



STATEMENT CONCERNING THE USE OF
PROFILES DATA

The undersigned:

First name: Initials:

Last name: male female

Position: student Ph.D. Researcher professor other:

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Affiliation:

Postal address of affiliation:

.....

Country:

Telephone number:

E-mail address:@.....

hereby undertakes to carry out work on the PROFILES data, in accordance with
the following conditions:

1. He/she undertakes to keep confidential any information in the PROFILES data concerning individual persons, households, enterprises or institutions which comes to his/her knowledge during the work on the data.
2. He/she undertakes not to distribute data of the PROFILES to others without written permission from PROFILES.
3. He/she undertakes to use the PROFILES data for purely scientific (i.e. non-commercial) research only.
4. He/she provides a copy of all publications based on the data to PROFILES.
5. He/she includes the following acknowledgement: In this paper use is made of data of PROFILES (Patient Reported Outcomes Following Initial treatment and Long-term Survivorship)" and refers to the European Journal of Cancer publication : *van de Poll-Franse LV, Horevoorts N, van Eenbergen M, Denollet J, Roukema JA, Aaronson NK, Vingerhoets A, Coebergh JW, de Vries J, Essink-Bot ML, Mols F; Profiles Registry Group. The Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry: scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. Eur J Cancer. 2011 Sep;47(14):2188-94. Epub 2011 May 27*
6. He/she refers to the European Journal of Cancer publication in the situation when normative data are being used: *van de Poll-Franse LV, Mols F, Gundy CM, Creutzberg CL, Nout RA, Verdonck-de Leeuw IM, Taphoorn MJ, Aaronson NK. Normative data for the EORTC QLQ-C30 and EORTC-sexuality items in the general Dutch population. Eur J Cancer. 2010 Dec.*
7. He/she refers to the JAMA publication in the situation when normative data from 2020 are being used: *van de Poll-Franse LV, de Rooij BH, Horevoorts NJE, May AM, Vink GR, Koopman M, van Laarhoven HWM, Besselink MG, Oerlemans S, Husson O, Beijer S, Ezendam NPM, Raijmakers NJH, Wollersheim BM, Hoedjes M, Siesling S, van Eenbergen MC, Mols F. Perceived Care and Well-being of Patients With Cancer and Matched Norm Participants in the COVID-19 Crisis Results of a Survey of Participants in the Dutch PROFILES Registry. JAMA Oncol. 2021 Feb 1.*
8. He/she includes a member of the PROFILES research group as co-author.
9. PROFILES does not grant exclusivity on the data or the subject. In the situation when proposals with a comparable subject will be submitted, PROFILES will try to find agreement between the different parties.
10. This statement shall remain valid, even after conclusion of the work of the PROFILES data.

Requested dataset(s):

Normative population:

- Normative data 2009
- Normative data 2010
- Normative data 2011
- Normative data 2012
- Normative data 2013
- Normative data 2014
- Normative data 2017
- Normative data 2018
- Normative data 2019
- Normative data 2020

Intended use of data (please describe the overall goal):

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Signature:

Date:..... Place:

Please return this statement to:

PROFILES, Antwoordnummer 10154, 5600 VB Eindhoven, The Netherlands;
or scan and e-mail to n.horevoorts@iknl.nl