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1. **What is the aim of this handbook**

The purpose of this handbook is to provide patients representatives advice on developing an EAU guideline and the methods used. It aims to provide a clear path through the process and seeks to ensure that the resulting guidelines have credibility and meet the EAU’s criteria for content, methods and presentation.

2. **Background**

Clinical Practice Guidelines (CPGs) are a highly influential tool for the improvement of clinical care, the harmonisation of healthcare provision as well as the management of healthcare associated resources across Europe. Therefore, clinical guidelines must be free of bias, presenting a balanced view of risks and benefits, in which the preferences of patients, best clinical practice and healthcare policy needs are underpinned by the best available scientific evidence. Ultimately, promoting effective therapy and discouraging/avoiding ineffective or potentially harmful interventions.

3. **Structure of the EAU Guidelines Office**

Within the EAU CPG production is co-ordinated by the EAU Guidelines Office. The EAU Guidelines Office (GO) consists of:

1. **The EAU Guidelines Office Board**
   Roles and responsibilities:
   - Guide, support and facilitate all aspects relating to guidelines development (e.g. methodology, dissemination and implementation);
   - Actively promote continuous quality improvement;
   - Set future goals and establish priorities for the strategic development of the guidelines project;
   - Development of a robust conflict of interest (COI) policy and overall responsibility for the appraisal of COI information provided by all those involved in the production of EAU guidelines.

2. **The EAU Guidelines Office Methods Committee**
   Roles and responsibilities:
   - Development and implementation of methodological standards across all EAU guidelines;
   - Provision of methodological support and comprehensive training in Cochrane systematic review methodology;
   - Overall quality control relating to all systematic reviews produced by the EAU Guidelines Panels.

3. **The EAU Guidelines Office Associates Committee**
   Roles and responsibilities:
   - Development and co-ordination of the EAU Guidelines Office Associates programme;
   - Co-ordination and management of all senior and junior associates;
   - Co-ordination and management of all ongoing systematic review activities.
4. The EAU Guidelines Office IMAGINE Group (Impact Assessment of Guidelines Implementation and Education)
   Roles and responsibilities:
   • Quantify the adherence to recommendations from CPGs among different healthcare systems and physicians;
   • Identify existing obstacles and facilitators to adoption of CPG recommendations;
   • Identify interventions to facilitate adoption of recommendations from CPGs in different European healthcare systems;
   • Evaluate and quantify the effectiveness of the interventions applied to facilitate guideline adoption and adherence to recommendations.

5. The EAU Guidelines Office Dissemination Committee
   Roles and responsibilities;
   • Active engagement with National Societies to garner endorsement of the EAU Guidelines;
   • Effective dissemination of EAU Guidelines and EAU Guidelines Office projects;
   • Promotion of discussion and triggering of feedback from guidelines users via Facebook and Twitter;
   • Co-ordination of all social media activities of the guidelines panels.

6. The EAU Guidelines Central Office
   Roles and responsibilities
   • Coordinate all organisational aspects (meetings, conference calls, training, agendas, reports, traditional and electronic delivery of manuscripts and files, update schedules, and review and scientific paper submission);
   • Project management - overview of time lines and adherence to deadlines;
   • Assistance with reference management (coordinate literature searches, and liaise with research specialist);
   • Interact with other organisations e.g., guidelines producers, national associations, members, journals, and companies;
   • Attend meetings and liaise with guidelines panels;
   • Editing of guidelines documents for publication – maintenance of standardised guidelines formats;
   • Support the technical needs of the panel members;
   • Coordinate in-office activities related to the guidelines e.g. social media, web-based guidelines material and EUT.

Table 1. Who is who in the EAU Guidelines Office

<table>
<thead>
<tr>
<th>Guidelines Office Committee</th>
<th>Chair</th>
<th>Members</th>
</tr>
</thead>
</table>
| EAU Guidelines Board        | Prof. Dr. Maria J. Ribal| Prof. Dr. Anders Bjartell
                                |                         | Prof. Dr. Alberto Briganti
                                |                         | Prof. Dr. Philip Cornford
                                |                         | Prof. Dr. Thomas Knoll
                                |                         | Prof. Dr. Monique Roobol
                                |                         | Prof. Dr. James N’Dow (ex-officio) |
| EAU Methods Committee       | Dr. Imran Omar (vice-chair) | Dr. Thomas Van den Broeck |
                                |                         | Prof. Dr. Steve Canfield |
                                |                         | Dr. Steven MacLennan    |
4. **EAU Guideline Panels**

The EAU GO oversees the activity of sixteen EAU Guidelines panels and one EAU Ad-hoc Guidelines panel, a full list of all panels and panel members is available upon request from the Guidelines Office or online at [www.uroweb.org/guidelines](http://www.uroweb.org/guidelines). Panels are comprised of a Chair and Vice-Chair, Panel members (both urologists and other specialisms), associates and up to two patient representatives.

