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The Heart Failure Policy Network

The HF Policy Toolkit was developed by the European Heart Failure Policy Network, an independent, multidisciplinary platform whose goal is to raise awareness of the unmet needs surrounding heart failure and its care. The Network is supported through grants from Novartis Pharma and St Jude Medical.

The Toolkit is fully endorsed and owned by the members of the Network, who have full editorial control over its contents. For further information, contact: info@hfpolicynetwork.eu

The Heart Failure Policy Toolkit



Helping advance meaningful policy change on heart failure

The Heart Failure Policy Network is supported through grants from Novartis Pharma and St Jude Medical

About the HF Policy Network

The HF Policy Network is a multidisciplinary group of politicians from across Europe working with patients, health professionals and other stakeholders to lead significant policy changes that may improve the lives of people with heart failure (HF).

Our members



The Secretariat for the HF Policy Network is provided by The Health Policy Partnership, an independent consultancy. To find out more, please visit www.healthpolicypartnership.com
Design and layout by Vanilla Creative, www.vanillacreative.co.uk

The
Health Policy
Partnership

Why this toolkit

“Heart failure is the single greatest threat to the sustainability of our health care systems – yet very few people know much about it.”

Dr José Ramón Juanatey, President of the Spanish Society of Cardiology

For too long, heart failure has been a forgotten condition in health policy (HF), despite its economic significance for healthcare systems, and the great burden carried by those living with the condition.

The HF Policy Toolkit was developed to help address this – and place HF firmly in the minds of policymakers across Europe.

The HF Policy Toolkit is a starting point for meaningful policy action on HF - designed with the policymaker in mind.

It provides a clear, evidence-based, and comprehensive overview of the key policy issues surrounding HF. It offers a clear way forwards, backed by patients, clinicians, parliamentarians, and other key opinion leaders.

This toolkit should help policymakers lead a new generation of policies that can make a real difference to people living with HF across Europe.

The toolkit is designed as a web-based tool, and provides **10 priority actions** for policymakers to follow – each backed up by a summary of the evidence, the economic case for change and views from patients, clinicians and policy makers on why this is important. It also features several examples from across Europe of what has been done to help improve the lives of patients with HF in the form of case studies.

This document presents a summary of the contents of the toolkit.

To see the full web-based version, and to sign the Call to Action, please visit:

www.hfpolicynetwork.eu



Call to action

Heart failure (HF) is a forgotten condition and few countries feature it in their cardiovascular health strategies. What's more, it is often considered a lost cause – when in fact appropriate diagnosis and care can make a huge difference to improving patient outcomes, avoiding unnecessary suffering by patients and decreasing costs for society.

With the number of people living with HF increasing rapidly, forward-thinking strategies are urgently needed to reduce the burden HF poses on our societies and ensure that every person with HF is offered the best-quality diagnosis and care possible.

We call upon governments across Europe to commit to improving the lives of people living with HF by focusing on the following priority actions:

Make HF a national priority

1

National HF strategies with measurable goals

Every country should feature HF as a major condition within their cardiovascular disease and chronic disease strategies.

2

Public awareness campaigns

Ministries of health should work with public health authorities, professional societies and patient organisations to help people recognise the signs of HF and encourage them to seek appropriate care.

3

Data-driven resource planning

Ministries of health should invest in reliable data collection to guide improvements that will make the biggest difference to patient outcomes and make the best use of available resources.

Ensure timely diagnosis and prevention in those at risk

4

Professional training

All healthcare professionals who are in contact with people at high risk of HF should receive specific training in HF diagnosis and management.

5

Availability and reimbursement of diagnostics

National healthcare systems should provide appropriate reimbursement for guideline-recommended diagnostics and ensure their widespread availability in hospital and relevant community settings.

Deliver multi-disciplinary, person-centred care

6

A standardised HF pathway that reflects clinical guidelines

All patients with HF, regardless of where they are treated, should be offered high quality care consistent with ESC guidelines (or national equivalents) delivered by a specialist-led multidisciplinary team.

7

A dedicated contact for follow up care

Patients hospitalised for HF should leave the hospital with:

- **A clear discharge plan** which reflects individual patient needs and circumstances
- **A dedicated contact for follow up care**
- **An appointment to see an HF specialist within 2 weeks** of discharge.

