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**French neonatal society position paper stresses the importance of an early family centred approach to discharging preterm infants from hospital**

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Short title: Discharging preterm infants from hospital

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Accepted Article

## **Abstract**

**Aim:** The families of hospitalised preterm infants risk depression and post-traumatic stress and the preterm infants risk re-hospitalisation. The French neonatal society's aim was to review the literature on how the transition from hospital to home could limit these risks and to produce a position paper.

**Methods:** A systematic literature review was performed covering 1 January 2000 to 1 January 2018 and multidisciplinary experts examined the scientific evidence.

**Results:** We identified 939 English and French papers and 169 are quoted in the position paper. Most studies stressed the importance of early, personalised and progressive involvement of the family. Healthcare staff and families should assess discharge preparations jointly. This evaluation should assess the capacities of the newborn infant, with regard to its physiological maturity. It should also assess the family's ability to supply the medical, psychological and social assistance required before and after discharge. There should be a structured follow-up process that includes effective communication, various tools, interventions, networks, health and social professionals.

**Conclusion:** Discharge preparations may improve the transition from hospital to home and the outcomes for the parents and newborn preterm infant. This early family centred approach should be structured, coordinated and based on individual needs and circumstances.

## Key Notes

- The families of hospitalised preterm infants risk depression and post-traumatic stress and the preterm infants risk re-hospitalisation.
- Multidisciplinary experts from the French neonatal society carried out a literature review of French and English papers on the transition from hospital to home and assessed the findings.
- It has produced a position paper that advocates an early family centred approach that is structured, coordinated and based on individual needs and circumstances.

**Key words:** Family centred approach, Hospital discharge, Position paper, Preterm infants, Re-hospitalisation

## **INTRODUCTION**

The mothers and families of hospitalised preterm infants are at risk of depression and post-traumatic stress and the preterm infants are at risk of re-hospitalisation. These issues have been associated with difficulties in establishing the parent-child relationship in hospital settings.

Healthcare staff need to provide families with support as they prepare to discharge preterm infants. This should include encouraging parental resilience and supporting child development and high-quality parent-child relationships, while respecting the continuity of care. Taking their preterm infant home is a very emotional process for families. It triggers feelings of joy, but this process has also been associated with anxiety and fears for the future of the child (1) and feelings of relative insecurity or isolation (2). Several aspects warrant particular attention, to optimise the conditions of the transition from hospital to home. For example, about 20-50% of preterm infants are taken to the emergency department or re-hospitalised in the first few months after their initial discharge (3-5). It has also been reported that long hospital stays are a risk factor for excess morbidity, potentially leading to prolonged separation of the child and their family (6). This contributes to post-traumatic stress (7,8) and maternal depression (9,10), which occur in 20-50% of preterm births. The difficulties generally noted after hospital discharge suggest that practices vary widely and that there is a lack of suitable specialised support (11). Studies have shown that parents wish to be involved in the care of their newborn infant at the hospital, to help prepare for their discharge home (12).

The aim of this study was to review the published data on this subject and produce an updated position paper on how to prepare parents for the discharge of their preterm infant from hospital.

## **METHODS**

The method used was defined by a group set up by their French neonatal society who evaluated, and reflected on, the neonatal environments where preterm infants are treated (13). Seven questions were addressed by the systematic literature review. How should parental skills be evaluated and supported? How should the capabilities of the newborn infant be evaluated and supported? Which professional skills should be mobilised after discharge from conventional hospitalisation? How can re-hospitalisations be limited? What impact do early hospital intervention programmes have on the mode of discharge from hospital? Which specific situations should be taken into account? How should information be communicated to families?

Feeding and nutritional aspects, studies on inter-hospital transfers and post-hospital intervention programmes were outside the scope of the position paper. The bibliographic search was performed with MEDLINE and Cochrane databases. The key words used were readiness, parent, parenting, hospital discharge, newborn, competence, rehospitalisation, intervention programme, transition, preterm infant and ability. Various English and French spellings were used to pick up as many papers as possible. The papers selected by the review concerned preterm infants and related to the questions posed. Editorials, books, papers presenting opinions or proposed practices and case studies were excluded from the analysis. We also excluded studies that were not directly linked to the defined objectives, papers published before the year 2000, studies concerning specific problems, such as malformations, genetic abnormalities, palliative care, discharge with technological support such as oxygen therapy or ventilatory support and twin births

The review went up to 1 January 2018. We identified 939 English and French papers and 195 were selected after we had analysed the titles and abstracts and checked for duplicated content. These then served as the basis for our position paper. The types and main topics of the retained papers are presented in Figure 1. We selected 169 of these papers to be cited in the long version of the position paper. This is available from the recommendations section of the French neonatal society website, where the study type, sample and main results are presented (14). These 169 papers comprised 82 prospective studies, 35 retrospective studies and 52 other studies including systematic reviews, meta-analyses and benchmarking papers and recommendations (Figure 1).

