EULARAR Conference 2019
A sustainable and effective EU health policy for citizens: Focusing on chronic diseases and inclusion in social and economic life
Thon EU Hotel (Brussels), 16 October 2019 (9:00 — 17:00)

Agenda
Chair: Prof. Iain McInnes, EULAR President

8:00 – 09:00: Registration and networking breakfast

9:00 – 9:40: Opening session: RMDs, work and society?
  - Prof. Iain McInnes, EULAR President
  - Roberta Metsola, Member of the European Parliament
  - Theresa Griffin, Member of the European Parliament
  - Antonio Cammarota, Principal Administrator, DG EMPL (European Commission)

9:40 – 10:40: Key note speeches: Current and future challenges in chronic diseases
  ♦ Innovative medicines and their implications for health systems
    - Thomas Allvin (European Federation of Pharmaceutical Industries and Associations, EFPIA)
  ♦ Should health policy goals and priorities evolve from past imperatives? Individual, economic and political perspectives in future health policies
    - Prof. Jan de Maeseneer (Ghent University)

10:40 – 11:00: The EU’s contribution to the health of citizens: Achievements, lessons and pending issues
  ♦ Interview with John F. Ryan, Director – Unit C - Public health, country knowledge, crisis management, DG SANTE (European Commission) [Interviewer: Jennifer Baker, Journalist]
  ♦ Q&A

#EULARBrussels2019
11:00 – 11:20: Coffee break

11:20 – 12:50: Workshops
♦ Access to health care
  o Partner organisation: Health First Europe (HFE)
  o Moderators: Elsa Mateus (EULAR) & Melina Raso (HFE)
♦ Managing chronic diseases in the life course
  o Moderators: Prof. Tanja Stamm (EULAR) & Prof. Johannes W.J. Bijlsma (EULAR)
♦ Coordination between health and social affairs policies
  o Partner organisation: European Public Health Alliance (EPHA)
  o Moderators: Prof. Loreto Carmona (EULAR) & Fiona Godfrey (EPHA)

12:50 – 13:50: Lunch

13:50 – 14:15: Report of workshops

14:15 – 14:45: Economic impact of chronic diseases and the contribution of health policies: Two reflections from the same mirror?
♦ Health and economic benefits of the participation of people with chronic diseases in the labour market. The economists view.
  o Prof. Olivia Wu (University of Glasgow)
♦ Can health policies help people with chronic diseases participate in the labour market? The patient’s perspective.
  o Peter Boyd (Arthritis Ireland)

14:45 – 15:00: Coffee break

15:00 – 16:00: Panel debate:
♦ Do we need to redefine the role and priorities of EU health policies?
  o Panellists: Manuel Pizarro (Member of the European Parliament); John F. Ryan (European Commission); Marian Schaan (European Trade Union Institute — ETUI); Fiona Godfrey (EPHA); Neil Betteridge (EULAR)
  o Moderator: Jennifer Baker (Journalist)
16:00 – 16:15: Messages to the new Commission

16:15 – 16:45: EU Health policies: The way ahead
- Petr Karola, Head of Office to Kateřina Konečná, Member of the European Parliament
- Karin Sipido, Scientific Panel for Health
- José Valverde Albacete, Programme Officer, DG CNECT (European Commission)

16:45 – 17:00: Closing session
- Prof. Tanja Stamm, EULAR Vice-President, representing Health Professionals in Rheumatology
- Prof. Iain McInnes, EULAR President

17:00 – 18:30: Networking reception
A sustainable and effective EU health policy for citizens:
Focusing on chronic diseases and inclusion in social and economic life
Opening session
09:00 – 09:40

RMDs, work and society?

#EULARBrussels2019
About RMDs

• 1 out of 4 people affected

• Number one cause of physical disability

• Main cause of work loss, absenteeism, loss of productivity and early retirement
World Arthritis Day (WAD)

- WAD Brussels Annual Conference
  - Since 2010
  - Bring together RMDs community, EU and national policy makers, and other stakeholders
  - Focus on relevant policy developments
About the Conference

Goals:

• To contribute to the debate on the **future of EU public health**…

• …and its contribution to the **integration of people with chronic diseases in social and economic life**

• To develop **recommendations on:**
  
  » access to healthcare

  » management of chronic diseases in the life course

  » coordination between health and social affairs policy
Roberta Metsola
Member of the European Parliament
Theresa Griffin
Member of the European Parliament

#EULARBrussels2019
Ergonomic risks at the Workplace
An EU Scenario

EULAR WAD Conference 2019
Brussels, 16 October 2019

Antonio Cammarota
DG EMPL/B3
Health and Safety
The magnitude of the problem

• Ergonomic risks

- According to EWCS 2015 the most prevalent occupational risks in Europe, responsible for WRMSDs

- Some 61% of workers report exposure to posture-related (ergonomic) risks: vibrations, tiring positions, lifting people, carrying heavy loads and repetitive movements

- In terms of occupation, craft workers, plant and machine operators and agricultural workers are the occupations with the highest levels of exposure to posture-related risks
The magnitude of the problem

- **WRMSDs**
  - The main work-related health problem affecting European workers today
  - Affect both women and men and all sectors of activity across the European Union
  - A major cost burden for business and society
The magnitude of the problem

- WRMSDs represent today about 60% of all work-related health problems
- Account for 60% of all sickness absences in the EU and also for about 60% of all cases of permanent incapacity to work
- At least 11m workers are affected, i.e. 5% of the total EU working population
The magnitude of the problem

- Total cost of WRMSDs across the EU can be estimated at over EUR 163bn
  - Employers: 33% (productivity losses and turnover costs)
  - Workers: 65% (income and health-related quality of life losses)
  - Public authorities: 2% (impact on GDP)
The EU legal framework

- "Framework" Directive 89/391/EEC (Article 6.2d states the ergonomic principle of "adapting the work to the individual")
- Directive 90/269/EEC (manual handling of loads)
- Directive 90/270/EEC (work with display screen equipment)
- Directive 2002/44/EC (vibration)
The EU legal framework

- Directive 89/654/EEC (workplace)
- Directive 89/655/EEC (work equipment)
- 89/656/EEC (PPE)
- Directive 2006/42/EC (machinery) intended to ensure a common safety level in machinery placed on the market or put in service in the MSs
The EU legal framework

- Conclusions from the ex-post evaluation of the EU OSH acquis, completed by the Commission in 2017, show general agreement on the fact that control of ergonomic risks is a complex issue and that a significant part of those risks is not addressed by the existing legislation, in particular MH and DSE Directives.

- It is also recognized that due to complexity and multifactorial nature of the problem, the legislative route may not be the most appropriate way to tackle the problem and that other means (guidance, awareness raising, etc.) should be taken in due consideration.
The EU legal framework

- The reviewing programme of OSH Directives outlined in the 2017 Communication “Safer and Healthier Work for All” (COM(2017) 12) also includes a possible update of the DSE Directive.

- Discussion within the ACSH is open on the possible setting up of a dedicate WP to explore the issue.
Non-regulatory initiatives

- **CAMPAIGNS**
  - SLIC (2007-2008 & 2020-22)

- **GUIDANCE**
  - EU-OSHA - Guidance to help micro and small businesses tackle psychosocial risks, work-related stress and MSDs (2018)
  - SLIC - Guide for assessing the quality of risk assessments and risk management measures with regard to prevention of MSDs (2018)
Past trends

• Increasing trend in prevalence of WRMSDs in most Member States – Results from the 2009 Scoreboard of the EU OSH Strategy 2007-2012

  ▪ Decreasing rates in only 5 MS

  ▪ 2 MS show stable rates

  ▪ The remaining MS show consistently increasing trends
Future trends

- Demographic change (there is a positive correlation between a worker’s age and the likelihood of reporting a work-related health problem)
- Changes in the sectorial composition of European economies (increasing share of people working in services)
- Different prevalence in exposure to risks (repetitive work as the most important risk factor)
- Re-focussing existing provisions? - some provisions may need to be updated or complemented
Outlook

• Given current levels of prevalence as well as the dynamic of future trend factors, it is unlikely that the problem can be substantially reduced without additional action

• The topic will continue to be crucial also in the framework of future new Commission OSH initiatives

• New initiatives, in this as in all other policy areas, need to be in line with the principles of subsidiarity and proportionality and should be founded on consensus by all stakeholders
Outlook

