

Brussels, 11 November 2014

Workshop on "Health, demographic change and well-being: perspectives
from SSH on research and innovation"

Report

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Context

The Horizon 2020 regulation stipulates that "Social Sciences and Humanities research will be fully integrated into each of the priorities and each of the specific objectives" of the research and innovation programme. For this approach to succeed, research questions and solutions stemming from SSH disciplines and non-SSH disciplines, such as natural sciences or technology, need to be integrated through interdisciplinary work.

The RTD Action Plan for SSH Integration includes a series of interdisciplinary workshops on "promising research areas for the integration of SSH in thematic areas on the basis of the focus areas (in late 2014 and early 2015)".

This workshop was a joint effort of the Directorate General for Communications Networks, Content and Technology (DG CONNECT), the Directorate General for Research and Innovation (DG RTD) and the Joint Research Centre (JRC) in line with this specific action. The workshop was framed around Societal Challenge 1; it brought social scientists and technology-oriented researchers together to discuss successful experiences of working together, and to listen to suggestions and ideas on how to improve this in the future.

Expected outcome

The goals were to:

- a. Take stock and exchange information on what has been achieved so far in the area of health-SSH collaboration, and
- b. Explore how the embedding in SC1 of knowledge, methodologies, data, concepts and perspectives from SSH disciplines can improve not only the understanding of complex societal issues, but also the societal relevance and innovation potential of our proposed solutions.

The workshop was therefore expected to deliver SSH research questions and methodologies relevant for Societal Challenge 1 "Health, Demographic Change and Well-being" that may be addressed in future programming cycles.

Participants

There were approximately 50 participants (including Commission staff). Most of the experts have an SSH background and/or are heavily involved in projects in the fields covered by SC1. Participants were not limited to academia and research organisations, but also included delegates with hands-on experience in hospitals, care organisations, NGOs, interest groups of patients and carers, and industry.

Format

The workshop was a one-day event held in Brussels at Covent Garden building on 11 November 2014. In line with the content of the Specific Programme, three main areas of discussion were explored:

- Europe's demographic challenge – ageing societies
- Public health and healthy lifestyles
- Health systems and stakeholder engagement

There was a morning session in a classical format with presentations and a more open working group session in the afternoon. The morning session included a general introduction to SC1 and the integration of SSH perspectives, followed by short introductions linked to the three main areas covered by the workshop. For each area, one presentation was made by an external expert and one presentation by an EC representative, followed by questions and answers.

The four working groups which met during the afternoon were formed as a result of the discussions during the morning session. The working group topics were reformulated following a discussion in plenary session. The findings of these groups were then presented at a plenary session, which was followed by a brief discussion and an outline of the next steps to be taken, including the preparation of this report.

Morning Session

Introduction

Director Paul Timmers, DG CONNECT H (Sustainable and Secure Societies), said that the Commission wants to understand the interplay between health-related research and Social Sciences and Humanities and that while the Commission would be sharing its experiences, the main purpose was to listen to the contribution of the experts assembled for the workshop. The big societal challenge being explored at the workshop is described in Horizon 2020 Specific Programme: Health, Demographic Change and Well-Being and will set the tone for EU-funded research and innovation in related fields for years to come. Social Sciences and Humanities are now woven into all parts of Horizon 2020, not only the Societal Challenges part but also in the part on LEIT ("Leadership in Enabling and Industrial Technologies"). These really difficult cross-cutting projects will have a major impact on policy development and it is therefore vital to learn from experts so that the boundaries can be pushed and the right questions asked to shape our thinking in developing Horizon 2020 future work programmes.

In her opening remarks, **Director Ruxandra Draghia-Akli, DG RTD E (Health)**, expressed her appreciation for the joint effort of different services in DG RTD, CNECT and JRC in organising this workshop, which had the objective of obtaining advice from SSH experts working in the area of health which would contribute to the development of future work programmes. Horizon 2020 has a different approach compared to FP7, focusing on challenges that need to be tackled rather than disciplines to be financed, with Social Sciences and Humanities firmly embedded in all the challenges. The EU has supported Social Sciences and Humanities for two decades, since FP4 in 1994. DG RTD has had a growing portfolio of public health related research. Under the Health Thematic area of FP7 more than 40 projects of direct relevance to some of the topics for discussion at the workshop have been financed: health inequalities, health systems, mental health and social innovation.

"Health, Demographic Change and Well-being" calls are aimed at solving complex societal problems linked to the health and well-being of European citizens. The new RTD Commissioner Carlos Moedas in his speech for his hearing at the European Parliament recalled that "The problems that we will face in the future are about challenges; they are not about sectors. And that will allow us to have

more multidisciplinary in terms of research. The future of science is about sharing”. The aim, therefore, is to fund research that will bring evidence from bench to bedside. Population health and health systems research are important to achieve this, including social sciences and humanities.

