The Ophelia (OPtimise HEalth LIteracy and Access) Process

Using health literacy alongside grounded and participatory approaches to develop interventions in partnership with marginalised populations

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Roma populations in the Central and Eastern Europe live shorter lives and face greater burden of disease than their non-Roma neighbours (Cook, Wayne, Valentine, Lessios, & Yeh, 2013). For segregated Roma co-mmunities, where the health outcomes are ty-pically the worst, the core intermediate deter-minants behind the disparity are well docu-mented and known: radically poorer material circumstances, riskier health-related behaviours and greater health-care access barriers (European Union, 2014).

Several programs have been introduced to support Roma to live healthier lives but these have not generated many substantive impro-vements. Despite these findings, Roma health remains a European priority and there is strong policy promoting the need for innovative programs that generate improved outcomes while preserving Roma autonomy and cultural diversity (Koller, 2010).

In this setting, health literacy is a highly relevant construct. According to a recent WHO Health Literacy Toolkit from the South East Asia Regional Office (Dodson, Good, & Osborne, 2015), health literacy is the personal characteristics and social resources needed by individuals and communities to access, under-stand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions. The construct of health literacy is therefore of great importance when working with disadvantaged and marginalised groups who may have a range of educational, cultural and structural barriers that limit their access to and understanding of health info-rmation and health services.

This paper seeks to explore the potential of a newly developed, grounded and participatory approach to development of health-literacy and health-care access interventions for equity — the Ophelia (OPtimising HEalth LIteracy and Access) process (Batterham et al., 2014). The metho-dology involves undertaking a needs assessment of the target population using intensive qualitative and quantitative methods, developing vignettes of key sub-groups within the popu-lation based on their health literacy profile of strengths and weaknesses, and then engaging with frontline practitioners and community me-mbers in developing realistic solutions (Batterham et al., 2014). We will first review Ophelia's core components and then discuss why we believe this kind of approach might advance the current practice of interventions to promote health and access to timely healthcare within marginalized Roma.

The Health Literacy Questionnaire (HLQ) as a measure of health literacy needs

The HLQ was developed in partnership with patients, practitioners and managers in Australia and comprises nine separate dimensions that

Table 1
The Health Literacy Questionnaire scales with high and low descriptors of each construct*

Low level of the construct	High level of the construct
1. Feeling understood and supported by healthcare providers	
People who are low on this domain are unable to engage with doctors and other healthcare providers. They don't have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice.	Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.
2. Having sufficient information to manage my health	
Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns.	Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.
3. Actively managing my health	
People with low levels don't see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them.	Recognise the importance and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health. They make health a priority.
4. Social support for health	
Completely alone and unsupported for health.	A person's social system provides them with all the support they want or need for health.

(continued)

provide comprehensive information on health literacy abilities, strengths and needs, as well as indicators of the experiences an individual may have when attempting to engage with practitioners or a health service (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013). To assist users, practitioners and policymakers to understand the health literacy dimensions, the constructs were organised into clear high and low descriptors (Table 1). The HLQ has been translated and culturally adapted to many languages and is being used in over 30 countries.

The HLQ provides a fine-grained profile of the independent health literacy needs of individuals and their communities and therefore provides a framework for health workers to take action to build upon strengths and to introduce ways to improve weaknesses or assist people to compensate for weaknesses.

It is not always clear whose health literacy might be the most important (see Figure 1). When considering health literacy from an individual through to a whole-of-community perspective, integrated interventions that include the way individuals act, learn and behave within their family, with healthcare providers, and within their wider community can be considered. The intervention might include one-on-one coaching about risk factors, medical terminology or healthy food options, through to community-wide decision making.

The term 'interactive health literacy' proposed by Nutbeam (1998) includes literacy, but also social and other communication skills which enable a person to actively participate in everyday

activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances. The HLQ covers these skills and interactions very well (Osborne et al., 2013), but the emphasis in practice, however, needs to also include community-level empowerment. In marginalised communities, social cognitive processes need to be considered and this is akin to Nutbeam's asset-based model of health literacy (Nutbeam, 2008). The challenge now is how to build assets and empowerment at the individual, family and community level in partnership with marginalised communities such that substantive benefits are experienced by all members of the community in an equitable

Table 1 (continued)
The Health Literacy Questionnaire scales with high and low descriptors of each construct*

Low level of the construct	High level of the construct
5. Appraisal of health information	
No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information.	Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.
6. Ability to actively engage with healthcare providers	
Are passive in their approach to healthcare, inactive i.e., they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they do not understand. They accept what is offered without seeking to ensure that it meets their needs. Feel unable to share concerns. The do not have a sense of agency in interactions with providers.	Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional healthcare providers when necessary. They keep going until they get what they want. Empowered.
7. Navigating the healthcare system	
Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.	Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.
8. Ability to find good health information	
Cannot access health information when required. Is dependent on others to offer information.	Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.
9. Understanding health information well enough to know what to do	
Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms.	Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required.

