



IPNA

International Pediatric Nephrology Association

GREAT CARE FOR LITTLE KIDNEYS. EVERYWHERE

Practical organization for IPNA guidelines (SOP)

Best practice & standards committee

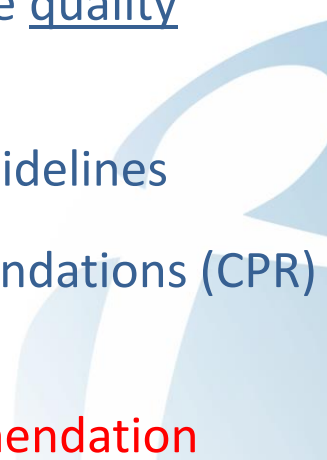
Chair: Dieter Haffner

Members: Detlef Böckenhauer, Paulo Koch,
Koichi Nakanishi, Alicia Neu, Hesham Safouh, Franz Schaefer,
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Approved by the IPNA Executive Council
London, February 7-8, 2018


Practical Organization of Clinical Practice Recommendations (SOP)

Type and quality of a new guideline

- The potential benefits of practice guidelines are only as good as the quality of the practice guidelines themselves.
 - High level of quality & strength (usually based on large RCTs) → Guidelines
 - Fair / poor level of quality & strength → Clinical Practice Recommendations (CPR) or Consensus Papers
 - Poor guideline development process → **Poor Guideline or Recommendation**
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Practical Organization of Clinical Practice Recommendations (SOP)

Methodology

- Pragmatic & standardized approach (SOP available online)
 - Focus on clinical usefulness
 - Suggestions will be made where there is no RCT to guide evidence based practice
 - Use the **GRADE** method (e.g. **PICO** questions) & follow the recommendations of the **Right Statement**
 - Set a schedule & adapt it during the process
 - Goal: finish guideline within 1 year (otherwise it is outdated by the time of publication)
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12 Steps in guideline development


1. Select the topic & define the population covered (1 coordinator)
2. Define type of guideline: consensus paper – CPR – (guideline)
3. Define working groups for guideline preparation:
 - Core group: max. 20 members + 1 epidemiologist
Set: at least 1 representative of each Regional Society
include all specialities needed & patient representatives
 - External expert group: preferentially from Regional or other Societies
 - Voting group: IPNA members and other WGs
4. Ask the right questions – selecting the right outcomes
 - Define PICO questions
 - Each question gets allocated to a subgroup of 2-4 core group members

Steps 1-4 may be done within a 2-3 hour face to face / skype meeting

PICO Questions: Example

- **P**atient (or Population) to whom the recommendation will apply:
short children with CKD stage 3-5D and after KTx
- **I**ntervention being considered: **GH treatment**
- **C**omparison (which may be “no action” or an alternative intervention): **no GH treatment**
- **O**utcomes affected by the intervention:
increase in standardized height

12 Steps in guideline development

5. Systematic literature review (RCTs, non-controlled / observational studies)
 - Prepare evidence tables
 - Check for risk of bias for an outcome in individual studies
 - Check for quality of evidence for each outcome across studies
 - Epidemiological support will be financed by IPNA
 6. Plan a 1 1/2 day face to face meeting (support by IPNA)
 - Half day meeting may be fine for consensus papers
 7. Before the meeting: subgroups are requested to prepare a preliminary answer & evidence text for each PICO question
This should be as concise and brief as possible (<1 page)
 8. At the meeting:
 - Formulate recommendations & evidence text
 - During this process new (sub)questions may arise
 - Grade recommendations (AAP system)
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American Academy of Pediatrics grading system

Strength of Recommendation

Aggregate Evidence Quality	Benefit or Harm Predominates	Benefit and Harm Balanced
<p>Level A Intervention: Well-designed and conducted trials, meta-analyses on applicable populations Diagnosis: Independent gold standard studies of applicable populations</p>	<p>Strong Recommendation</p>	<p>Weak Recommendation (based on balance of benefit and harm)</p>
<p>Level B Trials or diagnostic studies with minor limitations; consistent findings from multiple observational studies</p>	<p>Moderate Recommendation</p>	
<p>Level C Single or few observational studies or multiple studies with inconsistent findings or major limitations.</p>	<p>Weak Recommendation (based on low quality evidence)</p>	<p>No recommendation may be made</p>
<p>Level D Expert opinion, case reports, reasoning from first principles</p>	<p>Weak Recommendation (based on low quality evidence)</p>	

<p>Level X Exceptional situations where validating studies cannot be performed and benefit or harm clearly predominates</p>	<p>Strong Recommendation</p> <p>Moderate Recommendation</p>
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12 Steps in guideline development

9. Editing of draft by core group (within 3 months)
 10. Draft sent out to external experts & voting group (4 week deadline)
 - Delphi process for grading and changes
 11. Consider to endorse the guideline by other Societies before submission
 12. Publication in Pediatric Nephrology
- Thereafter: Distribution at IPNA congress, IPNA master class,
& regional society congress



IPNA procedure for core group members attend guideline meetings

1. **DESTINATION/VENUE:** The coordinator choose the meeting dates.
The first meeting will take place in Leuven (Leuven Institute for Ireland in Europe)
2. **MEETING DURATION:** one day and a half (Thursday morning to Friday noon)
3. **AGENDA:** will be sent out 3 months before
4. **LOGISTICS:** Hotel rooms and venue will be booked by the IPNA administrative office
5. **TRAVEL:** Each core group member is requested to contact FROSCH, the official IPNA travel agency for flight bookings:
vicki.czarnowski@frosch.com
joanne.columbo@frosch.com
6. **ACCOMODATION:** Core group members should not make their bookings individually as this complicates the reimbursement process. The accomodation including breakfast is directly paid by IPNA and coordinated by IPNA administrative office.
IPNA policy is to pay 2 up-to 3 (if required due to flight connections) days.
Hotel and meeting rooms are directly settled by IPNA. Any extras (nights, persons, drinks, etc.) are at the discretion of the attendees.
6. **DINNER:** A dinner will be held on the first evening and organized by IPNA Admin office.
7. **REFUND:** Expenses related to visa and transportation (taxi, train, parking) can be claimed by the refund form after the meeting.
The form must be addressed to the IPNA Admin office.