4.1. **Panel participation**

Guidelines panel participation, for which no financial remuneration is provided, involves a significant commitment and investment of time. The result of the work done by the EAU Guidelines expert panels is generally well received by the members of the organisation and clinicians worldwide, and most panel members consider their participation in the EAU Guidelines rewarding.

All panel members are required to submit potential COI information and sign a *Non-disclosure Statement* as well as a *Copyright Transfer Form*. Panel members COIs will be assessed and managed according to the GO’s COI policy which can be requested from the GO.

A policy of confidentiality regarding any guideline document applies until final publication of all related material. It is expected that details of panel discussions will always remain confidential.

The standard term of office for guidelines panel members is 4 years (assuming satisfactory annual assessment up to the end of the first 2 years), which can be renewed once at the sole discretion of the
GO Board (giving a maximum of 8 years). All physicians involved in the EAU Guidelines effort should be members of the EAU. Membership fees for non-urologists and patient representatives are waived.


4.2 Appointment of patient representatives

A patient representative is “an individual or advocacy group representing individuals who have a health condition and their caregivers, use health care services, and/or who are members of the community.”

Patient Members, where representing a patient organisation, are asked to submit a supporting letter from the patient association they are representing, endorsing their involvement on the Panel.

The EAU is committed to appointing people from all backgrounds as patient representatives to our Panels. We will take reasonable steps to ensure that people get any practical support they need when applying for or taking part in the Panels.

4.3 Roles and responsibilities of the Panel

4.3.1 Panel Chair

- Overall responsibility for the guidelines manuscript;
- Maintain overview of project and provide the primary direction for the work of the group;
- Adhere to and implement the agreed-upon production methodology (responsible for the evidence base and literature identification);
- Maintain effective communication with panel members, GO Board and office staff;
- Assessment of the functioning of panel members;
- Oversee and monitor the production process, time lines and quality and, together with office staff, decide on timing of meetings;
- Chair panel meetings and ensure that agendas are completed;
- Approve and sign off minutes resulting from meetings;
- Liaise with other guideline groups and external advisors;
- Keep an overview of any potential conflicts of interest and ensure that these cannot (be perceived of) interfere(ring) with any decisions made by the expert panel;
- Set an example by completing all assigned work on time;
- Maintain confidentiality.

In the absence of the Chair the Vice-Chair will assume these roles and responsibilities. The role of the Vice-Chair is to support the Chair in the effective running of the panel.

4.3.2 Panel Members

- Effectively communicate with the Chair and office staff (respond to emails in a timely fashion);
- Participate in meetings and conference calls;
- Follow instructions given by the panel Chair and adhere to the time lines set;
- Actively collaborate and perform assigned tasks (e.g., contribute constructively to discussion at meetings, evidence acquisition, drafting recommendations, and reviewing the manuscript);
- Maintain confidentiality;
- Support the Guidelines Associates in completion of systematic reviews undertaken by the panel.
4.3.3. Patient Representatives

All roles and responsibilities (outline above) assigned to Panels Members and additionally:

- Offer guidance so that the views, experiences and interests of all patients or people who use health services are considered by the Panel;
- Identify areas of concern to patients and review topic information and the guidelines from patient or caregiver perspective;
- Participate in induction training and other training which may be offered periodically; (paragraph 8.3);
- Actively engage with your relevant patient associations and networks to survey wider patient views and preferences to inform guideline development and to disseminate guidelines.

Please see the Role Description for Patient Representative Members for more information on tasks (appendix 1).

4.3.4. Guidelines Associates

- Assist with all tasks as determined by the Panel Chair;
- Core activities include but are not limited to systematic review activities and processing of annual horizon scope searches;
- Participate in meetings and conference calls;
- Follow Chair and supervising panel member’s instructions and adhere to the time lines set;
- Contribute to training and mentoring of newly appointed Guideline Associates;
- Maintain confidentiality.

Note: Guideline development requires the full and active participation of all panel members; producing a guideline requires substantial time and effort, which often tends to be underestimated by group members when they sign on. All members have a responsibility to other participants to behave with integrity, commitment, and with a fully professional demeanour.

