no longer provide any added information on the topic discussed (=data sufficiency). This can be difficult to achieve when the target group is limited or when no more persons are willing to participate. However, the same problem could also occur with individual interviews.

15.5.5 Strategies to accelerate the recruitment process in RQR

To speed up focus group recruitment, Vindrola-Padros suggests using natural groups and informal focus groups.²⁹ **Natural groups** are groups that were not specifically created for the study.²⁹ They can consist of individuals who congregate fortuitously (e.g. people waiting in line outside the bank) or be existing groups who meet on a regular basis for a specific (non-research related) purpose (e.g. parents who join baby playgroups). In the context of KCE research, patient associations, support groups organised in health services, existing working group of stakeholders on a defined topic or team meetings in a hospital ward are examples of natural groups that can be approached (considering the risk of bias and misinterpretation).

Informal focus groups are quite like natural groups, consisting in an opportunistic discussion based on an existing social group. The participants determine the content and duration of the discussion. It can also include other activities (if these remain sedentary and are not disruptive). As the discussion is open and flexible, participants may change over the course of the discussion (people arriving, people leaving).^{dd 205}

Theoretical example: the researchers attend an art-and-crafts workshop in a nursing home to talk with elders.

Using **unscheduled focus groups** can also be combined with other data collection methods. For example, Vindrola-Padros refers to a study where the researchers conducted informal focus groups while they carried out observations during staff tours in a community health centre.²⁹ The unscheduled focus groups gave the researchers the flexibility to incorporate these group discussions into other activities at the health centre.

^{dd} The authors explained, i.e., visiting a household while the family is prepping a meal.



Theoretical example: the researchers plan to visit a community health centre and are informed that on the day of their visit, there will be patients coming for a cooking workshop. After following an observation tour, they can attend the workshop and chat with the patients in an informal way.

The recruitment process can be accelerated by using natural groups and informal focus groups if the researchers have the possibility of visiting study settings; this is therefore limited to some topics (e.g. experiences in attending a specific health service or working behaviours in a chosen health care unit). It can also be facilitated by collaborating with stakeholders, who can act as intermediaries between the researchers and the participants. However, this can lead to a selection bias, an influence bias, or a social desirability bias.

15.6 Data collection tools

BEFORE GOING FURTHER – READ SECTION 12.4

The development of the focus group guide follows the same principles as the development of an interview guide / a topic list. In addition to the questions list, the focus group guide is structured by means of an agenda – including a timeline - to keep the group focused and on track. A focus group should be experienced as free-flowing and unstructured, but the moderator must follow a **pre-planned script of specific issues and set goals for the type of information to be gathered**. An introduction of up to 15 minutes should be carefully planned, as well as a good opening question. To keep the time schedule, as several people are going to participate and answer the questions, it is important to schedule a maximum amount of time for each question.

The use of a well-designed guide is helpful to compare information between groups, as more than one focus group is expected for any given topic.

15.7 Required human resources

15.7.1 Focus groups in a single language

In an “ideal” situation, focus groups require at least 3 members of the research team for a focus group conducted in a single language: **a moderator, a note-taker, and an observer**. However, it is important to consider the correct balance between the research team and the participants: for example, having 3 researchers for 5 participants is not adequate to ensure a smooth discussion.

15.7.1.1 Moderator

The moderator (also called ‘facilitator’) plays a crucial role in the success of a focus group and can have a major impact on the outcomes of the data collection. The moderator should lay down ‘rules,’ explain the duration of the focus group interview, plan a break in between and make everybody welcome beforehand. Before the opening question, it is important to ask everybody to briefly introduce themselves.

The moderator has to “*establish a relaxed atmosphere, enable participants to tell their stories, and listen actively*” (retrieved from Green, 2009, page 126).¹⁴⁹ Facilitating or moderating focus group interviews requires specific capabilities: **interpersonal skills** (including non-verbal communication skills) are needed as well as a non-biased attitude towards the issues discussed. However, the moderator does not need to be an expert in the field of the research. A focus group moderator should be able to keep the discussion on track and make sure every participant is heard: if participants get off track or get ahead of the issue being discussed, then the moderator must pull the group back together. The moderator must be **able to structure the discussion and summarise what has been said**. However, the moderator should not take a stand, and should avoid making quick assumptions or conclusions, developing answers for the participants or giving advice. Focus groups are intended as an in-depth exploration of the perceptions, attitudes, and opinions of the participants, not of the

research team (or moderator). The moderator makes it socially acceptable for participants to have another point of view.

The moderator needs to use '**probing techniques**' when necessary. Probing is a means of further investigating a topic that has already been introduced. It can be used to clarify, to obtain more detail and to ensure completeness. In the case of focus group interviews, the moderator could use disagreements in the group to force participants to develop and elucidate their point of view.

The role of the moderator in online focus groups is trickier, as the access to nonverbal cues is limited and distraction is higher. As pointed by Lobe, "*moderation online needs a delicate balance between influence that could increase moderator bias and sustaining the work of the group by providing adequate leadership*" (retrieved from Lobe, 2017, page 438).²⁰⁶ Additionally, in online spaces, moderator(s) must be familiar with the technology and trouble-shooting procedures and be ready to respond to the nuances of the online platform (e.g. discussions with multiple participants in one online space, movement of participants between a main space and 'smaller' spaces [such as Zoom breakout rooms], simultaneous verbal and chat function responses, participants' nonverbal cues and pauses).^{160, 207}

15.7.1.2 Note-taker

The **note-taker** will take notes during the discussion, while the moderator is introducing questions. The note-taker could sit next to the moderator. However, if the note-taker directly typewrites on a laptop, the sound of the typing on the keyboard could be disturbing. This is even more the case online; the notetaker should then turn off the microphone or move away from the room microphone. The note-takers can be external to the research team, providing they are briefed before the focus group.

Moderator and note-taker can take turns in asking questions and taking notes (this requires a well-functioning team that clearly understands its roles and can adapt to the situation). It should be discussed and reported whether the respective focus groups be facilitated by the same persons, or by different ones.

15.7.1.3 Observer

The **observer** could be useful to observe the focus group participants (non-verbal language) and to help the moderator identify less talkative participants. During online focus groups, the observer oversees the chatroom and can also connect with the IT support in case of problems.

The note-taker or the observers can oversee collecting the paperwork (e.g. informed consent) before starting the focus group.

15.7.2 Focus-groups in two languages

For focus-groups conducted in two languages (typically Dutch and French at KCE), there could be three configurations, leading to diverse needs in human resources:

- **Fully bilingual focus groups:** 2 moderators (one for each language), 2 note-takers (one for each language) and 2 observers (one for each language)
- **Focus-groups assisted by interpreters:** minimum 3 researchers (moderator, note-taker, and observer) + 2 interpreters (one per language).
- **Partially bilingual focus groups:** 1 bilingual moderator (C1 to C2 levels in both languages), 2 note-takers, 1 observer.



15.8 How to run the data collection in a focus group?

BEFORE GOING FURTHER – READ SECTION 12.5

15.8.1 Should the focus group be held in hybrid format?

This section concerns focus groups that aim to collect data, not hybrid meetings or conferences.

No, it is usually advised to opt for a full online discussion or for a full offline discussion, as a hybrid format could:

- Negatively impact the interactions between online and offline participants, by creating misunderstandings, gaps in the communication (particularly when there are technical problems), favouritism or exclusion of some participants and power imbalance.¹⁶⁸
- Require more attention and cognitive resources from all the participants to remain engaged in the discussion.¹⁶⁸
- Require more resources to effectively manage the discussions, hybrid events in general being reputed for requiring twice as many resources^{168, 208}

15.8.2 How to prepare for a focus group?

Table 23 presents the preparation for a face-to-face or online focus group.

Table 23 – How to prepare for a focus group?

Face-to-face	Online
(outside KCE) Submit a KCE mission request. (at KCE) Book a meeting room with sufficient time before and after the appointment to avoid being interrupted by colleagues. (at KCE) Do not forget to inform KCE support, who will arrange for access badges (and catering, if applicable).	Plan a demo session (if needed) Inform the participants before the meeting about the software that will be used and, if necessary, explain how to install and use it. Book a meeting room with sufficient time before and after the appointment to avoid interruption by colleagues.
Equipment • Digital tape recorder + spare batteries OR • Fully charged smartphone (providing that this smartphone has a sufficient level of protection to guarantee privacy) • Field notebook and pens	Equipment • Computer with charger (not on battery) • Webcam • Microphone • Headphones (if needed) • Field notebook and pens
Infrastructure • Quiet room where chairs are arranged preferably in a circle to ensure that all participants see each other. • Table with refreshments • If a board is used, ensure that all participants can see it. • Seat the moderator and the notetaker next to each other	Infrastructure • Book a meeting room to allow the team to sit together with the camera of their personal computers turned on (instead of the camera of the room) to facilitate contacts with participants OR • Ensure that each member of the research team participates from a quiet place. • Seat the moderator and the person overseeing the chatroom next to each other AND / OR



	Plan a separate conversation channel for the research team to facilitate the moderation.
Focus group packet: - Focus group guide (in the appropriate language) - Agenda and timeline - Informed consent forms (one for the interviewer, one for each participant, in the appropriate language) - Participant reimbursement (if applicable)	Focus group packet: - Focus group guide (in the appropriate language) - Agenda and timeline - Start the meeting by explaining the functions of the software. - Digital informed consent form to be completed and signed via Adobe Sign - Participant reimbursement (if applicable)
Human resources - A moderator - A note taker - An observer (Interpreters)	Human resources - A moderator - A note taker - An observer (also overseeing the chatroom) - IT support (can be remote) (Interpreters)

15.8.3 How to run the focus group?

15.8.3.1 Role of the moderator

The moderator should give a brief introduction to set everybody at ease. More concretely, the moderator should:

- Explain the purpose of the discussion and the way the information collected will be used and reported.
- Introduce the note-taker and the observer who will remain in the (online) room during the discussion.
- Explain that the discussion is for scientific purposes and that information will solely be used within the context of the research project.
- Assure participants that the rules of confidentiality apply to everyone in the (online) room, including the note-takers and observers.
- Explain how names will be used (real names or pseudonyms) – particularly in an online focus-group.
- Explain the group rules (speak one at a time, avoid interrupting or monopolizing the conversation, etc.).
- If the discussion is to be tape- or video-recorded, obtain verbal permission from the respondents first, and explain how the recordings will be used, stored, and eventually destroyed. For online discussions, participants should give their consent by using the thumb up / thumb down icon (or any symbol clearly indicating agreement / disagreement). Once done, the moderator should clearly state that “none of the participants rejected the recording” and ensure that this statement is recorded.
- The moderator will then begin the focus group interview by asking an ‘icebreaker question’ to facilitate the discussion in the group. Afterwards, he/she will come to the focus of the discussion.

Additionally, when conducting an online focus group, the moderator should also:

- Plan an activity to help participants to connect/ to humanise the interactions (in a ‘classic’ focus-group, these bonding moments are likely to occur when arriving, e.g. over coffee).²⁰⁶



► *For enabling techniques and their compatibility with online support, please refer to the KCE Report 340 bis¹⁵³*

- Explain how the online platform functions and how it will be used.
- Explain how cameras and microphones will be used.
- Adapt the group rules for speaking to the online environment (e.g. use of the raised hand or of the reaction icons).
- Clarify if the chatroom can be used for direct messages or not.

15.8.3.2 Note taking

Taking notes can either be done by the whole team of researchers during the focus groups, or each researcher can focus on collecting data on a specific topic. Audio recording of the conversations during the focus groups is still recommended as a backup and/or for the in-depth analysis process that will occur later. **Mind-maps** are a useful tool to summarise the main topics while the focus group discussion is ongoing.²⁰⁹ Participants are asked to comment on the accuracy of the mind-maps during the focus groups, as a kind of 'member checking' to the process.²⁹

15.8.3.3 Debriefing

A systematic **debriefing** with the moderators must be scheduled immediately after the focus group. The debriefing part is an essential step for the analysis and contributes to the reflexive posture of the research team (see section 9.4). The debriefing exercise is best supported by a template of dimensions, on which the moderator / team needs to comment. The research team should review the notes taken during the focus group and have a first assessment of clarity and understanding. They should discuss, compare, and record observations or impressions about the group that are not readily apparent from the notes. It is also recommended to discuss and record any insights or ideas emerging during the interviews while they are still fresh in the mind.

Resources

Template for guiding a debriefing is available on the KCE Extranet
<https://extranet.kce.be/index.php/s/TPQAWKGWMG3nHf7>

15.9 Specific practical aspects related to focus groups

BEFORE GOING FURTHER – READ SECTION 12.5

15.9.1 Location and timing

- The location where the focus groups will be held (including the question of offline/online) should be carefully selected.
- The timing of the (online or offline) focus group interview needs to be acceptable for all potential respondents in order to avoid selective 'non-response' as much as possible (take into account the socio-demographic profiles of the targeted participants such as working times, daily activities, family life, etc.).
- For face-to-face focus groups, the research team should consider potential accessibility, and transport issues (and mobility needs of participants).
- Noisy areas should be avoided, as they would make it difficult for participants and for the moderator to hear each other.

- The setting should be comfortable, non-threatening for the participants.
- For face-to-face focus groups
 - Refreshments should be provided (at minimum). When the activity exceeds 4 hours, a meal should be provided.⁵³
 - the tables can be organised beforehand, which allows the researchers to place name tags however they want (when used). Seating should be arranged to encourage participation and interaction, preferably in a circle, with or without name tags. Whether tables are needed can be discussed. Moderators/observers (and note takers) should be integrated as much as possible within the discussion setting.
 - When assisted by interpreters, the meeting room should allow for simultaneous interpreting.
- For online focus groups, the risk of technical issues and the digital skills of the participants should be considered. A contingency plan should be arranged ("what to do if") (see section 12.5.2.3).

At KCE

- Keep in mind that KCE rooms have equipment and furniture that are not easily removable.
 - Organising focus groups outside KCE can be considered, particularly with patients and patient representatives. For group-based data collection, organising the meeting outside KCE can even be of added value. For example, patient umbrella organisations have meeting rooms across Belgium (Brussels, Namur, Liège, Mons, Leuven, Eupen). Similarly, regional administrations, sickness funds or universities also have meeting rooms that can be used for this purpose. However, like KCE rooms, these are not 'neutral' places and, depending on the topic, it may be necessary to rent rooms.
- *Contact a KCE project manager and / or KCE support for help.*

15.9.2 Duration

The length of a face-to-face focus group should be **between one and three hours**. Online focus groups are usually shorter (between one and two hours), as they require more concentration from participants and from the research team. It is necessary to plan sufficient time at the beginning to welcome participants, introduce the project and let them introduce themselves. This part should not take too much time (about 10 minutes).

15.9.3 Material

Data is collected through diverse sources; **audio or videotaping** can be considered. When focus group interviews are recorded, the equipment should be of decent quality and easy to use (check batteries and microphone). For larger groups, it may be necessary to use two tape recorders or multi-channel equipment, strategically placed to maximise the probability of recording contributions from all participants.

For online data collection, discussions can be held via **Zoom or Microsoft Teams** – with possibilities for audio and video recording. The research team needs to check the IT equipment (computer, microphone, sound speakers or headphones) before the focus group discussion and have spare equipment at hand (especially if the researchers operate from home rather than from their workplace).

Field notes are an essential part during data collection. They capture all the essential "non-verbal" information during the focus group interview.

Information must be collected in an unbiased manner (avoid filtering out information as pre-interpreting it as unimportant, especially in the first focus groups).



The **context of statements** made during focus groups should be documented (important for giving meaning to the statements in the phase of analysis). Note-takers and observers should try to capture nonverbal behaviour of group participants (nonverbal reactions of other participants after a participant statement may indicate consensus or disagreement).

15.10 How to analyse data from focus groups?

- Go to Part 4 Qualitative Data Analysis

15.11 How to report findings from focus groups?

- Go to Part 5 Qualitative Data Reporting

16. ASYNCHRONOUS INTERACTIONS BETWEEN PARTICIPANTS: RESEARCH FORUM

This chapter addresses forums that are specifically launched to collect primary data, not the use of existing forums to collect primary (e.g. by asking the owner's permission to trigger discussions on the research topic) or secondary data.

- For the use of data from an existing forum, go to Chapter 11 Use of qualitative open data.

16.1 Should the study include a research forum?

Yes, if

- There is a need for interactions **AND**
- Participants have daily schedules that limit the possibility of interacting together at the same moment.
- The issue is dispersed among the population, and the target group is difficult to recruit.
- The issue is sensitive, intimate, or personal, there are controversial and divergent opinions.
- The participants are geographically dispersed.
- Participants experience mobility problems / difficulties to sustain their attention over extended periods of time / unstable symptoms / oral expression problems.
- The issue concerns marginalised groups (e.g. persons with at-risk behaviours, transgender persons, drug users...) for whom a guarantee of anonymity could be important.

No, if

- This is a RQR as the launch of the forum and the length for collecting data is time-consuming.
- Technical and human resources are limited.
- There is no moderator who can relaunch the discussion daily to keep it alive.
- There is a substantial risk of trolling, facilitated by the anonymity of the participants. The influence of this trolling deserves particular attention when it comes to forums. Coles and West define trolling as "*a specific type of malicious online behaviour, intended to disrupt interactions, aggravate interactional partners and lure them into fruitless argumentation*" (retrieved from Coles and West, 2016, page 233).²¹⁰ Although the risk of trolling is somewhat mitigated by carefully selecting the participants to the forum, the phenomenon can still occur and may be harmful for both the research team and the other participants. To some extent, trolling appears to be enabled or facilitated by anonymity.²¹¹

Key considerations

- Experiences with research forums at KCE fell short of the research team's expectations: overall, participation was low relative to the efforts involved in conceiving and managing the forum.
- The use of forums as part of data collection methods is still under discussion at KCE (October 2025). Please consult with the QRT for more information.

16.2 What is a research forum?

A research forum is specifically designed for **collecting primary data** with the aim of answering a preestablished research question. The research team controls the content, moderation, and other features. Forum has been used, for example, to conduct research with patients living with amyotrophic lateral sclerosis²¹², transgender and diverse gender young adults²¹³, patients with primary Sjögren's syndrome²¹⁴ and about sexual health care access among transmasculine individuals.²¹⁵

16.3 Strengths and weaknesses of research forum

Table 24 presents the strengths and weaknesses of research forum.

Table 24 – Strengths and weaknesses of research forum

Strengths	Weaknesses
• Access to large samples²¹⁶ • Wide geographical coverage²¹⁶ • Possibilities for holding forum in different languages simultaneously¹²⁰ • Added value of the interaction between participants²¹⁶ • More neutrality in the data collection as there is less pressure²¹⁶ / a reduction of the social barrier²¹⁷ • Opportunities for exploring sensitive and intimate topics²¹⁶ • Greater convenience for participants, as they decide when they participate: this is particularly valuable for those experiencing pain and / or fatigue²¹⁶ • Possibility of revisiting posts, editing or going deeper, help participants to have deeper discussions and counterbalance oral communication barriers for some participants. • Feeling of safety when sharing personal stories and experiences, greater disclosure • No more travel costs and time	• Difficult / impossible to collect sociodemographic data²¹⁶ • Superficial responses²¹⁶ • Communication noise²¹⁶ • Selection bias²¹⁶ • Loss of the paralinguistic cues²¹⁷ • Ambiguity in the use of capital letters, emoticons, and abbreviations (such as LOL for laughing out loud) • Lengthy data collection²¹⁷ • Duration or degree of interaction required by a researcher could still mean face-to-face methods are more efficient. • More difficult to build a connection with participants²¹⁷



16.4 Modalities of data collection

Table 25 presents the steps of planning an online forum for qualitative data collection, to guide the research team.

Table 25 – Questions to be addressed when planning a research forum

Steps of planning	Questions to ask
Purpose or the research and/or research questions	Is it essential to have an online forum to achieve the purpose of the research and/or to address research questions?
Logistics	Do you want to use user IDs and passwords? Facilitator-moderated? Format of the messages (e.g. short or long texts, other material than text)?
Moderation	Are experienced moderators available? How will the moderators intervene? At which frequency? How to manage conflicts / inappropriate behaviour between participants?
Informed consent	Is it feasible to get conventional informed consent or electronic informed consent?
Structure and functionality	What are the structure and functionality required to achieve the research purpose and to address research questions?
Expertise in computer and internet technology	Is a secure platform available to host the forum? Could an interdisciplinary research team be built? Does the study design require specific computer and Internet technologies?
Screening methods	How do you want to check if potential participants meet the inclusion criteria? Electronically (through a website or by email), by phone, or by face-to-face meeting?
Languages	What are the languages that will be used in the online forum? Single or multiple languages? Does the forum site support multi-language functionality? How do you want to translate the message in languages other than the original language used in the online forum?
Data analysis methods	Do you want to use computer software to manage and analyse the data? Should the data be extracted in a specific format? Do you want to print out the data as transcripts directly from the database? What specific qualitative data analysis method do you want to use to analyse the online forum data?
Getting participants' feedback	When and how do you want to get participants' feedback on your study findings?

