

# **Submission to Dept. of Health**

## Universal Health Insurance

**Pavee Point Traveller and Roma Centre**  
May 2014



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TRAVELLER AND ROMA CENTRE

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## Summary of recommendations

Travellers experience stark inequalities in health, including mortality outcomes, problems with quality, and trust in relation to the services. It is also acknowledged by health providers that they and their services discriminate against Travellers (as evidenced in the All Ireland Traveller Health Study).

Pavee Point holds to the principle that in order to achieve equality for Travellers and Roma, attention must be paid to the structural determinants/ issues that impact on them, including education, employment, poverty, health, discrimination and racism. This means that policy and practice must be underpinned by an inter-cultural approach and by principles of equality, diversity and anti-racism.

There is a need for an urgent response and positive action to address the current and historic discrimination, and to address the determinants that are leading to these unacceptable inequalities. Travellers and Roma should therefore be considered as important stakeholders in the development of health services and practice. The establishment of UHI and structures proposed under the White Paper must ensure that these principles are acted on.

Those with greater health needs and poorer health status will be disproportionately affected by issues and deficiencies in a health system. We hold that the proposed system of Universal Health Insurance (UHI) has the potential to address health inequalities, or exacerbate them, leading to even greater disparities in health outcomes for Travellers and Roma. Our response and recommendations to the White Paper are outlined below.

The World Health Organisation (WHO) describes the importance of robust mechanisms for ensuring accountability, participation, and outcomes' measurement, and Pavee Point endorses and strongly urges the institutionalisation of these mechanisms:<sup>1</sup>

Fair progressive realization of UHC requires tough policy decisions. Reasonable decisions and their enforcement can be facilitated by robust public accountability and participation mechanisms. These mechanisms are essential in policy formulation and priority setting and specifically in addressing the three critical choices on the path to UHC and the trade-offs between dimensions of progress. These mechanisms are also crucial in tracking resources and results. To properly play these roles, public accountability and participation should be institutionalized, and the design of legitimate institutions can be informed by the Accountability for Reasonableness framework.

A strong system for monitoring and evaluation is also needed to promote accountability and participation and is indispensable for effectively pursuing UHC in general.

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<sup>1</sup> World Health Organisation (2014) Making fair choices on the path to universal health coverage: Final report of the WHO Consultative Group on Equity and Universal Health Coverage (p. xii)

Countries must carefully select a set of indicators, invest in health information systems, and properly integrate the information into policy making. The selection of indicators should be closely aligned with the goal of UHC and in most settings include at least four types of indicators: indicators related to the priority-setting processes and indicators of coverage, financial risk protection, and health outcomes. The latter three types of indicators should reflect both average levels and equity in distribution.

### **IMPLICATIONS OF THE HABITUAL RESIDENCE CONDITION (HRC)**

1. The possibility of people may be denied health services on the basis of not meeting the HRC conditions is of critical importance, and must be reviewed as a matter of urgency.
2. Moreover, any transition to a system of UHI must ensure a rights-based system of access to healthcare, irrespective of the existence or otherwise of the HRC. Non-compliance with HRC criteria will not be a basis for exclusion from health services, whether tax-funded or UHI funded. This needs to be explicitly stated.

### **MONEY FOLLOWS THE PATIENT (MFTP)**

3. The new system and regulatory provisions to be established must ensure that quality of care is not undermined by targets or volume. This risk must be acknowledged as otherwise health inequalities could be exacerbated. The design and implementation of the regulatory environment and structures established to monitor must provide for the participation of representatives of Travellers and Roma communities, in order to ensure that the system is person-centred and needs based.

### **COST OF THE DUTCH SYSTEM AND IMPLICATIONS**

4. The implications for Travellers and Roma of higher costs (as experienced in the Dutch system) are serious – the reintroduction of a two-tier system through undermining the standard basket of services will disproportionately impact on Travellers and Roma, who are amongst the most disadvantaged communities in Ireland, and have more health difficulties, compared with the rest of the population. Travellers and Roma also experience educational disadvantage (and experience greater literacy difficulties which could compromise treatment).<sup>2</sup>
5. A system dominated by profit-motivated insurance companies, whereby hospitals compete with each other on the basis of cost poses serious risks of

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<sup>2</sup> For example, 'Our Geels' the All Ireland Traveller Health Study (2010) reported that more Travellers expressed difficulty with day-to-day literacy issues. Comprehension of written instructions provided with prescription medicines, providing a measure of practical and functional literacy, is lower amongst Travellers in the Republic of Ireland (ROI) (49.6%) compared with the settled population who are medical card holders (9.4%). The report concludes that this would constitute a significant health concern. The same study found that a third of respondents in ROI (31.3%) were on some form of prescribed medication, rising in a graduated manner to 77.9% of those aged 65 years and older in ROI.

further exacerbating health inequalities. The pressure of limiting costs could undermine emphasis on quality of treatment.

6. It is essential that prior to any UHI system introduction, a comprehensive commitment to equality of access for all in Ireland, with a particular emphasis on those who experience health inequalities, such as Travellers and Roma, is developed in collaboration with representative organisations including Pavee Point and other Traveller representative groups. A rights-based approach to health services must be enshrined in the legislative provisions giving rise to the UHI system.
7. Moreover, it is critical that there is a stated and explicit commitment to preventative actions as the basket of services being developed.

### **GP SERVICES**

8. It is essential that a period of capacity building in the health system is undertaken prior to any new system. This includes ensuring that sufficient GP services are in place to meet the population needs, and likely increased demand for GP services.
9. At present, GMS patients are required to register with a different GP if they move to different areas. This disproportionately affects Travellers and Roma communities, given the communities' nomadic culture, and can restrict access to GP services. This can exacerbate already health inequities and compromise continuity of care, and this requirement should cease immediately.

### **REGULATION OF HEALTHCARE PURCHASERS AND PROVIDERS**

10. Health insurers should have no role in diminishing the standard basket of health services, or rationing of health services, and the State should underwrite access to a standard basket of services in all cases. Health insurers should have no veto (over clinical recommendations) with regard to access to health services and treatments.
11. The introduction of UHI should not be disadvantageous for those on low incomes currently in receipt of medical cards. The State must underwrite provisions such that current entitlements to people in receipt of medical cards should be guaranteed as minimum provision under UHI. Moreover, out of pocket payments currently in operation (for example, for prescription charges) should not apply under the new system.
12. The State will adopt a stronger regulatory role of insurers and health providers under the proposed model. It is crucial that in designing these regulatory structures, that principles of participation and equality are cornerstones.

13. All regulatory structures of the State should ensure that a rights-based approach and principles to access to healthcare underpins policy and operations. Moreover, the principles for inclusion and equality, identified in this submission should be adopted as cornerstones of an effective and inclusive healthcare service. As such, the proposals in this submission should be included as important criteria in the licensing, implementation, and monitoring provisions undertaken within the new regulatory structures.
14. There must be in Inclusion of a commitment to Equality / Traveller/Roma proof UHI documents, including the basket of services proposed, and regulatory strategies and actions.

### **FUNDING OF SERVICES**

15. We strongly urge that the current primary health care project, as currently delivered to Travellers throughout Ireland continue to be resourced as part of tax-funded health services. The PHCTP's values of empowerment, participation, partnership and advocacy should be core to the design and implementation of tax-based health services. The UHI should present opportunities for greater integration between PHCTP initiatives and UHI and non-UHI (tax-funded).
16. Moreover, in the preparations for UHI, the PHCTP should be resourced to engage with local, regional and national initiatives developed in the lead up to the new system. Moreover, PHCTP should be resourced to commit extra resources to working with Travellers to support them in navigating the new system.
17. There should be a requirement for health services (both tax-funded and UHI-funded) to address the needs of marginalised and ethnic groups such as Travellers and Roma through a series of training, equality mainstreaming and proofing measures to secure greater integration between services (this is also discussed below in terms of regulation).
18. In terms of integration of primary health care principles (as outlined above) with general (and UHI funded) health services, a structured, inter-organisational response involving defined mechanisms to facilitate communication, information-sharing and collaboration should be provided for.

### **ELIGIBILITY MEASURES FOR LOW INCOME HOUSEHOLDS**

19. There will be no medical card provision in the new system, but the State proposes to fund USI for low income groups in society, such as current medical card holders. Pavee Point have already called for a period of time during which Travellers would retain their medical card (following access to employment or after they are no longer eligible for medical cards) in light of Travellers' poorer health status and experience of discrimination. We propose that the USI

funding system includes this provision for marginalised groups such as Travellers and Roma, providing extended coverage to account for this disadvantage.

20. Health services that are both tax-funded and insurance funded should be free at the point of access, with no out of pocket expenses, as research has indicated that health insurance models implemented internationally have resulted in poorer outcomes for those with greater healthcare needs. This would include repealing of prescription charges.

#### **PREPARATORY ACTIONS**

21. The process of developing a values framework must take into account specific cultural and health needs of relevance to marginalised and ethnic groups, such as Travellers and Roma, and this consideration must be core to the development of a values framework. All emerging and proposed frameworks should undergo a process of equality impact assessment. Representative organisations for ethnic and marginalised communities (including Travellers and Roma) must be part of decision-making structures, as well as implementation and regulating bodies.
22. This process of updating the values framework should include explicit reference to key marginalised and ethnic groups in Ireland (including Travellers and Roma) as important participants in the process.
23. We would urge that a rights-based approach to healthcare be incorporated into the vision statement as provided for in the White Paper (p.17)
24. We would urge the inclusion of 'equality of health outcomes' as one of the core principles that underpin the design of the future system. This should ensure that targets and outputs are put in place as part of provisions in the future system.

#### **DECISION-MAKING AND PARTICIPATION**

25. There should be a representation for marginalised groups on decision-making bodies, including the Commission to be established in implementing the proposals and preparatory actions. There should be at least one specific position for Traveller and Roma representation.
26. Working groups should be established around issues of positive action, equality, and inter-culturalism, with mandatory inclusion of Traveller and Roma representatives, as part of the preparatory measures.

