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Authors

Gandaglia, Giorgio
Bray, Freddie
Cooperberg, Matthew R
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Reply from Authors re: Julia Verne, Luke Hounsome, Roger Kockelbergh, Jem Rashbass. Improving Outcomes from Prostate Cancer: Unlocking the Treasure Trove of Information in Cancer Registries. Eur Urol 2016;69:1013–4

Giorgio Gandaglia^{a,*}, Freddie Bray^b, Matthew R. Cooperberg^c, R. Jeffrey Karnes^d, Michael J. Leveridge^e, Kim Moretti^f, Declan G. Murphy^g, David F. Penson^h, David C. Millerⁱ

^aUnit of Urology/Department of Oncology, IRCCS San Raffaele Hospital, Milan, Italy; ^bSection of Cancer Surveillance, International Agency for Research on Cancer, Lyon, France; ^cDepartments of Urology and Epidemiology & Biostatistics, Helen Diller Family Comprehensive Cancer Center, San Francisco, CA, USA; ^dDepartment of Urology, Mayo Clinic, Rochester, MN, USA; ^eDepartment of Urology, Queen's University, Kingston, Ontario, Canada; ^fSouth Australian Prostate Cancer Clinical Outcomes Collaborative, Repatriation General Hospital, Daw Park, and the University of South Australia and the University of Adelaide, South Australia, Australia; ^gDivision of Cancer Surgery, University of Melbourne, Peter MacCallum Cancer Centre, Melbourne, Australia; ^hDepartment of Urologic Surgery, Vanderbilt University, and the VA Tennessee Valley Geriatric Research, Education, and Clinical Center (GRECC), Nashville, TN, USA; ⁱDivision of Urologic Oncology, Department of Urology, University of Michigan, Ann Arbor, MI, USA

We thank Verne et al [1] for their thoughtful comments on our recently published review [2], which evaluated the role of population-based and prospective disease-specific registries in outcome research on patients with prostate cancer (PCa). In particular, our investigation was primarily aimed at describing the strengths and limitations of PCa registries, their main results in terms of advancing care, and the future role of these registries [2]. We were able to show that a large number of PCa registries are currently available and, as highlighted by Verne et al [1], unlocking the treasure trove of information contained in these data sources might play a major role in improving our knowledge of the disease itself. Although our review also focused on the potential advantages of population-based, disease-specific registries as compared to randomized controlled trials RCTs [2], the data generated from such registries cannot of course provide the same level of evidence obtained by well-designed and well-conducted RCTs [3]. We thus concur with Verne et al, who stated that owing to issues related to lead-time, length, and selection biases, registries cannot replace RCTs [1]. Some considerations of the specific roles of registries and RCTs warrant brief further discussion.

First, RCTs cannot replace the information provided by registries on the epidemiologic burden of specific diseases, including incidence and mortality rates, the adoption of certain treatments, and outcomes at a regional or national level [2,4]. Equally, only well-designed and well-performed RCTs can comprehensively address the safety and efficacy of a treatment and rule out the effect of potential selection bias [3,4]. It is the integration of data and results coming from these different settings that will provide us with the power to obtain the highest level of practice-changing evidence.

Second, implementation of automatic electronic data collection processes would allow PCa registries to include a large amount of information in a timely and accurate manner [1,5]. Disease-specific registries are characterized by the availability of detailed patient-related quality-of-life data [2]; in addition, several registries have recently started to collect biological material, including tissue specimens [2]. The availability and integration of these data into RCTs performed in selected cohorts of patients fulfilling specific selection criteria would increase the value of these studies, eventually providing clinically meaningful information.

In conclusion, population-based prospective and disease-specific registries will never replace RCTs. However, integration of RCTs, prospective studies, and registries can only serve to substantially improve our ability to manage patients with PCa.

Conflicts of interest: The authors have nothing to disclose.

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* Corresponding author. Unit of Urology/Division of Oncology, IRCCS Ospedale San Raffaele, 58 Via Olgettina, Milan 20132, Italy.

Tel. +39 022 6437286; Fax: +39 022 6437286.

E-mail address: giorgio.gandaglia@gmail.com (G. Gandaglia).