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Essential SSH Research for the Societal Challenge *Health, demographic change and wellbeing*

With this Note LERU wants to advise the European Commission to include essential Social Sciences and Humanities (SSH) research in the programme addressing the challenge 'Health, demographic change and wellbeing' in Horizon 2020. The seven Notes complement a 2012 LERU Advice Paper on the role of SSH in Horizon 2020 (LERU, 2012).

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Introduction

1. Ever increasing numbers of very old people can remember times when a person's final illness lasted for a couple of days or, at most, weeks. Now that we live longer, we may live with ill health for years, sometimes decades. At the same time, neonatal medicine rescues the lives of infants no larger than a human hand, sometimes at the cost of life-long developmental impact/disability,resulting in problematic functioning. At the same time our society gets increasingly more complicated and participation becomes difficult for less advantaged groups as we place more and more emphasis on self-reliance, flexibility and success. For people, especially children with developmental disorders such as a mild intellectual disability, psychiatric or behavioural disorders these changes mean there is increasingly less place for them in our workforce and in society in general, in an increasingly demanding society.
2. But institutions where those unable to lead independent lives used to be hidden from view, often in conditions of extreme misery, have closed. All these developments have their favourable aspects: there is more of life for more of us but recent budget cuts erode solidarity in our society and hit less advantaged groups hard. This will reduce their ability to participate and paints a bleak future in institutions and prisons (in the US one out of hundred inhabitants is currently jailed).
3. Demographic change as well as the definition and study of wellbeing and the mechanisms of adaptive abilities in humans, in and by themselves, require social sciences. Demographic change, wellbeing and adaptive behaviour are aspects that medical disciplines do not really know how to handle, focused as they are on diseases; moreover, even if there are quantitative approaches in medical sciences such as epidemiology, demographic change is a social issue more

than a medical one. Moreover, demographic change as well as wellbeing result from a true interaction of biological (and genetic, but not only), cognitive, social and cultural variables.

4. Therefore LERU would like to stress that the purpose of this note is not only to include essential SSH research in the programme, but also SSH researchers in *all* relevant committees so as to ensure that several perspectives are adopted on all the subtopics.

Developmental changes in the normal population

5. There have been too few studies on developmental changes in the normal population, whether throughout childhood or through the adult life period; most often one assumes that average values (of whichever variable, whether physical or mental) or group values apply to all "normal" individuals, and that only sick/ill persons do not conform. On the contrary, research is needed to understand

   - that inter- and intra-individual differences are the norm within the general population. LERU would also like to point to the growing interest in the medical world for what is now termed "personalised medicine"; it shows that there is a growing awareness that individual differences are crucial, but it tends to be restricted, once again, to the ill;
   - that, because of these differences in underlying mechanisms which regulate functioning, the same individuals are to be followed through longitudinal studies across a period of time;
   - that there is, in most cases, a continuum between normality and pathology. One is not ill or healthy; it is, in most cases, a question of threshold.

Somatic and mental health

6. The concept of health has important cultural, social, developmental, behavioural and psychological (neurocognitive) dimensions, which are not explicitly mentioned in the Horizon 2020 proposal (EC, 2011). Besides somatic health, health also involves mental health defined by the WHO as a "state of complete physical, mental and social wellbeing, and not merely the absence of disease". Following this definition, mental health is related to the promotion of wellbeing, the prevention of mental disorders, the early diagnosis of disorders and the treatment and rehabilitation of persons affected by mental disorders.

7. Thirty-eight per cent of the EU population in the age range of 2–65+ years are, or have been, affected by at least one mental disorder in the past year (e.g. anxiety disorders, major depression, somatoform disorders, conduct disorder/antisocial personality disorder, oppositional defiant disorder, attention deficit hyperactivity disorder, substance use disorders) and approximately 1.3 % of our population has a mild intellectual disability. Mental disorders account for almost one third of all disease burden, with depression alone being the largest component of Europe's total burden of all diseases.

8. Cost-of-illness studies consistently indicate that the economic and social costs of mental disorders are enormous - considerably larger, for example, than the costs of diabetes or cancer. Approximately €255 billion a year can be attributed to a mental disorder in a strict sense. Most of the mental disorders are characterised by proportionally low direct costs (diagnostic measures, treatment, care), but exceedingly high indirect costs (sick days and disability, early retirement but also relatively high societal costs like drug use and crime). Work-related stress accounts for 50-60% of workdays lost, which corresponds to 4% of the EU GDP.