#### **CONSULTATION PROCESSES**

27. For all consultation mechanisms proposed, specific engagement must take place with the Traveller and Roma communities, and this engagement should be developed and designed alongside Traveller and Roma organisations.
28. In addition, we believe that a process of consultation with Travellers and Roma in Ireland be undertaken on an ongoing basis, at key junctures in the development of the new system, and in addition to the participation of Traveller and Roma representatives on formal decision-making structures established.

### **EQUALITY PROOFING AND MAINSTREAMING**

29. All proofing measures should be overseen by a steering or working group comprised of stakeholders, including Traveller representatives, staff of the organisation (including senior management), board representation, and it should be resourced by staff members. Actions proposed as part of a proofing process should be referred to the board as recommendations.

### **NEEDS ANALYSIS AND EVIDENCE-BASED POLICIES**

30. The difference in demography between the majority population and Traveller community is important to highlight in the planning of future services, and must be taken into consideration in any needs analyses which will give rise to future planning of services and provisions in UHI. In particular, the findings of the All Ireland Traveller Health Study (AITHS) must be core to these considerations.
31. In order to identify needs, gaps in services, and difficulties in access, it is imperative that an ethnic identifier be introduced across all health services.

### **CULTURALLY APPROPRIATE SERVICES**

32. There is no current Traveller health strategy in place in Ireland. We believe that this provides a poor basis for ensuring that the Traveller and Roma communities' needs are met in any UHI provision, given their experiences of discrimination, poor accommodation, educational disadvantage as well as poorer health outcomes and difficulties in accessing a range of services. Prior to the introduction of UHI, there must be an updated Traveller Health Strategy, based on AITHS findings, with a detailed action plan, timeframe and framework for reporting and accountability. The Department of Health should advocate for this to take place as a matter of priority.
33. Health Services must provide a culturally appropriate health service to Travellers, to ensure that the health service reflects their needs and responds to their concerns. This will ultimately achieve better health outcomes for



Travellers as a result of enhanced access to healthcare provision. This must be led by the Department of Health, and involving discussions with Traveller representative organisations such as Pavee Point.

34. All UHI proposals that will be forthcoming must be equality proofed for their impact on Travellers, Roma and other groups (under the nine grounds of equality legislation) as to how such radical change to the system will impact on them.

#### **INFORMATION AND DATA COLLECTION**

35. There should be mandatory implementation of an ethnic identifier for all users of the services. This would support the identification of needs, combat racism and discrimination, promote equality, monitoring progress of programmes and policies and provide a basis for evidence-based policy-making and service provision.
36. Pavee Point continues to call for the recognition of Travellers as an ethnic group and for the implementation of an ethnic identifier to provide better services to minority groups.

### **1.1. HR and capacity building measures for health services**

#### **TRAINING**

37. Anti-racism and cultural awareness training should be mandatory, and repeated at regular intervals for all staff involved in health services, as well as staff and management in regulatory structures established in the new system. Such training should include provisions on the experience, situation and identity of Travellers and Roma in Ireland, as well as the policy dimension and how these affect Travellers. The Department of Health should enforce this provision.

#### **RECRUITMENT AND MONITORING**

38. As part of the recruitment process of staff, criteria for employment and job descriptions should include provisions for a commitment to anti-racist and equality perspective. Job descriptions of staff should also reflect this perspective in terms of essential skills.
39. The performance management system for the public sector (PMDS) for those staff who will be public sector employees, should also provide include wider criteria in their measurement of performance to include outcomes in terms of progressing equality for Travellers and Roma in Ireland.
40. Given the importance of adopting principles of inter-culturalism and equality, we would urge the Department of Health and regulatory structures established

to target the employment of Travellers and Roma in any future recruitment processes, and to advocate this with health services that they are overseeing and licensing. This would enhance the capacity of the agency and include the expertise of these communities.

#### **POSITIVE ACTION PROGRAMME**

- 41.** Drawing on good practice, and other good practice positive action measures documented by the HSE's Traveller Health Unit (Eastern Region),<sup>3</sup> we recommend a programme for positive action for key positions across health services be established. A working group, comprising senior management from the Department of Health, representatives of the health service providers and insurers, regulatory structures (e.g., HIQA) and Traveller and Roma representation would be convened to oversee the process.

#### **CULTURAL IDENTITY**

- 42.** This right to a cultural identity should underpin all values, policies and practices of health care provision, whether tax-funded or UHI funded, and all decision-making, implementation and regulatory structures established should be required to explicitly acknowledge this right.

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<sup>3</sup> For a model and examples of positive action measures within the HSE and the public sector as a whole, see TSA Consultancy (2007): *Toolkit and Guidelines for the Employment of Travellers in the Health Service Executive*. Dublin: HSE, Traveller Health Unit Eastern Region

## **2. Introduction**

### **2.1. Pavee Point Traveller and Roma Centre**

Pavee Point Traveller and Roma Centre (‘Pavee Point’) welcomes the opportunity to make this submission to the Department of Health regarding the proposals to introduce Universal Health Insurance (UHI) in Ireland.

Pavee Point is a voluntary, or non-governmental, organisation committed to the attainment of human rights for Irish Travellers and Roma. The group is comprised of Travellers and Roma, and members of the majority settled population working together in partnership. The aim of Pavee Point is to contribute to improvement in the quality of life and living circumstances of Irish Travellers and Roma<sup>4</sup> through working for social justice, solidarity, socio-economic development and human rights.

Our work involves research, local action, aware-raising, national resourcing and policy advocacy, and we undertake a community work approach based on the principles of human rights, equality, cultural diversity and inter-culturalism. Amongst the activities we undertake are training, technical support, information and communications resources.

All our work is undertaken using a community development approach, which seeks to challenge the causes of disadvantage / poverty and to offer new opportunities for those lacking choice, power and resources. Community development involves people experiencing disadvantage being the active agents in making changes they identify to be important. It supports them to draw upon their own knowledge and experiences to develop their skills. Crucially, it is based on the premise that policies, programmes and services intended to tackle or eliminate poverty are much more likely to be efficient and effective if the people who are part of communities affected by poverty and disadvantage are involved in the design and implementation of solutions.

We also recognise the importance of Traveller participation, self-determination and collective action, and also that the majority of the problems that Travellers experience are as a result of racism and a failure to recognise them as a minority ethnic group.

### **2.2. Health work of Pavee Point**

Our work is undertaken at national, regional and local level.

At a national level Pavee Point resources the National Traveller Health Network which is a national forum for all the Traveller PHCTPs in the country. Pavee Point represents

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<sup>4</sup> “Roma” used at the Council of Europe refers to Roma, Sinti, Kale and related groups in Europe, including Travellers and the Eastern groups (Dom and Lom), and covers the wide diversity of the groups concerned, including persons who identify themselves as “Gypsies”.

Travellers on a number of national committees including the National Traveller Health Advisory Committee (NTHAC) and the Traveller Health Advisory Forum (THAF).

At a regional level Pavee Point coordinates and provides technical support to the Traveller Health Unit (THU) in the Eastern Region. We also resource the Eastern Regional Traveller Health Network (ERTHN) which is a regional network of Travellers and Traveller organisations and other Non Government Organisations (NGOs) working with Travellers, who are committed to addressing health inequalities experienced by Traveller. Pavee Point work closely with the THU in the development of standards and models of best practise for Primary Health Care for Travellers Projects (PHCTPs), and also provide training and support for Coordinators, Assistant Coordinators and Community Health Workers of PHCTPs.

The main focus of the work at a local level is through the Primary Health Care for Travellers Project (PHCTP). The other local projects undertaken by Pavee Point is the Traveller Men's Health Project.

### **PRIMARY HEALTH CARE PROGRAMME**

Primary Health Care has been identified and used as an innovative approach to health care in the developing world. In the last decade there has been a growing interest and demand for such a service in the developed world as evidence from studies indicate that the expanding marginalised populations here are suffering disproportionately from poor health and have less access to health care services.

**Primary Health Care (PHC) is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community, through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It is the first level of contact of individuals, the family and community with the national system, bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.**  
*Alma Ata Declaration, 1978 (WHO/UNICEP)*

It is a flexible system which can be adapted to the health problems, the culture; the way of life and the stage of development reached by the community. Successful Primary Health Care Projects have emphasised a process that valued empowerment, partnership and advocacy when designing and implementing health care interventions. This allows the partners to highlight inequity and negotiate solutions with their relevant partners. Community participation and inter-sectoral collaboration are key requisites for the success of Primary Health Care.

Travellers require special consideration in health care because:

- They are a distinct cultural group with different perceptions of health, disease and care needs.

- These distinct characteristics imply that innovative approaches to service organisation, content and delivery are required if health conditions are to improve.

The PHCTP was established as a joint partnership initiative with the Eastern Health Board (EHB) and Pavee Point and began as a pilot initiative in 1994 with funding from the Eastern Health Board.

The Report of the Task Force on the Traveller Community (1995) and the National Travellers Health Strategy (Department of Health and Children, 2002) have both strongly endorsed the work of the PHCTP and recommended its replication. The National Travellers Health Strategy set many targets which are dependent on the development of an effective and inclusive local Traveller health infrastructure and recommended that the PHCTP are the ‘cornerstone’ of the strategy and should be developed as an effective mechanism to facilitate the implementation of its actions. Many Travellers participate in the PHCTP throughout the country. Since 2002, 40 PHCTPs have been established around the country and they have trained more than 300 Traveller women as Traveller Community Health Workers (TCHWs).