• Better synergy between EU and national initiatives and a stronger emphasis on assistance for better implementation and enforcement appear to be for the time being the most promising way forward
Thank you for attention!
Structure of the Conference

**Morning**
- 09:00 Opening session
- 09:40 Key note speeches
- 10:40 Interview
- 11:00 Coffee Break
- 11:20 Workshops
- 12:50 Lunch

**Afternoon**
- 13:50 Workshop Reports
- 14:15 Session on economic impact
- 14:45 Coffee Break
- 15:00 Panel Debate
- 16:00 Recommendations
- 16:15 The way ahead
- 16:45 Closing session
- 17:00 Networking reception
Workshops

1. Access to healthcare

2. Managing chronic diseases in the life course

3. Coordination between health and social affairs policies
Streaming and Pictures

- Live streaming (only plenary sessions)
- Videos and pictures to be uploaded to the EULAR Website

**Should you not want to appear in videos/pictures:**

- Please sit towards the back of the room;
- Let the organisers know, so we will delete any pictures of you
Social Media

- Livestream: over EULAR TV
- EULAR Facebook: @eular.org
- EULAR Twitter: @eular_org
- Hashtag: #EULARBrussels2019
Sli.do

- Session at 16:00 on Recommendations to the new Commission
- Easy to use audience interaction platform
- To join the conversation:
  - Open a browser and go to www.slido.com
  - Enter #EULARBrussels2019
  - Cast your vote in the poll
EULAR Vision paper on the future of European health policies
EULAR Vision Paper (I)
Giving health the right place in European policy-making

• A top priority for EU citizens
• Active health policy as a way to ensure sustainability of health care systems
• Steering role in the implementation of Commission’s 2019-2025 key strategic goal to create a healthy planet for healthy citizens
EULAR Vision Paper (II)
Integrating health in all policies

- EU health should look across sectors and link better to other policy fields
- Better coordination between institutions and actors
- Focus on outcomes: participation of people with chronic diseases in social and economic life
EULAR Vision Paper (III)
Strengthening the impact of health policy

• More strategic and better support to Member States
• Concrete, actionable strategies on major chronic diseases
• Framework on Health Impact Assessment (HIA) — socio-economic impact!
EULAR Vision Paper (IV)
Improving access and pathways in health care systems

• One of citizens’ main priorities
• Ensure equal rights in access to health care
• Integrated approach
• Remove hurdles preventing access to innovative products and services
EULAR Vision Paper (V)
Putting the citizen and patient in the centre

- Central role to citizens and patients
- Digitalisation of health
- Mechanisms governing data sharing, self-management and collaborative decision-making
- Health literacy and skills
Keynote speeches
09.40-10.40

Current and future challenges in chronic diseases

#EULARBrussels2019
Innovative medicines and their implications for health systems

Thomas Allvin
European Federation of Pharmaceutical Industries and Associations, EFPIA

#EULARBrussels2019
Health systems across Europe face unprecedented challenges created by ageing demographics and the impact of NCDs

Trends in European demographics & health spending:

- **11%** decrease in the size of the European work-force from 2010-2050
- **72%** increase in the number of Europeans aged ≥ 65 from 2010-2050
- **87%** of deaths in high-income countries are due to chronic disease
- **75%** of the European healthcare bill is spent on chronic diseases, amounting to €700 bn

Healthcare expenditure as a share of GDP under different scenarios:

- **Pure demographic scenario**: Gains in life expectancy are assumed to be spent in disabled health, while the number of years spent in good health remains constant.
- **Constant health scenario**: Gains in life expectancy are equally distributed between healthy and disabled years.
- **Improved health scenario**: Gains in life expectancy are more likely to be healthy than disabled life years.
Innovative medicines in late-stage pipeline
Success rates in clinical development vary widely by therapy area, from 26.1% in haematology to 5.1% in oncology.
As innovation in recent years has focused on unmet need of the time, today’s pipeline reflects tomorrow’s unmet needs.

20 leading causes of DALY in Europe (cause, DALYs)¹

<table>
<thead>
<tr>
<th>Rank</th>
<th>2000</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Ischaemic heart disease (52,152)</td>
<td>Ischaemic heart disease (43,956)</td>
</tr>
<tr>
<td>2</td>
<td>Stroke (27,332)</td>
<td>Stroke (20,247)</td>
</tr>
<tr>
<td>3</td>
<td>Trachea, bronchus, lung cancers (9,828)</td>
<td>Back &amp; neck pain (10,422)</td>
</tr>
<tr>
<td>4</td>
<td>Back &amp; neck pain (9,342)</td>
<td>Trachea, bronchus, lung cancers (10,170)</td>
</tr>
<tr>
<td>5</td>
<td>Lower resp. Infections (8,472)</td>
<td>Diabetes mellitus (7,675)</td>
</tr>
<tr>
<td>6</td>
<td>Self-harm (7,876)</td>
<td>Depressive disorders (7,670)</td>
</tr>
<tr>
<td>7</td>
<td>Road injury (7,713)</td>
<td>Alzheimer disease &amp; other dementias (7,178)</td>
</tr>
<tr>
<td>8</td>
<td>COPD (7,634)</td>
<td>COPD (6,639)</td>
</tr>
<tr>
<td>9</td>
<td>Depressive disorders (6,992)</td>
<td>Lower resp. Infections (6,335)</td>
</tr>
<tr>
<td>10</td>
<td>Falls (6,357)</td>
<td>Colon &amp; rectum cancers (5,629)</td>
</tr>
</tbody>
</table>

Share of EMA marketing approvals (2007-2012)²


COPD=Chronic obstructive pulmonary disease; DALY=disability-adjusted life year; source: 1. WHO, Global Health Estimates 2015 Summary Tables (2016); 2. EMA (European Medicines Agency), Database (accessed 2013)
Since the 1990’s, the industry has brought over 1,100 new medicines to European patients, radically improving their lives.

- **HIV**
  - 85% drop in the number of HIV deaths since its peak in 1995 in Europe and the US

- **Multiple sclerosis**
  - *Before*
    - “The whole week leading up to my infusion is very rough: a lot of my regular symptoms are slightly increased: intense burning pain in my legs, leg weakness, spasms, very bad fatigue, etc.”
  - *After*
    - “A day or two after that, I feel the best I ever feel. My head becomes clear, I remember more, I can walk and stand longer too. I still have issues, but overall I feel considerably better.”

- **Cancer**
  - 21% decline in cancer mortality rate since its peak in 1991 in Europe
  - 83% of cancer survival gains are attributable to new treatments

- **Hepatitis C**
  - 90% cure rate for treated patients with 8-12 weeks of treatment
  - +133% increase in cure rate for European patients

- RA patients receiving new biologics have the ability to remain in employment 31 weeks longer and earn €26,000 more than patients on conventional therapy
Immunotherapies have changed the lives of patients with RA, enabling them to continue living productive lives.

Impact of medicines on RA patients¹

**Before:**
- Treatments for RA were generally effective at reducing joint inflammation
- But old medicines treated only the symptoms of the disease, allowing for a steady rapid progression from disease onset to disability

**After:**
- Biologic disease-modifying anti-rheumatic medicines target the underlying sources of inflammation
- These medicines prevent irreversible joint damage, making disease remission possible

Percentage of arthritis patients with improvements due to new medicines³

- Patients receiving newer medicine
- Patients receiving older medicine
- Patients receiving placebo

- Improved disability: 35% (patients receiving newer medicine), 20% (patients receiving older medicine), 18% (patients receiving placebo)
- Increased physical functioning: 22% (patients receiving newer medicine), 15% (patients receiving older medicine), 3% (patients receiving placebo)
- Higher work productivity: 14% (patients receiving newer medicine), 15% (patients receiving older medicine), 1% (patients receiving placebo)

"After failing all other RA treatments, I was running out of options...Rituxan has improved my quality of life physically, mentally, emotionally."²

Medicine use yields significant health gains and savings in other parts of healthcare systems.