9. In 2009 the European Parliament passed a resolution calling for a coordinated effort

that is proactive, evidence-based and directed to the design and implementation of comprehensive, integrated, effective and cost-efficient mental health systems. Adopting an integrative and promotive approach to mental health and wellbeing, the full spectrum of mental health and wellbeing has to be covered –not only its biological, but also its psychological, epidemiological, public health, social and economic aspects.

10. Social Sciences and Humanities can contribute substantially to research into causes and determinants of specific mental and neuro-behavioural disorders, as well as their prevention, early diagnosis, treatment and rehabilitation. Such an approach recognises the fact that physical and mental health are closely connected and that mental health cannot be viewed or treated in isolation: mental health problems and their solutions will vary by age, gender, culture and socio-economic circumstances. Besides pharmacological interventions, psychological interventions (for example internet-interventions such as Cognitive Bias Modification) are established treatments for almost all mental disorders and mental health problems – and often a first-line treatment. They are also the preferred methods for increasing the general wellbeing of healthy people.

11. Behavioural science is extremely relevant for somatic health problems: psychological, behavioural and cultural factors are involved in the mechanisms that regulate physical health and illness, in addition to or in interaction with biological (epigenetic) factors. Psychological factors can affect health directly (e.g. high levels of stress causing a shift in the HPA-axis, changing the release of corticoid hormones which in time can damage the body and cognitive regulation functions over time) and indirectly via a person's own behavioural choices, which can harm or protect their own health (such as smoking or exercising) but also the wellbeing of others, e.g. risky behaviour or criminal conduct.

12. Factors that influence upbringing have high developmental impact on emotional and physical wellbeing and adult outcome in children and adolescents (e.g. in obesitas and behavioural problems). Opportunities for cognitive and social learning, in adaptation to genetic and epigenetic factors, influence life time self-regulation mechanisms that determine self-management and self-control. Behavioural scientists can improve health by unravelling mechanisms of self-regulation that are related to self-management and adaptive behaviour and by promoting healthy life styles, increasing quality of life and wellbeing. They do this both on a small scale - working with individuals and on a larger scale - in public health programs and by training healthcare professionals (e.g. physicians and nurses).

The true size and burden of mental disorders

13. Learning problems and behavioural dysfunction in the EU have been significantly underestimated in the past and are increasing as our society grows more complex. Concerted priority action is needed at all levels, including substantially increased funding for basic, clinical and public health research, in order to identify better strategies for improved prevention, early diagnosis and treatment for disorders of the brain and developmental disorders as the core health challenge of the 21st century (Wittchen et al., 2011).

14. Recent studies estimate that 38% of the EU population suffers from mental/brain disorders (Wittchen et al., 2011), with an estimated economic burden of €789 billion (Gustavsson et al., 2011). Note that this estimation does not include the costs of smoking and alcohol abuse, two of the most frequent and costly problems. When included, total costs are estimated to be €924 billion per year, with addiction (including harmful use of tobacco) ranked highest, mood disorders second, followed by dementia, psychosis and anxiety disorders

(Effertz & Mann, 2012). Interestingly, the large majority of people (78%) with the most costly disorders (addictive behaviours) do not receive formal treatment, and for the two other most costly mental disorders the treatment gap is estimated to amount to around 50% (Kohn et al., 2004). During the year before assessment, only 8% of people with an alcohol problem, 26% of people with an anxiety disorder and 37% of people with a mood disorder received formal treatment (Alonso et al., 2004). The majority of people suffering from common mental disorders are left untreated, which costs the EU much in terms of personal wellbeing and societal damage.

Medical humanities

15. Health and wellbeing are embedded in medical research but there is growing appreciation of the need for more holistic approaches which focus on broader health and wellbeing issues and wider systems of social care beyond the provision of medical care. Health problems are risk factors in the social development of children and adolescents into adults who can participate in society. SSH research is of great importance to create forward looking and effective medical education and practice.

16. The 'medical humanities' include an interdisciplinary field of humanities, social science and the arts, and provide insight into the human condition, development, suffering, personhood, our responsibility to each other as well as how social conditions and social institutions influence health and wellbeing and the effects of medical care. They also offer a historical perspective on medical practice. Attention to literature and the arts help to develop and nurture skills of observation, analysis, empathy, language and self-reflection - skills that are essential for humane adaptive function and medical care. Not only can humanities scholarship help foster these skills among medical practitioners, it also has the potential to participate more directly in the therapeutic process by helping patients suffering from disorders to achieve peace of mind and enjoy a more rewarding social life. Close cooperation between medical science and cultural scholarship, including practice-based research in the arts, is needed to test and develop this potential beyond the level of well-meant intuitions.