4.4. Conflict of Interest

Conflict of interest may be defined as a “set of circumstances that creates a risk that professional judgment or actions regarding a primary interest will be unduly influenced by a secondary interest.” Conflict of interest is an important potential source of bias when developing guidelines as it frequently results in overestimating benefit and underestimating harm. It is not appropriate for individual panel members to self-judge if a particular relationship causes conflict; their role is to declare, not interpret. The panel Chair, in consultation with the panel as a whole, must ultimately determine if a conflict may result in bias and whether or not the degree of conflict excludes the individual from participating in the entire guideline or selected sections. Panel members COI disclosure forms should be reviewed and updated prior to each panel meeting and prior to publication. The EAU COI policy is laid down in a formal document, which is available online at the individual guidelines sections: [http://uroweb.org/guidelines/](http://uroweb.org/guidelines/).

5. Principals of Guidelines Development

As defined by the Institute of Medicine (IOM) [1], clinical practice guidelines are “statements that include recommendations intended to optimise patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options.” Guidelines can never replace clinical expertise when making treatment decisions for individual patients, but rather
help to focus decisions - also taking personal values and preferences/individual circumstances of patients into account. Guidelines are not mandates and do not purport to be the legal standard of care.

Quality guidelines are characterised by [2];
1. Explicit scope and purpose: Specific descriptions are given of the overall guideline objective(s), the health question(s) covered, and the population to whom the guideline is meant to apply.
2. Stakeholder involvement: The guidelines panel includes individuals from all relevant professional groups, patients’ views and preferences are actively sought and target users are clearly defined.
3. Rigor of development: Systematic methods are used to search for evidence; methods for formulating recommendations are clearly described; strengths and limitations of the body of evidence are clearly described; methods for formulating the recommendations are clearly described; recommendations take into account health benefits, side effects, and risks; recommendations are linked explicitly to supporting evidence; the guideline is externally reviewed by experts prior to publication; and a procedure for updating the guideline is provided.
4. Clarity of presentation: Recommendations are specific and unambiguous, different options for management of the condition or health issue are clearly presented, and key recommendations are easily identifiable.
5. Applicability: The guideline provides advice and/or tools on how the recommendations can be put into practice, the guideline describes facilitators and barriers to its application, potential resource implications are considered, and the guideline presents key monitoring and/or auditing criteria.
6. Editorial independence: The views of the funding body have not influenced content; competing interests of guideline development group members have been recorded and addressed.

5.1. **Five Key Steps in the Development of an Evidenced-based Guideline**

1. Identify and refine the subject area.
2. Convene and effectively manage the guideline development panel.
4. Translate evidence into recommendations.
5. Subject the guideline to independent peer review.

Evidence-based CPGs rely on unbiased and structured literature reviews. The main objective of systematically reviewing the literature is to identify all relevant evidence sources, producing a comprehensive body of evidence that will allow clinical questions to be answered whilst highlighting gaps in the evidence base where formal consensus methods may be needed. The EAU CPGs development model is driven by continuous quality improvement using the literature search as one of many factors that help translate evidence into practice. The ratio of benefits to harms, patient and stakeholder preferences and costs are also considered in formulating recommendations.

Expert opinion or consensus finding outcomes may be used to make recommendations in topics with gaps in the evidence, however the strength of the recommendation will be limited. Discussing topics with limited evidence allows guideline developers to highlight future research needs and suggest how to best fill existing gaps. The guideline as a whole, however, must avoid over-reliance on expert opinion or clinical consensus as a primary decision making strategy.
5.2. Guidelines Production Process (training will be provided on the process)

It is important to be clear how the guideline is produced. The purpose of clinical guidelines is to enhance clinical decision making, therefore, the emphasis is on the development of recommendations. The inclusion of levels of evidence and grades of recommendation aims to provide transparency between the underlying evidence and the recommendations made, so that the clinician can assess how much confidence they can place in a given recommendation.

5.2.1. Definition of the subject/disease/condition of the guideline

The content of the guideline should be explicit from its title, however, any limitations should be stated and if necessary explained. The introductory section should explain the purpose and scope of the guideline as well as the methodology used. All introductory sections must comply with the standardised format which was introduced in 2016 [2]. Standard requirements for all introductory sections are listed in table 2.