The programme has the following objectives:

- To establish Primary Health Care as a model of good practice to address Travellers’ health
- To develop the skills of Travellers in providing community based health services
- To liaise and assist in dialogue between Travellers and health service providers
- To highlight gaps in health service delivery to Travellers and work towards reducing inequalities that exists in established services

This model of Primary Health Care for Travellers requires the use of a Community Development approach, engagement with health service providers, and effective Traveller participation to address the specific and collective needs of the Traveller community. The PHCTP employs two joint coordinators one with a health remit and background, the other with a community development approach. The work of the project is based on outreach work in the community with Traveller families. It also provides training on Traveller culture and specific Traveller health needs to service providers and other Traveller groups. Traveller Community Health Worker’s experience and understanding of the needs and concerns in their community is both comprehensive and extensive.

The work of the PHCTP was highlighted in the All Ireland Health Study as follows:<sup>5</sup>

- Significant sources of information trusted by Travellers (particularly for those with literacy problems) were the health care teams and Traveller health workers. Travellers indicated that in addition to information, the PHCTP crucially provided informal support and a network for information exchange and were more tuned-in to the specific health issues that Travellers faced.

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<sup>5</sup> Further information on the findings of the AITHS with regard to the health of Travellers and with regard to the impact of the PHCTP on Travellers’ health is outlined in section 2 of this submission.

- 83% of the Travellers interviewed said they got their health information and advice from the PHCTP and from the Travellers organisations. The PHCTP was the second most important source of health information for Travellers in Ireland after GPs.
- Traveller women thought that outreach services like the PHCTP facilitated Traveller trust. This was reported to enhance the uptake and use of services such as screening as borne out in the census data when Traveller health community workers were able to mediate between the services and individual Travellers in the community.
- Traveller projects were also said to have positive psychosocial benefits for those involved in the projects and for particularly vulnerable individuals. Concern about the closure of projects was also frequently expressed in Traveller narratives.

The All Ireland Traveller Health Study (Our Geels) is highlighted below.

#### **'OUR GEELS', ALL IRELAND TRAVELLER HEALTH STUDY (AITHS)**

Pavee Point supported the design, implementation and publication of Our Geels,<sup>6</sup> an all island of Ireland ground breaking piece of research conducted over three years on the Health needs of Irish Travellers. The study was undertaken by the UCD School of Public Health and Population Science in partnership with Traveller organisations and it was funded by the Departments of Health and published in September 2010.

This research was grounded in the community development approach to address Traveller health inequalities adopted by Pavee Point using a primary health care model since 1994. This approach ensures that Travellers are involved at all stages of the development and delivery of the project. It facilitates the involvement of both literate and pre-literate participants and can therefore be inclusive of those most marginalised in the community. It addresses the causes (social determinants) of ill health rather than just dealing with the consequences (health inequalities). The findings of the study are outlined in section 3.1.

#### **CONTEXT FOR SUBMISSION - UNIVERSAL HEALTH INSURANCE**

In April the Government published the White Paper on Universal Health Insurance, which promises to totally transform the way the Irish health service is structured and funded. The Department of Health notes that it recognises 'the importance of consulting extensively and inclusively with all interested parties' and views the consultation process as 'a valuable opportunity for citizens to contribute to the development of policy on the future of their health system.'

This submission is made to the Department of Health in order to outline our position on the implications and risks of the model of Universal Health Insurance (UHI) for Travellers and Roma. We make proposals based on the model of UHI proposed, on the basis that the certain details of the model are not yet detailed, and a costing exercise is currently taking place.

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<sup>6</sup> Our Geels means 'our community/lives' in Cant, Travellers own language.

We also make recommendations around general themes of good practice, including participation in structures, training and awareness, data collection and monitoring.

The format of the submission is as follows:

- Section 3 provides an outline of the profile and experiences of Travellers and Roma in Ireland and key issues affecting them, particularly as regards health.
- Section 4 outlines our response to the White Paper, and our proposals to advance equality for Travellers and Roma in Ireland, in the context of UHI.
- All recommendations are summarised in section **Error! Reference source not found.**

## 3. Travellers and Roma in Ireland

### 3.1. Travellers in Ireland

The number of people enumerated as Travellers in Census 2011 was 29,435, an increase of 32% since census 2006. All counties apart from Limerick and Waterford showed increases in the Traveller population that were larger than the increase in the general population.<sup>7</sup> The figure compares with 36,224 population of Travellers enumerated in the Traveller All Ireland Health Study (AITHS).<sup>8</sup>

#### AGE PROFILE OF TRAVELLERS

Census 2011 reports that the general age profile of Travellers is far lower than the population as a whole. This is an important consideration in planning health services.

- The average age of Travellers was 22.4 years compared with 36.1 years in the national population, and over half of Travellers (52.2%) were aged under 20 years.
- Traveller males of retirement age and above (65+) numbered only 337 accounting for 2.3% of the total Traveller male population, in stark contrast to the general population where males of retirement age and above accounted for 10.7% of all males.
- Traveller children account for 48% of the total Traveller population, whereas all children in the census account for 25% of the total national population.
- The number of Traveller children increased by 30.3% between 2006 and 2011.

#### HEALTH

In 2010, 'Our Geels', the All Island Traveller Health Survey (AITHS) was published. Key findings included:

- Life expectancy at birth for male Travellers is 15.1 years less than the general population, as 61.7 years. This is the same life expectancy age as found in research undertaken in 1987. The 2010 data represents a widening of the gap by 5.2 years (between 1987<sup>9</sup> and 2010). This is equivalent to the life expectancy of the general population in the 1940s. There are, however, marginal increases in male Traveller life expectancies at later ages. However, men in the community continue to have higher rates of mortality for all causes of death.
- Life expectancy at birth for female Travellers is now 70.1 which is 11.5 years less than women in the general population, and is equivalent to the life expectancy of the general population in the early 1960s. This has improved from 1987 when life expectancy was 65 years.
- Traveller infant mortality is estimated at 14.1 per 1,000 live births. This is a small decrease from an estimated rate of 18.1 per 1,000 live births in 1987. Over the

<sup>7</sup> This increase was attributed to a greater disclosure amongst the population as regards their ethnic status and identity following collaboration between Pavee Point and the CSO.

<sup>8</sup> All Ireland Traveller Health Study Team, School of Public Health, Physiotherapy and Population Science, University College Dublin (2010) *All Ireland Traveller Health Study: Our Geels*.

<sup>9</sup> When the last health study was completed.



same time period the general population infant mortality rate has reduced from 7.4 to 3.9 per 1,000 live births.

- There have been improvements in Traveller women's health, notably (1) a narrowing the gap in life expectancy between Traveller and non-Traveller women of 0.4 years, (2) reduction in fertility rates to 2.7 per 1,000 population and (3) uptake of cervical screening at rates higher than the general population and uptake of breast screening at rates similar to the general population.
- Access to health services is good, with Travellers stating that their access is at least as good as that of the rest of the population. Access to primary care services is an important element of health services delivery. Over 94% of Travellers have a medical card with this figure rising to 99% in the older age group and nearly 97% of all Travellers are registered with a GP. The aforementioned Traveller Primary Health Care Project delivers primary health to Travellers, and plays a key role in supporting access to and information about health services. The study found that 83% of the Travellers interviewed said they got their health information and advice from the PHCTP and from the Travellers organisations.
- Traveller women thought that outreach services like the PHCTP facilitated Traveller trust. This was reported to enhance the uptake and use of services such as screening as borne out in the census data when Traveller health community workers were able to mediate between the services and individual Travellers in the community. As a result, Traveller women have a higher rate of participation in screening programmes compared with the general population:
  - 25% of Traveller women compared to 13% of general population had a breast screening.
  - 23% of the Travellers had smear test compared to 12% of general population.
- Moreover, the location of PHCTP was positively correlated with improved access to health services, and the PHCTP were second most frequent contact after GPs for health advice.
- The research reports that the general healthcare experience of Travellers is not as good as the general population, with communication cited as a major issue by both Travellers and service providers. Moreover, trust in services is a theme, and the AITHS found that the level of complete trust by Travellers in health professionals was only 41%. This compares with a trust level of 83% by the general population in health professionals. Moreover, barriers of access to health services were identified in the research and included:
  - Waiting list (62.7%)
  - Embarrassment (47.8%)
  - Lack of information (37.3%)
  - Cost (31%)
  - Difficult to get to (25%)
  - Health settings (22%)
  - Refused service(15%)
- Regarding the incidence of specific illnesses, Travellers have a greater burden of chronic diseases than the general population, with conditions such as back conditions, diabetes, and heart attack increased by a factor of 2, and respiratory conditions such as asthma and chronic bronchitis increased by a factor of 2-4, in

comparison with the general SLAN<sup>10</sup> population. The AITHS also reported the following:

- Over 52% of Travellers aged 40 – 60 years, who were interviewed, had been diagnosed with high blood pressure in the last year, compared to 35% of the general population.
- Over 42% Travellers diagnosed with high cholesterol in last year, compared to 30% of the general population.
- 31.3% of Travellers are on some form of prescribed medication
- Just under half of all Travellers feel discriminated against. This is experienced in all aspects of life. However, least discrimination is experienced in sport, followed by the health sector. Travellers have a strong sense of community and high levels of community/family support.
- Suicide rates are nearly 7 times higher in Traveller men compared with the general male population. Suicide accounts for 11% of all Traveller deaths.

The AITHS findings reported that both Travellers and health service providers interviewed acknowledged that ‘social determinants’ were the main cause of the poor health status of Travellers, this includes accommodation, education, employment, poverty, discrimination, lifestyle and access and utilisation of services.

Pavee Point works on the basis of the ‘social determinants’ approach. In this respect the following considerations are relevant in determining the health status of Travellers:

- A study commissioned by Pavee Point in 2013 reports that a third of all Travellers who live in temporary accommodation have no sewerage disposal and one in five have no piped water.<sup>11</sup> The same study noted that Travellers live in smaller and more overcrowded homes than the settled community.
- The same report shows a fall in allocations by the Department of Environment, Community and Local Government in relation to Traveller-specific accommodation, from €40m in 2008 to €6m in 2012, a reduction of 85%. A further problem is that substantial parts of the allocation are unspent. For example in 2012, 34% of the reduced accommodation budget was unspent.<sup>12</sup>
- Unemployment in the Irish Traveller community was 84.3% in 2011, up from 74.9 per cent five years earlier. The Census 2011 reports that 19% across the whole population are unemployed. Barriers to labour market engagement experienced by Travellers include literacy confidence (more so than literacy problems); educational qualifications, prejudice in relation to where people live, and confidence.<sup>13</sup>
- Travellers experience educational disadvantage: census 2011 reports that 55% (of Travellers whose education had ceased) had completed their education before the age of 15, compared with 11% for the total population. Moreover, only 3.1% continued their education past the age of 18, compared with 41.2% for the total population, and only 1% of Travellers progressing to third level education (compared with 31% of the settled population).

