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Handle-On-QOL: A dedicated quality of life resource following the diagnosis and treatment of head and neck cancer

Abstract

Measuring quality of life (QOL) after head and neck cancer (HNC), is rapidly becoming the standard of care. The Head and Neck Database Listing Evidence on QOL (Handle-On-QOL) is a dedicated QOL resource, that includes articles published from 1982 onwards. The aim of this study was to assess the completeness of Handle-On-QOL, when compared with other non-specific search engines.

Six years were selected at random; 1982, 1990, 1998, 2003, 2006, 2016. Four search engines were used (Medline, EMBASE, CINAHL, PsycINFO). Reporting followed PRISMA methodology.

A total of 595 papers were assessed of which 200 met the inclusion criteria. 186 papers were present on Handle-On-QOL, 243 were found on Handle-On-QOL for these six years, but not identified in the other searches and 14 were missing from Handle-On-QOL. A search using standard engines, generated a large number of irrelevant papers.

Handle-On-QOL provides a comprehensive and accurate reflection of articles published using questionnaires to report QOL following HNC. This web-based repository (<http://www.handle-on-qol.com>) acts as a quick reference point for clinicians and researchers.

Introduction

Quality of life (QOL) is a complex topic with many facets. It includes physical/functional, emotional, social as well as more existential considerations such as well-being, purpose, and spiritual elements¹. When QOL is used in the assessment of outcomes following illness and treatments the focus tends to assess the impact on physical/functional, emotional and social and the terms health related quality of life is used (HRQOL)². Often in the literature little distinction is made between the terms QOL and HRQOL and they are used synonymously. The many aspects of QOL not only adds to the intricacy of the outcomes researched but also the number of articles published. It is a challenge to identify all the relevant studies. As the number of papers published increases, the time spent searching the literature and potential risk of missing an important study is likely to become worse.

QOL is an important outcome alongside survival^{3,4} that can guide treatment^{5,6} and help evaluate interventions⁷. The number of papers is increasing year on year and this not only reflects the significance of QOL as an outcome but also that it is collected and reported as secondary outcomes in clinical trials, and is becoming a focus of interventions intended to improve function and QOL. The measurement of QOL is mainly through questionnaire⁸, and items are given a value for quantitative analysis. Qualitative methodology is less frequently used but provides a more in depth understanding.

There are various search engines such as Medline, EMBASE, CINAHL, PsycINFO available for the clinician and researcher to use to identify studies on QOL following HNC. Searching the literature in a comprehensive way takes time. The objective of 'Handle-On-QOL' is as a repository of all articles published since 1982 that have used questionnaires to report on QOL in HNC. Although articles have been published using Handle-On-QOL as a data source⁹, the resource has never been evaluated in terms of the inclusion of articles. This element of validation is important if the site is to be confidently used by those interested in this field. The aim of this study was to assess the completeness of Handle-On-QOL and hence reflect on the value of this site to clinicians and researchers.

Methods

The four search engines of Medline, EMBASE, CINAHL, PsycINFO were accessed between August and September 2019. Librarian staff at both Leeds and Liverpool assisted in the searches. A download from Handle-On-QOL was made in early September before the findings of the searches was known. Search terms were 'head and neck cancer', 'quality of life' and 'questionnaire', however these broad terms were expanded with synonymous words to achieve the most comprehensive results possible:

1. 'Head and neck cancer': OR "head and neck carcinoma" OR "laryngeal cancer" OR "oropharyngeal cancer" OR "oral cancer" OR "nasal cancer" OR "paranasal sinus cancer" OR "salivary gland cancer"
2. "Quality of life" OR "health related quality of life"
3. "Questionnaire" OR "patient reported outcome".