8

A person-centred care plan

All patients with HF should be offered a personalised long term care plan to help them self-manage their condition.

Invest in tools and resources in primary care

9

Workforce planning in primary care

Governments should evaluate existing professional capacity in primary care to ensure dedicated professionals are available to provide comprehensive care to people living with HF.

All nurses should receive training in HF and, where appropriate, **HF specialist nurses should be officially recognised** as a profession.

10

Investment in innovative tools that promote self-care

Governments should invest in the implementation of tools which may enable patient self-care and reduce avoidable hospital admissions (e.g. patient monitoring devices).



The Heart
Failure Policy
Network

Signed by

The members of the Heart Failure Policy Network

What is heart failure?

Heart failure (HF) is a serious chronic condition where the heart cannot pump enough blood to support the needs of other organs in the body.

What causes HF?

The most common causes of HF in Europe include coronary heart disease, myocardial infarction (heart attack), congenital heart defects or damaged heart valves.

What are the symptoms of HF?

Red flag symptoms include breathlessness, fatigue and swollen limbs. Signs of HF may also be associated with an underlying cardiac disorder.

How does HF manifest itself?

Patients may have symptoms of HF for many years before receiving a proper diagnosis. Most often, HF is diagnosed when patients have an acute episode, due to worsening of their symptoms, and requiring emergency hospitalisation.



Of all conditions, why focus on heart failure?



Significant, and growing, costs

1 in 5 people in Europe are at risk of HF, and it is the single most frequent cause of hospitalisation in people over the age of 65



A debilitating condition causing considerable human suffering

Living with HF has been described as living ‘in the shadow of fear’ – and has a huge impact on people’s quality of life.



A forgotten condition within chronic disease

Yet appropriate diagnosis and treatment help reduce the risk of death, impact on quality of life and hospital re-admissions.

I. Make HF a national priority

“We have one opportunity to get this right. If we don’t, a tsunami of costs will hit us.”

Nick Hartshorne-Evans, CEO of The Pumping Marvellous Foundation and President, iHHUB

Until now, HF has been a **forgotten condition**. Yet **1 in 5** of us are at risk of developing HF over the course of our lives¹ and its cost to health care systems is considerable.

What’s more, HF is a **debilitating condition** which has a huge impact on the quality of life of those affected.² **Many patients are treated inadequately**, causing avoidable suffering and early death.

National leadership is key to raise awareness of the unmet needs surrounding HF. Every country should have a **written strategic plan** of reducing the burden of HF. **Public awareness campaigns** are needed to help everyone understand the symptoms of HF. **Reliable data** are also critical to identify **what needs to be done** to improve outcomes for patients, making best use of available resources.

“Public awareness is very poor for HF. People don’t really understand what it is. Some patients don’t even understand what it is. When I received my diagnosis, I’m not sure that I understood what HF was. It took a long time to get the information I was looking for.”

Sam, a woman living with HF

Priorities for action



National HF strategies with measurable goals

Every country should feature HF as a major condition within their cardiovascular disease and chronic disease strategies.



Public awareness campaigns

Ministries of health should work with public health authorities, professional societies and patient organisations to help people recognise the signs of HF and encourage them to seek appropriate care.



Data-driven resource planning

Ministries of health should invest in reliable data collection to guide improvements that will make the biggest difference to patient outcomes and make the best use of available resources.

Why is heart failure a forgotten condition?

Lack of knowledge – Even if people have heard of HF, many confuse it with a heart attack and would not be able to recognise its symptoms.³

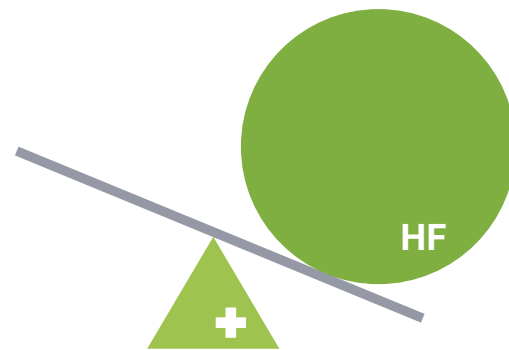
A condition, not an illness – Heart failure is not an illness in itself, but a condition that often results from other illnesses.⁴ As a result, many people (including doctors) may not realise that it needs to be treated in its own right.