Horizon 2020 will support research that “will optimise the efficiency and effectiveness of healthcare provision and reduce inequalities by evidence-based decision-making and dissemination of best practice, and innovative technologies and approaches”. The intention is to fund action oriented research that will help transform European health systems to make them safer, more person centred and cost effective. Dr Draghia-Akli emphasised that the workshop constituted a unique opportunity to deliver feedback and ideas to the EC for the preparation of the next round of work programmes.

Europe's demographic challenge - ageing societies

1. From comparative studies to co-creation - user involvement and interdisciplinary work in EU funded projects

Horst Krämer, Scientific/Technical Project Officer DG CONNECT H2, Digital Social Platforms, gave an account of achievements in user involvement and interdisciplinarity with particular reference to the evolution of ageing and ICT programmes from FP5 onwards. He emphasised the socio-economic dimensions of the FP7 programme and the support to the newly established European Innovation Partnership on Active and Healthy Ageing (EIP-AHA). The 2012 Programme already involved end-users (both patient and health professionals) in product development and implementation, and Social Sciences and Humanities were mentioned as a cross-thematic approach. The 2013 programme paved the way for Horizon 2020 societal challenges by exploring the socio-economic impacts of research, using a multidisciplinary approach and again engaging with stakeholders (e.g. patients' organisations, civil society organisations, policy-makers, user groups). Horst Krämer identified a number of projects with societal impact (SEACW and DOREMI being notable examples) and demonstrated that the first calls under Horizon 2020 (PHC 19, 20, 21 and 25) strongly emphasised stakeholder involvement and interdisciplinarity. Finally, he cited the 2013 Vilnius conference “Horizons for Social Sciences and Humanities” which formulated recommendations to the European Commission. The most relevant in the context of the event include:

- enable qualitative and quantitative interventions in policy and society
- demonstrate that a deep understanding of "environment" is needed to ensure positive health and well-being outcomes, and ethical agendas; show that demographic change is at the foundation of many socio-economic and cultural changes
- take seriously the "lifespan" approach
- take seriously global dimensions, inspiring cross-cultural and comparative research
- draw out the concept of "well-being" (distinct from health)

Against this background he concluded by putting forward a guiding question for the workshop: "What determines societal relevance and impact?"

2. The quest for more value in research and societal impact

Dr. Dragana Avramov, Director and Senior Scientific Fellow, Population and Social Policy Consultant posed the question as to why the quest for societal impact is gaining such importance. She suggested that, with budgetary constraints, the justification of the use of public funds has become increasingly important. This in turn has led to a shift towards a more knowledge-based approach to research questions which both address important societal issues and take on board end-user needs. There has also been a move to link research and innovation policy measures with broader objectives in society - "the grand challenges faced by society".

She pointed to two evaluation dilemmas: First, as science and technology are seen as driving forces of modern society and shape many aspects of public and personal lives, they often do so in a complex and unpredictable way, and second, research and innovation need to help deal with unexpected and unforeseeable futures. She posed a number of challenges for assessing the impact of research and innovation.

In relation to the Health, Demographic Change and Well-being Societal Challenge, Dr. Avramov suggested that well-being –the ultimate societal objective– was an umbrella notion on which there is no consensus in the research community, but that demographic changes were well researched and understood. While the short-term social benefits of well-being can be attributable to RDI, it is less easy to measure the longer-term economic, social, environmental and cultural aspects of well-being. One way forward, she suggested, was the framework developed in the Finnish holistic approach demonstrated in the TEKES/AKA/TIN project (2011) and the EU FP7 project IMPACT-EV.

She questioned whether medical and ICT technology can have an impact without replicability and scalability of service innovation as well as customisation/personalisation of service innovation. While replicability is easy to argue, scalability is more difficult, but without it there will be little impact. Equally, the absence of personalisation will lead to low take up and impact. Population ageing in Europe constitutes a strong pressure factor for structural changes to the ways our societies are organised, shaping the life-course of individuals, and the values attached to inter-generational solidarity. In the longer-term perspective -up to the mid-21st century- demography will be an even stronger driver for change. She emphasised that well-being should be considered at all ages in the context both of population ageing (Changes in age structures, ageing of vulnerable groups (e.g. immigrants, persons with disabilities)) and the ageing of individuals (memes and genes; women and men). Dr. Avramov raised the issues of trans-disciplinarity and the need for disciplines to integrate.

DG Connect has been particularly strong in *ex-ante* and *in itinere* evaluation. The challenge lies in *ex-post* evaluation –determining societal benefits and policy impacts.

Dr. Avramov concluded with a question: How can one ensure the authentic input of SSH in Horizon 2020, given the concerns in the SSH community that some lines of cultural and social research are at risk of being relegated into auxiliary disciplines and/or practices of technical expertise?

3. Discussion

The discussion, chaired by **Ilias Iakovidis, Acting Head of Unit DG CONNECT H2**, explored the following issues:

- **Defining impact.** One contributor asserted that we want to change our society but that the focus on impact is taking away potential for blue skies thinking. Well-being, for example goes beyond health and ICT. There is a need to work on redefining impact in terms of the evaluation process. It was acknowledged that both applicants and evaluators are often at a loss as to how to evaluate impact.
- **Demographic pressures.** Policy makers cannot sell “well-being”, but politicians are under pressure to meet demographic pressures and therefore more research is needed on demographic problems. It was argued that demographic changes are not fully understood –for example, the issue of shrinking populations in peripheral/rural regions.