<sup>10</sup> Survey of Lifestyle Attitudes and Nutrition

<sup>11</sup> Harvey, B. (2013) Travelling with austerity. Dublin: Pavee Point

<sup>12</sup> Harvey, B. (2013) IBID

<sup>13</sup> Murphy, P. (2003): Report on Community Employment Skills and Progression. Report carried out by Equal at Work on behalf of South Dublin Public Sector Site

### 3.2. Roma in Ireland

The situation of Roma in Ireland is very intricate and complex. There are an estimated 5,000 Roma in Ireland from countries including Romania, Bulgaria, Slovakia, Czech Republic, Hungary and Poland. However, there is very little accurate data available as Roma ethnicity is not collected in immigration, employment, or other Government statistics. Nor is Roma ethnicity included in the ‘ethnic and cultural background’ question in the Census. In any case, Roma participation in the Census is likely to be problematic given issues of social exclusion, discrimination and lack of trust in authority by many Roma. The lack of trust and isolation amongst Roma is exacerbated by recent events in Dublin and Athlone where children were removed from families by An Garda Síochána (under Section 12 of the Childcare Act) without any sound basis.

Research by the EU Fundamental Rights Agency (FRA) in 2012 found that in 11 EU countries:

- One out of three Roma are unemployed
- About 90% of the Roma live in poverty
- About half of the Roma said that they have experienced discrimination in the past 12 months<sup>14</sup>

Roma have long experienced racism and discrimination in Europe, and it has been estimated that the death toll of Roma in the holocaust ranges from 220,000 – 1,500,000 (it has also been estimated that around 25% of all European Roma were killed in the holocaust), and others endured forced sterilisation. More recently, Roma have been subject to violence, incitement to hatred, and segregated education.

The European Roma Rights Centre<sup>15</sup> reports that violence against Roma communities is rising across Europe. The attacks they have documented include police violence, arson attacks, mob violence and anti-Roma demonstrations.

Former Council of Europe Commissioner on Human Rights, Thomas Hammarberg, noted in 2012 that ‘in many European countries the Roma population is still denied basic human rights and made victims of flagrant racism. The Roma remain far behind others in society in terms of educational attainment, employment, housing and health standards, and they have virtually no political representation.’<sup>16</sup>

The lack of accurate information on Roma communities makes it difficult to develop effective and appropriate policies and to provide appropriate services. However, it does appear that Ireland has a relatively small Roma population compared to other western

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<sup>14</sup> European Union Fundamental Rights Agency (2012) The Situation of Roma in 11 EU Member States – Survey Results at a Glance. <http://fra.europa.eu/en/publication/2012/situation-roma-11-eu-member-states-survey-results-glance>

<sup>15</sup> The European Roma Rights Centre (ERRC) is an international public interest law organisation working to combat anti-Romani racism and human rights abuse of Roma through strategic litigation, research and policy development, advocacy and human rights education. Since its establishment in 1996, it has endeavoured to provide Roma with the tools necessary to combat discrimination and achieve equal access to justice, education, housing, health care and public services.

<sup>16</sup> Thomas Hammarberg is a Swedish diplomat who held the post of Council of Europe Commissioner for Human Rights in Strasbourg from 1 April 2006 to 31 March 2012.

European countries, so it should be possible to address the difficulties that they are experiencing.

### **3.3. Key policy issues**

Pavee Point believes that much of the difficulties faced by Travellers and Roma have their basis in racism and discrimination in Ireland, both at an individual and an institutional level. Much of the policy responses and practice has been characterised by a fragmented approach, which has led to state institutions undermining the policies of other state institutions. Examples of some policy issues which impact on Travellers and Roma are outlined below.

#### **HABITUAL RESIDENCE CONDITION**

Habitual residence is a condition which applicants must satisfy in order to qualify for certain social welfare assistance payments. Habitual residence essentially means an applicant must be able to prove a close link to Ireland. Five factors are considered to determine habitual residence:

- The length and continuity of residence in the state or in any other particular country;
- The length and purpose of any absence from the state;
- The nature and pattern of the person's employment;
- The person's main centre of interest;
- The future intentions of the person concerned as they appear from all the circumstances.

Pavee Point have noted that the application of HRC is having a disproportionate and devastating impact on Travellers and Roma in Ireland and raising serious human rights concerns. This arises in a number of ways: Travellers who are living a nomadic lifestyle may move between the UK and Ireland, and application of the HRC to the Common Travel Area will have a disproportionately negative impact, even though the movement by Travellers' does not reflect an intention to relinquish ties to Ireland. The provisions in the HRC guidelines make no provision for nomadism, make no consideration that Travellers and Roma may not in fact live in permanent housing.

In addition, the application of restrictions until July 2012 to labour market access for Roma from Romania and Bulgaria has in practice excluded many Roma from these countries from accessing employment and community employment schemes. This has also negatively affected their work record. Pavee Point also has concerns in relation to the gendered nature of the assessment of the nature and pattern of a person's employment, as women who perform caring roles are less likely to have been in formal employment.

These restrictions simply make it impossible for Travellers to travel across the island and place Roma and Travellers in destitution. Our position is that:

- HRC is having disproportionate effect on Travellers and Roma
- The Irish Government has human rights obligations and needs to ensure that all legislation, policy and practice are in line with the Treaties that it has signed up

to. It is clear that the impact of HRC is acting as a barrier to the realisation of Travellers' and Roma human rights in Ireland which needs to be addressed.

- The HRC needs to be reformed and more stringent proofing of the impact of economic and budgetary policies particularly on people in vulnerable situations needs to be put in place, as these restrictions go far beyond the intended purpose of controlling immigration.
- Application of the concept of a geographical 'centre of interest' to culturally nomadic communities such as the Traveller community is problematic, as it is interpreted from the viewpoint of the static majority population. Guidelines need to be amended to take into account differences in Traveller culture.
- The application of HRC to child benefit needs to be removed. All children living in Ireland should be treated equally and according to the principle of non-discrimination. This is in line with the UN Convention on the Rights of the Child, which Ireland has signed up to.
- HRC is not always applied in a consistent and timely manner. This is placing people who are already at risk into extremely vulnerable situations.

The restriction on benefits and services for people without what the state deems 'habitual residence' is resulting in families and children unable to access a range of services, including health and welfare services.

#### **TRAVELLER ETHNICITY**

Until Travellers' ethnicity is recognised by the State, we believe that such difficulties will remain, and that the health inequalities of Travellers will not be addressed. We believe that unanimous recommendation from *The Joint Oireachtas Committee on Traveller Ethnicity* that the State recognise Traveller ethnicity in April 2014 is an important step. The report outlines three steps on how formal State recognition of Traveller ethnicity could be brought about:

- Step 1: That either the Taoiseach or the Minister for Justice and Equality make a statement to Dáil Éireann confirming that this State recognises the ethnicity of the Travelling community.
- Step 2: That the Government then writes to the relevant international bodies, confirming that this State recognises the ethnicity of the Travelling community.
- Step 3: That the Government build on these initiatives and commence a time-limited dialogue with the Traveller representative groups about the new legislation or amendments to existing legislation now required.

This recognition would entitle Travellers and Roma to their right to a cultural identity. It would mean that Travellers and Roma would automatically be included in all State anti-racism and inter-cultural initiatives, and that discrimination that the communities experience would be recognised as racism. It would also ensure that Travellers would be afforded protection under the EU Race Directive. Recognition of the ethnic minority status of Travellers would open a new dialogue as to how the State and health services interact with Travellers into the future.

Pavee Point has called on the Minister to immediately act on this report recommending the recognition of Traveller Ethnicity and to accept this cross party recommendation.

**IRELAND'S NATIONAL TRAVELLER/ ROMA INTEGRATION STRATEGY**

Ireland's *National Traveller / Roma Integration Strategy* was submitted in 2012 (on foot of a requirement for all EU Member states to submit a strategy).<sup>17</sup> We believe that the plan provided a good opportunity to ensure a coordinated and consistent approach, to address policy gaps in relation to issues such as training, employment, and health, and to review existing strategies in relation to Travellers.

However, Traveller and Roma representatives had no involvement in the development of the strategy; no funding has been associated with any of the actions; and no targets and monitoring provisions have been specified as part of the policy framework of the plan. As a result, the strategy has been ineffective. The European Commission has conducted two assessments across all member states: both exposed serious gaps in Ireland's strategy, and in its most recent assessment, Ireland received a poor score of four out of 22 criteria for assessment established by the Commission.

Pavee Point has also called for a coordinated approach in the form of a Traveller and Roma Agency in Ireland, given the range of agencies and structures relevant to Travellers. At a minimum we call for the establishment of a Traveller and Roma Unit, which would be a structure that brings together policy-makers and senior civil servants, on a cross-departmental and inter-agency basis. Such a structure should be implemented by a national steering committee, with would include Traveller and Roma representatives.

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<sup>17</sup> The EU Framework for National Roma Integration Strategies, established in 2011, called on member states to develop national Roma Inclusion Strategies.

## **4. Response to the White Paper and proposals for Universal Health Insurance**

Those with greater health needs and poorer health status will be disproportionately affected by issues and deficiencies in a health system. We hold that the proposed system of Universal Health Insurance (UHI) has the potential to address health inequalities, or exacerbate them, leading to even greater disparities in health outcomes for Travellers and Roma.

