

Education materials on bladder cancer: a scoping review and recommendations for future initiatives

RC. Leenen (1) ; LD. Venderbos (1) ; A. Filicevas (2) ; MJ. Roobol (1) ; K. Beyer (1) ; M. Karavitakis (3) ; P. Nyirady (4) ; R. Sosnowski (5) ; E. Robijn (6) ; E. Attard (6) ; M. Boubakri (6) ; M. van Balken (6)

(1) Department of Urology, Erasmus University Medical Center, Rotterdam, Netherlands; (2) World Bladder Cancer Patient Coalition, Bruxelles, Belgium; (3) Hellenic Urological Association, Athina, Greece; (4) MAGYAR UROLOGUSOK TARSASAGA, Budapest, Hungary; (5) POLISH SOCIETY OF UROLOGY, Warsaw, Poland; (6) European Association of Urology, Arnhem, Netherlands

Background

Bladder cancer (BCa) is the fifth most common cancer in Europe and profoundly impacts patients and families. Despite its burden, BCa health literacy remains low across Europe, particularly in lower income countries. This hinders primary prevention, early symptom recognition, and informed shared decision-making (SDM). High-quality education materials are essential to enhance health literacy and informed SDM.

Aim

As part of the EAU Patient Office-led BCclear project (BCa Literacy for All: Advancing Knowledge and Care in Europe), this scoping review aims to (1) identify and synthesize existing BCa education materials, and (2) formulate recommendations for patients, the public, healthcare professionals, and future material development within BCclear.

Methods

A scoping review was conducted following JBI and PRISMA-ScR methodology (PMID: 33038124). Eligible sources included education materials for the public or BCa patients (MIBC/NMIBC) covering prevention, diagnosis, or care aspects, in any format or European language (incl. English). A comprehensive search of scientific and grey literature was conducted, supplemented by citation tracking. Outcomes of interest included content, accessibility, readability, impact, and quality.

Disclaimers Co-funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or HaDEA. Neither the European Union nor the granting authority can be held responsible for them. Information about the action and grant agreement no. The project leading to this application has received funding from the EU4Health programme under Grant Agreement n° 101219341.

