National Institute for Health and Care Excellence

Final

Subarachnoid haemorrhage caused by a ruptured aneurysm: diagnosis and management

[S] Evidence review for patient information

NICE guideline NG228

Methods, evidence and recommendations

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Evidence review underpinning recommendations 1.4.1 to 1.4.2 and 1.5.3 to 1.5.7 and 1.5.9 to 1.5.11 in the NICE guideline.

1.1 Review question: What patient information (including lifestyle advice) should be given to adults who have had an aneurysmal subarachnoid haemorrhage?

1.2 Introduction

Aneurysmal subarachnoid haemorrhage is a sudden onset, life-threatening condition with variable outcome. Despite advances in treatment and improved survival and functional recovery rates, many subarachnoid haemorrhage survivors report ongoing difficulties. It is common for them to experience fatigue, and cognitive, emotional and psychosocial issues. These problems are associated with reduced quality of life, social participation and community re-integration, and return to work.

People with aneurysmal subarachnoid haemorrhage and their family and/or carers require information that explains their diagnosis, treatment, expectations of recovery and follow up. Alongside information about their condition and treatment, patients and their family and/or carers often seek advice on actions to reduce the risk of recurrence and allow return to previous activities. Currently, the provision of this information varies widely between neurosurgical centres and across wider healthcare settings.

1.3 Characteristics table

For full details see the review protocol in Appendix A:.

Table 1: Characteristics of review question

Objective	To determine what information (such as lifestyle advice) should be given to people who have had a subarachnoid haemorrhage.
Population and setting	Inclusion: Adults (16 and older) who have had a confirmed subarachnoid haemorrhage caused by a ruptured aneurysm. Exclusion: • Adults with subarachnoid haemorrhage caused by head injury, ischaemic stroke or an arteriovenous malformation. • Children and young people aged 15 years and younger.
Context	aSAH is associated with significant sequelae and can have a notable effect on the person's life post-haemorrhage. Adequate information provision for a person with aSAH and their family and/or carer can aid care planning and management, improve understanding and accuracy of expectations, and can influence quality of life. As such, this information for a person with aSAH and their family and/or carer provided both within the immediate care setting and in the community following discharge can be invaluable.
Review strategy	Synthesis of qualitative and qualitative research. Results will be presented in table format. The quality of the qualitative evidence will be assessed by a GRADE CerQual approach for each review finding and results presented in summary tables. Descriptive quantitative data such as incidence rate or frequencies of information preference from survey questionnaires will be synthesised, quality assessed, and considered alongside qualitative evidence.

1.4 Qualitative evidence

1.4.1 Included studies

Six studies were included in the review,[3, 6, 8, 11, 21, 25] these are summarised in Table 2 below. Four studies provided qualitative data[3, 8, 11, 21] and 2 provided quantitative data.[6, 25] Key findings from these studies are summarised in Section 1.4.2 below. See also the study selection flow chart in Appendix C:, study evidence tables in Appendix D:, and excluded studies lists in Appendix E:.

1.4.2 Excluded studies

See the excluded studies list in Appendix E:.

1.4.3 Summary of studies included in the evidence review

Table 2: Summary of studies included in the review

Study	Design	Population	Research aim	Comments
Berggren 2010[3]	In-depth semi-structured interviews with thematic qualitative analysis. The interviews were reported to have taken place one year and seven months after the event for 60 – 90 minutes in the participants homes.	People who had experienced and were treated for SAH at a university hospital in Sweden were interviewed. Informants who were contactable and native language speaking at the time of their discharge were selected from the hospitals patient record system. N=9	The aim was to analyse peoples accounts of SAH and to describe how they create meaning for the SAH and the events that surround it. Specific questions were: - What is highlighted in the accounts of SAH? - How is the illness reconstructed? - How is meaning created through communicative interaction with others about SAH?	A study with some methodological limitations based in Sweden. Focused on specific topics so results appear to be partially applicable. The relevant data has been extracted for the review.
Dulhanty 2019[6]	A cross sectional postal survey, with quantitative collation of responses. The Self-Reported Needs after Stroke Questionnaire was modified and used to measure the self-reported needs of SAH survivors and the extent to which they were met 1–2 years and 3–5 years post haemorrhage.	People who had experienced a subarachnoid haemorrhage (SAH) in Greater Manchester between September 2010–September 2012 (late post-SAH group) and September 2013–September 2014 (early post-SAH group) were recruited. All adult patients admitted to the Regional Neurosciences Centre with SAH within these dates, who survived and were discharged home from the neurosciences centre or inpatient rehabilitation were identified from the centre's	Explore the type and frequency of self reported needs both early and late following SAH specifically to the extent to which they have been met.	A study with some methodological limitations based in UK. Focused on specific topics aside from patient information so results appear to be partially applicable. The relevant data has been extracted for the review.

Study	Design	Population	Research aim	Comments
		prospectively maintained clinical database. N=203		
Hedlund 2010[8]	A semi structured interview guide covering the following question areas: (1) what the participants perceived as important for recovery from aSAH, and (2) perceived consequences of SAH. The interviews were carried out 12 months after onset of aSAH. Each participant was asked to choose a time and setting for the interview (outpatient clinic or home).	Men and women of different ages and from different places in the catchment area who had undergone different treatment for aSAH and with no or minor neurological impairments at discharge from the neurosurgical unit. N=20	The study constitutes the qualitative part of an ongoing study investigating psychiatric morbidity, cognitive strategies, coping and quality of life in patients after aSAH. The aims of this study were to describe what participants with no or minor neurological deficits after aSAH perceived as being important for recovery, and perceived consequences of aSAH.	A study with some methodological limitations based in Sweden. Focused on specific topics in relation to depression or no depression, so results appear to be partially applicable. The relevant data has been extracted for the review.
Jarvis 2002[11]	Through qualitative methodology participants were interviewed using a semi-structured approach in their own homes.	Patients who had suffered a SAH within the last 14 – 18 months. Patients were excluded if they were continuing to receive treatment of any description. N=8	The study aimed to illuminate the experience of recovery from SAH.	A study with some methodological limitations based in UK. Focused on specific topics in relation to symptoms or stressful experiences post SAH, so results appear to be partially applicable. The relevant data has been extracted for the review.
Persson 2017[21]	Explorative interview study with a qualitative design. Individual interviews, with open ended questions, using an interview guide were performed with all participants. The participants chose the time and location of the interview (home or University of Gothenburg).	Participants were included from the Extended Stroke Arm Longitudinal study at the University of Gothenburg. The inclusion criteria were > 18 years of age, with an SAH between 4th February 2009 until the 2nd of December 2010, receiving care at the	To explore experiences of care and rehabilitation as well as the consequences and strategies used to cope with everyday life six years after SAH.	A well conducted study based in Sweden. Focused on the consequences of SAH and the coping strategies patients use to cope. Results should be generally applicable.

Study	Design	Population	Research aim	Comments
		Sahlgrenksa University Hospital in Gothenburg, Sweden, resident in the Gothenburg Urban area (<35km from the hospital), able to speak Swedish and at least some participants should be of working age. The participants were contacted by phone and if they agreed to participate, a time and interview was planned. N=16		
Von Vogelsang 2004[25]	Intervention study with quasi experimental design with qualitative and quantitative components to the study. Patients were divided into two groups while in hospital and either provided verbal and written information or only verbal information from medical professionals.	Participants with ruptured intracranial aneurysm treated consecutively at a Swedish neurosurgical clinic. Participants were recruited over a period of 12 months and recruitment was concluded in 2001. All patients in the sample were acute admissions; and those treated for non-ruptured aneurysms were not included. Patients were included if they were be able to understand, speak and read Swedish, and had a score of 4–5 on the Glasgow Outcome Scale (GOS). N=62	An investigation into the effects of increased information for patients treated for intracranial aneurysm rupture.	A study with some methodological limitations based in Sweden. Focused on specific topics in relation to patients information such as ease of understanding and matching of their needs as well as levels of anxiety, so results appear to be applicable. The relevant data has been extracted for the review.

See Appendix D: for full evidence tables.

1.4.4 Qualitative evidence synthesis

Table 3: Qualitative Review findings

Main findings	Statement of finding
Theme 1 - Clarity of information	
SAH event	People have difficulty in remembering what happened up to their SAH and immediately thereafter. There are some who want to know what happened, but others do not want to know what happened and prefer that to remain in the past.
Ongoing symptoms	People want to know what symptoms to expect after SAH treatment to enable their families and themselves prepare
Medical information	People want information on what to expect in the period immediately after surgery, both negative and positive outcomes and what kind of care they might expect.
Theme 2 - Support	
Social relationships	People value social relationships from a range of sources, to provide practical and emotional support through the process of care.
Theme 3 - Future	
Long term implications	In addition to immediate symptoms after surgery, people want to know what symptoms might be experienced long- term and potentially may not improve after SAH treatment
Reoccurrence	People value information about SAH, including information about risk factors for SAH, and risk and prevention of recurrent SAH.