Pavee Point holds to the principle that in order to achieve equality for Travellers and Roma, attention must be paid to the structural determinants/ issues that impact on them, including education, employment, poverty, health, discrimination and racism. This means that policy and practice must be underpinned by an inter-cultural approach and by principles of equality, diversity and anti-racism.

Delivering services based on equality does not mean treating people the same, but designing and implementing programmes that are inclusive, culturally appropriate, and appropriate to the needs of groups in society, including Travellers and Roma, and lead to better outcomes for disadvantaged groups, including Travellers and Roma. Fundamentally we believe that Travellers and Roma should be afforded rights to their cultural identity, without experiencing marginalisation and discrimination in the process.

As noted in sections 1 and 2 of this submission, the AITHS presented the overwhelming evidence that Travellers experience stark inequalities in health, including mortality outcomes, problems with quality, and trust in relation to the services. It is also acknowledged by health providers that they and their services discriminate against Travellers (as evidenced in the study). There is a need for an urgent response and positive action to address the current and historic discrimination, and to address the determinants that are leading to these unacceptable inequalities.

Travellers and Roma should therefore be considered as important stakeholders in the development of health services and practice. The establishment of UHI and structures proposed under the White Paper must ensure that these principles are acted on.

Ultimately, as outlined in section 3.3, we feel that until Travellers are recognised as a minority ethnic group in Ireland, as recommended (unanimously) by the Joint Oireachtas Committee on Traveller Ethnicity (in April 2014), the situation of Travellers as well as Roma will not be sufficiently progressed.<sup>18</sup>

In this section, we outline key recommendations which are specific to the proposals for Universal Health Insurance (UHI) as well as cross-cutting recommendations which will apply across many of the operational, decision-making and regulatory structures which will be developed under proposals for UHI.

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<sup>18</sup> And endorsed by other groups CERD

## 4.1. **Universal health insurance and the White Paper**

Universal healthcare is a single-tiered health system characterised by a mandatory universal health insurance (UHI), and underpinned by the following principles: equity of access to health care services determined by need rather than money, risk equalisation, chronic disease management in the community and a system of hospital funding whereby money follows the patient.

O’Ferrall (2009) suggests there are five main advantages to Universal Health Insurance: it enables a one-tier system of hospital care which is fairer and more efficient; it facilitates the delivery of GP services free at the point of delivery for all; it focuses attention on the person using the service rather than the service provider; it makes service provision transparent and therefore accountable; and it promotes social solidarity.

The World Health Organization (2010)<sup>19</sup> has identified three interrelated problems that can restrict countries moving to a UHI system. These include:

- The resources available for the provision of health services, which can lead to:
- Additional or supplementary payments for certain services, thereby restricting those on lower income to access services (these could typically refer to services which are not included in the ‘basket of services’), and
- An inefficient and inequitable use of resources that are available, which further reduces the amount of effective care that can be provided.

Therefore these issues are fundamental to ensuring a successful universal system.

The World Health Organisation (WHO) describes the importance of robust mechanisms for ensuring accountability, participation, and outcomes’ measurement, and Pavee Point endorses and strongly urges the institutionalisation of these mechanisms:<sup>20</sup>

Fair progressive realization of UHC requires tough policy decisions. Reasonable decisions and their enforcement can be facilitated by robust public accountability and participation mechanisms. These mechanisms are essential in policy formulation and priority setting and specifically in addressing the three critical choices on the path to UHC and the trade-offs between dimensions of progress. These mechanisms are also crucial in tracking resources and results. To properly play these roles, public accountability and participation should be institutionalized, and the design of legitimate institutions can be informed by the Accountability for Reasonableness framework.

A strong system for monitoring and evaluation is also needed to promote accountability and participation and is indispensable for effectively pursuing UHC in general.

Countries must carefully select a set of indicators, invest in health information systems, and properly integrate the information into policy making. The selection of indicators should be closely aligned with the goal of UHC and in

<sup>19</sup> World Health Organisation (2010) Financing for Universal Health Coverage.

<sup>20</sup> World Health Organisation (2014) Making fair choices on the path to universal health coverage: Final report of the WHO Consultative Group on Equity and Universal Health Coverage (p. xii)



most settings include at least four types of indicators: indicators related to the priority-setting processes and indicators of coverage, financial risk protection, and health outcomes. The latter three types of indicators should reflect both average levels and equity in distribution.

### **THE WHITE PAPER**

Following a commitment to introduce UHI in the Programme for Government, The White Paper on UHI ‘The Path to Universal Healthcare’ was published on 2 April 2014.

The stated aim of UHI proposals is to give all citizens equal access to healthcare in a single-tier system. This would eliminate the current two-tier system of public and private medicine, and mean a major transformation in how all healthcare is delivered in Ireland.

According to the proposals, once UHI is implemented, everyone will become a private patient. It will be mandatory to have cover for a basic package or ‘basket’ of services from a number of competing insurers. The State will pay the premium for the lowest income groups and provide subsidies for others. UHI will entitle people to a package of GP and hospital care.

Ireland has signalled an intention of following the Dutch model of UHI<sup>21</sup> which is a multi-payer model of health insurance. In other words, a number of private health insurance providers will compete with each other (and with the publicly-owned VHI) to provide health insurance.

Under the Dutch system, the minister for health makes decisions each year on what items should be included in the basic ‘basket’ of services to be provided under UHI. This decision is made in consultation with stakeholders such as patients, healthcare professionals and health insurers. The standard policy and the range of services it will cover is – as yet – unknown and is being determined at present through a costing exercise.

The proposed system will involve both a health insurance funded system for certain aspects of health care, including GP and hospital care. A tax-funded provision will deal with certain health services, such as accident and emergency, ambulance services, etc. Moreover, supplementary health insurance will be optional to cover those health services not covered in the standard package of health services.

## **4.2. Key aspects of the proposed system and issues arising**

Some of the key aspects of the White Paper that have particular implications for Travellers and Roma are outlined in this section.

Of key concern for the entire prospect of UHI is the status of those who may not be deemed habitually resident, by not meeting conditions under the HRC. As earlier stated, the HRC is having a disproportionate and devastating impact on Travellers and Roma.

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<sup>21</sup> Which was introduced in 2006.

**IMPLICATIONS OF THE HABITUAL RESIDENCE CONDITION (HRC)**

**The possibility of people may be denied health services on the basis of not meeting the HRC conditions is of critical importance, and must be reviewed as a matter of urgency.**

**Moreover, any transition to a system of UHI must ensure a rights-based system of access to healthcare, irrespective of the existence or otherwise of the HRC. Non compliance with HRC criteria will not be a basis for exclusion from health services, whether tax-funded or UHI funded. This needs to be explicitly stated.**

**MONEY FOLLOWS THE PATIENT (MFTP)**

The proposed UHI system operates on the basis of ‘the money follows the patient’ which incentivises health care providers to increase the volume of treatments and supposedly efficiencies in service provision. At present, the current system incentivises health services not to treat patients, or to extend waiting time for treatments, as budgets are fixed on an annual basis, and not linked to volume. The proposed MFTP is, however, not without its risks. In the first instance, it may lead to an over-emphasis on volume of patients, which could compromise quality of care. For example, in the Netherlands, Dutch patients were rated second most likely to be hospitalised due to a complication after hospital discharge<sup>22</sup> which could indicate that in order to improve volume, patients are discharged early.

**The new system and regulatory provisions to be established must ensure that quality of care is not undermined by targets or volume. This risk must be acknowledged as otherwise health inequalities could be exacerbated. The design and implementation of the regulatory environment and structures established to monitor must provide for the participation of representatives of Travellers and Roma communities, in order to ensure that the system is person-centred and needs based.**

**COST OF THE DUTCH SYSTEM AND IMPLICATIONS**

The Dutch system has experienced increased costs for a number of reasons. The multi-payer system there (and which will operate in Ireland) includes significant administrative costs and burdens, as different insurance companies have their own database systems, and administrative requirements. For example, the payment per treatment system leads to a plethora of different coding systems for treatment impacting on administrative burden.<sup>23</sup>

Moreover, the Dutch spent decades building up a highly functioning primary care sector based on significant investment in general practice. In the Netherlands 10

<sup>22</sup> Common Wealth Fund report, cited in Wilkinson, K and Brennan, D (2011) ‘Universal Health Care: Trick or Treat’, *Forum, Journal of Irish College of General Practitioners*. May 2011, and reproduced in <http://www.irishhealth.com/article.html?id=19208>

<sup>23</sup> According to Wilkinson and Brennan, Dutch hospitals have over 30,000 possible diagnosis and treatment combinations, making the system increasingly complex.

percent of the health budget is spent on general practice – in Ireland, the corresponding figure is just 2.3 percent.<sup>24</sup>

This raises fundamental concerns as there is an inherent assumption that UHI when introduced in Ireland will be based on a health system with no additional costs, and in fact assumes that cost reductions and greater efficiencies occur. This assumption poses significant risks leading to negative outcomes:<sup>25</sup>

- The cost of the basic insurance package in Netherlands has increased by 40 percent over a four year period.
- As a result of the increase in costs, the content of standard packages there have already been reduced (e.g. free provision of oral contraceptives, ulcer drugs, tranquillisers and anti-depressants have been withdrawn). This ‘rationing’ of services undermines the single-tier, equity-based system of healthcare.
- As insurers try to source the cheapest generic drugs, many patients obtain pills with different brand names and boxes every three months.