1.6-2.1 million
The number of influenza cases averted with the current use of seasonal influenza vaccination in Europe.¹

€250-330 million
Total influenza-related costs saved annually from averted GP visits, hospitalizations, and lost days of work as a result of the current use of seasonal influenza vaccination in Europe.¹

Per capita expenditure on cardiovascular hospitalizations would have been $89 (70%) higher in 2003 had new cardiovascular medicines not been introduced in the period 1995–2003.²
Medicines play an important role in avoiding healthcare costs

“Apart from contributing to an estimated 200 000 premature deaths, poor adherence to prescribed medication is thought to cost as much as EUR 125 billion in Europe each year in avoidable hospitalisations, emergency care, and adult outpatient visits (OECD, 2017).”

OECD Health at a Glance: Europe 2018
New medicines address healthcare challenges while also supporting economic growth.

Innovative treatments allow patients to work longer and more productively.²

Ability to remain in employment 31 weeks longer and earn €26,000 more than patient on conventional therapy.

When comparing worker productivity for European, Australian, and Canadian patients with rheumatoid arthritis (RA), researchers found that patients were able to work longer and earn more money when treated with a novel biologic rather than conventional therapy* over the study period of 2 years.

* Conventional therapy in study refers to conventional DMARDs = disease-modifying anti-rheumatic drugs.
* Note: Presenteeism is the act of attending work while sick.

Workforce productivity has improved thanks to new medicines across many therapy areas

**Return rates to work and savings from better medication in Europe**

£21.2 bn
- reduction in the cost of dementia due to a treatment delaying the onset of dementia by five years

83%
- of people diagnosed with head and neck cancer returned to work, most often within 6 months after treatment\(^2\)

£22 bn
- savings by 2040 from the development of new medicine that halts the progression of Parkinson’s Disease\(^4\)

82.1%
- of women diagnosed with breast cancer returned to work after 10.8 months\(^1\)

More than 75% of patients with a cancer diagnosis can now return to work thanks to innovative therapies\(^2\)

Action in several areas can improve the introduction of innovation medicines

<table>
<thead>
<tr>
<th>Action Area</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Updating regulatory guidance &amp; procedures</td>
<td>Regulatory guidance is needed to increase regulatory certainty regarding use and acceptance of evidence generated through novel RWD approaches and complex Clinical Trial designs</td>
</tr>
<tr>
<td>RWE to address payer clinical uncertainty</td>
<td>RWE generation through temporary access schemes or post-launch data collection should continue to be utilised to mitigate the benefit uncertainty at launch given limited data</td>
</tr>
<tr>
<td>Valuing and rewarding innovation</td>
<td>Continual adaptation of HTA/value assessment processes in order to fairly assess and reward the long term clinical, economic and societal value of innovation; given possibility of limited evidence at launch or large patient populations</td>
</tr>
<tr>
<td>Adapting financing models for upfront investment</td>
<td>Innovative finance models such as annuities should be considered given the long-term, system-wide benefits; these will help overcome limits posed by annual as well as siloed budgets</td>
</tr>
</tbody>
</table>
Action in several areas can improve the introduction of innovation medicines (2/2)

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Developing infrastructure to support care delivery. Optimisation of approaches to managing patients is needed to ensure that innovation is effectively incorporated into patients journeys; this will be key for optimising patient outcomes and reducing the risk of adverse events.</td>
</tr>
<tr>
<td>7</td>
<td>Optimising patient/treatment strategies. Healthcare systems and manufacturers need to work together to optimise approaches to managing patients; collaboration is key to optimise patient outcomes and reduce the risk of adverse events.</td>
</tr>
<tr>
<td>8</td>
<td>Enabling data science and technology partnerships. Regulations and infrastructure to support increasing use of health data and more sophisticated data science will be vital to enable better care pathways, more informed innovative agreements, and optimal patient outcomes.</td>
</tr>
<tr>
<td>9</td>
<td>Horizon scanning and stakeholder dialogue. Collaboration from early stages of innovation development ensures pan-stakeholder stake in its success and helps to ensure that innovation potential is fully realised.</td>
</tr>
</tbody>
</table>
Perceptions of PROs are evolving; further work is needed to ensure patient-centric endpoints are adequately valued by HTA bodies

**PROs will be vital where patient QoL is improved**

Patient-reported outcomes (PROs) are evaluated directly by the patient and are therefore *valuable* and, in some conditions, *critical*, to capturing the *patients' perspective* and significantly demonstrating the *value* of a new health technology.

The actual *influence* of PRO data on HTA bodies varies, but use is generally *increasing* over time:

- In *Germany*, *England*, *Scotland*, 70-80% of HTA submissions include PRO data.
- In *France*, PRO data is included in <60% of HTA submissions and only has a *very minor impact* on ASMR¹ rating.

**Consistent evaluation of PROs** by HTA bodies, alongside proactive planning of PRO endpoint development by manufacturers, will be important for acceptance of future innovations where the patient perspective is key.

- *For example, PROs will be key for CGRP inhibitors for migraine given their lack of mortality endpoints.*

---

**Increasing use of PROs in oncology submissions**

![Graph showing increasing use of PROs in oncology submissions from 2011 to 2016]
To ensure access to innovation, several innovative payment models could be employed.

**Pricing by Country Income**
- Different countries have a **different ability to pay**
- Differential prices **based on country income** would avoid the problem of different access scenarios and ensure access to the greatest number of patients
- However, **price would have to be confidential or IRP inactive** in order to avoid a regional price reduction

**Pricing by Indication**
- Evaluating a product for each indication would allow for a **more transparent pricing process, leading to a price that better reflects the value** the product delivers in clinical practise
  - Will also prevent the dis-incentivisation of innovation because of the price penalties suffered at indication expansion
- **Personalised pricing by patient or patient groups** depending on prognosis and goals

**Pricing by Performance**
- List price can be modulated based on collected real world evidence; this can enable **price to be increased over time**, if stronger efficacy is demonstrated compared to clinical trial data
- However, pricing by performance (PbP) will be difficult to achieve in the short term; **a stepping stone towards PbP is paying for performance**
- **Paying for performance** involves modulating net price, **based on individual patient outcomes**; rebates or discounts will be provided if a patient does not meet certain outcomes
Paying for performance, or outcomes-based agreements, have been implemented for high cost/budget impact therapies

**Case studies: Innovative payment models are starting to be implemented...**

<table>
<thead>
<tr>
<th><strong>Sofosbuvir (Sovaldi)</strong></th>
<th>CEPS secured a money-back guarantee as an MEA for Sovaldi in case of treatment failure, improving patient access to the high-cost drug</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ADA gene therapy (Strimvelis)</strong></td>
<td>AIFA negotiated price and outcomes-based agreement on behalf of other countries to enable cross-border funding</td>
</tr>
<tr>
<td>US payers are starting to discuss new models to manage high-cost upfront payments of cell and gene therapies</td>
<td></td>
</tr>
<tr>
<td><strong>Voretigene neparvovec (Luxturna)</strong></td>
<td>Spark will offer rebates to Harvard Pilgrim Healthcare upon failure to achieve outcomes in both short-term (30-90 days) and long term (30 months)</td>
</tr>
<tr>
<td><strong>Tisagenlecleucel (Kymriah)</strong></td>
<td>Novartis will only receive payment from CMS when patients respond to Kymriah by end of first month</td>
</tr>
</tbody>
</table>

- However, these innovative payment models are more suited to small patient populations, and where robust monitoring systems are in place and occur in the same setting of care, making outcomes tracking easier.
- As patient tracking improves, there is potential to increase the number of products using these models (e.g. microbiome therapies, tracking readmission and recurrence)
Current HC budgets are constrained to “silos” and are unable to adapt to finance new high-cost / high-budget impact innovations

Challenges with current healthcare budgets

<table>
<thead>
<tr>
<th>New Innovations</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>High cost/budget impact - e.g., - Upfront cost for one-off treatments - Budget impact for treatment where none existed (patient ‘warehousing’ effect)</td>
<td>Siloed healthcare budgets can prevent benefits of savings for either HC systems or society being shared between both areas; siloed budgets also prevent HTAs from assessing full value of innovations</td>
</tr>
<tr>
<td>Financial benefits beyond healthcare - greater efficacy means people living longer and requiring less social care, etc.</td>
<td>Funding Delays: Patient outcomes suffer as a result of delaying patient access in countries where treatments are covered by DRGs. Updating DRGs is a lengthy process between stakeholders at multiple levels; interim funding is often limited</td>
</tr>
<tr>
<td>Inequality of Access</td>
<td>Inequality within countries in terms of access to innovative therapies arises from local budgets which vary in size, formulary inclusion and availability of treatment centres; national budgets would help to alleviate this inequality</td>
</tr>
</tbody>
</table>

Potential Solutions

- National Funding Schemes
- Annuity-Based Agreements

Providing reimbursement upfront may not be feasible under annual funding cycles or when the cost-savings/benefits are only realised long-term

Current finance models provide upfront reimbursement, exposing healthcare budgets to risk with little evidence of lasting benefit
Horizon scanning will be vital for payers and providers to ensure awareness is high and that new innovations are planned for.