- **Ex-post evaluation.** While the Commission does not have good factual information on the long-term impact of projects - there is little doubt that there is considerable impact that is not measured or documented, largely because it is difficult to measure. There is a need for much more extensive ex-post evaluation, particularly the longer-term socio-economic impact.
- **Changing the behaviour of individuals is the holy grail of the quest for “well-being”.** But there needs to be a more system-oriented approach to the changing behaviour of individuals that is so deeply embedded in cultures. However, again, the challenge is to identify quantifiable indicators.

Public health and healthy lifestyles

1. Health and well-being -the contribution of public health research

Barbara Kerstiens, Head of Sector DG RTD E3, Public Health, highlighted that chronic and degenerative diseases are gaining importance in the context of the ageing population and that more than 70% of total healthcare spending (which itself is 10% of GDP) is on chronic diseases. In the light of these figures, there is a need for innovation and transformation of health care interventions, health systems and services and the EU must catch up with global health innovation leaders if it is to keep its biomedical industry. The public health research portfolio has grown substantially since 2000, with funding of € 364.5 million over 141 projects in FP7 (32% population health, 68% health service research).

Dr. Kerstiens said that, for research to inform policies, robust evidence is needed on what works in health promotion and health services interventions. Excellence in research requires capacity building and investment in research, education and training of students and researchers, development of better research methodologies including data collection, as well as multidisciplinary, inter-sectorial and international collaboration.

While highlighting some of the success stories in public health research, she pointed out that it is difficult to assess the impact of public health research because of the time lag between action and result. It is also difficult to establish the link between “successful” projects and policy changes.

Another challenge is that when you have the evidence of what works, how can you use it for policymaking? Asking how to better implement what works, she posed five questions:

- How do we link research, policy actions and social engagement?
- How do we stimulate dialogue between researchers and policy makers, citizens etc.?
- What tools are required to achieve the desired results?
- Can we learn from each other?
- Do we need a knowledge bank?

2. Vulnerable high need/high cost elderly patients: care arrangements and policy responses.

Prof. Elias Mossialos, Co-Director of the European Observatory on Health Systems and Policies, London School of Economics and Political Science, referred to a study that demonstrated that 1% of Ontario patients incurred 33% of the Provincial health expenditures, and that 5% incurred 33% of the expenditures. These complex, high cost users receive treatment from multiple health care sectors and often have long lengths of stay in inpatient settings. 75% of complex patients see six or more physicians, with 25% of those seeing more than 16 doctors. The number of morbidities and the proportion of people with multimorbidity increases substantially with age. By the age of 50 years, half of the population has at least one morbidity, and by the age of 65 years are multi-morbid.

He suggested that resources should be focused on the persistently high cost areas, and that management of chronic conditions, end-of-life care and expensive episodes hold the most promise even though it is not easy to identify or predict the “high spenders”. US research, though, has demonstrated that, out of the \$2000 billion healthcare budget (2008), 40% was used by 110 million people with chronic care, while 2.5% of the budget was spent on just 1 million people who were dying with a short decline, and 5% went to 2 million people with multiple chronic conditions with serious exacerbations or “advanced illness”.

Prof. Mossialos said that risk analysis research, as well as comorbidity data, is required for Europe if resources are to be allocated to the high cost areas. Measurements of medical and social needs, as well as risk and health status are essential if appropriate strategies are to be designed and implemented. Performance measures are also required if we are to evaluate how these strategies are performing.

He argued that care is often duplicated, or sometimes there are significant gaps in care. Patients don't get the care they need or deserve. This inefficiency costs the system and taxpayers with overuse of emergency room visits, hospital admissions, conflicting and overlapping prescriptions (with all the resulting dangers). Effectively integrated care between hospitals, home care, community and social services, specialists etc. would mean that providers work together to develop a coordinated care plan for each complex patient, by sharing information, eliminating duplication and provide better care for the patient. Integrated care is about everyone in the system working together, sharing their expertise and helping to strengthen partnerships, so that care can be organised around the patient.

He suggested that successful coordinated care can be measured. At the outset, all complex patients will have a coordinated care plan and complex patients and seniors will have regular and timely access to a primary care provider. Measures would include reducing the time from primary care referral to specialist, reducing the number of 30 day readmissions to hospital, reducing the number of avoidable ED visits for patients with conditions better managed elsewhere, reducing time from referral to home care visit, reducing unnecessary admissions to hospitals, and providing faster primary care follow-up after discharge from an acute care setting. These measures would enhance the health system experience for patients with the greatest health care needs and reduce the average cost of delivering health services to patients without compromising the quality of care.

He demonstrated that this type of approach had been successful in the UK and he instanced two particular projects –proactive management of vulnerable elderly, and the UK stroke service– where organisational change and innovation has had an impact on survival.