<table>
<thead>
<tr>
<th>Introduction Sub-headings</th>
<th>Description of content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aim and scope</td>
<td>Overall scope and purpose of the guideline (clinical, healthcare or social questions covered by the guideline). Also mention what has not been addressed and explain why.</td>
</tr>
<tr>
<td>Population to whom the guidelines apply</td>
<td>Population and/or target audience to whom the guideline applies (if this is not directly apparent from the title).</td>
</tr>
<tr>
<td>Panel Composition</td>
<td>Multidisciplinary panel, stakeholder involvement. Also rational for not including obvious groups.</td>
</tr>
<tr>
<td>Available publications</td>
<td>Brief description of all available scientific publications related to the guideline.</td>
</tr>
<tr>
<td>Publication history</td>
<td>Brief history on the guideline when it was first published and last updated.</td>
</tr>
<tr>
<td>Methods</td>
<td>Description of methodology used in which the level of evidence and grade of recommendation are addressed.</td>
</tr>
<tr>
<td>Review</td>
<td>Description of the guidelines peer review process.</td>
</tr>
<tr>
<td>Future Goals</td>
<td>If relevant, comment on the continual work within the panel and the when this be presented in the guideline</td>
</tr>
</tbody>
</table>

5.2.2. List of subtopics to be included

These form the chapters of the guideline. The exact outline is dependent on the guideline subject; however, all guidelines must make the utmost effort to conform to either the oncology or non-oncology template. Both templates are summarised in table 3.

<table>
<thead>
<tr>
<th>Template</th>
<th>Chapters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oncology</td>
<td>1. Introduction</td>
</tr>
<tr>
<td></td>
<td>2. Methods</td>
</tr>
<tr>
<td></td>
<td>3. The Epidemiology, Aetiology and Pathophysiology</td>
</tr>
<tr>
<td></td>
<td>4. Staging and classification systems</td>
</tr>
<tr>
<td></td>
<td>5. Diagnostic evaluation</td>
</tr>
<tr>
<td></td>
<td>6. Prognosis</td>
</tr>
</tbody>
</table>
7. Disease management  
8. Follow-up  
9. References  
10. Conflict of interest

**Non-oncology**

1. Introduction  
2. Methods  
3. Guideline  
   3.1 Condition A  
      3.1.1 Epidemiology, Aetiology and Pathophysiology  
      3.1.2 Classification system  
      3.1.3 Diagnostic evaluation  
      3.1.4 Disease management  
      3.1.4.1 Conservative management  
      3.1.4.2 Pharmacological management  
      3.1.4.3 Surgical management  
      3.1.5 Follow-up  
3.2 Condition B (if applicable)  
4. References  
5. Conflicts of interest

### 5.2.3. Data identification

#### 5.2.3.1. Horizon scoping search

All panels are expected to perform an annual horizon scoping search covering their entire guideline. The results of this search will result in one of three scenarios:

1. Signing off the guidelines as still current for the upcoming edition i.e. no changes will be made to the text following assessment of the search.
2. Minor adaptions to the upcoming edition for example identification of higher quality studies, which may be used to replace current references. These data do not, or will only marginally, affect recommendations.

All search stages must be documented for transparency and reproducibility. Specific considerations include databases, time periods, keywords, subject headings, language restrictions, use of grey literature (e.g. conference abstracts not published in an indexed journal), and selection criteria. The various search strategies can be found online in the folder ‘Scientific publications and appendices’ for each individual guideline. Further information regarding the use of Mesh terms and search design may be found at [https://www.nlm.nih.gov/mesh/meshhome.html](https://www.nlm.nih.gov/mesh/meshhome.html).

Update scoping searches should be limited strictly to the time frame covering the cut-off date of the latest scope search and today. Initially, scoping searches should focus on the identification of publications that may change the recommendations (scientific papers matching the evidence level of those publications currently supporting the recommendations).

All abstracts should be screened with reference to the panels predefined inclusion/exclusion criteria as outlined in their study eligibility form. The Methods Committee have produced two template study eligibility forms, one for adaption by panels whose guideline topics have an abundance of high level evidence and the other for panels where high level evidence is limited or lacking altogether.
During full text screening each panel member must record why the text is either included or excluded from the guideline. These reasons must be returned to the GO where they will be compiled into a spreadsheet and be used as supporting documentation (and potentially also for submission to the National Guidelines Clearing House [NGC]). Upon completion of the scope search the GO will produce a “Scope Management Flow Chart” for each panel which was part of the supporting documentation (figure 1.).

5.2.3.2. Systematic reviews

The GO has systematically introduced Cochrane review methodology across all 20 guidelines panels, ensuring that high quality systematic reviews underpin key recommendations. The responsibility for completion of systematic reviews rests with the Associates together with the senior panel leads, who are supported by methodologists and statisticians.

