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Changing current practice in urology: improving guideline development and implementation through stakeholder engagement

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There is a common consensus among practitioners that clinical practice guidelines (CPGs) improve care. [1] Moreover, CPGs empower patients to make informed healthcare choices, influence healthcare policies, promote distributive justice and advocate better delivery of services. However, it is currently unclear how key stakeholders (eg. patients, carers, charitable organisations, healthcare funders) can be active in the development and implementation of guidelines in a meaningful way alongside the traditional clinical and methodological membership. The hurdle of including key non-medical stakeholders is perceived as substantial despite patient-focused outcomes.

CPGs could also work very effectively to promote user engagement in treatment choices and decision-making. Inclusion of patients and other key stakeholders could potentially facilitate direct discussions regarding the process of care, outcomes of importance, and patient preferences, while weighing experiential benefits and harms of different treatment regimens. [2] Ultimately, all parties would benefit from informed choice and improved treatment adherence. [3] Examples where patients are successfully engaged in specific circumstances include the James Lind Alliance methodology [4] and the COMET initiative for core outcome set development. [5] These coalitions represent excellent but isolated efforts which would ideally be "joined up" to a wider process subject to systematic evaluation.

Here, we propose a model that addresses all different agents (patients, carers, charitable organisations, healthcare funders, in addition to specialists) involved in health-related decisions. Importantly, our proposed model incorporates key stakeholders as non-tokenistic panel members with clearly defined responsibilities (Box 1).

The role of stakeholders in the development of CPGs should be shaped to minimize bias within this process. All panel members are expected to contribute appropriate comments to the discussion. [6] For patient-members, discussion needs to be framed in terms of the process of care, and how to prioritise clinical questions. [2] Importantly, the patient representative brings another perspective on the design and delivery of care to the discussion, rather than making decisions on which treatment is best. However, in helping to prioritise the *outcomes* of most importance in deciding whether one treatment is better than another, the patient voice is clearly important.

Three main models of how to elicit meaningful stakeholder participation in CPG development exist: (1) direct membership of the panel, (2) evaluation of evidence outside of panel meetings (e.g. through the formation of an expert patient guideline group, through a 'one-off' meeting or through a series of CPG workshops with stakeholders), or (3) having a "skilled member" to speak for the wider patient/stakeholder group (e.g. the director of a charity). [6] The "skilled member" model has been favored in practice, [2] but this raises the question of how this can then transcend individual bias, national boundaries, cultures, differences in the process of healthcare and how it is to be funded. Finally, there is a question of how the input of each panel member is assessed, in parallel with the evaluation of the guidelines themselves, and the costs/benefits of different stakeholder engagement. Measurable outcomes (e.g. adherence to CPGs, adherence to treatment, costs of care) will define CPG efficacy, together with qualitative outcomes such as patient-centred care, or shared-decision making.

Proposed model:

The core principles of CPG development are transparency, accountability, and the harmonisation of patient care based on the best available scientific evidence. We propose a feasible model, currently being operationalised by the European Association of Urology (EAU), for CPGs to serve key stakeholders, which will also benefit the implementation of guidelines (Figure 1).

Firstly, an effective panel must be redefined. Historically, panels have grown organically from the network of the appointed chair/vice-chair. To professionalise this process, the skills and qualities/backgrounds desired for each seat should be defined *a priori*, and then appropriate members appointed in a transparent process, preferably balanced for area of expertise, gender, geography, experience and perspective. All members should be interviewed. Once appointed to a panel, members should go through methods training to serve a time-limited appointment.

A guidelines panel should have at least one patient representative as a non-expert member, although preferably additional professionals allied to medicine could also be invited (nurse practitioners, social workers, healthcare economists, etc.). The selection procedure non-medical members should be equally transparent. Ideally the patient advocate will be able to represent the broad interests of the target group and will have an education level appropriate to the tasks provided. Masterclasses like those provided by the European School of Oncology

aiming to train aspiring patient advocates to work with professionals to promote their interests should be considered as necessary investment. The non-medical panel members should be supported with appropriate-level material to enable participation in priority-setting, conveying patient-important outcomes, and CPG development.

Importantly, we propose that the role of the patient advocate is to link the panel's guidelines back to their national and international community to canvas opinion on priority setting and outcome measures (Figure 1). This feed-back/feed-forward loop will also contribute to the prioritisation of research. Current examples within Urology of the provision of evidence-based care through a partnership between the clinical team, the patients and researchers include UCAN (Urological CANcer charity) and the IKCC (International Kidney Cancer Consortium), respectively. [12, 13-15, 16]. A key advantage of these linkages with large national and multinational stakeholder groups is that they are almost by definition trained at a professional level of communication with medical experts, pharmaceutical companies, and other patients alike.

Conclusion:

Patient advocates and other stakeholders can add substantial value to CPG development, dissemination and implementation. We propose modifying guidelines panel composition and using measurable outcomes to improve guidelines practice. Ineffective dissemination of recommendations risk variations in practice. Consequently, patients will not always receive the best possible care, with greater potential to experience harm. Furthermore, if all stakeholders, including patients, are meaningfully included in discussions about which research areas should be prioritised, what outcomes are of the highest importance, or which recommendations are made, then informed shared decision-making should result. In short, our model aspires to truly capture the voice of the local and national stakeholder communities and feed this forward to an international guideline panel to improve outcomes and adherence to CPGs.