The Handle-On-QOL database extends from 1982, so for the purpose of this study, the years 1982 to 2017 were included. This 36 year time period was divided into six equal six-year time periods; 1982-1987, 1988-1993, 1994-1999, 2000-2005, 2006-2011, 2012-2017. From each time period one year was selected randomly by rolling a dice, and the years were 1982, 1990, 1998, 2003, 2006, 2016. Inclusion criteria was HNC, but for the purpose of Handle-On-QOL this has not historically included thyroid cancer or skull base. All studies had to be on adult humans with paediatric as an exclusion. In terms of questionnaires, studies using a non-validated, study specific questionnaire were included. Articles had to be available in full text and written in the English language. Review articles were included so long as the focus of the review was QOL. Studies where HNC patients were part of a cancer cohort were only included if the proportion of HNC was clearly identified in the results and comprised of twenty percent or more of the sample. Papers were excluded if they were conference abstracts, opinion papers, and not written in the English language. Anatomical sites excluded were thyroid, skull base, oesophageal cancer, and head and neck skin cancers. Papers were excluded if the use of questionnaires related to 'function' only such as eating, voice, xerostomia, depression and the questionnaire used did not include an item of the impact on QOL / HRQOL, and no attempt was made to measure this through the addition of another QOL/HRQOL questionnaire.

The research team was made up of all four authors. The search of the literature and abstract screening was carried out by two individuals (EW, MS). Each worked independently, separately scanning and analysing the databases for eligible papers using the specific search criteria. Each paper was documented and classified as included, excluded, or unsure if the information from the title and abstract was insufficient to decide. Where the abstract was insufficient to allocate inclusion, a full-text was requested and reviewed by EW and MS. When there were disagreements regarding whether a paper should be included or excluded, all four authors would express an opinion and the discrepancy resolved. Results of the literature search were downloaded into Excel and duplicate articles removed, this collated dataset was used to perform the descriptive analysis. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed for this systematic review¹⁰.

Results

The findings from the searches are outline in the 5 PRISMA flow diagrams, figures 1 to 5. Because only four papers were identified on Handle-On-QOL in 1982 and none on the other databases, a flow diagram for

1982 is not included. In 1998, 4 papers were identified that were missing from other databases. For 2003, 16 papers were missing from other databases; in 2006, 31 papers were missing and in 2016, 185 papers were missing. In the six years searched there was a total of 595 papers identified across the four search engines. (Table 1) 200 (33.6%) met the inclusion criteria. Common reasons for exclusion were papers that did not utilise a QOL questionnaire, were not specific to HNC, were focussed on function rather than QOL and oesophageal papers.

On Handle-On-QOL for the six years there were 429 articles of which 186 (43.4%) were on identified in the search engines. 243 papers (56.6%) were missed from the search engines. There were 14 (7%) papers missing from Handle-On-QOL that were found on the search engines. Of these 5 were in Medline, 5 in EMBASE and 4 in CINAHL

Discussion

Clinicians and researchers keep up to date through accessing progressively evolving scientific literature. This information leads to changes in patient care and the design of audits and clinical trials. Up to date resources are essential as treatments change and new areas of research interests emerge. Keeping up to date is time consuming and it is helpful to have specific and accessible resources that collate available data for clinicians. This is particularly the case for QOL outcomes following HNC as the topic is complex and the evidence base is considerable and expanding year on year. Handle-On-QOL is a specific resource and unique. This study has shown that those interested in this topic can locate with confidence all the relevant papers without having to search in several non-specific sites.

It is accepted as a limitation of the study that only six years of articles were evaluated for the content of Handle-On-QOL. However, it is likely that the findings are reflective of the whole resource as the years sampled were randomly selected. It would have been too time consuming to compare all 36 years on Handle-On-QOL, with the four search engines and would have added little, in the way of accuracy. By assessing six years it is expected that this is a representative sample. Individual interpretation of eligibility was minimised as each search was independently undertaken by two authors and discrepancy agreed by all authors.

Although the search headings were expanded beyond the terms 'quality of life', 'head and neck cancer', 'questionnaire', it is still possible that a number of articles have been missed in screening of the four search engines. The main loss of papers will be those written in other languages. Hence, Handle-On-QOL potentially lacks cultural inclusivity and is an area that can be improved in the future. There are other reasons for missing papers, such as several assumptions being made regarding what does and doesn't constitute QOL. Some papers focused on an aspect of function that might have been reported within the text and linked with QOL, as opposed to QOL independently. However, function is related to QOL and therefore

studies on function can be of interest to clinicians and researchers searching issues such as appearance, depression, dry mouth, shoulder function, speech, and swallowing. Some papers are likely to have been missed if HNC was combined with other cancer groups; this was true for a few papers identified within our searches which were then excluded as they were not HNC specific.