Retrieved and adapted from Im and Chee, 2012, page 12²¹⁸

16.5 Data collection tools

BEFORE GOING FURTHER – READ SECTION 12.4

Like for other qualitative data collection techniques, the research team needs a **topic list and a discussion guide** to frame the discussions between participants. The discussion guide needs to include probing and relaunching questions for the moderators to stimulate the interactions. In KCE project 344 on the needs of patients with Long Covid, the themes of the forum mirrored the themes used in individual semi-directive interviews.⁵⁴ However, the forum can also be used to further investigate emerging results, like in KCE project 296 on appropriate care at end of life, where participants received preliminary results to react to.¹²¹

The research team also needs to decide whether all the topics are made available for discussion simultaneously or whether there is a schedule for posting new topics (e.g. one new topic every week). Additionally, like in a semi-structured interview or a focus group discussion, the moderation can build on the responses shared by the participants and inject emerging topics, based on a preliminary analysis.

16.6 Specific aspects of sampling for research forum

BEFORE GOING FURTHER – READ SECTION 12.3

No specific guideline was found regarding the number of participants for an online research forum. It is usually advised, as there is a higher risk of drop-out and disengagement, to over-sample the number of participants, particularly if the forum is expected to be active for several weeks.

Im et al. included an **average of 30 participants per group** (with several parallel forums in the described studies).^{119, 120} In KCE project 344 on the needs of patients with Long Covid, the number of participants per group was of 100 individuals (with two parallel forums).⁵⁴

When creating a research forum, the research team has to recruit all the participants for the forum, which can hamper the naturalistic nature of conversations and discussions, as participants will be aware that they are being observed.²¹⁹

16.7 Required human resources

A forum requires at least three persons: an administrator, a moderator, and an observer.^{ee}

16.7.1 Forum administrator

The forum administrator is the person who holds full **control and responsibility for the management and the operationalisation of the forum**. Administrators have the highest-level authority, which implies that they have access to the entire forum (content and users).

In the case of a research forum, the administrators can be IT specialists, as their duties include the configuration of the forum (including determining the roles of users), backend access (functionality and technical aspects), user management (adding, removing, assigning specific roles...), security and overall maintenance of the forum (management of the technical issues).

It is recommended to have a forum administrator, with a generic contact address for the users, and a back-up administrator with the same access rights to prevent any disruption.

^{ee} This section includes technical information retrieved and adapted from the website of Moodle: https://docs.moodle.org/4x/sv/Forum_moderator_role



16.7.2 Forum moderator

The forum moderator plays the same role as an online focus group moderator by supporting a respectful and dynamic interaction between participants while generating data to answer the research questions. As in a live discussion, the moderator is expected to prompt or relaunch participants to go deeper, to clarify or to complete their contribution (see section 15.8.3.1).

In an online forum, the moderator might also edit or delete posts, split discussions, or move discussions to another forum (e.g. a participant starts posting about financial problems on a forum on mental health).

It is advised to have a moderator per forum, with a back-up (e.g. the observer).

16.8 How to run the data collection in a research forum?

At KCE

- If the project requires an online research forum, please consult with the Qualitative Research Team.

16.9 Specific practical aspects related to research forum

16.9.1 Location

The forum should be hosted on a **secure online platform** where participants can register. It should be decided whether the participants can register directly or whether they will receive a token to prevent random people accessing the forum.

In KCE project 344 on the needs of patients with Long Covid, the forum was hosted via Moodle® (Modular Object-Oriented Dynamic Learning Environment).⁵⁴

16.9.2 Duration

The literature reports **various durations for forums** (from a few days to several months). Again, there is no consensus on this. Duration is usually influenced by the number of topics to be discussed among participants. A **minimum of 4 weeks**, excluding preparation, appears to be appropriate in the context of KCE research.

16.10 How to analyse data from a research forum?

- Go to Part 4 Qualitative Data Analysis

16.11 How to report findings from a research forum?

- Go to Part 5 Reporting Qualitative Data

17. CONSENSUS WITHOUT INTERACTIONS: DELPHI PROCESS

17.1 Should the study include a Delphi process?

Yes, if

- The research question aims to understand agreement and disagreement on a complex issue and when the opinion of experts (in the broad sense) is the only source of evidence.²²⁰
- Experts are easy to identify.
- Experts can be retained during the complete process (minimal risk of drop-out).
- Interactions have no added value, or the issue is particularly controversial.

No, if

- Interactions are needed.
- Experts have low / poor digital skills.
- The search for consensus is part of a Rapid Qualitative Research.

► Go to Chapter 18 Nominal groups.

17.2 What is a Delphi process?

The **Delphi method** (named so because of the Delphi Oracle) was initiated by the RAND corporation.^{ff} The original definition given in the fifties was that it “*entails a group of experts who anonymously reply to questionnaires and subsequently receive feedback in the form of a statistical representation of the “group response,” after which the process repeats itself. The goal is to reduce the range of responses and arrive at something closer to expert consensus.*”²²¹ Today, the method has evolved and Delphi surveys can pursue different goals or have several designs.^{76, 77, 220, 222, 223} The method could also be defined as “*a systematic collection and aggregation tool of informed judgment from a group of experts on specific questions and issues*” (retrieved from Hasson, 2011, page 1696).²²⁴ Delphi surveys are used in several fields (politics, psychology, agriculture, etc.) and can vary in different ways. Table 26 presents a non-exhaustive list of Delphi designs used in health research. The **modified Delphi** is the most frequently used type of Delphi at KCE.

Table 26 – Types of Delphi designs

Design Type	Aim	Target participants	Administration	Number of rounds*	Round 1 design
Classical	To elicit opinion and gain consensus	Experts selected based on aims of research	Traditionally postal	Three or more rounds	Open qualitative first round, to allow participants to record responses
Modified	Aim varies according to project design, from	Experts selected based on aims of research	Varies (postal, or online)	May have fewer than three rounds	Participants are provided with pre-selected items (drawn from

^{ff} RAND is a nonprofit institution that helps improve policy and decision making through research and analysis. More information on RAND: <http://www.rand.org>



	predicting future events to achieving consensus				various sources) and asked to give a response that falls within these items
Decision	To structure decision-making and create the future, rather than predicting it	Decision-makers selected according to hierarchical position and level of expertise	Varies	Varies	Similar process to classical Delphi
Policy	To generate opposing views on policy and potential resolutions	Policymakers selected to obtain divergent opinions	Can have a number of formats, including bringing participants together in a group meeting	Could be done in three or four rounds	Similar process to classical Delphi OR 1- the obvious issues are preformulated by the research team. 2- the list comprises an initial range of options, which respondents are allowed to complete ^{225, 226}
Real time/consensus conference	To elicit opinion and gain consensus in real time	Experts selected based on aims of research	Use of computer technology (e.g. a voting system) that participants use in the same room to achieve consensus in real time rather than by post or through the Internet ²²⁷	Varies	Similar process to classical Delphi

* The number of rounds should ideally be based on the saturation of the responses; it is therefore difficult to determine in advance. Numbers of rounds in the table are indicative. ^{224,228}

17.3 Why and when to use a Delphi process?

The following goals could be achieved by using a consensus-reaching method such as the Delphi panel, in situations where **personal contact is not necessary**.²²⁹

- Helping the decision-making process.
- Choosing the most appropriate method or tool (e.g. data collection technique, scales, questionnaires, etc.).²²⁹
- Identifying the best choice of treatment (when no other evidence is available, or to complete it).
- Identifying what form a programme should take.
- Clarifying professional roles.²³⁰
- Developing clinical guidelines.²³¹

17.4 Strengths and weaknesses of the Delphi process

Table 27 presents the strengths and the weaknesses of the Delphi process.

Table 27 – Strengths and weaknesses of the Delphi process

Strengths	Weaknesses
• It has a lower production cost compared to individual interviews with experts.²³² • It produces relatively rapid results.²³² • Participants can express their opinion anonymously, without external (perceived) pressure, while the process makes it possible to capture the view of the entire group.²²⁹ • It avoids domination by individuals or professional interests.²³⁰ • Participants can participate in their own time. • Participants can participate in their own language. • Participants can belong to an international panel.	• Success depends on the qualities / expertise of the participants. • Reliability depends on the number of participants (and the number of rounds). In addition, it is difficult to keep everybody in successive rounds.²²⁹ • Coordination is difficult.²²⁹ • The existence of a consensus does not automatically mean that it reflects an appropriate or “correct” answer.²³⁰ • Digital literacy is required.

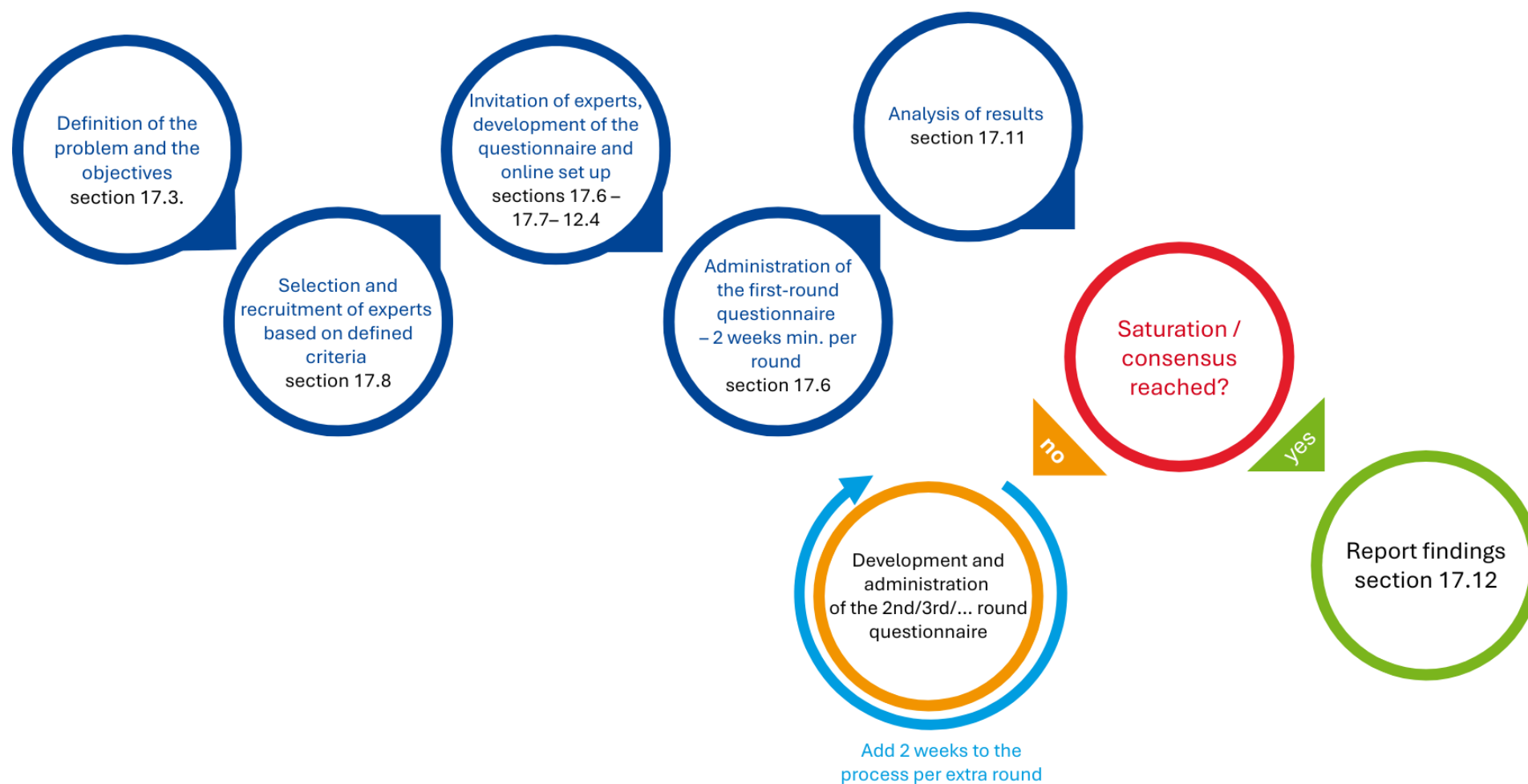
17.5 How to plan the research design?

A Delphi survey takes **several weeks**, even if the number of participants is small. It should be planned at the beginning of the project. If the necessity of such a study emerges later during the project, it is important to be aware that the whole process takes **at least one month** (excluding preparation time), depending on the number of rounds needed.

Figure 6 illustrates the complete process: number of sections indicate where detailed instructions can be found. On average, **a minimum of two weeks need to be planned per round of questionnaire**. For each additional round, two additional weeks are needed.



Figure 6 – The Delphi process



Adapted from Slocum et al.2006²²⁶

Textbox 7 presents an overview of the RAND recommendations when developing the design of a Delphi study.

Textbox 7 – Recommendations for design of Delphi studies

- Use Delphi in forward-looking studies on topics for which expert opinion is the only source of evidence and for studies that explore areas of agreement and disagreement on complex issues.
- Use the study research question to determine the most appropriate type of Delphi.
- Include researchers with expertise in the topic under investigation and expertise in the Delphi method in the study team.
- Assemble panels that represent diverse perspectives and experiences.
- Employ a multipronged recruitment approach to assemble diverse panels.
- Recruit more participants than needed.
- Use a range of retention strategies (e.g. frequent reminders, personal contact with experts).
- Summarize what is known about the topic to help develop a shared, baseline understanding of the issue at hand.
- Conduct a small pilot test to ensure that the data collection process, instructions, and questions are clear to participants.
- Use the study's design, goals, and needs to determine the composition of the expert group.
- (in case of real-time Delphi) recruit discussion moderators who have a broad understanding of the discussion topic and know how to manage group dynamics.
- Use task complexity, number of questions and participants, and panel format to decide on the length and timing of each round.
- Conduct at least two concurrent Delphi process that use the same data collection protocol and randomly assign participants to one of the two expert groups to increase validity of Delphi results.
- Include all relevant stakeholders to ensure the validity of panel findings.
- Determine panel size by considering the mode of data collection and panel interaction, the level of panel heterogeneity, and the likely attrition rates.
- Ensure that feedback reports include statistical summaries of participants' responses and list participants' own answers.
- Determine the level of panellist anonymity before enrolling panel members.
- Decide on the number of Delphi rounds before the start of data collection (but keep in mind that the number of rounds remains difficult to predict, and that the consensus may not be reached after the number of rounds that you fixed).

Retrieved and adapted from Khodyakov et al. 2023, page 53⁷⁷



17.6 Modalities of data collection

Delphi surveys are preferably **administrated by e-mail** (though paper-and-pencil Delphi have existed in the past).

Textbox 8 presents the RAND recommendations for organising the data collection in a Delphi study. The number of rounds is not necessarily defined a priori (often because of budgetary, time or human resources constraints): data collection must stop when saturation or consensus is reached. Therefore, it is recommended to **anticipate the minimal number of rounds** that will be conducted (also to inform the participants).⁷⁷

Textbox 8 – Recommendations for data collection in Delphi studies

- Ask the same questions about all items considered to compare and contrast participants' views along several dimensions.
- Ask specific, clear, unambiguous, and unbiased questions; provide response options that are exhaustive and relevant to the question.
- Do not include "I do not know" as a response option as participant may avoid taking position. An alternative is to use "I am not competent" as it empowers the participant.
- Choose what response scales to include as they may affect consensus development.
- Decide whether modifications to items and questions will be made between rounds before the start of the data collection.
- (in real-time Delphi) ensure that moderators facilitate the exchange of ideas, ask neutral probing questions, engage all participants in the discussion, and keep the discussion on track.

Retrieved and adapted from Khodyakov et al., 2023, page 54⁷⁷

At KCE

- Delphi surveys are organised and distributed via the platform LimeSurvey; a specific plug-in has been designed to this end.
- ▶ *Information about the KCE Delphi plug-in in the KCE Project Guide.*

17.7 Data collection tools

BEFORE GOING FURTHER – READ SECTION 12.4

The Delphi method uses iterative (e-)mailed questionnaires in successive rounds. Because there is no interaction between the respondent and the researcher, **the formulation of the questions must be unambiguous, and definitions should be given where necessary.**

The questionnaire of the first round encompasses open-ended questions, to identify items to include in the second round.

The next rounds could be exclusively qualitative or consist of closed questions with scales (from totally agree to totally disagree, i.e. from 1 to 9) or combine both qualitative and quantitative questions. They include a synthesis of the results of the previous round.

In the case of closed questions, agreement is usually summarized by using the median and consensus is assessed by presenting interquartile ranges for continuous numerical scales.²³⁰ Graphical presentations of the results are welcomed.

17.8 Specific aspects of sampling for the Delphi process

BEFORE GOING FURTHER – READ SECTION 12.3

Participants must **be carefully chosen because of their expertise, experience, or knowledge in the field of the research question**. In addition, the various positions in the field or opinions regarding the subject should be covered. In that spirit, lay people could be included to increase the variety of viewpoints.²²³

Participants could be identified through publicly available bibliographic information.²²³ Snowballing recruitment could be useful to secure easy agreement to expert invitation and strengthen expert retention.²²³

There is no practical limit to the number of participants in a Delphi survey.²²¹ The same participants should therefore be present during the whole process.

17.9 Required human resources

At least one researcher develops the questionnaires, identifies, and recruits participants, analyses findings and reports them. The research team is responsible for keeping a low attrition rate and ensure the coherence between the different steps of the method. Administrative support could be needed to (e-)mail the questionnaires and manage reminders and answers.

17.10 Practical aspects

It is important to clearly explain the goal of the questionnaire and the way it will be analysed. The **formulation of the invitation / introduction** letter is therefore crucial. “*Stressing the practical policy application of the Delphi yield to experts panellists to aid their retention*” (retrieved from Rowe, 2011, page 1489).²²³

While anonymity is required in the process of the Delphi, using incentives and token of appreciation for recognition in participation, such as subsequently publishing expert membership listings could improve participants recruitment and retention.^{223,226}

17.11 How to analyse?

Each step of the Delphi requires a **specific analysis**. Textbox 9 provides recommendations for the analysis of data in a Delphi study.

In a classical Delphi, open-ended questions from round 1 should be content-analysed in order to group statements generated by the experts panel into similar areas (see section 20.1.1).²²⁸

Rounds that use closed questions should be statistically analysed. Summary statistics are used to decide whether consensus is reached. The level of the consensus must be defined in advance (e.g. 70% of agreement). There is **no agreement on the threshold indicating a consensus**, nor on the way of choosing this threshold.²²⁸ Each researcher must reflect on it, case by case. The proposals that have reached consensus should be eliminated from the next round.

**Textbox 9 – Recommendations for data analysis in Delphi studies**

- Show measures of central tendency and dispersion along with a frequency distribution of responses to each question to participants after each round.
- Investigate the stability of responses for each question between rounds using nonparametric tests or measures of dispersion.
- Choose and prespecify a measure of consensus that is appropriate for the type and goal of the study's Delphi panel.
- Use content analysis, thematic analysis, or framework analysis to summarise participants' comments and link them with the quantitative results (see Chapter 21).
- Develop a plan for handling missing data, explore the reasons for non-response, and look for patterns in the demographic characteristics of non-responders.
- Avoid differential weighting of responses during the same Delphi study without a clear empirical justification and evidence that doing so improves the quality of Delphi results in similar studies.

Retrieved and adapted from Khodyakov et al., 2023, page 54⁷⁷

17.12 How to report the findings?

- *For general principles about reporting the findings, go to Part 5*

Intermediary results are reported directly in the successive questionnaires. All the consensus and dissensus items are listed and discussed in the final report at the end of the process. Textbox 10 presents the recommendations for reporting the findings of a Delphi study.

At KCE

- The appendices of the scientific report should include the questionnaires used in each round.

Textbox 10 – Recommendations for reporting in Delphi studies

- Specify the panel's intended size, describe participants' demographic characteristics and areas of expertise, and present participation rates in each round.
- Consider the study's audience in determining what results and takeaways should be highlighted.
- Provide panel dates, summarise relevant evidence, and compare panel results with existing literature to help readers contextualise Delphi results.
- Interpret Delphi results by carefully considering the method's limitations.
- Register the study prospectively and share its protocol to increase the credibility of panel results.
- Account for human subjects' protection, consider potential conflicts of interest, and state the role of funding and endorsing organisations.
- Share both intermediary and final Delphi results with participants.

Adapted and retrieved from Khodyakov et al., 2023, page 54⁷⁷

17.13 Specific quality criteria

The variety of the Delphi surveys and the constant evolutions in this field complexify the evaluation of the quality of such data collection methods (see section 8.3.2).²²⁴

At KCE

- The Delphi Critical Appraisal Tool of RAND is the recommended appraisal tool.

18. CONSENSUS WITH INTERACTIONS: NOMINAL GROUPS

18.1 Should the study include the nominal groups?

Yes, if

- There is a search for consensus.
- Experts have low / poor digital skills.
- The search for consensus is part of a Rapid Qualitative Research.
- Experts include patient representatives or experts-by-experience alongside with academic and scientific profiles.
- There is an increased risk of drop-out if the data collection is organised during weeks.

No, if

- There is no need for a direct interaction between the experts to reach a consensus.
- Anonymity of the participants needs to be preserved.
- There is a large geographical dispersion of experts (for onsite nominal group).
- The panel of experts is international (in different time zones).