The concept of failure – The term ‘failure’ implies death or irreversibility – a ‘lost cause’ – when in actual fact, early diagnosis and appropriate treatment can prolong life and improve quality of life for patients.⁴

‘A disease of old age’ – Symptoms of heart failure are often thought to be the natural result of ageing.⁴

Limited data – There are relatively few reliable, up-to-date incidence and mortality data for HF, making it difficult to quantify its true burden.

HF is the biggest threat to our health care systems and we are approaching tipping point



At least

15 million

adults live with HF in Europeⁱ



1 in 5 adults are at risk of developing HF over their lifetimeⁱⁱ

And it's getting worse

Country	% change in of hospitalisations	Time period
France	14.4	2002 to 2008
Germany	39.8	2000 to 2007
Netherlands	21.0	2000 to 2010
Norway	2.4	1999 to 2008
Spain	22.3	2000 to 2011
Sweden	11.4	2001 to 2011
England	-13.1	2001-02 to 2011-12

adapted from Cowie 2014ⁱⁱⁱ

The prevalence of HF is expected to increase by 25% by 2030^{iv}

25%



HF is an incredibly debilitating condition^v

? Most people do not know what heart failure is...

...and would not recognise symptoms if they had them.

86% have heard of heart failure^{vi}

03% can correctly identify its symptoms^{vi}

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ii. Lloyd-Jones et al. Circulation 2002 106: 3068-72.
iii. Cowie et al. ESC HFA 2014.

iv. Heidenreich et al. Circulation 2011.
v. Jeon et al. BMC Hth Serv Res 2010;10:77.
vi. Remme et al. Eur Heart J 2005;26: 2413-21.

II. Diagnosis and prevention of those at risk



“There are clear ‘red flag’ symptoms of HF that all doctors should be aware of.”

Penilla Gunther, MP from Sweden

Early detection is key in HF – as putting patients on appropriate treatment as early as possible is vital to help minimise the risk of their HF symptoms getting worse, prolong their lives and improve their quality of life.⁴

Unfortunately, HF is often not on many healthcare professionals’ radars. As a result, they may not always recognise symptoms of HF, and patients only get diagnosed once severe damage to their heart has already taken place.⁴ **Equally, they may not be aware that HF can occur in young as well as older people.**

Doctors may also not think to try to prevent HF in their high risk patients through appropriate lifestyle changes or medication.

Improving healthcare professionals’ understanding of HF is therefore urgently needed.

Time is of the essence...

- Early diagnosis of HF (i.e. before severe damage to the heart has occurred) provides an opportunity to give patients life-prolonging medication which is more effective when given early in the natural course of HF.
- A delay to hospital treatment as little as 4-6 hours after acute onset of HF symptoms can increase a patient’s risk of death.⁴

Appropriate diagnostic tools should also be available and reimbursed in all relevant settings of care to help avoid any delays in diagnosis.

Priorities for action



Professional training

All healthcare professionals who are in contact with people at high risk of HF should receive specific training in HF diagnosis and management.



Availability and reimbursement of diagnostics

National healthcare systems should provide appropriate reimbursement for guideline-recommended diagnostics and ensure their widespread availability in hospital and relevant community settings.



“It took over three years for my diagnosis. Doctors were too quick to blame everything on being middle aged. It was only when I collapsed and was rushed to hospital that I was diagnosed, and even that took five days.”

Gina, a woman living with HF



Many health care professionals do not know enough about HF. Many may not recognise HF symptoms in their patients as a result

Time is critical with HF:

A delay to hospital treatment as little as 4-6 hours after acute onset of HF symptoms appear can increase a patient's risk of death.ⁱ



The risk of developing HF can be reduced by as much as 80%

through the adoption of healthier lifestyles and treatment of cardio-vascular risk factors.

Risk

There are clear

'red flag'

symptoms to look forⁱ

- ! Shortness of breath
- ! Fatigue
- ! Swollen limbs

ⁱ Ponikowski et al. ESC 2014.

III. Multidisciplinary, person-centred care

“HF care does not stop in the hospital – it has to span across all settings of care and focus on improving the quality of life of each person living with HF.”