Having a dedicated resource with papers measuring QOL has advantages. The cancer workforce does not have to work in isolation through the literature in order to identify suitable QOL instruments; a major challenge faced clinical trials during the early 1990's related to the lack of standardised measures and the onerous task to identify a suitable tool in the literature⁸. A dedicated and sustainable QOL resource can help to avoid such issues.

All the other four databases use medical subject headings (MeSH) as their method of indexing, however, MeSH can be vague and non-related to the subject matter of the paper. Consequently, the other databases, particularly Ovid, tended to produce a large volume of irrelevant journals.

Many of early studies suffered problems of low compliance and it was suggested that investigators' unfamiliarity with QOL instruments created such a poor compliance¹¹. It is possible that this was also a reflection of the lack of investigator experience in working with QOL data. A database such as the Handle-On-QOL may help to avoid such issues.

From the results it is obvious that the number of papers related to QOL have been increasing over the years. A large number of papers were identified via Handle-On-QOL but missed from other research engines. This may be that several papers were not focused primarily on QOL and hence missed from other search engines. Also, we must remember that many of the studies they identified, reported on trials that were designed in the mid to late 1990s and, as a result, may not reflect the many improvements in study design, data collection, keyword choice that are now standard in clinical trials that incorporate patient-reported outcomes.

Over the years the number of papers with a qualitative methodology has been increasing. Handle-On-QOL does not include those at present and there is scope for further development to include these publications. In addition, with the emergence of skull base and thyroid cancer multidisciplinary teams, robust collations of papers inclusive of these anatomical sites will be included within Handle-On-QOL in future years.

Conclusion

Handle-On-QOL is a resource that contains more papers on HNC QOL measured by questionnaire than can be easily identified from conventional search engines. Handle-On-QOL can therefore be considered a robust site that contains the vast majority of studies within this rapidly expanding clinical area.

Conflict of interest statement

The main researchers (EW and MS) have no conflicts of interest. The two senior authors are involved in the Handle-On-QOL website hence might have conflict to show the site in the best possible light. However, the study design is such that EW and MS followed a strict methodology separate to the involvement of the senior author.

Ethics statement/confirmation of patient's permission

The data collection and analysis did not involve patients and did not require ethical or local Clinical Governance Department approval.

