



The HFE Secretariat wishes you a Merry Christmas and Happy New Year!

Editorial

Multiple Sclerosis

Information Dividend (MS-ID) project - a model of combined programmatic and political actions

The Information Dividend (MS-ID) project is about collecting information on Multiple Sclerosis (MS) and using this information for the benefit of patients and health service providers. There is very little available data on MS in Europe: its incidence; who is affected by it; how MS impacts on the lives of people who are diagnosed; what it results in for their participation in the labour market; and the additional services that the State provides and needs to provide for people with MS. In order to better understand the impact of MS, we have to know its effect on society at large.

■ What is the MS-ID project?

There are two main priorities to the project:

1. The development and piloting of a European Register on MS. This register gathers medical and socio-economic data on people with MS from six different countries. The advantage of developing this tool on a European level means that the information is known to be comparative across borders.
2. The promotion of the European Code of Good Practice in MS across participating partner organisations and the eventual roll-out to all EMSP members. The Code is based on a series of consensus papers drafted by expert groups in medical areas such as immunomodulatory treatment, symptomatic treatment, rehabilitation, palliative care, and other areas considered more societal - such as quality of life.

■ Who is involved in MS-ID?

The European MS Platform (EMSP) is leading this project with active participation from six national societies in Germany, Iceland, Poland, Romania, Spain and the UK. The remainder of the EMSP membership base is also involved in contributing to the promotion and distribution of the project's results.

■ What is this project seeking to achieve?

- Raising awareness across the EU on multiple sclerosis (MS)
- Identification and addressing of the major inequalities of MS treatment and care across the European Union and within the EU Member States through the development of new and effective strategies and



indicators to measure performance

- Use of high quality comparable data at EU and transnational levels to positively impact on EU / national policy and programmes towards MS and to ultimately empower EU citizens directly and indirectly affected by MS

■ What concrete actions are being undertaken within the MS-ID project?

- The development and piloting of a European MS Register
- A comprehensive report on national MS Registries in Europe
- A health economic analysis of the cost of MS in Europe
- National Roundtables promoting the Code of Good Practice in EU member states, led by the national MS society
- A lobbying campaign to increase the scope of the European Parliament resolution of 2003 in which the Code of Good Practice in MS was unanimously agreed upon by all Members of the European Parliament
- Development of an MS Barometer - a benchmarking tool that highlights the inequalities that exist in the treatment and management of MS across 32 different European countries, administered annually
- Annual reporting using the Open Method of Coordination on the endorsement and promotion of the Code of Good Practice in MS at national level across the 27 EU member states
- Continued development of the Code of Good Practice to broaden the range of subjects covered in identifying best practice in the management and treatment of MS

■ What political support has been gathered and remains to occur?

The Code of Good Practice in MS has been endorsed by the European Parliament and the European Commission, as well as being supported by a number of national health administrations. The real challenge is for the Code to be formally recognised as the basis

for the development of all policies and programmes related to the care, employment, advocacy and quality of life of people with MS. Through the parallel development of information and benchmarking of the MS Barometer, we highlight the necessary combination of adequate policy development, resource allocation and service planning to ensure that people with MS are properly empowered to achieve their potential as equal and active citizens in the labour market, as users of health services and whilst maintaining an optimal quality of life appropriate.

■ Of what interest can the MS-ID project be to other patient and healthcare organisations?

The model developed for implementation within the framework of the MS-ID project can be applied to other chronic disease groups and patient organisations. The key lies in identifying the precise tools to use in highlighting and communicating ones needs.

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HFE News

■ The Health First Europe's New Horizons Congress

The HFE New Horizons' Congress, held at the Committee of the Regions on 12 November, brought together 130 health stakeholders who addressed today's healthcare challenges during the three conference sessions, focusing on patients, healthcare professionals and, respectively, healthcare innovation.

Following the presentations from the speakers, many of the stakeholders contributed to further discussion by asking questions and promoting their own views on the future of the healthcare sector.

Of special interest to all participants was the keynote speech by the European Commissioner for Health, Androulla Vassiliou, who described in detail the European Commission's Europe for Patients Campaign, which seeks to adopt and implement ten initiatives aimed at better healthcare for all European citizens. The numerous initiatives mentioned by the Commissioner show that the European Union is becoming an increasingly important player in addressing European healthcare issues.