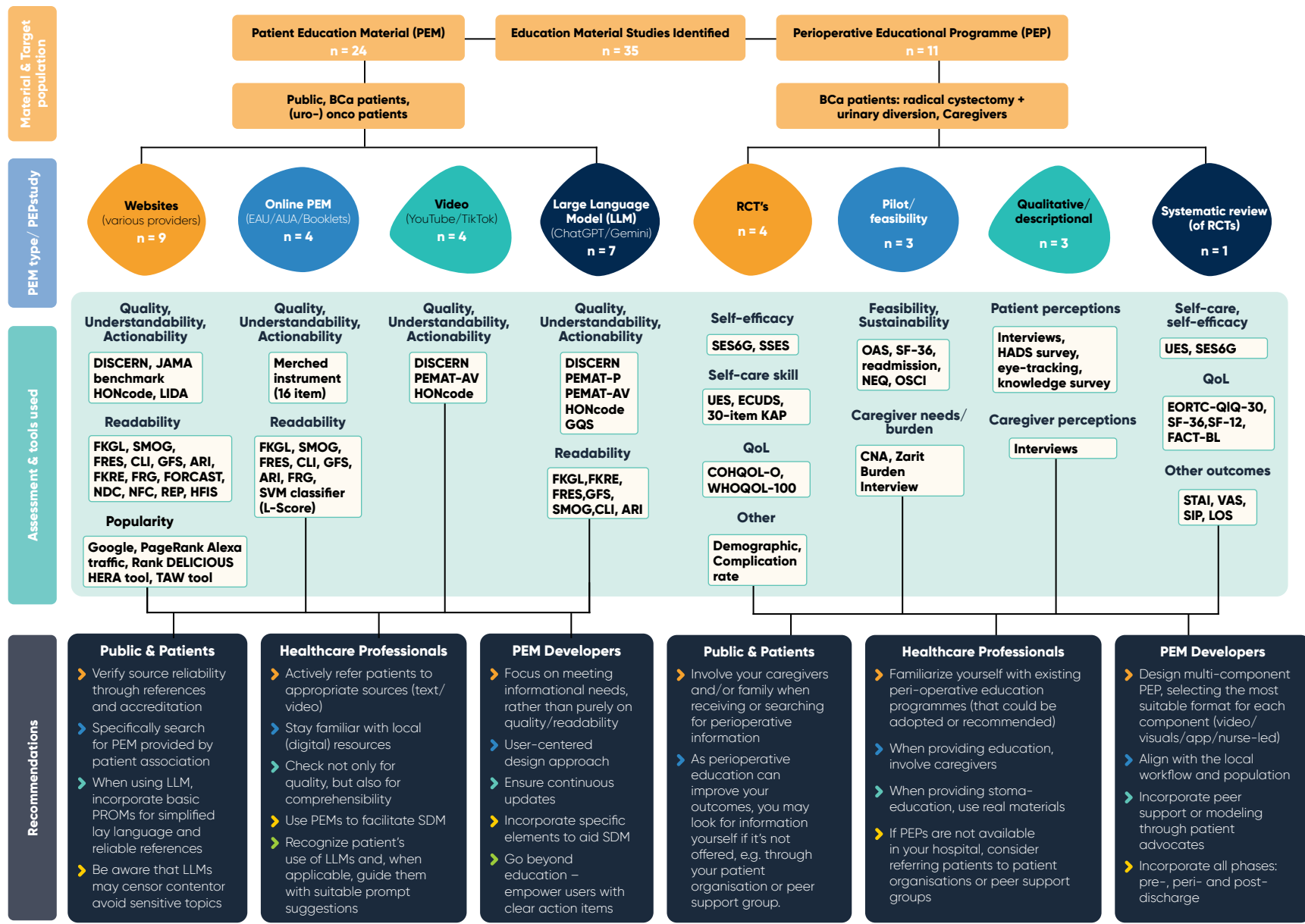
Results

Of 1253 titles screened, 35 met inclusion criteria. Studies were grouped by focus: any assessment of patient education materials (PEMs, n=24) and evaluation of perioperative education programmes (PEPs, n=11). Fig. 1 summarises target populations, PEM or study types, assessments, and corresponding tools. Overall, PEMs were often of poor to moderate quality, difficult for lay persons (readability above average levels), and lacked patient involvement in design or review, limiting comprehension and actionability. PEPs improved short-term physical and psychological outcomes, but evidence was mostly non-European. Recommendations for three groups (Fig.1) were developed based on the synthesis of the included studies.



Conclusion

This scoping review identified a wide range of BCa education materials, though overall quality was limited. PEM assessments mainly rely on objective metrics, overlooking actual patient comprehension and usability. This review provides recommendations for public, patients, healthcare professionals and developers to inform the creation of educational toolboxes and decision aids within BCclear.



PEM: Automated Readability Index (ARI), Flesch-Kincaid Grade Level (FKGL), Flesch-Kincaid Reading Ease (FKRE), Flesch Reading Ease (FRE), Coleman-Liau Index (CLI), Fry Readability Graph (FGR), DISCERN Instrument (DISCERN), Patient Education Materials Assessment Tool- Audiovisual version (PEMAT-AV), Gunning Fog Index (GFI), Simple Measure of Gobbledygook Index (SI), New Fog Count (NFC), Raygor Estimate Plot (REP), Huertas Formula - Inflesz Scale (HfIS), Shared-Decision Making (SDM), Artificial Intelligence (AI), PEM: Automated Readability Index (ARI), Flesch-Kincaid Grade Level (FKGL), Flesch-Kincaid Reading Ease (FKRE), Flesch Reading Ease (FRE), Coleman-Liau Index (CLI), Fry Readability Graph (FGR), DISCERN Instrument (DISCERN), Patient Education Materials Assessment Tool- Audiovisual version (PEMAT-AV), Gunning Fog Index (GFI), Simple Measure of Gobbledygook Index (SI), New Fog Count (NFC), Raygor Estimate Plot (REP), Huertas Formula - Inflesz Scale (HfIS), Shared-Decision Making (SDM), Artificial Intelligence (AI).