Acknowledgements

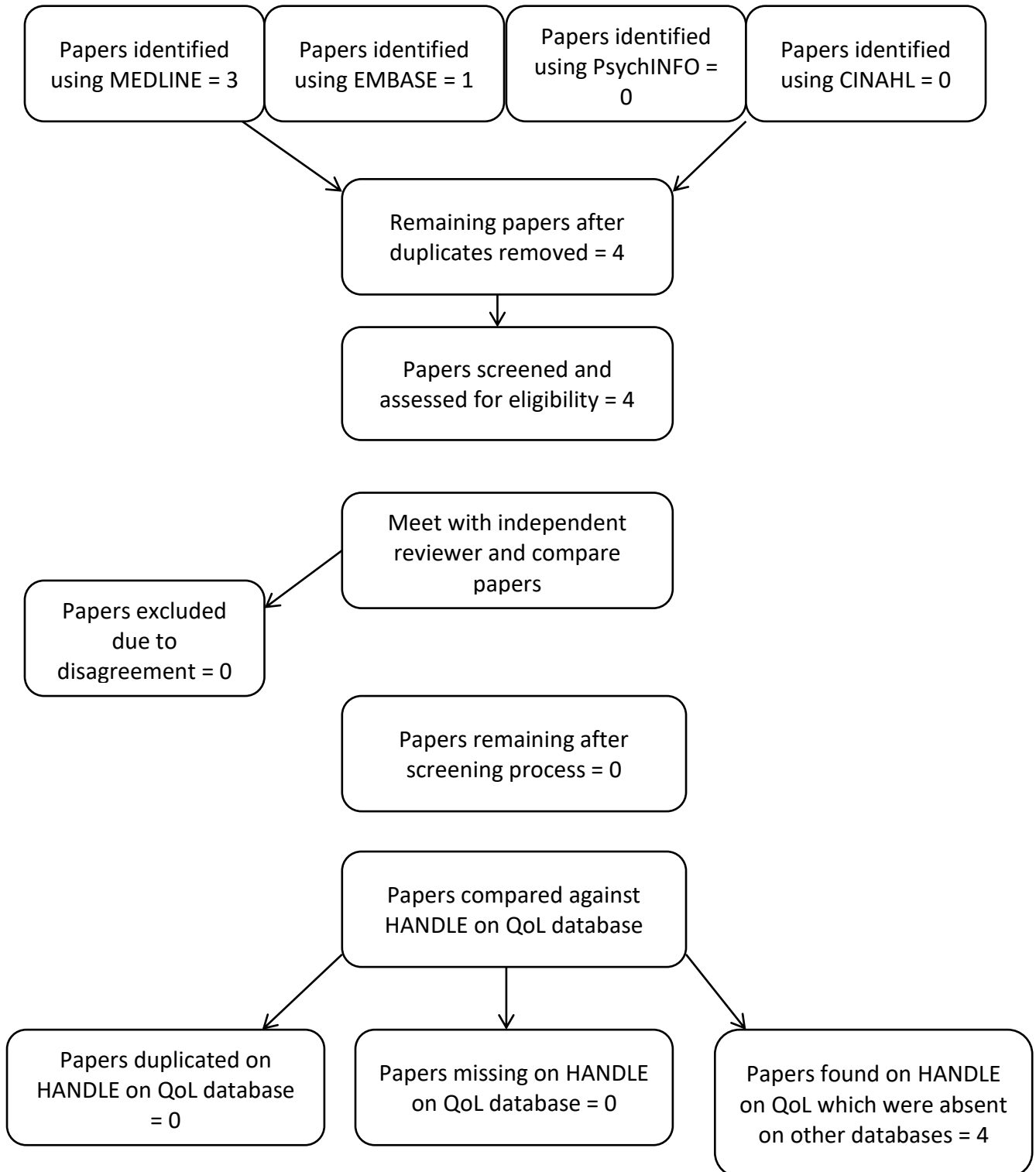
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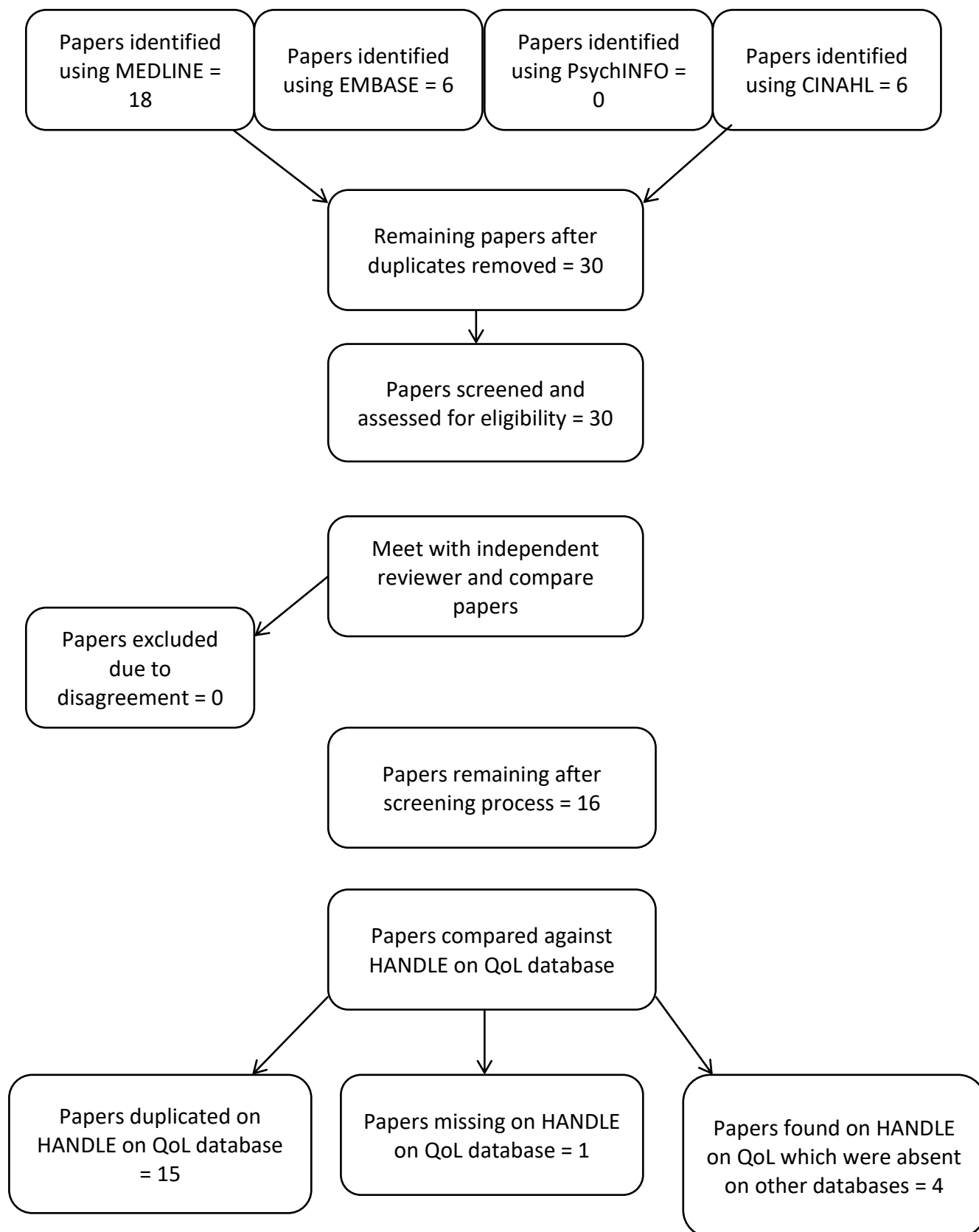
1990 PRISMA