► Go to Chapter 17 Delphi Processes

18.2 What are nominal groups?

Developed in 1975 by Delbecq and Van de Ven, the nominal group technique (NGT) is “*a structured variation of a small-group discussion to reach consensus*”.¹²³ Nominal groups **gather information by asking participants to share their opinions about a defined topic before gaining a consensus through a structured process**. Lennon also defines the NGT as an evaluative methodology.²³³

“Nominal” stands for “in name only”, putting the emphasis on the fact that the “*session is only nominally, ‘in name’, a group, whilst it is relying on individual input in a group environment; the interactions between individuals during the sessions are actively discouraged*” (O’Neil and Jackson 1983 as cited by Varga-Atkins et al. 2011, page 4).²³⁴

18.3 Why and when to use nominal groups?

The NGT aims to support **consensus among a heterogeneous group of stakeholders**, particularly when the objective is to construct a logical model and when there is a lengthy list of outputs for the components that need to be prioritised.¹²³ To achieve this aim, the following questions are asked:

- Which of the outputs listed are most important to achieving our goal and are easier to measure?¹²³
- Which of our outputs are less important to achieving our goal and are more difficult for us to measure?¹²³



McMillan et al. also suggest using the NGT when the objective is “to explore ideas in relation to a problem or question” as the first step of the NGT consists in generating ideas” (retrieved from McMillan, 2016, page 655).²²⁰

18.4 Strengths and weaknesses of nominal groups

Table 28 present the strengths and weaknesses of nominal groups.

Table 28 – Strengths and weaknesses of nominal groups

Strengths	Weaknesses
• More ideas and contributes to a better balance of the influence games between the different participants when compared to a group discussion.²³³ • Promotion of a democratic and non-hierarchical dialogue because of the structure of the process.²³³ • Encouragement of each participant to participate, giving all of them an equal voice; this supports the inclusion of more introvert or quiet participants. • Reduction of the personality effect when the group is made up of a diverse sample of participants intertwined with hierarchical, power and influence relationships.²³⁴ • More suitable when participants are patients or citizens rather than professionals or experts (participant focused process).²³³ • More acceptable for some participants than a Delphi process because of face-to-face interactions.²²⁰ • More adapted to people with poor literacy.²²⁰ • Possibility of having a diverse group of participants (with various backgrounds, priorities, and perspectives).^{220, 235} • Cost-effective research method: availability and analysis of the results once the group is over, no need for transcription. • One session is enough to generate results, only a few hours are needed.^{220, 234} • Requires only one skilled facilitator.²³⁵	• Regimented aspect: each NG meeting can only focus on a single purpose / single topic.¹²³ • Need to have more than one meeting / sequence to cover complex topics. • Limited time available for in-depth discussion and development of the ideas: can be less stimulating and may lead to frustration. • Structured dimension not adapted to all kinds of participants. • Not suitable for all topics • If pre-existing strong opinions and conflicts between the participants, increased risks that face-to-face meetings become a confrontation.²³⁵

From the perspectives of the research commissioners, Varga-Atkins et al. reported the following benefits:²³⁴

- More generation of ideas in terms of volume than other face-to-face group approaches, e.g. focus groups.
- Immediate availability of the results presented as a priority list.
- Easier to compare results between distinct groups of participants.
- Combination of quantitative and qualitative approaches ('hard' data remain – for some – more convincing).

18.5 How to organise nominal groups?

BEFORE GOING FURTHER – READ SECTION 12.3 AND FOLLOWINGS

Figure 7 presents a simplified model of the NGT process and the possible adaptations as found in the literature by McMillan et al.²²⁰

18.5.1 Group size and length

Like for focus groups, the 'ideal' number of participants per group can vary.^{123, 220, 233-235} Usually, the expected number of participants will be **between 6 and 12 participants**; as recalled by Lennon et al., the authors of the method suggested 5 to 9 participants.²³³ If the number of participants exceeds 12, it is recommended to divide the group in smaller ones.²³⁵

A session should last at least **one hour for a group of 5 to 9 persons** (considering that one session will only solve one question / one problem). When groups are larger (although this is, again, not recommended) or diverse, the session will last longer. It is therefore recommended to plan a session of 2h / 2h30 per topic.¹²³

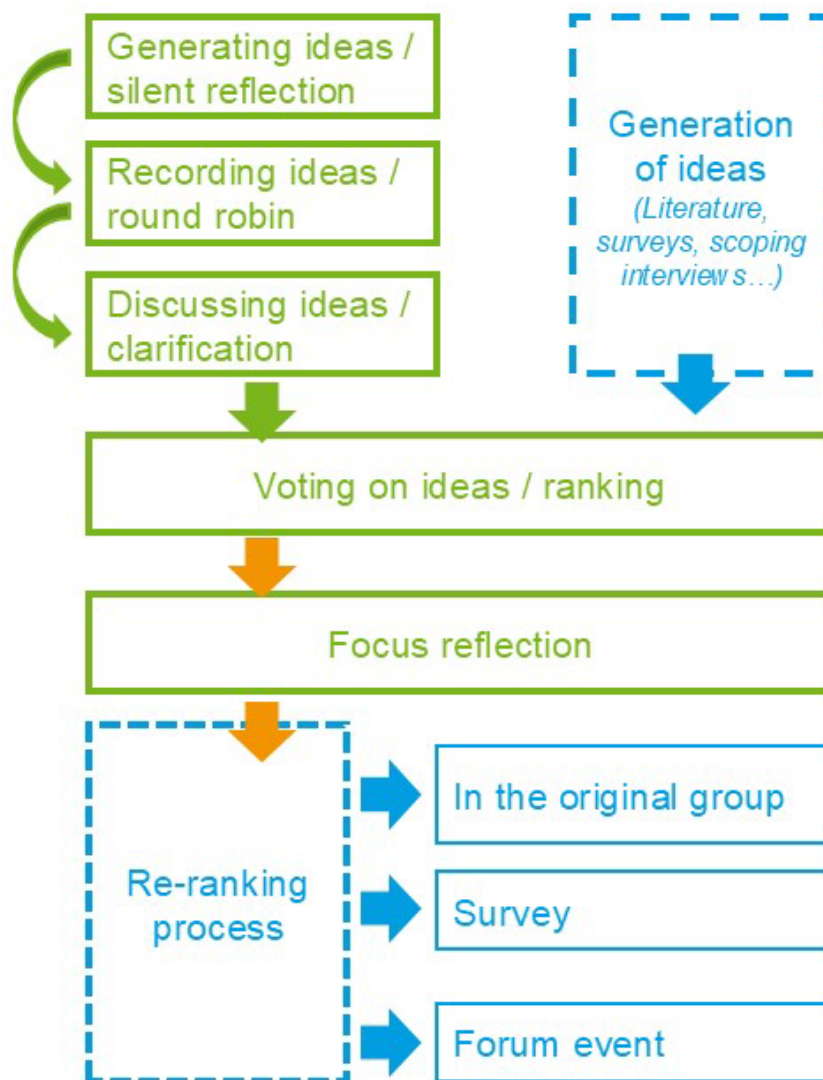
18.5.2 Nominal groups technique essentials

Vahedian-Shahroodi et al. identify what they call the NGT essentials:²³⁵

- **“A carefully prepared question that evokes responses at the desired level of specificity”** – implying that the research objectives should be specific, measurable, and realistic.
- **“A group of task-oriented participants with expertise in the topic”** - this refers to the notion of 'casting' often used in co-creative and collaborative approaches.¹³⁹ In this case, the research team needs sufficient time to carefully identify and invite participants because of their expertise, but also because of their ability to work together.
- **“A group leader who understands the process and is willing to act as a process facilitator, not a substantive expert”** – this emphasises the need for having a well-trained moderator, with relational skills and a sense of diplomacy to ensure a constructive dialogue. We recommend that moderators first acquire experience with focus groups before moderating a nominal group.



Figure 7– Simplified model of the process of nominal groups, including adaptations



Retrieved and adapted from McMillan et al. 2016, page 657.²²⁰ Elements in bold cases are components of a 'traditional' nominal group. Elements in interrupted lines are optional.



18.5.3 Process

Before the nominal group

Lennon et al. insist on the **minimal preparation** expected from the participants.²³³ However, not all sources converge about the minimal preparation as, in some studies, the research team asked the participants to prepare the first step of the process before the NG meeting.^{123, 220, 233, 235} While some consider the lack of preparation of added-value, other authors feel that there is a need for preparation of both participants and research team, with a critical role to be played by the moderator.¹²³ Preparation could also help speed up the process, although there is no guarantee that all the participants will prepare.

	ROLE OF THE MODERATOR	ROLE OF THE PARTICIPANTS	ADDITIONAL INFORMATION
STEP 0	OPENING STATEMENT		
	Warmly welcoming participants Clarifying the role of the group members Highlighting the importance of the contribution and the expertise of each person (this is particularly the case for 'lay' experts such as patient representatives, experts by experience or peer-educators who may feel intimidated by academics or professionals). ¹²⁵ Clarifying the group objectives Reminding of the importance of the task Explaining how the outputs will be used ¹²³	/	A crucial step of the NGT is to make " <i>clear to all the participants that everyone in the group is following the same, prescribed methods and that all participants have an equal voice in the process, and all responses are valid</i> " (retrieved from Lennon et al., 2012, page 3). ²³³
STEP 1	GENERATING IDEAS / SILENT REFLECTION		
	Presenting the problem / topic / research question	Writing of ideas / statements, independently and silently (personal and individual work)	Could be prepared by the research team beforehand through a literature review or another data collection (e.g. quantitative surveys, interviews, observations...). ²²⁰



	ROLE OF THE MODERATOR	ROLE OF THE PARTICIPANTS	ADDITIONAL INFORMATION
STEP 2	RECORDING IDEAS / ROUND ROBIN		
	Engaging participants in a round robin feedback, i.e. all participants have the same time to report their input. Concise writing of each idea i.e. key message, key words, by the moderator on a flip chart / digital whiteboard (e.g. Miro) – visible to all participants.	Presenting their inputs to the other participants. No debating of the idea at this point. No need to repeat ideas that are already mentioned.	Pursuing feedback rounds until all ideas are written down.
STEP 3	STEP 3 DISCUSSING IDEAS / CLARIFICATION		
	Moderating the discussion with statements like “are there questions / comments about the item”. ²²⁰	Discussing each idea to determine its clarity and importance: explanation must not necessarily be provided by the person who proposed the item it can also come from another participant.	Opportunity for expressing the understanding of the logic / relative importance of the item.
STEP 4	VOTING ON IDEAS / RANKING		
	Choosing the criteria for establishing the priorities. Counting of the votes to identify the highest-rated ideas: it can be useful to list them alongside the ideas of the round robin. Tally table or ranking sheet can help to organise the scores.	Individual (anonymous) voting to establish priorities. Putting vote on a card (e.g. choosing the 5 most important items) / vote via an online voting system.	Depending on the group composition and on the topic, one may prefer an anonymous vote to prevent any bias of influence. <u>Alternative:</u> ranking could be achieved via the allocation of a score or by using a Likert scale.



STEP 5

ROLE OF THE MODERATOR

ROLE OF THE PARTICIPANTS

ADDITIONAL INFORMATION

OPTIONAL - FOCUS REFLECTION AND NEW RANKING PROCESS

Discussion about the statements retrieved during step 4 / statements that were not retrieved.²³³

Additional vote if a stronger consensus is needed, if additional validation is needed, if the aim is to obtain definitive solutions for which no more changes are expected.²²⁰

Reranking and additional voting are particularly important when different groups are held in parallel.

Alternative: a new vote could be obtained at another point in time through a survey, a forum, with the same group or with different participants. Theoretical example: the NG aimed to establish priority criteria for assessing a program with a group of patient representatives, professionals, and academics. A total of 15 criteria are issued, but the order of the criteria needs further consensus. The 15 criteria are then included in an online survey submitted to other participants.



18.5.4 Practical aspects

Table 29 offers a checklist to help prepare a face-to-face or online nominal group.

Table 29 – Checklist for preparing face-to-face or online nominal groups

	Face-to-face nominal groups	Online nominal groups
Before the session	- Check if ethical approval / informed consent / conflict of interest is needed (see Chapter 7). - Check if the session will be recorded and inform participants. - Draft a timeline to ensure that the flow is respected (particularly when there are groups held in parallel). - Have a discussion guide with clearly defined questions. - Send preparatory material (optional). - Plan a test of online tools for the team / for the participants (optional but strongly recommended).	
Length of a session	2h-2h30	1h30-2h
Group size	8 to 10	6 to 8
Human resources	1 moderator per group 1 note taker per group	1 moderator per group 1 note taker per group IT support
Location	One room per group One room for all the groups together	Break-out rooms
Material	Catering Board / flipchart Large sticky notes (step 1), at least 3 per participant Pens Individual voting sheets Support for collecting the votes	Online whiteboard (e.g. Miro®) Virtual sticky notes (step 1), at least 3 per participant Online anonymous voting system

18.6 Specific quality criteria

To date, **no specific quality criteria have been identified for nominal groups**. It is recommended to apply the criteria of the Delphi Criteria Appraisal Tool (section 8.3.2) and the general principles of validity and quality of qualitative research.

► For more about quality and validity, go to Chapter 8

◆ PART 4 – QUALITATIVE DATA ANALYSIS

“Unlike quantitative analysis, there are no clear rules or procedures for qualitative data analysis, but many different possible approaches” (retrieved from Spencer et al., 2014, page 270).²³⁶

“Qualitative analysis transforms data into findings. No formula exists for that transformation. Guidance, yes. But no recipe” (retrieved from Patton 2002, page 432).¹³²

Part 4 provides an overview and brief description of approaches useful for qualitative data analysis (QDA) in the context of KCE projects. It is **impossible to write a precise manual** on how to perform a good QDA, as there is no universal set of clear-cut procedures which fit every type of data. Moreover, QDA requires a good dose of **“fingerspitzengefühl”** (a unique and personal combination of experience, intuition and knowledge), **creativity** and **imagination**.²¹ The researchers have some theoretical background, due to their training, professional background, previous research, theoretical knowledge, etc. These elements will influence the way they will read, analyse, and therefore chose themes to be applied to the corpus and the way they will interpret the data. On the one hand, the researchers will have a **certain level of sensibility** that will increase through readings, experience of research and reasoning. It will also improve during the analysis of the corpus itself. On the other hand, they will develop their **theoretical capacities** with new concepts, or models. This is also why analysing qualitative data is not a simple nor a quick task. Done properly, **it is systematic and rigorous, and therefore labour-intensive and time-consuming**: “[...] good qualitative analysis is able to document its claim to reflect some of the truth of a phenomenon by reference to systematically gathered data.” In contrast, “poor qualitative analysis is anecdotal, unreflective, descriptive without being focused on a coherent line of inquiry” (retrieved from Fielding, 1993, page 116).²³⁷ QDA is a matter of **deconstructing the data to construct an analysis or theory**.⁶³

19. FREQUENTLY ASKED QUESTIONS IN QUALITATIVE DATA ANALYSIS

19.1 Should all the data be collected before starting the analysis?

No, analysis can start during the data collection process, as it may help to further refine the data collection material or reorient the recruitment strategy.

Additionally, as part of the RQR, it is recommended to initiate a primary field analysis. During data collection, brief summaries of data are already made. Also, frequent meetings within the research team to discuss emerging findings enhance the data analysis in parallel with data collection.^{29, 238}

19.2 Should the researcher in charge of data collection conduct the data analysis?

Ideally, the same researchers should conduct the data collection and run the analysis, as collecting data is already starting the analysis. During the data collection, the researchers already start to think about their data and the analysis, i.e. by writing memos or summaries (see section 12.5.6). Doing the data collection helps them familiarise with the data.

When another researcher than the researcher who collected the data performs the analysis, the researcher in charge of the data collection should review and complete the transcriptions with field notes and remain available for discussion with the researcher doing the analysis. Additionally, the researcher doing the analysis should have access to the recordings to have access to the raw data. The two researchers should meet regularly and the researcher who conducted the data collection could endorse the role of cross-checker (see below).



19.3 Should one researcher conduct the entire analysis of the corpus?

It is recommended to have **at least two researchers** for conducting the QDA to enhance the quality and the validity of the findings, meaning that these two researchers will code the same dataset and compare their coding. This is usually done after coding a few interviews or focus groups.

At KCE

- Data are collected in Dutch and in French. It implies that two researchers will code separately a first set of data in their own language before comparing their coding and establishing a common coding tree. Based on the common coding tree, the two researchers complete the full coding of the dataset in their own language. Once the coding is completed in both languages, one researcher can take the lead for analysing, interpreting, and reporting the findings. The other researcher then checks the interpretation and final report.

19.4 Can the analysis process be expedited?

In the context of a RQR, **a single researcher could lead the analysis**, with all necessary precautions. In RQR, there is sometimes not enough time for double coding of the initial dataset and cross-checking between research members, which could affect the consistency of data collection and analysis. The use of manuals (= coding book), tables, or other kinds of pre-established forms for data collection is then highly recommended. Endorsing a team member with a **cross-checker role** (responsible for going through the data and identifying inconsistencies to be brought up in team meetings) can also be a solution to avoid this bias.⁹⁹

19.5 Should the data be analysed according to their source?

Depending on the research question, it is **possible to apply the same analytical strategy** to all the qualitative material collected during a project. This could be, for example, using the same coding book or applying the same theoretical framework to the data emerging from the interviews, the literature, and focus-groups, because these different data sources aim to answer the same research question (triangulation of sources). The challenge will be to report the findings in such a way that the readers understand where they come from.

However, findings from Delphi processes and nominal groups should be analysed separately, as they have a specific objective.

► *For the analysis of results in a Delphi study, go to Textbox 9*

19.6 Should the data be analysed with a qualitative data analysis software?

The researchers can analyse data **manually** or by using **qualitative data analysis software**.

In its simplest form, analysis could be performed by printing transcripts, annotating them by hand, and using sticky notes or a whiteboard to organise and analyse the data. The analysis could also be supported by basic computer software such as Microsoft Word or Excel (e.g. creating the analytic framework and using the Excel spreadsheet as a classification tool).

At KCE

- Researchers use Nvivo®, a Computer-Assisted Qualitative Data Analysis Software (CAQDAS) offering support to the analyst with the storage, coding, and systematic retrieval of qualitative data.⁹⁹ It allows managing different types of qualitative materials such as transcripts, texts, pdf files, videos, pictures, etc. It also includes a feature for collaborative work (but those without the

⁹⁹ See more about Nvivo here: <https://lumivero.com/products/nvivo/>

Nvivo licence cannot access the project). Textbox 11 presents a selection of resources for using Nvivo.

The version Nvivo15 integrates an AI assistant (paid add-on module with annual subscription).^{hh} This AI assistant is a built-in feature, meaning that there is no need to connect outside Nvivo. This makes it possible to respect ethical use and data privacy. The AI assistant integrated in Nvivo supports the following tasks:

- Producing summaries of transcripts, with the possibility of choosing the length of the summary.
- Suggesting descriptive codes in the first stage of coding (indentation of children codes): AI does not produce interpretation or analytical, theory-based coding.
- Producing summaries of coded material.

These tasks help to prepare the initial step of the analysis, but the final outputs require human insights.

Textbox 11 – Useful resources when using Nvivo

Nvivo YouTube channel

- <https://www.youtube.com/@NVivosoftware>

QDA YouTube Channel

- <https://www.youtube.com/@qdatraining/videos>
- https://www.youtube.com/watch?v=VriAQRQDByk&ab_channel=QDATRAINING

Useful tips when using Nvivo (in English and French)

- <https://lumivero.com/products/nvivo/>

Useful tips when using Nvivo (in Dutch)

- <https://onderzoektips.ugent.be/nl/tips/00001699/>

Demo video of the AI assistant

- https://www.youtube.com/watch?v=VriAQRQDByk&ab_channel=QDATRAINING

At KCE

- *Not all KCE computers have a Nvivo licence: contact KCE ICT for more information.*

^{hh} In October 2025, KCE has the licence for Nvivo14.



20. THEORETICAL APPROACHES FOR QUALITATIVE DATA ANALYSIS

Qualitative data analysis (QDA) varies in terms of basic epistemological assumptions about the nature of the research and the posture of the researchers, the research questions and the aims of the analytic process (see Table 1).¹⁷³ The analysis process starts with data management and ends with abstraction and interpretation, from organising and describing the data to explaining them.¹⁷³

The key features of a rigorous and well-founded substantive, cross-sectional QDA analysis are:¹⁷³

- **Remaining grounded in the data**, which implies that the analysis starts from the data to develop an interpretation. To do so, the researchers need to be able to access their original data during the analysis process (e.g. the full transcript of the interview rather than a summary of the interview, complete field notes) but also to be able to distinguish their interpretation from the data (see section 21.6). This is particularly important when the researchers analysing the data are not the ones who conducted the data collection (this situation can occur at KCE).
- **Allowing systematic and comprehensive coverage of the data set**, implying that the researchers analyse each 'unit' / each 'case' (interview, focus group or observation) in the same way. This requires a clear documentation of the analytic strategy and its understanding by the team members, particularly when multiple researchers participate in the analytic process.
- **Permitting within- and between-case searches**. The researchers need to navigate the dataset to identify common and diverging elements across different cases, relations between elements within one case and relations between elements between groups of cases.
- **Affording transparency to others**, implying that the researchers need to ensure that the building blocks of the analysis are accessible (and comprehensible) to others. This requires keeping track of all the steps and actions taken during the analysis process and reporting them properly.