Pascal Garel, European Hospital and Healthcare Federation (HOPE)

Clinical guidelines for HF exist, however **many people with HF still do not get the right treatment,⁴ even in hospital.**

Evidence has shown that patients who receive **input from a cardiologist,⁵** are given **evidence-based treatment** to help stabilise their condition, and are discharged from hospital with a clear **discharge and follow-up plan⁶** have a **lower risk of being re-admitted to hospital or of dying** within one year.⁶

HF is a long-term condition. A key goal of care must therefore be to **help patients engage in their care** and **maintain as good a quality of life as possible** over the course of their condition. To do this, patients need a **personalised care plan** tailored to their individual needs.

“Health professionals should look at the person holistically, ensuring our mental health is taken care of and referral to other services if needed. The journey is different for everyone, therefore services should be flexible.”

Liz, a woman living with HF

Priorities for action

6 A standardised HF pathway that reflects clinical guidelines

All patients with HF, regardless of where they are treated, should be offered high quality care consistent with ESC guidelines (or national equivalents) delivered by a specialist-led multidisciplinary team.

7 A dedicated contact for follow up care

Patients hospitalised for HF should leave the hospital with:

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8 A person-centred care plan

All patients with HF should be offered a personalised long term care plan to help them self-manage their condition.

“The frustrating thing with HF is that we know what works to help improve patients’ lives - we are just not applying it as consistently as we should.”

Dr Mark Dancy, cardiologist and clinical lead of NHS Improvement Programme on Heart Failure, England

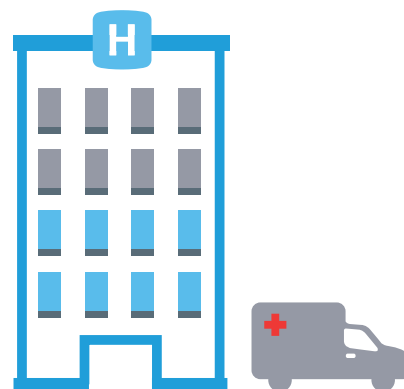
Outcomes for people with HF are worse than breast, prostate, and bowel cancer.ⁱ

Of patients hospitalised with HF:

1 in 4 will be readmitted to hospital within one month ^{ii,iii}



1 in 3 will die within 1 year ^{iv}



Over 50% of unplanned hospital admissions for HF can be prevented

through better follow-up and transitions of care ^{v,vi,vii,viii}

Multidisciplinary care for patients hospitalised with HF works. ^{ix,x,xi,xii,xiii}

We are just not applying it as consistently as we should



Cost-effective



Reduces length of stay

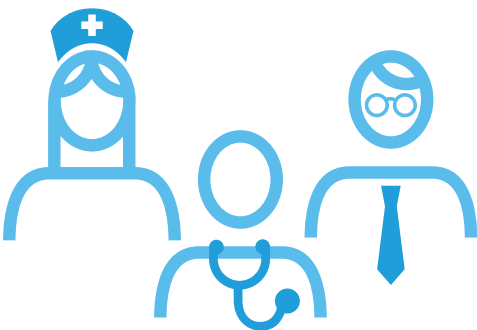


Leads to lower rates of death

Who should be involved in the multidisciplinary team?

- Internists
- GPs
- Cardiologists
- Psychologists
- Physiotherapists

- Nurses
- Dieticians
- Social workers
- Pharmacists
- Palliative care specialists



Person-centred approaches are

essential
in heart failure



Self-management is a critical part of good HF care

It can enhance quality of life and improve adherence to treatment^{xiv,xv}

i. Stewart et al. Eur J Heart Fail 2001;3:15-22.
ii. Cowie et al. ESC HFA 2014.
iii. Sutherland K. Health Foundation, 2010.
iv. Ponikowski et al. ESC 2014.
v. Paul S. Critical care nurse 2008;28:66-82.
vi. Mocillo et al. Revista Española de Cardiología 2005;58:18-25.
vii. Roig et al. Revista Española de Cardiología 2006;59:109-16.
viii. Anderson et al. Congestive heart failure 2005;11:315-21.

ix. Ledwidge et al. Eur J Heart Fail 2003;5:381-9.
x. Anguita Sánchez et al. Revista Española de Cardiología 2005;58:32-6.
xi. Roccaforte et al. Eur J Heart Fail 2005;7(7):1133-44.
xii. McAlister et al. JACC 2004;44:810-19.
xiii. Zuily et al. Arch Card Dis 2010;103:90-96.
xiv. Jaarsma et al. Patient Education and Counseling 2013;92:114-20.
xv. Price A. Nursing times 2012;108:22-4.