**The implications for Travellers and Roma are serious – the reintroduction of a two-tier system through undermining the standard basket of services will disproportionately impact on Travellers and Roma, who are amongst the most disadvantaged communities in Ireland, and have more health difficulties, compared with the rest of the population. Travellers and Roma also experience educational disadvantage (and experience greater literacy difficulties which could compromise treatment).<sup>26</sup>**

**A system dominated by profit-motivated insurance companies, whereby hospitals compete with each other on the basis of cost poses serious risks of further exacerbating health inequalities. The pressure of limiting costs could undermine emphasis on quality of treatment.**

**It is essential that prior to any UHI system introduction, a comprehensive commitment to equality of access for all in Ireland, with a particular emphasis on those who experience health inequalities, such as Travellers and Roma, is developed in collaboration with representative organisations including Pavee Point and other Traveller representative groups. A rights-based approach to health services must be enshrined in the legislative provisions giving rise to the UHI system.**

<sup>24</sup> Dr Muiris Houston, ‘Six reasons why the universal health care plan is likely to fail’, Irish Times, Friday April 4th 2014 <http://www.irishtimes.com/news/health/six-reasons-why-the-universal-health-care-plan-is-likely-to-fail-1.1749314>

<sup>25</sup> According to Clinician Dr Kees in’t Veld, who is one of the Dutch Delegates to Equip (European Association for Quality in General Practice/Family Medicine). <http://www.irishhealth.com/article.html?id=19208>

<sup>26</sup> For example, ‘Our Geels’ the All Ireland Traveller Health Study (2010) reported that more Travellers expressed difficulty with day-to-day literacy issues. Comprehension of written instructions provided with prescription medicines, providing a measure of practical and functional literacy, is lower amongst Travellers in the Republic of Ireland (ROI) (49.6%) compared with the settled population who are medical card holders (9.4%). The report concludes that this would constitute a significant health concern. The same study found that a third of respondents in ROI (31.3%) were on some form of prescribed medication, rising in a graduated manner to 77.9% of those aged 65 years and older in ROI.

**Moreover, it is critical that there is a stated and explicit commitment to preventative actions as the basket of services being developed.**

### **GP SERVICES**

Universal primary care will replace GP fees with capitation fees. There is a risk with there will be a disincentive for GPs to take on patients with more health issues, and therefore more likely to visit GPs for longer. There are fears that consultation times will be reduced, as demand for GP services increases. This is likely to disproportionately affect Travellers and Roma, who have poorer health status and outcomes compared with the settled population.

**It is essential that a period of capacity building in the health system is undertaken prior to any new system. This includes ensuring that sufficient GP services are in place to meet the population needs, and likely increased demand for GP services.**

**At present, GMS patients are required to register with a different GP if they move to different areas. This disproportionately affects Travellers and Roma communities, given the communities' nomadic culture, and can restrict access to GP services. This can exacerbate already health inequities and compromise continuity of care, and this requirement should cease immediately.**

### **4.3. Regulation of healthcare purchasers and providers**

It has been suggested that the privatisation of insurance has led to the privatisation of healthcare, where the health insurers have too much power in the Netherlands. This can lead to issues of commercial viability having an inappropriate influence on decision-making. It has been suggested that in the Netherlands, the location of services has been impacted by commercial concerns, and access to treatment is compromised by location because people have to travel significantly as health centres' location are determined by commercial viability.<sup>27</sup> This has led to an over-emphasis on curative care rather than prevention. This is a key concern as it means there is no focus on social determinants of health or causal paths.

**Health insurers should have no role in diminishing the standard basket of health services, or rationing of health services, and the State should underwrite access to a standard basket of services in all cases. Health insurers should have no veto (over clinical recommendations) with regard to access to health services and treatments.**

**The introduction of UHI should not be disadvantageous for those on low incomes currently in receipt of medical cards. The State must underwrite provisions such that current entitlements to people in receipt of medical cards should be guaranteed as minimum provision under UHI. Moreover, out of pocket payments currently in operation (for example, for prescription charges) should not apply under the new system.**

<sup>27</sup> 'Dutch MP warns against introducing Universal Health Insurance', Irish Times, Tuesday 6 May, Paul Cullen. <http://www.irishtimes.com/news/health/dutch-mep-warns-against-introducing-universal-health-insurance-1.1784479>

The State will adopt a stronger regulatory role of insurers and health providers under the proposed model. It is crucial that in designing these regulatory structures, that principles of participation and equality are cornerstones.

**All regulatory structures of the State should ensure that a rights-based approach and principles to access to healthcare underpins policy and operations. Moreover, the principles for inclusion and equality, identified in this submission should be adopted as cornerstones of an effective and inclusive healthcare service. As such, the proposals in this submission should be included as important criteria in the licensing, implementation, and monitoring provisions undertaken within the new regulatory structures.**

**There must be in Inclusion of a commitment to Equality / Traveller/Roma proof UHI documents, including the basket of services proposed, and regulatory strategies and actions.**

### 3.4 **Funding of services**

#### **TAX BASED SERVICES AND THE PRIMARY HEALTH CARE FOR TRAVELLERS PROJECT**

As mentioned above, there will be a tax-funded aspect of the health services to be provided under the new system, as well as UHI funded provision. The tax-funded aspect will include a range of general services (as outlined in the White Paper, these will include Accident and Emergency and other services).

Research has shown that increased social health insurance models lead to greater levels of health expenditure, suggesting the importance of safeguarding prevention and screening health services.<sup>28</sup>

**We strongly urge that the current primary health care project, as currently delivered to Travellers throughout Ireland continue to be resourced as part of tax-funded health services. The PHCTP's values of empowerment, participation, partnership and advocacy should be core to the design and implementation of tax-based health services. The UHI should present opportunities for greater integration between PHCTP initiatives and UHI and non-UHI (tax-funded).**

**Moreover, in the preparations for UHI, the PHCTP should be resourced to engage with local, regional and national initiatives developed in the lead up to the new system. Moreover, PHCTP should be resourced to commit extra resources to working with Travellers to support them in navigating the new system.**

**There should be a requirement for health services (both tax-funded and UHI-funded) to address the needs of marginalised and ethnic groups such as Travellers and Roma through a series of training, equality mainstreaming and proofing measures to secure greater integration between services (this is also discussed below in terms of regulation).**

**In terms of integration of primary health care principles (as outlined above) with general (and UHI funded) health services, a structured, inter-organisational response involving**

<sup>28</sup> Wagstaff and Morena Serra (2008) cited in NDA (2012) 'Universal Health Insurance systems and the provision of health services for people with disabilities: A National Disability Authority Working Paper'

defined mechanisms to facilitate communication, information-sharing and collaboration should be provided for.

#### **ELIGIBILITY MEASURES FOR LOW INCOME HOUSEHOLDS**

Approximately 94 percent of Travellers are medical card holders. Successive research studies have reported that fears of loss of the medical card has prevented some Travellers from accessing employment and training opportunities. This arises for a number of reasons, not least because Travellers have greater health needs than the settled population, as stated earlier. This fact, coupled with fears of discrimination in the workplace itself results in a poverty trap for Travellers, where they may be required to choose between healthcare and employment opportunities.

**There will be no medical card provision in the new system, but the State proposes to fund USI for low income groups in society, such as current medical card holders. Pavee Point have already called for a period of time during which Travellers would retain their medical card (following access to employment or after they are no longer eligible for medical cards) in light of Travellers' poorer health status and experience of discrimination. We propose that the USI funding system includes this provision for marginalised groups such as Travellers and Roma, providing extended coverage to account for this disadvantage.**

**Health services that are both tax-funded and insurance funded should be free at the point of access, with no out of pocket expenses, as research has indicated that health insurance models implemented internationally have resulted in poorer outcomes for those with greater healthcare needs. This would include repealing of prescription charges.**

#### **4.4. Preparatory actions**

##### **DEVELOPMENT OF A VALUES FRAMEWORK**

The White Paper describes the consultation process which will give rise to a values framework which will underpin the system and service coverage. We welcome the assertion in the White Paper that it is 'imperative that the shared values of society are understood and underpin decisions in relation to the composition of the future health basket. The consultation process will support the development by the Joint Committee of a values framework which embraces the ethical, economic and technical aspects of coverage decisions and which will be used in assessing health services and technologies.' However, we emphasise the importance of including in this consideration the needs and values of key marginalised and ethnic groups, such as Travellers and Roma are undertaken, as a 'one size fits all' approach (institutional discrimination) will not be sufficient. This is particularly important as cultural and specific health considerations may impact disproportionately on groups such as Travellers and Roma.

**The process of developing a values framework must take into account specific cultural and health needs of relevance to marginalised and ethnic groups, such as Travellers and Roma, and this consideration must be core to the development of a values framework. All emerging and proposed frameworks should undergo a process of equality impact**

**assessment. Representative organisations for ethnic and marginalised communities (including Travellers and Roma) must be part of decision-making structures, as well as implementation and regulating bodies.**

The process of updating the values framework will come within the remit of HIQA, ‘in consultation with citizens and system stakeholders and will be submitted to the Minister for approval’.

**This process of updating the values framework should include explicit reference to key marginalised and ethnic groups in Ireland (including Travellers and Roma) as important participants in the process.**

**We would urge that a rights-based approach to healthcare be incorporated into the vision statement as provided for in the White Paper (p.17)**

**We would urge the inclusion of ‘equality of health outcomes’ as one of the core principles that underpin the design of the future system. This should ensure that targets and outputs are put in place as part of provisions in the future system.**

### **DECISION-MAKING AND PARTICIPATION**

We welcome the commitment of the Department of Health to consultation on the White Paper and its proposals. In order to achieve this, we would urge the agency to undertake the following measures:

- There should be a representation for marginalised groups on decision-making bodies, including the Commission to be established in implementing the proposals and preparatory actions. There should be at least one specific position for Traveller and Roma representation.
- Working groups should be established around issues of positive action, equality, and inter-culturalism, with mandatory inclusion of Traveller and Roma representatives, as part of the preparatory measures.

### **CONSULTATION PROCESSES**

We believe that a ‘one size fits all’ approach will not be sufficient to account for the diversity of situation, experience and identity of Travellers and Roma in Ireland in the planning and delivery of the new health system.

**For all consultation mechanisms proposed, specific engagement must take place with the Traveller and Roma communities, and this engagement should be developed and designed alongside Traveller and Roma organisations.**

In addition, we believe that a process of consultation with Travellers and Roma in Ireland be undertaken on an ongoing basis, at key junctures in the development of the new system, and in addition to the participation of Traveller and Roma representatives on formal decision-making structures established.