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Illustration

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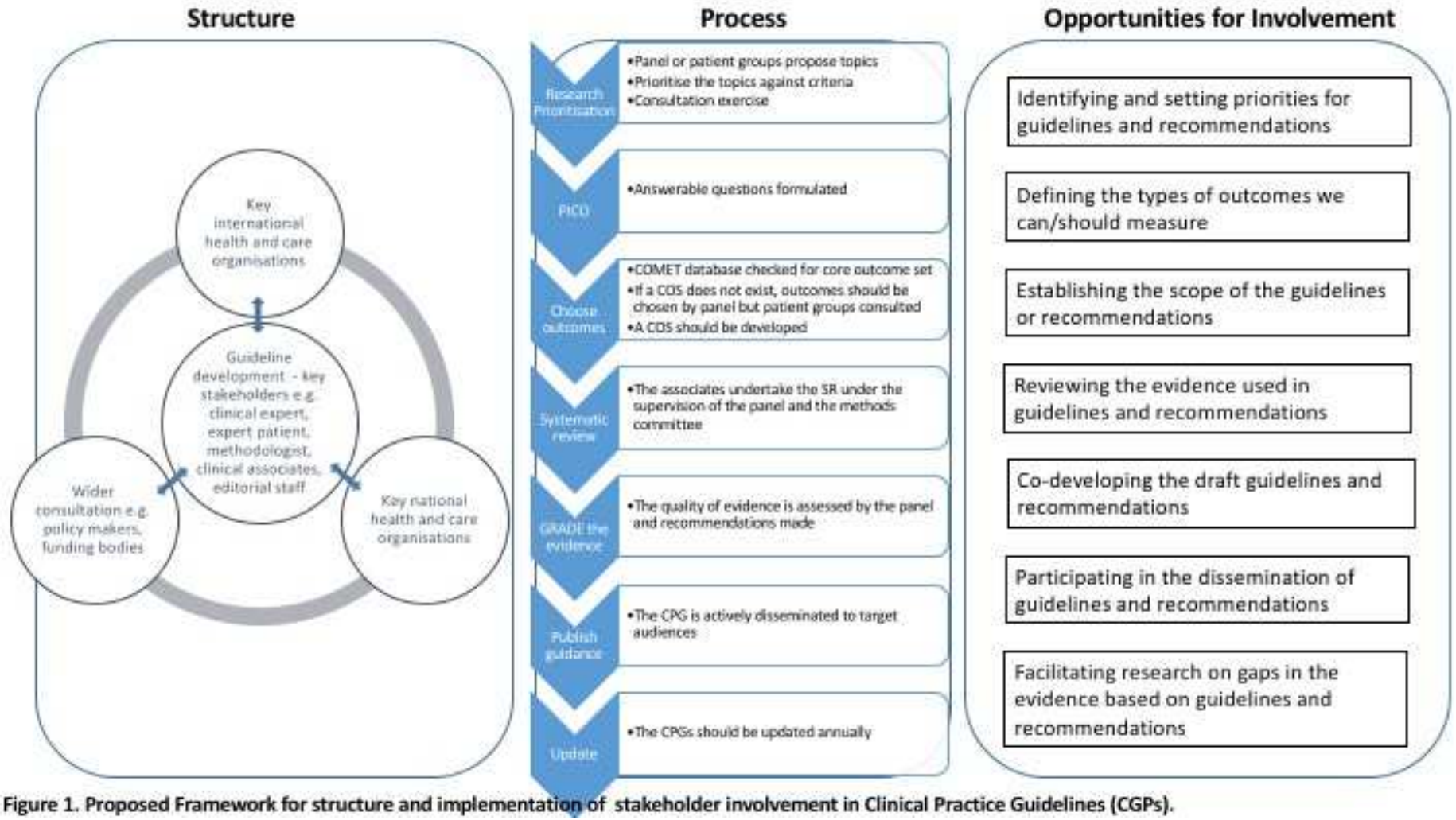

Figure 1. Proposed Framework for structure and implementation of stakeholder involvement in Clinical Practice Guidelines (CGPs).

Illustration

Breakout Box 1:

Checklist to achieve Multidisciplinary Stakeholders in a Clinical Practice Guideline Panel:

- ✓ Define the remit of the panel and the roles of each place on the panel; specify rules for the process

- ✓ Identify key stakeholder functions, potential members:
  - ➢ medical specialists
  - ➢ junior associates able to generate systemic reviews for recommendations
  - ➢ non-medical health professionals (nursing, paramedical, health economist)
  - ➢ patient representation (determine global/international/national)
  - ➢ healthcare funders
  - ➢ charitable organisations

- ✓ Interview all potential members for skill-based function on panel, impartiality, transparency, and ability to commit to a term and workload

- ✓ Assess conflicts of interest and ensure that panel members do not vote on or influence any issues where they are conflicted

- ✓ Train all panel members in evidence-based medicine methodologies

- ✓ Define outreach outcomes per member (eg for the patient representative feedback from the community, priority setting) to generate feedback cycle

- ✓ Evaluate member function annually, outcomes delivered

Disclosure

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_ conception and design — Sara MacLennan, Steven MacLennan, James N'Dow, Maria de Santis, Rachel Giles

_ acquisition of data — Karen Plass, Sara Maclennan, Steven Maclennan, Rachel Giles

_ analysis and interpretation of data

_ drafting of the manuscript — Sara Maclennan, Steven Maclennan, Rachel Giles

_ critical revision of the manuscript for important intellectual content — Axel Bex, Borje Ljungberg, James Catto, Hein van Poppel, Penny Wright, Adam Glaser, Marta Trapero-Bertran, James N'Dow, Maria de Santis

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_ administrative, technical, or material support

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Take-home message: Effective stakeholder integration into Guideline development should improve outcomes and adherence to CPGs.