Table 4: Quantitative Review findings

Main findings	Statement of finding	
Information Needs – people needed information and/or advice about		N (%)
Health	• SAH • General health (diet / alcohol / smoking) • Physical relationships	105 (58) 40 (21) 17 (9)
Travel	• Driving • Public transport	19 (10) 22 (11)
Finance	• Benefits • Money management	34 (17) 7 (4)
Home	• Home aids • Adaptations • Moving home	20 (10) 10 (5) 12 (6)
Information Needs – peoples satisfaction with information given		*P* value
Meeting information needs Scale: 0-5, low is poor outcome	Written + oral info: 4.4 (2.9) Oral info only: 3.3 (1.6)	0.06
Ease of understanding Scale: 0-5, low is poor outcome	Written + oral info: 3.9 (1.8) Oral info only: 3.3 (1.9)	0.24

1.4.4.1 Narrative summary of review findings

Clarity of information

Qualitative findings:

Review finding 1: SAH event

People felt that having a SAH was an extremely traumatic experience. However, most people can only clearly recollect their experience after intervention and the events leading up to surgery are not clear or missing. For some this was frustrating as they had been through a life changing event and undergone an intervention but could not recollect what happened. This set of people wanted to be know more and understand what an SAH is and what had happened to them. Other people do not wish to know more about their condition and prefer to focus on their current symptoms and recovery.

Some respondents could not recollect any information given to them while they were admitted in hospital, but were told by their families that they were given oral and written information. Overall, people and their families value information on the process of care throughout the interventional journey. Information would help to reduce anxiety after the SAH.

This review finding was based on primary research addressing the experiences of people who have had an SAH and their families, mostly in Sweden. There was a judgement of moderate confidence in this review finding, because of concerns about direct relevance and coherence.

Review finding 2: Ongoing symptoms

The side effects and symptoms after having a SAH varied from patient to patient. Fatigue, inability to concentrate and completing routine tasks were complications that people faced once discharged home. It is unclear whether people and their families were informed of what to expect once discharged. Therefore, it seems relevant to ensure that they are appropriately informed in person and through written information about common symptoms after having a SAH and how to manage those once home, with the support of families or carers.

This review finding was based on primary research addressing the difficulties people had once they were home and in their recovery period. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review finding 3: Medical information

People were suffering with the immediate and long-term consequences of intervention for SAH, often not knowing what to expect. It is important that they know and understand the impact of surgery on their quality of life, their ability to return to activities of normal daily life, how to manage pain, and how to identify and respond to complications. Topics such as risks for family members, surgical techniques of treatment, rehabilitation and future risks were also highlighted as important to be informed about.

Some people reported the feeling of abandonment once they were discharged from hospital and were unclear about ongoing medical support or follow up, and this had the potential to increase anxiety. Those who did receive rehabilitation support and follow up felt supported. However, some participants did not receive any rehabilitation support and felt unable to request it. This added to the feeling of abandonment.

This review finding was based on primary research addressing the experiences of people who have been discharged after SAH surgery. There was a judgement of moderate confidence in this review finding, because of minor concerns about relevance.

A point that was consistent through all three of these review findings was that respondents wanted information that was easy to understand for themselves, families or carers.

Support

Review finding 1: Different sources of support

People emphasized the importance of the support of family, friends, and community members throughout their journey. People also valued the support from the health care professionals involved in their care. Particularly after discharge, support involved practical help with activities of daily living, and in employment and emotional support during distress. Some people felt that they might be a burden for family and friends, but they appreciated the practical and emotional support through the process of care. People wanted their primary care provider to have more information about SAH, so they could be a source of information and support as this was lacking.

This review finding was based on primary research addressing the experiences of people after SAH intervention. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Future

Review finding 1: Long term implications

People wanted more information about the long-term consequences of having a SAH and neurosurgery. This is linked partially to the symptoms they faced once they were discharged, mainly what people called “invisible” symptoms such as fatigue and cognitive symptoms such as memory impairment, planning and concentration. Some participants were able to find their own adaptations to their day to day lives, especially in their places of work. Some participants struggled as their employers or team members were unaware of what support they may need and the consequences of having a SAH. A few also had to face unemployment as they were unable to continue their jobs, which affected them economically and psychologically.

This review finding was based on primary research addressing the experiences of people after SAH surgery. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Review finding 2: Recurrence

People wanted to know how likely it was that they would have another aneurysm or haemorrhage. At times this was referred to as existential threat or worry about reoccurrence and survival. People wish to understand the risks for reoccurrence and what modifiable risk factors they may also have.

This review finding was based on primary research addressing the experiences of people who underwent surgery for SAH. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

Quantitative findings

Information needs:

People highlighted that they wanted more information on a variety of different topics after their SAH. Linked to the other findings, people wanted more information about their SAH and as well as their general health and well being. This included modifications to their lifestyle but also information about resuming physical relationships. As the SAH may have an affect on a person’s cognitive and physical abilities, they wanted to know what aids are available for support and what adaptations could be made to support their recovery.

As the recovery period after an SAH may affect their ability to work or continue employment, more information was needed on benefit support and managing money. People also wanted more information on travelling and how the SAH would affect their ability to drive and using public transport.

Patients also reported that receiving information both written and orally better met their information needs and was slightly easier for them to understand than receiving only oral information.

This review finding was based on primary research addressing the experiences of people who had a SAH within the UK. There was a judgement of high confidence in this review finding, as there were no significant methodological limitations or concerns.

1.4.5 Qualitative evidence summary

Table 5: Summary of Qualitative evidence – CERQual checklist

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
Clarity of Information					
5	Semi structured qualitative interviews + intervention study with quasi-experimental design	**SAH event:** people have difficulty in remembering what happened up to their SAH and immediately thereafter. There are some who want to know what happened, but others do not want to know what happened and prefer that to remain in the past. *Berggren 2010*[3]*Hedlund 2010*[8] *Jarvis 2002*[11] *Persson 2017*[21] *Von Vogelsang 2004*[25]	Limitations	Minor methodological limitations [a, b] (five studies with minor methodological limitations due to responses to a variety of different open questions asked between the studies)	MODERATE
			Coherence	Minor concerns about coherence [a,c] (due to consolidation of multiple concerns into one theme)	
			Relevance	Minor concerns about relevance [a] (due to the difference of responses and importance under one theme)	
			Adequacy	Minor concerns [a]	

Study design and sample size			**Quality assessment**		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
				(five studies that overall offered moderately rich data)	
4		**Ongoing Symptoms:** people want to know what symptoms to expect after SAH treatment to enable their families and themselves prepare *Berggren 2010*[3] *Hedlund 2010*[8] *Jarvis 2002*[11] *Persson 2017*[21]	Limitations	Minor concerns about limitations [a] (four studies with minor methodological limitations)	MODERATE
			Coherence	Minor concerns [a] (data generally consistent within and across all studies)	
			Relevance	Minor concerns [a] (studies of people and families who have experienced SAH in the UK and Sweden)	
			Adequacy	Minor concerns [a] (four studies that together offered moderately rich data)	
5		**Medical information:** people want information on what to expect in the period immediately after surgery, both negative and positive outcomes and what kind of care they might expect. *Berggren 2010*[3]	Limitations	Minor concerns about limitations [a] (five studies with minor methodological limitations)	MODERATE

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
		Hedlund 2010[8] *Jarvis 2002*[11] *Persson 2017*[21] *Von Vogelsang 2004*[25]	Coherence	Minor concerns [a] (data generally consistent within and across all studies)	
			Relevance	Minor concerns [a] (studies of people and families who have experienced SAH in the UK and Sweden)	
			Adequacy	Minor concerns [a] (five studies that together offered moderately rich data)	
Support					
4	Semi structured qualitative interviews	**Social support: social relationships -** People value social relationships from a range of sources, to provide practical and emotional support through the process of care. *Berggren 2010*[3] *Hedlund 2010*[8] *Jarvis 2002*[11] *Persson 2017*[21]	Limitations	Minor concerns about limitations (four studies with minor methodological limitations)	MODERATE
			Coherence	Minor concerns (data generally consistent within and across all studies)	
			Relevance	Minor concerns (studies of people and families who have	