The suggestions in the position paper are presented as levels of evidence and grades (13).

These are based on the Haute Autorité de Santé (French High Authority of Health or HAS) grid to classify publications according to the level and quality of scientific evidence and to determine the strength and grade of the resulting suggestions, as presented in Table 1.

The three proposal sections should be seen as suggestions for tools and strategies based on an analysis of the data from the systematic review that was performed.

## **RESULTS**

### **Scientific rationale**

Our review of the literature showed that identifying, and supporting parental skills requires an understanding of the development of the interactions underlying attachment. Important precursors to attachment were identified (15). A key element was establishing and maintaining closeness

between the mother and parents and the infant. How the parents responded to the infant's behaviour signals was also essential. These helped to promote the development of parental responsibility and ensure the safety and comfort of the infant. Parental skills were acquired in several phases: parents were initially afraid that they might harm their newborn infant by interacting with them, but they eventually developed the confidence to care for them themselves. Joint assessments by parents and healthcare staff are necessary throughout hospitalisation. This enables staff to provide effective support to parents (16), which can be strengthened by relinquishing more and more control to them towards the end of their infant's hospital stay.

Evaluating and supporting the capacities of the newborn infant means assessing their maturity in terms of thermoregulation, cardiorespiratory stability and their ability to feed and demonstrate satisfactory increases in weight. Most of these capacities are acquired between 34 and 37 weeks of gestation. However, this varies between individuals and maturation often occurs later in very preterm infants, particularly with regard to cardiorespiratory events. Families often express fears that their infant will experience such an event at home.

There is no consensus when it comes to defining significant cardiorespiratory events. Most neonatologists include an event-free period in the criteria for the discharge of preterm infants. The intervals between occurrences of cardio-respiratory events gradually increase until some point at which clinically significant event ceases. The reported mean cardiorespiratory event-free interval until the last event is four to seven days (17,18). The risk of late recurrence is lower for infants born after 30 weeks of gestation, with the last episode of apnoea occurring before 36 weeks of postmenstrual age (17,18). Continuing caffeine treatment between 34 and 37 weeks of gestation, or up to a postmenstrual age of 44 weeks, probably stabilises ventilation and reduces the number of episodes of intermittent hypoxemia (19). However, there are currently insufficient data to determine the optimal time for withdrawing caffeine. Cardiorespiratory stability can also be defined in terms of oxygen saturation. It has been suggested that oxygen saturation in ambient air should be evaluated for one week before discharge, but the impact of such monitoring has not been evaluated in detail (20,21). The risks of life threatening event and sudden unexpected infant death are more than double in those with neonatal disorders, especially preterm infants, than in those without (22). The practice of placing an infant on their back to sleep should therefore be initiated before hospital discharge (22). Primary vaccination may impair cardiorespiratory stability in very preterm infants (23).

The benefits of delaying discharge should be weighed up against the risks associated with extended hospital stays, which have been associated with the risks of poor relationships between



parents and their child, child abuse and parental anxiety (24,25). Providing accommodation for the mother and her partner and home support during the transition period has been reported to reduce the number of re-hospitalisations and visits to the emergency department (26,27).

Several types of discharge after conventional hospitalisation can be envisaged. These include hospital-assisted home care which involves health care by paediatric nurses and early-intervention programmes after discharge (28) or in participation in follow-up networks or organisations. Whatever the mode of discharge, any residual problems should be identified and the post-discharge network should be informed and ready to act in a coordinated way. hospital-assisted home care and home support for gavage feeding of stable preterm infants who have not established full oral feeds have been shown to reduce the length of traditional hospitalisation (29,30). Families seem to feel more secure when hospital-assisted home care is used before discharge and this has been reported to result in a higher frequency and longer duration of breastfeeding and lower levels of parental anxiety (31,32).