**Horizon scanning is becoming increasingly important**

**Problem**
- Hepatitis C drugs (such as sofosbuvir) and immunotherapies (such as pembrolizumab) took some healthcare systems by surprise
- Prices were not adjusted to cover their impact, and has resulted in short-term concerns over affordability
- In the future, disruptive innovations have the potential to impact healthcare systems in similar ways, both in terms of step changes for patients, health system organisation and budget impact

**Solution**
- Horizon scanning will enable better prediction of the impact of new or pipeline drugs on the healthcare system
- Understanding the potential impact will enable HC systems to appropriately plan for innovation entry

**For example:**

**UK PharmaScan**
- In the UK, PharmaScan was set up as a secure horizon scanning database populated with information on new medicines in development for launch in UK
  - It considers medicines up to three years before their launch, or start of phase III clinical development, whichever is the earlier
- Run by NICE, >120 registered manufacturers provide information on all new medicines, indications, formulations and in-licensed medicines
- This mechanism allows the NHS to effectively plan budgets and services according to customers’ needs
  - NICE, NHS England, SMC, AWMSG, and NI Health and Social Care Board all use this information
Cross-stakeholder dialogue will ensure that stakeholders cooperate to increase efficiency and support optimal patient access

Cross-stakeholder dialogue is required for optimal access

- Informed physicians are aware of the benefits of upcoming innovation and can advise payers about access and are aware about how to maximise benefit for patients
- Informed patients will be a more empowered partner for introducing innovation and shaping their own care
- Informed payers understand the upcoming horizon of innovation entering the market and can prepare accordingly to ensure swift access for patients
- Providers can prepare for upcoming innovation and plan for training and financing to coincide with innovation launch
- Engaged politicians are able to set a comprehensive and actionable agenda addressing the concerns associated with innovative treatments and can drive lasting change
- The industry are able to drive the empowerment of all stakeholders, and also learn what is the best way of helping to ensure access to innovation now and in the future

Empowering stakeholders through early and continued dialogue sets clear expectations and is the best way to ensure long-term partnerships

This helps ensure that innovation potential is fully realised
The EU Health Coalition – together for a healthy Europe
EU Health Coalition recommendations

1. Invest in and support the implementation of evidence-based programmes for prevention
2. Support the implementation of standardised measurements of health outcomes and healthy life years
3. Identify and spread best practice in medical practice and care pathways
4. Support health system reform and capacity building
5. Facilitate multi-stakeholder partnerships with regions and cities
6. The European Commission should have a Vice-President for health to ensure effective coordination and leadership at high level
7. Establish a Steering Board for Health to ensure optimal coordination of research activities
8. Further the collaboration of public and private sectors in health research
9. Establish a European Health Data Institute
10. Establish a **Forum for better access to health innovation**
Should health policy goals and priorities evolve from past imperatives? Individual, economic and political perspectives in future health policies

Prof. Jan de Maeseneer
Ghent University
Should health policy goals and priorities evolve from past imperatives? Individual, economic and political perspectives in future health policies

1. The past: chronic care models
2. The present: multi-morbidity
3. Paradigm-shift: from disease-oriented to goal-oriented care
4. Economical and political perspectives
The Chronic Care Model

Community
- Resources and Policies
- Self-Management Support

Health Systems
- Organization of Health Care
- Delivery System Design
- Decision Support
- Clinical Information Systems

Improved Outcomes

Informed, Activated Patient
Productive Interactions
Prepared, Proactive Practice Team

Developed by The MacColl Institute
© ACP-ASIM Journals and Books
Should health policy goals and priorities evolve from past imperatives? Individual, economic and political perspectives in future health policies

1. The past: chronic care models
2. The present: multi-morbidity
3. Paradigm-shift: from disease-oriented to goal-oriented care
4. Economical and political perspectives

#EULARBrussels2019
Multimorbidity becomes the rule, not the exception

- More than half of the patients with COPD have either cardiovascular problems, or diabetes
- Patients with COPD have a 3- to 6-fold risk to have all these problems
  *(Eur Respir J 2008;32:962-69)*
- 50% of 65+ have at least 3 chronic conditions
- 20% of 65+ have at least 5 chronic conditions
  *(Anderson 2003)*
Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study

Karen Barnett, Stewart W Mercer, Michael Norbury, Graham Watt, Sally Wyke, Bruce Guthrie

Summary

Background Long-term disorders are the main challenge facing health-care systems worldwide, but health systems are largely configured for individual diseases rather than multimorbidity. We examined the distribution of multimorbidity, and of comorbidity of physical and mental health disorders, in relation to age and socioeconomic deprivation.

Lancet 2012; 380: 37-43
Published Online
May 10, 2012
DOI:10.1016/S0140-
Figure 1: Number of chronic disorders by age-group
Figure 2: Prevalence of multimorbidity by age and socioeconomic status
On socioeconomic status scale, 1=most affluent and 10=most deprived.
Challenges in patients with multimorbidity
Should health policy goals and priorities evolve from past imperatives? Individual, economic and political perspectives in future health policies

1. The past: chronic care models
2. The present: multi-morbidity
3. Paradigm-shift: from disease-oriented to goal-oriented care
4. Economical and political perspectives

#EULARBrussels2019
But…
Jennifer is 75 years old. Fifteen years ago she lost her husband. She is a patient in the practice for 15 years now. During these last 15 years she has been through a laborious medical history: operation for coxarthrosis with a hip prothesis, hypertension, diabetes type 2, COPD and osteoarthritis. Moreover there is osteoporosis. She lives independently at her home, with some help from her youngest daughter Elisabeth. I visit her regularly and each time she starts saying: “Doctor, you must help me”. Then follows a succession of complaints and unwell feeling: sometimes it has to do with the heart, another time with the lungs, then the hip, ...
Each time I suggest – according to the guidelines - all sorts of examinations that did not improve her condition. Her requests become more and more explicit, my feelings of powerlessness, insufficiency and spite, increase. Moreover, I have to cope with guidelines that are contradictory: for COPD she sometimes needs corticosteroids, which worsens her glycemic control.

The adaptation of the medication for the blood pressure (at one time too high, at another time too low), cannot meet with her approval, as does my interest in her HbA1C and lung function test-results.
After so many contacts Jennifer says: “Doctor, I want to tell you what really matters for me. On Tuesday and Thursday, I want to visit my friends in the neighbourhood and play cards with them. On Saturday, I want to go to the Supermarket with my daughter. And for the rest, I want to be left in peace, I don’t want to change continually the therapy anymore, ... especially not having to do this and to do that”.