Demography

17. Europe has to adapt to long-term social and demographic changes such as population ageing, below-replacement fertility, extended life expectancy, increased complexity of family networks, increased female labour force participation, and increased mobility both within and across countries. Across Europe, old forms of inequalities, e.g. between social classes, have resurfaced and new forms of social and economic inequalities, e.g. between the young and the old, and between dual-earner and single-earner couples, have developed. These social and economic developments pose key challenges to governments and other societal stakeholders across Europe.

18. An understanding of how these new social and economic realities impact European populations also requires a focus on generational and gender interdependencies in families and other social networks, and on how these dependencies are shaped by the educational system, labour market, housing market, civil society, and welfare state policies. Institutional frameworks support individual autonomy or impose dependencies between men and women and between family generations. Work, residential, and care arrangements are a reflection of cultural values shaped by socio-economic and political contexts. People take decisions related to schooling, work, leaving home, partner relationships, childbearing, housing, care, and their personal life with reference to moral and socially negotiated views about what conduct is right and proper.

19. In order for the social sciences to provide answers to these questions, data are needed

that (1) cover the complete adult life course and focus on key decisions and transitions in men's and women's lives, (2) are longitudinal, prospective, and forward-looking, (3) are cross-nationally comparable, and (4) combine information on institutional context and individual behaviour. If we want to prepare Europe for the future ahead, we need data that are based on a life course perspective, which views individuals' life course as shaped by earlier life circumstances, the families and social networks in which people are embedded, and the institutional, cultural and economic context.

Health, wellbeing, ageing and physical activity

20. Numerous studies have shown the impact of a moderate and regular activity on health. Thirty minutes of motor activity each day is associated with a 30% mortality decrease. Physical activity has a positive impact on, for example, cardio-vascular risks, type 2 diabetes and breast cancer, but also on depression and wellbeing; neurological diseases are affected as well. Recent studies show a 30% decrease of Alzheimer when people are physically active. More generally quality of life (physical, mental and social) and self-esteem improves when people are physically active (between 30 and 90 minutes of exercise daily). The latest studies show that this is particularly true for ageing people. Cognitive performance is impacted by physical activity at all ages.

21. The processes that lead to such results begin to be known: weight loss, hormonal impact, stress regulation, brain oxygenation, and immunity. But more needs to be done to understand the impact of physical activity on (mental) health and wellbeing. However, the challenge resides mostly in engaging people in staying physically active. Beside the physiological limitations, socio-environmental obstacles need to be taken into account as well as psychological beliefs and habits of modern life. Studies have to be done on the socio-psychological perspective. The social benefits are obvious: less dependence, less disease, less health cost.

Culture and ethics

22. Prevention efforts have recently turned to understanding how micro-environmental factors, such as physical living environments, impact on non-communicable diseases, such as overweight. Much less attention has been paid to how macro-environmental factors, such as the media environment, impact on health. Even though the larger part of the population now has access to health information 24/7 through entertainment and news media, little is known how media selectivity impacts on health risk perceptions and behaviours. Ecological approaches that integrate individual-level and micro- and macro-environmental level variables in the explanation and prevention of non-communicable diseases should be developed, tested and refined.

23. Furthermore, humanities scholarship can provide necessary protection against hasty extrapolations about human nature on the basis of neuroscientific findings and, more productively, can help neuroscience to refine its research questions and to achieve results at a level of precision adequate to the human condition. Equally important is the question of how cultural values and beliefs influence policies and legislation on medical research, e.g. in the recently contested EU ban on patents based on human stem-cell research.

24. In the Horizon 2020 proposals it has been signalled that the costs of health and social care systems are rising as a result of the care and prevention measures and the increasing life expectation. The aim is to ensure health and wellbeing, but at the same time to lower the costs to such an extent that the health system remains financially sustainable. To achieve this aim scientific tools and methods to support policy making and regulatory are needed. This includes the development of methods to monitor the

safety, efficacy and quality of health technologies. Additionally, support for "improved risk assessment methodologies, testing approaches and strategies relating to environment and health" are required (EC, 2011, p. 53).