Classically, three analytic approaches are used in qualitative health (care) research, each of them using specific methods and tools, and rooted in specific theoretical approaches: **thematic content analysis**, **analysis using conceptualising categories** and **phenomenological examination of empirical data**. In practice, the researcher often moves back and forward between the data and the emerging interpretations. Hence **induction and deduction are often used in the same analysis**. Also, **elements from different approaches may be combined in one analysis**.³ The way data will be analysed is part of the research design, hence chosen at the beginning of the research process and added to the research protocol.

20.1 Analytic approaches

20.1.1 Thematic content analysis

Thematic content analysis is the creation and refinement of categories to give a global picture of the material, helping to reduce data. It is not a deep analysis, but rather a way of describing the topic(s) appearing in the corpus. In other words, the researchers "*categorise the recurrent or common 'themes'*" (retrieved from Green and Thorogood, 2004, page 177).²¹ This is the most frequent approach in qualitative health research.^{21, 173} It addresses questions focusing on "*salient issues for particular groups of respondents or identifying typical responses*" (retrieved from Green and Thorogood, 2004, page 177).²¹ One application of thematic content analysis is the framework analysis.

Inspired by the thematic content analysis, **framework analysis is a deductive research strategy**, developed specifically for applied or policy-relevant qualitative research. The objectives of the study are set in advance. The thematic framework for the analysis of the corpus is usually identified a priori, at the beginning of the research. The tools for data collection usually include questions that will (directly or indirectly) be addressed the thematic framework.

Depending on the analysis strategy, framework analysis can also be inductive. Indeed, themes or issues “*may have arisen from a priori themes (...) however it is at this stage that the researcher must allow the data to dictate the themes and issues. [...] Although the researcher may have a set of a priori issues, it is important to maintain an open mind and not force the data to fit the a priori issues. However, since the research was designed around a priori issues, it is most likely that these issues will guide the thematic framework. Ritchie and Spencer stress that the thematic framework is only tentative and there are further chances of refining it at subsequent stages of analysis (1994)*” (retrieved from Srivastava, 2009, page 76).²³⁹

The decision of using frameworks when analysing data is closely related to the purpose for which the qualitative material will be used in the overall research strategy. ‘Frameworks’ are generally deducted from theories and conceptual models, e.g. applying the Andersen’s model of access to health care to a study investigating the facilitators and barriers to mental health care, or using the self-care deficit theory of Orem to understand the compliance of chronic pain patients to physical therapy.^{32, 33} The reason for it could be that the research object is already well studied, that the research is commissioned by an institution or that the research is spread through different teams in separate locations.²⁴⁰

Applying framework analysis concretely means that the **themes emerging from the data are placed in a framework that was defined a priori**. The framework is systematically applied to all the data. Although an analytical framework can be very useful, it is not suited if the aim is to discover new ideas, since a framework or grid could be blinding.²⁴⁰

Example: in KCE project 257 on access to health care for undocumented migrants, data were collected through semi-structured interviews with undocumented migrants and focus-groups with professionals.⁵² The 7B framework for access to health care of Roose and De Bie²⁴¹ was combined with the dimensions of a SWOT²⁴² to develop the data collection material and then applied as a framework for the analysis of the data.

Thematic content analysis and framework analysis are the **privileged approach to QDA in RQR**.²⁹ In RQR, thematic content analysis is adapted in order to accelerate the QDA process: mapping of the code structure during data collection (this reduces the amount of time needed to develop the initial codes), dividing the interview transcripts and field notes between different members of the team and no double coding of the data, but a limited amount of cross-checking between researchers.²⁹

20.1.2 Analysis using conceptualising categories

The **analysis using conceptualising categories** aims to create and refine categories to go further than a mere description, to reach conceptualisation of the data. This approach is mainly applied in **grounded theory**. Developed by Glaser and Strauss, grounded theory is a methodology for extracting meaning from qualitative data. Typically, the researcher does not start from a preconceived theory but allows the theory to emerge from the data.²⁴³ Hence grounded theory is an **inductive** rather than a deductive methodology. Emergence is also a key assumption in grounded theory: data, information and knowledge are seen as emergent phenomena that are actively constructed. They can only have meaning when positioned in time, space and culture.²⁴³

Grounded theory is a complete method, a way of conceptualising a qualitative research project. It explains rather than describes and aims for a deep understanding of phenomena.²⁴³ This methodology focuses on generating or discovering a theory about a social process or phenomenon. It uses systematic data collection and analysis to identify patterns, categories, and relationships within the data, leading to the development of a theory.

The power of grounded theory lies in the **depth of the analysis**.^{244, 245} Key to grounded theory is the emphasis on theory as the final output of research. Other approaches may stop at the level of description or interpretation of the data (e.g. thematic analysis).



Example: Using grounded theory, Didier et al. conducted comprehensive interviews with 32 patients to “examine patients’ perspectives on interprofessional collaboration within multidisciplinary or interprofessional healthcare teams” (retrieved from Didier et al., 2022, page 1179).²⁴⁶ Based on their analysis, they found that “the theory of protecting personhood emerged as the core concept of hospitalized patients, cared for by interprofessional healthcare teams” (retrieved from Didier et al., 2022, page 1177).²⁴⁶

20.1.3 Phenomenological examination of the empirical data

The **phenomenological examination of the empirical data** aims to report the authentic comprehension of the material. This approach explores the “what” and “how” of individuals’ experiences with a particular phenomenon, aiming to understand the essence of those experiences. It emphasizes **rich, descriptive accounts of lived experiences**. In-depth interviews (=unstructured interviews) with people who have directly experienced the phenomenon of interest, are the most used data collection technique. The phenomenological method aims “*to describe, understand and interpret the meanings of experience in human life*” (retrieved from Bloor and Wood, 2006 page 128).⁵⁹ Typically, it addresses questions focusing on the experiences of the persons in a particular situation, for example, “how do cancer patients experience integrated care pathways?”.⁵⁹ Phenomenology focuses on “*how human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning*” (retrieved from Patton, 2015, page 115).²⁴⁷ It is about understanding the nature or meaning of everyday life.

Example: Combining several data collection methods (case vignettes, observations, diaries, and interviews), Duffy et al. aimed to explore the infant experience of hospitalisation in neonatal intensive care.²⁴⁸

20.2 How to choose the analytical approach

The analytical journey starts with determining which analytical approach will be used, considering the **level of analysis (descriptive versus interpretative), the inductive versus deductive approach and the method that will be used**. This choice needs to be coherent with the research question and research aims, the design and the data collection strategy. Some designs and/or research questions require an inductive, others a deductive approach.

As stated above, one should therefore recall that the level of analysis and the inductive-deductive continuum are not clear-cut and that elements from different approaches can be combined.

20.3 Approach to qualitative data analysis at KCE

In the context of KCE studies, the two major QDA approaches are the **thematic analysis** and the **framework analysis**. They are described in the next sections.

The basic level is a **descriptive account** of what was said, by whom, in which context, in relation to which event, in relation to which particular topics and questions.²⁴⁹ Due to the resources available for QRM in KCE studies, **the expected level of analysis is, at a minimum, descriptive** (see section 4.3).

The higher level of analysis is **interpretative**: this is the level of identifying the ‘meanings,’ e.g. understanding why poor people smoke more than more affluent ones or how an interdisciplinary team can manage complex situations. It is sometimes called the latent level of analysis. The focus of qualitative research at KCE is mostly applied, and the interpretative level of analysis is less relevant to achieve this goal. However, this does not prevent the KCE researchers from adopting a more interpretative approach.

QDA at KCE is also **mostly deductive**, with predefined categories to which the data are coded; for example, a priori concepts can be adopted from the literature or a relevant field (see section 20.1.1).

Again, this does not prevent KCE researchers from adopting a **more inductive approach** when relevant, meaning that themes emerge from the data. Both approaches can also be combined.

In Rapid Qualitative Research (RQR), it is recommended to start from an existing framework where possible, implying that the data will mainly be submitted to a deductive approach.²⁹ In the literature, there is no information on the minimal expected level of QDA. Rapid ethnographies (in health care) most often use thematic analyses that can remain at a 'relatively' basic level, with minor modifications to the methodology to increase the speed of analysis.²⁹

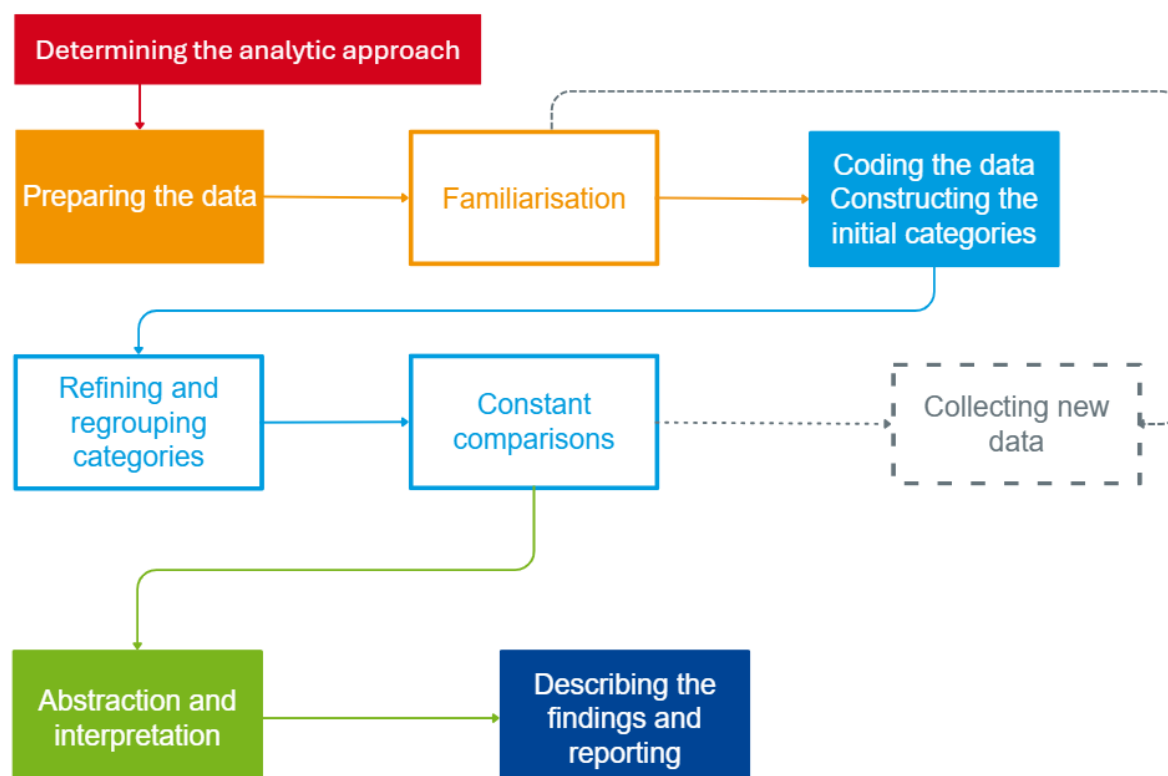
21. ANALYTIC JOURNEY

Once the analytical approach has been chosen, the research team can start the analytic journey. Figure 8 presents a generic conceptual representation of the analytic journey of qualitative data. Independently of the analytical approach, the researchers go through the different steps, considering that each analytical approach adds its own typical emphases. The next sections develop the different steps of the journey.

This journey applies to all the qualitative material collected during a project. It can be used for analysing data from a primary data collection (e.g. interviews, focus groups, or observations) or data from a secondary data collection (e.g. literature or online data). It might also be useful in the processing of qualitative data following a systems thinking approach.

- To know more about Systems Thinking, please refer to the KCE Process Note Systems Thinking: <https://processbook.kce.be/introduction-systems-thinking-health-services-research>.

Figure 8 – Conceptual representation of the analytic journey of qualitative data



21.1 Preparing the data for analysis

The researchers gather transcripts, field notes, scientific and grey literature and any other material that will be analysed.



In practice

- The researchers in charge of the data collection should store audio / video recordings of the interviews, focus groups and any other data collection activity on the dedicated secure server:
- It is advisable to determine a common denomination system for the audio/video recordings and the transcripts to facilitate their storage and reuse.
- Transcripts should be quickly reviewed by the researcher who conducted the data collection to ensure that anonymity is preserved (e.g. if the person introduces herself/himself, if the participant cites the name of a professional or of a hospital, it should be replaced by keywords such as [GP name] or [university hospital]). This quick review could also serve to check the quality of the transcription and, if needed, to complete it with field notes.

At KCE

- *Procedure for the secured storage of qualitative data is available in the KCE Project Guide.*

When using Nvivo

- Import and organise data that will be analysed in Nvivo.
- (in framework analysis) include the framework that will be used (option “framework matrix” in Nvivo) – this also applies when a framework is defined to analyse the literature.
- When importing articles for a QDA of the literature, Nvivo creates attributes related to the document, that will be useful to describe the material (e.g. authors, year of publication...).

21.2 Familiarisation

The researchers **read the transcripts and field notes** to immerse themselves in the data, gaining an overview of the substantive content and identifying topics of interest.^{173, 250} By doing this, they get familiar with the data.

In a framework analysis, familiarisation is helped by keeping the research question in mind, to consider the aims of the study and the themes contained in the interview / topic guide.

When using Nvivo

- Read the material directly in Nvivo.
- Personal notes can be added when reading and memos can be drafted.

21.3 Coding the data

21.3.1 Initial coding

The researchers identify an **initial set of labels** by reading (and re-reading) the data to develop a profound knowledge of the data. This step can be very laborious (especially with substantial amounts of data and in inductive approach).

The initial coding is **applied to the text kept in the original language** (hence the codes are kept in the language of the transcript). The switch from the original language to another language (usually the one in which the final report will be written) can occur sooner or later in the process (when needed): this is influenced by the topic, the research team, the time required for the analysis, and the inductive versus deductive approach to coding (a deductive approach will always mean that the coding remains in the original language longer).

The researchers **code pieces of text**, i.e. given a label or a name. Generally, in the qualitative analysis literature, ‘data coding’ is used to refer to this data management. However, data coding refers to distinct levels of analysis (see Table 31). The coding of qualitative data isolates meanings in function

of answering the research question. One piece of text may belong to more than one category or label, which means overlap between categories is likely. Major attention should be paid to 'rival explanations' or interpretations about the data.

Initial coding of the data is **usually descriptive, staying close to the data**, whereas labels developed later in the analytic process tend to be more abstract concepts.²³⁶ The researchers list all the labels that are relevant for the research question. They then document each label: they identify the importance of specific themes, repetitions, crosschecks, which elements go together, which are opposites...

Spencer et al. identified three requirements to retain the essence of the original material (Spencer et al., 2014, page 309).²⁵⁰

- Key terms, phrases or expressions should be taken as much as possible from the participant's own language.
- Interpretation should be kept to a minimum at this stage.
- Material should not be dismissed as irrelevant just because the way it can be included is not immediately clear.

21.3.2 Thematization

Based on the labels, the researchers **transpose the corpus into a number of themes** originating from the analysed content and according to the problem under investigation. A theme is a set of words aiming to identify what is covered in the corresponding extract of the corpus text, while providing guidance on the substance of what is said. Table 30 compares continuous thematization versus sequential thematization.

Table 30 – Continuous thematization versus sequential thematization

Characteristics	Continuous	Sequential
<i>How to do it?</i>	• Identification of the themes when reading of the text. • Progressive building of the thematic tree in parallel (fusion, regrouping, hierarchical classification...) • Obtention of a final tree at the end of the research.	• Hypothetico-deductive analysis in 2 steps. • Elaboration of the themes based on a sample of the corpus (e.g. based on the first 3 interviews), with the attribution of a clear definition to each theme and possible hierarchy (not compulsory at this stage). • Strict application of the list of themes to the whole corpus, with the possibility to add a limited number of new themes.
<i>Strengths</i>	• Rich and accurate analysis • Adapted to small corpus	• More effective • Appropriate for analysis in team
<i>Weaknesses</i>	• Complex and time-consuming • Not adapted for analysis in team	• Less deep analysis
<i>Used in</i>	• Thematic analysis	• Thematic analysis • Framework analysis – the themes can be based on the framework and applied to a sample of the corpus

Retrieved and adapted from Paillé and Mucchielli, 2011²⁴⁰



As explained above, in framework analysis, the definition of the themes depends on the framework of the research and the expected level of generality or inference. Indeed, the analysis will be conducted in a specific framework, i.e. the aim of the research, and with a certain orientation and some presuppositions. These are linked to the data collection and the position of the analyst.

The inference will be done following the next reasoning: because the presence of this or this element or indication in the extract, it is possible to assign it the theme X.

Example: The two following quotes are retrieved from the KCE project 344 on Long Covid.⁵⁴

“Ik kan mijn huishouden nog altijd niet doen. Dus ik had geprobeerd om te regelen dat ik hulp kreeg voor... Te koken, wat te poetsen, eens naar de winkel te gaan. Wachtijd, drie maanden.” (Patient 2, hospitalised)

« J'aurais bien aimé avoir quelqu'un pour faire par exemple le ménage chez moi parce que jusqu'à aujourd'hui c'était trop difficile. Mon mari fait ce qu'il peut mais on a 3 enfants, il faut déjà s'en occuper, il faut faire la cuisine et tout. Mais je m'étais dit "où est-ce que je peux même demander de l'aide pour avoir une femme de ménage de temps en temps ? ». (Forum)

Retrieved from Castanares-Zapatero et al. 2021, page 217⁵⁴

Applying the inference to these quotes, both patients explain that they cannot keep up with their housekeeping anymore. The theme “Practical support” was then applied to both quotes.

It is not because a theme appears only once that it is not important. If this theme is identified while still collecting the data, it might be interesting to discuss whether this theme should be integrated in the next interviews / next focus-groups (see Chapter 12).

If different researchers analyse the data, ending up with different themes according to each of them is far from unlikely, and even natural and to be expected. However, this issue will be limited by everyone adopting the same approach to QDA and by having the researchers in charge of the analysis **meet on a regular basis**.

At this stage of the process, it is useful to develop a **coding book**, where themes and labels that will be used for further coding the data are defined to ensure a homogenous approach to the QDA.

At KCE

- It is recommended to have a coding book, as this helps to be more systematic in the QDA, particularly if the analysis is interrupted (e.g. because the KCE researcher works on different projects) or when different researchers are involved in the analysis (e.g. when data was collected in Dutch and in French).

21.3.3 Refine and regroup categories

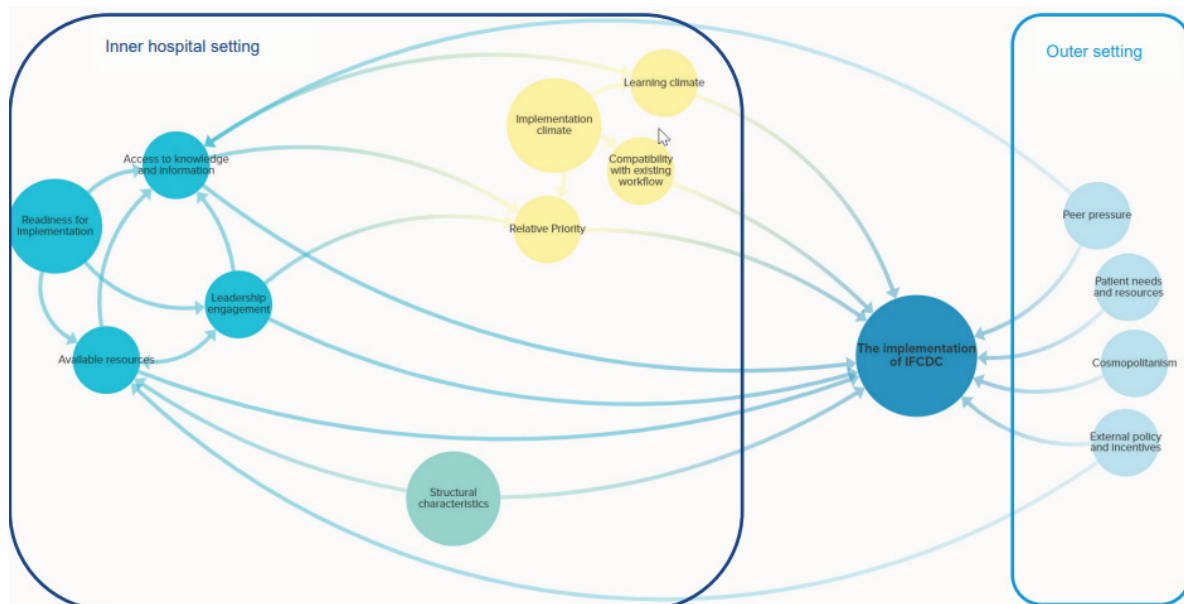
The researchers further **refine the categories and group them together**. “While reading through extracts of the data that have been labelled in a particular way, the researchers assess the coherence of the data to see whether they are indeed ‘about the same thing’ and whether labels need to be amended and reapplied to the data” (retrieved from Spencer et al., 2014, page 282).¹⁷³

In the thematic analysis, the refinement and regrouping of categories builds a **thematic tree**. It is a synthetic and structured representation of the analysed content. Categories are regrouped in main themes subdivided into subsidiary themes and sub-themes in a schematic way.²⁵¹ⁱⁱ Figure 9 gives an example of a thematic tree based on interviews conducted with parents of preterm newborns in neonatal care. It illustrates the conditions facilitating the implementation of Infant- And Family-Centred Developmental Care using the consolidated framework for implementation research. Note that this

ⁱⁱ Del Hoyo et al. (2020) published an interesting example of a thematic tree displaying various levels of coding.²⁵¹

tree is retrieved from a published KCE report and does not reflect how the tree appears in a QDA software.²⁵²

Figure 9 – Example of a thematic tree illustrating the conditions facilitating the implementation of Infant- And Family-Centred Developmental Care (IFCDC)



Retrieved from Detollenaere et al., 2022, page 142²⁵²

In framework analysis, the categories are – to some extent – already organised – depending on the model / theory / framework used. Therefore, the researchers could also decide to refine and regroup categories, particularly if there are emerging themes.