To read the Congress' presentations and final report, please click [here](#).

■ Health First Europe held its Annual General Meeting

On 25 November, HFE held its Annual General Meeting and elected a new Executive Committee. The members also had the opportunity to discuss the role that HFE, as an association bringing together patients, healthcare workers and the healthcare industry, has been playing in providing valuable first-hand information to the European health stake-

holders.

The next HFE Annual General Meeting will be held on 5 November 2009.

■ Health First Europe welcomes the European Commission's adoption of the Communication and the proposed Council Recommendation on patient safety and quality of health services

On 15 December, HFE welcomed the adoption by the European Commission of the Communication and the proposal for a Council Recommendation on patient safety but stressed the need for more reliable and comparable data.

Although it is estimated [1] that between 8% and 12% of patients admitted to hospitals in the EU each year suffer from adverse effects whilst receiving healthcare, there is still insufficient reliable EU statistical data on patient safety. Comparable information should be made available as a tool for identifying best practices and as a way to allow patients to make informed decisions.

The first step in ensuring patient safety is the enhancement of the quality and transparency of standards and guidelines. For this reason, HFE reiterated the opinion that a Code of Practice on the Prevention and Control of healthcare-associated infections (HCAIs) would be beneficial to the European Union. HFE also encouraged the Commission to drive efforts to develop common terminology and indicators, and welcomed the proposal to increase the engagement of the European Centre for Disease Prevention and Control in the surveillance of HCAIs and in the formulation of best practices for prevention and control.

To read the full press release, please click [here](#).

[1] This estimate is drawn from: a report by the UK Chief Medical Officer on an organization with a memory, in 2000; a Spanish National Study on Hospitalisation-Related Adverse Events (ENEAS) in 2006; a French national survey of in-patient adverse events (Michel, 2007) and interviews conducted for the Commission impact assessment in preparation for the Patient Safety Communication.

The International Alliance of Patients' Organisations launches Patient Safety Advocacy Toolkit in Uganda

On 3 November, the International Alliance of Patients' Organisations (IAPO) launched an advocacy toolkit for patient groups to inform and support their activities for improved patient safety. The toolkit, "Addressing Global Patient Safety Issues: An Advocacy Toolkit for Patients' Organisations", is the first multi-issue resource for patient groups, providing the means for patients and patients' organisations to engage in the provision of healthcare and to contribute to a healthcare system based on quality and safety.

For more information, please click [here](#).

The European Federation of Nurses Associations urges the European Commission to take action regarding Directive 2000/54/EC

On 20 November, the European Federation of Nurses' Associations (EFN) wrote a letter to the EU

European Federation

of Nurses Associations



Commissioner for Employment, Social Affairs and Equal Opportunities, Vladimir Špidla, to express the EFN concern about the delay of more than two years in the publication of an amendment to the Directive 2000/54/EC, on the protection of workers from risks related to exposure to biological agents at work, to protect health care workers from potentially fatal needlestick injuries. This is a very serious occupational risk and 6 million nurses have been exposed to more than 2 million unnecessary needlestick injuries since the European Parliament's Resolution of July 2006 (2006/2015). The EFN urges the European Commission to urgently and positively respond to the European Parliament Resolution, which is intended to protect all of Europe's healthcare workers. This small amendment to Directive 2000/54/EC can have a big impact on the safety and peace of mind of nurses and other healthcare workers across Europe.

For more information on the EFN, please click [here](#).

EU Health News

European Parliament issues draft Report on mental health

On 16 October, the European Parliament (EP) Committee on Environment, Public Health and Food Safety (ENVI) issued an own initiative draft Report on Mental Health, by Rapporteur Evangelia Tzampazi (PSE, Greece). This report is in response to the establishment of the European Pact for Mental Health and Well-being by the EU Health Commissioner, Androulla Vassiliou, on 13 June 2008.

The draft Report welcomes the European Pact and makes specific recommendations for the five priority areas identified by the Pact: prevention of suicide and depression, mental health in youth and education, mental health in workplace settings, mental health of older people, and combating stigma and social exclusion.

