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Professor Mushabbab Alasiri General Director of Saudi National Cancer Institute Riyadh, P.O. Box 13315-3161 Kingdom of Saudi Arabia

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Dear Professor Alasiri,

Participation of the Saudi National Cancer Registry in the CONCORD programme

We would like to invite you to help arrange the participation of the Kingdom of Saudi Arabia in the CONCORD programme for the global surveillance of cancer survival, which is led by the Cancer Survival Group at the London School of Hygiene and Tropical Medicine.

We issued the call for data for CONCORD-4 in December 2022, to provide up-to-date, real-world evidence on trends and inequalities in cancer survival for patients diagnosed between 2000 and 2019, as a contribution to global cancer control. We will include data for 2020-21 where possible, to assess the impact of the COVID pandemic. We hope to recruit up to 400 cancer registries, with a combined population coverage of over 1 billion people in up to 80 countries.

The CONCORD programme has become the *de facto* reference for international comparisons of cancer survival, widely used by national and international agencies in developing cancer control policy, and in assessing the overall effectiveness of national health services in delivering cancer care. The CONCORD-3 summary article¹ was published in *The Lancet* in 2018. The editors recently told us that it is one of their 10 most cited articles published during 2018-2019 (attached; currently over 3,000 citations).

Saudi Arabia

The Saudi Cancer Registry participated in CONCORD-2,² with data for 20,860 adults diagnosed with one of 10 cancers during 1995-2004. The 5-year survival estimates derived from these data were not optimally reliable, because the minimum 5-year follow-up for vital status was not available for 61% of patients. We were unable to use the data submitted for CONCORD-3 for similar reasons.

However, we now know that complete follow-up in Saudi Arabia is possible.³ Dr Eman Alkhalawi MD recently completed her PhD with us on trends and regional variations in cervical cancer survival in Saudi Arabia.⁴ Her research showed the crucial importance of linking the SCR with the National Information Centre (NIC), to ensure complete ascertainment of the vital







































status of all registered cancer patients, regardless of when they were diagnosed or the cause of death. We are aware of legal and administrative barriers to making this linkage between the SCR and the NIC a routine operation, as it is in many countries.

It is important that cancer registration in the Kingdom is now statutory, under royal decree. The SCR has been operating for nearly 30 years, with 100% population coverage. We have examined the quality of the SCR data, and we know that SCR could provide high-quality survival estimates, if follow-up for vital status were complete. That would enable SCR to play a valuable role in cancer control policy in the Kingdom. It could help to monitor several aims of the National Health Sector Transformation Program, including improving healthcare timeliness, affordability, access and quality, increasing geographic coverage and the distribution of health services, improving clinical outcomes and raising life expectancy. It would also enable Saudi Arabia to be included in global comparisons of trends in population-based cancer survival.

Completeness of follow-up for the vital status of all registered cancer patients is critical to ensure robust estimation of cancer survival.

We believe that with your leadership and support, it would become possible to ensure that upto-date linkage between the SCR and the NIC becomes a routine operation.

In the immediate future, a full SCR-NIC linkage would enable Saudi Arabia to re-join the global surveillance of cancer survival, in CONCORD-4. The deadline for data submission is 30 June 2023, but we could arrange later submission if that would help.

Yours sincerely

Prof Michel Coleman

Prof Claudia Allemani

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on behalf of the CONCORD Central Analytic Team

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- 2. Allemani C, Weir HK, Carreira H *et al.* Global surveillance of cancer survival 1995-2009: analysis of individual data for 25,676,887 patients from 279 population-based registries in 67 countries (CONCORD-2). *Lancet* 2015; **385**: 977–1010. https://doi.org/10.1016/S0140-6736(14)62038-9.
- 3. Alkhalawi E, Allemani C, Al-Zahrani AS *et al.* How does linkage to the National Death Index affect population-based net survival estimates for women with cervical cancer in Saudi Arabia? *Gulf J Oncol* 2023; **41**: 17-22.
- 4. Alkhalawi E, Allemani C, Al-Zahrani A *et al.* Cervical cancer in Saudi Arabia: trends in survival by stage at diagnosis and geographic region. *Ann Cancer Epid* 2022; **6**: 7-20. https://doi.org/10.21037/ace-22-2.