When using Nvivo

- In thematic analysis, it is possible to reorganise the labels, themes, and categories.
- It is possible to attribute additional properties between nodes, e.g. hierarchical relationships between nodes (parent-child).
- It is also possible to create matrix queries by using cases and attributes.

Table 31 presents the key terms related to the level of coding of qualitative data. Examples in Table 31 are based on the following quote, retrieved from the KCE report 344 on Long Covid.⁵⁴

« Après remboursements. Donc on a dû sortir 400 € de notre poche et ça on n'était pas prévenu. Ça, j'étais un peu... pas fâchée mais bon elle aurait pu prévenir et dire qu'elle avait fait des tests qui ne sont pas bon marché. Et au CHU, par exemple ils ont dit "on va vous faire" je ne sais plus quoi, une prise de sang ou quoi, mais ce sera une centaine d'euros, est-ce que vous êtes pour ou contre ? Mon mari avait dit "ben je suis pour", mais on avait prévenu. Mais la neurologue, elle n'avait pas prévenu... quand on a reçu la note, 400 €, pfou ! » (Patient 26, hospitalised) – Retrieved from Castanares-Zapatero et al. 2021, page 210⁵⁴



Table 31 – Commonly used level of codes in QDA

Term	Definition	Question addressed	Examples
Label	Identification of the topic of the extract, not what is said about it. First classification of the documents/ extract. Useful in a first quick reading of the corpus.	“What is the extract about?”	Patients are not informed that medical examinations are not reimbursed
Theme	Goes further than the label. Requires a more attentive reading. Topic of the narrative.	“What is the topic more precisely?”	Information on the cost of the examinations
Category	Similar elements of texts are grouped together. Enable the researchers to identify and describe the characteristics of the category. Prelude tree / typology (Morse)		Information needs

Retrieved and adapted from Paillé and Muchielli, 2011²⁴⁰

21.3.4 Constant comparison

During the analysis, the researcher can constantly compare the constructed categories with new data, and the new categories with already analysed data. This results in a kind of inductive cycle of **constant comparison** to fine-tune categories and concepts arising from the data.

In the case of focus groups, separate analyses must be performed on data gathered “within focus group” and continuously compared “between focus groups.” This is also an iterative process.

When using Nvivo

- It is possible to use automatic queries to facilitate the comparison.

21.3.5 Accelerating the coding process

In the context of a RQR, it is recommended to **develop a codebook in advance** or during the initial stages of data collection: this allows the researchers to start the data analysis while data collection is ongoing. However, setting pre-established categories might blind the researchers to findings they had not anticipated. An in-between approach is then suggested with some codes decided on a priori and others added during and after data collection, but the time-saving benefits of this approach is limited.^{29, 55, 238}

It is also possible to reduce the data to brief overviews by using tables and matrices such as **RAP sheets**.²⁹ RAP sheets were used in the KCE project 374 on the organisation of medical care in case of CBRNe incidents to compile and analyse data from interviews, while still collecting the data.²⁷

Resource

Template of a RAP sheet is available on the KCE Extranet
<https://extranet.kce.be/index.php/s/TPQAWKGWVG3nHf7>

When using Nvivo

- Coding can be done directly on the material.
- In a framework analysis, codes can be pre-recorded in the project and then applied to the text.
- The coding book can also be integrated in Nvivo (e.g. by adding definitions to the properties of the nodes).
- The function 'Memos' can be used to annotate the transcripts when coding and thematizing.
- The add-on AI can help to draft summaries of the transcripts and of the articles.

21.4 New data collection (optional)

The researchers may decide to conduct a new data collection to verify new points of view or insights emerging from the analysis.

Theoretical example: after analysing the first interviews with chronic patients in a project about self-care, the research team realises that all patients have a diagnosis of rare disease. These patients experienced delayed diagnosis, forcing them to develop their own self-care strategies. A new data collection was then conducted with patients with more frequent chronic diseases.

At this stage, the researchers may decide to write a **description for each subtheme in the study**.¹⁷³ This can help for preparing the final reporting of the results. It can also be useful when more than one researcher participates in the analysis.

21.5 Abstraction and interpretation

The researchers “*make use of the ordered data to identify key dimensions, develop categories, map the range and diversity of each phenomenon, map links between categories, and account for patterns in the data*” (retrieved from Spencer et al., 2014, page 292).²⁵⁰

This is the stage where “*fingerspitzengefühl*,” **creativity** and **imagination** play a significant role. The researchers analyse the data to identify the key ideas, which they gradually refine into more abstract themes. They **cut up and reorganise the data** to understand and classify the data better.¹⁷³

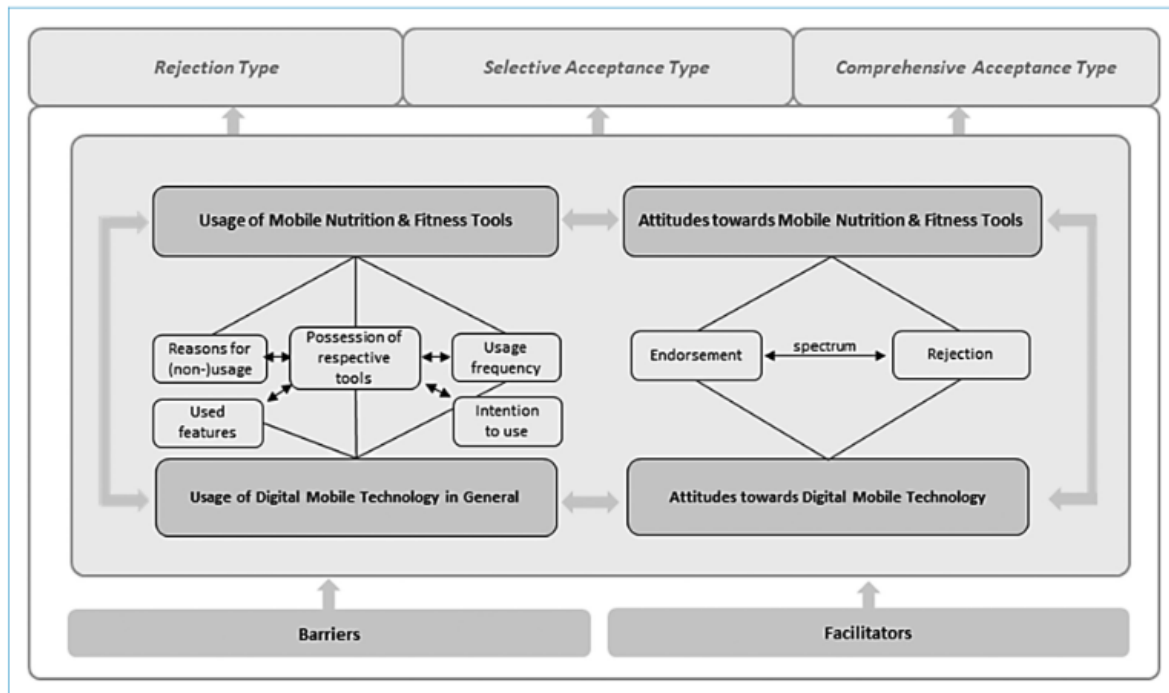
At this stage, the researchers can create simple **typologies**, which is locate “*categories in a more ordered way along a dimension*.” (retrieved from Spencer et al., 2014, page 317).¹⁷³ Typologies contribute to facilitating the connection between the comparisons within and between data.²⁵³ Mandara defines a typology as “*a hierarchical system of categories used to organize objects according to their similarities and dissimilarities*” (retrieved from Mandara, 2003, page 132).²⁵³ To build a typology, the researchers group cases or participants into “*different types on the basis of their common features, with consideration of how each unique individual represents a particular pattern of features*” (retrieved from Stapley et al., 2022, page 1).²⁵³

Example: In KCE report 299 on the evaluation of the rehabilitation conventions of the National Institute for Health and Disability Insurance, a typology of the different conventions was elaborated based on the analysis of the conventions. The typology was reported in a narrative way (see page 11 of the KCE report 299).²⁵⁴

Example: Vietzke et al. developed a typology to understand acceptance of mobile tools for nutrition and fitness among middle-aged and older adults.²⁵⁵ Based on 21 interviews, they reconstructed a typology organised around three acceptance types, as illustrated in Figure 10.



Figure 10 – Example of a qualitative typology about the acceptance of mobile tools



Retrieved from Vietzke et al., 2023, page 8²⁵⁵

21.6 Description of the findings and reporting

The last step of the analytic journey is the **description** and the **reporting** of the findings.

- For how to report qualitative findings, go to Part 5.

◆ PART 5 - QUALITATIVE DATA REPORTING

This final part focuses on the reporting of qualitative findings. Rigorous, transparent, and accurate reporting of results is important to assess the quality of a qualitative study, independently of the methodological approach that was actually used.²⁵⁶

22. QUALITATIVE DATA REPORTING

“We have to approach it [the reporting] as an analytical task, in which the form of our reports and presentations is as powerful and significant as their content. We also argue that writing and representing is a vital way of thinking about one’s data. Writing makes us think about data in new and different ways. Thinking about how to represent our data forces us to think about the meanings and understandings, voices and experiences present in the data. As such, writing actually deepens our level of analytic endeavour. Analytical ideas are developed and tried out in the process of writing and representing” (retrieved from Coffey and Atkinson, 1996, page 109).²⁵⁷

At KCE

Audiences likely to be interested in qualitative research include: 1) academics; 2) policymakers; 3) professionals; 4) the public; 5) participants to the study. KCE researchers write for policymakers, academics, professionals and, to a lesser extent, for the participants to the study. In collaboration with the research team, the KCE Communication Cell develops various simplified communication mediums which focus more on the context and results of the study, and less on the research process, e.g. a synthesis of approximately 15 pages, a press release of 1-2 pages, etc. Policymakers and professionals typically use the (much shorter) synthesis as their main source of information, though those with a particular interest in the topic may also find it necessary to delve into the scientific report. The synthesis is designed to be accessible and understandable for interested citizens, but the press release and the derived press articles disseminated through the media and the KCE newsletter are likely to be the main source of information of the public. The KCE research team is responsible for providing the scientific report and the communication to the study participants.

In this chapter, the focus is on the scientific report targeting an academic audience, including the validators (=external reviewers). The focus is on written deliverables and not on the various other forms of research outputs (e.g. conference, slides, videos....).

22.1 How to report qualitative research findings?

22.1.1 Is there a standardised structure for reporting qualitative findings?

No, qualitative research findings can be presented in different ways. **There is no specific format.** Standardising the reporting structure for qualitative research is not desirable, as it comes with a risk of reducing the diversity and the richness of the methodologies used in qualitative research.²²

Nevertheless, like for other research methods, justification and methodology of the study should be provided and the research process should be **fully transparent to ensure reproducibility**. In addition, it should be understandable to the reader.

Table 32 lists elements that could potentially be included in a qualitative research report. In a KCE report, depending on the structure chosen by the team, these elements can be integrated in an existing or in a separate chapter.



Table 32 – Elements to include in qualitative research report*

1. Introduction, justification, and qualitative research question

2. Methodology – see Table 34 for detailed overview

2.1. Overall research design, including choice of qualitative research method, time span of data collection, target population...

2.2 Recruitment strategy

2.3 Description of the sample

2.4 Description of selection biases (if any)

2.5 Instruments used to collect the data

2.6. Analysis, including the theoretical approach, the use of software...

2.7. Ethical aspects – including privacy issues

If an ethical approval was granted, do not forget to put the name of the Ethics Committee, the application number, and the date the approval was obtained.

2.8. Role and posture of the researchers, including reflexivity

2.9. Disclaimer about the use of AI (if needed)

3. Results: key findings

4. Discussion

4.1 Strengths and limitations of the qualitative study, including criteria for validity in qualitative research (*tools for quality appraisal can be used*).

4.2 Comparison with findings from other studies (if any)

This section is informed by literature.

5. Conclusions (and recommendations, if applicable)**

6. Appendices

including the interview guide(s)/ topic guide, material used to support data collection and data analysis.

Retrieved and adapted from Kohn and Christiaens, 2012, page 47²

*Final content needs to be adapted to the project. **In the context of KCE, recommendations are part of the synthesis and not of the scientific report.

At KCE

- *Refer to the editorial charter available on the KCE Intranet for general guidance about reporting at KCE.*

22.1.2 How to present the qualitative research methods used?

The research protocol established at the beginning of the project (and adapted along the process) is the basis for the methods section. Table 33 summarises the elements of the methods section to be considered in the final report. There is no need to translate data collection tools and other support material used during data collection, they are kept in their original language in the appendices. If AI was used to conduct a specific task during the project, the methods section should clearly report it.

Table 33 – Elements for the methods section*

<i>Elements of research design</i>	<i>Details</i>
<i>Overall research design</i>	Overview of the rationale for the research design How the different elements / components of the qualitative research part fit together. Congruence with the overall design of the KCE study
<i>Sampling design and achieved sample</i>	Description of the study population Rationale for key sampling criteria (could refer to literature) / quota aimed for Details of actual sample (socioeconomic characteristics, key features related to the topic...)
<i>Methods of recruitment and selection</i>	Description of the recruitment strategy – see Table 34 For primary data collection (e.g. interviews, focus groups, Delphi...): description of participant selection and of participation consent procedure. If gatekeepers were used: how this worked, bias and mitigation methods For secondary data collection (e.g. literature review and use of online data, documentary analysis / observational studies): explain how sources were obtained or subjects identified and / or selected, whether any screening tools were used, how the quality of the source was assessed
<i>Fieldwork</i>	Provide an overview of how the fieldwork was conducted and of any issues that might have affected the quality of the collected data. Give a brief description of any fieldwork material, such as topic guides, facilitation supports, observation schedules... Mention any adaptation to the planned methodology during the process (e.g. modifications of the interview guide)
<i>Approach to analysis</i>	Provide an overview of the overall approach to and aims of the analysis (thematic, framework, level of analysis, inductive/deductive...) Provide an overview of the data management process. Discuss any tools used to manage the data (e.g. Nvivo) and the way these were used (e.g. to code and summarise data, to search for keywords, to help with visualisation...) Summarise approaches to investigating and interpreting the data. Explain how the linkage between findings (if any) was established (e.g. explicit or implicit relationship found during the data collection; linkage found during the analysis or hypothesis supported by literature) Define and explain the elements used for the development of the typology (if any)
<i>Scope and limitations</i>	Discuss the scope of the research (e.g. aspects related to the topic that are not considered) Identify limitations of the approach adopted. Identify known issues related to the achieved sample, to the way in which fieldwork was conducted. Report how the limitations were mitigated (if this was possible)
<i>Ethics and privacy</i>	Key ethical issues for the study Measures adopted to mitigate ethical risks.



	Ethical approval (when applicable) Management of privacy issues
Appended materials	(non-exhaustive list) Full sample details Topic guides, observation schedules Selection and recruitment material Enabling and facilitating support Thematic framework ...

Retrieved and adapted from White, Woodfield, Ritchie and Ormston, 2014, page 378.¹¹⁷ *Final content needs to be adapted to the research project.

Table 34 presents an example of display of the outcomes of a recruitment strategy according to the category of participants. It contributes to the transparency of the overall recruitment process and helps account for the difficulties when recruiting participants. In this example, 51 participants declined participation despite agreeing to be interviewed.¹³⁹

Table 34 – Example of display of a recruitment strategy of participants in a qualitative study on personalised health care planning

	Professionals	Patients	Relatives	Total
<i>Interviews done</i>	46	26	0	72
<i>Invited for a focus-group in the 2nd phase of the project*</i>	3	2	0	5
<i>Withdrawals</i>	25	24	2	51
<i>Refusals</i>	1	0	0	1
<i>Excluded</i>	0	10	0	10
Total	75	62	2	139

*Did not participate to an interview but wanted to contribute to the project. Retrieved and translated from Aujoulat et al. 2021, page 15¹³⁹

At KCE

- Using of AI should be reported in the methodology. For example, it can be reported as follow: “the interviews were audio-recorded and transcribed using an in-house tool combining Whisper for speech recognition and pyannote.audio for speaker segmentation.^{258, 259} Transcriptions were manually reviewed and corrected.”
- For additional guidance for reporting the use of AI at KCE, please refer to the KCE Technology Watch Group

22.1.3 How to present qualitative findings?

As there is no standardised way of presenting findings from qualitative research, it is important to **distinguish the findings emerging from the data collection itself from the researchers’ interpretation**. This is essential to ensure the integrity and validity of the research.

This approach does not prevent the researchers from expressing their posture and reflexivity.

► For more about Reflexivity, go to Chapter 9

Researchers need to **pay attention to confidentiality** when reporting qualitative study findings. Sufficient details about the context and the respondents need to be provided to obtain a meaningful reporting, while still preserving the anonymity of respondents / locations.¹¹⁷

► For reporting the findings of Delphi studies, go to Textbox 10

22.1.3.1 Can numbers be used to present qualitative findings?

No, never, except in the context of a Delphi process, which is a form of mixed method and includes quantitative data.

Table 35 presents five strategies **preventing quantification** when reporting qualitative study findings. Qualitative reporting of findings should never refer to an exact number of participants or use statements like 'most', 'many' or 'a few', as these statements are vague and lead to confusion.¹¹⁷

As stated by White et al.: "If qualitative reports do refer to the recurrence of particular views or experiences or to clusters of responses within the sample, this should be in order to explain why such patterns occur, derived from the qualitative analysis undertaken. In such circumstances, it may be appropriate to refer to a perspective or response as 'dominant', 'recurrent', 'consistent', 'widespread' or 'commonly held' or conversely 'more exceptional', 'less common', or 'rare' provided that this is accompanied by discussion of the reasons for its dominance or rarity within the project sample" (retrieved from White et al. 2014, page 379).¹¹⁷

Table 35 – Strategies to avoid quantification of qualitative findings

Strategies	Theoretical examples
Focusing on issues rather than people or cases: <i>rephrasing the sentence to make it start with beliefs / opinions / experiences / motivations / circumstances...</i>	• The motivations that palliative care patients shared for dying at home were... • Experiences reported by mothers of premature babies were... • The circumstances in which first responders felt uncertain were...
Present the range of responses	• Participants supporting nursing consultations explained that... participants who did not support nursing consultations highlighted that... • Experiences of advance care planning were divided. Patients with dementia expressed that ... Conversely, patients with psychotic disorders... • Views on the future of general practice ranges from ... to ...
Present categories / clusters of responses	• Four motivations for having a case manager were found in the interviews. • Psychosocial managers gave five reasons for developing a communal intervention plan. • Three issues with the multimodal treatment of chronic pain emerged
Focus on differences between groups of people or cases	• Gynaecologists suggested five topics for patient health education that can be better developed by midwives. Midwives agreed but had concerns that ...



	Patients attending consultations for Long Covid fall into three main groups, each with different expectations and needs
<i>If recurrence is discussed, focus on the reasons for the recurrence</i>	- In interviews with GP, professional responsibility was a recurring concern. This was because... Nurses mentioned professional responsibility more rarely, but they were worried about their degree of autonomy... - There was a dominant view that the quality of care was high and that patients were satisfied with... A more exceptional view was...
<i>If divergences are discussed, focus on the reasons for the divergence</i>	Among GP, opinions diverge about the need to have an agreement with the national health insurance funds. GP supporting the agreement explained that... GP who expressed their disagreement said...

Retrieved and adapted from White et al., 2014, page 380¹¹⁷

In general, as much as possible, it is recommended to write numbers up to twenty in letters in situations where you can/need to use them as done in Table 35. It makes a psychological difference to the reader to see a word rather than a number.

22.1.3.2 Can focus groups and interviews be reported together?

Yes, if the topics and themes emerging from the analysis are similar in both datasets. In this case, the text should differentiate the findings to prevent confusion for the readers.¹⁵² In other words, when presenting the findings of different data collections (e.g. interviews, site visits and focus groups), it is recommended to establish a legend/use different wording to distinguish the participants in a straightforward way, and to use it throughout the whole document.

Example: KCE project 394 on palliative care included interviews with professionals during site visits and workshops with patient representatives.¹⁶⁹ To correctly identify the source of the findings, professionals were systematically referred to as 'respondents' and patient representatives as 'patient representatives'. An introductory text before the findings explained the reporting strategy.

"Some respondents explained that they can have an agreement with the municipal welfare centre where they are located but that problems occur when the patients come from another municipality, as each municipal welfare centre has different procedures. As explained by patient representatives, asking for financial support can be difficult for some patients and is considered by some as taboo, which reinforce the financial barriers." (retrieved from Dauvrin et al., 2025, page 181)¹⁶⁹

22.1.3.3 Can vignettes be used to present the findings?

Yes, if there are diverse sources of qualitative data (or even quantitative data), vignettes might allow for a better understanding of the complexity of the findings.