Study design and sample size			Quality assessment		
Number of studies contributing to the finding	**Design**	**Finding**	**Criteria**	**Rating**	**Overall assessment of confidence**
				experienced SAH in the UK and Sweden)	
			Adequacy	No concerns (four studies that together offered moderately rich data)	
Future					
4	Semi structured qualitative interviews	**Long term consequences:** in addition to immediate symptoms after surgery, people want to know what symptoms might be experienced long- term and potentially may not improve after SAH treatment *Berggren 2010*[3] *Hedlund 2010*[8] *Jarvis 2002*[11] *Persson 2017*[21]	Limitations	Minor concerns about limitations (four studies with minor methodological limitations)	MODERATE
			Coherence	Minor concerns (data generally consistent within and across all studies)	
			Relevance	Minor concerns (studies of people and families who have experienced SAH in the UK and Sweden)	
			Adequacy	Minor concerns (four studies that together offered moderately rich data)	
4			Limitations	Minor concerns about limitations	MODERATE

Study design and sample size		Finding	Quality assessment		
Number of studies contributing to the finding	**Design**		**Criteria**	**Rating**	**Overall assessment of confidence**
		Reoccurrences: people value information about SAH, including information about risk factors for SAH, and risk and prevention of recurrent SAH. *Berggren 2010*[3] *Hedlund 2010*[8] *Jarvis 2002*[11] *Persson 2017*[21]		(four studies with minor methodological limitations)	
			Coherence	Minor concerns (data generally consistent within and across all studies)	
			Relevance	Minor concerns (studies of people and families who have experienced SAH in the UK and Sweden)	
			Adequacy	Minor concerns (four studies that together offered moderately rich data)	

Table 6: Summary of Quantitative evidence

Study design and sample size			
Number of studies contributing to the finding	**Design**	**Finding**	**Risk of Bias**
1	Cross-sectional survey	**Information needs – people needed information and/or advice about** Health: SAH – 105 patients, general health (diet / alcohol / smoking) – 40 patients, physical relationships – 17 patients Travel: driving – 19 patients, public transport – 22 patients Finance: benefits – 34 patients, money management – 7 patients Home: home aids – 20 patients, adaptations – 10 patients, moving home – 12 patients. *Dulhanty 2019*[6]	Moderate[a]
1	Intervention study with quasi experimental design	**Information Needs – people satisfaction with information given** Meeting information needs: Written + oral info: 4.4 (2.9) compared to Oral info only: 3.3 (1.6) Ease of understanding: Written + oral info: 3.9 (1.8) compared to Oral info only: 3.3 (1.9) *Von Vogelsang 2004*[25]	High[b]

Moderate risk of bias due to (a) outcome measurement bias, 203 (51%) participants responded to the questionnaire (JBI checklist for cross sectional study), and (b) potential selection bias with intervention start and follow-up start differing between intervention and control groups, and potential confounding bias with no adjusting for possible confounding factors between control and intervention groups (ROBINS-I).

1.5 Economic evidence

The committee agreed that health economic studies would not be relevant to this review question, and so were not sought.

1.6 The committee's discussion of the evidence

1.6.1 Interpreting the evidence

1.6.1.1 The quality of the evidence

<u>Qualitative Findings</u>

The quality of evidence was of moderate quality. Evidence was downgraded for minor concerns about methodological limitations with responses to a variety of different open questions asked between the included studies, minor concerns about contextual relevance with inclusion of studies of people and families who have experienced SAH in the UK and Sweden, and minor concerns about adequacy of data in the quantity and richness of data available. The committee highlighted that each of these concerns were minor and considered the evidence to be reliable.

<u>Quantitative Findings</u>

The quantitative evidence was considered to be at moderate to high risk of bias. This was mostly due to low rates of participants questionnaire response and potential selection bias.

Overall, the committee agreed that the evidence provided a rich understanding of the different themes and topics people would like information about after having a SAH. In addition to this evidence, the committee used their experience to agree topics that should be included, as a minimum, in the information given. Therefore, the committee were able to make strong recommendations for patient information.

1.6.1.2 Findings identified in the evidence synthesis

The committee discussed the findings of the review and felt the themes identified reflected their experience of the information needs of patients and was from well-conducted qualitative and quantitative studies. The committee considered the evidence helpful in highlighting people's specific information needs at a challenging time due to the effects of aneurysmal SAH on memory and recall of information in the peri-operative and early recovery period.

The qualitative evidence showed that patients described some themes that were important for the content of information considered useful after an SAH. One of the themes highlighted was the clarity of information people were given. Patients described that recall of information was a challenge with regards to the SAH event, but any information given after the event too. This contributed to people's understanding of what ongoing symptoms they could expect and their understanding of the long-term medical implications after having an SAH. A specific point raised was that patients wanted to know what their medical follow up after the event would entail, as some felt abandoned once discharged from hospital.

Another theme identified from the evidence was the support that people with an SAH received. They were grateful for all the support received from formal medical service providers and informal carers and family, which all contributed to activities of daily living. People wanted their carers and families to also be well informed about SAH and what to expect after an SAH in order to support their family member with the SAH effectively.

An important theme drawn from the evidence was that people wanted to know the long term medical and social implications of having a SAH. This ranged from what symptoms they could face because of the SAH, but also the implications on daily functioning including employment. Recurrence of SAH was also a topic which was important to people to be well informed about.

The quantitative evidence supplemented what the qualitative evidence showed in that it also highlighted similar areas of information preference from the participant responses. The quantitative data also identified that people wanted more information on specific topics such as future health, travel, finance and home life. Notably, ~60% of participants from one study reported that they wished for more information on SAH and how it could impact on their health. The evidence conveyed that patients wanted information that was easy to understand, so they wanted information in both written and verbal formats. The written format would allow patients and their families to refer to information after they had left hospital and aid ongoing understanding through the recovery phase. One study showed that satisfaction with information received was higher in patients who received written and oral information compared to patients who received only oral information.

The committee noted that information provision may help to inform people’s expectation of recovery after a SAH and this may help the recovery process and reduce potential stress or anxiety. The evidence also found that some people do not want in-depth information about their SAH as this may contribute to anxiety or stress during their recovery period. A person’s choice about the level of information wanted should also be taken into account after an SAH.

The recommendations made by the committee outlined the areas important to include in patient information: providing information to the person on what an aneurysmal subarachnoid haemorrhage is and what caused it, treatment options and the possible side effects, ongoing symptoms or complications from having had an aSAH, ongoing support available from local and national groups, and advice on resuming usual activities such as returning to work, and driving. The importance of written information was highlighted, in order that people were able to review the information at a time suitable for themselves.

The committee also drew from their experience to suggest some additional and more specific areas of information provision, which might be useful for patients and their families or carers. These included explaining how aSAH has been treated and how effective the treatment has been, and any follow-up plan for the patient including a named contact within the specialist centre who could be contacted for future advice. The committee also agreed that information should be provided about other possible symptoms that in their experience were common such as sleep disturbance, headache, low mood, changes to taste and smell and other advice such as medications the person may be taking, and wound care.

There is variation in information provision for people who have had a SAH. The committee highlighted within the recommendations that information provision and support should be given to people on admission with a SAH, after treatment, and post discharge.

The committee noted that verbal information and support needs to be tailored to the individual. The guideline committee were aware that this would be especially applicable for people with learning disabilities, concerns with capacity and those with language difficulties.

1.6.2 Cost effectiveness and resource use

Cost effectiveness evidence was not sought as this is a qualitative review. The recommendations provide guidance regarding what topics should be covered within a patient review, but the committee agreed that this will not impact consultation time.

The committee considered that increased provision of information might be required where it does not already exist in a suitable format. However, this is in line with the general principles of provision of information already established in the existing NICE Patient experience guideline and so the recommendations based on this review do not represent an additional resource impact. The committee noted that good quality information was accessible from sources such as The British Stroke Association and Headway.

1.6.3 Other factors the committee took into account

When a person has a SAH, patient information should be communicated and delivered clearly, openly and in a manner that enables the person and their family to be involved in shared decision making about their treatment and recovery pathway. The committee considered that improved information provision may enhance understanding of SAH, and could aid recovery and influence expectations of the possible positive and negative outcomes. The committee highlighted that some people may not want information about their SAH or would prefer their family or carers receive the information instead of them. The committee considered these general principles in providing information and support to be covered by the Patient experience in adult NHS services and a cross reference to this guideline was added to the recommendations.

The committee also agreed that the person should be provided with a paper copy of the follow-up care plan, which should also be included in their healthcare record.