Parents want to be involved in the care of their newborn infant in the run-up to discharge (12) and this has been incorporated into a number of programmes. These include the Creating Opportunities for Parent Empowerment programme (33), the Stockholm Neonatal Family Centred Care model (34), the Mother-Infant Transaction Programme (35,36), the Newborn Individualized Developmental Care and Assessment Programme (37) and the Family Integrated Care programme (38). The implementation of these programmes have been associated with decreases in hospital stay and readmission rates (33,34) persistent benefits from mother-child interactions at the age of two years (35), cognitive and behavioural development (35,36). Benefits have also been reported in terms of the risk of maternal depression (39), anxiety and parental stress (40). These programmes have sometimes led on to post-hospital intervention programmes (28) or to programmes run by other organisations. These interventions have included helping to care for siblings, organising meetings between parents of preterm infants or organising paternity leave for the fathers of hospitalised children.

Late preterm infants born at 34 to 37 weeks of gestation account for 4.0 to 4.5% of births in France. During the first few weeks after birth, they are still more vulnerable than infants born at full term. Therefore, it is just as important to anticipate how they are discharged in the same way that planning takes place for the other preterm newborn infants. Attention must be paid to family-associated risk factors, both during hospitalisation and at the time of discharge, (41). These include isolated single-parent families, family conflicts and parents who have mental health or addiction issues. Social conditions and poor housing should also be taken into account, as should any abnormalities identified in the mother-child relationship or relationships within the family.

Families feel that information is essential to help them to prepare for their infant's discharge from hospital (42), but there are still problems with how this information is communicated and how parents adhere to the advice given. There are no formal rules, but several principles can be applied. The information that is provided should be repeated and personalised and should be delivered to both parents and backed up with well organised written material. A follow-up plan should be established at an early stage to see if the parents have understood what they have been told. This plan could be based on interviews, formative evaluation (43), meetings between parents and professionals or other methods.

### **Position paper**

This position paper is presented as grades and levels of evidence as presented in Table 1 (13). The position paper focuses on preterm newborn infants hospitalised in neonatal intensive care units and late preterm newborn infants hospitalised in a maternity unit or a Kangaroo care unit.

Involving parents in discharge plans at an early stage has been associated with shorter hospital stays and lower readmission rates and benefits with regard to mother-child interactions (level two). Parents should be involved with clinicians that have expertise in neonatology and at-risk pregnancies from the time of the prenatal interview or as quickly as possible after the initial phase of hospitalisation. The infant's discharge must also be planned early, in consultation with the parents, to allow adequate preparation (grade B). Involving the parents in the decision-making process during hospitalisation should include discussions on the mode and date of discharge (grade C, level four). It should also include the organisational and practical aspects of caring for the infant at home, including any equipment that is needed (grade C, level four).

Early prolonged periods of contact between the parents and their newborn infant, with support from care teams, are required. The experts agreed that these should not entail any additional costs to the parents for accommodation, meals or parking in line with the European Charter for the Rights of Hospitalised Children.

The mode of support should be appropriate and anticipated, with particular attention paid to the economic, social, linguistic difficulties, cultural specificities and the requests from the family (grade B, level two). In this context, the availability of social services, translators and cultural mediators is important. Assessments by a psychologist and, or, child psychiatrist are also of great importance in the most difficult situations, such as the death of infants during multiple births, prolonged hospitalisation with multiple complications and particular family risk factors.

Hospital staff and the mother and the father may differ when it comes to their assessments of the how well the infant's capacity is developing (level three) and this calls for joint assessments (grade C). The capacities assessed should particularly include thermal and cardiorespiratory stability and feeding (grade C, level four).

