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FOUNDATION FOR THE RIGHTS OF
CITIZENS WITH OBESITY

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Reply to Open Consultation on the revision of the Belgian Patient Rights Law of 2002

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The Belgian Foundation for the rights of Citizens with Obesity warmly welcomes the proposed revision of the 2002 Patient Rights legislation.

We are **encouraged by the holistic view taken by legislative proposals** as to embedding legal rights for patients for access to health system services and related enablers such as access to data etc.

In this spirit, the Foundation for the Rights of Citizens with Obesity would like to provide the following comments. These comments are based on citizen-led research in partnership with VUB and KU Leuven presented as part of our Citizens' Rights Charter for the Rights of People Living with Obesity.

We would strongly encourage consideration of these points in the furtherance of the legislative development process and remain at your disposition for further dialogue.

Regarding definition of "Patient' in the context of the legislative proposal.

In Belgium, 60% of the population is living with obesity according to conservative estimates (only measured by surrogate population level marker of BMI). However, as obesity is not currently uniformly implemented as like other major chronic diseases by the Belgian health system for early diagnosis and screening, acute treatment and long term management, there are a number of people living with obesity who are not part of the health system.

Furthermore, due to the general lack of health literacy about the disease of obesity, our research further demonstrated across stakeholder groups (including health professionals, policymakers and citizens and patients) that the vast majority of people living with obesity in Belgium do not self-identify as "patients" and for the most part are not aware that they are living with a disease which is the chronic malfunctioning of their adipose tissue. As a result of all of the above, very few citizens living with obesity are accessing or even seeking to access health services and would therefore currently fall outside the scope of the proposed legislation. This situation would be in direct contradiction to the ethos and spirit of the legislative review.

We would therefore encourage a discussion around "citizens and patients" as part of a broader definition and scope for this legislative package.

Regarding Access to health data

Our research and related points in the Citizens Charter, clearly demonstrated that for people with obesity, being able to access a comprehensive dataset of our state of health is extremely important (primary use of health data). Currently, this is not the case.

Under the proposed text, our data sources may once more be excluded from scope for primary use of data purposes due to the fact that a significant proportion of ongoing long term management such as therapeutic physical activity, therapeutic nutrition may not be offered by a physiotherapist or other medical professional and hence will be excluded from the scope of the law on patient rights.

In addition, citizens and patients with obesity (regardless of if they self-identify as such or not) live with many co-morbidities and/ medical complications of obesity such as certain cancers, Type 2 Diabetes, Heart Disease Respiratory disorders as well as Mental Health and Neurological Disorders. ***Currently, there is no provision on the Electronic Health Record***.

We would very much welcome a broadening of scope of health data sources to include the right to include "consumer grade" or real world data in "personal data vaults".

We would further encourage policymakers to seek ways in which the rights of citizens and patients can benefit from the incoming Health Data Agency.

Read the Situational Analysis here

Find out more about the Citizens Rights Charter here