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Appendices

Appendix A: Review protocols

Table 7: Review protocol: Patient information

ID	Field	Content
0.	PROSPERO registration number	CRD42019160099
1.	Review title	What patient information (including lifestyle advice) should be given to adults who have had an aneurysmal subarachnoid haemorrhage?
2.	Review question	What patient information (including lifestyle advice) should be given to adults who have had an aneurysmal subarachnoid haemorrhage?
3.	Objective	To determine what information (such as lifestyle advice) should be given to people who have had a subarachnoid haemorrhage.
4.	Searches	The following databases will be searched: • Embase • MEDLINE • CINAHL • PsycINFO Searches will be restricted by: • English language only The searches may be re-run 6 weeks before the final committee meeting and further studies retrieved for inclusion if relevant. The full search strategies will be published in the final review.
5.	Condition or domain being studied	Aneurysmal subarachnoid haemorrhage
6.	Population	Inclusion: Adults (16 and older) who have had a confirmed subarachnoid haemorrhage caused by a ruptured aneurysm. Exclusion: • Adults with subarachnoid haemorrhage caused by head injury, ischaemic stroke or an arteriovenous malformation. • Children and young people aged 15 years and younger.
7.	Intervention/Exposure/Test	Views, opinions and experiences relating to any information, education or support specified in studies
8.	Comparator/Reference standard/Confounding factors	n/a
9.	Types of study to be included	Qualitative studies such as interview and focus group studies (including studies using grounded theory, phenomenology or other appropriate qualitative approaches); quantitative data such as incidence rate or

		frequencies of information preference from questionnaires will also be considered alongside qualitative evidence.
10.	Other exclusion criteria	Exclusions: • Adults with subarachnoid haemorrhage caused by head injury, ischaemic stroke or an arteriovenous malformation. • Children and young people aged 15 years and younger. • Non-English language studies.
11.	Context	aSAH is associated with significant sequelae and can have a notable effect on the person's life post-haemorrhage. Adequate information provision for a person with aSAH and their family and/or carer can aid care planning and management, improve understanding and accuracy of expectations, and can influence quality of life. As such, this information for a person with aSAH and their family and/or carer provided both within the immediate care setting and in the community following discharge can be invaluable.
12.	Primary outcomes (critical outcomes)	Themes will be derived from the evidence identified for this review and not pre-specified. Quantitative data such as incidence rate or frequencies of reported information preference will be extracted and presented alongside the themes identified from qualitative analysis.
13.	Secondary outcomes (important outcomes)	n/a
14.	Data extraction (selection and coding)	EndNote will be used for reference management, sifting, citations and bibliographies. All references identified by the searches and from other sources will be screened for inclusion. 10% of the abstracts will be reviewed by two reviewers, with any disagreements resolved by discussion or, if necessary, a third independent reviewer. The full text of potentially eligible studies will be retrieved and will be assessed in line with the criteria outlined above. A standardised form will be used to extract data from studies including the study aim, population setting, design, methodology, findings and limitations (see Developing NICE guidelines: the manual section 6.4).
15.	Risk of bias (quality) assessment	Risk of bias will be assessed using the appropriate checklist as described in Developing NICE guidelines: the manual Critical Appraisal Skills Programme (CASP) qualitative checklist with be used to assess included qualitative studies. Risk of bias for quantitative data will be employed depending on the design of the study: • Randomised Controlled Trial: Cochrane RoB (2.0) • Non randomised study, including cohort studies: Cochrane ROBINS-I • Case control study: CASP case control checklist • Controlled before-and-after study or Interrupted time series: Effective Practice and Organisation of Care (EPOC) RoB Tool • Cross sectional study: JBI checklist for cross sectional study

		- Case series: Institute of Health Economics (IHE) checklist for case series 10% of all evidence reviews are quality assured by a senior research fellow. This includes checking: - papers were included /excluded appropriately - a sample of the data extractions - correct methods are used to synthesise data - a sample of the risk of bias assessments Disagreements between the review authors over the risk of bias in particular studies will be resolved by discussion, with involvement of a third review author where necessary.
16.	Strategy for data synthesis	The synthesis of qualitative data will follow a thematic analysis approach. Information will be synthesised into main review findings. Results will be presented in a detailed narrative and in table format with summary statements of main review findings. GRADE CERQual will be used to synthesise the qualitative data and assess the certainty of evidence for each review finding. Quantitative data from surveys reporting patient information preferences will be reported narratively and presented alongside thematic analysis. Risk of bias will be assessed to ascertain outcome quality. Endnote will be used for bibliography, citations, sifting and reference management.
17.	Analysis of sub-groups	n/a
18.	Type and method of review	☐ Intervention ☐ Diagnostic ☐ Prognostic ☒ Qualitative ☐ Epidemiologic ☐ Service Delivery ☒ Other (mixed methods)
19.	Language	English
20.	Country	England
21.	Anticipated or actual start date	
22.	Anticipated completion date	3 February 2021
23.	Stage of review at time of this submission	

Review stage	Started	Completed
Preliminary searches	☑	☑
Piloting of the study selection process	☑	☑

		Formal screening of search results against eligibility criteria	☑	☑
		Data extraction	☑	☑
		Risk of bias (quality) assessment	☑	☑
		Data analysis	☑	☑
24.	Named contact	5a. Named contact National Guideline Centre 5b Named contact e-mail SAH@nice.org.uk 5e Organisational affiliation of the review National Institute for Health and Care Excellence (NICE) and the National Guideline Centre		
25.	Review team members	From the National Guideline Centre: • Ms Gill Ritchie • Mr Ben Mayer • Mr Audrius Stonkus • Mr Vimal Bedia • Ms Emma Cowles • Ms Jill Cobb • Ms Liz Pearton • Ms Amelia Unsworth		
26.	Funding sources/sponsor	This systematic review is being completed by the National Guideline Centre which receives funding from NICE.		
27.	Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		
28.	Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website.		

29.	Other registration details		
30.	Reference/URL for published protocol		
31.	Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.	
32.	Keywords	Subarachnoid haemorrhage; patient information; lifestyle advice	
33.	Details of existing review of same topic by same authors	None	
34.	Current review status	☐	Ongoing
		☐	Completed but not published
		☐	Completed and published
		☐	Completed, published and being updated
		☐	Discontinued
35..	Additional information		
36.	Details of final publication	www.nice.org.uk	

Table 8: Health economic review protocol

Review question	**All questions where health economic evidence applicable**
Objectives	To identify health economic studies relevant to any of the review questions.
Search criteria	• Populations, interventions and comparators must be as specified in the clinical review protocol above. • Studies must be of a relevant health economic study design (cost–utility analysis, cost-effectiveness analysis, cost–benefit analysis, cost–consequences analysis, comparative cost analysis). • Studies must not be a letter, editorial or commentary, or a review of health economic evaluations. (Recent reviews will be ordered although not reviewed. The bibliographies will be checked for relevant studies, which will then be ordered.) • Unpublished reports will not be considered unless submitted as part of a call for evidence. • Studies must be in English.
Search strategy	A health economic study search will be undertaken using population-specific terms and a health economic study filter.
Review strategy	Studies not meeting any of the search criteria above will be excluded. Studies published before 2003, abstract-only studies and studies from non-OECD countries or the USA will also be excluded.

Each remaining study will be assessed for applicability and methodological limitations using the NICE economic evaluation checklist which can be found in appendix H of Developing NICE guidelines: the manual.[16]

Inclusion and exclusion criteria

- If a study is rated as both ‘Directly applicable’ and with ‘Minor limitations’ then it will be included in the guideline. A health economic evidence table will be completed and it will be included in the health economic evidence profile.
- If a study is rated as either ‘Not applicable’ or with ‘Very serious limitations’ then it will usually be excluded from the guideline. If it is excluded then a health economic evidence table will not be completed and it will not be included in the health economic evidence profile.
- If a study is rated as ‘Partially applicable’, with ‘Potentially serious limitations’ or both then there is discretion over whether it should be included.

Where there is discretion

The health economist will decide based on the relative applicability and quality of the available evidence for that question, in discussion with the guideline committee if required. The ultimate aim is to include health economic studies that are helpful for decision-making in the context of the guideline and the current NHS setting. If several studies are considered of sufficiently high applicability and methodological quality that they could all be included, then the health economist, in discussion with the committee if required, may decide to include only the most applicable studies and to selectively exclude the remaining studies. All studies excluded based on applicability or methodological limitations will be listed with explanation in the excluded health economic studies appendix below.

The health economist will be guided by the following hierarchies.

Setting:

- UK NHS (most applicable).
- OECD countries with predominantly public health insurance systems (for example, France, Germany, Sweden).
- OECD countries with predominantly private health insurance systems (for example, Switzerland).
- Studies set in non-OECD countries or in the USA will be excluded before being assessed for applicability and methodological limitations.

Health economic study type:

- Cost–utility analysis (most applicable).
- Other type of full economic evaluation (cost–benefit analysis, cost-effectiveness analysis, cost–consequences analysis).
- Comparative cost analysis.
- Non-comparative cost analyses including cost-of-illness studies will be excluded before being assessed for applicability and methodological limitations.

Year of analysis:

- The more recent the study, the more applicable it will be.
- Studies published in 2003 or later but that depend on unit costs and resource data entirely or predominantly from before 2003 will be rated as ‘Not applicable’.
- Studies published before 2003 will be excluded before being assessed for applicability and methodological limitations.