Systematic reviews are based on clinical questions prioritised by the Guideline Panel responsible for each topic, and their findings are incorporated into the EAU guidelines as they become available. Benefits and harms of interventions are addressed in detail, both in the development stage of the clinical question and when review findings are being incorporated and treatment recommendations formulated. Whenever possible, patient input is sought at both the development stage of the SR questions as well as when guidelines recommendations are being drafted.

All SRs are performed using standard Cochrane SR methodology: [http://www.cochranelibrary.com/about/about-systematic-reviews.html](http://www.cochranelibrary.com/about/about-systematic-reviews.html). Two independent reviewers screen abstracts and full texts, carry out data abstraction, assess risk of bias and do a GRADING exercise. The results are presented in tables showing baseline characteristics and summaries of findings. Meta-analyses are performed only as part of a SR when several randomised controlled trials have addressed the same question and outcomes reported homogenously. For lower level data, narrative syntheses of the evidence are provided. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidance is followed.

The GO has produced a step-by-step handbook the “EAU Guidelines Systematic Reviews Methods and Processes Handbook” which must be followed when undertaking SR work for the EAU guidelines, this handbook is available from the GO.
5.2.4. **Text presentation**

Each chapter/subchapter should be concluded by a summary of evidence table and a summary of boxed, graded recommendations. Summaries and recommendations must be clearly distinguished.

Uniformity is strived for; care should be taken to avoid expanding on guidelines documents indefinitely, where a textbook format is created. Use of tables and algorithms is encouraged for presenting important information whilst helping to keep texts concise. Texts submitted for publication are edited by at least two native English speakers and reformatted, if needed, to comply with the standard publication format. All amendments resulting from the editing process are initially sent to the panel Chair for review. Accuracy of the contents of the Guidelines is the responsibility of the guidelines panel. All Guidelines texts include the following disclaimer;

“It must be emphasised that clinical guidelines present the best evidence available to the experts. However, following guideline recommendations will not necessarily result in the best outcome. Guidelines can never replace clinical expertise when making treatment decisions for individual patients, but rather help to focus decisions - also taking personal values and preferences/individual circumstances of patients into account. Guidelines are not mandates and do not purport to be the legal standard of care”
5.2.5. Recommendations

Recommendations should be quality driven and propose actions that will improve quality of care. These actions include, but are not limited to:

- Reducing variations in care;
- Improving diagnosis/recognition;
- Promoting appropriate care;
- Avoiding unnecessary tests or interventions;
- Improved coordination of care;
- Improved patient safety.

The aim of recommendations is to influence the behaviour of a clinician in a given situation; recommendations should be actionable and use clear language.

An ideal recommendation describes:

- When → under what specific conditions should the recommendation be implemented
- Level of obligation → this is linked to the grade of recommendation
- Do what → precisely what action/s should be implemented
- To whom → specifically who the recommendation should be implemented on

Recommendations should be precise. The supporting text, which precedes the recommendations should amplify why the recommendation is important and how it is to be carried out (present a summary of all supporting data). Furthermore, the recommendation should reflect the degree of obligation linked to the intervention. In cases where multiple treatments are equally effective, identical phrasing must be used.

5.2.5.1. Levels of evidence and grades of recommendation

Levels of evidence and grades of recommendations are included in the guidelines in order to provide clinicians with a clear frame of reference by which to rate the statements and recommendations made. Providing transparency between the underlying evidence and a recommendation made, allows users to judge the validity of the statement made, which should enhance confidence in the quality of the guidelines.

Currently, the EAU GO uses a modified level of evidence/grade of recommendation table from the Oxford Centre for Evidence-based Medicine Levels of Evidence (modified March 2009).

Table 4. EAU Guideline’s levels of evidence

<table>
<thead>
<tr>
<th>Level</th>
<th>Type of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>Evidence obtained from meta-analysis of randomised trials</td>
</tr>
<tr>
<td>1b</td>
<td>Evidence obtained from at least one randomised trial</td>
</tr>
<tr>
<td>2a</td>
<td>Evidence obtained from one well-designed controlled study without randomisation</td>
</tr>
<tr>
<td>2b</td>
<td>Evidence obtained from at least one other type of well-designed quasi-experimental study</td>
</tr>
<tr>
<td>3</td>
<td>Evidence obtained from well-designed non-experimental studies, such as comparative studies, correlation studies and case reports</td>
</tr>
<tr>
<td>4</td>
<td>Evidence obtained from expert committee reports or opinions or clinical experience of respected authorities</td>
</tr>
</tbody>
</table>
Each recommendation should be graded A–C and justified by using the strongest, clinically relevant data. It is important to point out any flaws in the evidence used to support any given recommendation. The panel can also make a recommendation AGAINST performing a certain action.