In the conversation that followed it became clear to me how Jennifer had formulated the goals for her life. And at the same time I felt challenged how the guidelines could contribute to the achievement of Jennifer’s goals. I visit Jennifer again with pleasure ever since: I know what she wants, and how much I can (merely) contribute to her life.
Sum of the guidelines

Patient tasks

- Joint protection
- Energy conservation
- Self monitoring of blood glucose
- Exercise
- Non weight-bearing if severe foot disease is present and weight bearing for osteoporosis
- Aerobic exercise for 30 min on most days
- Muscle strengthening
- Range of motion
- Avoid environmental exposures that might exacerbate COPD
- Wear appropriate footwear
- Limit intake of alcohol
- Maintain normal body weight

Clinical tasks

- Administer vaccine
- Pneumonia
- Influenza annually
- Check blood pressure at all clinical visits and sometimes at home
- Evaluate self monitoring of blood glucose
- Foot examination
- Laboratory tests
- Microalbuminuria annually if not present
- Creatinine and electrolytes at least 1-2 times a year
- Cholesterol levels annually
- Liver function biannually
- HbA1C biannually to quarterly

Patient education

- Foot care
- Osteoarthritis
- COPD medication and delivery system training
- Diabetes

<table>
<thead>
<tr>
<th>Time</th>
<th>Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 AM</td>
<td>Ipratropium dose inhaler</td>
</tr>
<tr>
<td></td>
<td>Alendronate 70 mg/wk</td>
</tr>
<tr>
<td>8:00 AM</td>
<td>Calcium 500 mg</td>
</tr>
<tr>
<td></td>
<td>Vit D 200 IU</td>
</tr>
<tr>
<td></td>
<td>Lisinopril 40mg</td>
</tr>
<tr>
<td></td>
<td>Glyburide 10mg</td>
</tr>
<tr>
<td></td>
<td>Aspirin 81mg</td>
</tr>
<tr>
<td></td>
<td>Metformin 850 mg</td>
</tr>
<tr>
<td></td>
<td>Naproen 250 mg</td>
</tr>
<tr>
<td></td>
<td>Omeprazol 20mg</td>
</tr>
<tr>
<td>1:00 PM</td>
<td>Ipratropium dose inhaler</td>
</tr>
<tr>
<td></td>
<td>Calcium 500 mg</td>
</tr>
<tr>
<td></td>
<td>Vit D 200 IU</td>
</tr>
<tr>
<td>7:00 PM</td>
<td>Ipratropium dose inhaler</td>
</tr>
<tr>
<td></td>
<td>Metformin 850 mg</td>
</tr>
<tr>
<td></td>
<td>Calcium 500 mg</td>
</tr>
<tr>
<td></td>
<td>Vit D 200 IU</td>
</tr>
<tr>
<td></td>
<td>Lovastatin 40 mg</td>
</tr>
<tr>
<td></td>
<td>Naproen 250 mg</td>
</tr>
<tr>
<td>11:00 PM</td>
<td>Ipratropium dose inhaler</td>
</tr>
<tr>
<td>As needed</td>
<td>Albuterol dose inhaler</td>
</tr>
<tr>
<td></td>
<td>Paracetamol 1g</td>
</tr>
</tbody>
</table>

Boyd et al. JAMA, 2005
Goal-Oriented Medical Care

James W. Mold, MD; Gregory H. Blake, MD; Lorne A. Becker, MD

ABSTRACT

The problem-oriented model, upon which much of modern medical care is based, has resulted in tremendous advancements in the diagnosis and treatment of many illnesses. Unfortunately, it is less well suited to the management of a number of modern health care problems, including chronic incurable illnesses, health promotion and disease prevention, and normal life events such as pregnancy, well-child care, and death and dying. It is not particularly conducive to an interdisciplinary team approach and tends to shift control of health away from the patient and toward the physician. Since when using this approach the enemies are disease and death, defeat is inevitable.

Proposed here is a goal-oriented approach that is well suited to a greater variety of health care issues, is more compatible with a team approach, and places a greater emphasis on physician-patient collaboration. Each individual is encouraged to achieve the highest possible level of health as defined by that individual. Characterized by a greater emphasis on individual strengths and resources, this approach represents a more positive approach to health care. The enemy, not disease or death but inhumanity, can almost always be averted.

1. There exists an ideal "health" state which each person should strive to achieve and maintain. Any significant deviation from this state represents a problem (disease, disorder, syndrome, etc.).
2. Each problem can be shown to have one or more potentially identifiable causes, the correction or removal of which will result in resolution of the problem and restoration of health.
3. Physicians, by virtue of their scientific understanding of the human organism and its affections, are generally the best judges of their patients' fit with or deviation from the healthy state and are in the best position to determine the causes and appropriate treatment of identified problems.
4. Patients are generally expected to concur with their physicians' assessments and comply with their advice.
5. A physician's success is measured primarily by the degree to which the patients' problems have been accurately and efficiently identified and labeled and appropriate medical techniques and technologies have been expertly applied in an effort to eradicate those problems.

This conceptual model is ideally suited to the understanding and management of acute and curable illnesses. It has potential applicability for chronic care. Many modern health care problems are not tractable to the problem-oriented model and are better handled by the goal-oriented approach.
“Problem-oriented versus goal-oriented care”

<table>
<thead>
<tr>
<th>Definition of Health</th>
<th>Disease-oriented</th>
<th>Goal-oriented</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Absence of disease as defined by the health care system</td>
<td>Maximum desirable and achievable quality and/or quantity of life as defined by each individual</td>
</tr>
</tbody>
</table>
“Problem-oriented versus goal-oriented care”

<table>
<thead>
<tr>
<th>Measures of success</th>
<th>Problem-oriented</th>
<th>Goal-oriented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accuracy of diagnosis, appropriateness of treatment, eradication of disease, prevention of death</td>
<td>Achievement of individual goals</td>
<td></td>
</tr>
</tbody>
</table>
“Problem-oriented versus goal-oriented care”

<table>
<thead>
<tr>
<th>Evaluator of success</th>
<th>Problem-oriented</th>
<th>Goal-oriented</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>Patient</td>
<td></td>
</tr>
</tbody>
</table>
What really matters for patients is

- Functional status
- Social participation
International Classification of Functioning

Health condition
(disorder or disease)

Body Functions & Structure

Activity
Participation

Environmental Factors
Personal Factors

Contextual factors
Evolution from
‘Chronic Disease Management’
towards
‘Participatory Patient Management’

Puts the patient centrally in the process.
Changes the perspective from ‘disease-oriented care’.
towards ‘goal-oriented’ care.
FRAGMENTATION
Vertical Disease Oriented Approach

• Mono-disease-programs? Or…
• Integration in comprehensive PHC
The challenge: vertical disease-oriented programs and multi-morbidity

- Create duplication
- Lead to inefficient facility utilization
- May lead to gaps in patients with multiple co-morbidities
- Lead to inequity between patients: “inequity by disease”
Resolution WHA62.12 “Primary Health Care, including health systems strengthening”

The World Health Assembly, urges member states: ... (6) to encourage that vertical programmes, including disease-specific programmes, are developed, integrated and implemented in the context of integrated primary health care.
Should health policy goals and priorities evolve from past imperatives? Individual, economic and political perspectives in future health policies

1. The past: chronic care models
2. The present: multi-morbidity
3. Paradigm-shift: from disease-oriented to goal-oriented care
4. Economical and political perspectives
Expert Panel on Effective Ways of Investing in Health
Report of the EXPERT PANEL ON EFFECTIVE WAYS OF INVESTING IN HEALTH (EXPH)
on Definition of a Frame of Reference in relation to Primary Care with a special emphasis on Financing Systems and Referral Systems
Opinion on Definition primary care – Definition

Core-definition

'The Expert Panel considers that primary care is the provision of universally accessible, integrated person-centered, comprehensive health and community services provided by a team of professionals accountable for addressing a large majority of personal health needs. These services are delivered in a sustained partnership with patients and informal caregivers, in the context of family and community, and play a central role in the overall coordination and continuity of people’s care.

The professionals active in primary care teams include, among others, dentists, dieticians, general practitioners/family physicians, midwives, nurses, occupational therapists, optometrists, pharmacists, physiotherapists, psychologists and social workers.'
Community Health Centre:

- Family Physicians; nurses; dieticians; health promoters; dentists; social workers; psychologists…

- 6400 patients; 95 nationalities

- Capitation; no co-payment

- COPC-strategy
Accessible: ambulatory and approachable

no physical, administrative, financial, cultural,… barriers
INTEGRATED NEEDS-BASED CAPITATION

Contract between health care workers and insurance companies in the framework of the National Institute for Health and Disability Insurance (NIHDI)
INTEGRATED NEEDS-BASED CAPITATION

ADVANTAGES:
• accessibility
• better continuity and comprehensiveness
• a more horizontal relationship between provider and patient, leading to e.g. less prescription of drugs
• opportunities for better compliance
• focus on prevention
• quality improvement
• subsidiarity and task delegation/competency sharing
Health care for undocumented residents

Mr. Onugu, Nigeria

- “illegal status”/’undocumented’
- Payment through Public Centre for Social Welfare
- No patient contribution
INTERDISCIPLINARY TEAM

Family physicians

Nurses

Social workers

Health promotion worker

Dietician

Administrative staff and receptionist

Ancillary staff

Dentists

External health care workers: physiotherapists, psychologists, …
Integrated care

• Comprehensive goal-oriented approach!
• Taking environment/context at home into account! Integration health and social care.
• Coordination by patient, informal caregivers, professional
INTERPROFESSIONAL DISCUSSION

NURSING TEAM: PLANNING MEETING
Towards an overarching model for electronic medical-record systems, including problem-oriented, goal-oriented, and other approaches

Huibert Tange, Zsolt Nagykaldi & Jan De Maeseneer

To cite this article: Huibert Tange, Zsolt Nagykaldi & Jan De Maeseneer (2017) Towards an overarching model for electronic medical-record systems, including problem-oriented, goal-oriented, and other approaches, European Journal of General Practice, 23:1, 257-260, DOI: 10.1080/13814788.2017.1374367

To link to this article: https://doi.org/10.1080/13814788.2017.1374367
“Organizing primary care in decentralized entities, for example, primary care zones (PCZs), can contribute to the visibility of primary care. Defining the population that accesses a certain group of services and providers in primary care, can contribute to the accountability of providers in terms of outcomes, access and quality of care.”