Reasons for excluded papers from system searches 1990:

- Incorrect year = 1
- No QOL questionnaire = 1
- Focus on function = 2

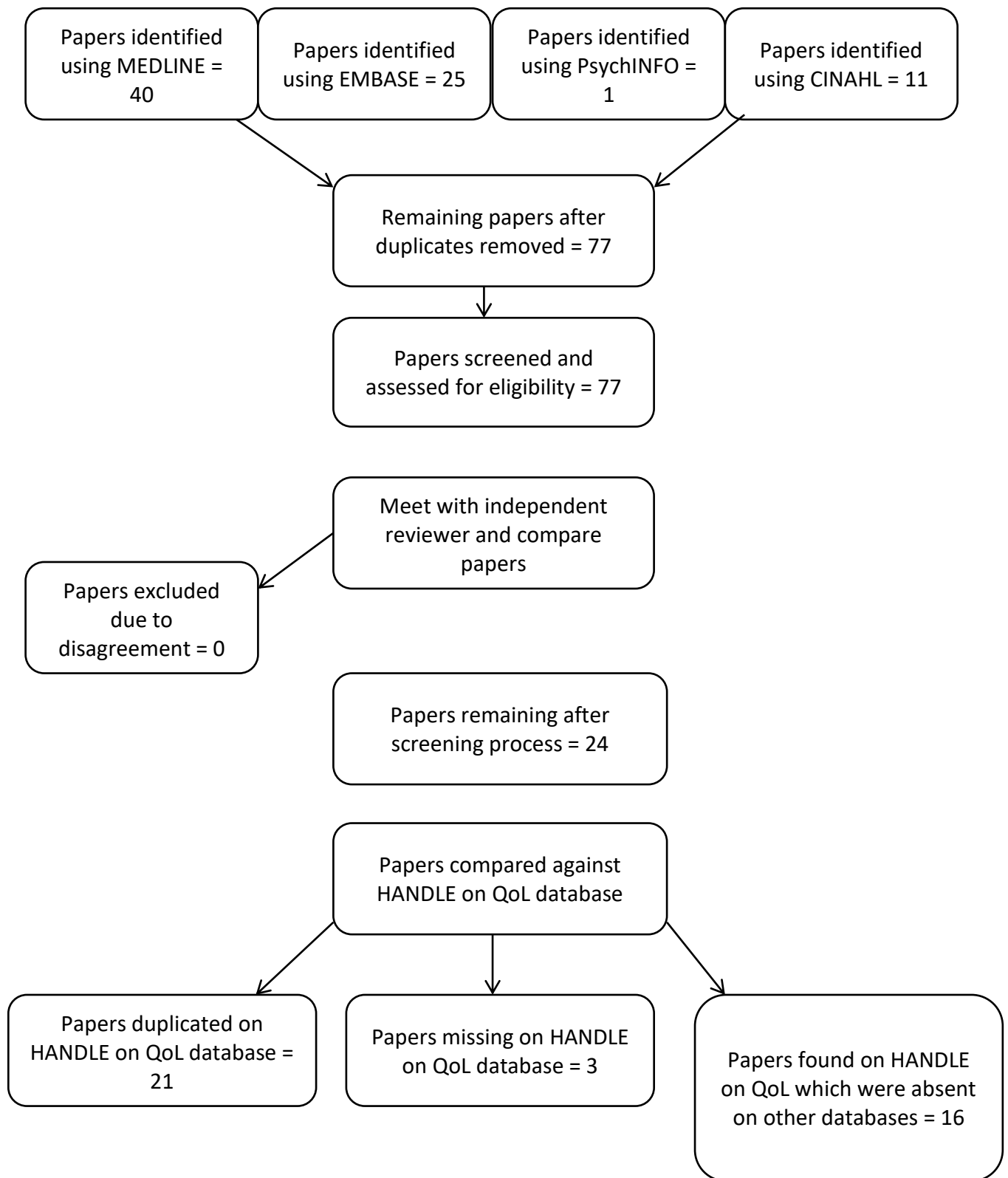
1998 PRISMA



Reasons for excluded papers from system searches 1998:

- Oesophageal focus = 4
- No QOL questionnaire = 5
- Acoustic neuroma focus = 2
- Not HNC specific = 3

2003 PRISMA



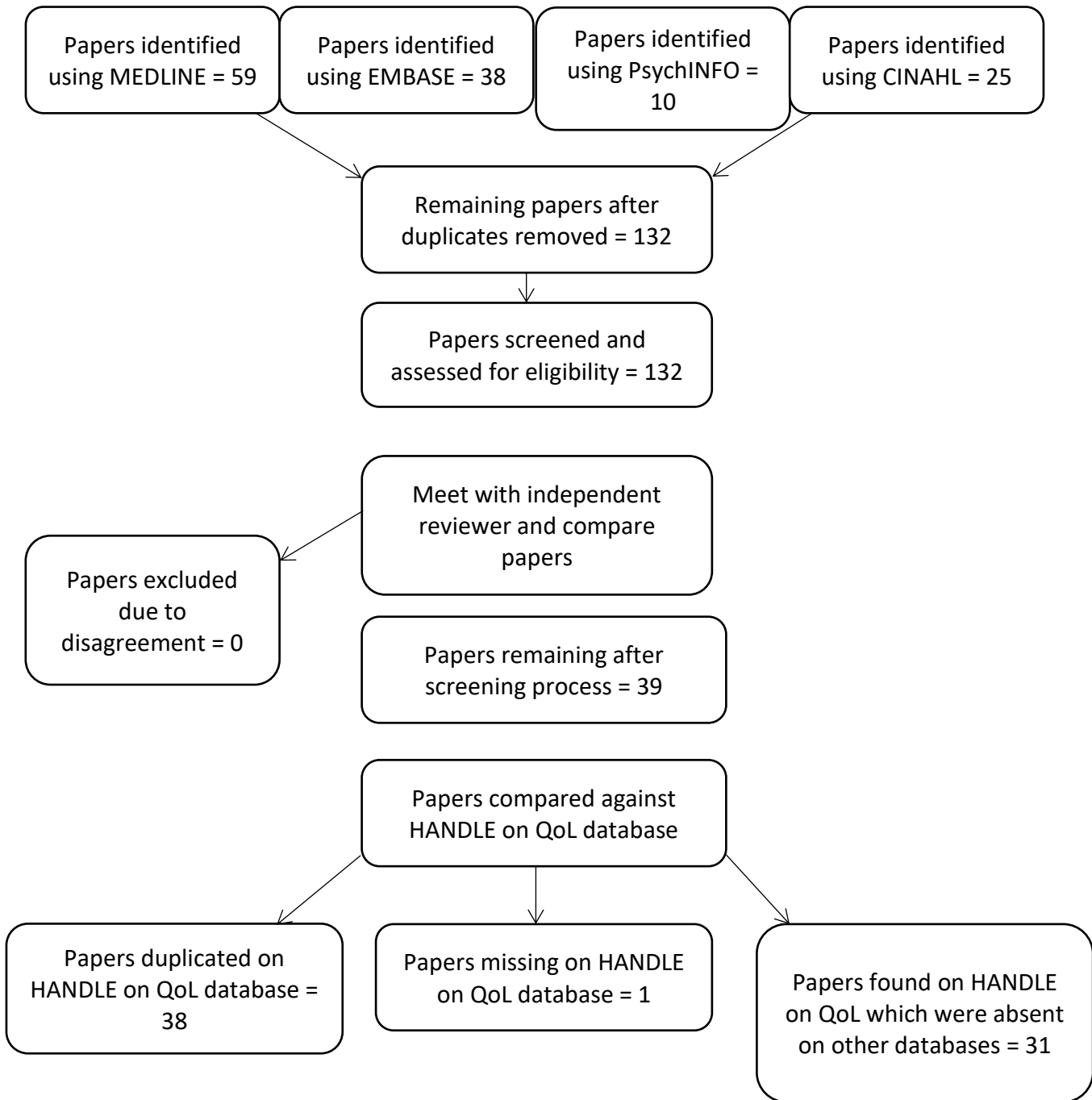
Reasons for excluded papers from system searches 2003:

Oesophageal focus = 4
No QOL questionnaire = 13
Acoustic neuroma focus = 3
Not HNC specific = 12
Xerostomia focus = 4

Medication focus = 1
Cochlear stimulation = 1
Depression focus = 1
Lung cancer focus = 1
Melanoma focus = 2

Not English = 7
Social status focus = 1
Skull base focus = 1
Thyroid focus = 2

2006 PRISMA



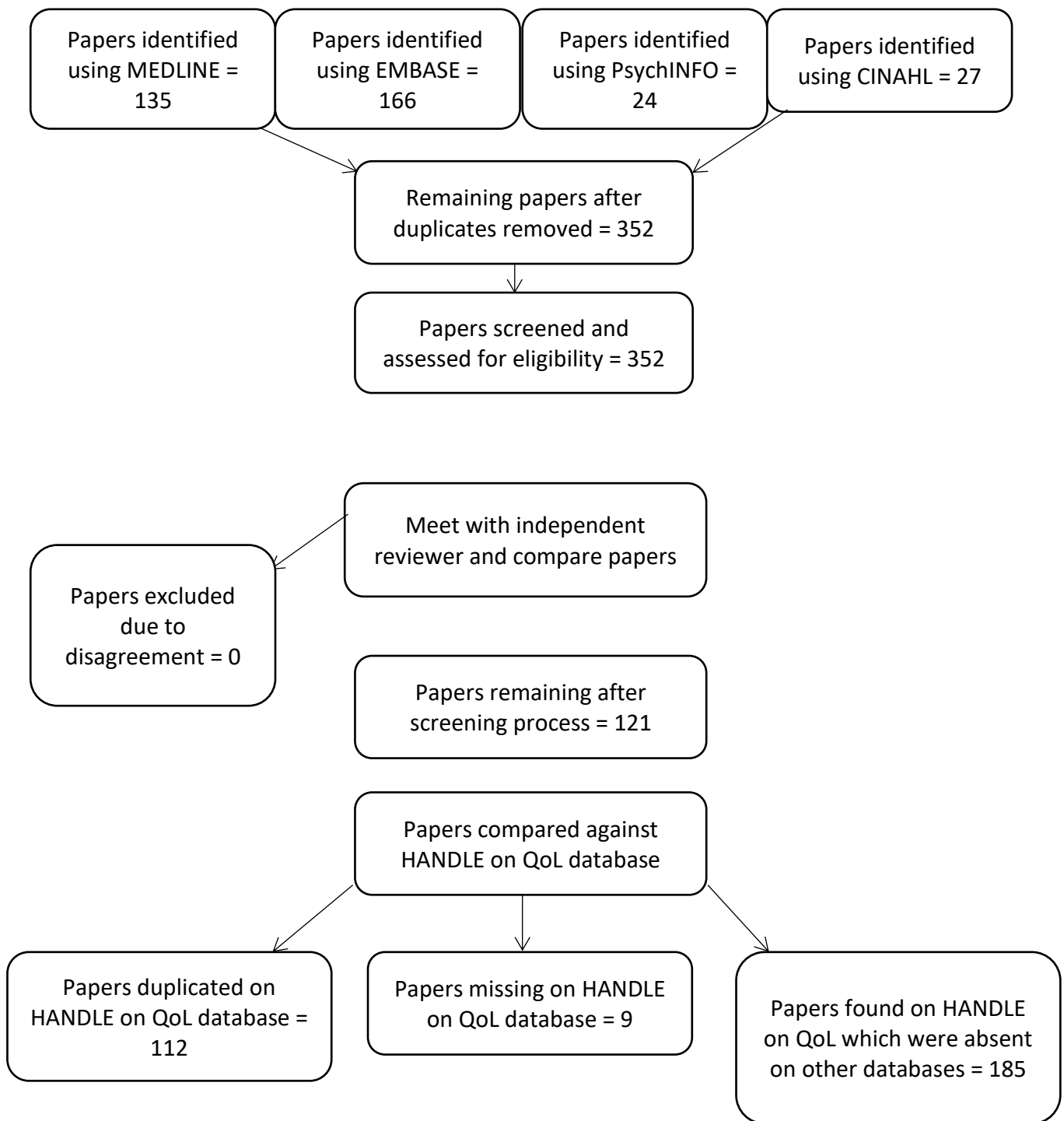
Reasons for excluded papers from system searches 2006:

Xerostomia focus = 4
 Taste focus = 1
 Oesophageal focus = 14
 Not English = 12
 Swallowing focus = 1

Acoustic neuroma = 5
 No QOL questionnaire = 23
 Not HNC specific = 18
 Otitis media focus = 1
 Melanoma focus = 1

Not primary study = 5
 Benign condition = 1
 Clinical questionnaires = 2
 Thyroid focus = 4
 Skull base focus = 1

2016 PRISMA



Reasons for excluded papers from system searches 2016:

Oesophageal focus = 7	Not English = 8
No QOL questionnaire = 43	Function focus = 11
Not HNC specific = 75	Poster = 1
Melanoma focus = 3	Thesis summary = 1
Review papers = 12	Meningioma = 1
Clinician questionnaire = 2	
Caregiver questionnaire = 2	
Parents questionnaire = 1	
Letter to editor = 5	
Implant focus = 1	
Thyroid focus = 27	
Abstract = 9	
No full paper = 17	

Table 1 Summary of searches

Year	Medline	EMBASE	CINAHL	PsycINFO	Total abstracts identified from systems search	Total abstracts identified from Handle-On-QOL search	Present in Handle-On-QOL <u>and</u> other search engines	Missed from Handle-On-QOL	On Handle-On-QOL but not in other engines
1982	0	0	0	0	0	3	0	0	3
1990	3	1	0	0	4 (0 meet inclusion criteria)	4	0	0	4
1998	18	6	6	0	30 (16 meet inclusion criteria)	19	15	1	4
2003	40	25	11	1	77 (24 meet inclusion criteria)	37	21	3	16
2006	59	38	10	25	132 (39 meets inclusion criteria)	69	38	1	31
2016	135	166	27	24	352 (121 meet inclusion criteria)	297	112	9	185

Abstracts found on systems search (total)	595 (200 meet inclusion criteria)
Abstracts found on Handle-On-QOL search (total in designated years)	429
Abstracts in BOTH searches	186
Abstracts only on Handle-On-QOL (total in designated years)	243
Abstracts missed from Handle-On-QOL	14

Of the 14 articles missed from Handle-On-QOL, they were found in the following search engines; MEDLINE (5), EMBASE (5), CINAHL (4).