It should be noted, however, that when recommendations are graded, the link between the level of evidence and grade of recommendation is not always immediately apparent. Availability of RCTs may not necessarily translate into a grade A recommendation where there are methodological limitations or disparity in published results.

Alternatively, absence of high-level evidence does not necessarily preclude a grade A recommendation, if there is overwhelming clinical experience and expert consensus. In addition, there may be exceptional situations where corroborating studies cannot be performed, perhaps for ethical or other reasons, and in this case, unequivocal recommendations are considered helpful for the reader. The quality of the underlying scientific evidence – although an important factor – has to be balanced against benefits and burdens, values and preferences, and cost when a grade is assigned.

From 2018 onwards, all EAU Guidelines will switch to a modified Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach for the grading of recommendations. Assessment of the evidence using GRADE methodology has been the standard for all new systematic reviews undertaken by the GO in the past two years. To allow for a transparent assessment of how recommendation statements have been developed, a Summary of Evidence (SOE) table will be provided for each recommendation within the guidelines which will address a number of key elements:

1. The overall quality of the evidence which exists for the recommendation,
2. The magnitude of the effect (individual or combined effects),
3. The certainty of the results (precision, consistency, heterogeneity and other statistical or study related factors),
4. The balance between desirable and undesirable outcomes,
5. The impact of patient values and preferences on the intervention, and
6. The certainty of those patient values and preferences.

These key elements in the SOE tables are the basis which panels use to define the strength of each recommendation. The strength of each recommendation will no longer be represented by alphabetic characters, but rather by the words ‘strong’ or ‘weak’. The panels will provide both ‘strong’ and ‘weak’ recommendations ‘for’ or ‘against’ recommending an action based on the information found in the SOE tables. The strength of each recommendation is determined by the balance between desirable and undesirable consequences of alternative management strategies, the quality of the evidence (including certainty of estimates), and nature and variability of patient values and preferences.

Under this system each recommendation will have a corresponding ‘Recommendations Worksheet’ which will be available online for all users of the Guidelines to access.

5.2.5.2. Summary of key points to remember/consider when formulating recommendations

- Recommendations must be actionable.
- The total evidence base, level of evidence (quality of the studies) as well as the number of studies affect the grade of recommendation. As does the uniformity of the studies.
- Are the findings from the scientific data relevant for the population for whom the recommendation is made (generalisability)?
- Is there a logical link between the supporting text, evidence summary statement and the recommendation?
- The health benefits for each statement must be clear.
• Potential harms and side-effects need to be addressed (potential for overtreatment as well as efficacy and effectiveness of the treatment modality).
• Patient views and preferences.

6. Review

The aim is to ensure double-blinded peer review of all guidelines material produced prior to publication. This applies to the extended documents as well as scientific papers published in either the association’s journals, “European Urology, European Urology Oncology & European Urology Focus”, or other peer reviewed journals.

The EAU GO are responsible for review of all extended guidelines (sections). A minimum of 3-4 international expert reviewers are invited to review each document. Furthermore, where possible, a representative from patient advocacy groups will be included as a lay reviewer as well as the patient representative on the Panel being involved in the whole process of guidelines development.

All scientific papers (summaries of the EAU guidelines and SRs) will be peer reviewed by Eur Urol, Eur Urol Focus or Eur Urol Oncol.

7. Authorship

All full panel members who have contributed to a published text (update) will be listed as authors on the title page of the document. Unless otherwise decided, standard listing is, Chair first, followed by all other authors in alphabetical order. Experts are credited in the methodology section and/or with a footnote in the document itself. Associates who have directly contributed to the guidelines text will also be listed, in alphabetical order, as associate members on the title page of the document. In case of any disputes, the GO Board can be called upon to referee.

8. Logistics and other practical matters

8.1. Panel meetings

The number of panel meetings required may vary, but is ultimately decided by the chair of a panel, in collaboration with the GO Board. All panels should schedule a meeting at least once each year. Panel members are expected to attend all panel meetings. In case he/she is unable to participate, notification of the panel Chair/GO staff is expected. The panel Chair can request that any assigned activities are made available in a timely fashion. In case of non-availability there is the option to schedule a telephone/video conference allowing the missing panel member to contribute. It is the responsibility of the Chair to decide whether frequent failure to attend scheduled panel meetings is reason to re-discuss panel participation.

8.2. Logistical support

Logistical support will be provided by the GO in conjunction with the EAU Central Office, this includes:
• Hotel and meeting room bookings (IT requirements)
• Flight arrangements
• Any meals – the GO will arrange for drinks, snacks, lunch and dinners during meetings
The Central Office will confirm any hotel bookings in a timely fashion ahead of the meeting. Incidentals such as minibar, telephone calls and other personal expenses are not reimbursed and will be charged to the panel member by the hotel directly (credit card deposit).

