Response to the draft WHO European Roadmap for implementation of health literacy initiatives through the life course

Overall EuroHealthNet welcomes the Roadmap. It is a good summary for the specific purposes of the concept, which needs to be established by the Regional Committee of WHO and taken forward seriously. It identifies the main need, the main health sector situations and responses, and some channels which can be enhanced in the WHO context if taken up. It is good to see that strategic approaches are being developed. EuroHealthNet members should be at the heart of that and it needs to reach wider audience. So the two specific questions asked can be answered positively, it is relevant and reasonable.

In terms of the third question about omissions, we have the following concerns.

1. Given the pace and extent of the digital innovation in and transformation of the health sector (and society at large), a critical element of health literacy - digital health literacy – needs to be urgently addressed. It brings a new dimension to the ‘traditional’ health literacy approach, new opportunities and challenges, new stakeholders and actors that need to be sensitized on vulnerabilities, including the digital divide in access and technological skills.

2. The Roadmap starts with the (Nutbeam et al) basic definition from 1998, 21 years old. While being relevant however, the world has moved on. The paper alludes to it, without giving any clear indications of actually how it plans to address the vast gaps. Nutbeams definition doesn’t follow obvious steps like Access, Knowledge/information, Understanding, Application, Action. Furthermore the definition is mainly individually oriented. The definition can of course not be changed, so we propose an addition spelling out WHO’s view as a broader one also including the society and whole-of-society approaches.

3. We also recommend to introduce digital health literacy at the start, as an integral part of the roadmap, not just as an add-on. It could be strengthened all throughout the document and would serve as a positive sign of the WHO staying up to date and on top of such quick disruptive transformations of healthcare and society at large as digitalization. The paper is not yet making a compelling case for urgent shifts needed (especially in face of other competing priorities).

4. Scotland is cited as a good example, having a national strategy since 2014. So practical evaluation lessons would be good already. But of course the paper admits most states are lacking in approaches. EuroHealthNet is well aware of all this and has substantial experience, but it has not been consulted in earlier stages. Working with non state actors, multiple governance levels, civil society and commercial entities is mentioned as desirable but not elaborated. How can accountability, stewardship, effectiveness, equity and governance be assured? Who will actually be most involved in design as well as implementation planning of the Road Map?

5. There is scant evidence that patient/public involvement – as opposed to individual engagement and expectation in self-management – is being fully taken into account and
applied at outset. However, the paper discount the unwillingness and concerns of large parts of populations to take up new learning rapidly without clear and tangible incentives or explanation of risks, and overlook major cultural and social inequalities between communities and demographies. That is not just about formal education status, ageing or digital immigrants and natives, it is more complex.

6. Many people and public professionals are concerned by the growing inappropriate use of data. Often scientific benefit is assumed without clear consent, on the basis that social media and corporate sources already access it. Anonymity is promised but cannot be guaranteed. Those downsides are becoming more apparent. Knowledge is powerful: the lack of it can be stigmatised and abused.

7. The question of trust is far from resolved in digital applications. Most literacy initiatives (“innovations”) will, in reality, be delivered digitally and corporately from now on, including in health and education systems, where sources of knowledge are ever more controlled and delivered individually rather than shared collectively. That will offer some new opportunities, but can also be divisive, inequitable and in many cases not based on best evidence. This issue of trust and resistance must be better factored in.

8. We all know how easy it is to talk of working with “policy and decision-makers”, “other sectors” and at “all levels”, and how hard it is to “build capacities”. Other sectors are under pressure and do not seem to have been consulted systematically yet. This paper feels too ‘standalone’ at this stage (and in fact it is how it indicates itself in the opening analysis). Therefore, it risks being perceived as not central to how the world of delivery and co-creation of health has been already transforming itself. It’s behind digital, commercial, corporate and professional developments.

9. The paper should also make a more compelling case for health and financial policy makers and practitioners to shift their focus and resources. There is little on the nature of cost-effectiveness, problem and opportunity cost analysis, resources and resources shifts needed, including in sectors such as education. It should be completed with a return on investment analysis, and give strong health economics arguments.

10. Generally, the way health literacy is described between health systems/health promotion is unbalanced and more health promotion perspectives are needed. As it stands now health literacy is presented too much as a concept in itself, we prefer to link it with public health and health promotion and make those links concrete and visible so the added value of health literacy becomes significant.

We support this initiative in general and we understand this is work in progress. It may be a solution to split the paper into a political and a technical document. In a political document the main avenues can be outlined based on the Agenda 2030, SDGs and Health 2020 directions. Currently, the dimensions of human rights and inequalities in health are almost left out, and this must of course be taken on board. In a technical document the action points can be presented as a menu to be adapted and tailored to the given circumstances.

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