The Report calls for:

- Cooperation between the EU institutions, Member States, local and regional bodies and the social partners in the five priority areas identified by the European Pact
- The adoption of a Consultative Platform to monitor and coordinate measures to implement the Pact
- The development of a "European Action Plan on the Mental Health and Well-Being of Citizens"
- The identification of comparable and appropriate

mental health indicators in order to improve assessment of the needs at national and European levels

- Promotion of mental health through the funding of research into the prevention of mental health problems, new structures for effective treatment, and labour market integration programmes
- High-quality, accessible, effective and universal mental health services
- Training programmes on mental health for key health stakeholders (for example, healthcare practitioners, teachers, etc.)
- Appropriate education, training and employment opportunities for people with mental health problems.

The Report is scheduled for adoption in the ENVI Committee on 21 January 2009 and for discussion in the EP Plenary on 19 February 2009.

To read the Report, please click [here](#).



The European Parliament Committee on Employment and Social Affairs adopts Recommendation for second reading on the draft Working Time Directive.

On 5 November 2008 the European Parliament (EP) Committee on Employment and Social Affairs adopted the Recommendation for a second reading on the Council Common Position for adopting a directive amending Directive 2003/88/EC concerning certain aspects of the organisation of working time. The EP Rapporteur is Alejandro Cercas (PSE, Spain).

The draft Directive was first proposed by the European Commission in September 2004, and was aimed at improving legal certainty for regulating working time. This was motivated by the case law of the European Court of Justice, where it was judged that on-call duty performed by a doctor when he/she is required to be physically present in the hospital must be regarded as working time.

One of the most contentious points between the Council and the EP is to decide whether the inactive part of on-call time should be regarded as working time or not. Contrary to the EP's view, the Council is of the opinion that the inactive part of on-call time should not be regarded as working time unless national law decides otherwise. In its recommendation for second reading, the EP reiterated its initial position that the entire period of on-call time, including the inactive part, shall be regarded as working time.

The Report is scheduled for vote in the EP Plenary on 17 December 2008.

To read more about the negotiations on the draft Directive, please click [here](#).

To read the European Parliament's Recommendation for second reading, please click [here](#).

The first European Antibiotic Awareness Day was launched on 18 November 2008

The first European Antibiotic Awareness Day was launched on 18 November by EU Commissioner for Health, Androulla Vassiliou. This will be an annual event designed to raise awareness about the risks associated with the inappropriate use of antibiotics and to provide information on their proper use.

On this occasion, a Scientific Briefing and a Press Conference were organised in the European Parliament. Commissioner Vassiliou announced the intention of the European Commission to strengthen current and future European strategies for fighting anti-microbial resistance, by adopting a wider and more comprehensive approach, integrating all useful links between human health concerns and animal and food born diseases. In this regard, Commission priorities are:

- The launch of a Eurobarometer survey aimed at gaining better understanding of public attitudes towards antibiotics with a view to identifying ways to reduce their misuse;

- The improvement of the health care professionals' training concerning the prescription of antibiotics according to scientific and evidence based guidelines;

- A Commission proposal for a Council recommendation including measures to reduce and control hospital acquired infections, which are often related to antimicrobial resistance.

To see Androulla Vassiliou's speech, please click [here](#).

For an overview of the Scientific Briefing and of the Press Conference organised in the European Parliament, please click [here](#).

The European Commission adopts Green Paper on Consumer Collective Redress

On 27 November, the European Commission's Directorate General for Health and Consumers adopted the Green Paper on Consumer Collective Redress, seeking to facilitate redress in situations where a large number of consumers have been harmed by a single trader's practice which is in breach of consumer law.

The Green Paper identifies barriers to effective consumer redress in terms of access, effectiveness and affordability and presents four main options to close the identified gaps. These options are:

- No immediate actions;

- Co-operation between Member States extending national collective redress systems to consumers from other Member States without a collective redress mechanism;

- A mix of policy instruments to strengthen consumer redress (e.g. collective consumer alternative dispute mechanisms, power for national enforcement authorities to request traders to compensate consumers and extending small claims to deal with mass claims);

- Binding or non binding measures for a collective redress judicial procedure in all Member States;

A combination of different elements from the above options.

Stakeholders can send their comments on the Green Paper (with a deadline of 1 March 2009) to:

European Commission
Directorate-General Health and Consumers
1049 Brussels
Belgium

Or to:

Sanco-consumer-collective-redress@ec.europa.eu

The Commission will examine the contributions and will publish a summary in the first half of 2009. On the basis of the consultation outcome, the Commission will present another policy paper in 2009.