Quality and relevance of effectiveness data used in the health economic analysis:

- The more closely the clinical effectiveness data used in the health economic analysis match with the outcomes of the studies included in the clinical review the more useful the analysis will be for decision-making in the guideline.

Appendix B: Literature search strategies

This literature search strategy was used for the following review:

- What patient information (including lifestyle advice) should be given to adults who have had an aneurysmal subarachnoid haemorrhage?

The literature searches for this review are detailed below and complied with the methodology outlined in Developing NICE guidelines: the manual.[16]

For more information, please see the Methods Report published as part of the accompanying documents for this guideline.

B.1 Clinical search literature search strategy

Searches for patient views were run in Medline (OVID), Embase (OVID), CINAHL and PsycINFO (ProQuest). Search filters were applied to the search where appropriate.

Table 9: Database date parameters and filters used

Database	Dates searched	Search filter used
Medline (OVID)	1946 – 26 June 2020	Exclusions Qualitative studies
Embase (OVID)	1974 – 26 June 2020	Exclusions Qualitative studies
CINAHL, Current Nursing and Allied Health Literature (EBSCO)	Inception – 26 June 2020	Qualitative studies
PsycINFO (ProQuest)	Inception – 26 June 2020	Qualitative studies

Medline (Ovid) search terms

1.	exp Subarachnoid Hemorrhage/
2.	((subarachnoid* or arachnoid* or cerebral or intracerebral or intra-cerebral or intracranial or intra-cranial) adj3 (hemorrhag* or haemorrhag* or bleed* or blood*)).ti,ab.
3.	(SAH or aSAH).ti,ab.
4.	Intracranial Aneurysm/
5.	((subarachnoid* or arachnoid* or cerebral or intracerebral or intra-cerebral or intracranial or intra-cranial or brain) adj3 (aneurysm* or aneurism* or hematoma* or haematoma*)).ti,ab.
6.	or/1-5
7.	letter/
8.	editorial/
9.	news/
10.	exp historical article/
11.	Anecdotes as Topic/
12.	comment/
13.	case report/
14.	(letter or comment*).ti.
15.	or/7-14
16.	randomized controlled trial/ or random*.ti,ab.
17.	15 not 16

18.	animals/ not humans/
19.	exp Animals, Laboratory/
20.	exp Animal Experimentation/
21.	exp Models, Animal/
22.	exp Rodentia/
23.	(rat or rats or mouse or mice).ti.
24.	or/17-23
25.	6 not 24
26.	(exp child/ or exp pediatrics/ or exp infant/) not (exp adolescent/ or exp adult/ or exp middle age/ or exp aged/)
27.	25 not 26
28.	limit 27 to English language
29.	Information centers/
30.	information services/ or library services/
31.	Information Dissemination/
32.	Libraries/
33.	health education/
34.	publications/ or books/ or pamphlets/
35.	Patient Education Handout/
36.	patient education as topic/
37.	consumer health information/
38.	counseling/ or directive counseling/ or distance counseling/
39.	psychosocial support systems/
40.	Needs Assessment/
41.	life style/
42.	Social Support/
43.	Adaptation, Psychological/
44.	Financial Support/
45.	or/29-44
46.	((patient* or user* or consumer*) adj4 (educat* or literature or leaflet* or book* or pamphlet* or fact sheet* or factsheet* or publication* or librar* or inform* or advice or need* or requirement* or support* or service* or communication* or involv)).ti,ab.
47.	((patient* or user* or consumer*) adj4 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact*)).ti,ab.
48.	((patient* or user* or consumer) adj4 (financial* or income or earning* or psych* or work* or job or employ* or social)).ti,ab.
49.	(lifestyle* or life style*).ti,ab.
50.	((inform* or advice or educat* or learn* or support* or financial* or counsel* or psych* or mental health or work* or job* or employ* or social) adj4 (service* or literature or leaflet* or booklet* or pamphlet* or manual* or brochure* or publication* or handout* or fact sheet* or factsheet* or material* or program* or service* or centre* or center* or hub* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*)).ti,ab.
51.	((financial* or income or earning* or psych* or counsel* or mental health or work* or job* or employ* or social or coping) adj4 (inform* or educat* or learn* or help or service* or need* or requirement* or support* or communication* or involv* or attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact*)).ti,ab.
52.	((return* or back) adj2 (work* or job or employ*)).ti,ab.

53.	or/46-52
54.	28 and (45 or 53)
55.	Qualitative research/ or Narration/ or exp Interviews as Topic/ or exp "Surveys and Questionnaires"/ or Health care surveys/
56.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
57.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
58.	or/55-57
59.	54 and 58

Embase (Ovid) search terms

1.	*subarachnoid hemorrhage/
2.	((subarachnoid* or arachnoid* or cerebral or intracranial or intra-cranial) adj3 (hemorrhag* or haemorrhag* or bleed* or blood*)).ti,ab.
3.	(SAH or aSAH).ti,ab.
4.	exp intracranial aneurysm/
5.	((subarachnoid* or arachnoid* or cerebral or intracranial or intra-cranial or brain or saccular or berry or wide-neck*) adj3 (aneurysm* or aneurism* or hematoma* or haematoma*)).ti,ab.
6.	or/1-5
7.	letter.pt. or letter/
8.	note.pt.
9.	editorial.pt.
10.	Case report/ or Case study/
11.	(letter or comment*).ti.
12.	or/7-11
13.	randomized controlled trial/ or random*.ti,ab.
14.	12 not 13
15.	animal/ not human/
16.	Nonhuman/
17.	exp Animal Experiment/
18.	exp Experimental animal/
19.	Animal model/
20.	exp Rodent/
21.	(rat or rats or mouse or mice).ti.
22.	or/14-21
23.	6 not 22
24.	(exp child/ or exp pediatrics/) not (exp adult/ or exp adolescent/)
25.	23 not 24
26.	limit 25 to English language
27.	information service/
28.	documentation/
29.	publication/
30.	book/

31.	library/
32.	information dissemination/
33.	health education/
34.	publication/
35.	book/
36.	patient education/
37.	counseling/ or anticipatory guidance/ or directive counseling/ or e-counseling/ or patient counseling/ or patient guidance/ or peer counseling/
38.	social support/
39.	psychosocial care/
40.	needs assessment/
41.	lifestyle/ or healthy lifestyle/ or lifestyle modification/
42.	coping behavior/
43.	consumer health information/
44.	or/27-43
45.	((patient* or user* or consumer*) adj4 (educat* or literature or leaflet* or book* or pamphlet* or fact sheet* or factsheet* or publication* or librar* or inform* or advice or need* or requirement* or support* or service* or communication* or involv)).ti,ab.
46.	((patient* or user* or consumer*) adj4 (attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact*)).ti,ab.
47.	((patient* or user* or consumer) adj4 (financial* or income or earning* or psych* or work* or job or employ* or social)).ti,ab.
48.	(lifestyle* or life style*).ti,ab.
49.	((inform* or advice or educat* or learn* or support* or financial* or counsel* or psych* or mental health or work* or job* or employ* or social) adj4 (service* or literature or leaflet* or booklet* or pamphlet* or manual* or brochure* or publication* or handout* or fact sheet* or factsheet* or material* or program* or service* or centre* or center* or hub* or need* or requirement* or support* or seek* or access* or disseminat* or barrier*)).ti,ab.
50.	((financial* or income or earning* or psych* or counsel* or mental health or work* or job* or employ* or social or coping) adj4 (inform* or educat* or learn* or help or service* or need* or requirement* or support* or communication* or involv* or attitud* or priorit* or perception* or preferen* or expectation* or choice* or perspective* or view* or satisfact*)).ti,ab.
51.	((return* or back) adj2 (work* or job or employ*)).ti,ab.
52.	or/45-51
53.	26 and (44 or 52)
54.	health survey/ or exp questionnaire/ or exp interview/ or qualitative research/ or narrative/
55.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*).ti,ab.
56.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*).ti,ab.
57.	or/54-56
58.	53 and 57

CINAHL (EBSCO) search terms

S1.	SU Subarachnoid Hemorrhage

S2.	TI (((subarachnoid* or arachnoid* or cerebral or intracerebral or intra-cerebral or intracranial or intra-cranial) n3 (hemorrhag* or haemorrhag* or bleed* or blood*))) OR AB (((subarachnoid* or arachnoid* or cerebral or intracerebral or intra-cerebral or intracranial or intra-cranial) n3 (hemorrhag* or haemorrhag* or bleed* or blood*)))
S3.	TI ((SAH or aSAH)) OR AB ((SAH or aSAH))
S4.	TI (((subarachnoid* or arachnoid* or cerebral or intracerebral or intra-cerebral or intracranial or intra-cranial or brain) n3 (aneurysm* or aneurism* or hematoma* or haematoma*))) OR AB (((subarachnoid* or arachnoid* or cerebral or intracerebral or intra-cerebral or intracranial or intra-cranial or brain) adj3 (aneurysm* or aneurism* or hematoma* or haematoma*)).ti,ab.)
S5.	S1 OR S2 OR S3 OR S4
S6.	(MH "Qualitative Studies+")
S7.	(MH "Qualitative Validity+")
S8.	(MH "Interviews+") OR (MH "Focus Groups") OR (MH "Surveys") OR (MH "Questionnaires+")
S9.	(qualitative or interview* or focus group* or theme* or questionnaire* or survey*)
S10.	(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* adj3 analys*) or theoretical sampl* or purposive sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)
S11.	S6 OR S7 OR S8 OR S9 OR S10
S12.	S5 AND S11