A vignette is a *"brief descriptive writing focused on a specific moment, scene, character, or idea"* (retrieved from Chubb, 2023, page 3).⁴⁰ It is often used as part of data collection but can also be used for presenting the findings of a qualitative research project.

Cited by Chubb, Reay et al. used vignettes as a **useful way of presenting findings** *"when the nature of the data is textual, narrative, or both, with the goal of demonstrating insights around an overarching theme"* (retrieved from Chubb, 2023, page 3).⁴⁰ Reay et al. highlighted that using vignettes to present findings *"foregrounds the interconnections among categories and gives space to show the findings in*

ways that capture more richness in an easily-readable and credible way”, satisfying the criterion of credibility in qualitative research.⁴⁰ It also appears as an interesting way of presenting findings in projects involving a research collaboration with patients, professionals or stakeholders.⁴⁰ In other words, it is a more concrete and understandable way of presenting the findings to non-researchers.

Chubb identified a large number of studies where vignettes are used to present findings from interviews or other qualitative data collection activities: experiences of migration and education, institutionalised young people, incarcerated adolescents, movement in physical education, coaching, families who homeschool, ethics of care when working with refugee families during COVID-19, refugees' sense of community, chronic illness and Cloud computing.⁴⁰

Example: Maslen and Lupton presented their findings on the perspectives of patients with chronic illness via vignettes.²⁶⁰

22.1.3.4 *Can qualitative findings and quantitative results be presented together?*

This will depend on the structure chosen for the report (a chapter per method or one chapter integrating results from different data sources).

There is **no black or white answer to this question** but, when choosing to merge data, one should remember that qualitative and quantitative data provide different insights to the research topics. Also, one methodological approach could be more dominant and this will be, in turn, influencing the place of the other method.

Example: the research team can conduct interviews with patients to complete the results of a quantitative online survey.

It is also important to recall that diverging results are not an indicator of something being 'wrong,' but rather of the complexity of the topic under investigation. Nevertheless, results that diverge between different sources of data need to be explored and explained to avoid leaving readers to identify the contradictions themselves.¹¹⁷

Example: the results of an online quantitative survey show that the patients are extremely satisfied with the quality of care delivered in specialised cancer centres. However, during interviews, other patients are negative about the quality of the care that they received. The text should provide hypotheses / theoretical background to explain why their opinions diverge.

22.1.3.5 *How to display qualitative evidence?*

A key aspect of qualitative reporting is the **presentation of the range and diversity of the data**. The researcher should:

- *“Provide a comprehensive ‘map’ of the range and variation of the evidence detected (e.g. the full range of views, experiences, or beliefs)”*
- *Illustrate the basis of any subsequent classification and how the different elements and categories have been assigned, and*
- *Provide examples of the original material on which description and classification is based”* (retrieved from White et al., 2014, page 386)¹¹⁷

The reporting of the findings should be **consistent with the methodology applied**. This means that the results should be classified / categorised in accordance with the approach described in the methods section. For example, the researcher can use the themes retrieved from the analysis as headings for the findings.

The reporting can use the following strategies:

- *“Showing extracts from the original material first, followed by a description of the elements that have been found and the categories and classes derived.”*



- *Describing all the elements, categories, classes that have been found, illustrated by a selection of the original material.*
- *Showing a selection of the different elements within categories and classes, followed by examples within each category or class*” (retrieved from White et al., 2014, page 386).¹¹⁷

Reporting should make it possible to **display linkages**, i.e. the relationships and associations between the data (this will also depend on the level of the analysis).

Depending on the research question, analyses can lead to **typologies**, which constitute another type of qualitative evidence. Typologies “*provide descriptions of the different segments in the project population or of different manifestations of phenomena*” (retrieved from White et al., 2014, page 390).¹¹⁷ It might be useful to complement the typology with vignettes that help the readers to understand how the typology is operationalised.¹¹⁷

22.1.3.6 *Can qualitative findings be presented through a visual display?*

Yes, but a supporting text should always accompany a visual display.

The use of diagrams or other forms of visual representation makes it possible to highlight the complexity and the relationship between findings. The degree of elaboration of such visual displays will vary according to the objectives of the project and the depth of the analysis. They should be used sparingly, as too many visuals might distract the reader from the key messages.

White et al. proposed using a visual display of qualitative findings to:¹¹⁷

- Present the diversity and the range of the study topic.
Example: a visual display was used to present the barriers to health care in KCE report 361 on access to health care for persons with intellectual disability.⁷
- Illustrate the relationships and associations between different elements (or actors).
Example: visual displays can be found in KCE report 311 on the development of an effective antibiotics policy in Belgium.²⁶¹
- Explain highly complex processes – this also makes it possible to show interactions and influences.
Example: in KCE report 257 on access to health care for undocumented migrants, the procedure for accessing urgent medical aid was presented in a visual display.⁵²
- Summarise data when different elements, phenomena, groups, or positions have been described.
- Help readers to refocus their attention by ‘breaking’ the text.

At KCE

- Specifically, for KCE, visual displays can help reduce the length of the report and improve readability.
- Ask KCE Layout and/or the KCE Communication cell for help when developing visual displays and pay attention to accessibility standards. Remember that they do not read the reports or work on the content: they can help you make sure the visual is understandable, not too complicated, not too detailed, and suggest improvements.
- Nvivo can also help to develop visual displays.

22.1.3.7 How to explain qualitative findings?

Researchers often see it as the most complex part of qualitative study reporting as it is not always easy to clearly identify the source of explanations, notably because of the iterative character of qualitative research methods.

White et al. reported 5 explanatory mechanisms in QRM:¹¹⁷

- **Explicit reasons and accounts:** participants to the data collection themselves provide the explanation.

Theoretical example: patients report not going to the physiotherapist because they lack time and motivation.

- **Implicit explanation:** the researchers construct the meaning based on connections found during the analysis or 'common sense' when it is obvious.

Theoretical example: patients complain that there is a shortage of physiotherapists in their area. The researcher can infer that this is a barrier to physical therapy.

- **Explanatory concepts:** a theoretical model or concept emerges as an explanation for the data. It is then necessary to define the concept, its relevance and how it emerges in the data.

Theoretical example: patients explain that they prefer going for a walk with their dog than going to a physiotherapist to improve their mobility. This approach is related to the concept of self-care, where patients choose activities (in a broad sense) that make them feel better.

- **Existing theoretical or empirical evidence:** the researchers rely on concepts or ideas from previous research to explain their own findings. It is then necessary to provide background on the concept and evidence in the existing literature that the concept / theory applies to their findings.

Theoretical example: Dorothea Orem developed a theoretical model of self-care where she identifies the elements that support the ability of patients to care for themselves and maintain their health.³³ This theory includes the concept of 'self-agency'. If the researchers want to apply to their findings, they need to find literature to support their own analysis.

- **Insights evolving during the study:** *"the inferences that can be drawn from a research study, in terms of wider applications to theory or policy, evolve and develop through the course of a study"* (retrieved from White et al., 2014, page 396).¹¹⁷

Theoretical example: based on the findings on the study on physiotherapy and self-care, the researchers can recommend that the health care plan for patients who need physiotherapy should include activities that patients identify as contributing to their self-care to enhance their compliance.

22.2 How to use quotes?

When writing out findings, qualitative researchers use **quotes from respondents**. Quotes are useful to:²⁶²

- Illustrate the themes emerging from the analysis.
- Provide evidence for interpretations, comparable to the use of tables of statistical data appearing in reports based on quantitative findings.
- Strengthen credibility of the findings.
- Deepen understanding. The actual words of a respondent can sometimes be a better representation of the depth of feeling.
- Give a voice to research participants. This enables participants to speak for themselves and is especially relevant in a participatory paradigm.



- Enhance readability by providing vividness and sometimes humour: breaking up long passages of text by inserting spoken words could help keep the reader focused.

To facilitate the reading of the quotes and avoid making the text heavier, the researchers can edit quotes as presented in Textbox 12.

Textbox 12 – Theoretical example of quote editing

Original text*

I had erm, had troubles with my, my GP but, erm, she was able to, to find a solution for me. She decided to, to make an, the appointment for me with one of her friends, at the Sacred Heart Hospital in Brussels. Dr Dorian was able to see me the day after I had a, a, a problem.

**Example drafted for the purpose of this report*

Edited text

I had troubles with my GP, but she was able to find a solution for me. She decided to make an appointment for me with one of her friends, at [university hospital] in Brussels. [name of the specialist doctor] was able to see me the day after I had a problem.

Ideally, quotes are **anonymous** and accompanied by a **pseudonym** or description of the respondent.

Theoretical example: in research about normal birth, this could be (Midwife, 36 years).

There are, however, exceptions to the rule of anonymity, e.g. stakeholder interviews, in which the identity of the respondent is important for the interpretation of the findings. In that case, the research team need to inform the respondents and ask their agreement.

Theoretical example: in research about the implementation of a new health care policy, researchers conducted interviews with the heads of the different health administrations. Quotes will be identified as follows: (Head of public health cabinet, head of regional health agency).

Quotes are used to strengthen the argument but should be used sparingly and in function of the findings. Researchers need to choose the quotes in such a way that these quotes reflect the diversity of the participants. They therefore must be aware that readers might give more weight to themes illustrated with a quotation.

When the research is conducted in another language than the language of the report in which the findings are presented, quotes are most often translated. *“As translation is also an interpretive act, meaning may get lost in the translation process”* (retrieved from Van Nes et al., 2010, page 313).²⁶³ It is recommended to stay in the original language as long and as much as possible and delay the use of translations to the stage of writing out the findings.²⁶³

At KCE

- The usual KCE practice is to translate quotes only for publications in international scientific journals, but not for KCE reports.
- Although KCE reports are written in English, it is possible to insert quotes in Dutch or French to stay close to the original meaning. However, the authors should also consider the readability of the text and make sure that it remains comprehensible for English-speaking readers even without the quotes.
- Researchers can include the quote in both the original language and in the English translation using an assorted colour.
- Editing of quotes can be acceptable, but this needs to be clearly stated in the report by using a formula as *“Quotes have been edited for length and clarity.”*



- The quotes should be translated via a **secure translation tool**^{jj} and never via free online translators like Google Translate or DeepL because of privacy issues (see section 5.9).
 - *There is a recommended different layout for the quotes: please refer to the editorial charter and / or ask the KCE Layout team for help.*

^{jj}EU translation portal (requires the creation of an account): <https://webgate.ec.europa.eu>



■ REFERENCES

1. Nelson AM. Addressing the threat of evidence-based medicine practice to qualitative inquiry through increasing attention to quality: a discussion paper. *International Journal of Nursing Studies*. 2008;45:6.
2. Kohn L, Christiaens W. The use of Qualitative Research Methods in KCE studies. Method. Brussels: Belgian Health Care Knowledge Centre (KCE); 2012. KCE Reports 187C (D/2012/10.273/68) Available from: <https://doi.org/10.57598/R187C>
3. Pope C, Mays N. Qualitative research in health care. Blackwell Pub./BMJ Books; 2006.
4. Barbour RS. The role of qualitative research in broadening the 'evidence base' for clinical practice. *Journal of Evaluation in Clinical Practice*. 2000;6(2):155-63.
5. Leroy R, Desimpel F, Ombelet S, De Jaeger M, Benahmed N, Camberlin C, et al. How can we improve endometriosis care in Belgium? Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Center (KCE); 2024. KCE Reports 378C Available from: <https://doi.org/10.57598/R378C>
6. Maertens de Noordhout C, Detollenaere J, Primus-de Jong C, Kohn L, Devleeschauwer B, Charafeddine R, et al. Identifying Patient needs: methodological approach and application. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2022. KCE Reports 348C Available from: <https://doi.org/10.57598/R348C>
7. Ricour C, Desomer A, Dauvrin M, Devos C. How to improve Access to health care for people with intellectual disabilities? Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2022. KCE Reports 361C Available from: <https://doi.org/10.57598/R361C>
8. Jaspers V, Christiaens W, Kohn L, Savoye I, Mistiaen P. Somatic health care in a psychiatric setting. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2021. KCE Reports 338C Available from: <https://doi.org/10.57598/R338C>
9. Vinck I, Benahmed N, Dauvrin M, Desomer A, Cornelis J, Jonckheer P, et al. Assessment and support of decisional capacity in persons with dementia or mental health problems. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2022. KCE Reports 349C Available from: <https://doi.org/10.57598/R349C>
10. Roberfroid D, Castanares-Zapatero D, Chalon P, Costa E, Dauvrin M, de Meester C, et al. Expedited Scientific Research and Reporting (ESRO) at KCE. Method. Brussels: Belgian Health Care Knowledge Centre (KCE); 2024. KCE Reports 386C
11. Bates MJ. Design of browsing and berrypicking techniques for online search interface. *Online Review*. 1989;13:7.
12. Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ*. 2001;322(7294):1115-7.
13. Mays N, Pope C. Qualitative Research: Rigour and qualitative research. *BMJ*. 1995;311(6997):109-12.
14. Geertz C. Thick Description: Toward an Interpretative Theory of Culture. In: *The interpretation of cultures: selected essays*. New York: Basic Books; 1973. p. 3-30. Available from: <http://www.alfrehn.com/fahlner/tko/resources/Kultur/Thick-Description.pdf>
15. Sofaer S. Qualitative methods: what are they and why use them? *Health Service Research*. 1999;34(5 Pt 2):1101-18.
16. Huston P, Rowan M. Qualitative studies. Their role in medical research. *Canadian Family Physician*. 1998;44:2453-8.
17. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*. 1995;311(6996):42-5.
18. Mucchielli A. Dictionnaire des méthodes qualitatives en sciences humaines. 3ème ed. Paris: Armand Colin; 2011.
19. Moser A, Korstjens I. Series: Practical guidance to qualitative research. Part 1: Introduction. *European Journal of General Practice*. 2017;23(1):271-3.

20. Ormston R, Spencer L, Barnard M, Snape D. 1 The Foundations of Qualitative Research. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative Research Practice. A guide for social science students and teachers*. London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 1-26.
21. Green J, Thorogood N. *Qualitative methods for health research*. SAGE Publications Ltd; 2004.
22. Kivits J, Balard F, Fournier C, Winance M. *Les recherches qualitatives en santé*. 2 ed. Paris: Armand Colin; 2023.
23. Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a Definition of Mixed Methods Research. *Journal of Mixed Methods Research*. 2007;1(2):112-33.
24. Zhang W, Creswell JW. the use of "Mixing" procedure of mixed methods in health services research. *Medical Care*. 2012;00(00):7.
25. Patton MQ. Enhancing the quality and credibility of qualitative analysis. *Health Service Research*. 1999;34(5 Pt 2):1189-208.
26. Benahmed N, Jonckheer P, Zeevaert R, Vos B, Kohn L. Assessing and monitoring waiting times in healthcare: how to proceed in Belgium? *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Center (KCE); 2024. KCE Reports 383C Available from: <https://doi.org/10.57598/R383C>
27. Cornelis J, Dauvrin M, Desomer A, Gerkens S, Primus-de Jong C, Christiaens W. Organisation of medical care in CBRNE incidents – a guidance. *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Center (KCE); 2023. KCE Reports 374C Available from: <https://doi.org/10.57598/R374C>
28. Mistiaen P, Dauvrin M, de Meester C, Pouppez C, Vinck I. For-K, Forensic-psychiatric intensive treatment units for adolescents in prison: Supply, use and need. *Health Services Research (HSR)*. Brussel: Belgian Health Care Knowledge Centre (KCE); 2021. KCE Reports 339C Available from: <https://doi.org/10.57598/R339C>
29. Vindrola-Padros C. *Doing Rapid Qualitative Research*. First ed. London: SAGE Publications Ltd; 2021.
30. Salomao A. Recherche primaire et recherche secondaire : Une analyse comparative [Web page]. *Mind the Graph*;2023 [updated 2023/01/09; cited 03/06/2024]. Available from: <https://mindthegraph.com/blog/fr/quest-ce-que-le-raisonnement-deductif-2/>
31. UK Data Service. Approaches to reusing qualitative data [Web page]. London: Economic and Social Research Council;2025 [cited 2025/16/07]. Available from: <https://ukdataservice.ac.uk/learning-hub/qualitative-data/reusing-qualitative-data/approaches-to-reusing-qualitative-data/>
32. Andersen R, Newman JF. Societal and individual determinants of medical care utilization in the United States. *Milbank Mem Fund Quarterly Health Social*. 1973;51(1):95-124.
33. McEwen M, Wills EM. *Theoretical Basis for Nursing*. Philadelphia: Wolters Kluwer 2014.
34. Piérart J, Léonard C, Chalon PX, Daue F, Mertens R. Stakeholder Involvement in KCE working processes. *Method*. Brussels: Belgian Health Care Knowledge Centre (KCE); 2012 20120402. KCE Reports (D/2012/10.273/11) Available from: <https://doi.org/10.57598/R174C>
35. Kohn L, Dauvrin M, Cleemput I. Patient involvement in policy research at KCE: process note. *Health Services Research (HSR)*. Brussel: Belgian Health Care Knowledge Centre (KCE); 2021. KCE Reports 340C Available from: <https://doi.org/10.57598/R340C>
36. Cleemput I, Dauvrin M, Kohn L, Mistiaen P, Christiaens W, Léonard C. Position of KCE on patient involvement in health care policy research. *Method*. Brussels: Belgian Health Care Knowledge Center (KCE); 2019 2019/11//. KCE Reports Available from: <https://doi.org/10.57598/R320C>
37. Hitch D. Artificial Intelligence Augmented Qualitative Analysis: The Way of the Future? *Qualitative Health Research*. 2024;34(7):595-606.
38. Christou P. How to Use Artificial Intelligence (AI) as a Resource, Methodological and Analysis Tool in Qualitative Research? *The Qualitative Report*. 2023.
39. Christou P. Thematic Analysis through Artificial Intelligence (AI). *The Qualitative Report*. 2024.



40. Chubb LA. Me and the Machines: Possibilities and Pitfalls of Using Artificial Intelligence for Qualitative Data Analysis. *International Journal of Qualitative Methods*. 2023;22:16094069231193593.
41. Cheligeer C, Huang J, Wu G, Bhuiyan N, Xu Y, Zeng Y. Machine Learning in Requirements Elicitation: A Literature Review. *Artificial Intelligence for Engineering Design, Analysis and Manufacturing*. 2022;36:1-23.
42. Morgan DL. Exploring the Use of Artificial Intelligence for Qualitative Data Analysis: The Case of ChatGPT. *International Journal of Qualitative Methods*. 2023;22:16094069231211248.
43. Gal U. ChatGPT is a data privacy nightmare. If you've ever posted online, you ought to be concerned, says researcher. *The Conversation*. 2023.
44. Butler A, Hall H, Copnell B. A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care. *Worldviews in Evidence Based Nursing*. 2016;13(3):241-9.
45. Adriaenssens J, Maertens de Noordhout C, Kohn L, Castanares-Zapatero D. Prevention of post-intensive care syndrome (PICS). *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Centre (KCE); 2023. KCE Reports 364C Available from: <https://doi.org/10.57598/R364C>
46. Webster S, Lewis J, Brown A. 4 Ethical Considerations in Qualitative Research. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative Research Practice. A guide for social science students and teachers*. London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 77-110.
47. O'Conner H, Madge C. 24 Online interviewing. In: Fielding N, Lee R, Blank G, editors. *The SAGE Handbook of Online Research Methods*. Second ed. London: SAGE Publications Ltd; 2017. p. 655.
48. Yeo A, Legard R, Keegan J, Ward K, McNaughton Nicholls C, Lewis J, et al. 7 In-depth Interviews. In: London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 177-210.
49. Green J, Thorogood N. *Qualitative methods for health research*. 4th ed. London: Sage Publications Ltd; 2018.
50. Freeman M, Mathison S. Chapter 5. Ethical Challenges in Social Constructivist Research with Children. In: *Researching children's experiences*. London / New-York: The Guilford Press; 2009. p. 69-85.
51. Gumede D, Ngwenya NB, Namukwaya S, Bernays S, Seeley J. A reflection on ethical and methodological challenges of using separate interviews with adolescent-older carer dyads in rural South Africa. *BMC Medical Ethics*. 2019;20(1):47.
52. Roberfroid D, Dauvrin M, Keygnaert I, Desomer A, Kerstens B, Camberlin C, et al. What health care for undocumented migrants in Belgium ? *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Centre (KCE); 2015. KCE Reports 257C Available from: <https://doi.org/10.57598/R257C>
53. Belgian Association of Research Ethics Committees. Guidance on fair compensation of subjects to their participation in clinical research in Belgium. Brussels: BAREC; 2023. V21_11_2023 Available from: https://barec.be/wp-content/uploads/2023/11/BAREC-Guidance-on-Compensation-of-Clinical-Research-Participants-Version-21_11_2023.pdf
54. Castanares-Zapatero D, Kohn L, Dauvrin M, Detollenaere J, Maertens de Noordhout C, Primus C, et al. Long COVID: Pathophysiology – epidemiology and patient needs. *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Centre (KCE); 2021. KCE Reports 344C Available from: <https://doi.org/10.57598/R344C>
55. Vindrola-Padros C, Chisnall G, Cooper S, Dowrick A, Djellouli N, Symmons SM, et al. Carrying Out Rapid Qualitative Research During a Pandemic: Emerging Lessons From COVID-19 (74). *Qualitative Health Research*. 2020;30(14):2192-204.
56. Snijders C, Vos B. Whatever the method, it needs to be well-defined, well-argued, and well-executed. *Journal of Purchasing and Supply Management*. 2007;13(3):169.
57. Reynolds J, Kizito J, Ezumah N, Mangesho P, Allen E, Chandler C. Quality assurance of qualitative research: a review of the discourse. *Health Research Policy & Systems*. 2011;9:43.