Prof. Mossialos concluded by arguing that the key issue is not always about new products but about organisational and behavioural change and how existing procedures are implemented. Change cannot be achieved without either information or incentives (and maybe even regulation, even if this might be unfashionable!). This will require the right payment mechanisms, the right information infrastructure, data sharing and linkages across settings, the right workforce model, and a patient-centred approach.

3. Discussion

In the discussion that followed, chaired by **Philippe Keraudren, Acting HoU DG RTD B6, Reflective Societies**, the following points were made:

- **Encouraging creativity and innovation.** There are many barriers placed in the way of change. How do we encourage innovation and make it acceptable? Perhaps the submissions process for Horizon 2020 should be even less prescriptive, allowing for more creativity, and placing the onus on applicants to demonstrate their creativity. There is always failure in high-risk research. The Commission should accept that some research will fail and that the risk may be worth taking to encourage innovation and creativity.
- **Lack of research on human resources.** There is a serious lack of research on human resources, particularly given that 60% of health services funding is spent on human resources. Why do some countries have many more specialists, or fewer nurses, than other countries? Research is also needed to demonstrate that, for example, training primary care providers in geriatrics, would improve the effectiveness of healthcare. The return on investment in these areas, involving SSH, would be significant.
- **Research in IT.** The investment in IT has been very substantial but (not only in the UK) the results have been disappointing. What type of IT services/resources should we have for our health services? Instead of trying to have ERCs for all our citizens, should we be targeting IT resources at the top 2% of vulnerable people?
- **The definition and context of innovation.** Is there clarity as to whether innovation is something new or also a new way of implementing something? There is insufficient research on the context of innovation –the surrounding circumstances. If, for example, there is to be research on innovations connected with multi-morbidity, the context in terms of the activities which preceded multi-morbidity should also be researched. There is a need to link up relevant data, and to explore the context of organisational and legal barriers.
- **Organisational change and development.** It was suggested that it is difficult to get Commission funding for organisational change and development (although it was pointed out that PHC 25 was a step in the right direction). More attention needs to be given to the ways in which

researchers can influence policy. How do we ensure that policy makers hear about research activities in a disciplined manner and –perhaps even more importantly– how can they be engaged in the research process? There is a nexus of conflicting concerns that policy makers are facing -how to balance the issue of growth and innovation versus reducing costs. Of course, cost reduction may be the result of innovation and may in itself lead to growth. There is substantial inefficiency in the provision of health services. If the trend continues at current rates, healthcare costs will move towards 15% of GDP, and this would lead to politicians pushing for privatisation (with the inherent risks that we might end up with a US-type healthcare system). By using our resources more effectively, healthcare costs might remain within sustainable levels at 10-12% GDP.

- **Mental health. Mental illnesses contribute more to the global burden of disease in Europe than any other illnesses.** 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. In particular, investment in early years can prevent mental, somatic and social problems in adolescence, early adulthood and older age with widespread benefits for health and wellbeing.

Dialogue – Healthcare 2030. There is a need for greater dialogue between industry, policy makers, users and researchers to discuss what the health care system might look like in 2030. If we ask the big questions first, we can then look for the means to address them. Sometimes the private sector is well ahead in its thinking, and certainly each sector has its own priorities. We need to get together to establish shared priorities.

Health systems and stakeholder engagement

Dr. Kristrún Gunnarsdóttir, Senior Research Associate, Lancaster University was due to speak on “Making Sense of wearable care and the politics of public healthcare” but was unable to attend the workshop.

1. Participatory Healthcare: insights from a case study.

Prof. Annibale Biggeri, Università degli Studi di Firenze, defined participatory healthcare as personalised management of chronic pre-disease conditions. The participatory eHealth ecosystem involves sources of knowledge (questionnaires and diaries, self-tracking using wearable sensors, external data such

as air pollution, and community-based bio-repositories), a platform, and the users (stakeholders, policy makers, scientific community, and the healthcare system). Comparing self-tracking as against “other-tracking”, the advantages of other-tracking are the protection of individual from abuses, restrictions on data access, usage, and distribution, and anonymization, while self-tracking provides data accessibility and portability, controllability of data access, usage, and distribution by the individual concerned, and preservation of precision.

In participatory healthcare, third-party data service providers should support self-tracking, not just other-tracking. Ideally, these would provide clear privacy, use, and data ownership policies, preserve privacy and precision, allow individual to exert fine-grained control of authorization for data access, and support meaningful data portability.

A case study on participatory population bio-banking for health and well-being promotion was presented. A key component of the Romagna Bioteca Project is the creation of an independent Foundation, with its own Board of Trustees, which acts as a third actor between the researchers and the donors of biological specimens. The Foundation (a BioTrust) is responsible for the conservation and use of the conferred biological specimens, providing the necessary safeguards and allowing donor participation. The Romagna Bioteca case study represents a participatory context in which collective values and well-being are the main goal to be achieved. The collective well-being at population level embeds the self-tracking approach in a vision of the society based on solidarity.