25. At this point, ethical aspects are already mentioned explicitly. This does not come as a surprise, because debates on all the mentioned topics already exist in bioethics. These are debates with established methodologies, publication media and research institutes. In the last 20 years the European Commission has strongly facilitated the debate in Europe. Currently, there is a need to further develop the methodology of ethics research in this area. Important research topics are:

    - The further development of the human rights-regime as normative framework for bioethics.
    - The ethical significance of instruments for the measurement of welfare and their applicability in health care.
    - The role of health care towards the background of demographic changes.
    - The ethical assessment of the whole genome diagnosis.
    - New possibilities of prenatal testing which will influence the scope of the application of genetic testing.
    - New possibilities with respect to enhancement, especially related to the question of who has access to this new development and who has not.

    A focus on these topics will further improve the quality of the systematic reflection on the normative dimensions of the health related challenges.

Recommendations

26. It is clear from the above that there is an urgent need for the European Commission to consider the inclusion of SSH research in the programme for addressing the challenge Health, demographic change and wellbeing. LERU also wishes to stress that all programme committees and sub-committees should be composed of several disciplines, first of all SSH. This is the only way to achieve the breakthrough progress in research that Horizon 2020 is supposed to achieve.

LERU suggests the following research lines:

Horizontal issues and framework conditions

27. For basic, clinical and public health research it is crucial to increase the participation of mental health professionals and organisations, patients and service users, families or carers, policy makers and administrators and donor organisations. Stakeholder involvement adds value to mental health research, e.g. by suggesting feasible research designs or patient relevant optimal research outcomes. This improves the real world value of research.

28. Mental health research covers a wide range of disciplines ranging from social science, psychology, educational sciences and cognitive sciences to genetics, biomedical research, imaging, basic neuroscience, etc. Funding allocated to mental health research is not proportionate to the burden of disease and is fragmented among disciplines. What is needed is a consistent strategy at the national and European levels for the development of a coordinated approach for mental health research integration.

29. The 'medical humanities' include an interdisciplinary field of humanities, social science and the arts, and provide insight into the human condition, suffering, personhood, our responsibility to each other as well as how social conditions and social institutions influence health and wellbeing and the effects of medical care. Again, a consistent strategy at the national and European levels is necessary to develop a coordinated approach to medical humanities research.

30. Applied cognitive sciences and neurosciences involving natural and artificial mind studies should be considered as a privileged paradigm in order to study the relationship between lifestyle, individual choices, wellbeing and health. Furthermore, within the same paradigm it is possible to design, test and validate new tools to improve individual and social wellbeing, both supporting prevention activities and specific therapeutic programmes.

31. Research training and critical mass should be enhanced by providing incentives for research careers in mental health, medical humanities and applied cognitive sciences research and encouraging broader, structured training programmes across all relevant disciplines and careers.

Pillar 1: Prevention, screening and early diagnosis

32. To obtain optimal health outcomes, research on communication processes (mass media, social media as well as interpersonal), health promotion and education is crucial. For instance, mass media strategies can be used to effectively communicate a healthier lifestyle, interpersonal communication strategies can be used by caregivers in prevention, detection and/or treatment of health problems. Healthy behaviour promotion needs large-scale studies in order to test which action at social and individual level are actually efficacious in helping people to adopt healthier lifestyles, thus preventing known risk factors. (Neuro)cognitive and behavioural approaches should be enhanced, also through the development of technological innovations (web-based tools, social networks applications, portable communication and assessment devices), with the aim to increase the efficacy of policies and educational programmes.

33. As mental disorders result from the interplay of genetic and environmental factors, interdisciplinary population-based research by biological, neurocognitive and behavioural scientists is needed to identify their developmental and life-course determinants. Large-scale datasets and repositories of biological, (neuro)cognitive and social determinants of mental health as well as large-scale longitudinal cohort studies are needed in order to unravel the multiple genetic, social and environmental mechanisms involved in mental health problems. But also small studies targeting the 'frontiers' of social and psychological science are in dire need of funding.

34. Knowledge of the adverse environmental influences on brain and social development is crucial for developing and testing primary preventive strategies at the level of the individual (e.g. cognitive-behavioural therapy for ultra-high risk groups for schizophrenia to prevent conversion into caseness; therapy and treatment of a growing number of developmental disorders like autism, attention deficit problems and behavioural problems in children). Especially early detection of individuals at risk to develop mental disorders or behavioural problems allows intervening at an early stage or before the worst symptoms occur and help to prevent long-term cognitive and social-emotional damage. Prevention programmes for various (often transgenerational) mental disorders need to be developed and tested as regards (cost-) effectiveness and feasibility.