IV. Investment in tools and resources in primary care



“With more and more people suffering from chronic conditions such as HF, the main challenge for all health care systems across Europe is to provide patients with high quality care and support outside of the hospital. But most health care systems are poorly equipped to do this.”

Cristian Silviu Busoi, MEP

Inadequate follow-up and long-term care in primary care is one of the key reasons why patients with HF often end up being admitted to hospital.⁷⁻¹⁰ GPs are usually the first point of contact for patients with HF. However, they often do not have the time or resources to monitor their patients and **nurses with specific training in HF** are usually not available to fulfil this role.

Innovative tools that encourage self-care - for example patient self-monitoring tools – **may also help keep HF patients out of hospital.**¹¹ However, in most countries these tools are often stuck in ‘pilot’ mode because of logistic or institutional barriers and are not implemented on a broad scale.

If we are to improve outcomes for people living with HF, we urgently need careful workforce planning and better use of tools that encourage self-management in primary care. Each healthcare setting needs to explore the feasibility of different approaches to suit their particular context.

Priorities for action

Workforce planning in primary care

9

Governments should evaluate existing professional capacity in primary care to ensure dedicated professionals are available to provide comprehensive care to people living with HF.

All nurses should receive training in HF and, where appropriate, **HF specialist nurses should be officially recognised** as a profession.

10

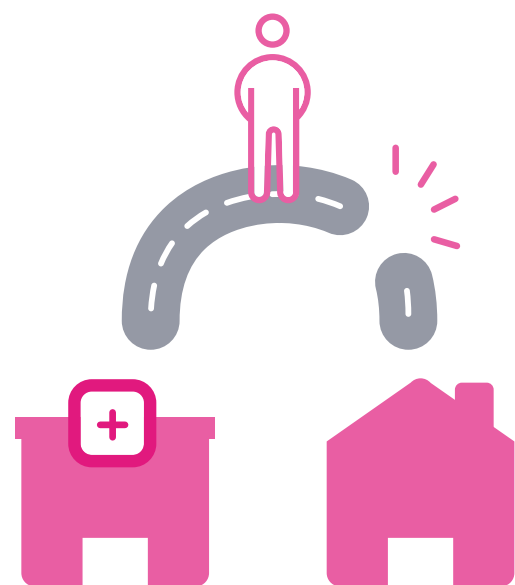
Investment in innovative tools that promote self-care

Governments should invest in the implementation of tools which may enable patient self-care and reduce avoidable hospital admissions (e.g. patient monitoring devices).



“I can’t believe not everyone has a heart failure nurse – I would be lost without mine.”

Julie, a woman living with HF

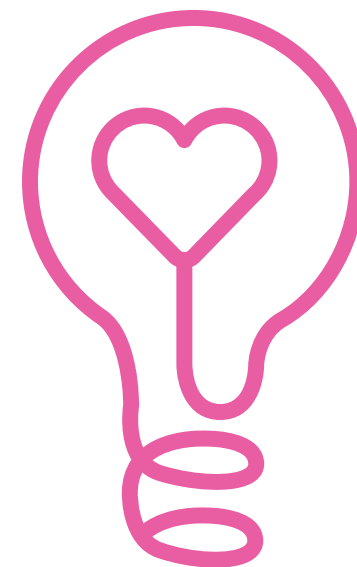
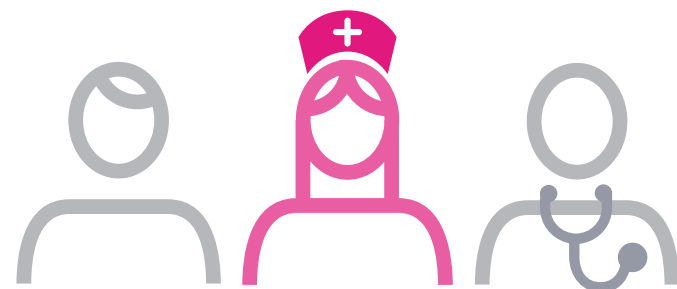


Health care systems are often poorly equipped

to provide HF patients with the quality care they need outside hospital.