PsycINFO (ProQuest) search terms

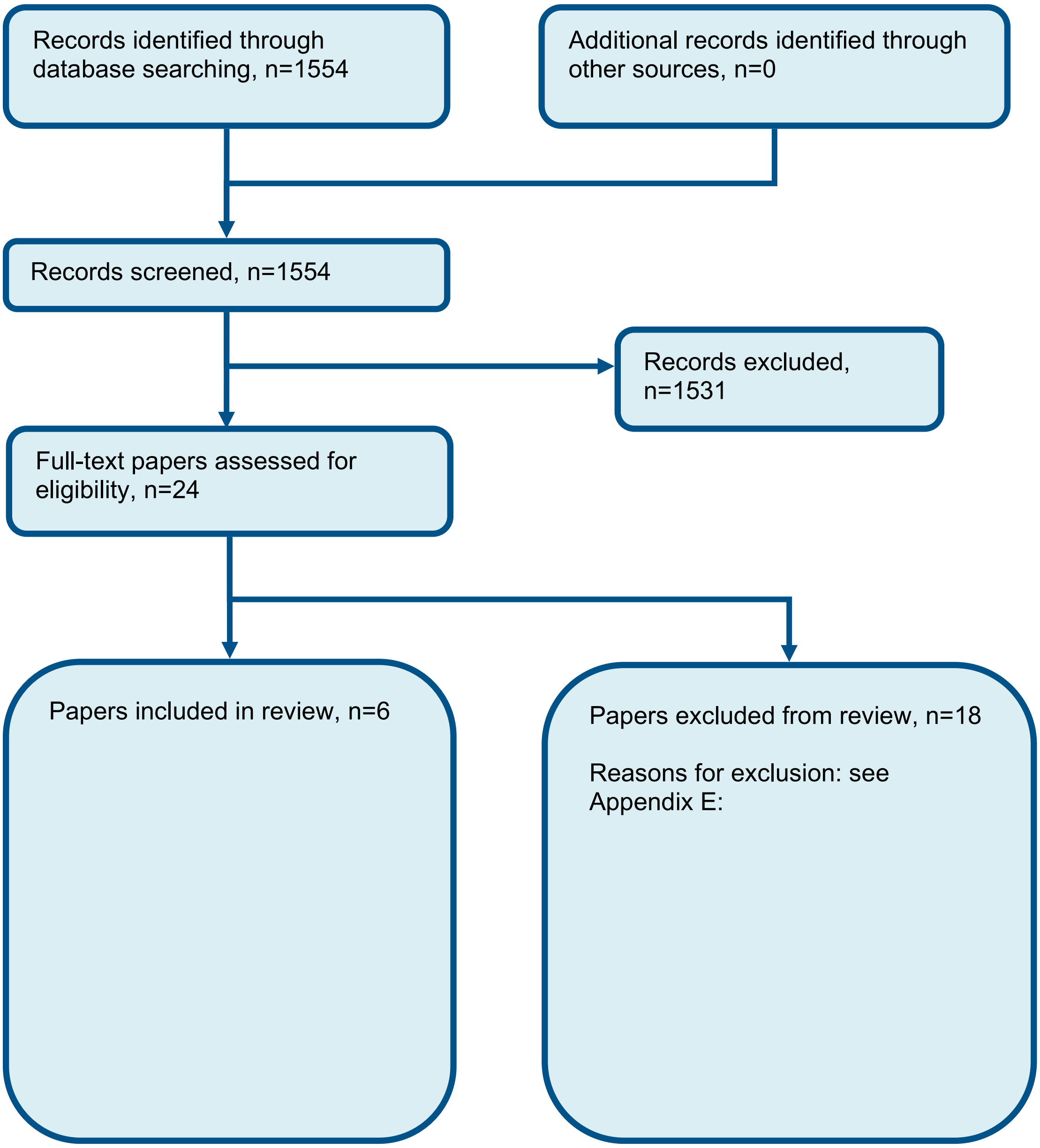
1.	(ti(((subarachnoid* OR arachnoid* OR cerebral OR intracerebral OR intra-cerebral OR intracranial OR intra-cranial) NEAR/3 (hemorrhag* OR haemorrhag* OR bleed* OR blood*))) OR ab(((subarachnoid* OR arachnoid* OR cerebral OR intracerebral OR intra-cerebral OR intracranial OR intra-cranial) NEAR/3 (hemorrhag* OR haemorrhag* OR bleed* OR blood*))) OR ti(((subarachnoid* OR arachnoid* OR cerebral OR intracerebral OR intra-cerebral OR intracranial OR intra-cranial OR brain) NEAR/3 (aneurysm* OR aneurism* OR hematoma* OR haematoma*))) OR ab(((subarachnoid* OR arachnoid* OR cerebral OR intracerebral OR intra-cerebral OR intracranial OR intra-cranial OR brain) NEAR/3 (aneurysm* OR aneurism* OR hematoma* OR haematoma*))) OR MAINSUBJECT.EXACT.EXPLODE("Subarachnoid Hemorrhage") OR ti(SAH OR aSAH) OR ab(SAH OR aSAH)) AND ((su.exact.explode("qualitative methods") or su.exact("narratives") or su.exact.explode("questionnaires") or su.exact.explode("interviews") or su.exact.explode("health care services") or ti,ab(qualitative or interview* or focus group* or theme* or questionnaire* or survey*) or ti,ab(metasynthes* or meta-synthes* or metasummar* or meta-summar* or metastud* or meta-stud* or metathem* or meta-them* or ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or (thematic* near/3 analys*) or theoretical-sampl* or purposive-sampl* or hermeneutic* or heidegger* or husserl* or colaizzi* or van kaam* or van manen* or giorgi* or glaser* or strauss* or ricoeur* or spiegelberg* or merleau*)))

B.2 Health Economics literature search strategy

Health economic evidence was not required for this review.

Appendix C: Qualitative evidence selection

Figure 1: Flow chart of qualitative study selection for the review of Patient information



Appendix D: Qualitative evidence tables

Study	Berggren 2010[3]
Aim	The aim was to analyse peoples accounts of SAH and to describe how the initiate and create meaning for onset and events surrounding the SAH. Specific questions were: - What is highlighted in the accounts of SAH? - How is the illness reconstructed? - How is meaning created through communicative interaction with others about SAH?
Population	Nine people who had experienced and were treated for SAH at a university hospital in Sweden were interviewed. Informants who were contactable and native language speaking at the time of their discharge were selected from the hospitals patient record system. Characteristics: n=9; 3 male/ 6 female; mean age (range) 33 - 67; interviews took place 1 year and 7 months after the SAH.]
Setting	Participants homes
Study design	Qualitative
Methods and analysis	In-depth semi-structured interviews with thematic qualitative analysis. Discourse analysis was used to describe meaning – making in the accounts of the experience onset of a SAH. The text was read several times to acquire a full appreciation of the data and to elucidate patterns. Both the information (what), and the interaction (how) were studied according to the model of Linell and Thunkvist (2003). Interesting content and statements which occurred together were grouped together in content and topics and then subjected to discourse analysis. Sequences and episodes were extracted from the accounts and critical events were identified. The sequences and episodes were then analysed with the support of data extracts. The accounts were rich in fact and interest constructions. The extracts were translated from Swedish to English by a native English speaker so that the subtleties and meaning from the original language were not lost.
Findings	**SAH event**
	a) **Memory –** informants report memory and memory gaps for the event of SAH and the period following the SAH. They may suddenly remember what bits of information they were missing but heavily relied on their support systems to inform them of what had happened. There are differences in understanding related to the event, where some informants remember the symptoms related to the SAH clearly which was linked their own survival and an existential crisis.
	Support
	a) **Different sources of support** – extracts included in the review identify that informants relied on information provided by relatives, friends or carer’s to understand what actually happened to them medically and to find some sense of meaning.

Study	Berggren 2010[3]
Limitations and applicability of evidence	A study based in Sweden with some methodological limitations, due to their line questioning to understand how people initiate and create meaning. The study focused on specific topics but results appear to be generally applicable. The authors have focused on very specific outcomes and areas of interest such as finding meaning after an SAH through communication. The relevant data has been extracted for the review.