Pillar 2: Care and cure

35. It is necessary to develop and test new, more effective treatments for mental and developmental disorders and implement them more rapidly. Developments in genetics, developmental biology and neurobiology are beginning to answer the question how genes and their interactions with the environment influence neural systems underlying aberrant cognitive processes of mental disorder (such as inattention, impulsivity and emotional instability like aggression, empathy and insufficient self-control) (Baron-Cohen, 2012). Multidisciplinary interaction between the disciplines of behavioural science, neuroscience, genetics medicine and more

specific neurology and psychiatry will result in more stratified treatment options for various mental disorders.

36. Only one third of persons in the EU with mental disorders receives adequate treatment. Since the available treatment resources are limited, new science-based models of service delivery have to be developed and tested - especially for those conditions with the highest prevalence (e.g. depression), highest economic costs (e.g. autism, learning disorders, ADHD) and harder to reach individuals (e.g. the homeless, delinquents, the elderly and migrant patients). One opportunity to reduce the 'treatment gap' is to use innovative IT approaches based on the web and use of Ipad or mobile phones. The development of innovative IT approaches could be done with greater partnership with industry to increase leverage.

37. Addressing the organisation of mental health care could also reduce the burden of mental disorders. Models of timely targeted diagnoses, prevention programmes and early intervention, collaborative care of general practitioners with psychologists/psychiatrists and training of general practitioners and health psychologist in somatic, psychological, behavioural and social determinants of mental health have to be developed and tested for (cost-) effectiveness and feasibility.

38. The medical humanities should also be given attention, including issues related to the arts and the brain – how does the experience of music, pictorial art and literature interact with cognitive and affective function? Or literature as a facilitator of understanding – how can the study of fiction, poetry and drama improve the emotional intelligence of the caring professions? Or cultural activity as self-therapy – how does the adoption of a cultural activity (art or music classes, literary expression) assist the healing process? Healing in other cultures should also be researched – what do the practices of past and foreign civilisations tell us about ways of reducing human suffering and anxiety? Work in the related interdisciplinary fields of memory studies and trauma studies has become increasingly comparative and multidirectional in recent years and holds valuable potential for addressing human distress caused by medical disorder and societal breakdown.

Pillar 3: Wellbeing and health development

39. Mental wellbeing is more than the absence of somatic or mental disorder and involves the presence of positive characteristics such as participation, resilience, self-esteem, empathy for others and self-control, determining quality of life. Pivotal for wellbeing is the capacity to live and cooperate with other people, the social adaptive development. Studies to identify the neurobiological and psychological underpinnings of wellbeing across the life span and health development are needed. These could provide the basis for evidence-based public health strategies to promote wellbeing in the workplace and in schools, educational and social care services for the elderly and group-based parenting programmes.

40. Given the rapidly ageing European population, in particular "independent" living of the elderly in different social and cultural contexts within Europe should be facilitated by developing programmes for self-management including smart assistive technology. Other questions which should be addressed include issues related to ICT and disability – how can people with learning disabilities and physical impairments use information and communication technology in life-enhancing ways? Or related to faith, mind and body – what are the mechanisms behind the longer spans of healthy life observed in regular worshippers?

41. There is an urgent need for large-range, longitudinal studies (prospective studies in which the same individuals are followed through time) in order to adapt to long-term social and demographic changes such as population ageing, below-replacement fertility, extended life expectancy,

increased complexity of family networks, increased female labour force participation, and increased mobility both within and across countries.

Pillar 4: The ethical dimension of health and wellbeing

42. Across the whole medical and health remit there are also important ethical and cultural issues related to end of life, treatment interventions, genetics, reproduction and healthcare regulation. Questions which should be addressed by research include life choices and prioritisation in health care – what, if any, ethical rationales can be found for the allocation of health-care resources in the context of individual responsibility? Organ trafficking – what are the ethical implications for all agents in this trade, including the recipients of organs? Infertility – what are the ethical implications of granting and withholding treatment on the basis of various criteria, such as parental age? The termination of life – how can life-terminating and non-life-prolonging measures be given a basis in a code of practice resting on shared and recognised ethical principles? 'The long goodbye' – what cultural elements associated with funeral practices and grave-sites can be seen to enhance the quality of life of survivors? Research is needed on the ethical significance of instruments for the measurement of welfare and their applicability in health care, the role of health care towards the background of demographic changes, the ethical assessment of the whole genome diagnosis, the new possibilities of prenatal testing, which will influence the scope of the application of genetic testing and the new possibilities with respect to enhancement, especially related to the question of who has access to this new development and who has not.

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