Flights will be booked based on economy fare, reimbursement of costs in case a panel member arranges his/her own travels will also be based on economy fare. A standard EAU reimbursement form is to be used. Train tickets will be reimbursed based on first class fare. Car travel will be reimbursed at Euro 0.19 per km.

All other reimbursable expenses when traveling for the EAU GO must be listed on the standard EAU reimbursement form. Panel members may submit electronic copies of their receipts along with their individual reimbursement forms, however, the all original receipts must be kept and can be request by the EAU Central Office, if deemed necessary.

Note: The Guidelines Office will not be responsible for any costs resulting from panel members who withdraw from meetings having previously confirmed their attendance. The relevant panel member will be asked to reimburse the cost of cancellation. If this cancellation is outside the control of the panel member the GO can choose to absorb the cost upon consultation with the panel member in question.

8.3 Training

All Panel members must attend a training course when becoming a member of a Panel.

- Patient representatives will be offered training and guidance to make sure they feel confident on the Panel and in addition a staff member of the EAU Guidelines Office and a nominated Panel Member will be available throughout to offer help and support;
- A training programme is offered by the European Patient Ambassador Programme (EPAP) for new patient members of EAU Guidelines Panels. The EPAP training modules can be accessed for free at this link: https://www.epaponline.org/. Participants simply need to create an account and then complete the training modules in their own time.
- Training modules will be provided by the EAU Guidelines Office – covering an introduction to the Guidelines Office and guideline production methodology – virtual or a face-to-face course.
- The EAU has established a Patient Advisory Group (EPAG) which will allow knowledge exchange and mutual support for patient representatives involved in guideline development and implementation.

9. Honoraria

Panel membership does not involve any remuneration, aside from reimbursement of panel meeting expenses. In case a Chair/panel wish(es) to contract assistance elsewhere for any activity e.g. literature, writing or statistical support a prior request must submitted to the GO along with an approximate estimate of the costs involved.

10. References

Appendix 1 – EAU GO Patient Representative Panel Member Role Description

European Association of Urology (EAU) Patient Representative Panel Member Role Description

“Name of Guideline Working Group”

Please read this information before applying to ensure you are fully aware of the role and expectations of a Patient Representative Member of an EAU Guidelines Panel.

1. EAU Patient Engagement in Guideline Development

Patient involvement in guideline development and appraisal is recognised as a fundamental requirement for the development of high-quality clinical practice guidelines. Patient representatives ensure that the guideline meets the needs of patients and ultimately improves the implementation of guideline recommendations across healthcare systems.

A patient representative is “an individual or advocacy group representing individuals who have a health condition and their caregivers, use health care services, and/or who are members of the community.”

The aim of the EAU Guidelines Office Patient Engagement Strategy is to involve patients in Guideline development and appraisal in a meaningful way from the outset and in each step of the process, ensuring that patients’ personal circumstances, values and preferences are taken into account and their needs are met.

2. The Guidelines Panels

Our urological clinical guidelines are developed through EAU Guideline Panels covering 20 topics. The Guidelines Office oversees the activity of sixteen Guidelines Panels and one Ad-hoc Guidelines panel. As well as patient representatives, the Panels are made up of specialists mainly from across Europe appropriate to the Panel on which they serve. Patient representatives will have the same status and carry out the same functions as other Panel members and it is anticipated that two patient representatives, ideally with links to larger patient groups and/or organisations, will serve on each Panel. It is hoped they will share particular activities and, in addition, be able to get feedback from a wider group.

A full list of all panels and panel members is available upon request from the Guidelines Office or online at www.uroweb.org/guidelines.

Further information relating to the roles and responsibilities of these groups can be found in the EAU Handbook for Guidelines Development EAU Handbook for Guidelines Development.

Additional information for patient representatives can be found in the EAU Patient Handbook and a staff member of the EAU Guidelines Office and a nominated Panel Member will be available throughout the appointment to offer help and support.

3. Patient Member Aim and Role

As a Patient Member of an EAU Guidelines Panel, you are asked to offer guidance so that the views, experiences and interests of all patients or people who use health services are considered by the Panel, identify areas of concern to patients and review topic information and the guidance from patient or caregiver perspective by:-
• Communicate effectively with the Chair and Guidelines Office staff (e.g. respond to emails in a timely manner);
• Participate in meetings and conference calls, taking part in discussions to shape the guidelines;
• Participate in induction training and other training which may be offered periodically;
• Follow instructions given by the panel Chair and adhere to the timelines set;
• Actively collaborate and perform assigned tasks (e.g., contribute constructively to discussion at meetings and commenting on drafts);
• Actively engage with your relevant patient associations and networks to survey wider patient views and preferences to inform guideline development and to disseminate guidelines;
• Maintain confidentiality.