**EQUALITY PROOFING AND MAINSTREAMING**

We would strongly recommend that be mandatory equality/Traveller and Roma proofing of all strategies, policies and action plans takes place. This would establish the potential impact (positive and negative) of strategies and policies on Travellers and Roma with regard to achieving equality of outcome. This would involve implementing equality impact assessments on programmes and policies. It must also involve a programme of monitoring changes arising from equality impact assessment.

**All proofing measures should be overseen by a steering or working group comprised of stakeholders, including Traveller representatives, staff of the organisation (including senior management), board representation, and it should be resourced by staff members. Actions proposed as part of a proofing process should be referred to the board as recommendations.**

**NEEDS ANALYSIS AND EVIDENCE-BASED POLICIES**

**The difference in demography between the majority population and Traveller community is important to highlight in the planning of future services, and must be taken into consideration in any needs analyses which will give rise to future planning of services and provisions in UHI. In particular, the findings of the All Ireland Traveller Health Study (AITHS) must be core to these considerations.**

**In order to identify needs, gaps in services, and difficulties in access, it is imperative that an ethnic identifier be introduced across all health services.**

**CULTURALLY APPROPRIATE SERVICES**

**There is no current Traveller health strategy in place in Ireland. We believe that this provides a poor basis for ensuring that the Traveller and Roma communities' needs are met in any UHI provision, given their experiences of discrimination, poor accommodation, educational disadvantage as well as poorer health outcomes and difficulties in accessing a range of services. Prior to the introduction of UHI, there must be an updated Traveller Health Strategy, based on AITHS findings, with a detailed action plan, timeframe and framework for reporting and accountability. The Department of Health should advocate for this to take place as a matter of priority.**

**Health Services must provide a culturally appropriate health service to Travellers, to ensure that the health service reflects their needs and responds to their concerns. This will ultimately achieve better health outcomes for Travellers as a result of enhanced access to healthcare provision. This must be led by the Department of Health, and involving discussions with Traveller representative organisations such as Pavee Point.**

**All UHI proposals that will be forthcoming must be equality proofed for their impact on Travellers, Roma and other groups (under the nine grounds of equality legislation) as to how such radical change to the system will impact on them.**

We recommend that the preparatory actions follow the World Health Organisation's (WHO) recommendations for robust mechanisms for ensuring accountability,



participation, and outcomes' measurement, and that they are core to the design of the programme. An extract from the WHO follows:<sup>29</sup>

Fair progressive realization of UHC requires tough policy decisions. Reasonable decisions and their enforcement can be facilitated by robust public accountability and participation mechanisms. These mechanisms are essential in policy formulation and priority setting and specifically in addressing the three critical choices on the path to UHC and the trade-offs between dimensions of progress. These mechanisms are also crucial in tracking resources and results. To properly play these roles, public accountability and participation should be institutionalized, and the design of legitimate institutions can be informed by the Accountability for Reasonableness framework.

A strong system for monitoring and evaluation is also needed to promote accountability and participation and is indispensable for effectively pursuing UHC in general.

Countries must carefully select a set of indicators, invest in health information systems, and properly integrate the information into policy making. The selection of indicators should be closely aligned with the goal of UHC and in most settings include at least four types of indicators: indicators related to the priority-setting processes and indicators of coverage, financial risk protection, and health outcomes. The latter three types of indicators should reflect both average levels and equity in distribution.

#### **4.5. Information and data collection**

The White Paper notes the importance of information as 'central to delivering responsive, integrated care across multiple.' Pavee Point strongly endorses this position as it believes that information and data collection is essential for the effective monitoring of access to services. We would urge the Dept of Health to put in place a system for capturing data on the participation of Travellers and Roma (as well as other ethnic groups) in all health services, and ensure that this is included in the regulatory and licensing arrangements established as part of the UHI proposals.<sup>30</sup> Without disaggregated data, it is not clear how Travellers' access to services, and overall health are progressing. If an ethnic identifier was introduced, it would enable the monitoring and assessment of the effectiveness of health initiatives directed at Travellers and Roma.

**There should be mandatory implementation of an ethnic identifier for all users of the services. This would support the identification of needs, combat racism and discrimination, promote equality, monitoring progress of programmes and policies and provide a basis for evidence-based policy-making and service provision.**

**Pavee Point has long called for the recognition of Travellers as an ethnic group and for the implementation of an ethnic identifier to provide better services to minority groups.**

<sup>29</sup> World Health Organisation (2014) Making fair choices on the path to universal health coverage: Final report of the WHO Consultative Group on Equity and Universal Health Coverage (p. xii)

<sup>30</sup> The Council of Europe Convention 108 specifies certain conditions for the processing of personal data and in order for the collection of ethnic data to be legitimate and lawful, these requirements must be fulfilled.

The State has refused to implement these protective actions, but has failed to address the unethical recording of Traveller and Roma children on the PULSE database, or to disclose the nature and extent of such data recording.

Pavee Point calls for an ethnic identification and ethnic monitoring process which will collection of data disaggregated on basis of ethnicity (inclusive of Travellers) within a human rights framework. This requires:

- A universal question for all service users
- Based on principle of self-identification of ethnic status
- Data collected is aggregated and anonymised
- Data is only used for the purpose for which it was collected
- It is available in a timely manner
- It is analysed in consultation with the organisations representing minority ethnic groups

Any system should include the voice of minority ethnic groups, and Pavee Point has supported the design and implementation of ethnic identifiers in Ireland (for example, with the central statistics office as part of Census 2011).

#### **4.6. HR and capacity building measures for health services**

It is essential that given the proposed transformation of health services, that human resource policies and practices adhere to best practices in order to ensure that the needs of marginalised and ethnic groups, including Travellers and Roma are fully addressed in a new health service.

##### **TRAINING**

Underlying the above measures identified is the need for all staff involved in health services to be fully aware of the context in which Travellers and Roma live in Ireland.

**Anti-racism and cultural awareness training should be mandatory, and repeated at regular intervals for all staff involved in health services, as well as staff and management in regulatory structures established in the new system. Such training should include provisions on the experience, situation and identity of Travellers and Roma in Ireland, as well as the policy dimension and how these affect Travellers. The Department of Health should enforce this provision.**

Pavee Point and other Traveller organisations have extensive expertise in the design and delivery of training in these areas. This is of particular importance given the reconfiguration of health service providers, and the engagement of health insurers more centrally in the purchase of health services.

##### **RECRUITMENT AND MONITORING**

**As part of the recruitment process of staff, criteria for employment and job descriptions should include provisions for a commitment to anti-racist and equality perspective. Job descriptions of staff should also reflect this perspective in terms of essential skills.**

**The performance management system for the public sector (PMDS) for those staff who will be public sector employees, should also provide include wider criteria in their measurement of performance to include outcomes in terms of progressing equality for Travellers and Roma in Ireland.**

**Given the importance of adopting principles of inter-culturalism and equality, we would urge the Department of Health and regulatory structures established to target the employment of Travellers and Roma in any future recruitment processes, and to advocate this with health services that they are overseeing and licensing. This would enhance the capacity of the agency and include the expertise of these communities.**

### **POSITIVE ACTION PROGRAMME**

We would also recommend that a positive action measure with respect to employment opportunities for Travellers and Roma should be a key policy for all regulatory structures and the Department of Health. As outlined in section 3.1, Travellers and Roma are the most marginalised groups from the labour market, with barriers experienced including:<sup>31</sup>

- Literacy confidence (to a greater extent than literacy problems).
- Educational qualifications – particularly where the Leaving Certificate is an entry level requirement for jobs.
- Ageism – particularly for those older workers who have not had the opportunity to complete the Leaving Certificate.
- Prejudice
- Confidence

There are examples of good practice in positive action for Travellers recruitment in Ireland within the public sector.<sup>32</sup>

**Drawing on good practice, and other good practice positive action measures documented by the HSE's Traveller Health Unit (Eastern Region),<sup>33</sup> we recommend a programme for positive action for key positions across health services be established. A working group, comprising senior management from the Department of Health, representatives of the health service providers and insurers, regulatory structures (e.g., HIQA) and Traveller and Roma representation would be convened to oversee the process.**

The following actions should come within its remit:

- Examination of roles and programmes to prioritise positive action measures

<sup>31</sup> For example, see Pearn Kandola Occupational Psychologists (2003) *Barriers Travellers Experience Accessing and Participating in Labour Market Programmes – Report for the equality studies unit*. Dublin: Equality Authority and WRC Social & Economic Consultants (2003) *Accommodating Diversity in Labour Market Programmes*. Dublin: Equality Authority

<sup>32</sup> For example, the civil service internship programme for Travellers, South Dublin County Council and others.

<sup>33</sup> For a model and examples of positive action measures within the HSE and the public sector as a whole, see TSA Consultancy (2007): *Toolkit and Guidelines for the Employment of Travellers in the Health Service Executive*. Dublin: HSE, Traveller Health Unit Eastern Region

- Design of programme and planning (including needs analysis)
- Clear objective for outcomes (across different grades and positions)
- Recruitment processes
- Support in the workplace (and engagement with training providers)
- Progression opportunities (within the agency)
- Monitoring and evaluation of programme

A staff member should be tasked with the role of coordinating the process and should report to the working group.

### **CULTURAL IDENTITY**

Ultimately we believe that Travellers and Roma communities have a right to a cultural identity, and that this should be recognised and reflected in policy, strategy development and in the delivery of services within the new system of USI:

This is entirely consistent with Article 30 of the *UN Convention on the Rights of the Child* which Ireland has ratified.<sup>34</sup> This states that ‘In those States in which ethnic, religious or linguistic minorities or persons of indigenous origin exist, a child belonging to such a minority or who is indigenous shall not be denied the right, in community with other members of his or her group, to enjoy his or her own culture, to profess and practise his or her own religion, or to use his or her own language.’