Prof. Biggeri suggested that the following was still required:

- A new language – research on communication on risk
- A new biology lab – research on sustainable labs
- A new way to deal with personal rights on conferred biological samples
- A new definition of BioTrust/Foundation or Bioteca/Biobank
- A network of groups and institutions and authorities
- A new community space – research on ICT tools

Ângela Guimarães Pereira, JRC-ISPRA, indicated that she would cover the subject matter that Dr. Krístrún Gunnarsdóttir was intended to present- “Making Sense of wearable care and the politics of public healthcare”. She used the European Commission’s green paper on mHealth to reflect on its promises and

the expectations it may trigger, as far as citizen engagement in health systems is concerned. For example, she has indicated that through sensors and mobile apps, mHealth promises the collection of considerable medical physiological, lifestyle, daily activity and environmental data. This scenario according to the green paper is seeking a basis for evidence-driven care practice and research activities, while facilitating patients' access to their health information anywhere and at any time. The green paper also states that mHealth can contribute to the empowerment of patients as they can manage their health more actively, living more independent lives in their own home environment thanks to self-assessment or remote monitoring solutions and monitoring of environmental factors such as changes in air quality that might influence medical conditions. So, this paper seems to advocate that information from wearable sensors is more objective in some cases than patients' own histories.

She offered examples from citizen-led initiatives with regards to their health, such as the self-tracking and quantified-self movements; these movements herald such self-veillance practice as useful because people and context differ, while self-tracking can be individualised and can be tried using different strategies. In other words, these types of technologies are helping citizens to take control over their own health who may therefore be more committed to finding solutions for themselves, rather than being told what to do by doctors. One such example is The BodyTrack project which, in the words of Anne Wright, the founder, is working to build and/or integrate open-source and open-API tools and foster technological and cultural developments which empower individuals to embark on the process of self-discovery with greater hope and pursue it with greater satisfaction. Through empowerment, the project hopes to foster a cultural shift for individuals to take more responsibility for their own health and well-being.

Ms. Pereira raised five questions to trigger a debate about the current views of citizen engagement in health care systems and the automation of some aspects of care:

- What societal challenges, of social and ethical nature, does the choice of automated and digitally mediated care lead to?
- Will these technologically mediated systems of engagement enhance inequalities?
- What forms of disempowerment and agency loss may emerge?
- How does one ensure trust in the emerging spaces?
- What are the meanings of care with which these systems are programmed and offered to the publics?

She suggested that the engagement between objects (health care systems) and subjects (people) will be different from the manner in which they currently relate, and that in itself should be the object of thorough reflection and negotiation amongst all relevant stakeholders and not left solely to economic interests.

2. Discussion

The discussion which followed, chaired by Ângela Guimarães Pereira, JRC-ISPRA, considered the following:

- **Self-tracking and a knowledge base.** Self-tracking data needs to be bounced against a knowledge base -a gap that needs to be filled. Self-trackers are already convinced of the need to change. This needs, however, to be mainstreamed to those who are not already convinced.
- **Self-tracking capacity gaps.** There are significant capacity gaps in this area. Other disciplines need to be engaged and there is a need to build leadership in multidisciplinary skills. This cannot be done without engagement of health systems, shaped by the people who are posing the problems on the ground – and this in itself is a huge challenge. The system has difficulty in engaging with researchers. Could the Commission incentivise national researchers to address these issues?
- **Taking control of one's health.** People want to take more control of their health –the momentum is there and modern technology will help. The devices increasingly exist, but we need to have the knowledge to use them appropriately. Horizon 2020 Programmes need to recognise the key role that patient empowerment has to play –that individuals need to be informed and make decisions on their own health.

Afternoon Session

Acting Director Peter Droll, DG RTD B, introduced the afternoon session, emphasising the importance of this workshop to achieving the Commission's ambition of integrating SSH into H2020. The focus cannot only be on technology and growth, with the social sciences seen as merely an add-on. In particular, the Societal Challenges are urged to consider the potential relevance of SSH contributions beyond societal acceptance and marketing models and to broaden the scope of disciplines involved. SSH must be embedded throughout all parts of Horizon 2020, and this meeting is part of the process to deliver on full integration. The 2016-17 programme should, as a result, be

much stronger in the way SSH are integrated as a framing element in the key stages of the R&I cycle.

Philippe Cupers, DG RTD E1, Acting Head of Unit, proposed the working group topics to be discussed during the afternoon, following from the main points discussed in the morning. Participants were free to take part in the working group of their choice. It was agreed that three areas – trans-disciplinarity, impact and demographic change – should be treated as cross-cutting issues.

Reports from the working groups

Group 1: How research should be developed around organisational issues in health systems and social care (with a focus on demographic change, transdisciplinarity and impact)?

Rapporteur: Diane Whitehouse

As one participant to the group discussion said, "The problems are not with the technologies, but with organisations, deployment and making progress."