4. **Patient Member Person Specification**

You do not need any formal qualifications to be a patient member. The following experience and skills will be considered useful:

**Experience and Understanding**

• Direct experience of the condition the guideline relates to;
• An understanding of the issues important to people with this condition, their families and carers;
• Experience representing a patient association or being an active member of a patient association or support group (e.g. as an advocate, volunteer, or officer).

**Skills and aptitude**

• Good communication, listening and team-working skills;
• Ability to present reports verbally and in writing;
• Good time management skills.

**Personal qualities**

• Ability to distinguish between personal and wider patient views and a willingness to put across the wider views and preferences of patients;
• Ability to listen and take part in constructive debate, while being respectful of other people’s views and expertise;
• Reliability;
• Time to commit to the work of the Panel by attending meetings, doing background reading and commenting on drafts.

**Knowledge**

• An understanding of the needs and concerns of global, European or national networks of patients guided by your involvement in these networks;
• A good understanding of verbal and written English;
• A good understanding of medical terminology or a willingness to become familiar with medical terminology.
• An understanding of keeping information confidential, if necessary.

5. **Tasks Associated with the Role**
Patient representatives will be involved at all levels and may undertake the following tasks:

- Comment on what is missing from the existing Guideline (perhaps one section as a starting point);
- Work with the Panel on guideline scope, target population and clinical questions (PICO) to ensure they are informed by the needs of patients and families;
- Provide feedback on the recommendations via the worksheets and provide the patient views/experience in terms of values, and benefit/harms and impact of alternative care options by engaging with the appropriate patient communities for disease specific activities;
- Assist and give feedback on the development of care pathways for each Panel;
- Assist with dissemination and increasing awareness of the Guidelines to the wider patient community via appropriate channels (social media, websites, patient organisations);
- Contribute to the development and dissemination of information to ensure they are patient centred by reflecting and meeting the needs of patients;
- Assist with stakeholder relationships;
- Involve in consensus finding projects where there are gaps in the evidence.

6. **Further Details**

   a. **Time commitment**

   Depending on the Guideline Panel’s work programme, there will be up to XXX meetings per year and between meetings Patient Members would be expected to contribute to reading, commenting on draft recommendations and engaging with patient networks. Meetings will be held at accessible venues across Europe or via videoconferencing online.

   b. **Tenure of office**

   The standard term of office for Guidelines Panel members is 4 years (assuming satisfactory annual assessment up to the end of the first 2 years), which can be renewed once at the sole discretion of the Guidelines Office Board (giving a maximum of 8 years). However, some patient representatives will be appointed on an ad hoc basis for shorter periods, as appropriate, to cover certain sections in some of the Guidelines.

   The role can be terminated by the Guidelines Office Board in the event of unsatisfactory performance and the patient representatives can terminate their role at any time.

   c. **Conflict of interest**

   All Guidelines Panel members are required to submit a Conflict of Interest (COI) declaration form and a Non-disclosure Statement and are expected to remain independent. Potential Conflicts of Interest must be declared in formal meetings in accordance with the COI policy.

   d. **Evidence of support from a Patient Organisation**

   Patient Members, where representing a patient organisation, are asked to submit a supporting letter from the patient association they are representing, endorsing their involvement on the Panel.

   f. **Additional Support for Patient Members**
• Out-of-pocket expenses for travel to any meetings will be provided. We will contact you before the meeting to arrange transport that meets your needs and book and pay for your tickets (e.g. flights, public transport, travel to and from airports and venues;
• For meetings which run for more than one day, or start early in the morning, we will book and pay for suitable overnight accommodation;
• We will provide all meals and refreshments during the meeting and you can claim for food and drink cost incurred during the travel to and from the meeting;
• You will be offered training and guidance to make sure you feel confident on the Panel;
• A staff member of the EAU Guidelines Office and a nominated Panel Member will be available throughout to offer help and support.
• Ideally two patient representatives will be appointed to each Panel to offer support to each other.

How to Apply

Please complete and return the application form, which can be found on the EAU website [insert link]. If you would like to discuss the opportunities before expressing interest or receive further information, please contact Julie Darraugh at j.darraugh@uroweb.org