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Title: Development of a framework and toolkit for patient and public involvement in cancer research focusing on patient reported outcome / experience measures

Background: Patient and public engagement and involvement in research is gaining increasing importance. The aim is to facilitate research being carried out with patients / members of the public rather than about them (<https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>). While patient engagement focuses on the sharing of information and knowledge about research with the public/ patients, patient and public involvement (PPI) in research intends to consult and collaborate with patients to help shape the projects in all stages of the research cycle. In Switzerland, some early attempts have already been made to facilitate PPI in cancer research (e.g. SAKK Patient Advisory Board of the Swiss Group for Clinical Cancer Research (SAKK <https://www.sakk.ch/en/about-us/patient-advisory-board>) and the platform “partenariat patient” from HUG in Geneva). PPI is particularly important in research with patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) (Haywood et al. 2014).

Aim: The aim of this project is to develop a framework and toolkits for patient and public involvement focusing on PROMs and PREMs in cancer research.

Method: Based on models developed in other countries (Carlton et al. 2020; Greenalgh et al. 2019) and in collaboration with a group of local stakeholders (patients, relatives, researchers, experts in PPI), we will adapt a framework and toolkit that can be used for a partnership with patients and public over all steps of research in the context of French Switzerland. The project will include site visits to different institutions (e.g. <https://www.pcori.org/>, <https://www.invo.org.uk/>) and interviews with international experts in the field. The framework and toolkit will be pilot tested in the local context.

Implications: Compared to other countries, PPI in cancer research is still in its infancy in Switzerland. The development of a framework and toolkits will support the incorporation of PPI into patient-reported outcome / experience measures. Furthermore, it will allow to plan research on the impact of patient and public involvement after its implementation.

References:

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