Everybody counts!
No one should be left behind!
PRIMARY CARE ZONE: MESO-LEVEL: 70.000-125.000 INHABITANTS

Flemish Region of Belgium (2019)
PRIMARY CARE NETWORKS: > 5,000 INHABITANTS (RURAL)
> 10,000 INHABITANTS (URBAN)
CITY HEALTH COUNCIL/ PRIMARY CARE ZONE: INTEGRATION PRIMARY CARE, PUBLIC HEALTH, SOCIAL SECTOR
More than half of health care spending is on behalf of people with multiple chronic conditions

Percent of total health care spending by number of chronic conditions (Percent of population)

- 1 chronic condition: 21% (23% of population)
- 2 chronic conditions: 18% (11% of population)
- 3 chronic conditions: 15% (5% of population)
- 4 chronic conditions: 12% (3% of population)
- 5+ chronic conditions: 14% (2% of population)

*Equal to more than 100% due to rounding.

Sipkoff M. Health Plans Begins To Address Chronic Care Management. Managed Care, 2003.
FINANCIAL RESOURCES:

- **INCREASE INVESTMENT IN HEALTH CARE:** BY 2050 COUNTRIES SHOULD SPEND 10-15% OF GDP ON HEALTH

- **REDISTRIBUTE HEALTH CARE RESOURCES TOWARDS PRIMARY HEALTH CARE:** AT LEAST 25-30% OF HEALTH CARE BUDGET SHOULD BE INVESTED IN PHC

Figure 1.2. Health care is progressively shifting out of hospitals but progress in some countries is still low.

Panel A: Average annual growth rate of hospital beds, 2000-14 (or nearest year)
Een spuitje van twee miljoen
New ways for development, production and payment of innovative medicines?

- Delinkage of Research & Development on the one hand and Production & Sales on the other hand?
- Price negotiations at EU-level?
- Avoid co-payments that lead to catastrophic health expenditure.
- Learn from good practices (e.g. CEPI,....)
Solidarity
Connectedness
Resilience of Communities

Jan De Maeseneer
Family Medicine and Primary Care
At the Crossroads of Societal Change
The EU’s contribution to the health of citizen: Achievements, lessons and pending issues

10.40-11.00
Interview with John F. Ryan
Director – Unit C - Public health, country knowledge, crisis management, DG SANTE, European Commission

Interviewer:
Jennifer Baker
Journalist
Prof. Iain McInnes

Workshops

#EULARBrussels2019
Workshops
11:20-12:50

Follow the colour listed on your badge:
Workshop 1: Room Netherlands III
Workshop 2: Room Netherlands I & II
Workshop 3: Room Belgium I

#EULARBrussels2019
Report of workshops
13:50-14:15
Workshop 1
Access to healthcare

Partner organisation: Health First Europe (HFE)
Moderators: Elsa Mateus (EULAR) & Melina Raso (HFE)
Out of these challenges, which are the top 3 to address?

1. Better education and training at all levels
2. Integrated care and digitalisation
3. Measure impact and outcomes relevant for patients
**What are the solutions to these 3 challenges?**

<table>
<thead>
<tr>
<th>Challenge: Better education and training at all levels</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recommendation(s):</strong> To provide education on RMDs at different levels, raising awareness and enhancing training.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Challenge: Integrated care and digitalisation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recommendation(s):</strong> To provide timely consistent patient-centred care in multi-disciplinary team with a clear roadmap.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Challenge: Measure impact and outcomes relevant for patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recommendation(s):</strong> To capture patient-relevant outcomes including through registries and harmonised database on EU-level for better policies.</td>
</tr>
</tbody>
</table>
Workshop 2
Managing chronic diseases in the life course

Moderators: Prof. Tanja Stamm (EULAR) & Prof. Johannes W.J. Bijlsma (EULAR)
Out of these challenges, which are the top 3 to address?

<table>
<thead>
<tr>
<th>Challenge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health literacy and lack of patient centricity</td>
</tr>
<tr>
<td>Lack of an EU wide, overarching strategy</td>
</tr>
<tr>
<td>Lifestyle</td>
</tr>
</tbody>
</table>
What are the solutions to these 3 challenges?

<table>
<thead>
<tr>
<th>Challenge: Health literacy and lack of patient centricity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendation(s): Health literacy addressed from cradle to grave</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Challenge: Lack of an EU wide, overarching strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendation(s): Overarching care plan including multimorbidities</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Challenge: Lifestyle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommendation(s): Awareness and education employing digital technologies in all phases of life</td>
</tr>
</tbody>
</table>
What are the key lessons learned?

<table>
<thead>
<tr>
<th>Life path not always linear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Addressing gender diversity</td>
</tr>
<tr>
<td>Further innovation in drug research necessary</td>
</tr>
<tr>
<td>Develop recommendation on value based healthcare covering RMDs</td>
</tr>
</tbody>
</table>
Workshop 3
Coordination between health and social affairs policies

Partner organisation: European Public Health Alliance (EPHA)
Moderators: Prof. Loreto Carmona (EULAR) & Fiona Godfrey (EPHA)
Out of these challenges, which are the top 3 to address?

<table>
<thead>
<tr>
<th>Budget (separation/silos, volume)</th>
</tr>
</thead>
</table>

| Information & Coordination: Care - rehabilitation – multidisciplinary teams – work place – compartmentalised training – lack of communication between actors (incl. administrations); information often either not shared or too complex; psychological barriers |

| Role of patient/citizen: not sufficiently put in center; recognition as key stakeholder |
## What are the solutions to these 3 challenges?

<table>
<thead>
<tr>
<th>Challenge: Budget</th>
</tr>
</thead>
</table>
| Recommendation(s): Flexibility (individual/backpack budget) - Cross-departmental (share)  
Research on best value for money - Better quality measures                                                                                      |

<table>
<thead>
<tr>
<th>Challenge: Coordination &amp; Information</th>
</tr>
</thead>
</table>
| Recommendation(s): Implement chronic care models  
Sharing information – involve patient organisations in coordination of HC – better dissemin. of best practice  
Roadmap to complement SDGs                                                                                                                             |

<table>
<thead>
<tr>
<th>Challenge: Patient role</th>
</tr>
</thead>
</table>
| Recommendation(s): Health literacy measures  
Systematic patient representation in decision making bodies – Measure of need-driven approaches                                                      |
What are the key lessons learned?

Communication = paramount
Economic impact of chronic diseases and the contribution of health policies: Two reflections from the same mirror?

14.15 -14.45
Health and economic benefits of the participation of people with chronic diseases in the labour market. The economists' view

Prof. Olivia Wu
University of Glasgow
What is a health economist’s perspective?

- Budget constraint
- Health maximisation


Saeid Safiri,1,2 Ali Asghar Kolahi,3 Damian Hoy,4 Emma Smith,5,6 Deepti Bettampadi,7 Mohammad Ali Mansournia,8 Amir Almasi-Hashemi,8 Ahad Ashrafi-Asgarabad,9 Maziar Moradi-Lakeh,10 Mostafa Qorbani,11 Gary Collins,12 Anthony D Woolf,13 Lyn March,5 Marita Cross5

ABSTRACT

Objectives To provide the level and trends of prevalence, incidence and disability adjusted life years (DALYs) for rheumatoid arthritis (RA) in 195 countries from 1990 to 2017 by age, sex, Socio-demographic Index (SDI; a composite of sociodemographic factors) and Healthcare Access and Quality (an indicator of health system performance) Index.