Study	Dulhanty 2019[6]		
Aim	Explore the type and frequency of self reported needs both early and late following SAH specifically to the extent to which they have been met.		
Population	A census sample of people who had experienced a subarachnoid haemorrhage (SAH) in Greater Manchester between September 2010–September 2012 (late post-SAH group) and September 2013–September 2014 (early post-SAH group) were recruited. All adult patients admitted to the Regional Neurosciences Centre with SAH within these dates, who survived and were discharged home from the neurosciences centre or inpatient rehabilitation were identified from the centre’s prospectively maintained clinical database. People requiring nursing home or residential care were excluded as it is assumed that their needs are being met and were unlikely to be able to consent.		
	Variable	1 – 2 years post SAH (n=122)	3 – 5 years post SAH (n=81)
	Age, mean (SD)	55.0 (11.6)	55.4 (10.5)
	Male / female	45/77	31/50
	WFNS Grade	Grade 1 – 83	Grade 1 – 54
		Grade 2 – 21	Grade 2 – 18
		Grade 3 – 3	Grade 3 – 3
		Grade 4 – 9	Grade 4 – 5
		Grade 5 – 6	Grade 5 – 1
	Fisher Grade	Grade 1 – 19	Grade 1 – 7
		Grade 2 – 18	Grade 2 – 1
		Grade 3 – 22	Grade 3 – 33
		Grade 4 – 63	Grade 4 – 40
	Treatment	Coiled – 78	Coiled – 47
		Clipped – 16	Clipped – 10
		None – 28	None – 24
	Length of stay (IQR)	13.0 (8 to 20.25)	13.0 (9 to 21.5)

Study	**Dulhanty 2019[6]**		
Setting	Regional Neurosciences centres within Greater Manchester		
Study design	Cross sectional postal survey		
Methods and analysis	Potential participants were sent an invitation letter followed by a study pack containing the patient information sheet, data collection tool, a request for researchers to access the clinical data stored on the centre's database and a stamped-return envelope. They were also given details of how to access the same questionnaire online to submit their data electronically if they preferred, or they could arrange to complete the questionnaires by telephone interview.		
Findings	**Patient information needs:**		**People reporting info need: N (%)**
	Health	• SAH	105 (58)
		• General health (diet / alcohol / smoking)	40 (21)
	Travel	• Driving	19 (10)
		• Public Transport	22 (11)
		• Benefits	34 (17)
		• Money management	7 (4)
	Home	• Home aids	20 (10)
		• Home adaptations	10 (5)
		• Moving home	12 (6)
		• Physical relationships	17 (9)
Limitations and applicability of evidence	This paper had reported some quantitative results directly relevant to patient information needs by respondents. A study based in the UK. The quantitative results were used to understand requirements for patient information and are generally applicable. Moderate risk of bias – outcome measurement bias 203 (51%) participants responded to the questionnaire. The relevant data has been extracted for the review.		

Study	**Hedlund 2010[8]**
Aim	The study constitutes the qualitative part of an ongoing study investigating psychiatric morbidity, cognitive strategies, coping and quality of life in patients after SAH. The aims of this study were to describe what participants with no or minor neurological deficits after SAH perceived as being important for recovery, and perceived consequences of SAH.
Population	Men and women of different ages and from different places in the catchment area who had undergone different treatment for SAH and with no or minor neurological impairments at discharge from the neurosurgical unit.

Study	Hedlund 2010[8]
	N=20 The median age of the participants was 51 years (range 30 – 64 years). On arrival to the neurosurgical clinic, 18 patients were fully alert, one patient scored 2 and one patient scored 3 (Reaction Level scale RL 85). The most common localization of the aneurysm was arteria communicans anterior. At the time of the qualitative interview, 18 participants lived with spouses, 10 had children at home and 2 participants lived alone. Eleven participants had returned to work, one with an adjusted workplace situation. Five participants were still on sick leave, one participant retired due to age and one retired due to disability prior to the onset of SAH. Only one of the 20 participants had continuous contact with a neurological rehabilitation clinic at the time of the interview.
Setting	The interviews were conducted at the neurosurgical outpatient clinic or in the participants' home on average 12 months after the onset of SAH
Study design	Semi-structured qualitative review
Methods and analysis	A semi structured interview guide covering the following question areas: (1) what the participants perceived as important for recovery from SAH, and (2) perceived consequences of SAH. The data analysis was conducted in two steps: 1) To explore the research questions, a qualitative manifest content analysis inspired by Graneheim and Lundman was used as a first step. All interviews were transcribed verbatim. The interview test was read through several times to become familiar with the data and acquire an overall understanding of the text. Discussions on the content of the text in relation to the aim of each research question were held to reach consensus. Meaning units (related by their context and content) were identified, condensed (shortened with preserved core), abstracted and labelled with a code. All codes were compared and sorted into categories based on shared similarities. 2) After categorisation, the authors went backwards through the codes and meaning units to identify the person behind each statement to see if the person had been previously diagnosed with depression. When going forwards again the authors revealed that some categories were synthesized exclusively of codes and meaning units from depressed participants while some of the other categories were exclusively synthesized of codes and meaning units from participants without depression.
Findings	**Clarity of information**
	a) **SAH event** – those who continually suffered from memory loss wanted to get more information about SAH and the course of events that led to their SAH from their physician
	b) **Symptoms** – informants suffered from multiple consequences from their SAH which affected their cognitive, physical, psychosocial and emotional functioning. The findings of these consequences was linked to how much information and support they felt they received after the SAH from families or informal care givers.

Study	Hedlund 2010[8]
	c) **Medical information** – Participants generally felt that there was insufficient follow up from their local medical providers once they were discharged from the hospital. Some reported not receiving any rehabilitation support and felt unable to ask for support.
	Support
	a) **Different types of support** – participants were grateful for the care that they had received in hospital. Majority of participants were grateful to their families or care givers for constant support after their SAH, especially once discharged. Some, were worried about the responsibilities at home that were now upon their families and felt worried about being burdensome. These participants were also worried about expressing the ongoing symptoms they were facing, weakening relationships with significant others or families for not fully understanding what they were experiencing.
	Future
	a) **Long term implications** – most participants were eager to return to their “normal” lives and were slowly adjusting to their new reality. Despite the physical consequences they were making efforts to try and return to their day to day lives. But there were some participants who longed for their old lives, wanting to know when they will be able to go back to “normal” so they don’t feel dependant or have constant uncertainty.
	b) **Reoccurrence** – Some participants were worried about headaches, follow up scans and procedures as they related these experiences to SAH or potentially to having another SAH
Limitations and applicability of evidence	A study based in Sweden with some methodological limitations due to the consolidation of multiple concerns under one themes and the focus on specific topics in relation to depression or no depression, but results appear to be generally applicable. The relevant data has been extracted for the review.

Study	Jarvis 2002[11]
Aim	The study aimed to illuminate the experience of recovery from SAH.
Population	Patients who had suffered a SAH within the last 14 – 18 months. Patients were excluded if they were continuing to receive treatment of any description. Characteristics: n=8 ; 6 male/ 2 female; age (range) 30 – 80;
Setting	Interviews took place in the participants homes
Study design	Qualitative interviews with a semi – structured approach
Methods and analysis	The researcher opted for an inductive data analysis, however accepted that specific themes in relation to the objective of the review already existed. These were: illness understanding or knowledge; problem experience; experiences of recovery; questions and queries and feelings or emotions. Therefore, the researcher opted for deductive method of analysis. This is where previously identified themes are examined for their presences within data, sometimes referred to as thematic analysis.

Study	**Jarvis 2002[11]**
	While carrying out the deductive analysis it was vital for the researcher to note any new individual issues that arose in order to keep the link with the process of discovery or inductive analysis. Secondary analysis of the data, inductive analysis, ensured that important content would not be missed or left undiscovered. The third stage of analysis was a validation process and took the form of a brief interpretative account of the patient's story.
Findings	Clarity of information
	a) SAH event – some participants were extremely scared about the potentially fatal incident they had undergone but wanted more information and know exactly what had happened to them so they could piece things together and fill the gaps in their memory. Whereas other participants instead felt a sense of anxiety and dread having such large memory gaps and not feeling in control of their health.
	b) Ongoing symptoms – participants felt uninformed about the persistent symptoms that they would face once discharged home after treatment for the SAH. The main physical consequence was fatigue / tiredness, which was considered to be an invisible complication because it couldn't be seen by others.
	Future
	a) Long term implications – Informants felt that some consequences of SAH persisted beyond the initial recovery period and impacted their lives at a greater scale. This was related to ongoing tiredness, lack of concentration and inability to handle multiple tasks (e.g. at a place of work), which lead to dependence and unemployment.
	b) Reoccurrence – Participants were fearful of reoccurrences of SAH. This was closely linked to the memory of having the initial event - the fear of not knowing what was happening or happened.
Limitations and applicability of evidence	A study with some methodological limitations based in UK. Some themes were put forth to participants and others were offered by participants themselves through questioning. The study focused on specific topics in relation to symptoms or stressful experiences post SAH, but results appear to be generally applicable. The relevant data has been extracted for the review.