To read the Green Paper and the consultation questions, please click [here](#).

For more information on the collective redress, please click [here](#).

European Commission adopts Communication and proposal for a Council Recommendation on rare diseases

On 11 November, the European Commission adopted a Communication and a proposal for a Council Recommendation on rare diseases, aiming at setting out an overall Community strategy to support Member States in ensuring effective and efficient recognition, prevention, diagnosis, treatment, care of, and research on rare diseases.

The Communication is based on the public consultation "Rare Diseases: Europe's Challenges" carried out at the beginning of 2008 and it stresses that the Community action in this field is all the more important because of the special characteristics of rare diseases, i.e. scarcity of relevant knowledge and expertise due to the limited number of patients. Therefore, the Communication encourages more European cooperation, which would help to ensure that scarce knowledge can be shared and resources combined as efficiently as possible at EU level.

The proposed Strategy focuses on three main areas:

- Improving recognition and visibility of rare diseases;
- Supporting national plans for rare diseases in the Member States;
- Strengthening cooperation and coordination on rare diseases at European level.

On 4 December, Trakatellis Antonios (PPE-DE, Greece) has been appointed Rapporteur for the Communication on behalf of the European Parliament Committee on Environment, Public Health and Food Safety.

The Report on the Communication is scheduled for discussion in the European Parliament Plenary on 1 April 2009.

The Communication provides for the creation of an EU Advisory Committee on Rare Diseases, to provide advice on the proper implementation of the Strategy. Therefore, the next European Commission's actions in the field of rare diseases would depend on the decisions made within the EU Advisory Committee.

The proposal for a Council Recommendation calls for the establishment, by 2011, of strategies and national plans for rare diseases in order to ensure that patients with rare diseases gain universal access to high quality care throughout their national territory. The Recommendation also encourages an adequate definition, codification and inventorying of rare diseases in Europe, more research and gathering of expertise in this field at the European level, as well as more involvement of patients in the decision-making process in the area of rare diseases.

The Council Recommendation is expected to be approved during the Czech Presidency which will be held in the first half of 2009.

To read the Communication, please click [here](#).

To read more about the consultation process, please click [here](#).

To read the proposal for a Council Recommendation, please click [here](#).

European Parliament Environment, Public Health and Food Safety Committee issues draft report on the proposed Health Services Directive

On 20 November, the European Parliament's Environment, Public Health and Food Safety Committee (ENVI) issued a draft report on the proposed directive on patients' rights in cross border healthcare [Rapporteur: John Bowis (EPP-ED, UK)].

Relevant amendments have been made in relation to reimbursement, recognition of medical prescriptions, information for patients on healthcare standards, and Health Technology Assessment:

- **Reimbursement:** The Report suggests putting in place a system of reimbursement directly from the home country to the Member State of treatment. Initially, this would be done through the establishment of a bilateral voucher system guaranteeing later payment by the home country. This is related to the prior authorisation provisions in the sense that, if a patient chooses to use the prior authorisation process set up by the home country, they would receive a voucher to present at the treating hospital. Without a voucher, the patients would have to pay themselves and claim the money back later.

However, a long term solution would be the establishment of a Central Clearing House, which would replace the voucher system.

The reimbursement should also be extended to packages of treatment, for example, convalescence or physiotherapy, provided that the total cost does not exceed the amount payable in the home country.

- **Recognition of medical prescriptions:** In the case of drugs prescribed in another Member State that are not available in the home Member State, the report gives the home Member State the power to decide whether to exceptionally authorise that drug or to provide an alternative similar drug. However, the report suggests that it would be preferable for Member States to accept drugs prescribed as part of treatment within a Cross Border Care context, based on a supplementary prescription list.

- **Information to patients and healthcare standards:** The Report advises that the definition of standards on quality and safety by the European Commission in cooperation with the Member States should not be made compulsory. The Member States are responsible for their healthcare delivery and a Member State of treatment should ensure that such standards are described publicly.

The Report added a provision concerning the information that should be made available to health professionals advising a patient. This should be available through a secure system and should include details of registered health professionals in the Member State of treatment and any disciplinary proceedings against them. An information exchange system between Member States concerning disciplinary proceedings should also be put in place.