There is only low-level evidence and little expert opinion about the conditions that define cardiorespiratory stability and the recommendations concerning discharge. Establishing rules of conduct with regard to this is subject to several limitations. For example, bradycardia and desaturation are easier to detect than apnoea in current practice. Moreover, there is no consensus definition of a significant cardiorespiratory event. The proposals below may help to guide decisions following the clinical evaluation of each particular case. Apnoea can be considered significant if it lasts more than 20 seconds, which is a rare situation at the time of discharge. It can also be considered significant if it lasts more than 10-20 seconds in association with a bradycardia of less than 80 beats per minute or a percutaneous saturation in oxygen of less than 80% (grade C, level four). The median interval between the last observed episode of clinically significant apnoea and the previous apnoea is four to eight days, but this interval varies with the infant's gestational age at birth and pathological conditions (level four). Prolonged hospitalisation affects the prognosis (level four). The time between the onset of clinically significant apnoea and clearance for discharge may, therefore, be no more than four to eight days, according to the infant's gestational age and pathological condition (grade C). This duration could be four days for preterm infants born before 34 weeks of gestation with uncomplicated evolution or for preterm infants born between 30-34 weeks of gestation with a last episode of apnoea recorded before a postmenstrual age of 36 weeks. It could be eight days for cases of preterm infants born before 30 weeks of gestation or for preterm infants who have significant complications, such as brain lesions, bronchopulmonary dysplasia or vulnerable family situations. Preterm infants with apnoea persisting beyond a postmenstrual age of 36 weeks could also fall into this eight-day category. No recommendations can be made about when to stop in-hospital monitoring, as this depends on the discharge strategy adopted by the care team.

Very preterm infants should have percutaneous saturation in oxygen in ambient air levels of between 91-95% for more than 95% of the time they are asleep, without significant episodes of intermittent hypoxaemia. Moderate desaturations can be observed during feeding or sleep, which must to be analysed before discharge. Quantitative analyses of percutaneous saturation in oxygen during hospitalisation and before discharge are desirable for preterm infants on oxygen therapy or ventilatory support for more than 28 days. These suggestions are based on expert agreement.

In cases of preterm birth before 32 weeks of gestation, the incidence of apnoea may increase within 36 hours of vaccination if primovaccination is performed before discharge (level two). Post-vaccination monitoring for at least 36 hours is, therefore, suggested in this context (grade B).

Some authors have proposed that caffeine treatment should be prolonged in some patients, beyond a postmenstrual age of 34 weeks and up to a postmenstrual age of 44 weeks in some cases. The aim of this is to reduce irregularities in respiratory rate and decrease the intermittent hypoxaemia associated with episodes of periodic breathing (grade C, level four).

Our experts agreed that before infants are discharged their hospitalisation history should be discussed in an interview involving the parents and the medical and care teams. Appropriate multidisciplinary follow-up care must also be organised and coordinated and future appointments scheduled. These tasks should be performed in consultation with the parents, as their knowledge of local resources should enable them to find the most appropriate solutions to questions and possible problems at home more easily (grade C, level four). Support for breastfeeding makes it more likely that breastfeeding will continue, particularly in vulnerable families (level one). Specific follow-up for breastfeeding should be provided by trained professionals, possibly with the support of organisations that specialise in access to breastfeeding support or from mothers' networks (grade B).

Home-based hospitalisation structures attached to neonatal units have beneficial effects on both infants and their families, as they decrease the duration of conventional hospital stays (level three). The creation of such structures for neonatal hospitalisation at home should be supported (grade C).

Our experts agreed that birth professionals should be trained to prepare newborn infants and their parents for hospital discharge.

### **Early anticipation and follow-up strategy**

A suitable strategy can only be developed if there is a care philosophy framework that brings the parents and the care team together and takes changes in the infant's condition into account.

Parents should be encouraged to get involved with their infant at an early stage and the level of involvement should increase against a background of a personalised, family-centred approach (grade B, level two). The parents need to understand how the neonatology unit operates and their role needs to start developing well before discharge is considered. The aim is to enable the parents to take part in the care of their child and to become increasingly independent during hospitalisation, by learning to observe and understand their child's reactions and gain confidence

in their own abilities (grade B, level two). Our experts agreed that the neonatal team should provide personalised support to the parents before discharge and this should be structured around reference documents, specific training and tools that effectively communicate information. This support should be a two-way process and it should take into account the strengths and weaknesses of the family. It should also take into account the feelings of both parents and not rely exclusively on the mother. At least one other person should be involved (grade C, level four). This support should be based on precise objectives at different times during hospitalisation. These could be summarised by checklists, care plan that involve the family or self-assessment documents recording the needs and expectations of the family (grade C, level four). The care plan guide is usually based on a nurse's analysis and this identifies a set of objectives that need to be achieved through a framework of targeted care interventions. The risks associated with prolonged hospitalisation should be considered in the discussions leading up to the decision to discharge the child (grade B, level two). The preparation for discharge can be facilitated by the team using a pre-established programme of personalised, pre-discharge support for the parents. Our experts agreed that this programme should be shared with the parents and based on simple criteria for observing the newborn infant and taking into account the home environment.