* *Note:* Source: Batterham et al. (2014)

What is most important in determining health equity and outcomes?

– Is it the health literacy of the individual?
– Is it the health literacy of the person in the family who cares for domestic issues like buying and cooking food?
– Is it the average health literacy of people in a family?
– Is it the average health literacy of the individual's peer group?
– Is it the health literacy of the 'highest status person' in the individual's age group?
– Is it the health literacy of settlement leaders?
– Is it the health literacy of health navigators if they exist?

Figure 1. Levels of health literacy that are worth considering when seeking to improve health and equity outcomes in communities

manner.

The use of locally-derived vignettes – finding hearts and wisdom of those targeted

In Ophelia, the health needs assessment doesn't finish with aggregate HLQ numbers. Among its premises belongs the understanding that in many communities, self-determination down to the level of individuals (such as it strongly is the case among the segregated Roma) is paramount. Therefore, participatory approaches, which actively and overtly seek local wisdom, are often more effective – imported one-size-fits-all interventions may not match the distributions of local settings and priorities (Minkler & Wallerstein, 2011). While procedures for participatory community development have been in place for many years, e.g. the Asset-based community development (http://www.abcdinstitute.org/), the Ophelia process proposes a novel strategy for bringing the voice of all stakeholders to the table.

While the nine HLQ domains provide detailed profile of health literacy distribution and identify groups and subgroups with low, average or high health literacy, the application of a multivariate technique (cluster analysis) to HLQ data makes the data much more powerful. Cluster analysis groups together individuals with similar scores across each of the individual HLQ scales. From the HLQ scales, demographic and clinical data where available, as well as from qualitative interviews to obtain data on context and a sense of the daily challenges of individuals within the cluster subgroups, vignettes (i.e., scenarios or short stories) are developed. Such vignettes, which represent the range of individuals across a community, are profoundly engaging for stakeholders as they bring the HLQ data to life, enabling vivid visualisation of a range of community members (empirically selected), that become the focus in co-production workshops. In the Ophelia process about 5 to 7 vignettes are developed covering individuals with low, mixed and high health literacy scale score profiles (See Figure 2 for an example of a vignette). Community stakeholders are asked to respond to three questions:

(1) Do you recognise the individual in the story as someone living in your community?

(2) How can we work with this person so they have the best chance of getting and maintaining good health?

(3) If we have a large number of people like this in our community, how can we organise the community

1. Feeling understood and supported by healthcare providers	2. Having sufficient information to manage my health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability of actively engage with health care providers	7. Navigating the health system	8. Ability to find good health information	9. Understanding health information well enough to know what to do
Very High	**Low-moderate**	**Moderate-high**	**Modera te-high**	**Low-moderate**	**Low**	**Low-moderate**	**Very low**	**Low**

Giovanni is a 73 year old Italian man whose wife died 3 years ago. He now lives alone. Giovanni has type 2 diabetes and arthritis, and was recently diagnosed with heart failure. Although he trusts everything the doctor tells him and tries to follow instructions (scale 1), he gets very confused about how to manage all his new heart failure medications, and his fluid restriction (scales 2 and 9). He never feels certain that he is actually doing the right thing. He doesn't feel right about asking questions of the doctor (scale 6) because he was brought up to never question what a doctor says. He doesn't really look for information elsewhere either (scale 8). His daughter helps when she can (scale 4), but she doesn't always have the knowledge to explain things to him. The doctor referred him to a lifestyle education program at the community health center, but a lot of the information seemed very complicated, and because it doesn't come from his doctor, Giovanni doesn't try to take it all in.

(Giovanni is likely to score poorly on a health literacy screening test due to his poor reading and writing (scale 9) but this is partly compensated by his good relationship with his doctor. Health literacy interventions could focus on strengthening his social support further (scale 4) and building trust in the advice of social care services (scales 6) and provision of information endorsed by his doctor.)

Figure 2. Vignette representing a health literacy profiles derived from the nine dimensions of the Health Literacy Questionnaire (HLQ). Overall, this person doesn't really understand what to do, but would trust the doctor

to ensure they have the best chance of getting and maintaining good health?