What kind of mechanisms could be used to do such research? It was suggested the focus should be on "low-hanging fruit" among the major organisational challenges, particularly where there could be innovations in both health and social care. Some suggestions were: health conditions where patients have to make transitions between different areas of care e.g., mental health care; Alzheimer's and other degenerative conditions; assistive technologies (whether it is best provided by a [public] service or should be bought "off-the-shelf").

Examples of research approaches or techniques can include co-production among SSH researchers working with engineers or with healthcare or social care professionals or a "tailored approach or intervention, responding to the needs of end-users"; user-centred design; focus on genuine end-user involvement from the very beginning of the research process; mutual learning or peer learning approaches; peer reviews, so as to learn from others and avoid making the same mistakes as others; focus also on "failures" (e.g., non-acceptance of organisational change or equipment or devices) and not just on successes or good practices and, finally, encouraging marketing or promotions to be a fundamental part of all research.

It was suggested that co-production should involve a whole range of disciplines in the co-production process (e.g., including young researchers at arts and design colleges) and a whole range of disciplines in evaluating and assessing the research proposals. There must be sufficient time, organisationally, to do co-production, and that assessment processes are available (including self-assessment!). One approach is to ask different groups to brainstorm ideas, but keep the groups separate rather than forcing them to talk to each other.

Focusing on the *demographic change issues*, the working group said that consideration should be given to a "lifecycle health-friendly environment" approach. By focusing on a lifecycle approach, demographic change would automatically be explored. Such an approach would avoid the fragmentation of health and care, and it would ensure that different phases of the whole lives of people are borne in mind in any research. It would also place a focus on prevention. The topics are focused on healthy aging where the first 5 years of life are quite relevant. Based on the life-course approach, calls should be more comprehensive as to age populations referenced in the projects.

The World Health Organization's age-friendly environment approach, thinking about age-friendly neighbourhoods, villages, towns, cities, regions and countries should also be explored. This would encourage participants to focus on how organisations in their own [geographic or topographic] area matter. "Joint welfare" approaches should also be explored. Be aware of the impact and importance of the first five years of life: if, as a policy-maker, you cut childcare support this may have a massive impact on those individual children's eventual future health. Gender differences, particularly in terms of the life expectancy differences between low/high educated men and low/high educated women might also be further examined.

Transdisciplinarity

Some organisations take transdisciplinarity for granted: it is good/sobering to be reminded that in some fields transdisciplinarity is still problematic for some. Never forget that the social sciences in their own right are very diverse and heterogeneous in their philosophies, approaches and methodologies. Realistically speaking, it is also possible to be critical of the involvement of "social scientists in health" (health is a very practical field, whereas not all social scientists are practical). "Non-formal knowledge" is not clear as a condition or criteria for involvement in European Commission co-financed research. Work needs to be done to help define what the intention and expectations are in using such a term. Pragmatically

speaking, it would appear to be an easier approach for many researchers to select partners who come from two or three other disciplinary areas so as to meet the selection criteria.

Impact

Take a longer-term approach: Concentrate on long-term planning; consider phasing/staging of research, over time; offer second and third lives to projects, so that they can build stepwise on their results, over time; develop and use mixed models for commissioning of research.

Take a systems approach: Never look at a single project or just one trial. Look instead at the whole body of evidence i.e., a whole initiative or a whole programme; consider how ranges of projects need to collaborate together.

Explore how the research impacts policy, particularly future policy by asking researchers to show their proposed "pathways to impact"¹ and what they will do to encourage uptake. Ensure that such approaches are embedded in the research itself.

To obtain inspiring ideas, explore various social science, and arts and humanities, research evaluation approaches with e.g., personnel who represent social science/humanities research councils in Member States to find out what types of methods they use to evaluate and assess research and its impact.

Take two views - a historical overview and a future-looking approach: Do impact evaluation (track forward to what the impact might be or track back to see what the policy was). Deliberately go back 20+ years and track progress, over time² and forward 15/20 years (Health 2030 or eHealth 2030), as suggested by Elias Mossialos of the London School of Economics and Political Science and use forecasting methods and scenario building (for future foresight). Former projects could be interviewed for some time afterwards to explore with them their results (e.g., earlier Daphne funding programmes³ were able to influence a charter of rights presented to the Council of Europe and the United Nations). A website or web

¹ Cf. Research Councils UK: <http://www.rcuk.ac.uk/ke/impacts/>

² Such an approach could be of interest to historians, particularly of technology or innovation.

³ Cf. http://ec.europa.eu/justice/grants/programmes/daphne/index_en.htm

archive could be created where former projects can report back on their longer-term results even after the end of the projects themselves.

Group 2: Research and Innovation in Participatory health and well-being.

Rapporteur: Sara Riggare

- Clearer definitions on personal health and well-being are needed, and whether participation is a method or a means?
- Consideration needs to be given to what kind of (potential) impact, from whose perspective and at what level (personal, societal, research, innovation)? It was noted that impact is not always about money.
- Issues for consideration:
 - What are (ageing) citizens/patients already doing?
 - Scaling of current practices
 - Methodologies for social return on investment
 - Reducing public health spending
 - Changing power balances
 - New insights into the management of chronic conditions
 - New business models/reimbursement systems

Group 3: Incentive and engagement of health systems owners with researchers.