The end-of-hospitalisation goals should include measures to limit the anxiety and vulnerability that the parents may feel when the infant is sent home and help to promote a feeling of resilience. Families must be confident about the infant's cardiopulmonary status, breastfeeding, other feeding and how their child grows. They must also have a formalised medical debriefing interview that covers the entire period of hospitalisation and this must particularly cover their child's state of health. The parents need to have an appropriate perception of their newborn infant's medical situation and the follow ups that will be needed (grade C, level four). The role of the families in caring for the child should be increased before discharge by allowing the parents extended periods of autonomy. (grade C, level four). Our experts agreed that monitoring should be stopped sufficiently early before discharge, in consultation with the family, to support parental autonomy. Ideally, the parents, the medical and all the healthcare teams should jointly decide the discharge date based on shared assessments of the level of preparation. These should take into account the child, the mother and the environment (grade C, level four).

### **Support measures around the time of discharge**

Our experts agreed that it may be important for families that the newborn infant's departure from the hospital is recognised by the healthcare team as a significant event in his or her life and

marked as such. The time of day at which the child is discharged should be discussed in advance with the family. The morning is ideal as it leaves sufficient time for the discharge procedures and for the family to take their infant home during the day (grade C, level four). In the short term, medical or nursing contact is beneficial during the week following discharge and this should include an assessment of any needs and difficulties. Different possibilities exist, including telephone contact 48 hours after discharge, consultation, mother and child services or a transition process that involves hospital-assisted home care (grade C, level four). The first medical appointment with the attending physician and, or, a paediatrician should be planned before discharge. (grade C, level four). The mother should have the support of her partner or a close relative or friend during the first few days after she and her infant return home (grade C, level four).

The organisation of a structured transition between follow-up teams or professionals is necessary (grade C, level four). A medical and care relay team should be identified, informed of the time of discharge and ready to provide support. If possible they should have contact with the family before discharge. This team may include family doctors, paediatricians, medical specialists, midwives, psychologists, healthcare professionals and monitoring networks (grade C, level four). Our experts agreed that coordinated follow-up networks should be mobilised, including specific follow-up networks for vulnerable newborn infants and centres for early medical and, or, social care. Coordination and collaboration between members of this team are essential when interventions involving several different professions are envisaged (grade C, level four).

### **Communicating information about prevention and follow up**

The information that is communicated should be personalised and should occur both before and after discharge (grade B, level two) using a follow-up plan (grade C, level four). This information should be repeated and well organised written materials should be made available (grade C, level four). The family should be provided with appropriate telephone contacts and Internet resources (grade C, level four) and our experts agreed that they should have copies of the child's health records. The use of checklists can be proposed (grade C, level four). These checklists could include items concerning parental and newborn infant evaluations and follow-up planning. They could also include items about how prevention advice and practical issues should be communicated, in particular about feeding, nutrition, safe sleeping, coping with the infant crying and gastro oesophageal symptoms. Our experts agreed that the involvement of perinatal

networks should be encouraged and their role could include training during discharge interviews, constructing shared tools and sharing information.

## **DISCUSSION**

The position paper that we have presented is based on a systematic evaluation of French and English literature by a panel of international multidisciplinary French-speaking experts. The systematic review mainly suggests adequate preparation for discharge may improve the transition from the hospital to the infant's home and the outcomes for the parents and the newborn infant.

This evidence-based position paper mainly points out that this should be achieved through a standardised, progressive, individualised, family centred and coordinated discharge programme.

A limitation of this systematic review was that only 18 prospective controlled studies and 29 qualitative studies were retained for analysis and that most of the studies were retrospective or observational with low levels of evidence. Another limitation of this review was that we didn't consider the initiation of oral feeding, the transitional methods of tube feeding, nutritional management, gastro-oesophageal reflux and the growth rates of preterm newborn infants.

## **CONCLUSION**

Research has shown that the mothers and families of hospitalised preterm infants risk depression and post-traumatic stress and the preterm infants risk re-hospitalisation. The French neonatal society's aim was to review the literature on how the transition from hospital to home could limit these risks and to produce a position paper. Most of the studies that we reviewed strongly supported the suggestions made in this position paper which calls for the implementation and evaluation of strategies that improve the transition from hospital to home by making sure that families are more involved and better informed.