- **Health Technology Assessment:** The Report

integrates the amendments on Health Technology Assessment (HTA) put forward on 12 November by the European Parliament's Committee on Industry, Research and Energy. As such, HTA should be based on clear principles of good practice, be extended to already existing technologies and involve all stakeholders, from patients to healthcare professionals and the industry.

The report is scheduled for adoption in Committee on 12 March 2009 and for discussion in the European Parliament Plenary on 23 April 2009.

Currently, the European Parliament Committees are considering the amendments.

To read the draft Report, please click [here](#).

To read the Industry, Research and Energy Committee's draft opinion, please click [here](#).

To know more about the Health Services Directive, please click [here](#).

European Commission publishes Communication on "Telemedicine for the benefit of patients, healthcare systems and society"

On 4 November, the European Commission published a Communication on "Telemedicine for the benefit of patients, healthcare systems and society" aimed at improving access of EU citizens and healthcare workers to telemedicine services.

The Communication defines the concept of telemedicine and highlights the benefits it can have on patients, the use of healthcare resources and the EU economy as a whole. However, it also points out that the use of telemedicine services is still limited in the Member States and that the market remains highly fragmented.

In order to encourage the use of these services, the document identifies current barriers and defines a set of actions to be taken at both Member State and EU levels, revolving around three main goals:

- Building confidence in and acceptance of telemedicine services;
- Providing legal clarity concerning their use;
- Solving technical issues and facilitating market development.

Among others, the Commission calls on Member States to assess their needs and priorities in telemedicine by the end of 2009, adapt their national regulations enabling wider access to telemedicine services by the end of 2011 and address, in the framework of these regulations, such issues as accreditation, liability, reimbursement, privacy and data protection. In 2009, the Commission, in cooperation with the Member States, will publish an analysis of the Community legal framework applicable to telemedicine services and will establish a European Platform to support Member States in sharing information on current and planned national legislative frameworks in this field.

By the end of 2010, the industry and the international standardisation bodies should also issue a proposal on the interoperability of telemonitoring systems.

The Communication is currently under consideration within the European Parliament Committee on Environment, Public Health and Food Safety.

To read the Communication, please click [here](#).

The EUnetHTA Conference on the future of Health Technology Assessment was held in Paris on 20 November

The European Network for Health Technology Assessment (EUnetHTA) Conference was held in Paris on 20 November.

The conference addressed the current developments in European HTA and presented the results of the EUnetHTA project as well as its planned steps for the future.

The upcoming work of the EUnetHTA was presented in relation to the latest developments in cross-border healthcare.

A representative of the European Commission's Directorate General for Health and Consumers (DG SANCO) presented the provisions on cooperation between Member States in the field of HTA in the proposed Health Services Directive. According to Article 17 of the draft directive, Member States should facilitate the development and functioning of a HTA network that should connect national authorities/bodies responsible for HTA. He concluded that future developments in the area of HTA are dependent on the decisions taken by the Council and the European Parliament on the proposed Directive. Depending on their position on article 17, preparatory work for the assessment of options would be launched by DG SANCO and a possible Communication on HTA could be issued in 2010.

The EUnetHTA was created in 2005 at the initiative of the European Commission and Council of Ministers with the aim of coordinating national efforts in assessing health technology and to improve HTA-related policy decisions through the creation of a platform of discussion among the main European Health Technology Assessment (HTA) stakeholders.

To read the conference presentations, please click [here](#).

To read the European Commission's presentation, please click [here](#).

To read more about the EUnetHTA, please click [here](#).



European Commission adopts Directive and Action Plan on organ donation and transplantation

On 8 December, the European Commission adopted a draft Directive on standards of quality and safety of human organs intended for transplantation and a 10 point Action Plan aimed at collaborating with Member States on strengthening organ donation and transplantation systems in Europe.

The two proposals focus on the three main challenges identified in the Communication "Organ donation and transplantation: policy action at EU level", adopted by the Commission in May 2007:

- Improving quality and safety of organs across Europe;
- Increasing organ availability;
- Making transplantation systems more efficient and accessible.