**This right to a cultural identity should underpin all values, policies and practices of health care provision, whether tax-funded or UHI funded, and all decision-making, implementation and regulatory structures established should be required to explicitly acknowledge this right.**

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<sup>34</sup> United Nations. Convention on the Rights of the Child, Article 27(1)  
<http://www2.ohchr.org/english/law/pdf/crc.pdf>

**APPENDIX**

A summary of key concerns and challenges based on international evidence and the experience of countries who have UHI is reflected in this article:

**The seven sins and the seven virtues of Universal Health Coverage<sup>35</sup>**

Universal Health Coverage is likely to become the backbone on which the health development agenda beyond 2015 will be constructed. To avoid unintended effects, Universal Health Coverage should keep away from committing seven sins and should try to practice seven virtues.

Backed by most actors in the global health scene, Universal Health Coverage (UHC) is likely to become the mantra that will drive health transformations for years to come and the backbone on which the health development agenda beyond 2015 will be constructed. There is now widespread agreement on the need to extend access to health care to all individuals and populations, as illustrated by UN statements (1), WHO reports (2), and a number of articles in medical journals, including a Lancet series (3). The call for UHC comes at a time when, after decades of neoliberal policies, privatization of health care services has reached a peak leading in many countries to further exclusion and/or catastrophic expenditures. To help reverse this trend, however, and to avoid unintended effects, UHC should keep away from committing seven sins and try to practice seven virtues.

*1. Sloth (failure to do things that one should do and to make the most of one's talents and gifts) vs. Diligence (upholding one's convictions at all times, especially when no one else is watching)*

To many people, UHC may sound like Health for All (4). However, what is currently proposed differs substantially from what was proposed in Alma Ata. Primary health care intended to transform health systems, as opposed to health care systems, within a broader social transformation. The signatories of the Declaration were aware of the importance of the social determinants of health well before the report of the WHO Commission (5). Primary health care included education, nutrition, water and sanitation, in addition to essential health care. Unless UHC is served with an extensive dressing of primary health care and social determinants of health, i.e. unless it is implemented within a framework of social and economic transformation, it will not transform health as profoundly as hoped. Paradoxically, an excessive focus on UHC could divert attention and resources from other sectors with a bearing on health (6).

*2. Greed (inordinate desire to acquire or possess more than one needs) vs. Charity (benevolent giving and caring, solidarity)*

To some people, UHC may seem to be synonymous of health insurance schemes that would fund a limited package of services, with governments playing a range of different

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<sup>35</sup> <http://getinvolvedinglobalhealth.blogspot.ie/2013/06/the-seven-sins-and-seven-virtues-of.html>  
Wednesday, 26 June 2013

and often minimal roles. The equation of UHC with financial coverage is implied also in the title of the WHO World Health Report for 2010 (7). Such an interpretation of UHC focuses on the mere element of affordability, or economic accessibility. It may pave the way to a massive infiltration of the private sector into health care systems that in some countries are still mostly public, and it may undermine the efforts of those countries that have undertaken reforms towards a stronger public sector. To avoid this, UHC should aim at increasing the proportion of health care services that are mastered and managed by the public sector (8), and financed by progressive taxation systems. In places where the private sector is prevalent and likely to remain so for a long time, governments should strongly regulate it, especially as far as quality of care and lucrative attraction for health professionals are concerned, while progressively investing to reinforce the public sector (9). Also, UHC should be robust enough to accommodate new challenges, e.g. the new burden brought about by the changing epidemiology of non-communicable diseases (10), and to resist the downwards swings brought about by present and future economic and financial crises (11). Ad hoc goals and targets on access to the public sector should be developed if UHC is included in the post-2015 development agenda.

*3. Gluttony (over-consumption of anything to the point of waste) vs. Temperance (self-control, abstention, moderation)*

Trade mechanisms will keep influencing the delicate balance between demand for and supply of health care services. Given the well known asymmetry of information between providers and users in this atypical market, UHC should include mechanisms aimed at moderating any inappropriate excess of supply that in turn may end up in increasing demand. Historically, this point has been pointed up by Ivan Illich: “although physicians did pioneer antisepsis, immunization, and dietary supplements, they were also involved in the switch [from breastmilk] to the bottle.” (12) Currently, demand may be artificially inflated by the push for new pharmaceutical or technological solutions to real or presumed health needs, in what is known as disease mongering (13). Moreover, due to the liberalization of global trade, the associated dissemination of unhealthy lifestyles, the aggressive marketing of health care products, the drive towards increasing consumption and waste, the legal obligations brought about by global trade treaties, and the lack of public regulations to protect public health, demand may rise above the capacity of health care systems to respond, creating imbalances that are difficult to address and that would be an obstacle to UHC itself (14).

*4. Pride (failure to acknowledge the good work of others) vs. Humility (thinking of oneself less in a spirit of self-examination)*

UHC will positively affect health only if due attention is paid to its quality. Quality care is the delivery of safe and effective interventions in ways that, by taking into account the needs and the background of users and their communities, ensure the best possible outcomes to all. Quality of care has only recently been recognized as a neglected issue in the international health agenda, particularly as far as care around childbirth is concerned (15,16). Several studies and reports indicate that quality may be far from acceptable, thus jeopardizing the ultimate aim of health services. Delivering care which is not technically sound implies increasing the costs for the system and households

without achieving health. Improving quality, however, implies no less difficulty than increasing access. A variety of approaches have been proposed, but reports of successful quality cycles are scanty. Efforts to improve paediatric quality of care in district hospitals through systematic standard-based peer-review assessment have been successful, particularly when action at facility level is combined with action at national health system level, through introduction of national standards and improvement in all the building blocks of the health system (17). The tool for paediatric care developed by WHO, and the equivalent maternal and neonatal assessment tool, are able to identify quality gaps and prompt quality cycles at local level and systemic action at national level (18,19). Market mechanisms alone, like those described by proponents of health insurance reforms (20), are unlikely to have a sustained effect on quality of care.

*5. Envy (desire to deprive other people of their abilities or rewards) vs. Kindness (empathy and trust without prejudice or resentment)*

Health is a complex adaptive system within wider cultural, social and economic complex adaptive systems.<sup>21</sup> Changes in access to health brought about by UHC are likely to affect other building blocks within the health system, the training and distribution of the health workforce for example, or in other social sectors, the transport system for example.

Needless to say, the reverse is also true. A systems thinking approach is compulsory to try and predict the effects that modifications of the health system may have on other complex adaptive systems, and viceversa (22). Parallel to UHC, capacity for a systems thinking approach should be built among policy and decision makers, as well as planners and researchers. This would be easier if UHC was integrated into a wider social protection framework (23). To avoid increasing the gap between the better and the worse off, coverage and social protection should be preferentially provided to the latter group, at least initially (24). This would be particularly important in places where financial risk protection and health insurance have proven to be difficult to implement and scale up, e.g. in remote contexts and poor, underserved communities.

*6. Wrath (impatience, revenge and vigilantism) vs. Patience (creating a sense of peaceful stability rather than hostility and antagonism)*

The implementation of UHC, with all its corollaries of principles, policies, activities and constraints has to be properly governed and monitored. Governments will obviously be in charge of it at national and local levels. But who will be in charge of its governance at global level? The WHO is the natural candidate, but in recent years it has failed to provide an effective and coherent leadership based on the principles of the right to health for all. Critical budgetary and organisational constraints, including donor dependence, contradictions in the management of human resources, excessive decentralisation and lack of accountability to member states, weaken the role of WHO in global health governance. The current process of reform suffers from many of the very problems that it is meant to address, and may fail to re-qualify WHO for the governance of global health (25). However, there are possibly no alternatives to a strengthened normative role of the WHO as advocated by Chen and Berlinguer a decade ago (26). With patience, and courage, WHO could lead the development of new ad hoc regulatory frameworks, modelled on the Framework Convention on Tobacco

Control. A strong alliance with civil society organizations that look after the public interest and identify global health as a common good would be an asset. While the authority of WHO and its treaty making power remain necessary, the potential role of bottom up strategies involving community participation should be also acknowledged. By encouraging social empowerment, increasing the potential to strengthen health systems at local levels, organizing demand for services prioritized by communities, and linking generation of knowledge to its use in action, strategies such as participatory action research and community based monitoring are increasingly recognised as key elements towards UHC (27).

*7. Lust (intense desire of money, fame or power) vs. Chastity (to be honest with oneself, one's family, one's friends, and to all of humanity)*

Finally, UHC should be spelled out and positioned within a human rights framework. The Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights clearly state that the fulfilment of the human right to health relies on the fulfilment of other rights, e.g. food, housing, work, education, non discrimination, participation and freedom of association. More in detail, the International Covenant states that while “the right to health is not to be understood as a right to be healthy”, it is “an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health”, and adds that “a further important aspect is the participation of the population in all health-related decision-making at the community, national and international levels.” (28) It states also that “The right to health [care] in all its forms and at all levels contains the following interrelated and essential elements”: (a) availability, (b) accessibility in its four overlapping dimensions: non-discrimination and physical, economic (affordability) and information accessibility, (c) acceptability, and (d) quality of services. Unless the international community pushes the right to health up in its scale of values and stops considering health as a dependent variable of the global economy, and unless it makes the respect of human rights mandatory and those who violate them legally accountable, UHC is unlikely to yield the expected results.

To conclude, the incorporation of the UHC concept in the post-2015 development agenda should aim at maximizing benefits and minimizing harm. This can be achieved only if all the above criteria are met and built into UHC, with enforceable mechanisms to hold governments accountable. In particular, UHC should be understood as a way to ensure the right to health. Only within a human rights framework UHC would benefit from a comprehensive approach, as opposed to the fragmented, vertical approach entrenched in the health (insurance) coverage approach with multiple actors either on the payer or on the provider side that focus on personal, mostly disease-centred and curative services. Addressing UHC in a human rights framework will help re-position the right to health in the context of the post-2015 development agenda.

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