What does this study add?

► Globally, the age-standardised point prevalence and annual incidence rates of RA increased by 7.4% (95% uncertainty interval (UI) 5.3 to 9.4) and 8.2% (95% UI 5.9 to 10.5) from 1990, respectively.
► The global age-standardised disability adjusted life year rate decreased from 1990 to 2012 but then increased and reached higher than expected levels in the following 5 years to 2017.
► The UK had the highest age-standardised prevalence and incidence rates in 2017.
► Canada, Paraguay and Guatemala showed the largest increases in age-standardised prevalence and incidence rates between 1990 and 2017.
Figure 4  Age-standardised DALY rates for rheumatoid arthritis for 21 Global Burden of Disease (GBD) regions by Socio-Demographic Index (SDI), 1990–2017; expected values based on SDI and disease rates in all locations are shown as the black line. Twenty-eight points are plotted for each GBD region and show observed age-standardised DALY rates from 1990 to 2017 for that region. DALY, disability adjusted life year  
Resource Use and Costs

Direct costs
• Diagnostics, drug treatment and monitoring, outpatient clinics, hospitalisation, devices and adaptations
• Informal care, home help, transportation

Indirect costs
• Sick leave, productivity loss
• Presenteeism
• Disability pensions, early retirement

Who’s perspective?
“Chronic diseases... have important labour market impacts: reduced employment, earlier retirement, and lower income.”

Economic costs of chronic disease through lost productive life years (PLYs) among Australians aged 45–64 years from 2015 to 2030: results from a microsimulation model.

Table 4 National annual economic impacts of lost labour force participation caused by chronic disease (million $A)

<table>
<thead>
<tr>
<th>Cost</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$A impact</td>
<td>95% CI</td>
<td>$A impact</td>
<td>95% CI</td>
</tr>
<tr>
<td>Lost income</td>
<td>12 593</td>
<td>(11 560 to 13 630)</td>
<td>15 277</td>
<td>(13 880 to 16 428)</td>
</tr>
<tr>
<td>Extra welfare payments</td>
<td>6188</td>
<td>(5719 to 6780)</td>
<td>6668</td>
<td>(6248 to 7406)</td>
</tr>
<tr>
<td>Lost tax revenue</td>
<td>3090</td>
<td>(2850 to 3398)</td>
<td>3617</td>
<td>(3281 to 3993)</td>
</tr>
</tbody>
</table>
1. Invest in prevention and early detection of chronic diseases
2. Integrate primary and specialist care
3. Develop adequate policy frameworks and incentives to support the (re)employment and retention at work
4. Educate employers on the issue of chronic diseases and working conditions, and promote chronic disease awareness at the workplace
Weighing health and economic benefits

“Health technology assessment (HTA) refers to the the systematic evaluation of properties, effects, and/or impacts of health technology. It is a multidisciplinary process to evaluate the social, economic, organizational and ethical issues of a health intervention or health technology”
Going forward…

- Which intervention/policy?
  - What are the options?
  - For whom?
  - How to implement?
- Who’s perspective(s)?
  - Health service
  - Patient and carers
  - Employers
  - Government

Health policies need to address multidimensional benefits and costs
Can health policies help people with chronic diseases participate in the labour market? The patient’s perspective

Peter Boyd
Arthritis Ireland

#EULARBrussels2019
Employment rate among people aged 50–59, with and without chronic diseases, 14 European countries, 2013

Source: OECD, Health at a Glance (2016)
Work-related concerns associated with having RMD (n=372) (UK, percentages)

- Managing my symptoms: 35.5%
- Not being able to carry out my work responsibilities adequately: 26.1%
- Losing my job: 18%
- My employer not being flexible to my needs: 6.2%
- Not being able to find a job that fits around my condition: 3.0%
- Being discriminated against: 2.7%
- Something else: 3%

Source: The Work Foundation / Fit for Work UK
Number (median) of sick days in the last 12 months among employed people aged 50–59, by chronic diseases, 14 European countries, 2013

1.7% of GDP is spent on disability and paid sick leave each year on average in EU countries, > public expenditures on unemployment benefits

Source: OECD, Health at a Glance (2016) & European Chronic Disease Alliance
Decrease in sick leave among patients with rheumatoid arthritis in the first 12 months after start of treatment
Tiring or painful positions at work (percentage of respondents)

Source: Eurofond, European Working Conditions Survey
Irish Situation

- 7 million days in absenteeism
- Half of the total in Ireland
- €750 million each year
- €295 million is paid out in illness benefit
- €1.6 billion – Arthritis Ireland estimate lost productive time
- Fit for Work coalition
  - a. improve employees’ ability to work with RMDs,
  - b. reduce the impact of MSDs on workplace absenteeism
  - c. contribute positively to getting Ireland competitive again
European Scene

- 80% - adult population affected by RMD at some time
- 49% - work-related disorders in Europe down to RMDs
- 40% - those with RMDs out of work at some point
- 40 million - workers in the EU (1 in 7) affected by RMDs caused by work
- 60% - permanent work incapacity due to RMDs
- 2% - GDP each year accounted for by the direct costs of RMDs
Impact

- Significant associated costs
- Increase in absenteeism
- Increase in ‘presenteeism’
- Loss of productivity
- Reduced employee engagement/morale
- Higher staff turnover, recruitment and training costs
- Higher early retirement costs
Direct Costs

- Direct costs of MSDs include the cost of prevention, detection, treatment, rehabilitation and long-term care.
- Healthcare costs
  - Physician visits, physiotherapist, occupational therapist, chiropractic visits, social worker, medications, diagnostic / therapeutic procedures and tests, devices and aids, imaging, laboratory monitoring, toxicity (diagnosis, treatment), medical assist devices, emergency room, hospitalisations, outpatient surgery, complimentary and alternative medicine
- Personal costs
- Transportation, patient time, carer time
Economy

- €750 million – Estimated direct cost of RMDs at work in Ireland
- 40.9% - Cost per capita on sickness and healthcare benefits, more than 24 other countries featured in a Europe wide study.
- 7m working days lost every year due to RMDs
- €1bn – Cost to the Exchequer in sick pay for public and private sector workers in 2010 (Dept. of Social Protection).
- Loss in tax revenues
- Compared with other EU countries, Ireland has a young workforce, and the MSD problem will get worse as it ages
Individual, Family, Society

- Loss of earnings essential for material well-being
- Increases poverty in society
- Loss of an individual’s identity, social roles and social status
- Reduced quality of life
- Healthcare costs such as doctor visits, physiotherapy, medical equipment, alternative therapy, medication etc
- Health consequences such as further deterioration in aspects of physical and mental well-being
- A waste of human capital and productive capacity which affects our competitiveness, social and community cohesion and family stability
- Loss of family productivity - lost opportunities and/or lost earnings for family members
- Work meets important psychosocial needs in societies where employment is the norm
- Negative well-being of an individual affects those around them including families, friends and communities.
Total Costs

• It estimated that the total cost of treating RA patients in Ireland was €19,596 per patient per year or €544 million.
• These costs included medical costs, drug costs, non-medical costs, the costs of informal care and other indirect costs, but do not differentiate between those of working age and those above retirement age.
• These figures are slightly higher, per patient, than those for other western European countries.
• The limitations of data collection outlined above highlight some of the difficulties encountered in trying to cost the impact of RMDs for Irish employers and society.
Model of Care:

- Be patient-centred
- Provide better outcomes
- Actively managed patient pathway
- Develop services at community, hospital level and integration between the two
- Key challenge is integrated care protocols at the interface between services
- Be applicable to the existing Irish health and social care system
- Consistent with recent healthcare strategic initiatives
- Emphasise community models of care, reducing the requirement for hospitalization
- Adopt an holistic approach which will address psychological and social needs as well as physical needs
Importance of Policy:

- Health Policy – requires coordination between groups, departments, and medical systems
- 25% - have never seen a doctor about their pain.
- Job retention and return to work contingent on appropriate medical care as quickly as possible
- The risk of RMDs increases with aging workforce
- Impact of RMDs on work disability will intensify
- Don’t have to be 100% fit for work to be able to return to their workplace
Panel debate
15:00-16.00

Do we need to redefine the role and priorities of EU health policies?
Panellists:

Manuel Pizarro, MEP
John F. Ryan, European Commission
Marian Schaapman, European Trade Union Institute — ETUI
Fiona Godfrey, European Public Health Alliance — EPHA
Neil Betteridge, EULAR

Moderator:

Jennifer Baker, Journalist

#EULARBrussels2019
Messages to the new Commission
16:00 - 16:15
Messages to the new Commission:

Join the conversation using Sli.do

- Open a browser and go to www.slido.com
- Enter #EULARBrussels2019
- Cast your vote in the poll
Petr Karola
Political Advisor to Kateřina Konečná, Member of the European Parliament
Karin Sipido
Chair of the Scientific Panel for Health
José Valverde Albacete
Programme Officer, DG CNECT, European Commission
eHealth developments in Europe.