Study	**Persson 2017[21]**
Aim	To explore experiences of care and rehabilitation as well as the consequences and strategies used to cope with everyday life six years after SAH.
Population	Participants were included from the Extended Stroke Arm Longitudinal study at the University of Gothenburg. The inclusion criteria were > 18 years of age, with an SAH between 4th February 2009 until the 2nd of December 2010, receiving care at the Sahlgrenksa University Hospital in Gothenburg, Sweden, Resident in the Gothenburg Urban area (<35km from the hospital), able to speak Swedish and at least some participants should be of working age. The participants were contacted by phone and if they agreed to participate, a time and interview was planned.

Study	Persson 2017[21]
	[Characteristics: n=16; 8 male/ 8 female; mean age (range) 57 (45-76);
Setting	Participant chose location
Study design	Qualitative descriptive design
Methods and analysis	Explorative interview with a qualitative descriptive design, using an inductive driven thematic analysis. All interviews were performed face-to-face using an interview guide with open ended questions: 1) What type of treatment (acute and rehabilitation) did you receive? 2) What type of consequences (such as cognitive and physical) do/did you have post SAH? 3) What strategies have you used to cope with the consequences of SAH in daily life? 4) What impact do the consequences post SAH have on your social function and in daily life? The interview guide was discussed among the authors prior to the interviews, and some questions were changed/added. The first interview was a pilot for the interview guide, and the questions seemed to cover the research areas of interest. The interviews took place on average six years (SD 0.5) post SAH. The data was analysed according to thematic analysis described by Braun and Clarke as a flexible method. The thematic analysis used in this study was inductive and can be referred to a realist/essentialist paradigm.
Findings	**Clarity of information**
	a) **SAH event** – while some participants felt grateful for the care they have received, others felt that they were not cared for properly and were not adequately informed about the SAH event and their treatment pathway. Patients also worried about the implications of the event on their families and this wasn't helped by having gaps in their memory and not having a proper understanding of what had happened to them.
	b) **Medical information** – many patients felt like they were abandoned after discharge from the acute neurosurgical unit and were not given enough information about cognitive symptoms they could face which became evident only once they were discharged. They felt they did not have enough knowledge about the consequences of SAH and wanted more information about the course of the illness prior to discharge. Experiences of medical support after discharge also varied, where some had follow-ups arranged. Others did not have any pre-arranged follow-ups and had to contact their medical providers for support themselves, which added to the feeling of abandonment. Conversely, those patients who had been referred to a rehabilitation centre felt quite supported and they were given the right level of information that they required. But this group of patients also felt unclear about the medical follow ups after the discharge from these facilities and would have liked to be followed up.
	Support
	a) **Different sources of support** – Patients received various levels of support from families and care givers to rehabilitation clinics as well. Patients wished that their primary care provider had more information about SAH, so they could be a source of information and support as this was lacking. They were grateful for the support that they had received but were worried about the feeling of being a burden and having to make major adaptations to their lives to accommodate the consequences of SAH.

Study	Persson 2017[21]
	Future
	a) **Long term implications** – participants would have liked to know about the long-term implications of SAH, to better understand how their lives would be going forward. On top of the cognitive symptoms, some participants had to change their homes, lost their licenses, and became unemployed
	b) **Coping** – patients wanted to get back to their daily lives and routines and most were able to do so. Some constantly knew the SAH had changed their life, so tried not to talk about too much and hid symptoms to avoid any extra attention with their friends or even in their workplace. Coping was linked to the level of information they knew about the long-term consequences of SAH. From a practical and physical level, many employers were unaware of what their employees would need to deal with the SAH consequences in the workplace. Coping at the workplace varied for participants from some feeling really well supported, to others feeling neglected due to no knowledge of SAH.
Limitations and applicability of evidence	A well conducted study based in Sweden. Focused on the consequences of SAH and the coping strategies patients use to cope. Results are generally applicable.

Study	von Vogelsang 2004[25]		
Aim	An investigation into the effects of increased information for patients treated for intracranial aneurysm rupture.		
Population	Participants were 62 patients with ruptured intracranial aneurysm treated consecutively at a Swedish neurosurgical clinic. Participants were recruited over a period of 12 months and recruitment was concluded in 2001. All patients in the sample were acute admissions; and those treated for non-ruptured aneurysms were not included. Patients were included if they were be able to understand, speak and read Swedish, and had a score of 4–5 on the Glasgow Outcome Scale (GOS).		
	Variable	Comparison group (n=34)	Intervention group (n=28)
	Age in years, mean (range)	53.7 (32–78)	56.2 (35–76)
	Male	14	6
	Female	20	22
	Days spent in institutional care, mean (range)	20.6 (9–54)	20.9 (10–35)
	Glasgow Outcome Scale, (range 1–5), mean (SD)	4.4 (0.6)	4.5 (0.6)

Study	**von Vogelsang 2004[25]**			
	Surgical treatment	30	25	
	Endovascular treatment	3	3	
	Both surgical and endovascular treatment	1	0	
Setting	Swedish neurosurgical clinic			
Study design	Non randomized comparative study			
Methods and analysis	The intervention group (n = 28) received oral as well as written information, while the comparison group (n = 34) received only oral information. Existing written information, produced by neurosurgical clinics and patient associations, was not considered suitable, hence a new information leaflet was written. The content included explanations of the medical condition and treatment, diagnostic procedures, risk factors, physical and psychological symptoms after treatment, explanation of key terms, and addresses of patient associations. The content was determined by suggestions from a neurosurgeon specializing in intracranial vascular diseases, and by a nurse with 4 years' experience of follow-up interviews with patients who had experienced an intracranial aneurysm. Care was taken to make the written information as easy to read and understand as possible. When the comparison group was complete, the information leaflet was distributed consecutively to patients in the intervention group, who received the same questionnaire and informative letter, and were subject to the same time interval and reminder call as the comparison group. When the information leaflet was distributed, a delivery note was included and the patient's data were recorded on this by the person who distributed the leaflet. The delivery note was handed over to the nurse who conducted the study as a receipt. The delivery note was included to ensure that every patient in the intervention group got the information leaflet.			
Findings	**Question/instrument**	**Comparison group**	**Intervention group**	**P value**
	Question 1: Information difficult/easy to understand? (range 1–5: the lower the score the more difficult to understand), mean (SD)	3.3 (1.9)	3.9 (1.8)	0.24
	Question 2: Information corresponding/not corresponding to patients' needs for information? (range 1–5: the lower the score the less correspondence with patients' needs for information), mean (SD)	3.3 (1.6)	4.4 (2.9)	0.06
	Clarity of information			

Study	von Vogelsang 2004[25]
	a) **SAH event –** participants preferred written information to refer back to as most of them did not remember any oral information due to difficulties with memory in the acute phase after an SAH. Families were the initial source of information and some participants felt they couldn't assimilate any information due to the shock.
	b) **Medical information –** respondents generally wanted a better quality of information from all medical professionals. Topics such as SAH, heredity, surgical techniques, rehabilitation, and future risks were highlighted as important topics to be covered better in information given to patients, families and carers.
Limitations and applicability of evidence	Paper reported both qualitative and quantitative data which has been extracted for the review. A study based in Sweden. This study was comparing the use of written and oral information compared to oral information only. This was investigated using self report questionnaires. The quantitative information used from this study was elicited using a Likert style response format. However, open ended questions were also used to get more a richer understanding of the participants experiences. Potential selection bias with intervention start and follow-up start differing between intervention and control groups, and potential confounding bias with no adjusting for possible confounding factors between control and intervention groups (ROBINS-I). Overall, the results are generally applicable.

Appendix E: Excluded studies

E.1 Excluded qualitative studies

Table 10: Studies excluded from the qualitative review

Reference	Reason for exclusion
Berggren 2010[1]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Berggren 2011[2]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Cedzich 2005[4]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Covey 2013[5]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
He 2014[7]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Hellawell 2001[9]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Hutter 2014[10]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Karic 2016[12]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
King 2006[13]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Morris 2004[14]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Murgo 2016[15]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Nishino 1999[17]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Nordenmark 2020[18]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Ogden 1997[19]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Passier 2013[20]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Preiss 2012[22]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Ross 2013[23]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice
Stegen 1991[24]	No relevant outcome - patient outcome data, no reference to information needs or lifestyle advice