HF specialist nurses may provide a key link

between professionals and ongoing support to patients

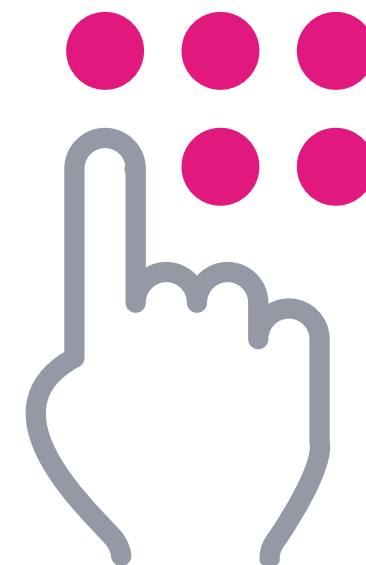


Innovative approaches to encourage self-care

(e.g. patient monitoring) may help keep HF patients out of hospital

Patient monitoring tools may also help

give patients a sense of control over their condition.



Special feature

Heart failure specialist nurses across Europe

Gaps, potential and opportunities



What are heart failure (HF) specialist nurses?

HF specialist nurses are fully qualified nurses with specialist knowledge and advanced skills to treat, manage and care for people with HF.

How can they benefit people with HF?

HF specialist nurses play a vital role in the multidisciplinary care team, acting as a key contact for patients and offering much needed continuity of care across their entire care pathway. They have been shown to benefit patients in a number of ways:

- **They offer support to patients when they are discharged from hospital** – providing smoother transitions back into the community.
- **They provide ongoing follow-up care** to patients within their own homes through regular monitoring and tailored education to patients and their families to enable self-care.¹²
- When needed, they can **assist individuals reaching end-stage HF** by acting as care coordinators¹³ and referring patients onto specialist palliative care services.¹²

What does the evidence say?

- Nurse-led interventions have been shown to **reduce hospital admissions for HF patients**.¹²⁻¹⁴
- HF specialist nurses have been shown to enhance HF patients' **quality of life and adherence to treatment**.¹²
- **Greater investment in HF specialist nurses is likely to be cost-effective in the long-term**¹⁵ – as has been shown with other conditions such as cancer, diabetes, Parkinson's disease and epilepsy.¹⁵

What is the current situation across Europe?

Unfortunately, HF specialist nursing roles are poorly developed across Europe and a number of barriers exist to changing this situation.

- **In most countries, there are no requirements for local hospitals or GPs to provide HF specialist nurses** and therefore many patients do not have access to such services. For example, in **England**, HF specialist nurses have been largely supported by charities and independent funders.¹²
- **HF specialist nurses are often not offered any additional remuneration** for their role. For example in **Belgium**, this remuneration is left to the discretion of individual hospitals. Similarly in **France**, nurses working in the community (*infirmiers libéraux*) may provide therapeutic education and follow up to HF patients on an informal and voluntary basis, however they do not receive any formal reimbursement for these roles.¹⁶
- **Training courses are not readily available**, and there is often no single accreditation for HF specialist nurses.
- **In some countries, nursing roles in general are poorly developed**. For example, **Bulgaria** for example has a very low proportion of nurses compared to the EU average.¹⁷ Primary care nurses are also not readily available in **Italy**. GPs are usually the ones managing HF patients in the community, however they do not have the resources to do so proactively.⁹

What is needed?

Greater investment in HF specialist nurses – or at least, nurses with training in HF – is urgently needed to ensure patients receive multidisciplinary and person-centred HF care:

- **First and foremost, HF specialist nurses must be officially recognised as a profession** and their roles formalised through professional codes and specific remuneration appropriate to the professional structure of each healthcare system
- **Nationally accredited training courses need to be developed**
- **Official care coordination roles** for HF specialist nurses within multidisciplinary teams should be created
- **HF specialist nurses should be included in hospital discharge plans** as the dedicated contact for patients when they leave hospital.

What is being done to improve HF across Europe?

The Toolkit features a number of best practice examples of what is being done across Europe to help improve the prevention and management of HF. Some of these featured examples are illustrated here. For more information, visit the Toolkit online at www.hfpolicynetwork.eu