While the questions are slightly reframed for professionals, the same vignettes and same rich discussion unfolds. A full range of ideas for improvement, redesign, or novel interventions are volunteered from stakeholders and these are organised into level of the system targeted for improvement (individual, family, community, practitioner, organisation or inter-agency). The ideas are then prioritised by local stakeholders for action and referenced against the published literature.

The marginalized Roma, health-mediation and Ophelia's promises

As indicated above, marginalized Roma might represent an ideal place to implement a wide range of published, well-tested public health interventions, each aspiring to be evidence-based, practical and scalable. It is critical to recognise that segregated communities have profound challenge, and compared to their non-Roma counterparts have: worst health: materially most deprived: worst socioeconomic position: in many respects quite heterogeneous both across and within communities. Plus, as it has been well documented for Roma and analogous groups across the continent (Stewart, 2013), the observed 'multi-dimensional social exclusion' is also supported also by a consistent practice of self-exclusion based on a counter-cultures understanding particular aspects of non-Roma

Table 2
The Health Literacy Questionnaire scales with high and low descriptors of each construct

Original domain title	How most marginalized Roma might understand it*
1. Feeling understood and supported by healthcare providers	The healthcare providers are polite, not blaming for arising health needs, avoid technical healthcare jargon and take time to explain and facilitate more complex clinical procedures (medication intake, visits by other specialists, etc.)
2. Having sufficient information to manage my health	Feeling capable of distinguishing safely between serious and minor health issues, and of arranging for appropriate HC involvements with respect to the former; especially when children involved
3. Actively managing my health	Having (non-Roma like) interest in health issues; Taking care of minor health issues without involving HCP; Deliberately following generally known clinical or public health recommendations with respect to serious health issues
4. Social support for health	Having enough relatives in the extended family in the community of residence (solidarity in health issues comes here automatically within such social networks)
5. Appraisal of health information	Having some basic theoretical biomedical knowledge (= much higher than present level of formal education)
6. Ability to actively engage with healthcare providers	Sufficient income (access barrier), personal confidence and practical experience in dealing with the (mostly non-Roma) HCP
7. Navigating the healthcare system	Sufficient income (access barrier), personal confidence and good practical knowledge of the HC system procedures (including patient rights and legal obligations of the HC providers)
8. Ability to find good health information	Access to and proficiency in the use of the Internet + Good appraisal of health information
9. Understanding health information well enough to know what to do	Ability to understand technical HC language (= much higher than present level of formal education)

Note: * assessement based on: Belak, A. (2013). Health-system limitations of Roma health in Slovakia: A qualitative study. Bratislava: WHO Country office in Slovakia.

ways as socially and morally inappropriate (see also Table 2).

While this combination of challenges may sound intractable, over the last decade, in isolation from both government agencies and scientific communities, a new trend has emerged in the region, initiated by small local NGOs, which appears unprecedentedly promising – health-mediation for marginalized Roma communities (Open Society Institute, 2011; World Health Organization, 2013). Despite many voids

at the formal level, at least some of the programs appear to be very successful in their actual practice: apart from significantly decreasing healthcare access barriers, they also seem capable of dramatically increasing particular communities' social capital and improve their infrastructure directly significant for health (Dodson et al., 2015).

Ophelia appears capable of passing the "marginalized Roma acceptability test" because aspects that are working well in the health-

mediation programs are based and operationalized in a very similar way to Ophelia: they focus on broadly defined health-literacy elements including structural aspects such as healthcare access: participatory approach to health-needs assessment: and participatory approach to development of solutions through networking with other local stake-holders. In fact, the resonance between the emergent grass-roots processes of the health-mediator program and the formalised Ophelia process is so striking, the health-mediator leadership in Slovakia – since last year including the Slovakian Ministry of Health - have approached our team to apply HLQ as a key element of the evaluation to formally assess the impacts of health-mediator intervention.

Going forward: Health literacy development and equity.

The use of local HLQ data (or other relevant health literacy data) that captures the voice of the target populations and feeds into real-world vignettes, uses co-production and local priority setting, not only assists with ensuring intervention are fit-for-purpose, but also increases trust and commitment by stakeholders to implement them. The Ophelia process is a promising mechanism to enable systems-level improvements. The evaluation of many current Ophelia projects will help this novel approach mature and hopefully generate wide ranging benefits across marginalised and other population groups experiencing health inequalities.

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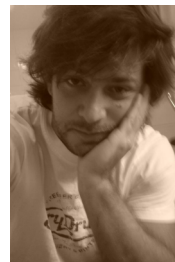
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