Rapporteur: Eugenio Mantovani

- Priority setting. Encourage dialogue between health system owners and researchers so that the research questions are agreed by both groups from the outset
- Make explicit the involvement of health system owners in the consortium (what is the goal, the direction of technology change, etc.)

- Encourage capacity building at the national level. This will ensure respect for national differences (principle of subsidiarity). Capacity building will require that part of the funds is allocated to blue sky research, as well as the development of appropriate expertise.
- Develop evaluation mechanisms with a clear role for researchers in assessing (long-term) implementation.
- Require transfer of knowledge (ToK) strategy in applications (i.e. think about how the results of the research can be translated). Applicants should have to explain this up front, showing more creativity in translating their research results.

Group 4: How can the research programme contribute to well-being?

Rapporteur: Joanna Bryson

- Well-being should be a very broad remit. We need to encourage co-created, transdisciplinary efforts, so the proposals themselves should suggest definitions and measurements.
 - We should require qualitative as well as quantitative measurements, individual & social measures (e.g. for security feeling able to go outside at night vs. # of murders)
 - We should require real engagement with the users / people / other populations.
- We must consider well-being in healthy people as well as unhealthy, from conception to grave.
 - We need to consider sustainability, look at inexpensive products & services, derive lessons from developing countries.
- Well-being is context driven. It involves our ability to have a purpose and make contributions. There is a social component: are we connected, and are our contributions recognised by others in society?
 - What capabilities we have and therefore need to realise will vary by person and by stage of life.
 - Different across regions as well as countries, and within populations by ability.
- Well-being has to be multidimensional. How can research contribute to well-being and what is the societal value for research?

- Need to guide applicants: do you feel happy? Can you realise your ambitions? (Do you have any ambitions?) Do you participate in society?
- Dimensions include: material living standard, health, education, working conditions-unemployment, political voice, social relations, security, socio-political voice, quality of the environment, culture / access to culture, gender dimension. Subjective & objective dimensions (security for examples: number of murders, vs personal sense of security)
- Longitudinal studies should be encouraged, with a very long-term view. Things that will have impact in 5-50 years. Documentation of outcomes that span these kinds of times.

Final Session

Philippe Keraudren, Acting HoU, DG RTD B6, concluded the workshop by thanking the speakers and participants for their valuable contributions. He said that the rapporteur, Philip Berman, would be preparing a report which will be issued to all participants and put on the Commission website. The report would be carefully studied by the Commission and will provide a valuable contribution in preparing for future programmes.

Workshop conclusions

TERMINOLOGY:

1. There is a lack of clarity about the term "well-being". Since this a key term in H2020, this is a matter of concern. Policy makers and politicians cannot "sell" well-being, but on the other hand there is a real need to address demographic pressures.
2. There is also a need to better define participation/engagement in healthcare and well-being. In particular, individual and community-based approaches need to be explored, particularly with regard to their effectiveness in inducing positive behavioural change.
2. Equally, while transdisciplinarity has been defined by the Commission, project proposals should seek to respond to the requirement for transdisciplinarity in innovative and creative ways, and not merely by having experts from SSH disciplines on their teams. How, in reality, does one involve stakeholders with non-academic and non-formalised knowledge, and how can this be evaluated?
3. What is innovation? Does it mean something new, or a new means of implementation? There is a need to explore the context of innovations - organisational and legal barriers.

MEASURING IMPACT IN SSH

1. Are SSH-related projects losing out to the "harder" sciences, because it is more difficult to evaluate their impact?
2. How does one evaluate the changed living circumstances of people?
3. It was acknowledged that, at least in DG CONNECT, both applicants and evaluators are at a loss as to how to evaluate impact, and it was suggested that an over-emphasis on impact is at the expense of potentially higher-risk projects that might push out the boundaries (even at the risk of failure). It was suggested that the Commission should accept the possibility of project failure if it is to support projects that stretch the boundaries. Further work needs to be done to redefine impact in relation to Commission-funded projects.

4. Consideration should be given to a much more extensive ex-post evaluation process which would measure the long-term impact of projects. The possibility of grouping related projects for such an evaluation process was suggested. This would be particularly helpful for SSH-related projects.

5. Public health research faces similar difficulties in assessing impact, because of the time lag between action and result.

6. Perhaps the application process - including impact - could be less prescriptive, allowing for greater creativity, and putting the onus on applicants to demonstrate their creativity.

A SYSTEMS-ORIENTED APPROACH TO CHANGING BEHAVIOUR

1. If the aim of Horizon 2020 is to change the behaviour of individuals, there needs to be a more systems-oriented approach. But determining quantifiable indicators will be a significant challenge.

2. Information and incentives are a prerequisite to changing behaviour. But it is also necessary to change organisational processes - the correct payments system, appropriately trained workforces, mix of interdisciplinary skills etc.