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## **CONFLICTS OF INTEREST**

The authors have no conflicts of interest to declare.

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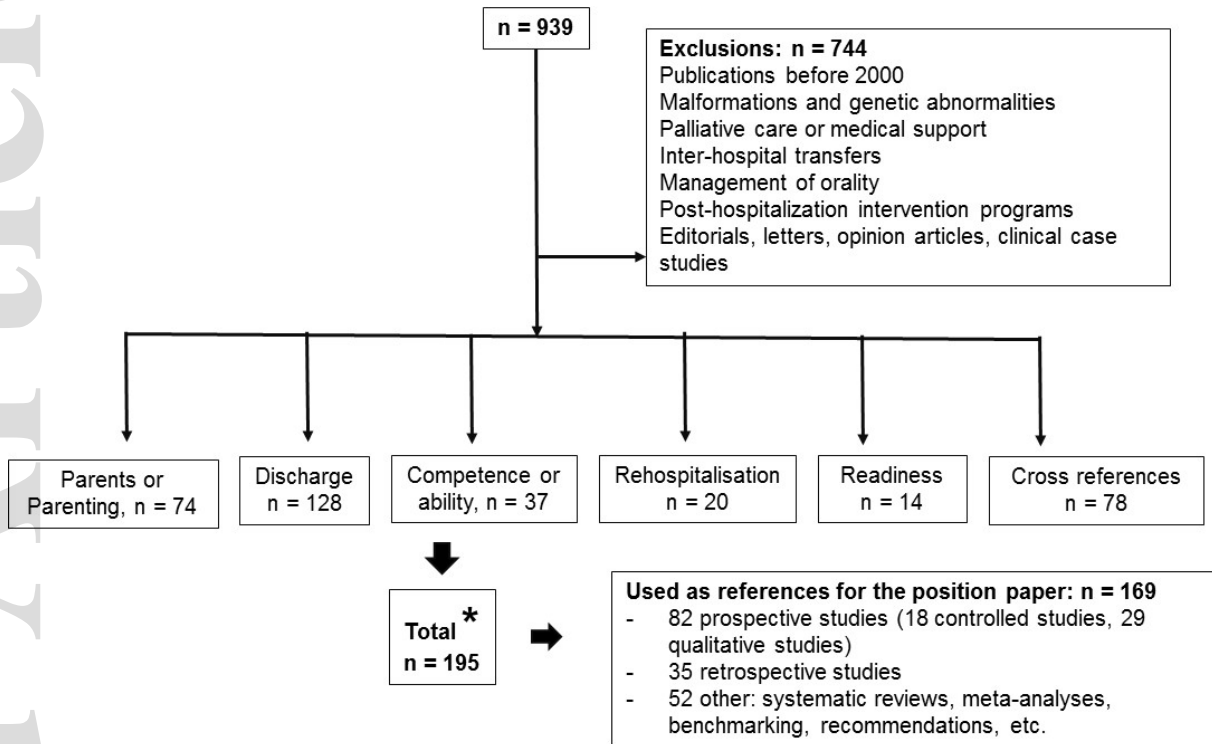
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**Table 1.** Level of scientific evidence and grading of the suggestions used in this review

<b>Level of scientific evidence and type of study</b>	<b>Grade of suggestion</b>
<b>Level 1</b> <ul style="list-style-type: none"><li>- High-powered randomised controlled trial</li><li>- Meta-analysis of randomised controlled trials</li></ul>	A: Established scientific evidence
<b>Level 2</b> <ul style="list-style-type: none"><li>- Low-powered randomized comparative studies</li><li>- Well-conceived non-randomized comparative studies</li><li>- Cohort studies</li></ul>	B: Scientific presumption
<b>Level 3</b> <ul style="list-style-type: none"><li>- Case control studies</li></ul>	C: Low scientific evidence
<b>Level 4</b> <ul style="list-style-type: none"><li>- Comparative studies with major biases</li><li>- Retrospective studies and case series</li><li>- Descriptive epidemiological studies</li></ul>	

Level of scientific evidence and grading are based on the Haute Autorité de Santé (French High Authority of Health or HAS) grid to classify publications according to the level and quality of scientific evidence and to determine the strength and grade of the resulting suggestions

**Figure 1** - Flow chart of the selected papers analysed during the systematic review



\* Each selected paper can cover more than one category