58. Walsh D, Downe S. Appraising the quality of qualitative research. *Midwifery*. 2006;22(2):108-19.
59. Bloor M, Wood F. Keywords in qualitative methods. A vocabulary of research concepts. Thousand Oaks: Sage; 2006.
60. Riehle D. What is Self-Selection Bias in Qualitative Research? [Web page]. Erlangen: QDAcity; n.d. Available from: <https://qdacity.com/self-selection-bias/>
61. Busetto L, Wick W, Gumbinger C. How to use and assess qualitative research methods. *Neurological Research and Practice*. 2020;2(1).
62. Cohen D, Crabtree BF. Qualitative Research Guidelines Project. In: RWJF, editor. *Using Qualitative Methods in Healthcare Research*. Princeton; 2008.
63. Mortelmans D. *Handboek kwalitatieve onderzoeksmethoden*. Leuven: Acco; 2009.
64. Finley L. 'Rigour', 'ethical integrity' or 'Artistry'? Reflexively reviewing criteria for evaluating qualitative research. *British Journal of Occupational Therapy*. 2006;69(7):319-26.
65. Shenton AK. Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*. 2004;22:63-75.
66. Merriam SB. *Qualitative research and case study applications in education*. San Francisco: Jossey-Bass; 1998.
67. Firestone WA. Alternative arguments for generalizing from data as applied to qualitative research. *Educational researcher*. 1993;22:16-23.
68. Megheirkouni M, Moir J. Simple but Effective Criteria: Rethinking Excellent Qualitative Research. *The Qualitative Report*. 2023;28(3):848-64.
69. McLeod S. Audit Trail In Qualitative Research. *SimplyPsychology*. 2024.
70. Côté L, Turgeon J. Comment lire de façon critique les articles de recherche qualitative en médecine. *Pédagogie médicale*. 2002;3(2):81-90.
71. Côté L, Turgeon J. Appraising qualitative research articles in medicine and medical education. *Medical Teacher*. 2005;27(1):71-5.
72. Walsh D, Downe S. Appraising the quality of qualitative research. *Midwifery*. 2006;22(2):108-19.
73. Vermeire E, Van Royen P, Griffiths F, Coenen S, Peremans L, Hendrickx K. The critical appraisal of focus group research articles. *European Journal of General Practice*. 2002;8(3):104-8.
74. Majid U, Vanstone M. Appraising Qualitative Research for Evidence Syntheses: A Compendium of Quality Appraisal Tools. *Qualitative Health Research*. 2018;28(13):2115-31.
75. Lewin S, Booth A, Glenton C, Munthe-Kaas H, Rashidian A, Wainwright M, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. *Implementation Science*. 2018;13(1):2.
76. Niederberger M, Schifano J, Deckert S, Hirt J, Homberg A, Koberich S, et al. Delphi studies in social and health sciences-Recommendations for an interdisciplinary standardized reporting (DELPHISTAR). Results of a Delphi study. *PLoS One*. 2024;19(8):e0304651.
77. Khodyakov D, Grant S, Kroger J, Bauman M. RAND Methodological Guidance for Conducting and Critically Appraising Delphi Panels. Santa Monica, CA: RAND Corporation; 2023. Available from: <https://www.rand.org/pubs/tools/TLA3082-1.html>
78. Detollenaere J, Dauvrin M, Deschodt M, Cerulus M, Dobbels F, Heeren P, et al. Nursing consultations for patients with complex health conditions. *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Center (KCE); 2023. KCE Reports 373C Available from: <https://doi.org/10.57598/R373C>
79. Korstjens I, Moser A. Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*. 2018;24(1):120-4.
80. Alaszewski A. *Using Diaries for Social Research*. London: SAGE Publications Ltd; 2006.
81. Emerson RM, Fretz RI, Shaw LL. Writing Fieldnotes I: At the Desk, Creating Scenes on a Page. In: Emerson RM, Fretz RI, Shaw LL, editors. *Writing Ethnographic Fieldnotes*. 2nd ed. Chicago: The University of Chicago Press; 2011. p. 45-88.



82. McMahon SA, Winch PJ. Systematic debriefing after qualitative encounters: an essential analysis step in applied qualitative research. *BMJ Global Health*. 2018;3(5):e000837.
83. Given LM. *The Sage Encyclopaedia of Qualitative Research Methods*. Los Angeles SAGE Publications Ltd; 2008.
84. Carmichael P. 29 Secondary Qualitative Analysis using Online Resources. In: Fielding N, Lee R, Blank G, editors. *The SAGE Handbook of Online Research Methods*. Second ed. London: SAGE Publications Ltd; 2017. p. 509-24.
85. Mistiaen P, Leroy R, Van de Voorde C, Stordeur S, Van Den Heede K. HSR Process Notes: literature review and international comparison. Brussels: Belgian Health Care Knowledge Centre (KCE); 2016. Method D/2016/10.273/107 Available from: https://processbook.kce.be/sites/default/files/2021-11/2015-72-%28Method%29_HSR%20Process%20Notes%20Literature%20review%20and%20international%20comparison_Report_0.pdf
86. Walcott S, Caires Januario R, Cunningham M, Brown E, Bernard R, Vega Rodriguez Y, et al. A Systematic Review and Narrative Synthesis of Studies using Community-Centred Qualitative Methods, Participatory Action Research and Creative Methods in Research with Marginalised and Underrepresented Communities. Online: PROSPERO; 2025. CRD420250651475 Available from: <https://www.crd.york.ac.uk/PROSPERO/view/CRD420250651475>
87. Ambrosio L, Senosiain García JM, Riverol Fernández M, Anaut Bravo S, Díaz De Cerio Ayesa S, Ursúa Sesma ME, et al. Living with chronic illness in adults: a concept analysis. *Journal of Clinical Nursing*. 2015;24(17-18):2357-67.
88. Dixon-Woods M, Fitzpatrick R, Roberts K. Including qualitative research in systematic reviews: opportunities and problems. *Journal of Evaluation in Clinical Practice*. 2001;7(2):125-33.
89. Campbell F, Tricco AC, Munn Z, Pollock D, Saran A, Sutton A, et al. Mapping reviews, scoping reviews, and evidence and gap maps (EGMs): the same but different— the “Big Picture” review family. *Systematic Reviews*. 2023;12(1):45.
90. Munn Z, Pollock D, Khalil H, Alexander L, McLnerney P, Godfrey CM, et al. What are scoping reviews? Providing a formal definition of scoping reviews as a type of evidence synthesis. *JBI Evidence Synthesis*. 2022;20(4):950-2.
91. Silberg T, Kapil N, Caven I, Levac D, Fehlings D. Cognitive behavioral therapies for individuals with cerebral palsy: A scoping review. *Developmental Medicine & Child Neurology*. 2023;65(8):1012-28.
92. McLean LJ, Paleg GS, Livingstone RW. Supported-standing interventions for children and young adults with non-ambulant cerebral palsy: A scoping review. *Developmental Medicine & Child Neurology*. 2023;65(6):754-72.
93. James KL, Randall NP, Haddaway NR. A methodology for systematic mapping in environmental sciences. *Environmental Evidence*. 2016;5(1):7.
94. Claerman R, Kohn L, Schönborn C, Obyn C, De Pauw R, Cleemput I, et al. NEED assessment framework 2025: EU expert consensus and core version. Needs Brussels: Belgian Health Care Knowledge Center (KCE); 2025. KCE Reports 401C Available from: <https://doi.org/10.57598/R401C>
95. Booth A, Noyes J, Flemming K, Moore G, Tunçalp Ö, Shakibazadeh E. Formulating questions to explore complex interventions within qualitative evidence synthesis. *BMJ Global Health*. 2019;4(Suppl 1):e001107.
96. Cooke A, Smith D, Booth A. Beyond PICO: The SPIDER Tool for Qualitative Evidence Synthesis. *Qualitative Health Research*. 2012;22(10):1435-43.
97. Wosny M, Strasser LM, Hastings J. Experience of Health Care Professionals Using Digital Tools in the Hospital: Qualitative Systematic Review. *JMIR Hum Factors*. 2023;10:e50357.
98. Ayorinde A, Mensah DO, Walsh J, Ghosh I, Ibrahim SA, Hogg J, et al. Health Care Professionals' Experience of Using AI: Systematic Review With Narrative Synthesis. *J Med Internet Res*. 2024;26:e55766.
99. Centre for Reviews and Dissemination. *Systematic reviews. CRD's guidance for undertaking reviews in health care*. York: University of York; 2009.

100. Thomas S, Fayter D, Misso K, Ogilvie D, Petticrew M, Sowden A, et al. Population tobacco control interventions and their effects on social inequalities in smoking: systematic review. *Tob Control*. 2008;17(4):230-7.
101. Noyes J, Popay J. Directly observed therapy and tuberculosis: how can a systematic review of qualitative research contribute to improving services? A qualitative meta-synthesis. *Journal of Advanced Nursing*. 2007;57(3):227-43.
102. Harden A, Brunton G, Fletcher A, Oakley A, Burchett H, Backhans M. Young people, pregnancy and social exclusion: A systematic synthesis of research evidence to identify effective, appropriate and promising approaches for prevention and support. London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London; 2006.
103. Janetzko D. 5 Nonreactive Data Collection Online. In: Fielding N, Lee R, Blank G, editors. *The SAGE Handbook of Online Research Methods*. Second ed. London: SAGE Publications Ltd; 2017. p. 77-91.
104. Hookway N, Snee H. 22 The Blogosphere. In: Fielding N, Lee R, Blank G, editors. *The SAGE Handbook of Online Research Methods*. Second ed. London: SAGE Publications Ltd; 2017. p. 380-98.
105. Gibson A, Latimer AL, Silberman DR, Schuman DL. Dying Online: An Analysis of End-of-Life Narratives. *Journal of Social Work in End-of-Life & Palliative Care*. 2020;16(1):57-76.
106. Cook N, O'Halloran O. Using YouTube vlogs to study women's experiences of participating in #MeToo. *Canadian Review of Sociology/Revue canadienne de sociologie*. 2023;60(3):502-15.
107. Wikipedia. Internet forum [Web page].2003 [updated 2025/07/15]. Available from: https://en.wikipedia.org/wiki/Internet_forum
108. Alzahrani AS, Greenfield SM, Paudyal V. Complementary and alternative medicine use in self-management of diabetes: A qualitative study of patient and user conversations in online forums. *International Journal of Clinical Pharmacy*. 2022;44(6):1312-24.
109. Mitchell JT, Sweitzer MM, Tunno AM, Kollins SH, McClernon FJ. "I Use Weed for My ADHD": A Qualitative Analysis of Online Forum Discussions on Cannabis Use and ADHD. *PLoS One*. 2016;11(5):e0156614.
110. Sharma AE, Khosla K, Potharaju K, Mukherjea A, Sarkar U. COVID-19–Associated Misinformation Across the South Asian Diaspora: Qualitative Study of WhatsApp Messages. *JMIR Infodemiology*. 2023;3:e38607.
111. Kemei J, Alaazi DA, Tulli M, Kennedy M, Tunde-Byass M, Bailey P, et al. A scoping review of COVID-19 online mis/disinformation in Black communities. *Journal of Global Health*. 2022;12:05026.
112. Petty S, Allen S, Pickup H, Woodier B. A Blog-Based Study of Autistic Adults' Experiences of Aloneness and Connection and the Interplay with Well-Being: Corpus-Based and Thematic Analyses. *Autism in Adulthood*. 2023;5(4):437-49.
113. Murphy E, Donohue G, McCann E. Exploring Mental Health Issues through the Use of Blogs: A Scoping Review of the Research Evidence. *Issues in Mental Health Nursing*. 2020;41(4):296-305.
114. Tamminga MA, Lipoff JB. Understanding sunscreen and photoprotection misinformation on parenting blogs: A mixed-method study. *Pediatric Dermatology*. 2021;38(1):88-91.
115. Hanquet G, Benahmed N, Castanares-Zapatero D, Dauvrin M, Desomer A, Rondia K. Post intensive care syndrome in the aftermath of COVID-19. Brussels: Belgian Health Care Knowledge Centre (KCE); 2020. COVID-19 KCE Contributions Available from: https://kce.fgov.be/sites/default/files/2021-11/PICS_scientific_report_NL%20%281%29.pdf
116. Reda O, Zellou A. Assessing the quality of social media data: a systematic literature review. *Bulletin of Electrical Engineering and Informatics*. 2023;12(2):1115-26.
117. White C, Woodfield K, Ritchie J, Ormston R. 13 Writing up qualitative research. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative Research Practice. A guide for social science students and teachers*. London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 367-400.



118. Bowling A. Research method in health: investigating health and health services. 4th ed. Buckingham-Philadelphia: Open University Press; 2014.
119. Im E-O, Chee W. Practical guidelines for qualitative research using online forums. *Computers, Informatics, Nursing*. 2012;30(11):604-11.
120. Im E-O, Chee W. An online forum as a qualitative research method: practical issues. *Nursing Research*. 2006;55(4):267-73.
121. Van den Broeck K, Schmitz O, Aujoulat I, Mistiaen P, Friedel M, Genet M, et al. Appropriate care at the end of life. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2017. KCE Reports 296C Available from: <https://doi.org/10.57598/R296C>
122. Black N. Consensus development methods. In: Pope C, Mays N, editors. *Qualitative Research in Health Care*. 3rd ed. Hoboken, New Jersey: Blackwell Publishing/ BMJ Books; 2006. p. 132-41.
123. Centre for Disease Control and Prevention. Nominal Group Technique. CDC; 2006 2006. Evaluation Briefs
124. Godrie B. Une tradition de recherche méconnue - Histoire et épistémologie de la recherche sociale en milieu d'intervention au Québec. In: Artois P, Moriau J, Wagener J, editors. *Décloisonner les savoirs. Retours d'expériences de recherches collaboratives* Bruxelles: Editions de l'Université Libre de Bruxelles; 2025.
125. Dauvrin M, Lenoble T, Servais J, Schmitz O, Simar D, Beaudelot M-C, et al. Participate Brussels - Quand des patients, professionnels et chercheurs, oeuvrent ensemble à la personnalisation des soins pour les Bruxellois vivant avec une maladie chronique. In: Artois P, Moriau J, Wagener J, editors. *Décloisonner les savoirs. Retours d'expériences de recherches collaboratives* Bruxelles: Editions de l'Université Libre de Bruxelles; 2025.
126. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research*. 2015;42(5):533-44.
127. Ritchie J, Lewis J, Elam G, Tennant R, Rahim N. 5 Designing and Selecting Samples. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative Research Practice. A guide for social science students and teachers*. London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 111-46.
128. Lewis-Beck M, Bryman A, Futing Liao T. Nested Design. In: *The SAGE Encyclopaedia of Social Science Research Methods*; 2004.
129. Lapin B, Cohen ML, Corsini N, Lanzi A, Smith SC, Bennett AV, et al. Development of consensus-based considerations for use of adult proxy reporting: an ISOQOL task force initiative. *Journal of Patient-Reported Outcomes*. 2023;7(1):52.
130. Webb K, Cuskelly M, Owen C. The use of proxy measurement of internal states in people with intellectual disability: A scoping review. *Journal of Applied Research on Intellectual Disabilities*. 2024;37(4):e13241.
131. Miles MB, Huberman AM, editors. *Qualitative data analysis: an expanded sourcebook* Beverly Hills, CA: Sage Publications; 1994.
132. Patton MQ. *Qualitative research & evaluation methods*. Thousand Oaks: SAGE Publications Ltd; 2002.
133. Corbin J, Strauss A. *Basics of qualitative research. Techniques and procedures for developing grounded theory*. 3 ed. Thousand Oaks: SAGE Publications Ltd; 2008.
134. Campbell S, Greenwood M, Prior S, Shearer T, Walkem K, Young S, et al. Purposive sampling: complex or simple? Research case examples. *Journal of Research in Nursing*. 2020;25(8):652-61.
135. De Jaeger M, Van Goethem R, Dobbelaere J, Léonard U, Zhi Tan Y, Van Montfort T, et al. Needs Examination, Evaluation and Dissemination (NEED): Identification of unmet health-related needs associated with Crohn's disease. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Center (KCE); 2024. KCE Reports 377C3 Available from: <https://doi.org/10.57598/R377C3>

136. De Gendt T, Desomer A, Goossens N, Hanquet G, Léonard C, Mertens R, et al. Etat des lieux de l'homéopathie en Belgique. Brussels: Centre fédéral d'expertise des soins de santé (KCE); 2011. (D/2011/10.273/13) Available from: https://kce.fgov.be/sites/default/files/page_documents/kce_154b_homeopathie_en_belgique.pdf
137. De Gendt T, Desomer A, Goossens M, Hanquet G, Léonard C, Melard F, et al. Etat des lieux de l'ostéopathie et de la chiropraxie en Belgique. Brussels: Centre fédéral d'expertise des soins de santé (KCE); 2010. (D/2010/10.273/92) Available from: https://kce.fgov.be/sites/default/files/page_documents/kce_148b_ost%C3%A9opathie_et_chiropaxie_en_belgique.pdf
138. De Gendt T, Desomer A, Goossens M, Hanquet G, Léonard C, Roberfroid D, et al. Acupuncture: State of affairs in Belgium. Brussels: Belgian Health Care Knowledge Centre (KCE); 2011. (D/2011/10.273/06) Available from: [https://kce.fgov.be/sites/default/files/page_documents/kce_153c_acupuncture_in_belgium\(2\)_0.pdf](https://kce.fgov.be/sites/default/files/page_documents/kce_153c_acupuncture_in_belgium(2)_0.pdf)
139. Aujoulat I, Dauvrin M, Lenoble T, Schmitz O, Servais J. Participate Brussels : méthodologie de l'enquête de terrain, des activités de croisement des savoirs et de la co-construction des pistes pour la personnalisation des soins. Cahier 2. Bruxelles: UCLouvain & HE Vinci; 2021. (2)
140. Sandelowski M. Sample size in qualitative research. *Research in Nursing & Health*. 1995;18(2):179-83.
141. Boyce C, Neale P. Conducting in-depth interviews: a guide for designing and conducting in-depth interviews for evaluation input. Watertown, USA: Pathfinder International; 2006. Pathfinder International Tool Series. Monitoring and evaluation - 2 Available from: https://nyhealthfoundation.org/wp-content/uploads/2019/02/m_e_tool_series_indepth_interviews-1.pdf
142. Khayyat S, Walters P, Whittlesea C, Nazar H. Patient and public perception and experience of community pharmacy services post-discharge in the UK: a rapid review and qualitative study (57). *BMJ Open*. 2021;11(3):e043344.
143. Skillman M, Cross-Barnet C, Friedman Singer R, Rotondo C, Ruiz S, Moiduddin A. A Framework for Rigorous Qualitative Research as a Component of Mixed Method Rapid-Cycle Evaluation (92). *Qual Health Res*. 2019;29(2):279-89.
144. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine*. 2022;292:114523.
145. Morse JM. Confusing Categories and Themes. *Qualitative Health Research*. 2008;18(6):727-8.
146. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology*. 2018;18(1):148.
147. Leighton K, Kardong-Edgren S, Schneidereith T, Foisy-Doll C. Using Social Media and Snowball Sampling as an Alternative Recruitment Strategy for Research. *Clinical Simulation in Nursing*. 2021;55:37-42.
148. Parker C, Scott S, Geddes A. *Snowball Sampling*. London: SAGE Publications Ltd; 2019.
149. Green J, Thorogood N. *Qualitative Methods for Health Research*. SAGE Publications Ltd; 2009.
150. Emans B. *Interviewen. Theorie, techniek en training*. Groningen: Wolters-Noordhoff; 1986.
151. Arthur S, Mitchell M, Lewis J, McNaughton Nicholls C. 6 Designing Fieldwork. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative Research Practice. A guide for social science students and teachers*. London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 147-76.
152. Caillaud S, Flick U. Focus Groups in Triangulation Contexts. In: *A New Era in Focus Groups Research. Challenges, innovation and practice*: Palgrave MacMillan; 2017. p. 155-77.
153. Dauvrin M, Kohn L, Cleemput I. Patient Involvement – KCE Process Book. *Animation Techniques for better patient involvement*. 2021. D/2020/10.2733/25 Available from:



- https://kce.fgov.be/sites/default/files/2021-11/KCE_340bis_Process_Note_animation_techniques_0.pdf
154. Singh H, Tang T, Thombs R, Armas A, Nie JX, Nelson MLA, et al. Methodological Insights From a Virtual, Team-Based Rapid Qualitative Method Applied to a Study of Providers' Perspectives of the COVID-19 Pandemic Impact on Hospital-To-Home Transitions (21). *International Journal of Qualitative Methods*. 2022;21:16094069221107144.
 155. Rzeszewski M, Osborne T, Jones P, Evans L, Weitkamp G. Interviewing in the metaverse: The renewed importance of location and embodiment. *Applied Geography*. 2024;167:103295.
 156. Pocock T, Smith M, Wiles J. Recommendations for Virtual Qualitative Health Research During a Pandemic. *Qualitative Health Research*. 2021;31(13):2403-13.
 157. Fripiat D, Marquis N. Les enquêtes par Internet en sciences sociales : un état des lieux. *Population*. 2010;Vol. 65(2):309-38.
 158. Seymour WS. In the flesh or online? Exploring qualitative research methodologies. *Qualitative Research*. 2001;1(2):147-68.
 159. Krouwel M, Jolly K, Greenfield S. Comparing Skype (video calling) and in-person qualitative interview modes in a study of people with irritable bowel syndrome – an exploratory comparative analysis. *BMC Medical Research Methodology*. 2019;19(1):219.
 160. Abrams KM. 25 Online Focus Groups. In: Fielding N, Lee R, Blank G, editors. *The SAGE Handbook of Online Research Methods*. Second ed. London: SAGE Publications Ltd; 2017. p. 435-50.
 161. Abrams KM, Wang Z, Song YJ, Galindo-Gonzalez S. Data Richness Trade-Offs Between Face-to-Face, Online Audiovisual, and Online Text-Only Focus Groups. *Social Science Computer Review*. 2015;33(1):80-96.
 162. Beaton B, Perley D, George C, O'Donnell S. 32 Engaging Remote Marginalized Communities using Appropriate Online Research Methods. In: *The SAGE Handbook of Online Research Methods*. Second ed. London: SAGE Publications Ltd; 2017. p. 655.
 163. Mubarak F, Suomi R. Elderly Forgotten? Digital Exclusion in the Information Age and the Rising Grey Digital Divide. *INQUIRY*. 2022;59.
 164. Reeves S, Peller J, Goldman J, Kitto S. Ethnography in qualitative educational research: AMEE Guide No. 80. *Medical Teacher*. 2013;35(8):e1365-79.
 165. Daniels N, Gillen P, Casson K, Wilson I. STEER: Factors to Consider When Designing Online Focus Groups Using Audiovisual Technology in Health Research. *International Journal of Qualitative Methods*. 2019;18:1609406919885786.
 166. Rowen D, Mukuria C, Bray N, Carlton J, Longworth L, Meads D, et al. Assessing the comparative feasibility, acceptability and equivalence of videoconference interviews and face-to-face interviews using the time trade-off technique. *Social Science & Medicine*. 2022;309:115227.
 167. Lee J. A Neuropsychological Exploration of Zoom Fatigue. *Psychiatric Times*. 2020.
 168. Ellis R, Goodacre T, Mortensen N, Oepfen RS, Brennan PA. Application of human factors at hybrid meetings: facilitating productivity and inclusivity. *British Journal of Oral and Maxillofacial Surgery*. 2022;60(6):740-5.
 169. Dauvin M, Desomer A, Savoye I, Adriaenssens J, Ricour C. Propositions for reinforcing and expanding the Belgian palliative care offer: the right care at the right moment at the right place. *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Center (KCE); 2025. KCE Reports 394C Available from: <https://doi.org/10.57598/R394C>
 170. Mack N, Woodsong C, MacQueen KM, Guest G, Namey E. *Qualitative research methods: a data collector's field guide*. North Carolina, USA: Family Health International; 2005.
 171. McGrath C, Palmgren PJ, Liljedahl M. Twelve tips for conducting qualitative research interviews. *Medical Teacher*. 2019;41(9):1002-6.
 172. Birks M, Chapman Y, Francis K. Memoing in qualitative research: Probing data and processes. *Journal of Research in Nursing*. 2008;13(1):68-75.
 173. Spencer L, Ritchie J, Ormston R, O'Connor W, Barnard M. 10 Analysis: principle and processes. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative*

- Research Practice. A guide for social science students and teachers. London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 269-93.
174. Tenny S, Brannan JM, Brannan GD. Qualitative Study. In: StatPearls. Treasure Island (FL): StatPearls Publishing; 2025.
 175. Renjith V, Yesodharan R, Noronha JA, Ladd E, George A. Qualitative Methods in Health Care Research. *Int J Prev Med*. 2021;12:20.
 176. Rubio-Navarro A, Garcia-Capilla DJ, Torralba-Madrid MJ, Rutty J. Ethical, legal and professional accountability in emergency nursing practice: An ethnographic observational study. *Int Emerg Nurs*. 2019;46:100777.
 177. Farzi S, Taleghani F, Yazdannik A, Esfahani MS. Communication culture in cancer nursing care: an ethnographic study. *Support Care Cancer*. 2022;30(1):615-23.
 178. Moreno Lozano C. The imperative of teamwork in antimicrobial stewardship (AMS) interventions: insights from an ethnographic study with practitioners in Spain. *JAC Antimicrobial Resistance*. 2024;6(5):dlae133.
 179. Mulhall A. In the field: notes on observation in qualitative research. *Journal of Advanced Nursing*. 2003;41(3):306-13.
 180. McNaughton Nicholls C, Mills L, Kotecha M. 9 Observation. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative Research Practice. A guide for social science students and teachers*. London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 243-68.
 181. Jaffer N. Se soigner en prison? Non merci ! Étude qualitative sur les déterminants du non-recours et du refus de soins à la maison de peine de Forest. Bruxelles: UCLouvain; 2022. Available from: <http://hdl.handle.net/2078.1/thesis:38407>
 182. De Brauwier I, Cornette P, D'Hoore W, Lorient V, Verschuren F, Thys F, et al. Factors to improve quality for older patients in the emergency department: a qualitative study of patient trajectory. *BMC Health Service Research*. 2021;21(1):965.
 183. Spradley JP. Participant observation. New York: Holt, Rinehart and Winston; 1980.
 184. Gold RL. Roles in sociological field observations. *Social Forces*. 1958;36(3):217-23.
 185. Van den Heede K, Camberlin C, Detollenaere J, Kohn L, Leroy R, Van Deynse H, et al. Pilot study on a new payment system for home nursing. *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Center (KCE); 2025 2025/07/10/. KCE Reports Available from: <https://doi.org/10.57598/R405C>
 186. Cultures&Santé. Territoires et santé. Bruxelles: Cultures&Santé; 2016. Dossiers thématiques 5
 187. Wolfinger NH. On writing fieldnotes: collection strategies and background expectancies. *Qualitative Research*. 2002;2(1):85-93.
 188. Scrimshaw SCM, Hurtado E. Rapid assessment procedures for nutrition and primary health care : anthropological approaches to improving programme effectiveness / Susan C.M. Scrimshaw and Elena Hurtado. 1989:ix, 70 p. .:
 189. Vindrola-Padros C, Froghi F, Gopalan V, Maruthan S, Filipe H, McNeil M, et al. The integration of rapid qualitative research in clinical trials: reflections from the ward-based goal-directed fluid therapy (GDFT) in acute pancreatitis feasibility trial (9). *Trials*. 2023;24(1):227.
 190. Marshall J. *First Person Action Research: Living Life as Inquiry*. 55 City Road, London: SAGE Publications Ltd; 2016.
 191. Waddington D. Participant observation. In: Cassell C, Symon G, editors. *Qualitative methods in organizational research. A practical guide*. London: SAGE Publications Ltd; 1994. p. 107-22.
 192. Fontana A, Frey JH, editors. *The interview: from neutral stance to political involvement*. Thousand Oaks: Sage; 2005.
 193. Atkinson P, Silverman D. Kundera's Immortality: The Interview Society and the Invention of the Self. *Qualitative Inquiry*. 1997;3(3):304-25.
 194. DiCicco-Bloom B, Crabtree BF. The qualitative research interview. *Medical Education*. 2006;40(4):314-21.



195. Denzin NK, Lincoln YS. Collecting and interpreting qualitative materials. Thousand Oaks: SAGE Publications Ltd; 2008.
196. Britten N. Qualitative Research: Qualitative interviews in medical research. *BMJ*. 1995;311(6999):251-3.
197. Halpern C. Group interviews. In: Revillard A, editor. *Policy Evaluation: Methods and Approaches*. Québec city: Éditions science et bien commun 2023.
198. Williams CL, Heikes EJ. The Importance of Researcher's Gender in the In-Depth Interview: Evidence from Two Case Studies of Male Nurses. *Gender & Society*. 1993;7(2):280-91.
199. Eguluz I, Sy A, Brage E, Gonzalez-Aguero M. Rapid qualitative health research from the Global South: Reflections and learnings from Argentina, Brazil, Chile, and Mexico during the COVID-19 pandemic (17). *Front Sociol*. 2022;7:983303.
200. Graetz DE, Sniderman E, Villegas C, Ragab I, Laptsevich A, Maliti B, et al. Utilizing Multilingual Methods and Rapid Analysis for Global Qualitative Research During a Pandemic (22). *Glob Qual Nurs Res*. 2022;9:23333936221080969.
201. Kitzinger J. Focus Group. In: Pope C, Mays N, editors. *Qualitative Research in Health Care*. 3rd ed. Hoboken, New Jersey: Blackwell Publishing/ BMJ Books; 2006. p. 21-31.
202. Barbour RS. Focus Groups. In: Bourgeault I, Dingwall R, De Vries R, editors. *The SAGE Handbook of Qualitative Research in Health Research*. Los Angeles / London / New Delhi / Singapore / Washington DC: SAGE Publications Ltd; 2010.
203. Cohen DJ, Crabtree BF. Evaluative criteria for qualitative research in health care: controversies and recommendations. *Annals of Family Medicine*. 2008;6(4):331-9.
204. Baribeau C. L'entretien de groupe : considérations théoriques et méthodologiques. *Recherches Qualitatives*. 2010;29(1):28-49.
205. Khan ME, Manderson L. Focus Groups in Tropical Diseases Research. *Health Policy and Planning - HEALTH POLICY PLANN*. 1992;7:56-66.
206. Lobe B. Best Practices for Synchronous Online Focus Groups. In: *A New Era in Focus Groups Research. Challenges, innovation and practice*. London: Palgrave MacMillian; 2017. p. 433.
207. Fox FE, Morris M, Rumsey N. Doing Synchronous Online Focus Groups With Young People: Methodological Reflections. *Qualitative Health Research*. 2007;17(4):539-47.
208. Nature. Hybrid conferences should be the norm - optimize them so everyone benefits. *Nature*. 2024;632(8024):229.
209. Tattersall C, Watts A, Vernon S. Mind mapping as a tool in qualitative research. *Nursing Times*. 2007;13(26):32-3.
210. Coles BA, West M. Trolling the trolls: Online forum users constructions of the nature and properties of trolling. *Computers in Human Behavior*. 2016;60:233-44.
211. Cheng J, Bernstein M, Danescu-Niculescu-Mizil C, Leskovec J. Anyone Can Become a Troll: Causes of Trolling Behavior in Online Discussions. In: *Proceedings of CSCW '17: Computer Supported Cooperative Work and Social Computing*; 2017 2017/02/25/: ACM; p. 1217-30. Available from: <https://dl.acm.org/doi/10.1145/2998181.2998213>
212. Genuis SK, Luth W, Weber G, Bubela T, Johnston WS. Asynchronous online focus groups for research with people living with amyotrophic lateral sclerosis and family caregivers: usefulness, acceptability and lessons learned. *BMC Medical Research Methodology*. 2023;23(1):222.
213. Gordon AR, Calzo JP, Eiduson R, Sharp K, Silverstein S, Lopez E, et al. Asynchronous Online Focus Groups for Health Research: Case Study and Lessons Learned. *International Journal of Qualitative Methods*. 2021;20.
214. Gairy K, Ruark K, Sinclair SM, Brandwood H, Nelsen L. An Innovative Online Qualitative Study to Explore the Symptom Experience of Patients with Primary Sjögren's Syndrome. *Rheumatology and Therapy*. 2020;7(3):601-15.
215. Reisner SL, Randazzo RK, White Hughto JM, Peitzmeier S, DuBois LZ, Pardee DJ, et al. Sensitive Health Topics With Underserved Patient Populations: Methodological Considerations for Online Focus Group Discussions. *Qualitative Health Research*. 2018;28(10):1658-73.

216. Salvador P, Alves K, Rodrigues C, Oliveira L. Online data collection strategies used in qualitative research of the health field: a scoping review. *Revista Gaucha de Enfermagem*. 2020;41:e20190297.
217. Synnot A, Hill S, Summers M, Taylor M. Comparing face-to-face and online qualitative research with people with multiple sclerosis. *Qualitative Health research*. 2014;24(3):431-8.
218. Im E-O, Chee W. Practical guidelines for qualitative research using online forums. *Computers, Informatics, Nursing* 2012;30(11):604-11.
219. Smedley RM, Coulson NS. A practical guide to analysing online support forums. *Qualitative Research in Psychology*. 2021;18(1):76-103.
220. McMillan SS, King M, Tully MP. How to use the nominal group and Delphi techniques. *International Journal of Clinical Pharmacy*. 2016.
221. RAND Corporation. Delphi Method [Web page].2012 [updated January 29, 2011; cited 13/06/12]. Available from: <http://www.rand.org/topics/delphi-method.html>
222. Linstone HA, Turoff M. Delphi: A brief look backward and forward. *Technological Forecasting and Social Change*. 2011;78(9):1712-9.
223. Rowe G, Wright G. The Delphi technique: Past, present, and future prospects — Introduction to the special issue. *Technological Forecasting and Social Change*. 2011;78(9):1487-90.
224. Hasson F, Keeney S. Enhancing rigour in the Delphi technique research. *Technological Forecasting and Social Change*. 2011;78(9):1695-704.
225. Turoff M. The Policy Delphi. In: Linstone H, Turoff M, editors. *The Delphi Method*; 2002.
226. Slocum N, Elliott J, Heesterbeek S, Lunkensmeyer C. Méthodes participatives. Un guide pour l'utilisateur / Participatieve methoden. Een gids voor gebruikers/ Participatory Methods Toolkit. A practitioner's manual. Fondation Roi Baudouin; 2006.
227. Gnatzy T, Warth J, von der Gracht H, Darkow I-L. A methodological comparison between real-time and conventional Delphi studies. *Technological Forecasting and Social Change*. 2011;78(9):1681-94.
228. Keeney S, McKenna HP, Hasson F. *The Delphi technique in nursing and health research*. Oxford Wiley-Blackwell; 2011
229. Fink A, Kosecoff J, Chassin M, Brook R. *Consensus Methods: Characteristics and Guidelines for Use*. Santa Monica, CA: RAND Corporation; 1991. Available from: <http://www.rand.org/pubs/notes/N3367>
230. Jones J, Hunter D. Qualitative Research: Consensus methods for medical and health services research. *BMJ*. 1995;311(7001):376-80.
231. Murphy E, Dingwall R, Greatbatch D, Parker S, Watson P. Qualitative research methods in health technology assessment: a review of the literature. *Health Technology Assessment*. 1998;2(16):iii-ix, 1-274.
232. Bourree F, Michel P, Salmi LR. [Consensus methods: review of original methods and their main alternatives used in public health]. *Revue d'Epidémiologie et de Santé Publique*. 2008;56(6):415-23.
233. Lennon R, Glasper A, Carpenter D. Nominal Group Technique: its utilisation to explore the rewards and challenges of becoming a mental health nurse, prior to the introduction of the all graduate nursing curriculum in England. *Working Papers in Health Sciences*. 2012;1(2).
234. Varga-Atkins T, Bunyan N, Fewtrell R, McIsaac J. *The Nominal Group Technique – a practical guide for facilitators*. ELESIG Small Grants Scheme. Liverpool, UK: University of Liverpool; 2011 2011.
235. Vahedian-Shahroodi M, Mansourzadeh A, Moghani SS, Saeidi M. Using the Nominal Group Technique in Group Decision-Making: A Review. *Medical Education Bulletin*. 2023;4(4):837-45.
236. Spencer L, Ritchie J, Ormston R, O'connor W, Barnard M. Analysis: principle and processes. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative research practice*. London: Natcen, Sage; 2014. p. 269-93.
237. Fielding N. Ethnography. In: Gilbert N, editor. *Researching Social Life*. London: SAGE Publications Ltd; 1993. p. 155-71.



238. Vindrola-Padros C, Johnson GA. Rapid Techniques in Qualitative Research: A Critical Review of the Literature. *Qualitative Health Research*. 2020;30(10):1596-604.
239. Srivastava A, Thomson SB, Fontana A. Framework Analysis: A Qualitative Methodology for Applied Policy Research. *JOAAG*. 2009;4(2).
240. Paillé P, Mucchielli A. *L'analyse qualitative en sciences humaines et sociales*. 2ème ed. Paris: Armand Colin; 2011.
241. Roose R, De Bie M. Children's rights: a challenge for social work. *International Social Work*. 2008;51(1):37-46.
242. Teoli D, Sanvictores T, An J. SWOT Analysis. In: StatPearls. Treasure Island (FL) StatPearls Publishing 2025. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK537302/>
243. Durant-Law G. Soft systems methodology and grounded theory combined - A knowledge management research approach? *Online Journal of Knowledge Management*. 2005;2(1):13-23.
244. Strauss A, Corbin J. Grounded Theory Methodology: An overview. In: Denzin NK, Lincoln YS, editors. *Strategies of Qualitative Inquiry*. London: SAGE Publications Ltd; 1998. p. 480.
245. Strauss AL, Corbin J. *Basics of qualitative research. Techniques and procedures for developing grounded theory*. Newbury Park, California: SAGE Publications Ltd; 1998.
246. Didier A, Nathaniel A, Scott H, Look S, Benaroyo L, Zumstein-Shaha M. Protecting Personhood: A Classic Grounded Theory. *Qualitative Health Research*. 2023;33(13):1177-88.
247. Patton MQ. *Qualitative research and evaluation methods: integrating theory and practice*. 4 ed. Thousand Oaks, California: Sage; 2015.
248. Duffy N, Hickey L, Treyvaud K, Delany C. 360-degree phenomenology: A qualitative approach to exploring the infant experience of hospitalisation in neonatal intensive care. *Early Human Development*. 2024;190:105963.
249. Dey I. *Qualitative Data Analysis: A User-Friendly Guide For Social Scientists*. London: Routledge; 1993.
250. Spencer L, Ritchie J, O'Connor W, Morrell G, Ormston R. 11 Analysis in Practice. In: Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R, editors. *Qualitative Research Practice. A guide for social science students and teachers*. London / Thousand Oaks / New Delhi / Singapore: SAGE Publications Ltd & NATCEN; 2014. p. 295-345.
251. Del Hoyo JD, Nos P, Faubel R, Bastida G, Muñoz D, Valero-Pérez E, et al. Adaptation of TECCU App Based on Patients' Perceptions for the Telemonitoring of Inflammatory Bowel Disease: A Qualitative Study Using Focus Groups. *International Journal of Environmental Research in Public Health*. 2020;17(6).
252. Detollenaere J, Benahmed N, Costa E, Christiaens W, Devos C, Van den Heede K. Infant- and family-centred developmental care for preterm newborns in neonatal care. *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Centre (KCE); 2022 2022/03//. KCE Reports Available from: <https://doi.org/10.57598/R350C>
253. Stapley E, O'Keeffe S, Midgley N. Developing Typologies in Qualitative Research: The Use of Ideal-type Analysis. *International Journal of Qualitative Methods*. 2022;21.
254. Vandebroek P, Christiaens W, Dauvin M, Wickert R, Becher K, Hendrickx E, et al. An evaluation protocol for NIHDI conventions. *Health Services Research (HSR)*. Brussels: Belgian Health Care Knowledge Centre (KCE); 2018 2018/02//. KCE Reports Available from: <https://doi.org/10.57598/R299C>
255. Vietzke J, Schenk L, Baer NR. Middle-aged and older adults' acceptance of mobile nutrition and fitness tools: A qualitative typology. *Digital Health*. 2023;9:20552076231163788.
256. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*. 2014;89(9):1245-51.
257. Coffey A, Atkinson P. *Making sense of qualitative data: Complementary research strategies*. London: SAGE Publications Ltd; 1996.
258. Radford A, Kim JW, Xu T, Brockman G, McLeavey C, Sutskever I. Robust speech recognition via large-scale weak supervision. In: *Proceedings of, 2023 2023//23/juillet: JMLR.org*; p. 28492-518.



259. Bredin H, Yin R, Coria JM, Gelly G, Korshunov P, Lavechin M, et al. Pyannote.Audio: Neural Building Blocks for Speaker Diarization. In: Proceedings of ICASSP 2020 - 2020 IEEE International Conference on Acoustics, Speech and Signal Processing (ICASSP); 2020 2020/05//; p. 7124-8. Available from: <https://ieeexplore.ieee.org/document/9052974>
260. Maslen S, Lupton D. Enacting chronic illness with and through digital media: a feminist new materialist approach. *Information, Communication & Society*. 2020;23(11):1640-54.
261. Leroy R, Christiaens W, Maertens de Noordhout C, Hanquet G. Proposals for a more effective antibiotic policy in Belgium. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2019. KCE Reports 311C Available from: <https://doi.org/10.57598/R311C>
262. Corden A, Roy S. Using verbatim quotations in reporting qualitative social research: researchers' views. York: University of York; 2006.
263. van Nes F, Abma T, Jonsson H, Deeg D. Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing*. 2010;7(4):313-6.