3. There is a need for a more holistic healthcare system, and therefore the spaces - or relationships - between the key health agencies (i.e. hospital, home care, community care, social services) should be examined and reassessed.

THE IMPACT OF COMMISSION-FUNDED RESEARCH

1. It is difficult to get Commission funding for organisational change and development.

2. How does one influence policy, and how do policy makers, managers, and industry hear about these research activities in a disciplined manner?

3. More importantly, how can we get policy makers, managers, and industry involved in research, particularly SSH research?

4. There is a need for (greater) dialogue between industry, policy makers, users and researchers to establish shared research priorities. Are we asking the (correct) big questions?
5. There is a need to build leadership in multidisciplinary research skills, and there is a need for the Commission to incentivise national research programmes to develop research and programmes addressing multidisciplinary approaches to health systems.

THE ROLE OF THE INDIVIDUAL

1. There is a move from the sickness (patient) model to the well-being (citizen) model.
2. The move to self-monitoring, self-help, empowerment of citizens (and patients) may imply a diminished or different role for existing healthcare infrastructures, and the need to explore new participatory infrastructures.
3. Research programmes need to recognise that the momentum is gathering for people (both as individuals and as communities) to take control of their health, and that the technology exists - and is increasingly being developed - to support such a development.

ISSUES FOR CONSIDERATION BY THE EUROPEAN COMMISSION

The following issues have been drawn from the presentations and discussions during the workshop. Further details concerning each issue can be found in the text of this report.

A. Applications process

1. Make the H2020 applications process less prescriptive – place onus on applicants to be more creative, suggesting their own definitions and measurements.
2. Longitudinal studies with a very long-term view should be encouraged to address issues with impact in 5-50 years.
3. Well-being proposals should include qualitative as well as quantitative measures.
4. Clarify the intentions/expectations in relation to non-formal knowledge.
5. Promote co-production to avoid cultural and social research being relegated.

B. Evaluation

6. Pay greater attention to ex-post evaluation of projects – determining the longer-term societal benefits and policy impact, by assessing impact both backwards and forwards over 15-20 years.
7. Redefine impact in terms of the evaluation process, taking a longer-term systems approach, looking at the whole body of evidence, programmes not single projects, taking into account different perspectives (personal, societal, research, innovation). This redefinition/reconsideration should acknowledge that both applicants and evaluators are often at a loss as to how to evaluate impact.
8. Consider a web-based knowledge bank as a repository for information about project impact after project finalisation.

C. Research questions

9. The measurement of the longer-term economic, social, environmental and cultural aspects of well-being in order to make well-being easier to sell as a concept.
10. Development of quantifiable indicators on the impact of well-being on the behaviour of individuals.
11. Risk analysis, measurement of medical and social need, co-morbidity data and performance measures if resources are to be focused on high-cost areas.
12. How could IT resources be targeted to the high need areas?
13. What are the conditions for innovation success in the health sector?
14. How can researchers influence (health) policy, and how best can policy makers be engaged in the research process?
15. Research on the use of human resources in the health sector has significant potential RoI.
16. What is the social and ethical impact of automated and digitally mediated care on society? Will it enhance inequalities?

D. Horizon 2020 policy

17. The focus on impact is taking away potential for (inherently risky) blue skies thinking. There is always failure in high-risk research. The Commission and other funding agencies should accept that some research will fail and that the risk may be worth taking to encourage innovation and creativity.
18. Dialogue is required between all key stakeholders to establish shared priorities in relation to Healthcare 2030.
19. Need to focus greater research funding on organisational/ behavioural change and development, particularly in relation to integrated/coordinated health and social care. Look for

low-hanging fruit with potential innovations in health and social care.

20. Horizon 2020 programmes need to recognise the key role that patient empowerment has to play – that individuals need to be informed and make decisions on their own health.

21. A lifecycle approach to demographic change issues would avoid the fragmentation of health and care.

22. Encourage/support capacity building for research at national level, particularly leadership in multidisciplinary research skills, to develop research and programmes addressing multidisciplinary approaches to health systems.

RELEVANT LITERATURE MENTIONED DURING THE WORKSHOP

- (i) An article on transdisciplinary work co-written by Michael Wennsig
<http://www.ncbi.nlm.nih.gov/pubmed/25003371> ;
- (ii) B. Harrison, M. Mantei, G. Beirne, and T. Nairne (n/d) Communicating about Communicating. Cross-Disciplinary Design of a Media Space Interface. DGP. University of Toronto, Canada.
<http://www.dgp.toronto.edu/OTP/papers/x.disc.design.ms.interface/X.Disc.Design.MS.Interface.html>
Published circa 1993/1994.
- (iii) “Subjective well-being, health and ageing”. (Steptoe, Deaton, Stone) 2014
- (iv) “What happens when patients know more than their doctors?” (Snow, Humphrey and Sandall) 2013
- (v) “Understanding participation” (Prainsack) 2014.