The draft Directive stresses the risk of disease transmission posed by organ transplantation procedures and underlines that, although most Member States have adopted legislation on the ethical aspects of organ transplantation, many have yet to agree on rules covering quality and safety. Therefore, the draft Directive provides for the creation (or designation) of a national competent authority in each Member State, which would be responsible for supervising compliance with the quality and safety standards defined in the draft Directive. These standards include establishing a traceability system of human organs, a reporting system of serious adverse events and reactions, and the standardisation of data collection on specific organ characteristics in order to facilitate exchange of these organs. In addition, the draft directive also establishes a system for the authorisation of programmes of organ procurement and transplantation based on common quality and safety criteria.

The 10 priority actions established by the Action Plan seek to improve collaboration and exchange of best practices between Member States, with a view to increasing the number of available organs in each State, raising awareness of European citizens on organ donation, and strengthening the role of health professionals in providing information in this field.

To read the draft Directive, please click [here](#).

To read the 10 point Action Plan, please click [here](#).

European Commission adopts Green Paper on the EU workforce for health and launches consultation with stakeholders

On 10 December, the European Commission adopted the "Green Paper on the European workforce for health" and formally launched a consultation process during a conference that was held in Brussels.

The communication highlights the common challenges facing the EU health systems (for example,

ageing population, increasing demands on health services and restricted supply, new threats to health) and stresses that an effective response to these challenges depends to a considerable extent on a high quality healthcare workforce.

The public consultation process seeks to obtain stakeholders' views and to clarify the actions that can be taken at the EU level in relation to such issues as:

- Demography and the promotion of a sustainable workforce;
- Public health capacity;
- Mobility and training of the EU health workforce, including the impact of new technologies;
- Global migration of health workers;
- Data to support decision-making of planners, providers and managers of healthcare systems;
- The role of the "Small Business Act" and of the EU Cohesion Policy in improving the effectiveness of the EU health workforce.

Stakeholders can submit responses no later than 31 March 2009 to:

SANCO-health-workforce@ec.europa.eu

Or to European Commission, B-1049, Brussels, Belgium.

To read the Green Paper, please click [here](#).

The European Commission adopts Communication and proposal for a Council Recommendation on patient safety and quality of health services

On 15 December, the European Commission adopted a Communication and a proposal for a Council Recommendation on patient safety and quality of health services, including the prevention and control of healthcare-associated infections (HCAIs).

The two proposals are the result of a public consultation on patient safety conducted in the first half of 2008, providing the opportunity to stakeholders to report their experiences of adverse events in healthcare and to give their views on actions to be taken.

While efforts to improve patient safety have so far addressed specific issues, like medical devices or antimicrobial resistance, the Communication stands out by adopting a comprehensive approach to these efforts and by proposing actions to be implemented at either national or EU level.

Therefore, the Member States are encouraged to develop general patient safety policies and programmes, to involve the patients in the decision-making process, to train the healthcare professionals on patient safety issues and to improve data collection, recording and reporting of medical errors in a constructive rather than a punitive way.

At EU level, the Commission should support the development of common definitions and indicators on patient safety, as well as the research programmes dedicated to this. It should also facilitate the sharing of best practices and an effec-

tive collaboration on patient safety between Member States.

In addition to the actions already put forward by the Communication, the proposal for a Council Recommendation calls on the Member States to develop a national strategy to prevent and control HCAs, and to establish an inter-sectoral mechanism for its coordinated implementation, which would also facilitate effective information exchange with the Commission and the other Member States.

To read the Communication, please click [here](#).

To read the proposal for a Council Recommendation, please click [here](#).

Calendar of upcoming Events

13-16/02/09: The **International Meeting on Emerging Diseases and Surveillance (IMED 2009)** will be organised by the International Society for Infectious Diseases (ISID) in Vienna, Austria.

The meeting will embrace the 'One Medicine, One Health' concept recognising that, just as diseases reach across national boundaries, so do they transcend species barriers. For this reason, participation of both human and animal health communities is welcome.

The ISID seeks to improve the care of patients with infectious diseases, the training of clinicians and researchers in infectious diseases and microbiology, and the control of these diseases around the world.

For more information on the Meeting, please click [here](#).

18-20/02/09: The **eHealth2009** conference will be organised by the Czech Presidency in cooperation with the European Commission in Prague. The 2009 edition of the eHealth conference series will focus on three main themes: eHealth for individuals, eHealth for society and eHealth for the economy.

For more information on the conference, please click [here](#).

For more information, please visit www.healthfirsteurope.org