Jose A. Valverde
Policy & Programme Officer
Unit eHealth, Well-being and Ageing
DG CONNECT
European Commission

Jose.VALVERDE-ALBACETE@ec.europa.eu

Brussels, 15 October 2019
Commission Communication COM (2018) 233

Digital transformation of health and care in the Digital Single Market empowering citizens and building a healthier society
Digital Transformation of Health and Care

- Use digital services for citizen empowerment and person-centred care
- Connect and share health data for research, faster diagnosis and better health outcomes
- Give citizens better access to their health data, everywhere in the EU

Key Technologies:
- High-performance computing
- Artificial Intelligence
- Internet of Things (IoT)
- Cloud computing

- mHealth
- Wearables
- Telehealth
- 4G/5G
(I) Giving citizens better access to their health data

The eHealth Digital Service Infrastructure (eHDSI) enables exchange of patient data across borders

- **Patient Summary** provides access to health professionals to verified key health data of a patient during an unplanned care encounter while abroad

- **ePrescription** enables patients to receive equivalent medication while abroad to what they would receive in their home country
IMPACT OF EUROPEAN EXCHANGE FORMAT OF EHRs ON:

CITIZENS
PEDRO
Pedro, Spanish, is visiting his friend Manuel in Vienna. Unfortunately, as he walks down the street, Pedro slips and hits his head on the ground and loses consciousness.

He’s led to a nearby hospital to get an urgent life-saving operation. Since Pedro’s Electronic Health Record is accessible in Austria, all previous operations, allergies and intolerances are available. Pedro is safely operated and can join his friend Manuel for a nice cup of coffee.

MEDICAL PROFESSIONALS
ELENA
Elena is a Bulgarian doctor who examines many expat patients. When Jean consults her with a persisting very high blood pressure, she can easily access his Electronic Health Record and medical history. This saves her time to enter information in her system about his age, weight, intolerances and allergies.

She can also see how Jean reacted previously to medication when he was treated for his high blood pressure. This makes Elena’s life easier, since she can quickly diagnose Jean and prescribe him the best medication, to which he would react positively.

PUBLIC ADMINISTRATORS
GIUSEPPE
Giuseppe works in an Italian hospital which is regularly referred patients from other EU Member States. Having the ability to receive and read the Electronic Health Record of his foreign patients makes it easy for him to know what relevant tests have been performed recently and avoid repeating them. It also saves the patient from unnecessary intrusive testing and lowers the costs for the hospital.
(II) Pooling health data for research and personalised medicine
IMPACT OF GENOMICS ON HEALTH

IMPROVING CANCER TREATMENT

LOUISE

Louise has a long family history of breast cancer. One day, she heard on TV that the BRCA1 and BRCA2 genes' mutation increases the risk of breast cancer by up to 80%. Although it turned out that she doesn’t have this particular gene mutation, her risk of developing the condition is still high due to her family history. In order to detect early potential breast cancer, she started breast cancer screening at age 35, much earlier than the usual recommended routine screening (at age 50).

A few years later, Louise developed breast cancer. In order to determine the most suitable type of treatment, she underwent a genetic test predicting the risk of breast cancer recurrence and the need for chemotherapy. Test results showed that Louise would not have benefited from chemotherapy, so doctors opted for a more effective personalized treatment, which also prevented her from suffering the unpleasant side effects of chemotherapy.

IMPROVING PROGNOSIS FOR RARE DISEASES

MARTIN

In 2015 Martin was born in Dublin, Ireland. Doctors recorded an abnormally small head and face, as well as a slow development rate. Genome sequencing identified many possible candidates for the genes that were causing his slow development. However, a precise diagnosis would be needed to start treatment. Launching a query through an EU federated platform facilitating matching of cases with similar phenotypic and genotypic profiles, this allowed his doctors to find a second case with similar symptoms and the same mutation in Spain, and therefore to reach an accurate diagnosis and treatment for Martin’s condition.

PREVENTION OF COMMON AND COMPLEX DISEASES, INCLUDING PHARMACOGENOMICS

JUSTYNA

Justyna heard about the ongoing biobanking project in her country in the media, so she read more about the genetic risks of certain diseases. Her healthcare provider recommended her to take the polygenic risk score (PRS), which was just introduced as a new clinical tool in the university hospital. After a genetic analysis, it turned out she belongs to the top 5% of the PRS for coronary artery disease (CAD). Drugs such as statins and other preventive measures lower the cholesterol levels in the blood and reduce the CAD risk. Now, Justyna has to avoid one specific statin which could increase her risk for muscle inflammation. This information made Justyna more aware of how to prevent CAD and make adjustments in her lifestyle, as well as receive treatment and regular check-ups, if needed.
Genomics has the potential for determining future risk of disabling diseases such as cancer, chronic disorders of aging and neuropsychiatric pathology. Through genome sequencing, clinicians can improve personalised treatment, predict the susceptibility to disease and even prevent life threatening adverse reactions to medication. Currently 30-40 million Europeans are affected by rare diseases of which over 80% are genetic origin. Genome sequencing and complementary molecular analysis will in the future help tailor treatments and preventative health measures. When scientific expertise and data are pooled across borders, waiting 5-6 years for a diagnosis has the potential to become history.

COUNTRIES AGREED TO COOPERATE IN LINKING GENOMIC DATA ACROSS BORDERS:

- Austria
- Bulgaria
- Croatia
- Cyprus
- Czech Republic
- Estonia
- Finland
- Greece
- Hungary
- Italy
- Latvia
- Lithuania
- Luxembourg
- Malta
- Netherlands
- Norway
- Portugal
- Slovenia
- Spain
- Sweden
- UK

SECURE AND AUTHORISED CROSS-BORDER ACCESS TO GENOMIC AND OTHER HEALTH DATA IN THE EUROPEAN UNION IS NECESSARY TO:

- Advance the understanding of genetic associations that cause or predispose complex diseases
- Learn to identify cancer in a much earlier stage, improving preventative options
- Identify new target genes for the development of new target drugs in less time
- Strengthen the effectiveness of prevention by improving the screening accuracy and reducing its costs
- Improve patient outcomes and ensure sustainability of health and care provisions in the EU
- Contribute to investments, economic growth and jobs.

The initiative is open to Member States of the European Union, the European Economic Area (EEA) and the European Free Trade Association (EFTA) and it is facilitated by the European Commission.
(III) Digital tools to foster citizen empowerment and person-centred care

By allowing feedback communication and interaction between users and health care providers, digital solutions can improve quality of services and better planning/management by healthcare systems.
Key challenges

• **Transparency and accountability**: explain digital solutions, mitigate bias, increase trust
• **Security and data protection**: protect medical data & right to confidentiality
• **Safety and liability**: ensure data quality, increase reliability, sort out responsibilities
• **Ethics and governance**: ensure privacy and adequate management of data and processes
• **Expertise and digital skills**: train workforce and digital literacy
Funding opportunities digital health 2021-2027

- Digital Europe Programme and Connecting Europe Facility
- Horizon Europe
- European Social Fund + and European Globalisation Adjustment Fund
- European Regional Development Fund
- InvestEU Programme
Thank you!
Prof. Tanja Stamm
EULAR, Vice-President, representing Health Professionals in Rheumatology

#EULARBrussels2019
Networking reception
17:00 – 18:30
A sustainable and effective EU health policy for citizens:
Focusing on chronic diseases and inclusion in social and economic life

#EULARBrussels2019